Functional recovery and rehabilitation for low anterior resection syndrome and supportive care for people with colorectal cancer

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

2026

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STATEMENT OF ORIGINALITY

This is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged in the text.

Kin Yin Chan

Date: 18th December 2025

SUPERVISOR'S STATEMENT

This is to certify that the thesis entitled "Functional recovery and rehabilitation for low anterior resection syndrome and supportive care for people with colorectal cancer" by Kin Yin Chan in fulfilment of requirements for the degree of Doctor of Philosophy is in a form ready for examination.

Professor Janette Vardy
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COVID-19 IMPACT ON THESIS

This research was conducted between 2019 and 2024, overlapping with the major COVID-19 lockdowns and service disruptions from March 2020 to October 2021. During this period, various isolation measures, public health restrictions, and reduced clinical operations substantially disrupted the conduct of clinical research across the health district until the COVID-19 pandemic was declared no longer a communicable disease at the end of 2023.

The clinical service was significantly impacted by emergency measures introduced to control disease transmission and manage surges. These measures included reducing outpatient activity, cancelling or postponing non-urgent procedures such as elective surgeries, specialist consultations, and clinical trials, adjusting staff deployment, and rapidly shifting to telehealth. As a result, access to eligible participants was limited, and in-person assessment opportunities were decreased. Patient avoidance of hospital settings further diminished clinical activity, particularly among individuals with co-morbidities and respiratory or flu-like symptoms.

These system-level disruptions directly impacted the thesis. To comply with institutional ethics and governance directives, recruitment and follow-up activities were paused or delayed across all studies. Several methodological amendments were necessary to maintain continuity, including:

- Adoption of telehealth delivery for the pelvic floor rehabilitation program (Chapter 6), which partially substituted all planned in-person sessions.
- Extension of the recruitment period for studies in Chapters 3, 6, and 8. Despite these extensions, some target sample sizes were not fully achieved, especially the cross-sectional study of work participation (Chapter 8).

These adaptations were necessary to ensure participant safety and research integrity; however, COVID-19 impacts resulted in prolonged timelines and affected the final dataset's size and completeness. Nonetheless, methodological rigour was preserved through ethical amendments,

transparent reporting of modifications, and strategies to mitigate bias caused by COVID-19-related disruptions.

ABSTRACT

Low anterior resection syndrome (LARS) is a common consequence of colorectal cancer (CRC) surgery and treatment, significantly impacting survivors' physical and psychosocial well-being. Despite this, LARS remains under-recognised in CRC survivorship. The current Australian healthcare system lacks a standardised pathway for screening, preoperative preparation, rehabilitation services, and supportive care in survivorship, particularly for work reintegration for those experiencing LARS and other treatment-related side effects. These gaps leave many cancer survivors without adequate information and coordinated care to self-navigate coping strategies for managing persistent bowel dysfunction in their daily lives.

This thesis aims to investigate the prevalence, lived experience, and management of LARS in Australian colorectal cancer survivors, using a biopsychosocial approach. It sought to evaluate the feasibility and efficacy of multimodal rehabilitation strategies and to understand broader survivorship impacts, particularly in relation to work reintegration.

A mixed-methods, multi-phase approach is undertaken, which includes a prospective longitudinal study, qualitative and quantitative interviews, intervention feasibility studies, and a systematic review. The main body of this research is organised into seven interconnected chapters that examine LARS burden and progression, survivors' information and support needs, the feasibility of preoperative video education and pelvic floor rehabilitation, and work-related outcomes.

LARS is common, with 33% of cancer survivors experiencing either minor or major LARS in our longitudinal cohort, and some also have bladder and sexual dysfunction symptoms. Severity improved over 12 months; however, the rate of change remained slow. Smoking and low anastomotic height were associated with more severe LARS.

Cancer survivors reported that limited information about LARS affected their understanding of functional recovery, and within the limited options for symptom management, as shown in our qualitative study. We conducted two studies to evaluate the feasibility of a multi-modal structured

approach before and after surgery and to determine whether the interventions were practical and beneficial for supporting rehabilitation. Preoperative video education was feasible and acceptable, improving survivors' preparedness and self-management skills. Our systematic review found that pelvic floor rehabilitation can reduce symptoms such as increased bowel frequency and faecal incontinence, but variability across trials limits confidence in targeted LARS management. Therefore, we tested a structured physiotherapist-led multimodal pelvic floor rehabilitation intervention with validated outcome measures, which proved feasible and resulted in 70% of cancer survivors achieving clinically meaningful improvements in LARS, with 60% maintaining these improvements 6 months later. Participants' quality of life was also improved.

A work reintegration analysis revealed that fatigue, bowel dysfunction, neuropathy, and cognitive issues often affect work performance. Although most survivors returned to their previous roles, many felt less confident, less prepared, and less supported during the transition.

This research highlights the disruptive impact of LARS on the well-being of colorectal cancer survivors. It introduces the Empowered Behavioural Adaptation Process as a novel model for behaviour change in the management of LARS. The findings highlight the importance of routine screening and a multimodal approach using a behavioural change model, which is feasible and potentially effective in addressing unmet needs. It also examines the underexplored connections between colorectal cancer and return-to-work challenges. These insights clarify research priorities and suggest an integrated approach to optimise conservative management and survivorship care. Future research should focus on the implementation of bowel function rehabilitation before and after surgery and treatment as an established pathway within colorectal cancer survivorship. More studies are needed on timely, context-specific communication and assessment to support return to work for survivors, helping them make informed decisions and to prepare for returning to work.

This thesis offers a comprehensive evaluation of LARS prevalence, the effectiveness of prehabilitation and rehabilitation, and broader challenges in colorectal cancer survivorship within the Australian healthcare setting. A mixed-methods approach reveals that LARS imposes significant

physical and psychosocial burdens, worsened by unmet information needs and fragmented support for functional recovery and work reintegration. It underscores the importance of optimised conservative management once LARS symptoms plateau and demonstrates the feasibility of coordinated multimodal supportive care and rehabilitation. The Empowered Behavioural Adaptation Process (EBAP) explains sustained recovery through guided behaviour change. Overall, the findings support routine LARS screening, structured referral pathways, and integrated interventions. Future research should focus on large-scale service implementation trials and on improving communication and rehabilitative pathways to improve survivorship outcomes.

AUTHORSHIP ATTRIBUTION STATEMENT

Chapter 1 thesis introduction

I, Kin Yin Chan, was responsible for conducting the literature review and writing the chapter.

Chapter 2 has been submitted for publication, entitled "Low anterior resection syndrome and longitudinal recovery of bowel, bladder, and sexual function after sphincter-preserving surgery for colorectal cancer: A repeated-measures prospective cohort study", with the following authorship: Chan KYC, Suen M, Coulson S, Warusavitarne J, Vardy JL.

I, Kin Yin Chan, was responsible for study conceptualisation, design and methodology, ethics application, data collection and curation, project administration, data analysis and results interpretation, manuscript drafting, revision, and finalisation.

Chapter 3 has been submitted for publication, entitled "Supporting psychological readiness for bowel function recovery before surgery: A feasibility study of preoperative video education in colorectal cancer care", with the following authorship: Chan KYC, Suen M, Lin JYL, Coulson S, Warusavitarne J, Vardy JL.

I, Kin Yin Chan, was responsible for study conceptualisation, design and methodology including designing and writing the videos, ethics application, ANZCTR clinical trial registration, data collection and curation, project administration, data analysis and results interpretation, and manuscript drafting, revision, and finalisation.

Chapter 4 is published as "Chan KYC, Suen M, Coulson S and Vardy JL (2021) Efficacy of pelvic floor rehabilitation for bowel dysfunction after anterior resection for colorectal cancer: a systematic review. *Supportive Care in Cancer,* **29**: p1795-809."

I, Kin Yin Chan, was responsible for the study concept, performed the literature review search, data extraction and analysis, drafted and revised the manuscript.

Chapter 5 is written entitled "A pelvic floor rehabilitation program for patients with bowel dysfunction after sphincter- preserving surgery for colorectal cancer: a feasibility study protocol"
I, Kin Yin Chan, was responsible for the study concept and design, development of the pelvic floor rehabilitation intervention, protocol implementation, manuscript drafting, revision and finalisation.

Chapter 6 has been submitted for publication, entitled "Structured pelvic floor physiotherapy rehabilitation for low anterior resection syndrome in colorectal cancer: An Australian feasibility study", with the following authorship: Chan KYC, Suen M, Collett G, Coulson S, Warusavitarne J, Vardy JL.
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Chapter 7 has been submitted for publication, entitled "Colorectal cancer survivors with low anterior resection syndrome experiences of a structured pelvic floor rehabilitation program: A qualitative study" with the following authorship: Chan KYC, Ratcliffe SE, Collett, G, Warusavitarne J, Suen M, Coulson S, Vardy JL.
I, Kin Yin Chan, was responsible for study conceptualisation, design and methodology, ethics application, data collection and curation, project administration, data analysis and results interpretation, and manuscript drafting, revision, and finalisation. S Ratcliffe assisted with the interpretation of the qualitative data.

Chapter 8 has been submitted for publication, entitled “Colorectal cancer and work participation: A cross-sectional survey study”, with the following authorship: Chan KYC, Suen M, Coulson S, Vardy JL. I, Kin Yin Chan, was responsible for study conceptualisation, design and methodology, ethics application, data collection and curation, project administration, data analysis and results interpretation, and manuscript drafting, revision, and finalisation.

Chapter 9 thesis discussion and conclusion

I, Kin Yin Chan, was responsible for conducting a literature review and writing the chapter.

In addition to the authorship attribution statements above, in cases where I am not the corresponding author of a published item, permission to include the published material has been granted by the corresponding author.

Signature:

Kin Yin Chan

Date: 18th December 2025

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Signature:

Janette Vardy

Lead Supervisor

Date: 18th December 2025

GENERATIVE ARTIFICIAL INTELLIGENCE DECLARATION

No content produced by generative AI tools has been used in the preparation of this thesis.

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PUBLICATIONS, AWARDS, AND CONFERENCE PRESENTATIONS RELATED TO CANDIDATURE

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Chapter 4

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Manuscripts under review with peer-reviewed journals

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Chapter 3

Chan KYC, Suen M, Lin JYL, Coulson S, Warusavitarne J, Vardy JL. Supporting psychological readiness for bowel function recovery before surgery: A feasibility study of preoperative video education in colorectal cancer care

Chapter 6

Chan KYC, Suen M, Collett G, Coulson S, Warusavitarne J, Vardy JL. Structured pelvic floor physiotherapy rehabilitation for low anterior resection syndrome in colorectal cancer: An Australian feasibility study

Chapter 7

Chan KYC, Ratcliffe SE, Collett G, Warusavitarne J, Suen M, Coulson S, Vardy JL. Colorectal cancer survivors with low anterior resection syndrome experiences of a structured pelvic floor rehabilitation program: A qualitative study

Chapter 8

Chan KYC, Suen M, Coulson S, Vardy JL. Colorectal cancer and work participation: A cross-sectional survey study

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2. Chan KY, Ratcliffe S, Collett G, Suen M, Coulson S, Warusavitarne J, Vardy J (2025). From Struggle to Strength: Experiences and Outcomes of Pelvic Floor Rehabilitation for Low Anterior Resection Syndrome in Colorectal Cancer Survivors. Accepted for Rapid Fire Oral Presentation. Joint Meeting of the COSA ASM and IPOS Congress. Adelaide 11-14 November 2025. 2025 Oral Abstracts Asia-Pacific Journal of Clinical Oncology 21 (164) 79-200 p.141
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Abbreviations

AGITG	Australasian Gastro-Intestinal Trials Group
AI	Artificial intelligence
ANZCTR	Australian and New Zealand Clinical Trials Registry
APASC	Australian Physiotherapy Association Scientific Conference
APR	Abdominoperineal resection
AR	Anterior resection
ARP	Anorectal physiology
ARP	Anal resting pressure
ARS	Anterior resection syndrome
ASM	Annual Scientific Meeting
ASP	Anal squeeze pressure
BCCA	Binational Colorectal Cancer Audit
BF	Biofeedback
BMI	Body mass index
BPS	Biopsychosocial
BSC	Bristol Stool Chart
CI	Confidence intervals
cm	Centimetres
COM-B	Capability, Opportunity, Motivation and Behaviour
COREQ	Consolidated Criteria for Reporting Qualitative Research
COFERO	Colorectal functional outcome
COSA	Clinical Oncology Society of Australia
COVID-19	Coronavirus disease of 2019
CRC	Colorectal cancer
CRGH	Concord Repatriation General Hospital

CSSANZ	Colorectal Surgical Society of Australia and New Zealand
EBAP	Empowered Behavioural Adaptation Process
EMG	Electromyography
EORTC QoL	European Organisation for Research and Treatment of Cancer Quality of Life questionnaire
FACT-C	Functional Assessment of Cancer Therapy-Colorectal Cancer
FIQL	Fecal Incontinence Quality of Life Scale
FITT	Frequency, intensity, time and type
FSFI	Female Sexual Function Index
GEE	Generalised estimating equations
Gy	Gray symbol: unit of ionizing radiation
HADS	Hospital Anxiety and Depression Scale
HCP	Healthcare professional
HRAM	High resolution anorectal manometry
HREC	Human Research Ethics Committee
ICIQ-LUT	International Consultation on Incontinence Questionnaire -Lower Urinary Tract Symptoms
IIEF	International Index of Erectile Function
IPOS	International Psycho-oncology Society
LARS	Low anterior resection syndrome
MANUEL	Management guidelines for low anterior resection syndrome
MCID	Minimal Clinically Important Difference
MCIS	Modified Cleveland Incontinence Score
MDT	Multidisciplinary team
MINORS	Methodological Index for Non-Randomised Studies
MSKCC-BFI	Memorial Sloan Kettering Cancer Centre Bowel Function Instrument
MTV	Maximum tolerable volume
NHMRC	National Health and Medical Research Council

NOS	Newcastle Ottawa Scale
NSW	New South Wales
OCM	Optimised conservative management
OR	Odds ratios
PoCoG	Psycho-oncology Co-operative Research Group
PFM	Pelvic floor muscle
PFMT	Pelvic floor muscle training
PFR	Pelvic floor rehabilitation
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PROMs	Patient-reported outcome measures
QOL	Quality of life
RCT	Randomised Controlled Trial
REDCap	Research Electronic Data Capture Database
RT	Radiotherapy
RTW	Return to work
SBO	Small bowel obstruction
SD	Standard deviation
SE	Standard error
SF36	Short Form 36
SMT	Symptom Management Theory
SLHD	Sydney Local Health District
SNM	Sacral neuromodulation
SPSS	Statistical Package for the Social Sciences
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TME	Total mesorectal excision
TIDieR	Template for Intervention Description and Replication
UICC TNM	Union for International Cancer Control TNM Classification of Malignant Tumours

UTI	Urinary tract infection
VAS	Visual analogue scale
WIS	Wexner Faecal Incontinence Score

Table of Contents

Chapter 1: Introduction

Introduction

Colorectal cancer (CRC) ranks as the third most common cancer worldwide, accounting for about 10% of all cancer cases globally [1] , and it was the fourth most diagnosed cancer in Australia, with 15,542 new cases reported in 2024 [2] . The advancement of prevention strategies, early detection, surgical techniques, oncological treatments, and surveillance has significantly reduced mortality over the past decades [3]. This multimodal treatment approach, with curative intent, improves survival and disease-free health outcomes. As a result, although people are living longer after a CRC diagnosis, they also face survivorship challenges [4]. One significant issue is bowel dysfunction following cancer resection and/or chemoradiotherapy, known as Low Anterior Resection Syndrome (LARS) [5]. These sequelae can greatly impact an individual's quality of life [6]. Despite its importance, this issue has not received as much targeted attention as other aspects of cancer and survivorship care. LARS adds to the complexity of other cancer-related complications, leading to multifaceted impacts on CRC survivors. There is a gap in our current health system's support for this group. This research explores ways to better support survivors who are experiencing LARS and other functional symptoms after a colorectal cancer diagnosis. In this introductory chapter, the incidence of colorectal cancer and its current management is reviewed, an overview of low anterior resection and LARS management within the existing survivorship care framework is provided, and the gaps in care that need to be addressed within the Australian healthcare system are identified. This information aims to highlight the important issues in colorectal cancer survivorship addressed in this thesis.

Colorectal Cancer

Epidemiology

CRC remains a major health challenge worldwide. In 2022, there were around 1.93 million new CRC cases and 935,000 CRC-related deaths globally, ranking it as the third most common cancer and the second leading cause of cancer deaths [1]. An ageing population and lifestyle risk factors, such as obesity, high-fat/low-fibre diets and lack of physical activity, drive the rising incidence of CRC [1, 7, 8]. In Australia, approximately 15,500 new cases and 5,200 deaths are projected for 2024, making CRC the fourth most common cancer and the second leading cause of cancer mortality [2]. While age-standardised incidence rates have declined by 33% since 2001, largely due to the Australian National Bowel Cancer Screening Program, the absolute number of cases is increasing because of population growth and an ageing population [2, 9]. Overall, CRC continues to place a significant health and economic burden on individuals and on society.

Advances in treatment, including minimally invasive surgery, improved chemotherapy and radiotherapy regimens, participation in multidisciplinary care and adherence to evidence-based guidelines, have contributed to better overall outcomes in CRC [10]. The five-year survival for CRC in Australia is approximately 71%, up from around 50% in the early 1990s. An estimated 56,200 people were living with CRC at the end of 2018 (diagnosed in the previous five years, 2014-2018), indicating a growing CRC survivorship cohort [2].

This improved survival means that tens of thousands of Australians are now living well beyond treatment, creating a growing demand for survivorship care, including management of long-term side effects, psychosocial support, and surveillance for recurrence [10, 11]. Recent studies highlighted that CRC survivors suffer from persistent late and long-term effects (e.g., bowel/sexual dysfunction, fatigue), variable pathways, and access barriers, reinforcing the demand for coordinated, guideline-based survivorship care [12].

Current Management of Distal Colorectal Cancer

Approximately 67% of CRC occurs in the distal sigmoid colon and rectum [1]. An oncological surgical resection of the involved large bowel with the surrounding draining lymph nodes remains the mainstay of distal CRC treatment, and anterior resection (AR) has become the primary surgical approach for distal CRC over recent decades. AR is a surgical procedure in which the diseased part of the rectum (and often part of the sigmoid colon) is removed, with the bowel continuity restored through a colorectal or coloanal anastomosis while preserving the anal sphincter [13]. In accordance with contemporary Australian colorectal surgical practice, AR encompasses three anatomical subtypes defined by the level of rectal transection: High Anterior Resection, involving resection of the sigmoid colon and upper rectum with an anastomosis above the peritoneal reflection; Low Anterior Resection, involving resection into the mid-rectum with an anastomosis at or just below the peritoneal reflection; and Ultralow Anterior Resection, involving resection of the entire rectum with a coloanal anastomosis at the level of the anal canal. This classification forms the basis of the inclusion criteria for Chapter 2. Traditionally, the standard surgical approach for distal rectal cancer was an abdominoperineal resection (APR), which led to a permanent colostomy and significantly impacted patients' quality of life [14, 15]. The introduction of circular stapling devices in the late 1970s and the adoption of total mesorectal excision (TME) revolutionised rectal cancer surgery, enabling safe sphincter-preserving procedures with satisfactory oncological results [16, 17]. Today, AR is performed in up to 80% of rectal cancer cases requiring surgery, often using minimally invasive techniques [18].

Neoadjuvant radiotherapy, often combined with chemotherapy, has recently become an integral part of rectal cancer management. It has improved the outcomes of rectal cancer treatment by significantly reducing local recurrence and enhancing resectability, particularly for stage II-III rectal cancers. Current guidelines recommend either short-course radiotherapy (5 × 5 Gy) or long-course

chemoradiotherapy (45–50.4 Gy) for locally advanced disease, enabling tumour downstaging and increasing the chances of performing a sphincter-preserving low anterior resection. Despite the superior oncological outcomes, these advances have increased the complexity of treatment paradigms and added to the potential long-term functional implications for patients following bowel cancer treatment [19].

The rectum plays a crucial role in distinguishing bowel contents, regulating storage, and facilitating evacuation. It acts as a reservoir for the gastrointestinal tract, relying on its ability to distend (compliance), coordinate colonic movements (motility), and maintain neural pathways that sense contents and reflexes. It functions as a gatekeeper between the proximal colonic flow and defaecation, when socially appropriate, allowing voluntary control through the anal sphincter complex. Sensory signals from rectal distension help differentiate between gas and stool, while the recto-anal inhibitory reflex and pelvic floor muscle coordination maintain bowel continence [15].

Removing the rectum during distal CRC treatment significantly changes the anatomy and physiology of the remaining structures. Anterior resection and radiotherapy can cause substantial impairment of rectal function. Partial or total resection reduces rectal capacity and affects compliance [20, 21]. TME and radiotherapy might damage autonomic nerves, impairing rectal motility and sensation [22, 23]. Studies indicate that even with reconstruction techniques like a colonic J-pouch, the neorectum cannot fully restore the original rectum's function. Consequently, an increasing number of cancer survivors who have successfully undergone bowel cancer treatment experience symptoms of bowel dysfunction due to a reconstructed neorectum that functions suboptimally – a condition known as Low Anterior Resection Syndrome (LARS) [6].

Low Anterior Resection Syndrome

Background: Definition, Pathophysiology, Risk Factors

According to the Low Anterior Resection Syndrome Collaborative Group, LARS is defined as '*disordered bowel function after rectal resection, leading to a detriment in quality of life*' [24]. This consensus definition emphasises both bowel symptoms and their impact on daily life, reflecting patient-reported priorities. LARS is a collective term characterised by a combination of faecal storage and evacuation symptoms, including increased stool frequency, faecal urgency, clustering of bowel movements, difficulty with evacuation, and faecal incontinence [5, 24]. These symptoms fluctuate throughout the cancer survivor's recovery journey and may occur either in isolation or together as a symptom complex. The validated LARS score, developed by Emmertsen and Laurberg in 2012, standardised the evaluation of these complex, dynamic bowel issues into a symptom-based assessment tool. It consists of five questions addressing key symptoms, including incontinence for flatus, incontinence for liquid stool, bowel frequency, clustering, and urgency. With a total score of 42, and higher score indicating increased symptoms, patients can be categorised as no LARS (0-20), minor LARS (21-29), or major LARS (30-42). This validated tool has been widely adopted in clinical practice and research [6].

The pathophysiology of LARS is multifactorial. It involves structural, neurological, and functional changes following rectal resection. Firstly, rectal resection results in loss of the rectal reservoir, decreasing rectal compliance and storage capacity, leading to a shift in sensation of urgency associated with rectal filling and, consequently, increased frequency. Secondly, both total mesorectal excision and neoadjuvant radiotherapy can affect autonomic nerves, disrupting colonic motility and anorectal reflexes, and impairing the coordination of faecal evacuation. Thirdly, disruption of the rectoanal inhibitory reflex and the faecal sensory pathway diminishes the patient's ability to distinguish between gas and stool. Finally, other non-anatomical factors, including stool

consistency, pelvic floor dysfunction, and psychological influences, all contribute to this complex, multifactorial syndrome [24-28].

Several proposed risk factors influence the prevalence of LARS. One of the most significant predictors is the short distance of anastomosis from the anal verge, resulting from ultra-low anterior resection, which causes a substantial loss of the rectal reservoir and nerve disruption. Total mesorectal excision, rather than partial mesorectal excision, is also a predictor of LARS as it increases the risk of nerve damage due to more extensive pelvic nerve dissection. Neoadjuvant chemoradiotherapy raises the risk of LARS through radiation-induced fibrosis and neuropathy. Other surgical factors, such as anastomotic leak and the use of a temporary diverting stoma, are also considered risk factors, especially when stoma closure is delayed. Finally, patient-related risk factors such as younger age, female sex, and smoking have been associated with higher LARS risks [24, 29-31].

Prevalence

LARS is prevalent in colorectal cancer survivorship, and significantly impacts the quality of life for CRC survivors. The current literature shows the rate of CRC survivors experiencing major LARS ranges from 18% to 56% after rectal cancer treatment worldwide. Long-term research indicates that 49% of patients still face major LARS five years post-surgery, underscoring its persistent and often debilitating nature. Symptoms of LARS, including increased bowel frequency, clustering, incomplete evacuation, urgency, and incontinence, affect not only physical health but also the psychological and social well-being of CRC survivors [32-34].

Although international research has provided substantial data on LARS prevalence and risk factors, evidence specific to Australia remains limited and is mainly cross-sectional. One Australian study from a regional centre reported a major LARS prevalence of 37.5%, but it was retrospective and

lacked longitudinal follow-up [35]. This highlighted the need for further research into LARS prevalence in Australia, to determine if rates are similar to the published literature.

Current LARS Management & Optimised Conservative Management

Due to the multifactorial pathophysiology of LARS, a range of treatment options has been suggested, including pharmacological approaches such as antidiarrheals and bulking agents, as well as conservative management strategies such as lifestyle adaptations, dietary modifications, pelvic floor muscle training, and anal irrigation. In severe or refractory cases, surgical options, such as implantation of a sacral neuromodulation device, are available [36]. These strategies often provide temporary, reactive symptom relief and are usually delivered in isolation, with mixed outcomes and varying tolerability. For example, dietary modifications and medications are considered to improve bowel motion consistency and possibly stool frequency, but do not address the underlying neuromuscular coordination issues. Conversely, anal irrigation and sacral neuromodulation are resource-intensive and less acceptable for long-term use.

Pelvic floor rehabilitation provides a structured, patient-centred multimodal approach through pelvic floor muscle training, biofeedback [37-39], behavioural strategies, and education. This includes toilet and bowel habit optimisation, dietary modifications, and lifestyle changes. The aim is to address the multifactorial nature [18, 37, 40], re-establish anorectal coordination and rectal sensory discrimination, and restore pelvic floor muscle function. Behavioural strategies and education involve patients actively engaging to reduce maladaptive behaviours such as excessive straining, urgency-triggering behaviours, and an imbalanced diet, which can lead to bowel motion inconsistency [41-43], ultimately improving quality of life [40]. These components are individualised and delivered by professional guidance within a biopsychosocial framework.

Emerging clinical frameworks suggest that effective LARS management requires a multidisciplinary, stepwise approach [39, 44], highlighting the importance of optimised conservative management

(OCM), which combines dietary advice, medication, and pelvic floor rehabilitation. However, in Australia, its implementation remains inconsistent and poorly integrated into survivorship care pathways. Notably, structured and supervised pelvic floor rehabilitation (PFR) represents a promising yet under-utilised part of optimised conservative management. Previous randomised controlled trials (RCT)s have shown that pelvic floor muscle training (PFMT) and multimodal PFR, led by physiotherapists, improve LARS scores and quality of life [36, 39, 45, 46], however, rehabilitation programs vary in protocol, timing, and delivery, which restricts their clinical application [46, 47].

Currently, there is no standardised or integrated pathway for LARS management in Australia. Patients often receive fragmented, reactive care instead of proactive, structured rehabilitation, which leaves them unprepared for the long-term effects of bowel dysfunction on daily life, including unrealistic expectations, psychosocial well-being, and broader participation in society [48-51]. These gaps reveal a significant misalignment with the survivorship framework, which emphasises a multimodal approach centred on the biopsychosocial model. To address this misalignment, it is essential to develop and test clinically feasible interventions that are grounded in theory, patient-centred, and suitable for resource-limited health systems.

CRC Supportive Care and Survivorship

Clinical Framework - unmet needs at different stages of the cancer journey using a multimodal approach

Although recognition of LARS is increasing in the international literature, awareness within Australian clinical practice remains limited. At the system level, there is currently no standardised approach to assessing LARS. Structured rehabilitation services are either absent or delivered inconsistently across Australia. Despite pelvic floor rehabilitation showing potential benefits for CRC-related bowel dysfunction [38, 40], their implementation remains inconsistent. Access to supportive care is often fragmented and lacks continuity, leading to inequities in service availability [52]. On the

patient level, education and counselling regarding bowel function are often unstructured, leaving patients unprepared for the chronic and multifaceted impact of LARS [53]. The effects of LARS extend beyond physical symptoms, with significant consequences for psychological well-being, social participation, quality of life, and, particularly, return to work as an essential part of functional recovery. Overall, these challenges highlight the lack of a coordinated approach across various stages of the colorectal cancer continuum from diagnosis through to survivorship.

Addressing the unmet needs of CRC survivors requires developing a clinical framework that incorporates a patient-centred, multimodal approach across the colorectal cancer journey. There is an urgent need to identify feasible and effective interventions and support systems for this patient group within Australia's limited healthcare resources.

Theoretical Framework - COM-B and BPS model in understanding cancer survivors' needs and designing interventions

A theoretical framework combining the biopsychosocial (BPS) model [54] with the Capability, Opportunity, Motivation and Behaviour (COM-B) model [55] and Symptom Management Theory (SMT) [56] provides a contextual and practical understanding of how LARS affects and is managed in colorectal cancer survivorship. The BPS model offers a foundational, multidimensional perspective, giving a comprehensive view of how colorectal cancer impacts individuals and recognises their needs. Survivorship outcomes are shaped not only by physical symptoms, such as LARS and other treatment-related side effects, but also by psychological factors [57, 58], including personal perceptions of abilities and self-efficacy, as well as social determinants such as interpersonal interactions, work participation, and access to supportive care. While the BPS model offers a holistic lens for understanding how the three domains influence LARS and functional recovery, it does not specify operational strategies for care aimed at improving long-term outcomes through behaviour change. The COM-B model addresses this by systematically identifying behavioural mechanisms that

can be optimised through building physical and psychological capabilities via education and skills development, creating opportunities through structured clinical pathways and supportive environments, and increasing motivation through counselling, preparing with realistic expectations, and goal setting [55]. Complementing these, SMT [56] explains how survivors perceive, interpret, and respond to symptoms over time, offering a process-oriented understanding of self-management that links lived experience with clinical strategies. This integrated framework ensures that LARS management and CRC supportive care are grounded in multifaceted realities of survivorship and theoretically informed and systematically structured to enable sustainable behavioural adaptation and long-term recovery.

Other Challenges CRC survivors face

CRC Survivorship Challenges

Although multimodal treatment has markedly improved survival rates, common side effects in CRC survivors include fatigue, diminished physical capacity, chemotherapy-related peripheral neuropathy, cognitive issues, bowel problems, and surgical complications such as stomas. Sleep disturbances and pain are also often experienced. These side effects significantly affect the physical and psychosocial well-being of cancer survivors, especially those who are still in the workforce at the time of diagnosis [59, 60].

Impact on return to work among CRC survivors

Engaging in work can help survivors regain a sense of normalcy, control, and self-identity after a major life event like a cancer diagnosis [61, 62]. For many, work provides a sense of fulfilment through contributing as a member of society, acting as a role model for younger generations, and experiencing a sense of achievement. The physical and cognitive activities involved in many routine jobs may form part of the rehabilitation. Additionally, the psychological engagement and social

interaction at work may serve as a distraction from fears and anxieties related to cancer and help eliminate the ‘sickness’ label. Nevertheless, work also plays a vital financial role in supporting survivors' livelihoods [63, 64].

Unfortunately, survivorship challenges can hinder work participation and make it difficult for survivors to meet their workplace responsibilities and remain employed. Beyond physical issues, survivors often face psychosocial and emotional challenges, including a lack of psychological readiness to return to work, social acceptance issues with colleagues, and a perceived loss of professional identity due to their physical limitations in fulfilling the work role [65, 66]. These difficulties can result in lower performance and reduced job satisfaction [67]. While many survivors return to work after or even during treatment, some encounter changes in employment or stop working entirely due to the disease’s impact [61, 68]. These unexpected changes can lead to financial hardship and emotional stress, ultimately affecting the quality of life for survivors and their families.

Therefore, health professionals and employers need to recognise these challenges and understand the specific needs of cancer survivors. Offering flexible work arrangements, fostering a supportive environment, and providing counselling can help facilitate a smoother transition from hospital to workplace and support survivors in resuming their professional roles [69].

Currently, there is limited support from health professionals to assist cancer survivors in transitioning from hospital to work. Most of the research in this field has been in women who are living with breast cancer. However, there has been limited research regarding CRC survivors’ readiness, needs, and barriers to returning to work.

Rationale of the Study

Although advanced curative surgery and adjunctive treatments have improved survival rates for people diagnosed with CRC, many survivors continue to experience debilitating bowel dysfunction - described as LARS. In addition to chemotherapy-related peripheral neuropathy and fatigue, LARS significantly compromises quality of life.

Within the Australian healthcare system, CRC survivorship after LARS remains under-recognised, with no structured rehabilitation pathway. Although evidence supporting pelvic floor rehabilitation and pre-surgery supportive care is prevalent in the international literature, data on its feasibility and acceptability in Australia remain limited. Consequently, the supportive care for people with colorectal cancer is fragmented throughout the colorectal cancer journey. Ultimately, the broader psychosocial consequences of bowel dysfunction and cancer-related issues on work participation remain insufficiently addressed.

Therefore, this body of research addresses these gaps through a multimodal, mixed-methods investigation examining the prevalence and severity of LARS within the Australian context. **The main research questions are**: How can functional recovery and rehabilitation for LARS be optimised, and how can supportive care for people with CRC be strengthened to improve survivorship outcomes across the cancer journey? To answer these questions, the research:

- Firstly examines the prevalence of LARS and bladder and sexual dysfunction in people after sphincter-preserving anterior resection for colorectal cancer.
- Secondly, it evaluates the feasibility and potential effectiveness of preoperative video-based pelvic floor education on improving CRC patients' readiness for functional recovery after their cancer treatment.
- Thirdly, it systematically reviews the evidence for pelvic floor rehabilitation.

- Fourthly, it evaluates the feasibility and potential effectiveness of a structured pelvic floor rehabilitation program. Additionally, from a psychological perspective, this study explores survivors' experiences with LARS using qualitative methods, and the COM-B framework extends beyond clinical outcomes to self-management and behavioural change.
- Finally, this thesis examines the impact of cancer on work participation.

This comprehensive, multi-phase study, integrating quantitative and qualitative evidence, aims to generate new knowledge and deepen understanding of this complex and debilitating condition, thereby supporting a sustainable, theory-informed framework for bowel function recovery and survivorship care for colorectal cancer survivors. This section provides an overview of the thesis's scope and structure, while the specific aims and objectives are formally defined in the following section.

Aims & Objectives

The main aim of this research is to enhance current knowledge about LARS prevalence and management in an Australian colorectal cancer survivorship setting. Using a biopsychosocial approach, this thesis provides a deeper understanding of functional recovery, its impact on the quality of life of colorectal cancer survivors, and how they can be better supported through a structured rehabilitation pathway and coordinated supportive care, addressing the current absence of an integrated colorectal cancer supportive care pathway.

Objectives:

1. To determine the prevalence of LARS in an Australian metropolitan cancer centre.
2. To develop and evaluate the feasibility and readiness of pre-surgery educational videos aimed at improving patients' preparedness, supportive care, and facilitating their recovery of bowel function.

3. To review existing evidence of PFR for patients with bowel symptoms after anterior resection through a systematic review.
4. To examine the feasibility and efficacy of a structured physiotherapy-led pelvic floor rehabilitation program on bowel function and quality of life.
5. To explore the experiences of people living with LARS and their perceptions of PFR.
6. To investigate return-to-work challenges among CRC survivors.

Outline of Chapters

Chapter 1 provides an introduction to the background, rationale and theoretical framework for the thesis, outlining the research objectives.

Chapter 2 is a manuscript that is currently under review for publication. It reports a prospective longitudinal observational study that determines the prevalence and severity of LARS, bladder, and sexual dysfunction after anterior resection and oncological treatment for CRC. It examines how these symptoms change over a 1-year period. This study also identifies factors associated with LARS. This chapter sets the context for the intervention for functional recovery with LARS that is presented in the subsequent chapters.

Chapter 3 is a manuscript that has been submitted and is currently under review for publication. It is a non-randomised single-arm study investigating the feasibility of video-based education before CRC surgery to psychologically prepare and support patients with bowel function recovery. An educational video set, developed by the candidate and consisting of four short videos, was used as the intervention.

Chapter 4 is a published systematic review that examined the literature on PFR's efficacy in treating bowel dysfunction after anterior resection for CRC: Chan KYC, Suen M, Coulson S, Vardy J. (2021) Efficacy of pelvic floor rehabilitation for bowel dysfunction after anterior resection for colorectal cancer: a systematic review. *Supportive Care Cancer* 29, 4, p.1795-18093

Building on this evidence base, **Chapters 5-7** evaluate a targeted intervention using mixed methods and provide an understanding that active intervention after surgery and treatment, which supports behavioural change, could enhance bowel function recovery and improve quality of life. They also address system-level gaps where structured pathways and coordinated services are lacking. Chapter 5 is a descriptive protocol of physiotherapist-led pelvic floor rehabilitation. Chapter 6 is a non-randomised single study examining the feasibility and efficacy of a 10-week structured physiotherapist-led pelvic floor rehabilitation program for LARS. We further explored the impact of LARS that could not be captured through patient-reported outcome measures (PROMs) by also conducting a qualitative study, detailed in Chapter 7. This study provides insights into the lived experience of living with LARS and the changes that result from participation in a PFR program. Both manuscripts have been submitted to international journals and are currently under review for publication.

Finally, **Chapter 8** highlights the barriers and challenges that cancer survivors face when returning to work after treatment, situating functional recovery within the broader context of survivorship by using a study-specific, self-administered survey completed by cancer survivors.

Together, these studies provide a comprehensive and multimodal examination of LARS, encompassing its prevalence, feasibility of interventions, survivor experiences, and participation in work. The research aims to contribute knowledge to support the development of structured rehabilitation pathways and integrated supportive care for colorectal cancer survivors in Australia.

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Chapter 2: Low anterior resection syndrome and longitudinal recovery of bowel, bladder and sexual function after sphincter-preserving surgery for colorectal cancer: A repeated-measures prospective cohort study

Overview

The previous chapter outlined the clinical relevance of Low Anterior Resection Syndrome (LARS) and its impacts on cancer survivors' quality of life. This chapter provides additional context regarding LARS prevalence within the Australian colorectal cancer landscape. In this study, patients were screened for LARS after distal colorectal cancer surgery, revealing that a significant proportion experienced either minor or major LARS. The findings aligned with existing literature showing high LARS prevalence in individuals with rectal cancer. The associated factors and the natural recovery trajectory over time were also examined. Additionally, this study assessed the relationship between LARS and pelvic organ dysfunction, including bladder and sexual symptoms, which are often affected together but have been less frequently studied in conjunction with LARS.

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Contribution of authors

I, Kin Yin Chan was responsible for study conceptualisation and design, project administration, dataset management and analysis, and drafting and finalising manuscript.

Michael Suen developed the concept, performed data analysis and reviewed the manuscript

Susan Coulson reviewed the manuscript

Janindra Warusavitarne reviewed the manuscript

Janette Vardy developed the concept and reviewed the manuscript.

Abstract

Aim: Low anterior resection syndrome (LARS) is commonly observed among colorectal cancer (CRC) patients following sphincter-preserving surgeries. However, prospective data regarding its prevalence, trajectory and its relationship with other pelvic organ dysfunctions remain limited. This study aims to evaluate the longitudinal prevalence of LARS, its association with bladder and sexual dysfunctions, and identify factors that predict LARS severity.

Method: We conducted a prospective observational cohort study of CRC patients who underwent sphincter-preserving anterior resection at an Australian tertiary hospital (2019–2024). Patients completed the validated LARS questionnaire and a screening questionnaire for bladder and sexual function at baseline (≥6 months post-bowel continuity restoration) and follow-up (≥12 months from baseline). Logistic regression and generalised estimating equations were used to examine associations and longitudinal changes.

Results: A total of 116 patients (mean age 64.3 years; 66% male) were included; 105 completed follow-up (mean interval 14.2 months). In the overall cohort, major LARS decreased from 14.7% at baseline to 7.6% at follow-up, while people without LARS increased from 67.2% to 78.1%. Among rectal cancer patients specifically, major LARS declined from 24.1% to 11.1%. LARS severity was significantly associated with sexual dysfunction at baseline (OR=4.45, p=.009) and follow-up (minor LARS OR=6.33, p=.008). LARS scores improved by an average of 2.3 points over 12-months (p=.007). Smoking (OR=6.71, p=.021) and low anastomotic height (≤5.9 cm vs ≥11 cm; OR=9.56, p=.004) predicted worse LARS.

Conclusion: LARS symptoms showed natural recovery over time, but progress was slow after 6-12 months, with severity associated with sexual dysfunction. Smoking and a low anastomotic height were significant risk factors. These findings underscore the importance of early risk assessment,

preoperative counselling, and timely referral for structured rehabilitation if natural recovery plateaus.

Keywords: Low anterior resection syndrome, colorectal cancer, bowel dysfunction, sexual dysfunction, longitudinal study, risk factors

What does this paper add to the literature?

This study enriches current literature by providing prospective evidence on LARS recovery, highlighting its ongoing improvement beyond 12 months. It establishes a link between LARS severity and sexual dysfunction and identifies smoking and low anastomosis height as key predictors, offering actionable insights for postoperative management and patient counselling.

Introduction

The survival rate and the preservation of anorectal continuity in colorectal cancer (CRC) have improved substantially due to advances in diagnostic investigations, surgical techniques, and oncological treatments [1]. Patients with CRC are living longer after treatment; however, they face ongoing challenges from treatment-related side effects impacting long-term quality of life [2]. In treating distal CRC, an anterior resection is often performed to preserve bowel continuity and avoid a permanent stoma. However, this surgical procedure inevitably alters the anatomy and physiology of the anorectum, potentially disrupting normal bowel function. This may result in low anterior resection syndrome (LARS), characterised as a range of symptoms of storage and evacuation difficulties [3, 4]. Patients with CRC are often confronted by these bowel control issues, which can affect their physical function and psychosocial wellbeing, substantially affecting their long-term survivorship quality [5]. A validated LARS score has been developed to standardise symptom reporting, assess LARS severity, and evaluate its impact on quality of life [6]. A systematic review of 11 studies using the LARS score estimates that approximately 41% (range: 18%–56%) of patients who have had an anterior resection suffer from major LARS, with a wide range of follow-up periods ranging from 17 days to 18 years [7]. Factors such as radiotherapy, resection location, anastomosis technique, and the presence of a defunctioning stoma have been linked to major LARS [7-10]. Furthermore, bladder and sexual dysfunction are common in both men and women following anterior resection and radiotherapy [11]. Bowel adaptation begins around 6 months following restorative surgery, with functional improvements reaching a plateau between 12 and 18 months. However, long-term symptoms often persist [12-14].

Although awareness of LARS is increasing, most prevalence studies are cross-sectional, with limited prospective research [15]. Additionally, there has been little research into the bladder and sexual dysfunction that frequently accompanies an anterior resection. The risk factors associated with LARS and its long-term trajectory are not well understood, leaving clinicians without clear guidance on

setting realistic recovery expectations. This creates a knowledge gap that hinders the standardisation of clinical practice, from screening to structured prehabilitation and rehabilitation pathways in CRC care. There is a need for more prospective data to help establish standardised methods for assessing bowel and pelvic floor function and to guide prehabilitation and rehabilitation strategies in CRC management.

This study aims to determine the longitudinal prevalence of LARS, using the validated LARS score, among cancer patients who have undergone sphincter-preserving anterior resection for CRC at an Australian metropolitan hospital. Secondary objectives include (i) assessing the prevalence of bladder and sexual dysfunction symptoms related to CRC treatment, (ii) evaluating the recovery trajectory of LARS following treatment, and (iii) identifying potential risk factors for LARS.

Methods

Study Design

This is a prospective observational cohort study of low anterior resection syndrome prevalence after CRC resection and treatment at Concord Repatriation General Hospital (CRGH), a tertiary teaching hospital in Sydney, Australia. Ethics approval was granted by the Sydney Local Health District Human Research Ethics Committee, Concord Repatriation General Hospital (ref. 2019/ETH09759). The study was conducted in accordance with the "NHMRC National Statement on Ethical Conduct in Human Research" (Commonwealth of Australia, 2007, updated 2018) and the ethical principles derived from the World Medical Association Declaration of Helsinki (Helsinki, 1964, updated 2016). A waiver of consent was granted because the study involved analysing routinely collected clinical data, including questionnaires. All data were de-identified before analysis. To minimise selection bias, all consecutive patients diagnosed with CRC who attended follow-up appointments at the Concord Colorectal Outpatient Clinic or The Sydney Cancer Survivorship Centre Clinic at CRGH between 2019

and 2024 were identified. The recruitment period was extended due to disruptions caused by the COVID-19 pandemic.

Participants

Patients who underwent sphincter-preserving anterior resection for sigmoid or rectal cancer, with bowel continuity restored for at least 6 months with or without prior temporary ostomy, were eligible for inclusion. The >6-month threshold was selected to ensure that participants had recovered from the immediate postoperative period, during which bowel function is known to fluctuate substantially. Longitudinal studies of postoperative bowel function demonstrate that the most substantial natural recovery occurs during the early postoperative months, with symptom trajectories stabilising thereafter [6, 10]. In addition, a proportion of the cohort comprised Stage III bowel cancer patients, who typically undergo approximately 6 months of adjuvant chemotherapy following surgery. It ensured that these patients had completed systemic therapy and recovered from its acute gastrointestinal effects before baseline assessment.

Patients were excluded if they had: (i) a permanent ostomy or de-functioning stoma awaiting reversal; (ii) evidence of cancer recurrence or metastases; (iii) difficulty understanding questionnaires due to language barriers or cognitive impairment; (iv) other co-morbidities or medical conditions that could affect bowel function, such as inflammatory bowel disease, neurological disorders, or previous radiotherapy for prostate or gynaecological cancers; (v) revision of surgery due to a local recurrence. Eligible patients were asked to complete the validated Low Anterior Resection Syndrome Score (LARS) [6] and a screening questionnaire developed by the authors on bladder and sexual function as part of standard care at baseline and during follow-up appointments (at least 12 months apart). Baseline and follow-up questionnaire data were collected. Demographic information, medical history, surgery and oncological treatment details were obtained from medical records.

Study Size

The sample size was determined by the number of eligible patients attending follow-up clinics at our institution during the recruitment period (2019–2024), aiming to include all available cases to maximise statistical power.

Data Collection

Patient demographics, cancer characteristics, surgery, and oncological treatment details were collected from three routinely used clinical data sources at our institution: the Concord Colorectal Cancer Database, the electronic medical record, and operative notes. The Concord Colorectal Cancer Database is a prospectively maintained institutional database used for clinical audit, quality assurance, and service evaluation of colorectal cancer care. It was not developed specifically for this study; however, it contains systematically collected demographic, tumour, treatment, and follow-up information for all colorectal cancer patients managed at our centre. The variables relevant to this study were complete within the database, and any missing data from other sources are reported in the manuscript.

Additional clinical variables—including operative findings, anastomosis height, surgical technique, postoperative complications, and details of neoadjuvant and adjuvant therapy—were extracted directly from the electronic medical record and operative notes. Data extraction involved review of the full electronic chart for each patient. Extraction was performed by a single investigator, consistent with standard practice for observational clinical studies. The combined use of a prospectively maintained database and contemporaneous clinical documentation ensured completeness and accuracy of the data used for analysis and modelling.

The LARS Score

The LARS score is a 5-item validated instrument to assess the severity of bowel dysfunction and its impact on quality of life after anterior resection surgery [6]. Scores are assigned to each response in the item, with a total of 42 points. The overall score is categorised as no LARS (0-20), minor LARS (21-29), and major LARS (30-42).

Bladder and sexual function screening

Patients completed a questionnaire for screening bladder and sexual dysfunction after anterior resection surgery and treatment. This questionnaire consisted of 4 dichotomous questions which patients responded with either a Yes or No for the presence of symptoms. Patients were asked to elaborate if they answered yes to a question (supp file 1).

Statistical Analysis

Patient characteristics and symptom prevalence were summarised using descriptive statistics. Categorical variables were reported as frequencies and percentages. Changes in symptom distribution between baseline and follow-up were examined using cross-tabulations. Associations between LARS category (No, Minor, Major) and bladder or sexual dysfunction were assessed with logistic regression, reporting odds ratios (OR) and 95% confidence intervals (CI), using “No LARS” as the reference. Separate models were fitted for baseline and follow-up.

Change in LARS score over time was evaluated using generalised estimating equations (GEE), modelling time as months since baseline. Predictors of LARS severity (Major vs. No/Minor) were identified using multivariable logistic regression. Variables included were selected *a priori* based on clinical relevance and evidence from previous literature (age, BMI, smoking status, anastomotic distance from anal verge, stoma formation, and neoadjuvant/ adjuvant therapy). ORs with 95% CIs and p-values were reported. Analyses were conducted using a complete case approach (n=116

baseline; n=105 follow-up); participants with missing outcome or covariate data were excluded from the respective analyses. No imputation was performed due to the low proportion of missing data (<10%). Significance was set at $p<0.05$. All analyses were performed in SPSS 31.0.

Results

A total of 116 patients were included in the study. The mean age was 64.3 ± 12.9 years (range 27–90), and two-thirds were male (66.4%, n=77). The mean BMI was 25.9 ± 4.5 kg/m² (range 17.0–38.2; n=111). Current smoking and alcohol consumption were reported by 6.9% and 36.2% of participants, respectively (Table 1).

Half of the cancers were located in the rectum (50.0%). The majority had Stage III disease (59.5%). Most patients underwent surgery via a laparoscopic approach (87.9%). High anterior resection was the most commonly performed procedure (52.6%), followed by ultra-low anterior resection (27.6%) and low anterior resection (19.8%). Stapled anastomosis was used in 96.6% of cases, with the most common being end-to-end anastomosis (89.7%). Anastomotic distance from the anal verge was ≥11 cm in 47.4%, 6–10.9 cm in 26.7%, and ≤5.9 cm in 25.9%.

A temporary stoma was formed in 28.4% of patients, with a mean duration *in situ* of 7.5 ± 4.4 months (range 1–20). Anastomotic leak occurred in 0.9% (n=1). Neoadjuvant radiotherapy was administered to 11.2% of patients, while 62.1% received adjuvant chemotherapy. The mean time from bowel continuity restoration to the baseline questionnaire was 16.8 ± 13.4 months (median 11), and the mean interval between baseline and follow-up questionnaires was 14.2 ± 4.2 months (median 13).

LARS, Bladder, and Sexual Symptoms at Baseline and Follow-up

At baseline, a mean of 16.8 months (range 6-72 months) since bowel continuity was restored, major LARS was present in 17/116 patients (14.7%), minor LARS in 21/116 (18.1%), and no LARS in 78/116 (67.2%). At follow-up (n=105), a mean of 14.2 months (range 7-42 months) later, the proportion with major LARS decreased to 8/105 (7.6%), minor LARS to 15/105 (14.3%), while no LARS increased to 82/105 (78.1%). Bladder symptoms were reported by 36/116 (31.0%) at baseline and 28/105 (26.7%) at follow-up. Sexual symptoms were reported by 28/116 (24.1%) at baseline and 12/105 (11.4%) at follow-up (Table 2). Missing follow-up data (n=11) were due to cancer recurrence (n=7) or loss to follow-up (n=4) (Figure 1).

Among rectal cancer patients, 28/58 (48.2%) reported LARS symptoms at baseline, with 14/58 (24.1%) experiencing major LARS and 14/58 (24.1%) minor LARS. At follow-up, major LARS decreased to 6/54 (11.1%), while minor LARS remained similar at 12/54 (22.2%). Bladder symptoms were reported by 19/58 (32.8%) patients with rectal cancer at baseline and 18/54 (33.3%) at follow-up, showing minimal change. Sexual symptoms were present in 22/58 (37.9%) rectal cancer patients at baseline but decreased to 11/54 (20.4%) at follow-up (Table 2)

Low Anterior Resection Syndrome and its Association with Bladder and Sexual Dysfunction

Across both baseline and follow-up questionnaires, the LARS categories did not show a statistically significant association with bladder dysfunction at the overall model level (baseline: $\Delta\chi^2(2) = 2.59$, $p = 0.275$; follow-up: $\Delta\chi^2(2) = 3.92$, $p = 0.141$), and effect sizes were small (McFadden $R^2 \leq 0.03$). Although statistical significance was not achieved, the findings suggest possible clinically relevant differences in absolute risk. At baseline, patients classified with major LARS had more than twice the odds of experiencing bladder dysfunction compared to those with no LARS (OR=2.41, 95% CI 0.82–7.08, p=.109). Minor LARS showed no meaningful association (OR=1.36, 95% CI 0.48–3.83, p=0.563). At follow-up, there was a non-significant trend for minor LARS to be associated with increased odds

of bladder dysfunction (OR=2.71, 95% CI 0.87–8.42, p=0.084), while major LARS showed no evidence of increased risk (OR=0.44, 95% CI 0.05–3.82, p=0.459) (Table 3).

Across both baseline and follow-up questionnaires, logistic regression analyses indicated an association between LARS severity and sexual dysfunction at the overall model level (baseline: $\Delta\chi^2(2) = 7.69$, $p = 0.021$; follow-up: $\Delta\chi^2(2) = 6.39$, $p = 0.041$), and effect sizes were modest (McFadden $R^2 = 0.060–0.089$). At baseline, individuals with major LARS had significantly higher odds of sexual dysfunction compared to those with no LARS (OR=4.45, 95% CI 1.45-13.67, p=0.009), with a non-significant trend observed for minor LARS (OR=2.50, 95% CI 0.84-8.42, p=0.098). At follow-up, minor LARS was associated with increased odds (OR = 6.33, 95% CI 1.63-24.64, p=0.008) of sexual dysfunction, whereas major LARS showed no statistically significant association (OR = 1.81, 95%CI 0.19-17.24, p=0.606) (Table 3).

Longitudinal recovery of LARS from baseline to follow-up assessment

In the follow-up questionnaire, patients classified as major LARS at baseline improved in 9/13 (69%) cases (95% CI 42–87%). Specifically, 4/13 (31%; 95% CI 13–58%) shifted to minor LARS and 5/13 (38%; 95% CI 18–64%) transitioned to no LARS. Among those with minor LARS at baseline, 13/19 (68%, 95% CI 46–85%) improved to no LARS. No individuals progressed from minor to major LARS. Most participants initially presenting with no LARS at baseline remained in that category at follow-up (64/73, 88%), with small proportions shifting to minor (7%) or major LARS (5%) (Figure 2). GEE analysis showed the LARS score decreased by 0.19 points per month on average ($B = -0.192$, 95% CI −0.333 to −0.051, $p = 0.007$). This equates to an average reduction of 2.30 points over 12 months (supp file 2).

Predictors of LARS Severity at baseline

An ordinal logistic regression (proportional-odds) model significantly improved fit over the intercept-only model ($\chi^2(10) = 30.94$, $p < 0.001$) and showed no lack of fit (deviance = 158.4, df = 210, p = 0.997). Current smoking status (OR = 6.71, 95% CI 1.33–33.92, p = 0.021) and anastomotic distance from anal verge of 0–5.9 cm versus ≥11 cm (OR = 9.56, 95% CI 2.06–44.35, p = 0.004) were associated with higher odds of worse LARS category. Other variables, including age, sex, BMI, stoma formation, neoadjuvant radiotherapy and adjuvant chemotherapy, were not statistically significant (Table 4).

Discussion

Our prospective cohort study showed that LARS remains common among distal CRC patients more than six months after restoring bowel continuity, with one third of patients reporting LARS symptoms (almost half in the rectal cancer subgroup). Sexual dysfunction was strongly linked to LARS severity, whereas bladder symptoms showed weaker, non-significant trends. Spontaneous recovery was limited after six months, with smoking and low anastomotic height identified as significant risk factors.

Our finding of higher LARS in patients with rectal cancer aligns with previous studies showing that more patients undergoing resection for rectal cancer met the criteria for major LARS compared to those having a resection for sigmoid cancer [9]. However, the prevalence of major LARS in our study was at the lower end of the reported range compared to the literature, where studies indicated 18-56% of CRC patients reported LARS, with pooled estimates of 41-44% based on meta-analyses at ≥12 months after sphincter-preserving surgery [7-9]. This difference may be due to variations in case mix, as our study also included high anterior resections for sigmoid cancer, a group typically associated with lower LARS severity. Additionally, our cohort had a low rate of neoadjuvant

radiotherapy and anastomotic leaks, both recognised risk factors for severe LARS [16, 17]. These factors might explain the reduced symptom burden observed in our population.

LARS has a functional interrelationship with sexual and bladder functions following anterior resection, as they share anatomical and neural pathways. Both sphincter-preserving bowel surgery and radiotherapy may cause autonomic and somatic neuropathy within the pelvic plexus, potentially leading to impaired pelvic floor muscle strength, coordination, and rectal sensation, which can contribute to bowel, bladder, and sexual dysfunction [11, 18]. Studies have reported that up to one-third of patients with LARS experience urinary symptoms and sexual dysfunction, reflecting this neurogenic overlap [11, 18]. Our findings deepen the understanding of pelvic dysfunction symptoms and LARS, with major LARS associated with worse sexual dysfunction at baseline, while minor LARS predicted subsequent sexual and bladder symptoms during follow-up. These differing patterns highlight that pelvic organ dysfunction does not follow a uniform trajectory, with patients experiencing variable and evolving symptoms over time. This variability suggests that survivorship care should be responsive to individual symptom profiles rather than relying on a single standardised model, with multidisciplinary input and staged support considered where clinically appropriate to address bowel, bladder, and sexual function needs as they arise.

LARS showed a trajectory of natural recovery, with over two-thirds of patients with major LARS at baseline improving in our study. This agrees with existing long-term studies indicating that bowel function after sphincter-preserving surgery slowly improves, although the timing and extent of recovery varies across publications. Several studies describe that most recovery occurred within the first 12 to 18 months before reaching a plateau [7, 13, 14, 19]. In our cohort, the mean improvement in LARS score was 2.30 points over 12 months from our baseline questionnaire, which is below the minimal clinically important difference of 5 points in the LARS score, a threshold used in a recent large, ongoing multicentre randomised controlled trial assessing LARS treatment outcomes [20],

suggesting that late spontaneous recovery may be limited. Our findings highlight the need to recognise the degree of spontaneous improvement that typically occurs and to assess which symptoms are likely to improve naturally and which require targeted intervention. This interpretation is consistent with the MANUEL guidelines, which emphasise understanding natural recovery patterns [21]. The broader literature presents differing viewpoints: some authors advocate for early, proactive management, while others note the practical challenges of delivering labour-intensive interventions such as pelvic floor rehabilitation early after surgery and report no significant difference in 12-month outcomes between early intervention and usual care [22-24]. Taken together, these findings indicate that the optimal timing of rehabilitation remains uncertain and requires further evaluation.

LARS severity is associated with current smoking and a shorter anastomotic distance from the anal verge in our study. This finding aligns with existing literature, which reports that a shorter anastomotic distance is strongly associated with LARS, often due to anatomical changes such as significant resection reducing the reservoir capacity of the neorectum and an increased risk of pelvic nerve injury from extensive pelvic dissection [7, 25]. Additionally, this study found that current smoking is an independent risk factor for impaired bowel function after rectal cancer surgery, possibly through mechanisms involving microvascular damage and delayed tissue healing [25]. Conversely, our study did not find associations between LARS severity and other previously reported risk factors, such as radiotherapy, stoma formation, and its duration [7, 25]; the absence of a link between radiotherapy or stoma formation and LARS severity may be due to the timing of assessment, as patients in our study were evaluated at least six months after bowel continuity was restored, by which time early postoperative effects, such as bowel adaptation immediately after reversal and radiotherapy-related neuropathy and fibrosis, have stabilised.

These findings offer further valuable information about the prevalence, impact, and recovery prospects of LARS among CRC patients, which has significant implications for delivering targeted interventions to support additional functional recovery beyond the first postoperative year. Preoperative counselling about potential recovery, prehabilitation, and intensive functional rehabilitation can be provided to patients at higher risk of LARS. This study also provides insights from a surgical perspective when comparing functional outcomes with other treatment options, such as watch-and-wait and total neoadjuvant therapy, which are increasingly being incorporated into the management of distal colorectal cancer.

Strengths

This study was designed as a prospective observational cohort, which minimises recall bias and allows for the temporal assessment of functional outcomes. We included the evaluation of pelvic organ dysfunction occurrence, providing an understanding of other physical challenges, such as bladder and sexual dysfunction, that patients potentially encounter in CRC survivorship. Furthermore, the detailed clinical data collection enables a more nuanced interpretation of risk factors and symptom trajectories. Compared to meta-analyses, which often rely on heterogeneous retrospective data, a prospective clinical study like ours offers more granular insights into longitudinal outcomes and patient-level variability, which are essential for developing personalised care pathways.

Limitations and Future Research

We acknowledge several methodological limitations. This was a single-centre study, which may limit generalisability to settings with different surgical practices, case-mix, or demographic characteristics, particularly centres managing more low rectal cancers or using different neoadjuvant protocols. The modest sample size (n = 116) limits statistical power to detect associations for several known risk factors—such as radiotherapy, chemotherapy, and stoma-related variables—and the

ability to perform subgroup analyses. Although the study was prospective, residual confounding remains possible for factors not systematically captured, including detailed radiotherapy parameters, preoperative pelvic floor function, and informal symptom-management strategies.

Variability in the timing of baseline and follow-up assessments also introduces uncertainty. Although all patients were assessed more than six months after restoration of bowel continuity, recruitment during routine follow-up led to heterogeneity in baseline timing, with follow-up occurring 12 months after each individual's baseline. This variation may reduce precision in interpreting early versus later recovery trajectories.

The absence of a standardised intervention pathway for LARS is a limitation. Patients occasionally received ad hoc dietary advice or over-the-counter medications, but these were not consistently documented and could not be included as formal variables, contributing to potential outcome heterogeneity.

A further limitation relates to the interpretation of risk-factor analyses. Several predictors known to influence LARS in prior studies—such as pelvic radiotherapy, chemotherapy, age, BMI, and stoma formation—were not statistically significant in our cohort. However, effect estimates were directionally consistent with published evidence but imprecise, with wide confidence intervals, suggesting that the lack of significance likely reflects limited sample size and reduced statistical power rather than a true absence of association.

Future multicentre studies with larger cohorts, standardised assessment intervals, systematic documentation of symptom-management strategies, and longer follow-up are needed to improve

generalisability, enable robust modelling of risk factors, support meaningful subgroup analyses, and better characterise long-term recovery trajectories.

Conclusion

Our study demonstrates the ongoing burden of LARS and the association with pelvic dysfunction among CRC patients, highlighting the limited natural improvement beyond the initial post-treatment recovery phase. Recognising current smoking and low anastomotic height as risk factors highlights the necessity for early risk assessment. The heterogeneity and evolution of bowel, bladder, and sexual symptoms observed in this cohort highlight the need for survivorship care that is responsive to individual functional trajectories, with routine assessment and consideration of rehabilitation once natural recovery has stabilised to support long-term outcomes.

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Figure 1. Study Recruitment

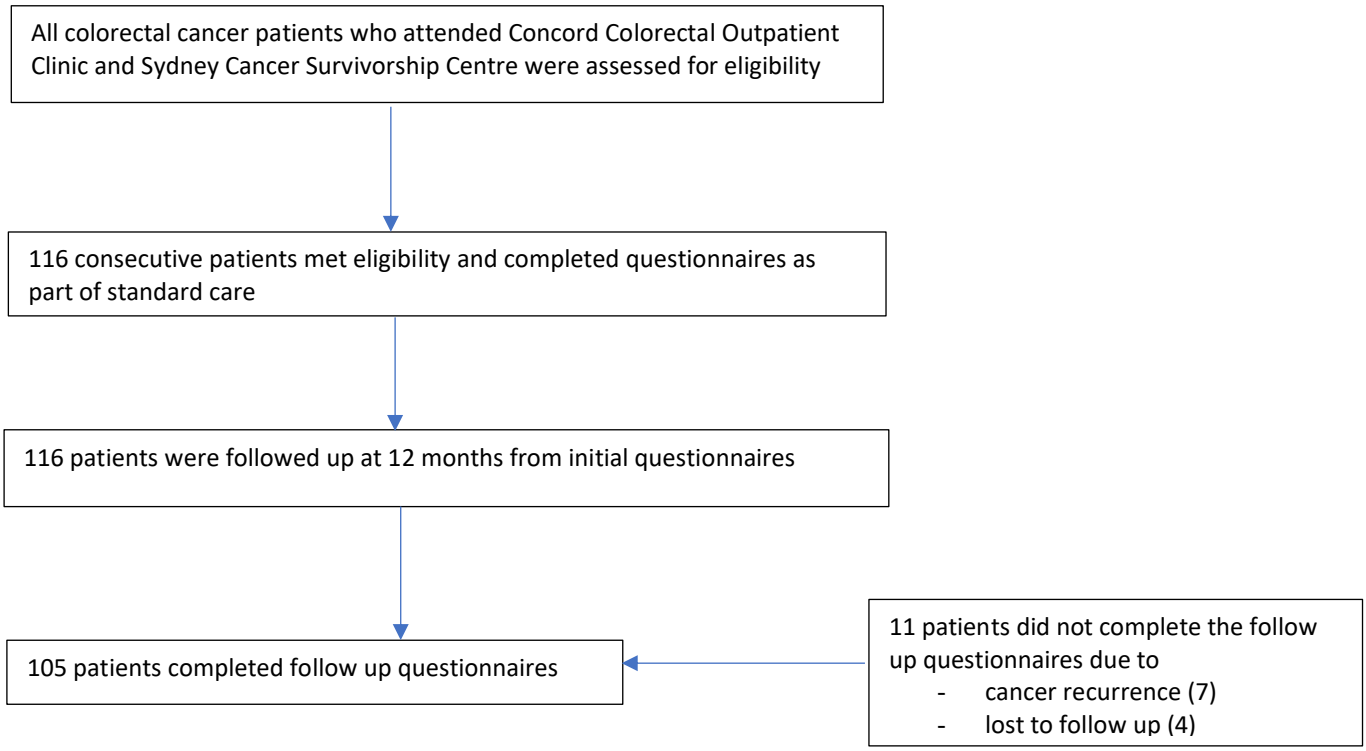


Table 1. Baseline Characteristics (n=116)

Demographics	
Age [mean ± SD (range)] (years)	64.3 ± 12.9 (27–90); n=116
Sex [n (%)] Male Female	 77 (66.4) 39 (33.6)
Body Mass Index (BMI) [mean ± SD (range)] (kg/m2) Missing data	25.9 ± 4.5 (17.0–38.2) 4
Smoking History [n (%)] Never	 65 (56.0)

Previous	43 (37.1)
Current	8 (6.9)
Alcohol Consumption	
Yes	42 (36.2)
No	73 (62.9)
Missing data	1 (0.9%)
Cancer characteristics	
Cancer location [n (%)]	
Sigmoid	58 (50.0)
Rectum (high)	22 (19.0)
Rectum (mid)	26 (22.4)
Rectum (low)	10 (8.6)
Cancer stage [n (%)]	
Stage I	22 (19.0)
Stage II	22 (19.0)
Stage III	69 (59.5)
Stage IV	3 (2.6)
Operative details	
ERAS pathway	
Yes	72 (62.1)
No	44 (37.9)
Operative approach [n (%)]	
Laparoscopic	102 (87.9)
Robotic	4 (3.4)
Laparotomy (open)	9 (7.8)
Laparoscopic converted to open	1 (0.9)
Type of surgical procedure [n (%)]	
High Anterior Resection	61 (52.6)
Low Anterior Resection	23 (19.8)
Ultra-low Anterior Resection	32 (27.6)
Anastomotic technique	
Staple	112 (96.6)
Handsewn	4 (3.4)

Anastomosis type End-to-end Side-to-end Coloanal	 104 (89.7) 8 (6.9) 4 (3.4)
Distance of anastomosis from anal verge 0 –5.9 cm 6–10.9 cm >=11 cm	 30 (25.9) 31 (26.7) 55 (47.4)
Stoma & anastomotic outcomes	
Temporary stoma formed Yes No	 33 (28.4) 83 (71.6)
Duration of temporary stoma [mean ± SD (range)] (months); n=33 (people had temporary stoma)	7.5 ± 4.4 (1–20)
Anastomotic leak Yes No	 1 (0.9) 115 (99.1)
Neoadjuvant/adjuvant therapy	
Neoadjuvant radiotherapy Yes No	 13 (11.2) 103 (88.8)
Neoadjuvant chemotherapy Yes No	 10 (8.6) 106 (91.4)
Adjuvant chemotherapy Yes No	 72 (62.1) 44 (37.9)
Follow-up timing	
Time since bowel continuity restored to baseline questionnaire [mean ± SD (range)] (months) Median	16.8 ± 13.4 (6–72) 11

Time between baseline and follow-up questionnaire [mean ± SD (range)] (months)	14.2 ± 4.2 (7-42)
Median	13

ERAS = Enhanced recovery after surgery
SD = Standard deviation

Table 2. Bowel, Bladder and Sexual Symptoms at baseline (n=116) and follow-up (n = 105)

Symptoms	N (%)			
	Baseline (n = 116)		Follow-up (n = 105)	
	Sigmoid Cancer (n = 58)	Rectal Cancer (n = 58)	Sigmoid Cancer (n = 51)	Rectal Cancer (n = 54)
Bowel Symptoms				
- Major LARS	3 (5.2)	14 (24.1)	2 (3.9)	6 (11.1)
- Minor LARS	7 (12.1)	14 (24.1)	3 (5.2)	12 (22.2)
- No LARS	48 (82.8)	30 (51.7)	46 (79.3)	36 (66.7)
Bladder Symptoms				
Yes	17 (29.3)	19 (32.8)	10 (19.6)	18 (33.3)
- Urinary frequency	13	10	4	5
- Voiding Issue	1	10	2	7
- Urinary Incontinence	6	5	6	8
No	41 (70.7)	39 (67.2)	41 (80.4)	36 (66.7)
Sexual Symptoms				
Yes	6 (10.3)	22 (37.9)	1 (2.0)	11 (20.4)
- Erectile Dysfunction	3	18	1	6
- Premature	0	1	0	0
Ejaculation	0	2	0	1
- Decreased Libido	0	0	0	2
- Dry Orgasm	0	1	0	0
- Vaginal Stenosis	1	0	0	0
- Vaginal Dryness	2	1	0	2
- Declined to answer	52 (89.7)	36 (62.1)	50 (98.0)	43 (79.6)
No				

Missing at follow-up = 11: Cancer Recurrence = 7; Lost to follow up = 4
Some patients reported more than one bladder and sexual symptom
LARS = Low anterior resection syndrome

Table 3. Association of Low Anterior Resection Score (LARS) Category with Sexual and Bladder Dysfunction at Baseline and Follow-up

Outcome	LARS Category	OR (95% CI)	p-value	Predicted Probability
Bladder Function (Baseline)	No LARS	—	—	26.9%
	Minor	1.36 (0.48–3.83)	.563	33.3%
	Major	2.41 (0.82–7.08)	.109	47.1%
Bladder Function (Follow-up)	No LARS	—	—	24.4%
	Minor	2.71 (0.87–8.42)	.084	46.7%
	Major	0.44 (0.05–3.82)	.459	12.5%
Sexual Function (Baseline)	No LARS	—	—	16.7%
	Minor	2.50 (0.84–7.40)	.098	33.3%
	Major	4.45 (1.45–13.67)	.009	47.1%
Sexual Function (Follow-up)	No LARS	—	—	7.3%
	Minor	6.33 (1.63–24.64)	.008	33.3%
	Major	1.81 (0.19–17.24)	.606	12.5%

Note: ORs from logistic regression (reference = No LARS). LARS = Low anterior resection syndrome

Figure 2. Transition Heatmap of LARS Category between baseline and follow up (Counts with row percentages)

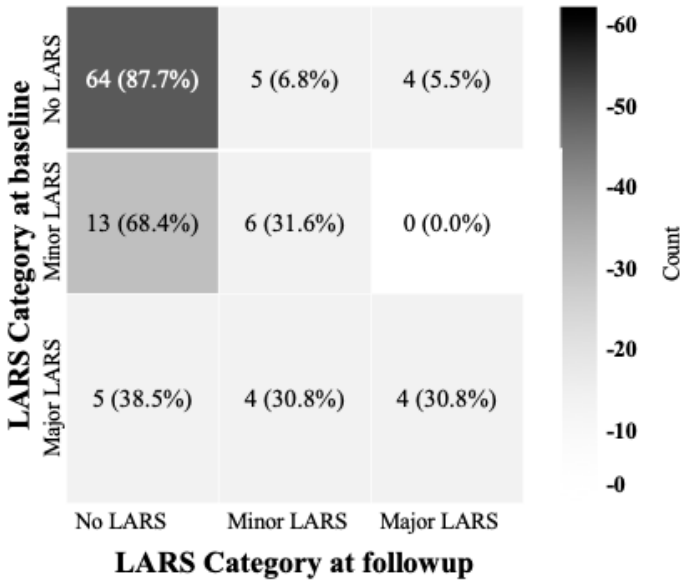


Table 4. Odds Ratios for Predictors of LARS Severity

Predictor	Odds Ratio (OR)	95% CI	p-value
Smoking: current (vs never)	6.71	1.33 – 33.92	0.021
Distance 0–5.9 cm (vs ≥11 cm)	9.56	2.06 – 44.35	0.004
Distance 6–10.9 cm (vs ≥11 cm)	1.94	0.60 – 6.35	0.270
Smoking: previous (vs never)	1.57	0.55 – 4.49	0.403
Age (per year)	0.97	0.93 – 1.01	0.091
BMI (per unit)	1.03	0.94 – 1.14	0.542
Stoma formed: Yes (vs No)	1.14	0.29 – 4.54	0.850
Neoadjuvant RT: yes (vs no)	1.52	0.36 – 6.37	0.568
Adjuvant chemo: yes (vs no)	1.47	0.52 – 4.12	0.467

Distance = distance (cms) from anal verge

Supplementary file 2.1 Study survey

Supp file 1 - Survey

Bowel, Bladder and Sexual Function Questionnaire

Name: _____

Date: _____

Put a tick in the box next to the answer of your choice

Please answer all questions

1. **Do you have other concerns about your bowel function that were not asked in the Bowel Function (LARS) questionnaire?**

   Yes ☐ No ☐

   If YES, please describe:

   _____

   _____

2. **Do you have any concerns about your bladder function?**

   Yes ☐ No ☐

   If YES, please describe:

   _____

   _____

3. **Do you have any concerns about your sexual function?**

   Yes ☐ No ☐

   If YES, please describe:

   _____

   _____

   _____

4. **Would you be interested in learning about a study that may help your bowel problems?**

   Yes ☐ No ☐

Low anterior resection syndrome (LARS) score

Name: _____

Date: _____

The aim of this questionnaire is to assess your bowel function. Please tick only one box for each question. It may be difficult to select only one answer, as we know that for some patients symptoms vary from day to day. We would kindly ask you to choose one answer which best describes your daily life. If you have recently had an infection affecting your bowel function, please do not take this into account and focus on answering questions to reflect your usual daily bowel function.

1. Do you ever have occasions when you cannot control your flatus (wind)?

□ No, never
□ Yes, less than once per week
□ Yes, at least once per week

2. Do you ever have any accidental leakage of liquid stool?

□ No, never
□ Yes, less than once per week
□ Yes, at least once per week

3. How often do you open your bowels?

□ More than 7 times per day (24 hours)
□ 4-7 times per day (24 hours)
□ 1-3 times per day (24 hours)
□ Less than once per day (24 hours)

4. Do you ever have to open your bowels again within one hour of the last bowel opening?

□ No, never
□ Yes, less than once per week
□ Yes, at least once per week

5. Do you ever have such a strong urge to open your bowels that you have to rush to the toilet?

□ No, never
□ Yes, less than once per week
□ Yes, at least once per week

Supplementary file 2.2 Additional data

Supp File 2. Change in LARS Score per Month (Generalised Estimating Equation Model)

Predictor	B (Mean Change)	95% CI	Wald Chi-Square	p-value
Intercept (Baseline)	13.12	10.74 to 15.49	117.45	<.001
Months since baseline	-0.19	-0.33 to -0.05	7.15	.007

Model details: GEE with Gaussian distribution, identity link, robust SEs, independent correlation structure. Negative B indicates improvement (lower LARS score). LARS = Low anterior resection syndrome

Chapter 3: Supporting psychological readiness for bowel function recovery before surgery: A feasibility study of preoperative video education in colorectal cancer care

Overview

As indicated in the previous chapter, cancer survivors with LARS continue to experience bowel symptoms months after surgery. This highlights the need for pre-surgery counselling to help patients anticipate potential bowel changes and to set realistic recovery expectations. This chapter describes a prospective study assessing the usefulness of video-based education and bowel function recovery before bowel cancer surgery. The results indicate that pre-operative pelvic floor education videos are a feasible educational tool and show patients were psychologically prepared for recovery. This study adds to the growing body of evidence supporting patient education and counselling on colorectal cancer care.

This chapter has been submitted for publication to a peer-reviewed journal and is currently under review. The manuscript is quoted verbatim and formatted according to the requirements of the journal.

Contribution of authors

I, Kin Yin Chan was responsible for study conceptualisation and intervention design and video production, project administration, dataset management and analysis, and drafting and finalising manuscript.

Michael Suen developed the concept, designed the intervention, performed data analysis and reviewed the manuscript

Jess Yanlan Lin was responsible for participant recruitment

Janindra Warusavitarne reviewed the manuscript

Susan Coulson reviewed the manuscript

Janette Vardy developed the concept, designed the intervention and reviewed the manuscript

Abstract

Purpose: Low anterior resection syndrome (LARS) and bowel symptoms are common after colorectal cancer (CRC) surgery. Limited preoperative preparation may result in mismatched expectations and suboptimal functional recovery. This study evaluates the feasibility and acceptability of video-based education in preparing patients for functional recovery after colorectal surgery.

Methods: Prospective, single-arm study conducted from March 2023 to December 2024 involved patients with stage I-III or limited-stage IV CRC treated with curative intent. Preoperatively, participants watched four 10-minute videos created by healthcare professionals. Primary outcome was feasibility. Secondary outcomes included: acceptability, changes in knowledge and distress, patient's perceived level of enablement, self-efficacy and empowerment, satisfaction via pre- and post-intervention surveys. Descriptive statistics were used.

Results: Participation rate was 70% (29 consented of 43 eligible patients). Among 28 participants, 27 watched all videos and 1 withdrew. Knowledge and distress levels improved. High levels of enablement, self-efficacy and empowerment were observed. Satisfaction level >80%.

Conclusions: Preoperative educational videos are feasible, acceptable and may have a role in supporting patients' psychological readiness and perceived capability to anticipate bowel function changes postoperatively. This study will inform a future randomised controlled trial.

Keywords: Low Anterior Resection Syndrome, Preoperative education, Colorectal Cancer, Educational videos, Psychological capability, Empowerment

Introduction

Patient education is essential for improving health outcomes and personal well-being. In modern cancer care, multimodal prehabilitation models emphasise the importance of informing patients to optimise physical and psychological readiness and to establish realistic expectations for recovery during upcoming surgery and treatments [1-3]. Incorporating multimedia tools into educational strategies can improve patients' understanding of complex health conditions and diseases [4]. However, many patients remain unaware of the significant impact of common post-surgical issues such as Low Anterior Resection Syndrome (LARS) and bowel dysfunction following colorectal cancer (CRC) treatment until after symptoms emerge, emphasising the need for proactive education.

Up to 80% of patients experience changes in bowel function following colorectal cancer surgery [5]. LARS, which results from surgeries for sigmoid and rectal cancers, includes bowel symptoms related to alterations in storage and evacuation functions, bowel motion consistency, and routine predictability. A systematic review found that about 40% of patients develop major LARS after rectal cancer resection [6], while LARS-like symptoms are increasingly recognised after colon cancer surgery (ranging from right sided to distal colon) [7-9]. This postoperative challenge significantly impacts a person’s overall physical and psychological recovery trajectories and their long-term function and quality of life (QOL).

Despite the high prevalence of bowel dysfunction, significant gaps persist in patient education about LARS and related dysfunctional symptoms. Patients frequently experience delays in receiving consistent information, often not until weeks after surgery, or when LARS symptoms fail to resolve spontaneously. This information is critical for understanding the condition and managing it effectively [10-16]. Our previous research examined (Chan, unpublished data, 2025) patients’ lived experience with LARS and revealed that they faced substantial delays in accessing sufficient and

accurate information from health professionals, which was essential for understanding their condition and making appropriate adjustments and coping strategies during recovery [17].

Current preoperative counselling about LARS and bowel function recovery remains inadequate, as discussions mainly focus on curative treatment while providing inconsistent, non-specific information about long-term bowel function [18-22]. Consequently, patients often enter surgery with unrealistic expectations regarding the restoration of normal bowel function, which can limit their ability to manage symptoms effectively [23].

Effective communication and supportive care that address patients' emotional and informational needs enhance psychological capacity and self-efficacy. These are essential for empowering patients to engage in behaviour change and achieve optimal long-term bowel function recovery following CRC surgery. Although various information delivery modalities have been investigated, no standardised approach exists. Video-based preoperative education offers distinct benefits for supportive care, including accessibility, scalability, and consistent delivery by trusted healthcare professionals in non-clinical environments without time constraints. Evidence demonstrates that such interventions provide empowerment and self-efficacy in CRC patients [24]. Patients are less likely to be overwhelmed by a significant amount of information in a non-stressful environment when it is received at a self-paced viewing, which allows for better information retention. Comprehensive preoperative video education increases condition understanding, psychological readiness, and sets realistic expectations, therefore empowering patients to make effective behaviour change in regaining control of function and quality of life [14, 23].

Knowledge gaps hinder self-efficacy and behaviour change. In theories of enablement and empowerment, knowledge underpins an individual’s psychological capability to promote behaviour change [25]. Enablement acts as a catalyst for empowerment; when people gain knowledge and develop essential skills along with external supports, they perceive themselves as confident and in

control, which encourages a proactive approach to better health outcomes [25, 26]. This framework guided the approach for LARS information dissemination and education during the early phase of care management. While there is an adjustment of expectations and reinterpretation of symptoms during recovery, shaped by patients' perspectives and experiences, the information helps develop self-managed strategies within guided and controlled settings [27-29].

Currently, there is a paucity of literature on preoperative video education regarding functional recovery after CRC surgery. Most previous studies focused on a combined approach incorporating education as part of LARS management in the postoperative phase. Feasibility and acceptability data to support scale-up are lacking, and evidence on the efficacy of preoperative education in measuring outcomes related to enablement and empowerment in bowel function recovery after CRC is limited [26, 27].

This study aims to evaluate the feasibility of a pre-operative educational video for people preparing for CRC surgery, recognising that bowel dysfunction and LARS-like symptoms may occur across surgical subgroups. The secondary objectives are to assess intervention acceptability and to explore the preliminary effects of video-based education on patients' psychological readiness for functional recovery after surgery.

Methods

Study Design

This is a non-randomised, single-arm, prospective study that evaluates the feasibility, acceptability and behavioural impact of educational videos for patients prior to curative-intent surgery for CRC. The study recruitment occurred at Concord Repatriation General Hospital (CRGH), a tertiary teaching hospital in Sydney, Australia, from March 2023 to December 2024.

Participants

Patients referred for admission to CRGH for their surgery were invited to participate. Eligibility criteria included: (i) Confirmed pre-operative clinical staging of stage I-III colorectal cancer, or limited IV CRC (being treated with curative intent); (ii) Elective colorectal cancer resection with or without a temporary stoma scheduled >7 days after referral to the study, allowing video viewing to be completed at least 5 days before the scheduled surgery; (iii) at least 18 years of age; (iv) ability to understand written and spoken English; (v) willingness to provide informed consent; (vi) willingness to participate and comply with study requirements. Exclusion criteria included: (i) inability to understand information due to cognitive difficulties; (ii) surgical resection requiring a permanent stoma. Written consent was obtained from participants before enrolment.

Intervention

After enrolment, participants received instructions and a secure link to access the educational videos, which included an electronic copy of the questionnaires (a paper version of the questionnaire was also available upon request). The intervention consisted of four individual videos, each of 6-10 minutes, which participants viewed on their electronic devices at their own pace, convenience, and in their preferred environment. The educational content was developed collaboratively by a pelvic floor physiotherapist, two colorectal surgeons, a medical oncologist, a dietitian specialising in oncology, and a colorectal cancer clinical nurse consultant. Content selection was based on common patient concerns identified during clinical encounters and pelvic floor rehabilitation. It reflected standard preoperative education practices and expert consensus. Stoma management was included to prepare participants who might need a temporary stoma after surgery and to guide them to appropriate support resources. All scripts underwent review by the research team and consumer representatives to ensure information accuracy and accessibility at an Australian Year 9 English literacy level. Two colorectal patients reviewed the scripts before filming to

assess clarity, relevance and accessibility. Professional film production services were utilised for the final video production. The videos were available in English only.

The four video modules covered:

1. Bowel, bladder, and sexual dysfunction after surgery.

2. General bowel health before and after surgery, including suggestions and advice.

3. Pelvic floor exercise demonstration.

4. Skin care, stoma management, and sexual activity.

The intervention was completed 3-5 days before their scheduled surgery date. Participants completed questionnaires before and immediately after viewing the video. A system-generated alert prompted follow-up phone calls to participants 5 days before surgery if study completion had not been achieved, ensuring timely intervention delivery and addressing any technical difficulties or barriers to participation. Participation in this study did not interfere with routine preoperative colorectal cancer procedures.

Outcomes

Outcome measures were chosen to assess feasibility, acceptability, and preliminary changes in psychological readiness for bowel function (non-specific to LARS) recovery associated with video-based education. Data were collected at two time points: before and after video viewing, using self-administered study-specific questionnaires.

The primary endpoint was feasibility, including recruitment and adherence rates. These were assessed by the percentage of eligible participants enrolled in the study and the number of enrolled participants who watched all four videos, as recorded through data collection in Research Electronic Data Capture (REDCap) and digital analytics of video access.

The secondary endpoints include acceptability and psychological readiness of individuals to cope with potential physical changes caused by CRC cancer and its surgery, as well as bowel function recovery. For acceptability measures, satisfaction, perceived usefulness, and appropriateness were

assessed using a self-reported, investigator-designed, study-specific questionnaire completed at the end of the intervention to determine whether the video was an acceptable method for delivering information about bowel function. The exploratory preliminary changes in individuals' psychological readiness to cope with potential physical changes caused by CRC and its surgery focused on descriptive changes in knowledge, stress levels, and feelings of enablement, self-efficacy and empowerment. These outcomes were measured using self-administered questionnaires, that included both validated instruments and study-specific tools developed by the investigators. The questionnaires included demographic details (before viewing the video), an 18-item true/false knowledge quiz, and the National Comprehensive Cancer Network Distress Thermometer (before and after viewing) [28]; and post-viewing measures of enablement, self-efficacy and empowerment [29-31], as well as satisfaction.

Feasibility justification

The sample size of 25 participants was selected based on recommendations for feasibility studies. This sample was considered adequate to assess the recruitment and retention process, intervention acceptability, and data completeness, while offering a preliminary estimate of outcome variability. This follows the guidance suggesting a minimum of 12 participants for parameter estimation and pragmatic benchmarks commonly used in pilot and feasibility trials [32, 33].

Statistical methods

Data were analysed using SPSS (Version 29.0). Feasibility was defined a priori as successfully recruiting eligible participants and achieving adequate intervention completion within the study period. The recruitment was considered feasible if 30% of eligible patients consented. Intervention completion was defined as successful if 80% of participants viewed the videos in their entirety, in line with benchmarks from previous studies [34, 35]. A threshold of 80% completion for survey items was set to confirm the survey's pragmatic utility in the clinical setting. Demographic characteristics

and exploratory outcomes in psychological readiness, including knowledge change, distress level, and feelings of enablement, self-efficacy and empowerment were reported with descriptive statistics presented as frequencies and percentages for categorical variables and means for continuous variables. A paired samples t-test was performed to compare the rate of correct responses on knowledge questions and their distress levels before and after the intervention. The mean difference between pre- and post-intervention scores was calculated, along with the 95% confidence interval (CI). A p-value less than 0.05 was considered statistically significant, indicating a successful change in knowledge and distress levels and providing preliminary evidence to inform future trial design. Effect size was reported using Cohen's d. For the exploratory evaluation of the preliminary intervention effect on feelings of enablement, self-efficacy and empowerment, an investigator-designed questionnaire was tailored to the specific aims of the intervention. The scoring threshold was established a priori as a mean score $\geq$4 out of 5 to indicate a "high" score, based on conceptual and pragmatic considerations rather than previous validation studies. It was not intended as a definitive clinical cut-off, given the exploratory nature of the evaluation and the lack of prior validated scoring thresholds. This value is generally seen as reflecting strong agreement. Scores were reported descriptively and should be considered provisional for estimating variability in future trial power calculations. Patterns of missing data were examined, and complete case analysis was employed for the primary analysis.

Results

Study recruitment occurred from March 2023 to December 2024, enrolling 29 participants. Figure 1 provides an overview of the recruitment process. Baseline characteristics are outlined in Table 1. No adverse events were reported. Two participants did not complete the post-video survey; therefore, 25 data sets were included in the final analysis.

Feasibility

Of 43 eligible patients approached, 29 consented to participate in the study; a recruitment rate of 70%. One participant withdrew. Of the remaining 28 participants, 27 (96%) watched all videos. One participant did not view all videos due to an earlier rescheduled surgery. Two participants did not complete all the surveys (92.6% survey completion rate). Participants watched the videos more than once (32-44%), particularly the pelvic floor exercise demonstration (Figure 2). Participants (67%) said they practised exercises after watching the videos, and 40% in the survey found the pelvic floor exercise demonstration most helpful.

Figure 1. Study Recruitment

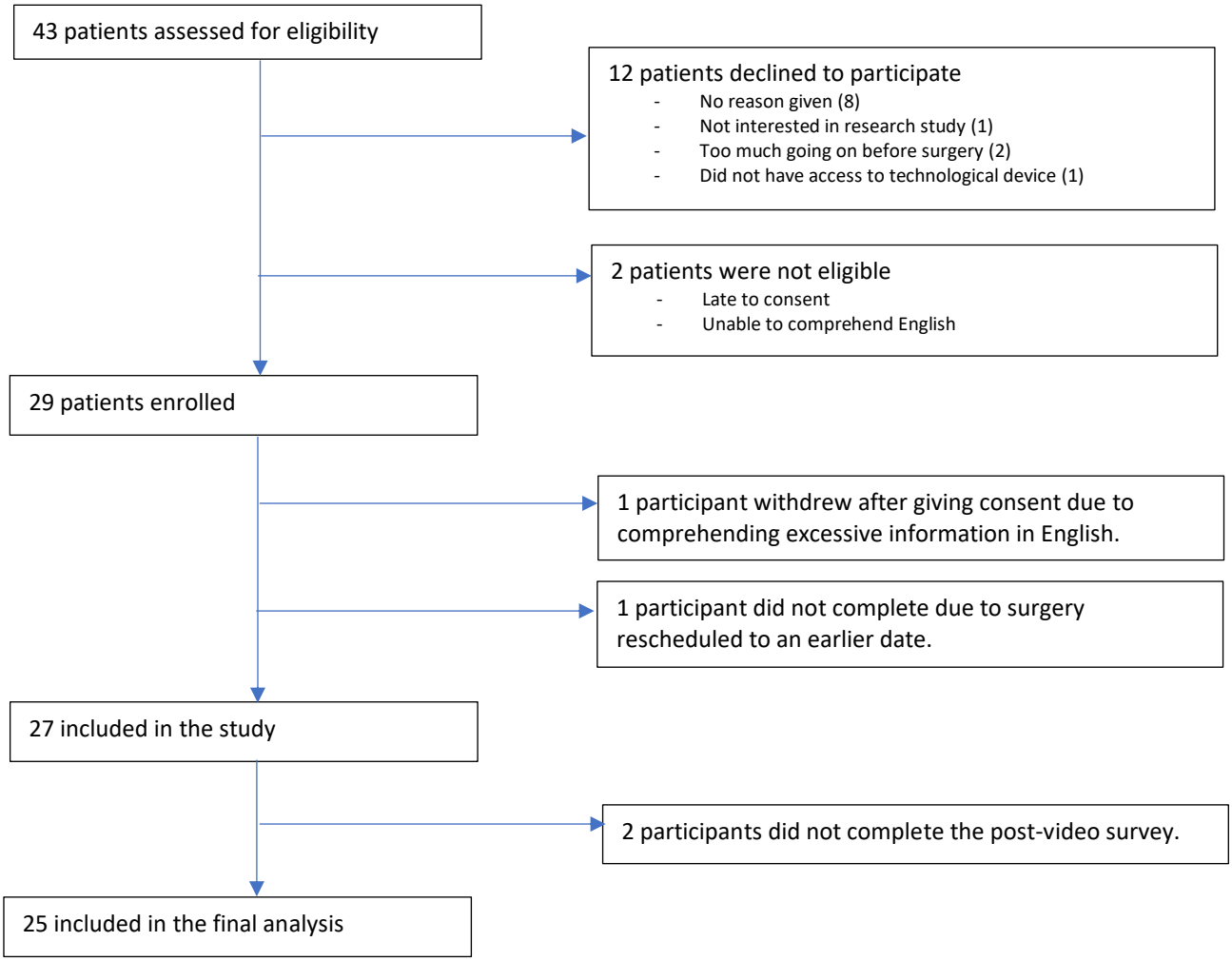
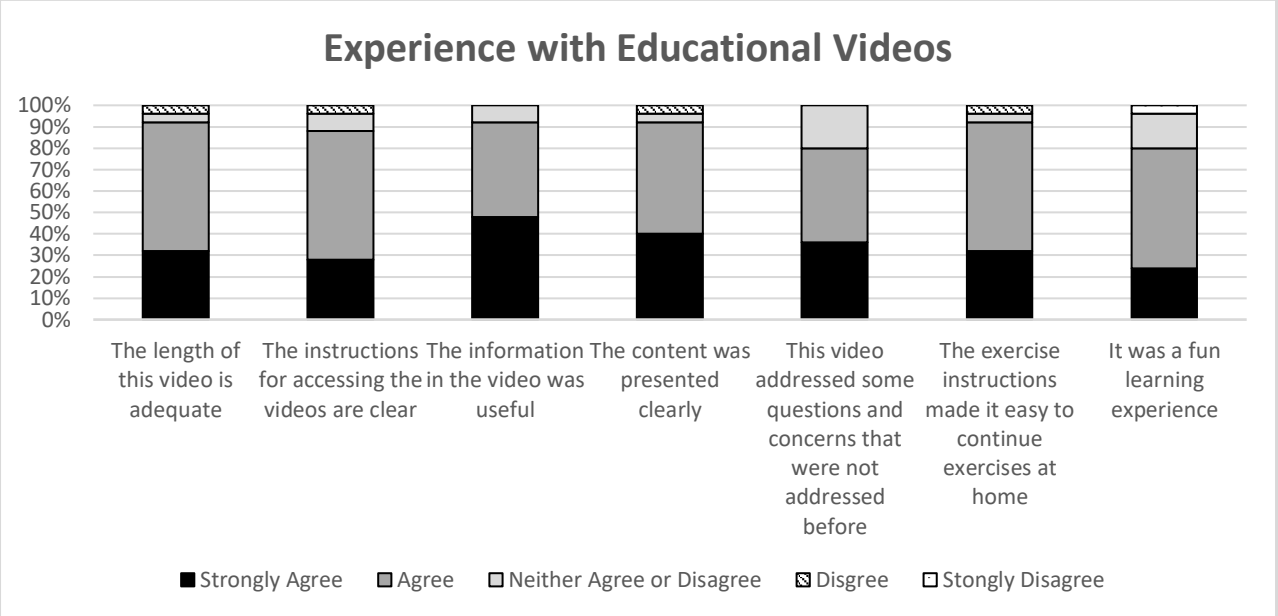


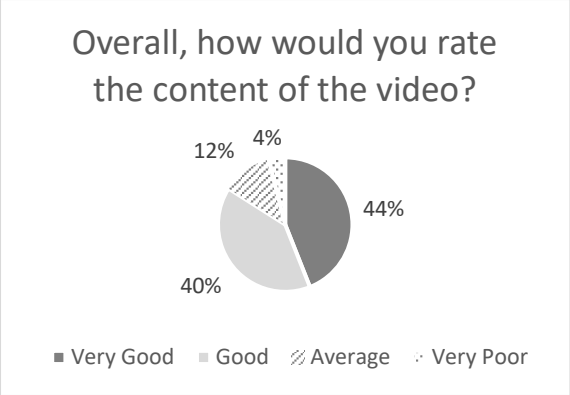
Table 1. Baseline characteristics of participants completed video viewing

Demographics (n=27)	
Age [mean (range)] (year)	59.8 (32-78)
Sex [n (%)]	
- Male	20 (74.1%)
- Female	7 (25.9%)
Body Mass Index [mean (range)] (kg/m^2)	24.6 (18.1 – 33.3)
Marital status [n (%)]	
- Single	2 (7.4%)
- Married	22 (81.5%)
- Defacto	1 (3.7%)
- Divorced	2 (7.4%)
Employment status [n (%)]	
- Employed	15 (55.6%)
- Unemployed	2 (7.4%)
- Retired	10 (37.0%)
Education status [n (%)]	
- Postgraduate Degree Level	1 (3.7%)
- Bachelor Degree Level	4 (14.8%)
- Graduate Diploma and Graduate Certificate Level	7 (25.9%)
- Advanced Diploma and Diploma Level	2 (7.4%)
- Certificate Level	4 (14.8%)
- Secondary Education	9 (33.3%)
Language Spoken at Home [n (%)]	
- Arabic	2 (7.4%)
- Cantonese	6 (22.2%)
- English	8 (29.6%)
- Greek	1 (3.7%)
- Hazaragi	1 (3.7%)
- Mandarin	8 (29.6%)
- Tagalog	1 (3.7%)
Pelvic Surgery History [n (%)]	
- No	27 (100%)
Cancer Stage [n (%)]	
- I	6 (22.2%)
- II	10 (37.0%)
- III	8 (29.6%)
- IV	1 (3.7%)
- Complete Response After Total Neoadjuvant Therapy	1 (3.7%)
- Did not proceed to surgery	1 (3.7%)
Cancer Location [n (%)]	
- Rectum	10 (37.0%)
- Sigmoid	10 (37.0%)
- Descending colon	1 (3.7%)
- Transverse colon	2 (7.4%)
- Ascending colon	3 (11.1%)
- Terminal ileum	1 (3.7%)
Operative Approach [n (%)]	
- Laparoscopic Hand-Assisted	10 (37.0%)
- Laparoscopic	14 (51.9%)

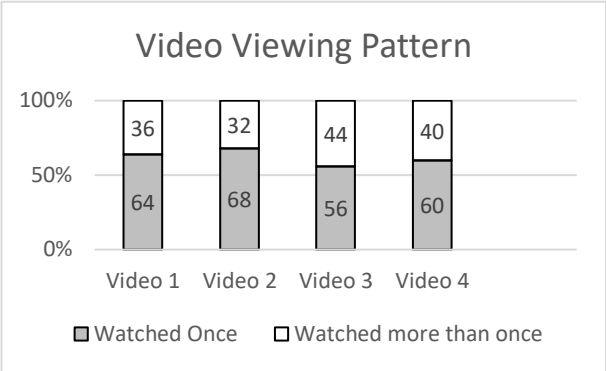
- Laparotomy	2 (7.4%)
- Did not proceed to surgery	1 (3.7%)
Procedure [n (%)]	
- Ultralow Anterior Resection	6 (22.2%)
- Low Anterior Resection	4 (14.8%)
- High Anterior Resection	9 (33.3%)
- Left hemicolectomy	1 (3.7%)
- Right hemicolectomy	4 (14.8%)
- Subtotal colectomy	2 (7.4%)
- Did not proceed to surgery	1 (3.7%)
Defunctioning stoma [n (%)]	
- Yes	3 (11.1%)
- No	23 (85.2%)
- N/A	1 (3.7%)
Neoadjuvant treatment [n (%)]	
- Yes	2 (7.4%)
- No	25 (92.6%)
Neoadjuvant Type [n (%)]	
- Long Course	2 (7.4%)
- Not Applicable	25 (92.6%)



a) The usability rating of videos



b) Overall rating of video content



c) Viewing frequency

Figure 2 (a,b,c). Experience with educational videos

Acceptability

Satisfaction, perceived usefulness and appropriateness

Between 80% and 90% of participants reported a positive experience with the usability (Figure 2). Participants suggested including subtitles in the videos and delivering them in other languages (Table 3). The content and purpose of the intervention were rated as clear, with 84% agreeing that the information in the video was easy to understand, and all participants agreed they had learnt new information. Self-reported feedback indicated that the video content was appropriate and helpful in improving knowledge and skills related to bowel function. Participants gave suggestions to improve the video series, such as "*video needs subtitles and in more than one language*" and a future follow-up: "*incorporate with a session with a physio working through exercises in person*".

Table 3. Satisfaction Feedback

Domain		Illustrative quotes
Knowledge & Emotional Response	Motivating, Reassuring	• The video helped me understand the importance of exercising before and after the surgery, and how things will change after surgery. • it guides me the right way to prepare and after the operation recovery faster • That you can get better and can control your bowel motion and more in future
Skill acquisition		• Pelvic floor exercises • The specific pelvic floor and stomach muscle exercises
Quality	Usefulness Clarity of content	• Educational aspect. • It was well presented with an even pace. It covered areas I had not thought to ask about • I found the whole contents very educational and well informative • Easy to understand • very well explained, very clear • the whole experience and better education. • the steps before and post surgery and helpful guidance. • clear and calm tone of the videos
	Language & Format (suggestions)	• Video needs subtitles and in more than one language • Could be a male video and a female video rather than combining into one • More interactive diagrams and animation
Behavioural impact	Confidence in applying knowledge	• It gave me confidence to resume normal life after surgery
	Engagement need (suggestions)	• Probably incorporate with session with a physio working through the exercises in person

Preliminary changes in psychological readiness

Change in knowledge and distress level

The knowledge quiz score increased post-intervention (mean change = 8.8, 95% CI: 3.97-13.78, p = 0.001, d = 0.748), showing a statistically significant increase. A small, non-statistically significant reduction was seen in the Distress Thermometer score (mean change = -0.68, 95% CI: -1.6 to +0.24, p=0.14, d = -0.305) (Table 2).

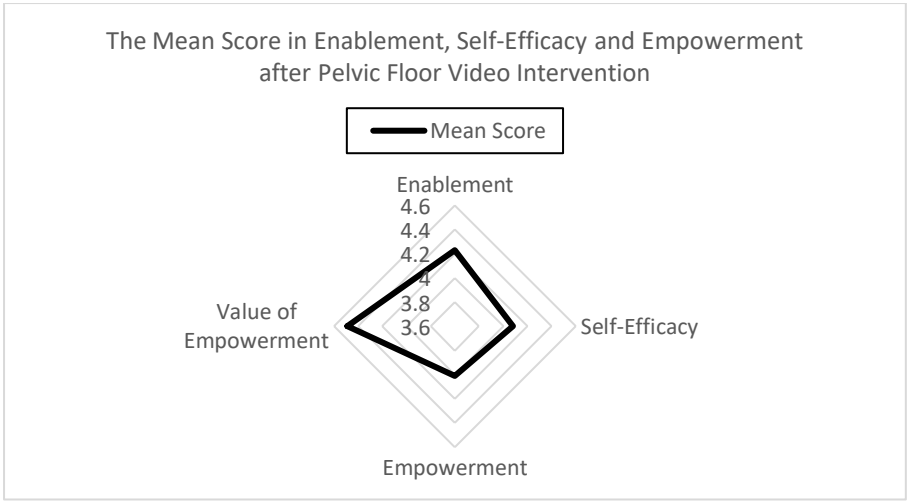
Table 2. Pair sample t-test on participants' score knowledge questionnaire and National Comprehensive Cancer Network (NCCN) distress thermometer before and after watching video

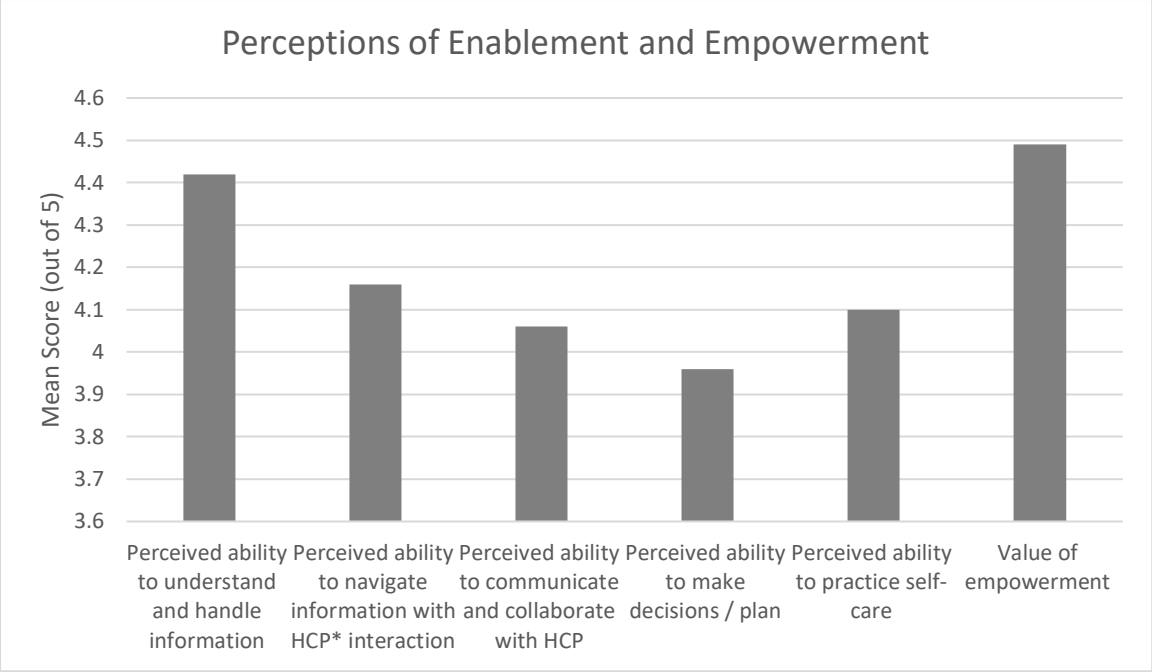
	t	df	p	Mean Difference	SE Difference	95% CI for Mean Difference		Cohen's d	SE Cohen's d
						Lower	Upper		
Score in knowledge questionnaire (pre vs post intervention)	3.74	24	0.001	8.880	2.374	3.979	13.781	0.748	0.240
NCCN distress thermometer score (pre vs post intervention)	-1.524	24	0.141	-0.680	0.446	-1.601	0.241	-0.305	0.180

Note. Student's t-test.

Enablement, Self-efficacy and Empowerment

On a 5-point Likert scale, the mean scores for enablement, self-efficacy, and empowerment were 4.23, 4.08, and 4.01 (Figure 3). Details for each domain are provided in the supplementary data. The subgroup category generally showed a high level of enablement and empowerment, apart from the subgroup "perceived ability to make decisions & plan," which had a mean score of 3.96 out of 5. The desire for empowerment was also high, at 4.49.





*Abbreviation: *HCP: Health Care Providers*

Figure 3. Enablement, Self-Efficacy and Empowerment

Discussion

The feasibility and acceptability of preoperative video-based education for colorectal cancer patients were demonstrated by meeting pre-defined recruitment, adherence and satisfaction thresholds. The three main purposes of the intervention were: improving psychological capability for postoperative behaviour change, establishing realistic expectations for bowel function recovery, and preparing patients for potential postoperative bowel dysfunction and management. The high participation rate demonstrated that the intervention is both feasible and acceptable, with over 95% of participants completing all video modules and 70% engaging in recommended exercises before surgery. However, self-participation should be considered during interpretation, given that 12 eligible patients declined to participate at recruitment. This self-selection is a recognised limitation of feasibility studies and may overestimate acceptability and engagement compared to an unselected clinical population. Nevertheless, our findings show that self-paced, individual learning delivered in a non-clinical setting can improve knowledge and skill acquisition.

Psychological capability is essential for an individual to engage in behaviour to manage their health [25] . Our exploratory findings indicate a relatively high level of self-reported psychological capabilities across all measured domains, as revealed in the post-intervention survey. On a 5-point Likert scale, score ≥4 were reported in enablement (mean=4.23), self-efficacy (mean=4.08), and empowerment (mean=4.01). Since this was an investigator-designed, study-specific questionnaire, a score ≥4 was predetermined as a pragmatic "high" score in early-phase exploratory work to indicate strong agreement. These results may suggest that participants perceived an increased ability to understand complex medical information and implement self-management strategies for the potential postoperative bladder and bowel symptoms. Furthermore, this may also indicate participants perceived psychological and behavioural readiness, with a clearer understanding of what to expect during recovery and a sense of empowerment to adopt health behaviours for potential functional changes. Participants developed a range of psychological resources to help them communicate actively with healthcare providers, enabling patients to seek help and feel more in control when managing physical symptoms after surgery [14] . Participants were motivated and willing to take proactive steps in preparing for potential disruptions to bowel function following surgery. These findings are consistent with Maalouf (2024), who believed that patients value empowerment, patient-centred support, and comprehensive informational strategies to increase their capability to adapt for a better quality of life [36]. This highlights the importance of accessible, accurate, and timely health information, alongside ongoing clinical support from health professionals in the early phase of the cancer journey.

Our findings contribute to the emerging evidence supporting patient education and counselling in colorectal cancer care, while filling a notable gap in preoperative preparation strategies. Previous research has shown patient education can improve LARS and QOL; however, most interventions occur after surgery as standalone treatments or alongside multiple modalities like peer support and formal rehabilitation programs [27]. In contrast, our study investigates the less-studied area of

preoperative video education in colorectal cancer care. It highlights that the timing and amount of information are crucial factors in patient education for engagement and confidence-building [14, 37, 38]. This preoperative method aligns with recent evidence indicating that video-based education can improve cancer knowledge and patient empowerment, particularly among populations with limited health literacy and resources [39]. Our videos were created by healthcare professionals and contain accurate, reliable content in plain English with visual aids to assist understanding, making them accessible to individuals with a Year 9 literacy level, thereby helping those with less education to comprehend and retain information [40]. Recently, a growing interest in AI has sparked public curiosity about health information, even though there remains a shortage of adequate health resources to meet patients' needs. Chatbots and online search engines generally offer ready to access information in cancer care; however, the readability of the generated content can sometimes be a concern, as it may be too generic, lacking appropriateness or specificity[26, 41, 42]

Effective preoperative education should be delivered through an iterative and research-informed approach. Our study supports this by providing information that was understandable, comprehensive, and patient-centred, which enables and empowers patients [43]. The high scores of enablement, self-efficacy and empowerment in our study reflect behaviour change potential, encompassing psychological capability, opportunity (enabling individuals and HCPS to work independently), motivation (perceived ability to perform exercises), expectation, readiness, and empowerment. Clinician-led information was particularly valued for setting expectations and clarifying the nature of LARS symptoms and recovery trajectories [44].

Several unexpected findings highlight the limitations of the immediate impact of preoperative education on certain outcome measures. Most notably, the intervention showed minimal effects on anxiety levels and early behaviour change indicators. Specifically, participants scored lower on measures of decision-making confidence and self-efficacy for coping with health problems after

surgery. These findings suggest three points for clinical consideration. First, reducing anxiety may require more comprehensive approaches beyond educational videos alone, as our intervention focuses on bowel and physical function. Various factors, such as psychosocial, emotional, premorbid health status, and gaining more accurate knowledge, can influence preoperative anxiety. Second, behaviour change likely needs reinforcement and practice opportunities that extend beyond the preoperative phase. Finally, confidence in managing specific postoperative challenges may only be developed through actual experience with symptoms and recovery processes, highlighting the importance of ongoing educational support throughout the postoperative period.

Our findings have important implications for integrating patient education into the comprehensive cancer care continuum. The demonstrated feasibility and acceptability of video-based preoperative education show that such an intervention could be incorporated into prehabilitation programmes, providing psychological preparation alongside physical conditioning. However, successful implementation will require addressing several key factors. Firstly, interventions must be culturally and linguistically appropriate, including multilingual options with subtitles and culturally relevant content to meet the needs of diverse groups. Secondly, digital literacy support may be necessary to ensure equity of access across different patient demographics. Lastly, the preoperative education should be linked to postoperative follow-up support, as our findings indicate that empowerment and knowledge need reinforcement during recovery and beyond.

Strengths and Limitations

The main strength is that using a pre–post design with self-administered surveys minimised researcher bias by enabling participants to report their perceptions and changes directly. Additionally, the study features a theory-informed questionnaire design and patient-reported outcome measures tailored for cancer survivorship. However, several methodological limitations

should be considered when interpreting these findings and planning future research. The main limitation is the single-arm study design, which prevents causal inference and limits conclusions about intervention effects. A pragmatic choice of a non-comparator was made to assess feasibility and acceptability rather than comparative efficacy. However, a two-arm design would have strengthened conclusions regarding effects and psychological outcomes. Additionally, participant self-selection may have introduced selection bias, as individuals who consented to participate might have been more motivated, engaged or receptive to additional information, potentially overestimating acceptability and engagement. The small, homogeneous sample (n=29) from a single metropolitan hospital, of mainly English-speaking patients with sufficient digital literacy, also limits generalisability to the broader colorectal cancer population. Future research should address these issues through a randomised controlled trial involving larger, more diverse groups across varying clinical settings. Long-term follow-up is also essential to assess knowledge translation, sustained behavioural change and clinical outcomes such as LARS, while also addressing barriers to access, such as health, digital, and academic literacy, and evaluating implementation.

Conclusion

In summary, the preoperative educational video is a feasible and acceptable method of delivering information to support preparation for recovery and setting realistic expectations for colorectal cancer patients before undergoing surgery. Preliminary descriptive findings suggest potential benefits for psychological readiness, including changes in knowledge and feelings of enablement, self-efficacy, and empowerment. These findings provide important information to inform the design, outcome selection and scalability considerations of a future randomised controlled trials evaluating the effectiveness of video-based patient education. Overall, the study supports the potential role of guided education videos as a component of patient-centered cancer prehabilitation programs.

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Supplementary file 3.1 Supplemental data

This is additional data on enablement, empowerment and self-efficacy

Descriptive Statistics on Enablement

	Valid	Mean	Std. Deviation	Minimum	Maximum
I feel capable of understanding the information I received in the video.	25	4.440	0.507	4.000	5.000
I feel capable of understanding that cancer surgery and chemoradiotherapy may have an effect on my bladder and bowel function.	25	4.400	0.707	2.000	5.000
I feel capable of managing potential side-effects or late complications from the cancer surgery and treatment.	25	3.880	0.833	2.000	5.000
I feel capable of assessing what I need from the healthcare professionals.	25	4.240	0.436	4.000	5.000
I feel capable of finding information or getting additional help to manage any bowel problems and other health issues.	25	4.080	0.640	2.000	5.000
The information given has prepared me for bowel symptoms and other side effects that may occur from bowel cancer surgery.	25	4.320	0.557	3.000	5.000

Descriptive Statistics on Empowerment

	Valid	Mean	Std. Deviation	Minimum	Maximum
I feel capable of applying the strategies presented to improve potential bowel problems and side effects after surgery and treatment.	25	4.160	0.624	3.000	5.000
I feel capable of practising the exercises before the surgery.	25	4.360	0.569	3.000	5.000
When I have health problems, I have skills that help me cope.	25	3.840	0.898	2.000	5.000
I feel capable of telling my healthcare professional about my most important challenges.	25	4.080	0.812	2.000	5.000
The videos have helped me to decide what questions I should ask when I see my surgeon.	25	4.040	0.735	2.000	5.000
The videos helped me to consider and have a discussion with my doctor about the rehabilitation plan.	25	3.960	0.841	2.000	5.000
It is important to me to be prepared for how my health and physical / psychological function could affect my daily life after treatment.	25	4.480	0.586	3.000	5.000
It is important to me that the health care staff take time to talk to me about my	25	4.520	0.510	4.000	5.000

Descriptive Statistics on Empowerment

	Valid	Mean	Std. Deviation	Minimum	Maximum
daily life and to provide information and strategies to manage health issues.					
It is important to me that the healthcare professionals support me in doing things that I believe can improve my well-beings.	25	4.480	0.510	4.000	5.000
The video has prompted me to ask the doctor more questions.	25	3.640	0.700	2.000	5.000

Descriptive Statistics on Self-efficacy

	Valid	Mean	Std. Deviation	Minimum	Maximum
I have learnt strategies to improve bowel function after surgery and treatment.	25	4.240	0.523	3.000	5.000
I feel capable of finding information or getting additional help to manage any bowel problems and other health issues.	25	4.080	0.640	2.000	5.000
I feel confident about my recovery after surgery.	25	3.920	0.702	1.000	5.000

Supplementary file 3.2. Preoperative Education Study Video links

The four video modules:

Video 1: What may happen to my bowel, bladder and sexual function after surgery
https://storydriven.wistia.com/medias/7guaxvqd8p

Video 2: Before and after surgery – your health and bowel
https://storydriven.wistia.com/medias/lxs1g93kt6

Video 3: Better pelvic floor muscles – better bowel function
https://storydriven.wistia.com/medias/1vr5pdmmpt

Video 4: Skin care, stoma management and sexual activity
https://20302102.wistia.com/medias/qnej4tc6df

Supplementary file 3.3. Survey 1

Pre-operative video about bowel function and supportive care in colorectal cancer - Questionnaire 1

Study ID: Date:

We would like to find out some information about your health and your understanding of bowel health before your cancer surgery. The information you provide in this survey will help us to determine if this video is appropriate for preparing patients who are going to undergo bowel cancer surgery and treatment. Please answer all the questions.

1. What is your age? _____
2. What is your gender? ☐Male ☐Female ☐Intersex
3. What language do you speak at home? _____
4. What is your highest completed level of education? _____
5. What is your marital status? _____
6. What is your current employment? _____

Information about your cancer treatment:

7. I am diagnosed with cancer in ☐ Sigmoid ☐ Rectum ☐Colon ☐Unsure
8. My surgery will be ☐ Keyhole ☐Open ☐Robotic ☐Unsure
9. I will receive/ have received radiation therapy and/or chemotherapy before surgery

   ☐Yes ☐No ☐Unsure

Information about your bladder, bowel and sexual health:

10. Do you suffer from bladder function issues? If yes, please list below:

    _____

11. Do you suffer from sexual health issues? If yes, please list below:

    _____

12. Do you suffer from bowel function issues? If yes, please list below:

    _____

13. Do you suffer from any chronic health issues? If yes, please list below:

    _____

Supplementary file 3.4 Survey 2

Pre-operative video about bowel function and supportive care in colorectal cancer
Questionnaire 2

Study ID: Date:

We would like to see if you have had any changes in your understanding after watching the video. The information you provide will help us to assess if this video is appropriate for preparing patients who are going to undergo bowel cancer surgery and treatment. Please circle the most appropriate answer and answer all questions.

1. I feel capable of understanding the information I received in the video

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

2. I feel capable of understanding that cancer surgery and chemoradiotherapy may have an effect on my bladder and bowel function

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

3. I have learnt strategies to improve bowel function after surgery and treatment

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

4. I feel capable of managing potential side-effects or late complications from the cancer surgery and treatment

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

5. I feel capable of applying the strategies to improve potential bowel problems and side effects after surgery and treatment

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

6. I feel capable of practising the exercises before the surgery

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

7. When I have health problems, I have skills that help me cope

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

8. I feel capable of assessing what I need from the healthcare professionals

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

9. I feel capable of telling the healthcare professionals about my most important challenges

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

10. I feel capable of finding information or getting additional help to manage any bowel problems and other health issues

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

11. The videos have helped me to decide what questions I should ask when I see my surgeon

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

12. The videos helped me to consider and have a discussion with my doctor about the rehabilitation plan

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

Before watching the video…

13. My doctor or nurse has given me enough information about my cancer diagnosis and treatment

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

14. My doctor or nurse has given me adequate information on the side effects or changes related to the surgery and treatment and how it may affect my daily life and recovery

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

15. I have been given the opportunity to ask questions about changes in bowel function that can occur due to the cancer surgery

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

After watching the video…

16. The information given has prepared me for bowel symptoms and other side effects that may occur from bowel cancer surgery

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

17. It is important to me to be prepared for how my health and physical/ psychological function could affect my daily life after treatment

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

18. It is important to me that the health care staff take time to talk to me about my daily life and to provide information and strategies to manage health issues

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

19. It is important to me that the healthcare professionals support me in doing things that I believe can improve my well-being?

Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree

Supplementary file 3.5 Survey 3

Pre-operative video about bowel function and supportive care in colorectal cancer – Questionnaire 3

Study ID: Date:

Questionnaire
This questionnaire is to be completed before and after watching the video.

True or False questions. Please tick one box for the correct answer to each question.

Questions	True	False
1. Large intestine is part of the digestive system		
2. Large intestine consists of colon, rectum and anal passage where each of them have a different role		
3. The function of the large intestine is to absorb water only		
4. Colonic movement affects bowel frequency and faeces consistency (hard or runny stool)		
5. The bowel must be removed if cancer is found		
6. A stoma is an artificial opening where the bowel is diverted to the tummy surface		
7. A stoma is given when the bowel can't be re-joined, and is permanent		
8. One should empty the bowel at least once every day		
9. Stool leakage is due to a weak bowel		
10. Surgery, radiation therapy and chemotherapy can affect bowel function		
11. Bladder and sexual function may be affected after cancer surgery and treatment		
12. It is normal to have stool leakage and frequency after surgery		
13. There is nothing you can do for the bowel changes after surgery and chemoradiotherapy		
14. Maintain physically active and nutritionally balanced diet is important before surgery		
15. Diet, medication and pelvic floor exercise can help to regain bowel control		
16. Pelvic floor exercise is about squeezing the bottom muscles		
17. Pelvic floor exercise should be done while you are urinating		
18. The health professionals who involve in bowel cancer care include: surgeon, oncologist, bowel cancer nurse, dietitian, physiotherapist, exercise physiologist, stomal therapist.		

Supplementary file 3.6 Survey 4

Participant Satisfaction Survey

Pre-operative video about bowel function and supportive care in colorectal cancer – Questionnaire 4

This survey is an opportunity to provide feedback about your experience watching the educational videos. The videos aim to increase your understanding of bowel function after bowel cancer surgery, to introduce pelvic floor muscle exercises, and provide support in preparation for your bowel cancer surgery.

You are asked to complete this survey after you have finished the program. Your feedback will help us to evaluate and to make future improvements to the service. We appreciate your participation and comments. This feedback may be given anonymously.

Instruction: Please tick the **ONE** box that is most appropriate and fill in the blanks.

1. How many times did you watch the videos?
   Video 1 ☐ Did not watch ☐ Once ☐ More than once
   Video 2 ☐ Did not watch ☐ Once ☐ More than once
   Video 3 ☐ Did not watch ☐ Once ☐ More than once
   Video 4 ☐ Did not watch ☐ Once ☐ More than once

2. Did you speak to a health professional, other than your doctor, about any questions you may have after watching the videos?
   ☐ Yes ☐ No ☐ I did not have any questions at all
   If yes, which health professional did you speak to? _____

3. Did you practice the exercises from the videos? ☐ Yes ☐ No
   If yes, how many times did you practice your exercises? _____

	Strongly Agree	Agree	Neither Disagree nor Agree	Disagree	Strongly Disagree
The information in the video was easy to understand					
The information in the video was useful.					
The content was presented clearly.					
The length of this video is adequate					
The instructions for accessing the videos are clear					
I have learnt new information from the video					
This video addressed some questions and concerns that were not addressed before					
The exercise instructions made it easy to continue the exercises at home					
It was a fun learning experience					
The video has prompted me to ask the doctor more questions					
I feel confident about my recovery after surgery					

4. Overall, how would you rate the content of the video?

Very poor	Poor	Average	Good	Very good

5. What did you find the most helpful aspect of the video education?

_____

_____

6. How could we improve this video?

_____

_____

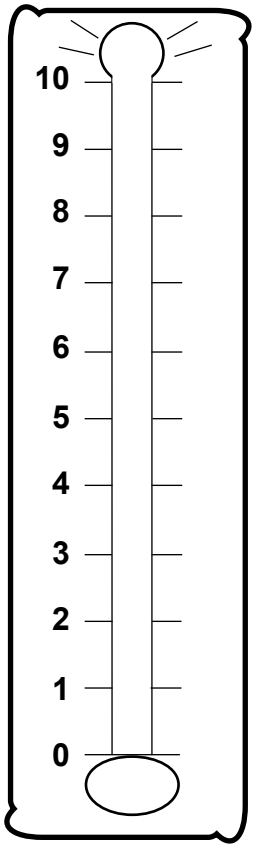
This is the end of the survey. Thank you

NCCN DISTRESS THERMOMETER

Distress is an unpleasant experience of a mental, physical, social, or spiritual nature. It can affect the way you think, feel, or act. Distress may make it harder to cope with having cancer, its symptoms, or its treatment.

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week, including today.

Extreme distress



No distress

PROBLEM LIST

Have you had concerns about any of the items below in the past week, including today? (Mark all that apply)

Physical Concerns

- ❑ Pain
- ❑ Sleep
- ❑ Fatigue
- ❑ Tobacco use
- ❑ Substance use
- ❑ Memory or concentration
- ❑ Sexual health
- ❑ Changes in eating
- ❑ Loss or change of physical abilities

Emotional Concerns

- ❑ Worry or anxiety
- ❑ Sadness or depression
- ❑ Loss of interest or enjoyment
- ❑ Grief or loss
- ❑ Fear
- ❑ Loneliness
- ❑ Anger
- ❑ Changes in appearance
- ❑ Feelings of worthlessness or being a burden

Social Concerns

- ❑ Relationship with spouse or partner
- ❑ Relationship with children
- ❑ Relationship with family members
- ❑ Relationship with friends or coworkers
- ❑ Communication with health care team
- ❑ Ability to have children

Practical Concerns

- ❑ Taking care of myself
- ❑ Taking care of others
- ❑ Work
- ❑ School
- ❑ Housing
- ❑ Finances
- ❑ Insurance
- ❑ Transportation
- ❑ Child care
- ❑ Having enough food
- ❑ Access to medicine
- ❑ Treatment decisions

Spiritual or Religious Concerns

- ❑ Sense of meaning or purpose
- ❑ Changes in faith or beliefs
- ❑ Death, dying or afterlife
- ❑ Conflict between beliefs and cancer treatments
- ❑ Relationship with the sacred
- ❑ Ritual or dietary needs

Other Concerns:

_____

_____

_____

Note: All recommendations are category 2A unless otherwise indicated.
Clinical Trials: NCCN believes that the best management of any patient with cancer is in a clinical trial. Participation in clinical trials is especially encouraged.

Chapter 4: Efficacy of pelvic floor rehabilitation for bowel dysfunction after anterior resection for colorectal cancer: a systematic review

Overview

As noted in Chapter 3, early video-based education may play an important role in improving patients' understanding and engagement with pelvic floor rehabilitation (PFR). However, the wider question of whether PFR can effectively reduce LARS symptoms after surgery still needs to be addressed. This chapter is a published systematic review that provides an overview of the efficacy of PFR for bowel dysfunction after anterior resection for colorectal cancer. By critically evaluating the scope, quality, and outcomes of existing studies, this chapter builds an evidence base to guide the design of a subsequent feasibility study, which aims to assess a structured PFR in the postoperative setting. Since the systematic review in this chapter was published in 2021, an updated search of the literature has been performed to identify any newly published studies, ensuring this thesis reflects the latest evidence. This manuscript is quoted verbatim with formatting as required by the journal.

Publication details

Chan KYC, Suen M, Coulson S and Vardy JL (2021) Efficacy of pelvic floor rehabilitation for bowel dysfunction after anterior resection for colorectal cancer: a systematic review. *Supportive Care in Cancer,* **29**: p1795-809.

I, Kin Yin Chan, was responsible for the study concept, performed the literature review search, data extraction and analysis, drafted and revised the manuscript.

Michael Suen assisted with the selection of articles and the risk of bias assessment strategy, reviewed and revised manuscript

Susan Coulson reviewed manuscript

Janette Vardy assisted with the selection of articles and the risk of bias assessment strategy, reviewed and revised manuscript

Abstract

Purpose: Bowel dysfunction is common after anterior resection for colorectal cancer (CRC). Pelvic floor rehabilitation (PFR) may improve functional outcomes after surgery. This review aimed to evaluate the efficacy of PFR for patients with bowel symptoms after anterior resection.

Methods: MEDLINE, CINHAL, PUBMED, EMBASE, Scopus, PsycINFO, Web of Science, PEDRO and Cochrane Library were searched from inception to June 2019. A final search was performed on 11th July 2020. Randomised controlled trials (RCTs), cohort studies, case-control studies and case series of bowel dysfunction after CRC surgery and PFR were eligible for review. Outcome measures were bowel function changes measured by patient-reported outcomes and manometric measurement. Risk of bias assessments using Methodological Index for Non-Randomized Studies (MINORS) tool and Newcastle Ottawa Scale (NOS) were conducted.

Results: Eleven trials met eligibility criteria: four retrospective studies and seven prospective, non-randomised controlled studies. A total of 516 participants were included, of which 455 received PFR. Functional outcomes were measured by bowel functional outcome questionnaires, patient diary, anorectal manometry, and three studies measured quality-of-life. Faecal incontinence was improved in seven studies and bowel frequency also decreased in five studies. The mean MINORS score was 10 (8-13) out of 16 in non-comparative groups and 18 (16-22) out of 24 in comparative groups; the NOS was 4.2 (3-7) out of 9. The overall risk of bias was high in most studies.

Conclusion: PFR appears to be beneficial for improving bowel function after anterior resection for CRC. However, the studies included had methodological limitations, so further investigation on the effectiveness of PFR is warranted.

Introduction

Colorectal cancer (CRC) is the third most commonly diagnosed cancer and accounts for 10% of all cancers worldwide [1]. There has been a shift in CRC management paradigms in the past two decades which has resulted in decreased mortality. Prevention, screening, surveillance measures, and a multimodal treatment approach to CRC have improved survival, achieving a 5-year survival rate between 60-70% internationally [2]. The evolution of diagnostic technology and surgical techniques, together with advancements in chemoradiotherapy, have contributed to these dramatic improvements in CRC oncological outcomes [3, 4]. Total mesorectal excision (TME) with anal sphincter preservation has been widely performed for distal colon and rectal cancer in the last 20 years to minimise the need for a permanent colostomy as it is believed that the health-related quality of life is poorer in patients with a stoma [5, 6].

Although sphincter-preserving surgery allows the restoration of bowel continuity, bowel function is often compromised due to alterations in anatomy and physiology in the anorectum after surgery. Up to 80% of CRC survivors experience bowel habit changes, including incontinence, frequency, urgency and emptying difficulties [7] with 40% reporting severe symptoms [8]. An international consensus has defined low anterior resection syndrome (LARS) as symptoms of: variable, unpredictable bowel function; emptying difficulties; altered stool consistency; urgency; increased stool frequency; incontinence; repeated painful stool; and soiling [9]. Some spontaneous recovery usually occurs in the first 6-12 months after bowel reconstruction but improvement often then plateaus, with symptoms frequently persisting beyond 10 years [10, 11]. The ongoing bowel disturbance often leads to physical and psycho-social health consequences, placing substantial restrictions on the cancer survivor's daily activities and impacting their quality-of-life [9, 12].

Anterior resection syndrome is multifactorial in aetiology. Currently, LARS is hypothesised to be caused by damage to the neuromuscular structures leading to alteration of anorectal physiology and anal sphincter function, lumbosacral neuropathy from chemoradiotherapy and reduced capacity of

the neorectum [10]. Risk factors for LARS include substantial involvement of the anorectum in resection surgery, administration of neoadjuvant therapy, and prolonged duration of a temporary defunctioning stoma [8, 11, 13]. Systematic reviews and narrative reviews have summarised the management of LARS including medication, dietary adjustment, anal and colonic irrigation, pelvic floor rehabilitation, and sacral nerve modulation [14-19]. The primary goals are to restore anorectal function using minimally invasive approaches and to optimise overall physical function after surgery to improve quality-of-life. Pelvic floor rehabilitation (PFR) consists of pelvic floor muscle exercises, biofeedback, rectal balloon retraining and electrostimulation that aims to improve pelvic floor muscle strength, rectal sensation and coordination [14]. Although PFR has been reported to be easy to deliver and inexpensive, with sustainable outcomes and minimal adverse effects, most of the studies have been non-randomised controlled trials and reviews limited by the poor quality of the study trials available [20, 21]. Lin et al (2015) gave a general overview of the efficacy of pelvic floor muscle training on bowel dysfunction following all types of colorectal cancer surgery. Another systematic review by Visser et al (2014) evaluated the effectiveness of PFR in improving functional outcome after a low anterior resection, concluding pelvic floor rehabilitation has a beneficial effect on bowel dysfunction after anterior resection [20].

The aim of this current systematic review is to update the literature with the inclusion of additional studies that specifically evaluate PFR after anterior resection surgery for CRC, as well as examining in more depth the design of the PFR programs, and their effectiveness in treating bowel dysfunction after anterior resection surgery for CRC. This review extends the extant literature by including four recently published trials with an additional 169 subjects and two relevant older trials to assess the efficacy of PFR on bowel function after anterior resection and examining the design of PFR programs in an attempt to identify discrepancies in current practice and gaps between evidence and application.

Methods

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [22]. No protocol for this review has been registered or published.

Eligibility criteria

Eligible studies were selected according to the criteria outlined below:

Study design: Quantitative study designs including randomised controlled trials (RCTs), cohort studies, case-control studies and case series were eligible for inclusion. Case reports, systematic reviews, commentaries, letters and editorials were excluded.

Participants: Participants in the studies were aged over 18, had undergone anterior resection for sigmoid or rectal cancer, and did not have a temporary or permanent ostomy at the time of the trial. Studies with mixed cohorts of participants with non-anterior resection and/or non-CRC were included if more than 80% of participants had an anterior resection for CRC, or if data were able to be reported separately.

Intervention: PFR consists of various components of training for regaining bowel function. Of interest were interventions focussing on pelvic floor muscle strength, anorectal coordination and rectal sensation. Studies that explicitly described the intervention with pelvic floor muscle exercises alone, or in combination with biofeedback, and/or electrical stimulation, were eligible for inclusion in the review. Electrical stimulation alone (interventions involving transcutaneous, percutaneous, intra-anal electrical stimulation or sacral neuromodulation), and behavioural education alone, were excluded. Pelvic floor muscle exercise was defined as any strength training to the pelvic floor muscle complex including external anal sphincter, puborectalis, as well as Kegel exercises. Types of biofeedback included visual, audio and sensory with the use of devices such as electromyography, ultrasound, digital guidance, anorectal manometry, and anorectal balloon catheter [23].

Outcomes: Studies were eligible for inclusion if the primary endpoint was bowel function measured by a validated questionnaire, patient reported symptoms, bowel diary and/or anorectal manometry.

Timing: There was no restriction on time from surgery to start of PFR.

Setting: There was no restriction by the type of clinical setting.

Language: Studies in languages other than English were included only if they were adequately translated.

Search strategy

Both qualitative and quantitative studies were sought. No restrictions on the date of publication or study designs were imposed. Eight electronic databases: MEDLINE (1946-2019), CINHAL (1982-2019), PUBMED (1996-2019), EMBASE (1947-2019), Scopus (1823-2019), PsycINFO (1806-2019), Web of Science (1900-2019), PEDRO (1999-2019) and Cochrane Library (2019) were searched in June 2019 by one reviewer (KYC) with assistance of an academic librarian. The following Medical Subject Heading (MeSH) terms were used: colorectal cancer; colorectal neoplasm; rectal cancer; rectal neoplasms; anterior resection; bowel function; fecal incontinence; anterior resection syndrome; pelvic floor; training; rehabilitation; biofeedback; exercise. (Appendix 1). Reference lists of identified articles were also checked. A final search was performed on 11th July 2020.

Study selection

Two of the authors (KYC, MS) independently screened the titles and abstracts generated by the search after duplications were removed. Full texts were obtained for all titles that met inclusion criteria. The review authors then screened and selected the full text against the eligibility criteria for inclusion of qualitative synthesis. Disagreement was resolved through discussion or with the assistance of a third reviewer (JV).

Data collection process

A data collection form was designed and utilised. Data were extracted from the included studies by one reviewer (KYC) and checked by a second reviewer (MS). Disagreement was resolved through discussion or with involvement of a third reviewer (JV). Data items for extraction included study methodology (author's name, year, study design, country, inclusion criteria, trial size), demographic information (gender, age), surgery details (stage of tumour, surgery technique, level of anastomosis, diverting stoma, neoadjuvant/adjuvant therapy, duration of bowel symptoms, time since surgery), pelvic floor rehabilitation intervention details (protocol details including duration, intensity, frequency, time, type and setting) and reported outcomes (bowel function scores, patient reported outcomes, quality-of-life, anal manometry and duration of follow up) of the reviewed studies.

Risk of bias in individual studies

The risk of bias was assessed by two reviewers independently using both the Methodological Index for Non-Randomized Studies (MINORS) tool and Newcastle Ottawa Scale (NOS). MINORS is a validated instrument consisting of 8-items (aim, inclusion criteria, data collection, endpoints, blinding of assessment, follow-up period, drop-out rate and study size calculation) with an extra 4-items (control group, contemporary group, baseline equivalence of group and statistical analyses) for comparative studies. Each item is allocated a score from 0-2 with a maximum score of 16 (or 24 for a comparative study) [24]. The Newcastle Ottawa Scale (NOS) is an 8-item instrument divided into three categories (selection, comparability, outcome). Both cohort and case-control scales were used. The total score of the instrument is 9. For both tools a higher score indicates lower risk of bias. The included studies were assigned an overall quality of "poor", "fair" or "good" based on the calculated score. A third reviewer was available to resolve any disagreement between the two independent reviewers. Both tools were used as they examined different perspectives of risk of bias

in non-randomised controlled trials. A NHMRC hierarchy ranking is used to determine the level of evidence[25].

Data analysis

Cohen's kappa statistic on IBM SPSS statistics (Version 26 2019) was used to measure inter-rater reliability for risk of bias in the methodology assessment. Values >0.8 indicated a strong level of agreement [26].

Results

Study selection

A total of 580 studies were identified following the electronic database search, and a further three studies were found through reference list checks. After removing the duplicated titles, initial screening by title and abstract, 32 full text articles were obtained to be assessed for eligibility. Twenty-one studies were excluded after review: nine were narrative reviews, two examined PFR in patients with an ileostomy, two consisted of non-colorectal cancer participants, two examined cases other than anterior resection, one examined electrical stimulation alone, one used the same data set from another included study, and the remaining four studies were an editorial, observational study, conference abstract and trial protocol respectively. Email contact was attempted on two occasions to one study author [27] to clarify the participant's characteristics but no response was received after two months. Eleven studies that met the eligibility criteria were included in the review (Figure 1). Seven studies were published in the past 10 years and two studies were published over two decades ago [28, 29]. There was minor disagreement between the two independent reviewers that was resolved after discussion with 100% consensus.

Study characteristics

Study designs

No randomised controlled trials were found. Four retrospective studies and seven prospective, non-randomised controlled studies were included.

Participants' characteristics

A total of 522 participants were included across all studies. Six were excluded due to unmet criteria [28], leaving 516 participants for the review: 61 subjects were in control groups [30-32]. The mean age of the participants ranged from 55 to 67 years. One participant had an anterior resection for radiation proctocolitis as a result of previous cervical cancer, and all others had rectal cancer. In total, 443 participants had undergone a sphincter preserving anterior resection and 73 had an intersphincteric resection. Eight of the eleven studies reported the mean distance of the anastomosis from the anal verge in centimetres:[30, 31, 33-38] 185 had the anastomosis at >5cm and 290 at $\leq$5cm. Overall 238 participants had radiotherapy alone or both radiotherapy and chemotherapy [28-31, 33-38]. Seven studies reported 161 participants had a diverting stoma reversed prior to the PFR intervention [30-32, 34-37]. Faecal incontinence and frequency were the most commonly reported bowel symptoms. The duration of symptoms varied from 1 month to greater than 1 year (Table 1).

Intervention

The PFR intervention protocols were very variable (Table 3). Most studies were carried out in an outpatient setting, with the exception of Liu et al (2011) and Lin et al (2016) who conducted home-based exercise programs. Biofeedback was used in 9 studies but varied in type. Electromyography biofeedback or rectal balloon biofeedback alone or in combination were used. Kuo et al (2015) performed electromyography biofeedback in adjunction with neuromuscular electrical stimulation for strength and coordination training. Allgayer et al (2005) applied electromyography biofeedback

for strength and sensory training with additional psychological support and light aerobic exercise. Two studies did not use any instrument but emphasised correct pelvic floor muscle exercise technique with the use of educational material for strength training [31, 32]. Six studies used rectal balloon biofeedback for strength, sensory and coordination pelvic floor training [28-30, 34, 36, 37]. One study used a tailored multimodal program with four regimes [38]. The duration of the rehabilitation program varied from 3 weeks to 29 months. The frequency of training for each study differed from a daily session to once every 2-3 weeks and the duration for each session from 10 minutes to 1 hour.

Outcome measures

Bowel function outcome measures were most commonly faecal incontinence episodes and bowel frequency. Wexner Fecal Incontinence Score (WIS) [30, 34-38], Modified Cleveland Incontinence Score (MCIS) [33], Vaizey Incontinence Score,[36] Gastrointestinal standardized questionnaire [30], patient report [32, 34-38], and a bowel diary[28, 29] were used. Two studies used anterior resection specific bowel function questionnaires [37, 38]. Three studies measured quality-of-life with questionnaires which included the Fecal Incontinence Quality of Life Scale, Short Form 36 and Functional Assessment of Cancer Therapy – Colorectal Cancer (FACT-C) [30, 32, 37]. Manometry investigations were used to measure anorectal function outcomes in 8 studies [28, 29, 33-38].

Study quality and Risk of Bias assessment

Risk of bias of studies were assessed with MINORS and NOS and are presented in Table 2. The inter-rater agreement of quality assessment was determined by Cohen's kappa statistic. The kappa coefficient was 0.838 for MINORS and 0.959 for NOS. Minor disagreements occurred (10 of 192 items) but 100% consensus was reached with discussion. The studies were limited by lack of: blinded assessment, adequate study size, and long term follow up [30-38]. Due to these limitations, most studies were rated "Fair" with less than 80% of the total score achieved in MINORS and less than 7 (out of 9) on NOS. Only two studies achieved a high score in both assessments [31, 32]. Based on the

risk of bias assessment, the level of evidence of all studies was rated between level III and IV on the NHMRC hierarchy ranking [25]. A summary table below shows the overall risk of bias interpretation (Table 7).

Table 7. Table of overall risk of bias

Study	MINORS	Minor Score	NOS	NOS Score	Overall Risk of Bias Interpretation
Nishigori H et al	Fair	8/16	Poor	3	High
Lin Y-H et al	Good	22/24	Good	7	Moderate-low
Liang Z et al	Fair	9/16	Poor	3	High
Kuo L-J et al	Fair	8/16	Poor	3	High
Laforest A et al	Fair	16/24	Poor	4	High
Kim K et al	Fair	12/16	Fair	5	Moderate
Liu C-H et al	Good	13/16	Good	7	Moderate-low
Pucciani et al	Fair	17/24	Fair	5	Moderate
Allgayer et al	Fair	11/16	Fair	6	Moderate
Ho and Tan	Fair	10/16	Fair	5	Moderate
Ho et al	Fair	10/16	Fair	5	Moderate

Results of the functional outcomes

Faecal incontinence

Faecal incontinence severity was reported based on questionnaire administration [30-38], patient bowel diary [28, 29], and verbal report [32]. Seven studies used WIS (n=381) and one study used MCIS (n=95). There was substantial score improvement at the end of the PFR ($p<0.05$) in most studies. However, one study did not show a significant difference in WIS after the intervention compared to the control group [30]. Two studies reported the number of episodes of faecal incontinence had decreased after four sessions of treatment ($p<0.05$). One study found the improvement continued after 1 year ($p<0.001$).

Bowel frequency

Bowel frequency per 24-hours was reported in nine studies (n= 367). Five studies showed the number of bowel movements decreased after the intervention ($p<0.05$) [28, 34-37]. One study also showed a significant improvement after rehabilitation compared with case-matched controls ($p=0.025$) [30]. Only one study reported no significant difference in bowel frequency before and

after the intervention [38]. One study reported the number of weekly bowel motions [29] and another study the number of participants who had >3 defaecations per day [32]. Due to the difference in reporting, the findings of these two studies were not included.

Quality-of-life

Quality-of-life was examined in three studies (n=98) with the use of FIQL, SF36 and FACT-C [30, 32, 37]. A significant difference was found in the total score for CRC-specific quality-of-life in the intervention group compared to controls (p=0.038) [32]. One study demonstrated some improvement in two domains (vitality and mental functioning) of SF36 [30]. A contradictory finding was shown in two studies where FIQL was used to assess the impact of faecal incontinence on quality-of-life [30, 37]. One study showed a significant improvement in the three domains except depression/self-perception after the intervention in the LAR group [37]. In contrast another study found significant improvement in depression/self-perception (p=0.005) but not in the other three domains [30].

Anal manometry

Bowel function was measured by anorectal manometry. Eight studies (n=394) examined the changes on resting pressure, squeeze pressure and maximum tolerable volume (MTV). Two studies showed significant improvement in resting pressure ($p \leq 0.001$) and in MTV ($p<0.05$) after the intervention [34, 36]. A significant change in squeeze pressures was demonstrated in three studies ($p<0.05$) [34-36]. However, three studies showed lack of significance in the change of all measures [28, 29, 37]. The outcome results in two studies did not compare patients outcomes pre and post intervention but rather compared the intervention against the control group [33, 38]. A summary table below shows the intervention effect by most reported outcome measures across the studies (Table 8).

Table 8. Summary of outcome measures

Outcomes	Number of studies assessing	Studies showing improvement	Overall interpretation
Wexner Fecal Incontinence Score	7	6	improved
Modified Cleveland Incontinence Score	1	1	improved
Vaizey Incontinence Score	1	1	improved
LARS	1	1	improved
Number of defaecation per 24 hours	6	5	reduced
FIQL	1	1	improved
SF36 – vitality	1	1	improved
SF36 – Mental functioning	1	1	improved
FACT-C	1	1	improved
Resting pressure	8	2	Improved
Squeeze pressure	8	3	Improved
Rectal capacity	8	2	Improved

Discussion

The aim of this systematic review was to critically evaluate the available evidence on the efficacy of PFR for bowel dysfunction after anterior resection for CRC. Bowel dysfunction and anterior resection syndrome were interchangeably used in the existing studies. These two terms were used to describe faecal incontinence, urgency, frequency, incomplete evacuation and stool fragmentation associated with anterior resection. This systematic review of 11 non-randomised controlled trials, in which seven studies were published within the past 10 years, demonstrated PRF can improve functional outcome after anterior resection for CRC. Most included studies produced a favourable result in achieving continence and reducing bowel frequency with the use of patient reported outcomes and manometry assessments. Quality-of-life was measured in three studies however there was only scant evidence for improvement in quality-of-life. A meta-analysis was not performed due to heterogeneity of treatment protocols and outcome measures, and limited methodology quality. Therefore, this review could not draw any valid conclusion on the size of effect of PFR for bowel dysfunction after CRC surgery.

PFR was demonstrated to be effective for managing faecal incontinence after anterior resection in 9 out of 11 studies based on the improved score of WIS, MCIS and number of incontinent episodes.

However, Laforest et al showed a contrasting result where PFR did not improve the WIS score. i.e. faecal incontinence. The differing outcome in this study could possibly be explained by the presence of associating factors for anterior resection syndrome. Firstly, subjects in this study were recruited one month after stoma closure. The post intervention (15-weeks) functional outcomes measuring period was within the first 6 months after bowel reconstruction. Previous studies have shown bowel function recovery occurs in the first 6-12 months after restoration of bowel continuity [39, 40]. Assessing bowel function in the early stages of bowel adaptation may lead to false-negative results, which may explain the insignificant improvement of faecal incontinence after PFR found in this study. Secondly, participants in the study had had a mix of surgical techniques for anterior resection; coloanal anastomosis or intersphincteric resection. Low anastomotic height is a major risk factor for LARS [8]. An anastomosis with intersphincteric resection indicated partial removal of the anal sphincter was required to try and achieve a good oncological outcome due to a low-lying rectal cancer. This is more likely to result in permanent muscle damage leading to poorer faecal continence outcomes. Other reasons such as radiotherapy and chemotherapy, presence and the duration of a defunctioning stoma, and the duration of bowel symptoms have been found to predict bowel function outcomes and responsiveness to PFR [8, 13]. The inadequate participant characteristics reported for a number of these factors in many of the reviewed studies could affect the generalisability of the studies on the efficacy of PFR for patients with bowel dysfunction. A checklist of associated factors would be beneficial if it was included in future trials.

The goal of PFR is to improve storage and evacuatory function of the neorectum by carrying out specific training on sphincter and pelvic floor muscle strength, rectal sensation and anorectal coordination. Muscle contraction and relaxation exercise and biofeedback therapy are often key components in the rehabilitation program. In this review, nine studies used a combination of sphincter muscle and pelvic floor muscle strengthening exercise and biofeedback therapy in the form of either electromyography biofeedback, rectal balloon catheter or both. One study incorporated neuromuscular electrical stimulation as additional treatment in the program. Two

studies used pelvic floor muscle exercise alone. A previous Cochrane review suggested biofeedback +/- electrical stimulation in conjunction with pelvic floor muscle exercise may be useful for benign faecal incontinence [41] and there was supporting evidence of biofeedback for dyssynergic defaecation [42]. ARS is multifactorial in aetiology and requires a progressive escalation of management to regain optimal bowel function. PFR should be considered in patients that do not respond to dietary adjustment or medications, before considering surgical options [19]. Although most studies in this review used similar PFR modalities, there was a wide variation of protocols used across studies. In addition, the reporting of interventions showed a lack of tailoring, modification and detailed information on Frequency, Intensity, Time and Type (FITT), and information on the intervention, adherence and fidelity according to the Template for Intervention Description and Replication checklist (TIDieR) [43]. This information is particularly important to determine if the protocol is suitable, viable and can be replicated in other clinical settings. Hence, it would be beneficial for future PFR studies to establish a standardised protocol with comprehensive intervention reporting in order to investigate the efficacy, appropriateness and feasibility.

Bowel functional outcomes were measured by a variety of assessment tools across studies. The most commonly used was WIS, but MCIS, Vaizey Incontinence score and patient diaries were also utilised for outcome evaluations. Three studies examined the impact of bowel dysfunction on quality-of-life with the use of FIQL, SF36 and FACT-C. Due to the heterogeneity of assessing tools used, a meta-analysis was not possible to determine the effect size of PFR on bowel dysfunction. Faecal incontinence is the major symptom of ARS, however high prevalence of faecal urgency and evacuation difficulty have also been reported [10]. Indeed, in a recent international consensus ARS was defined as experiencing at least one of the following symptoms after sphincter-preserving rectal resection: emptying difficulties, urgency, incontinence, soiling, variable and unpredictable bowel function, altered stool consistency, increased stool frequency and repeated painful stools [9]. Thus, a validated patient reported outcome assessment tool that covers these attributes should be

implemented in the evaluation process. Low Anterior Resection Syndrome (LARS) score [44] and Memorial Sloan Kettering Cancer Centre Bowel Function Instrument (MSKCC-BFI) were developed for the purpose of assessing bowel function in this specific population. In this review, only two studies used these questionnaires [37, 38]. The lack of consistency in using meaningful assessment tools has led to inaccurate measures of bowel functional outcome. Manometric measures have been used in eight studies. Three studies showed significant improvement in maximal squeeze pressure and two studies showed improvement in rectal capacity with an improved WIS. The findings of these studies demonstrated an association between physiological changes and faecal incontinence. The sustainability of any treatment effect is unknown due to insufficient long term follow up. There is an urgent need to standardise the selected bowel function outcome and quality-of-life measures in future studies, preferably with longer-term follow up, in order to provide more robust evidence concerning the efficacy of PFR for bowel dysfunction after anterior resection.

Strengths and Limitations

The main strength of this review is that it included a comprehensive literature search which yielded an additional four studies compared to previous systematic review [45]. There are several limitations, including low quality across all studies due to small sample sizes, insufficient long-term follow-up, and lack of randomisation and blinding assessment, leading to a high risk of bias. The heterogeneity of outcome measures, variations in intervention protocols and absence of training adherence reporting, meant pooling of data was not possible. These limitations reduce the certainty of evidence, and the findings should be interpreted as preliminary rather than conclusive. Although the overall pattern in the studies indicated a potential benefit, methodological weaknesses limit confidence in the size and generalisability of the observed effect.

Conclusion

In conclusion, this systematic review found that patients with bowel dysfunction symptoms after anterior resection for colorectal cancer may benefit from PFR. The findings of this review should be interpreted with caution due to several methodological limitations of the reviewed studies. Further well-designed PFR trials that include: detailed description of participants' characteristics, a comprehensive protocol to allow examination on its efficacy, appropriateness and feasibility, and use of standardised and validated outcome measures specifically for ARS evaluation, should be considered in order to produce valid and relevant evidence for future care pathway development in colorectal cancer management.

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Table 1 Patient characteristics

Author and year	Participants (n)	Gender M/ F	Age: mean±SD (range)	Stage of tumour n(%)	Surgery details	Mean distance of anastomosis from anal verge (cm)	Oncological treatment n(%)	Diverting stoma n(%) and Mean duration (months)	Symptom characteristics	Duration of symptoms (months)
Nishigori et al 2018	30 LAR 20 ISR 10	23M;7F LAR 16M;4F ISR 7M;3F	67 LAR 66.7±9.5 ISR 67.4±8.0	Not recorded	All straight anastomosis LAR 20 ISR 10	LAR 4.1±2.3 ISR 2±0	Neoadjuvant Radiotherapy LAR 0 ISR 0 Neoadjuvant Chemotherapy LAR 6(30%) ISR 4(40%)	LAR 13(65%) ISR 10(100%) Duration not specified	Faecal incontinence, Frequency defaecation, Faecal urgency	LAR 10.2±12.3 ISR 12±12.2
Lin et al 2016	54	42M;11F Ex 18M;9F NEx 24M;2F	64.1±12.6 (27-79)	Stage I 15(28.3%) 9:5 (Ex:NEx) Stage II 22(41.5%) 10:12 (Ex:NEx) Stage III 22(22.6%) 7:5 (Ex:Nex) Stage IV 4(7.5%) 1:3 (Ex:Nex)	All AR TME 17: 15 (Ex:NEx) PME 10:11 (Ex:NEx)	≤5cm 11:13 (Ex:NEx) >5cm 16:13 (Ex:NEx)	Neoadjuvant Radiotherapy 3(11.1%):5(8.5%) (Ex:NEx)	27(100%) 5.3±3.7	Not recorded	0
Liang et al 2016	61	40M;21F	63.1±10.5	Stage I +II 22(36.1%) Stage III+IV 39(49.2%)	All AR TME 100%	5.2±3.1	Radiotherapy 14(23%) Chemotherapy 13(21.3%)	33(54.1%) Duration not specified	Faecal incontinence, Frequency defaecation, Faecal urgency	7.7±2.9
Kuo et al 2015	32	17M;15F	56.5±9.75* (31-70)	Stage I 3(9.4%) Stage II 3(9.4%) Stage III 23(71.9%) Stage IV 1(3.1%)	Radical proctectomy ISR with hand-sewn CAA Laparoscopic 4.12.5% Robotic 28,87.3%	Not recorded. The distance from the AV to the lowest border of the tumour 3.89±0.875(1.5-5)	Neoadjuvant Chemoradiation 25(78.1%)	5(15.6%) 7(3-8)**	Faecal incontinence, Frequency defecation, Faecal urgency, Incomplete evacuation, Stool fragmentation	8.2±12.1**
Laforest et al 2012	46 Rehab 22 Control 24	26M;20 F	Rehab: 55.0±11.25* (33-78) Control: 60.0±11.25* (35-80)	Stage I+II Rehab: 8(36.4%) Control: 8(33.3%) Stage III+IV Rehab: 14(6.6%) Control: 16(66.7%)	Laparoscopic TME 1. Conventional, low, stapled colorectal anastomosis or hand-sewn CAA with side to end anastomosis. Rehab: 7,31.81% Control: 8,33.33% 2. Partial/ Total ISR Rehab: 15,68.18% Control: 16,66.67%	Not recorded. The distance from dentate line to the tumour: Rehab 3(0.5-9) Control: 2.5(1-9) Anastomosis located at or below 30mm from dentate line	Neoadjuvant radiochemotherapy Rehab: 15(68.2%) Control: 17(70.8%)	T3/T4 30 1.5-2	not recorded	1

Author and year	Participants (n)	Gender M/ F	Age: mean±SD (range)	Stage of tumour n(%)	Surgery details	Mean distance of anastomosis from anal verge (cm)	Oncological treatment n(%)	Diverting stoma n(%) and Mean duration (month)	Symptom characteristics	Duration of symptoms (months)
Kim et al 2011	70	49M;21F	58.1±10.1 (31-79)	not recorded	ARS TME 100%	4.1±1.8 (1.0-9.0)	Radiation therapy 49(70%) Neoadjuvant 30(61.2%) Adjuvant 19(38.8%) Chemotherapy 57(81.4%) Neoadjuvant 1(1.8%) Adjuvant 25(43.9%) Both 31(54.4%)	21(30%) 7(3-8)**	Faecal Incontinence, Frequency defaecation, Faecal urgency, Incomplete evacuation, Stool fragmentation	25.5±21.2
Liu et al 2011	22	12M;10F Ex 4(36.4%)M;7(63.6%)F NEx 8(72.7%)M;3(27.3%)F	Ex 55.27±14.26 (27-82) NEx 65.73±8.73 (45-73)	Not recorded	Not recorded	Not recorded	Not recorded	22(100%) 6-10	Faecal incontinence, Frequency defaecation	1 to >12
Pucciani et al 2008	88	34M;54F	59.6±6.75* (46-73)	Not recorded	LAR 69,79.4% CAA 19,21.5%	LAR 4.5±1 CAA 2.6±0.8	Neoadjuvant radiotherapy 19(21.5%) Adjuvant radiotherapy 34(38.6%)	Not recorded	Faecal incontinence	22.4±7.8*
Allgayer et al 2005	95 Irradiated 41,43.15% Non-irradiated 54,56.84%	61M;34F Irradiated 28(68.3%)M; 13(31.7%)F Non-irradiated 33(61%)M; 21(38.8%)F	Irradiated 58.5±11.25* (31-76) Non-irradiated 67.0±8.75* (48-83)	Stage II/III	AR 100%	Irradiated 7.6±3.1 Non-Irradiated 10.3±4.2	41(43.2%)	Not recorded	Faecal incontinence	1.5(1-10)**
Ho and Tan 1997	11	5M;6F	64.8±10.94*	Stage I:6 Stage II:1 Stage III:2 Stage IV:1	AR TME stapled anastomosis and colonic J pouch	Not recorded	Adjuvant radiotherapy 2(18.2%)	Not recorded	Faecal incontinence, Frequency defaecation, Faecal urgency, Incomplete evacuation	33.3±20.2*
Ho et al 1996	13	10M;3F	62.1±16.59*	Not recorded	AR TME Colorectal anastomosis cross-stapling 7,53.85% Total colectomy 4,46.15%	Not recorded	Adjuvant radiotherapy 4(30.8%)	Not recorded	Faecal incontinence, Frequency defaecation	27.0±22.7*

*SD=Range/4 or SEM/square root of n ; **median

Abbreviations: LAR=low anterior resection; ISR=intersphincteric resection; M=male; F=female; Ex=Exercise; NEx= Non-exercise; AR= anterior resection; TME=total mesorectal excision; CAA=coloanal anastomosis; AV=anal verge

Table 2. Risk of Bias Assessment

Table 2a. Methodological Index for Non-Randomized Studies (MINORS)

Reference	Year	Country	Study Design	MINORS score (total)	Quality Assessment
Nishigori H et al	2018	Japan	Retrospective analysis (case series)	8/16	Fair
Lin Y-H et al	2016	Taiwan	Longitudinal experimental (cohort)	22/24	Good
Liang Z et al	2016	China	Retrospective (case series)	9/16	Fair
Kuo L-J et al	2015	Taiwan	Prospective Observational (case series)	8/16	Fair
Laforest A et al	2012	France	Prospective Case Control (case control)	16/24	Fair
Kim K et al	2011	Korea	Retrospective Cohort (case series)	12/16	Fair
Liu C-H et al	2011	Taiwan	Retrospective Cohort (cohort)	13/16	Good
Pucciani et al	2008	Italy	Prospective non-randomised (case control)	17/24	Fair
Allgayer et al	2005	Germany	Prospective case control (case series)	11/16	Fair
Ho and Tan	1997	Singapore	Prospective (case series)	10/16	Fair
Ho et al	1996	Singapore	Prospective (case series)	10/16	Fair

The items are scored 0 (not reported), 1 (reported but inadequate) or 2 (reported and adequate). The ideal score being 16 for non-comparative studies and 24 for comparative studies.
<50% Poor, 51-80% Fair, >80% Good

Table 2b. Newcastle Ottawa Scale (NOS)

		Selection				Comparability	Outcome			
Reference	Year	Representativeness of the exposed cohort	Selection of the non-exposed cohort	Ascertainment of exposure	Demonstration that outcome of interest was not present at start of study	Comparability of cohorts on the basis of the design or analysis	Assessment of outcome	Was follow-up long enough for outcomes to occur	Adequacy of follow up of cohorts	Total Score
Nishigori et al	2018	*	(-)	(-)	*	(-) (-)	(-)	*	(-)	3
Liang et al	2016	*	(-)	*	(-)	(-) (-)	(-)	*	(-)	3
Kuo et al	2015	*	(-)	(-)	*	(-) (-)	(-)	*	(-)	3
Kim et al	2011	*	(-)	*	*	(-) (-)	(-)	*	*	5
Allgayer et al	2005	*	(-)	*	*	(-) (-)	*	*	*	6
Ho & Tan	1997	*	(-)	(-)	*	(-) (-)	*	*	*	5
Ho et al	1996	*	(-)	(-)	*	(-) (-)	*	*	*	5
		Selection				Comparability	Exposure			
Reference	Year	Is the case definition adequate?	Representativeness of the cases	Selection of controls	Definition of controls	Comparability of cases and controls on the basis of the design or analysis	Ascertainment of exposure	Same method of ascertainment for cases and controls	Non-response rate	Total
Lin et al	2016	*	*	*	*	* (-)	(-)	*	*	7
Laforest et al	2012	*	*	(-)	(-)	* *	(-)	(-)	(-)	4
Liu et al	2011	*	*	*	*	* (-)	(-)	*	*	7
Pucciani et al	2008	*	*	(-)	(-)	* (-)	(-)	*	*	5

* is allocated if the criteria is satisfied whereas (-) if criteria is not satisfied. Total of 9 (*)

Table 3. Intervention

Author and year	Intervention details	Frequency	Duration	Intensity	Time	Type	Setting
Nishigori et al 2018	1. EAS strength training with EMG visual biofeedback and home exercise 2. Coordination and sensory training with rectal balloon biofeedback	1 every 2-3 weeks	6 months	Not specified	Not recorded	Strength, coordination and sensory with EMG and rectal balloon biofeedback	Supervised OP. Self monitored home exercise
Lin et al 2016	1. Routine postop care with information pamphlet for diet and wound care. 2. PFM exercise with instruction for anal sphincter contraction. 3. Participants were educated on self-assessing muscle contraction and informational DVD and pamphlet were given.	4 sessions/ day	9 months (based on the time of evaluation)	20 contractions/ session	Not recorded	EAS strength training	Home; unsupervised
Liang et al 2016	Use of rectal balloon biofeedback and EMG biofeedback. EAS contraction without balloon for 30 min x2/ day at home.	Home exercise 2/day. Rectal balloon training either <15 or >15	Not recorded	Not recorded	30 minutes (Home)	Strength, coordination and sensory with EMG biofeedback and Rectal balloon biofeedback	Home and supervised OP
Kuo et al 2015	NMES for muscle re-education and contraction. After 2 sessions of NMES, EMG biofeedback was used.	NMES 2-3/ week EMG biofeedback 2-3/ week	NMES 12 sessions EMG BF 2-3 months	NMES: ramp up and down 2 sec with duration of 8sec Frequency 30Hz on/off 1:3 pulse. EMG biofeedback: 30-40sec hold each contraction	NMES 20 min. EMG biofeedback not specified	Strength and coordination of PFM during voluntary contraction	Supervised OP
Laforest et al 2012	Rectal balloon biofeedback: PFME with emphasis on maintaining relaxed abdominal muscle while squeezing the perineal muscle with maximum effort in order to achieve 150ml rectal capacity, 3/5 on perineal strength and the ability to perform perineal muscular locking.	1/week	15 sessions	Not recorded	1 hour	Strength and sensory	Supervised OP
Kim et al 2011	Rectal balloon biofeedback with 3 protocols for strength, coordination and sensory training. Participants were asked to practice EAS contraction without RBBF at home	1/week	10 weeks	Not recorded	several times for each component in each session.	Strength, coordination and sensory with EMG biofeedback and Rectal balloon biofeedback	Supervised OP and home
Liu et al 2011	Education. Use of hand out and demonstration for Kegel's exercise. Self-monitoring exercise technique. PFM contraction exercise. Non-PF specific exercise.	3-4/day	12-29 months (20±47)	Not recorded	10 min	Strength	Home. Unsupervised
Pucciani et al 2008	Multimodal rehabilitation based on manometry findings. Pelviperineal kinesitherapy (PK), Biofeedback (BF), Volumetric rehabilitation (VR) Electrostimulation (ES). Using visual or verbal feedback, tepid water enema and portable device.	PK 2/week BF 2/day VR 2/day ES 1/day	PK 7 sessions ES 3 months	121±34 days	BF 20 min	Strength, coordination and sensory	Supervised OP and home
Allgayer et al 2005	PFE. Routine rehabilitation program include information, psychological support, light aerobic exercise. EMG biofeedback with intra-anal EMG device. Home exercise with EMG biofeedback.	1/day	3 weeks	not recorded	30-40 min PFE. Home 1 hour training	Strength and sensory	Supervised OP and Home
Ho and Tan 1997	Rectal balloon biofeedback with visual display.	1/day	4 sessions	Not recorded	1 hour	Strength, coordination and sensory	Supervised OP and home
Ho et al 1996	Rectal balloon biofeedback with visual display.	1/ day	4 sessions	Not recorded	1 hour	Strength, coordination and sensation	Supervised OP and Home

Abbreviation: EAS= external anal sphincter; EMG= electromyography; NMES= neuromuscular electrical stimulation; OP= outpatient; PF= pelvic floor; PFM= pelvic floor muscle; PFE= pelvic floor exercise

Table 4. Functional Outcome

Table 4a. Patient reported outcome

Author and year	Functional outcome tool	Before intervention		After intervention		p-value
		Group 1	Group 2	Group 1	Group 2	
Nishigori et al 2018*	Wexner Fecal Incontinence Score †	10.7	13.1	5.7	12.6	**Group 1 0.01**; Group 2 0.73
	Fecal Incontinence Severity Index†	28	35	11	30	**Group 1 0.04**; Group 2 0.38
	LARS score†	33	35	26	29	**Group 1 0.02**; **Group 2 0.05**
	Number of defaecations per 24 hours	10.1±3.0	12±5.2	2.7±1.2	3.7±1.8	**Group 1 <0.01**; **Group 2 0.02**
	Bristol stool scale	5±1.0	5.1±0.5	4±1.1	3.2±1.0	Group 1 NS; **Group 2 0.02**
	Anti-diarrheal medication (n)	15	10	7	5	**Group 1 0.02**; **Group 2 0.03**
Lin et al 2016	Wexner Fecal Incontinence Score			3.3±2.4 (T3)	6.19±4.03 (T3)	**0.006** (other T NS)
Liang et al 2016	Wexner Fecal Incontinence Score	10.3±2.0		7.8±2.6		**<0.001**
	Vaizey Incontinence Score	13.1±2.2		10.6±2.3		**<0.001**
	Number of defaecations per 24 hour	8.7±3.8		6.2±3.8		**<0.001**
Kuo et al 2015	Wexner Fecal Incontinence Score	17.74±3.03		12.93±4.73		**<0.001**
	Number of defaecations per 24 hour	18.77±8.52		7.83±4.27		**<0.001**
	Stool urgency	30		25		0.063
	Stool fragmentation	31		24		**0.016**
	Anti-diarrheal medication (n)	27		9		**<0.001**
	Nocturnal defaecation	9		6		0.125
Laforest et al 2012	Wexner Fecal Incontinence Score			8.3±3	9.9±3	0.1
	Kirwan's classification (Type I-V)			4,6,8,4,0	3,7,11,3,0	1
	Number of defaecation per 24 hour^			2.6±1.25	4±2.25	**0.025**
	Stool urgency^			8	9	1
	Stool fragmentation (>2 evacuations in 1 hour)^			15	19	0.5
	Dyschezia (stretching to evacuate)^			5	15	**0.008**
	Anti-diarrheal medication (n)^			12	12	0.77
	Ailmentary restriction^			8	10	0.88
	SF36 - Vitality			47.3±9.9	39.3±8.2	**0.004**
	SF36 - Mental Functioning			48.3±7.1	42.7±8.6	**0.02**
	FIQL- Depression/ Self perception			3.2±0.6	2.6±0.7	**0.005**
Kim et al 2011	Wexner Fecal Incontinence Score	13.0±5.2		8.4±6.0		**<0.001**

	Number of defaecation per 24 hour	9.4±4.5		5.8±3.3		**<0.001**
	Anti-diarrheal medication (n)	24		9		NR
	Patient satisfaction VAS			61.9±27.6		
Liu et al 2011	Defaecation >3#			4	5	1
	Faecal incontinence or faecal seepage			5	5	1
	FACT-C			66.27±11.98	49.06±19.28	**0.038**
Pucciani et al 2008**	Wexner Fecal Incontinence Score	11.8±5.09	12.52±4.45	6.4±3.71	5.81±3.6	**<0.05; <0.02**
	MSKCC (1:LAR 2: CAA)†	32.8±5.4	26.6±4.1	16.6±6.3	14.6±3.1	NS
	Number of defaecation per 24 hour	2.9±0.7	4.4±0.8	1.8±0.6	3.4±0.7	NS
Allgayer et al 2005***	Modified Cleveland Incontinence score‡	7.4±2.2	8.6±2.8	(9.3±2.5) 8.1±3.6	(11.5±2.6)10. 5±4.4	**Both groups 0.001**
Ho and Tan 1997****	Number of defaecation per week	37.3	3	14.4	8.9	**Group 2 <0.05**
	Number of Incontinent episodes	14.8		1.8		**<0.05**
	Pad wearing (n)	5		0		
	Straining at defaecation		5		1	
	Sensation of incomplete emptying		3		0	
	Anti-diarrheal/ laxative medication (n)	6	5	0	2	**Group 1 <0.005**
Ho et al 1996	Number of defaecations per 24 hour	8.7		4.6		**<0.05**
	Number of incontinence episodes	2.7		0.4		**<0.05**
	Anti-diarrheal medication (n)	6		1		**<0.05**

*Group 1=CAA(coloanal anastomosis), Group 2=ISR(intersphincteric resection); **Group 1=LAR(low anterior resection), Group 2=CAA; *** Group 1=Irradiated, Group2=non-irradiation; **** Group 1=Faecal incontinence, Group2=Constipation; ^Gastrointestinal standardised questionnaire; #this outcome measured number of participants who had >3 defaecation; †=low score indicates better outcome; ‡=high score indicates better outcome

Table 4b. Manometric measures

Author and year	Group	Resting pressure (max)(mean±SD)			Squeeze pressure (max) (mean±SD)			Rectal capacity (MTV) (mean±SD)		
		Before	After	p-value	Before	After	p-value	Before	After	p-value
Nishigori et al 2018	LAR	NR	NR	NR	NR	NR	NR	NR	NR	NR
	ISR	35	44	0.39	188	275	0.14	110	131	0.43
Liang et al 2016		25.8±12.3	37.0±12.8	<0.001	120.2±42.0	146.5±40.9	0.001	119.0±50.7	143.6±52.8	0.015
Kuo et al 2015		(-)4.21±7.29*	(-)4.08±3.80*	0.061	34.43±35.37*	37.08±22.42*	0.014	NR	NR	NR
Kim et al 2011		39.1±11.1	44.9±18.1	0.01	136.4±45.2	162.7±56.1	0.006	102.3±42.3	120.3±30.6	0.003
Pucciani et al 2008	LAR	47.6±21.4	69.1±21.6	NR	88.3±49.1	107.1±79.8	NR	133.8±51.2	131±42.8	NR
	CAA	46.0±18.9	63.3±20.7	NR	86.9±56.1	98.8±37.7	NR	124±52.9	143.1±34.6	NR
Allgayer et al 2005	Irradiated	27.3±17.2	NR	NR	79.5±34.0	NR	NR	91.2±36.8	NR	NR
	Non-irradiated	33.3±17.8	NR	NR	79.5±34.1	NR	NR	103.0±29.5	NR	NR
Ho and Tan 1997	Incontinent	52.3	57.6	NS	89.3	108.2	NS	130.5	123	NS
	Constipation	50.4	71.3	NS	109.8	118.5	NS	89.5	148.5	NS
Ho et al 1996	AR	53.3	73.3	NS	134.7	171.7	NS	192	110	NS

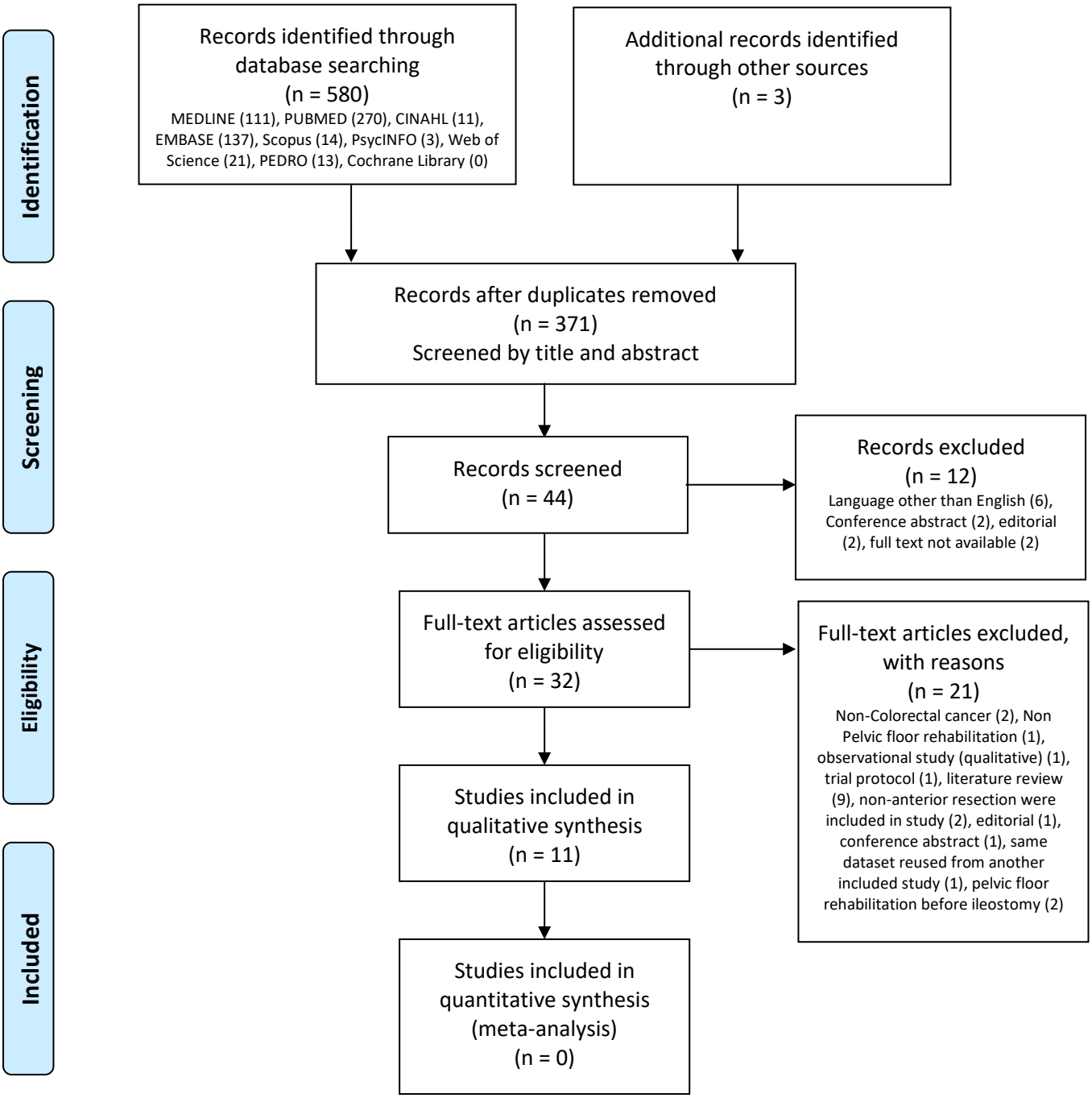
*unit measures: hPa; Abbreviation: NR=not reported, NS=not significant, LAR=low anterior resection, ISR=intersphincteric resection,CAA=coloanal anastomosis, AR=anterior resection

Table 5. Template for Intervention Description and Replication Checklist (TIDieR)

Study	Brief name	Why	What (materials)	What (procedures)	Who provided	How	Where	When and How much	Tailoring	Modifications	How well (planned)	How well (actual)
Nishigori et al 2018	Y	Y	Y	Y	Y	Y	Y	P	N	N	N	N
Lin et al 2016	Y	Y	Y	Y	Y	Y	Y	P	N	N	N	N
Liang et al 2016	Y	Y	Y	Y	N	Y	N	P	N	N	N	N
Kuo et al 2015	Y	Y	Y	Y	N	N	N	Y	Y	N	N	N
Laforest et al 2012	Y	Y	Y	Y	Y	Y	Y	P	Y	N	N	N
Kim et al 2011	Y	Y	Y	Y	Y	Y	Y	P	N	N	N	N
Liu et al 2011	Y	Y	Y	Y	N	N	N	P	N	N	N	N
Pucciani et al 2008	Y	Y	Y	Y	N	Y	N	Y	Y	N	N	N
Allgayer et al 2005	Y	Y	Y	Y	Y	Y	Y	P	N	N	N	N
Ho and Tan 1997	Y	Y	Y	Y	N	Y	Y	P	N	N	N	N
Ho et al 1996	Y	Y	Y	Y	N	Y	Y	P	N	N	N	N

Abbreviation: Y=Yes, N=No, P=Partial

Figure 1. PRISMA flow diagram of study selection



Updated search and evidence

The systematic review included in this thesis was published in 2021; therefore, an updated search was conducted in November 2025 to identify any newly published studies that could influence the findings and to ensure the thesis reflected the most current evidence evaluating pelvic floor rehabilitation (PFR) for bowel dysfunction after anterior resection for colorectal cancer.

Using the same databases as the original review, searches were re-conducted for the period from January 2022 to October 2025. The original eligibility criteria were maintained, and search terms were applied. A single reviewer performed a screening using EndNote for references.

A total of 239 records were initially identified and screened by title, resulting in 71 articles that progressed to abstract screening. Of these, eight full-text articles were assessed for eligibility, leading to the inclusion of three studies in the qualitative synthesis [1-3]. The remaining studies were excluded because they involved mixed anorectal functional disorders and did not evaluate a PFR intervention, which is consistent with the scope of the review [4-8].

The additional findings include three multicentre randomised controlled trials [1-3]. These studies examined PFR interventions delivered through supervised sessions lasting 1-3 months, incorporating a multimodal approach that includes pelvic floor muscle training (PFMT), rectal biofeedback for anorectal coordination, sensory training, and electrical stimulation. Regarding outcome measures, one study used the Low Anterior Resection Syndrome (LARS) score, while two studies employed the Wexner Incontinence Score (WIS) as the primary outcome measure, alongside other validated patient-reported outcome measures (PROMs), functional outcomes, quality-of-life assessments, and anorectal manometry. Two studies reported that PFR improved bowel function compared to the control group. Conversely, the other study found improvement in WIS within the study group but did not observe a statistically significant difference compared with controls. These additional studies

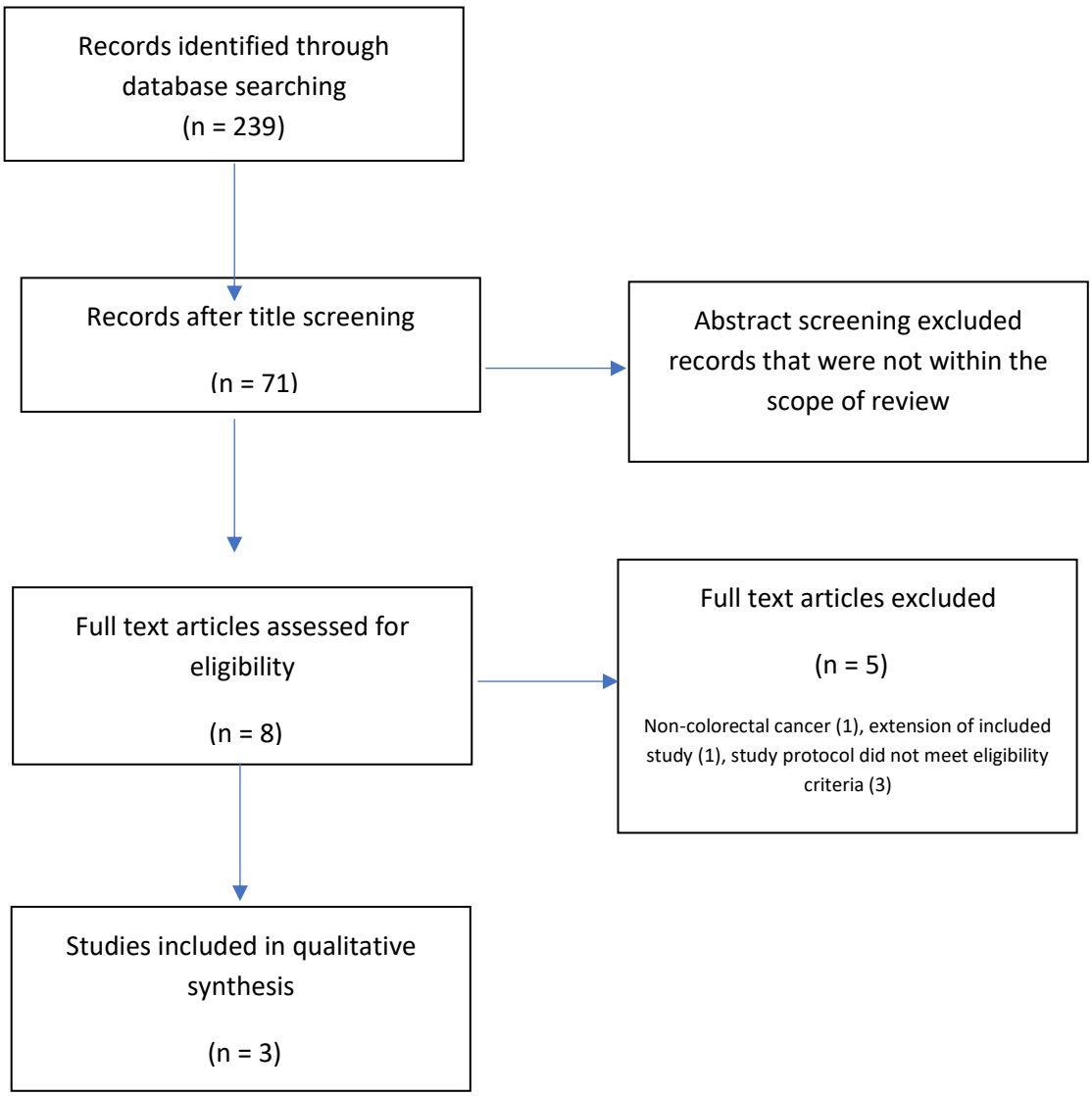
reinforce earlier conclusions from the published review, highlighting the heterogeneity of PFR protocols and the variety of outcome measures used. Overall, the emerging evidence continues to support the notion that PFR may improve functional outcomes after anterior resection for colorectal cancer.

Table 6. Summary of included studies

Study (Country)	Study Design	Participant Characteristics	Timing / Setting	Intervention	Outcome Measures	Effectiveness / Key Findings
Asnong et al., 2022 (Belgium)	Multicentre prospective RCT (control = no PFMT)	Patients after LAR with TME for rectal cancer; baseline LARS score ≈ 21/42	Intervention commenced 1 month after restoration of bowel continuity; delivered over 12 weeks	Supervised physiotherapy including education, PFME, EMG biofeedback/electrostimulation, and rectal balloon training	LARS score (1, 4, 6, 12 months), COREFO, VAS bowel symptom bothersome, stool diary	LARS significantly better in intervention group at 4 and 6 months, but not at 12 months. Both groups improved over time. PFR accelerated recovery in early months, but no sustained between-group difference at 12 months.
van der Heijden et al., 2022 (Netherlands)	Multicentre RCT (control = no PFR)	Post-LAR rectal cancer survivors	Intervention initiated 3 months post-primary surgery or 6 weeks post-stoma reversal; delivered over 12 weeks	Supervised PFR including PFMT, behavioural and coordination biofeedback therapy, functional electrical stimulation, rectal balloon training, and home exercises	WIS, FIQL, LARS score, EORTC QoL	WIS improved in both groups, but adjusted mean scores showed no significant between-group differences. No significant differences in FIQL, EORTC, or LARS improvement (mean −2.3). Urgency and moderate incontinence subgroups showed functional gains but no overall treatment effect.
Yuanyuan et al., 2023 (China)	RCT (PFMT + loperamide vs loperamide only	Post-LAR for rectal cancer; baseline LARS ≈ 21/42; 1 month post-primary surgery or within 6 months after stoma reversal	4-week intervention	Strength and sensory training using manometry; external anal sphincter exercises (30 min twice daily); balloon sensory training	ARP, ASP, HADS, BSC, WIS, stool frequency	Significant improvements in anal pressure, reduced WIS, lower stool frequency, and improved bowel symptom compared with control at 4 weeks.

Abbreviations: ARP - Anal resting pressure; ASP - Anal squeeze pressure; BSC - Bristol stool chart; COREFO - Colorectal functional outcome; EMG - Electromyography; EORTC QoL - European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; FIQL - Fecal Incontinence Quality of Life; HADS - Hospital Anxiety and Depression Scale; LARS - Low anterior resection; LARS - Low anterior resection syndrome; PFME - Pelvic floor muscle exercise; PFMT - Pelvic floor muscle training; PFR - Pelvic floor rehabilitation; RCT - Randomised controlled trial; TME - Total mesorectal excision; VAS - Visual analogue scale; WIS - Wexner incontinence score

Figure 2. PRISMA flow diagram of study selection in updated search



Reference

[1] Asnong A, D'Hoore A, Van Kampen M, Wolthuis A, Van Molhem Y, Van Geluwe B, Devoogdt N, De Groef A, Guler Caamano Fajardo I and Geraerts I 2022 The Role of Pelvic Floor Muscle Training on Low Anterior Resection Syndrome: A Multicenter Randomized Controlled Trial *Annals of Surgery* **276** 761-8

[2] van der Heijden J A G, Kalkdijk-Dijkstra A J, Pierie J, van Westreenen H L, Broens P M A and Klarenbeek B R 2022 Pelvic Floor Rehabilitation After Rectal Cancer Surgery: A Multicenter Randomized Clinical Trial (FORCE Trial) *Annals of Surgery* **276** 38-45

[3] Yuanyuan W, Shiyin H, Lei H and Ding D 2023 Pelvic floor muscle exercises alleviate symptoms and improve mental health and rectal function in patients with low anterior resection syndrome *Frontiers in Oncology* **13** 1168807

[4] Sahid S, Bin Kamarulzaman M Y, Mustafa J B, Sahid N A and Bin Mohamed Kamil N A 2022 Biofeedback therapy for anorectal functional disorder: Malaysian colorectal tertiary centre experience *Annals of Medicine & Surgery* **79** 103848

[5] Bosch N M, Kalkdijk-Dijkstra A J, van Westreenen H L, Broens P, Pierie J, van der Heijden J and Klarenbeek B R 2024 Pelvic Floor Rehabilitation After Rectal Cancer Surgery One-year follow-up of a Multicenter Randomized Clinical Trial (FORCE trial) *Annals of Surgery* **20** 20

[6] Ofluoglu C B, Aydin I C, Altuntas Y E, Cetin K, Inan R, Ilhan N, Mulkut F and Kucuk H F 2024 Impact of pelvic floor muscle training on sphincter function and quality-of-life in patients who underwent low anterior resection: A comparative evaluation *Northern clinics of Istanbul* **11** 336-42

[7] Jones S, Edie A, Troop E, Hill J S and Thompson J A 2024 The Effect of Pelvic Floor Rehabilitation on Low Anterior Resection Syndrome After Colorectal Cancer Treatment *J* 1-12

[8] Wang W, Cai Y, Peng J, Liu L, Feng X and Wan S 2025 Research on preventing low anterior resection syndrome following sphincter-preserving surgery for rectal cancer through high-risk screening and pelvic floor biofeedback therapy *Supportive Care in Cancer* **33** 291

Supplementary file 4.1. An example of search strategy

Database: Ovid MEDLINE(R) ALL <1946 to June 26, 2019>

Search Strategy:

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1 Colorectal cancer.mp. or Colorectal Neoplasms/ (116527)

2 rectal cancer.mp. or Rectal Neoplasms/ (46607)

3 anterior resection.mp. (4289)

4 bowel function.mp. (3320)

5 Fecal Incontinence/ or faecal incontinence.mp. (10106)

6 anterior resection syndrome.mp. (158)

7 pelvic floor.mp. or Pelvic Floor/ (10236)

8 training.mp. (404940)

9 rehabilitation.mp. or Rehabilitation/ (301618)

10 biofeedback.mp. or Biofeedback, Psychology/ (9837)

11 Exercise/ or exercise.mp. (327634)

12 1 or 2 or 3 (155700)

13 4 or 5 or 6 (13166)

14 7 or 8 or 9 or 10 or 11 (935614)

15 12 and 13 and 14 (111)

Supplementary file 4.2. Newcastle Ottawa Scale

NEWCASTLE - OTTAWA QUALITY ASSESSMENT SCALE

CASE CONTROL STUDIES

Note: A study can be awarded a maximum of one star for each numbered item within the Selection and Exposure categories. A maximum of two stars can be given for Comparability.

Selection

1) Is the case definition adequate?

a) yes, with independent validation

b) yes, eg record linkage or based on self reports

c) no description

2) Representativeness of the cases

a) consecutive or obviously representative series of cases

b) potential for selection biases or not stated

3) Selection of Controls

a) community controls

b) hospital controls

c) no description

4) Definition of Controls

a) no history of disease (endpoint)

b) no description of source

Comparability

1) Comparability of cases and controls on the basis of the design or analysis

a) study controls for _____ (Select the most important factor.)

b) study controls for any additional factor (This criteria could be modified to indicate specific control for a second important factor.)

Exposure

1) Ascertainment of exposure

a) secure record (eg surgical records) ☐

b) structured interview where blind to case/control status ☐

c) interview not blinded to case/control status

d) written self report or medical record only

e) no description

2) Same method of ascertainment for cases and controls

a) yes ☐

b) no

3) Non-Response rate

a) same rate for both groups ☐

b) non respondents described

c) rate different and no designation

NEWCASTLE - OTTAWA QUALITY ASSESSMENT SCALE

COHORT STUDIES

Note: A study can be awarded a maximum of one star for each numbered item within the Selection and Outcome categories. A maximum of two stars can be given for Comparability

Selection

1) Representativeness of the exposed cohort

a) truly representative of the average _____ (describe) in the community

b) somewhat representative of the average _____ in the community

c) selected group of users eg nurses, volunteers

d) no description of the derivation of the cohort

2) Selection of the non exposed cohort

a) drawn from the same community as the exposed cohort

b) drawn from a different source

c) no description of the derivation of the non exposed cohort

3) Ascertainment of exposure

a) secure record (eg surgical records)

b) structured interview

c) written self report

d) no description

4) Demonstration that outcome of interest was not present at start of study

a) yes

b) no

Comparability

1) Comparability of cohorts on the basis of the design or analysis

a) study controls for _____ (select the most important factor)

b) study controls for any additional factor (This criteria could be modified to indicate specific control for a second important factor.)

Outcome

1) Assessment of outcome

a) independent blind assessment

b) record linkage

c) self report

d) no description

2) Was follow-up long enough for outcomes to occur

a) yes (select an adequate follow up period for outcome of interest)

b) no

3) Adequacy of follow up of cohorts

a) complete follow up - all subjects accounted for

b) subjects lost to follow up unlikely to introduce bias - small number lost - > ____ % (select an adequate %) follow up, or description provided of those lost)

c) follow up rate < ____% (select an adequate %) and no description of those lost

d) no statement

Supplementary file 4.3. Methodological items for non-randomised studies

Methodological items for non-randomised studies	Score*
1. A clearly stated aim: the question addressed should be precise and relevant in the light of available literature	
2. Inclusion of consecutive patients: all patients potentially fit for inclusion (satisfying the criteria for inclusion) have been included in the study during the study period (no exclusion or details about the reasons for exclusion)	
3. Prospective collection of data: data were collected according to a protocol established before the beginning of the study	
4. Endpoints appropriate to the aim of the study: unambiguous explanation of the criteria used to evaluate the main outcome which should be in accordance with the question addressed by the study. Also, the endpoints should be assessed on an intention-to-treat basis	
5. Unbiased assessment of the study endpoint: blind evaluation of objective endpoints and double-blind evaluation of subjective endpoints. Otherwise the reasons for not blinding should be stated	
6. Follow-up period appropriate to the aim of the study: the follow-up should be sufficiently long to allow the assessment of the main endpoint and possible adverse events	
7. Loss to follow up less than 5%: all patients should be included in the follow up. Otherwise, the proportion lost to follow up should not exceed the proportion experiencing the major endpoint	
8. Prospective calculation of the study size: information of the size of detectable different of interest with a calculation of 95% confidence interval, according to the expected incidence of the outcome event, and information about the level for statistical significance and estimates of power when comparing the outcomes	
Additional criteria in the case of comparative study	
9. An adequate control group: having a gold standard diagnostic test or therapeutic intervention recognised as the optimal intervention according to the available published data	
10. Contemporary groups: control and studied group should be managed during the same time period (no historical comparison)	
11. Baseline equivalence of groups; the groups should be similar regarding the criteria other than the studied endpoints. Absence of confounding factors that could bias the interpretation of the results	
12. Adequate statistical analyses: whether the statistics were in accordance with the type of the study with calculation of confidence intervals or relative risk	

*The items are scored 0 (not reported), 1 (reported but inadequate) or 2 (reported and adequate). The global ideal score being 16 for non-comparative studies and 24 for comparative studies.

Supplementary file 4.4. Template for Intervention Description and Replication checklist

TIDieR
Template for Intervention Description and Replication

The TIDieR (Template for Intervention Description and Replication) Checklist*:

Information to include when describing an intervention and the location of the information

Item number	Item	Where located **	
		Primary paper (page or appendix number)	Other † (details)
	BRIEF NAME		
1.	Provide the name or a phrase that describes the intervention.	_____	_____
	WHY		
2.	Describe any rationale, theory, or goal of the elements essential to the intervention.	_____	_____
	WHAT		
3.	Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	_____	_____
4.	Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	_____	_____
	WHO PROVIDED		
5.	For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.	_____	_____
	HOW		
6.	Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	_____	_____
	WHERE		

7.	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	_____	_____
	WHEN and HOW MUCH		
8.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.	_____	_____
	TAILORING		
9.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	_____	_____
	MODIFICATIONS		
10.‡	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	_____	_____
	HOW WELL		
11.	Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	_____	_____
12.‡	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	_____	_____

** **Authors** - use N/A if an item is not applicable for the intervention being described. **Reviewers** – use '?' if information about the element is not reported/not sufficiently reported.

† If the information is not provided in the primary paper, give details of where this information is available. This may include locations such as a published protocol or other published papers (provide citation details) or a website (provide the URL).

‡ If completing the TIDieR checklist for a protocol, these items are not relevant to the protocol and cannot be described until the study is complete.

* We strongly recommend using this checklist in conjunction with the TIDieR guide (see *BMJ* 2014;348:g1687) which contains an explanation and elaboration for each item.

* The focus of TIDieR is on reporting details of the intervention elements (and where relevant, comparison elements) of a study. Other elements and methodological features of studies are covered by other reporting statements and checklists and have not been duplicated as part of the TIDieR checklist. When a **randomised trial** is being reported, the

TIDieR checklist should be used in conjunction with the CONSORT statement (see www.consort-statement.org) as an extension of **Item 5 of the CONSORT 2010 Statement.** When a **clinical trial protocol** is being reported, the TIDieR checklist should be used in conjunction with the SPIRIT statement as an extension of **Item 11 of the SPIRIT 2013 Statement** (see www.spirit-statement.org). For alternate study designs, TIDieR can be used in conjunction with the appropriate checklist for that study design (see www.equator-network.org).

Chapter 5: A pelvic floor rehabilitation program for patients with bowel dysfunction after sphincter-preserving surgery for colorectal cancer: a feasibility study protocol

Overview

Chapter 4 conducted a systematic review of current evidence suggesting that pelvic floor rehabilitation (PFR) may benefit individuals with bowel dysfunction after anterior resection, despite methodological limitations in the existing studies. Although the review showed promising trends in symptom management, the variability in PFR design, duration, and outcome measures underscores the need for a standardised, practical protocol in outpatient survivorship settings. Building on this, this chapter describes a structured 10-week PFR protocol designed for patients with low anterior resection syndrome (LARS). This protocol represents a key step in addressing gaps identified in the literature and provides a foundation for future feasibility and efficacy studies.

The manuscript is quoted verbatim.

Contribution of authors

I, Kin Yin Chan was responsible for study conceptualisation and design, including design of the study intervention and drafting and finalising manuscript

Michael Suen developed the concept and design of study, reviewed the manuscript

Susan Coulson reviewed the manuscript

Janindra Warusavitarne reviewed the manuscript

Janette Vardy developed the concept and design of study, and reviewed the manuscript

Abstract

Background: There is a high prevalence of bowel dysfunction (anterior resection syndrome) in survivors who have undergone colorectal cancer (CRC) surgery and treatment. This has a detrimental effect on quality of life and physical and psychosocial well-being. Pelvic floor rehabilitation (PFR) is one treatment option for faecal incontinence in patients with anterior resection syndrome.

Methods: This is a non-randomised, single arm, prospective study to explore feasibility and efficacy of a PFR program for CRC patients with bowel dysfunction symptoms after anterior resection. Major eligibility criteria: (i) anterior resection with sphincter preservation for CRC; (ii) onset of bowel dysfunction symptoms after surgery, with Low Anterior Resection Syndrome (LARS) Score >20; (iii) bowel continuity restored without stoma for >6 months; and (iv) no CRC recurrence or metastasis. Participants attend the program with one-to-one supervision for one 60-minute session per week for 10 weeks. The program consists of bowel education, PFR with anorectal coordination with biofeedback, supervised pelvic floor muscle training, and a prescribed home exercise program. Primary endpoint will be adherence and compliance (attendance) to the supervised PFR program. Secondary endpoints include bowel, bladder and sexual function, quality of life, anorectal function, and patient satisfaction using survey and exit interviews. Ethics approval was granted by Sydney Local Health District Human Research Ethics Committee, Concord Repatriation General Hospital (SLHD HREC, CRGH) (reference number 2019/PID 15308).

Discussion: We anticipate the PFR program will be acceptable to patients and results will inform a randomised controlled trial to examine effectiveness of the intervention.

Introduction

Colorectal cancer (CRC) is the fourth most frequently diagnosed cancer in Australia [1]. Surgery remains the primary curative treatment and a multimodal approach with chemotherapy and possibly radiotherapy has been adopted for managing more locally advanced cancer [2]. According to the Binational Colorectal Cancer Audit (BCCA) in 2021, 27% and 66% of surgeries performed were anterior resection for colon and rectal cancer respectively [3]. The evolution of surgical techniques and technology [4], with organ preserving surgery and the addition of chemoradiotherapy, has resulted in a dramatic improvement in oncological outcomes, but still comes at a considerable cost to patients' quality of life [5, 6].

Although nerves, anal sphincters and pelvic floor muscles are spared, altered and unpredictable bowel function is one of the common challenges CRC survivors confront following anterior resection and chemotherapy and/or radiotherapy; with up to 80% of CRC survivors experiencing one or more bowel symptoms [7], particularly anal incontinence and defaecation difficulties [8, 9]. Low anterior resection syndrome (LARS) is a collective term to describe the bowel dysfunction symptoms in people who have had an anterior resection and experience at least one of the following, resulting in biopsychosocial consequences: variable, unpredictable bowel function; altered stool consistency; increased stool frequency; repeated painful stools; emptying difficulties; urgency; incontinence and soiling [10].

Spontaneous improvement usually occurs between 6-18 months after bowel continuity is restored, but recovery often plateaus, with some symptoms persisting long term [11, 12]. Substantial involvement of the anorectum in resection surgery, administration of chemoradiotherapy, and a temporary defunctioning stoma are all predictors for poor functional bowel outcomes [13]. The LARS score is a commonly used, validated questionnaire to evaluate the severity and impact of LARS on an individual. Studies have shown ~41% of patients continue to suffer from major LARS (score >30/42) long after their cancer surgery [13-15].

The pathophysiology of LARS is multifactorial and is hypothesised to be due to anatomical alterations in neuromuscular structure of the anorectal complex from the surgery and oncological treatment [11, 16]. The primary goals are to restore anorectal function using a minimally invasive approach and to optimise the overall physical function after surgery to improve quality of life. Conservative management, such as medications, dietary adjustment, anal irrigation, pelvic floor rehabilitation and supportive care, is usually the first line approach to address both physical and psychological impacts from LARS [9]. Pelvic floor rehabilitation with biofeedback has been found useful for improving symptoms of faecal urgency, frequency, and incontinence after rectal cancer resection [17-19]. A recent randomised controlled trial demonstrated pelvic floor muscle training (PFMT) improved LARS score up to 6 months after resection surgery compared to no PFMT [20] but no difference was found in LARS between the groups at 12 months, suggesting it is unknown whether early intervention improves longer-term function. Although pelvic floor training has been found to have some positive effects on managing faecal incontinence after sphincter-preserving surgery for CRC, the evidence remains inconsistent across studies; potentially due to variability in patient eligibility, particularly timing after surgery, patient selection for the pelvic floor rehabilitation, and the heterogeneity of protocols [19]. The successfulness of a treatment may depend on appropriate selection of patients, having a feasible intervention with a specific regime that focuses on functional reconditioning, and the compliance and adherence of the individuals.

Between 2018-2020, there were 120 anterior resection surgeries performed for CRC at Concord Repatriation General Hospital (CRGH) however an individualised rehabilitation program is not currently available for cancer survivors with bowel dysfunction after surgery.

Objectives

The primary objective of the study is to determine the feasibility and acceptability of a short-term outpatient pelvic floor rehabilitation program for patients with bowel dysfunction after CRC surgery and treatment.

Secondary objectives are to explore the efficacy of a symptom-based pelvic floor rehabilitation program in improving bowel function, quality of life, and patients' satisfaction and experience.

Trial design

This is a non-randomised, single armed, prospective study that will evaluate the feasibility and efficacy of a short-term pelvic floor rehabilitation program for patients with bowel dysfunction symptoms after undergoing anterior resection for CRC. The design has considered pragmatic and ethical considerations, given the limited resources available for piloting a service that previously did not exist in the oncology setting, while maintaining a focus on safety, acceptability and implementation. The minimum recruitment period will be 24 months. The first participant was enrolled in May 2021. Figure 1 showed study flow chart.

Methods

Participants, interventions, and outcomes

Study setting

The study recruitment will take place at Concord Repatriation General Hospital (CRGH), a tertiary teaching hospital in Sydney, Australia. The assessment and intervention will be conducted at an external entity (colorectal surgeon's consultation clinic) which is already set up for pelvic floor assessment and training.

Eligibility criteria

Patients who attend The Sydney Cancer Survivorship Clinic, Colorectal Surgery Outpatient Clinics at CRGH, or clinics of colorectal surgeons in New South Wales (NSW), Australia will be invited to be

screened. Patients will be considered eligible if they meet all the inclusive criteria: (i) underwent anterior resection with sphincter preservation for CRC with or without neoadjuvant/adjuvant therapy; (ii) initial onset of bowel dysfunction symptoms occurred after surgery and treatment, with a Low Anterior Resection Syndrome (LARS) Score >20 (Minor [20-29] or Major LARS [30-42]), thereby ensuring sufficient baseline symptom severity to detect measurable change in a small sample and avoid potential floor effects in patients with minimal symptoms; (iii) bowel continuity restored without stoma for at least 6 months. The >6-month threshold was chosen to ensure that participants had recovered from the immediate postoperative period, and that the bowel function outcomes measured are not due to natural recovery; and (iv) no clinical evidence of recurrence of CRC or distant metastasis.

Patients will be excluded if they have one of the following: (i) under 18 years of age; (ii) unable to give informed consent or follow instructions due to cognitive or English language difficulties; (iii) neurological disorders or acute exacerbation of inflammatory bowel disease.

Study procedure

After screening and consent, participant's bowel function will be assessed individually with Patient Reported Outcome Measures (PROM) and a clinical examination to determine the ability of pelvic floor and anal sphincter muscle contraction, defaecatory coordination, and rectal sensory baseline values. Baseline demographic information, surgical history and oncological treatment information, and other medical history will be collected.

The program is specifically designed for this study, which aims to evaluate its feasibility in an outpatient cancer rehabilitation setting. The components in the PFR are chosen based on existing literature, clinical expertise, as well as the available resources for conducting this study. We aim to detect the signal of PFR efficacy in the multifactorial nature of LARS by restoring evacuation and storage functions through pelvic floor muscle and anal sphincter training, re-establishing anorectal coordination, improving rectal sensory discrimination with biofeedback, and behaviour modification.

The pelvic floor rehabilitation program will commence after the initial assessment is completed. This is a 10-week structured program (60-minute sessions) with one-to-one supervision by a physiotherapist trained in pelvic floor dysfunction, rectal balloon and biofeedback interventions and cancer rehabilitation (Table 1).

Table 1 Pelvic Floor Rehabilitation Outline

Category	Description
Educational session	• Provide an overview of pelvic floor and anorectum anatomy and physiology • Explain bowel changes or LARS after surgery and oncology treatment • Describe strategies to manage bowel symptoms which include dietary advice, good bladder and bowel habits and correct toileting technique • Demonstrate correct pelvic floor muscle activation and coordination. • Provide handouts with information about diet and pelvic floor muscle exercises • Give exercise and bowel symptoms diary
Supervised pelvic floor rehabilitation	• Anorectal coordination training with rectal balloon catheter biofeedback • Supervised pelvic floor muscle training • Home exercise prescription
Home exercise program	• Home based exercise with given instruction • Self-recording the frequency and type of exercise perform daily in the diary • Self-reporting bowel symptoms in diary

Educational Session

An individual education session will be given to participants at the first session. This will cover: i. an overview of pelvic floor and anorectal anatomy and physiology; ii. bowel changes or LARS after surgery and oncology treatment; iii. strategies to manage bowel symptoms including dietary advice, good bladder and bowel habits and correct toileting technique; and, iv. demonstration of correct pelvic floor muscle (PFM) activation and coordination. Study specific handouts with information about diet and pelvic floor muscle exercises will be given to the participants in the first session.

Pelvic Floor Rehabilitation

The rehabilitation program is designed to retrain anorectal coordination with biofeedback, PFM exercise and general exercise. Physical attendance at the clinic is essential for the biofeedback component.

1. Anorectal coordination with biofeedback:

Sensory biofeedback with a rectal balloon catheter. A single-use Ashley 2 Reflex Balloon Catheter will be inserted into the anorectal passage with the participant in the left side-lying position. The therapist will use a 60ml syringe to inflate the balloon with air via tubing and a 3-way tap with increments of 5ml every 5-10 seconds. During the procedure, participants will report and recognise 3 rectal sensations: initial sensation of rectal distension, urge to defaecate sensation, and maximal tolerable volume. The therapist will use the rectal sensory findings at the initial assessment as a reference and will ask participants to activate pelvic floor muscles and defer urge sensation. When the rectal distension reaches the perceived maximal tolerable volume, the participants will be asked to perform a balloon expulsion to simulate the defaecatory coordination. The procedure will be repeated 3-5 times with rests in between.

2. Pelvic Floor Muscle (PFM) training:

i. Visual biofeedback with transperineal ultrasound. A transperineal ultrasound will be used to provide visual feedback during PFM training. A convex probe with 3MHz frequency will be placed on the perineum. Participants will be able to visualise the activation and coordination to ensure correct engagement of muscle complex under therapist's instruction [21, 22].

ii. The training will consist of 3 sets of exercises for strength, endurance and reaction training of the PFM. The number of repetitions will be adjusted according to progress throughout the 10 weeks. Strength training exercises are slow voluntary maximal contractions, starting with 5 repetitions and aiming to increase to 10 repetitions for 3 sets. For endurance training, 15 repetitions of submaximal contraction of 5 sets will be performed and will be progressed

from a sustained contraction of 5 seconds to a maximum of 30 seconds. Lastly, timed fast PFM contraction with 10 repetitions will be performed. For all training exercises, a complete PFM relaxation, and breathing coordination should be observed, with adequate rest between repetitions or sets.

iii. Integrated functional PFM training. PFM training will be performed in both static and dynamic functional positions including supine, sitting, standing, and with movement. Upper and lower limb resistance exercises with a focus on PFM, abdominal and breathing coordination will be prescribed and equipment such as body weights and resistance bands will be utilised.

3. Home Exercise Program:

In the first session, participants will receive a home exercise and bowel symptom diary. Participants will be asked to bring the diary when they attend the weekly supervised training session. At each session the therapist will review the training progress and prescribe home exercises for the following week. The exercise instructions for the weekly prescribed exercise will be written in the diary. Participants will be advised to practice the exercises daily and to record the exercise frequency and type of exercise in their diary. Bowel symptoms will also be recorded in the diary.

The initial structured program was designed for physical attendance. In response to the COVID-19 pandemic, local lockdowns, and isolation recommendations, the study protocol was adapted in July 2021 to include a telehealth alternative. Participants not able to attend the training session in person were able to complete the supervised PFM training virtually via real-time videoconferencing and their exercise diaries were reviewed by the therapist.

Participants may discontinue the study protocol in the event of a hospital admission in the 10-week period due to intercurrent illnesses or at the request of the participant. Participants will still be encouraged to complete assessments at scheduled times and to continue follow-up even if they are not able to complete the pelvic floor rehabilitation program.

Prior to the start of the program, the therapist will discuss with participants time preferences for attendance. Participants will be given a table of scheduled dates and a reminder phone call before the sessions. Participants will be encouraged to discuss with the investigator any changes to their schedule. Adherence to the program will be monitored using participants' attendance and home exercise completion record. The therapist will provide support to promote compliance and adherence to the assessments and interventions.

During the trial, participants will attend their routine cancer care appointments.

Outcomes Assessments

Data will be collected at three assessments: baseline (T1), post intervention (T2, 12 +/- 2 weeks from T1) and follow up (6 months after intervention T3, 9 months +/- 1 month from T1). These time points are selected to evaluate immediate post-intervention effects and explore whether improvements are sustained within the first year after PFR. The first two assessments will be completed in person. The final assessment will be either by phone or an in-person interview. An exit interview will be conducted at T2 to obtain qualitative information (Table 3).

Outcomes

Primary endpoint

The primary endpoint will be feasibility, including adherence, completion and compliance with supervised pelvic floor rehabilitation program. Attendance will be assessed through therapist-recorded attendance for each individual at supervised sessions. Attendance will be recorded by the treating therapist and defined as the proportion of scheduled therapy sessions attended by the participant. Program completion will be defined as attendance at >80% of scheduled sessions. The therapist will review the completion of the exercise diary and frequency at each weekly treatment session. Exercise adherence will be assessed using home exercise diaries, where participants will record the frequency and completion of prescribed home exercises (one daily at the prescribed intensity and repetitions). The exercise diary will be reviewed by the physiotherapist at each session,

including telehealth consultations, and used to calculate the proportion of prescribed exercise performed over the study period. Exercise adherence is expressed as the proportion of exercise completed by each participant. Overall compliance will be defined as meeting >80% of both attendance and home exercise adherence requirements.

Secondary endpoint

Participant satisfaction will be assessed by a 14-item investigator-developed survey: questions 1-3 contain demographic information, questions 4-12 are items concerning program quality rated using a Likert scale from strongly agree, agree, disagree and strongly disagree, question 13 rates overall satisfaction with the program on a scale ranging from 0= very poor to 5= excellent. Question 14 is an open-ended question that allows participants to express their views on how to improve the program in a descriptive format. Secondary endpoints will include measuring bowel, bladder and sexual function, as well as quality of life using validated questionnaires, self-administered by participants at three time points. The validated questionnaires are listed in Table 2.

High resolution anorectal manometry (Solar GI HRAM) and a single use 24-channel water perfused manometry catheter will be used to assess the resting pressure, squeeze pressure, rectal capacity and rectal sensitivity [23]. Endoanal ultrasound will examine the morphology of the anal sphincter complex (Hitachi Aloka medical diagnostic ultrasound system). The anorectal function assessment will be performed by a trained physician and physiotherapist. Pelvic floor muscle tone and strength will be measured by digital palpation via the anal passage. The ability and technique of generating muscle contraction will be assessed using the Modified Oxford Scale for pelvic floor muscle testing. This Scale has been shown to be reliable [24], and is widely used in pelvic floor physiotherapy assessment.

A one-off, semi-structured exit phone interview of ~15-20 minutes duration will obtain information about the impact of the bowel symptoms in participant's day to day lives and any changes noted since doing the pelvic floor rehabilitation using Symptom Management Theory [25]. The interviews

will be conducted by an independent research assistant who is trained in carrying out interviews. The information will be recorded and transcribed with software (TRINT) for data analysis. A patient satisfaction survey developed by the investigator will also be completed at the end of the program.

The following data will be collected as part of the study:

	Pre-intervention Baseline (T1)	Post-intervention 12 weeks (T2)	Follow-up 9 months (T3)
Demographics, medical history, cancer characteristics and treatment details	X		
Bowel function: Low Anterior Resection Syndrome (LARS) Score [26], Memorial Sloan Kettering Cancer Centre – Bowel Function Instrument MSKCC[27], Bristol Stool Chart	X X X	X X X	X X X
Bladder function: International Consultation of Incontinence – Lower Urinary Tract ICIQ-LUT[28]	X	X	X
Sexual function: International Index of Erectile Function IIEF[29] (males only) Female Sexual Function Index FSFI[30] (females only)	X X	X X	X X
Quality of Life : Fecal Incontinence Quality of Life FIQOL[31], Functional Assessment of Cancer Therapy – Colorectal FACT-C[32], Hospital Anxiety and Depression Scale HADS[33]	X X X	X X X	X X X
Anorectal function assessment: Anorectal manometry, endoanal ultrasound,			

anal digital palpation	X	X	
Compliance and Adherence: Attendance record, exercise diary, patient satisfaction survey		 X	
Exit interview		X	

Table 2 data collection.

(X = data collected at timepoints)

Sample size

The sample size is pragmatic, with recruitment target of 15 participants. This estimate is based on the number of anterior resections performed for CRC and numbers attending the outpatient clinics at CRGH over the two years prior to start of the study, together with the estimated proportion of patients reporting LARS (approximately 30%) who may be eligible for recruitment through the clinics.

Recruitment

Participants are recruited from the Sydney Cancer Survivorship Centre and the Colorectal Outpatient Clinic at CRGH. Treating clinicians, medical oncologists, colorectal surgeons, and nursing staff are informed of the study and asked to identify potentially eligible patients during routine consultations at the clinics. Eligibility screening is based on pre-defined inclusion criteria, including the LARS score.

The LARS score will be forwarded to the investigator to confirm the patient's eligibility and enrolment. The patient will be contacted by this investigator, who is not involved in providing clinical care, to receive detailed information about the study, including the patient information sheet and consent form, and to minimise perceived coercion. Patients will be given at least 24 hours to consider participation and ask any questions before providing consent.

In 2021, the ethics protocol was amended to extend recruitment to additional colorectal surgeons' clinics within CRGH and across New South Wales. Patients referred from external clinics are required

to attend the investigation site to participate. This amendment is implemented to assist recruitment due to the impact of COVID-19-related disruptions on clinics and surgery.

All eligible patients identified through these pathways are provided with study information and invited to participate voluntarily.

Data collection, management, and analysis

Data collection methods

One of the investigators, a physiotherapist with experience in pelvic floor dysfunction and cancer rehabilitation will be responsible for data collection from participants. A second investigator will be responsible for exit interview data collection and transcription.

Participants will be given a program schedule to ensure their availability to attend. Participants will also be sent a reminder for appointments and questionnaire completion. In case of study discontinuation, the collected data will be kept as part of the analysis but no further data will be collected.

Data management and confidentiality

Participants will be allocated a study number. All participants' identification and information identifying the individuals will be removed from the data set prior to statistical analysis and results reporting. The completed questionnaires will be kept in a locked cabinet in the oncology department at CRGH. All collected information will be de-identified, and entered into project specific Research Electronic Data Capture Database at Sydney Local Health District Server (REDCap-SLHD) with password protection for data access. The identifiable information will be stored in a standalone instrument within the REDCap-SLHD database and access restricted to a limited number of investigators on the research team. The recorded audio data from the exit interview will be de-identified, transferred and stored on REDCap-SLHD. This will ensure data are securely stored with regular back-up. Audio recordings will be deleted from the recording device once transferred to a

secured server. The recordings will be transcribed by investigators and then deleted from the storage system.

Statistical methods

Adherence to the pelvic floor rehabilitation program will be derived as a proportion based on participants' attendance and exercise completion. Baseline characteristics will be reported using descriptive statistics (mean and deviation for normally distributed data or median and interquartile range for non-normally distributed data).

Bowel function and PROM will be analysed using paired sample t-tests, with 95% Confidence Interval (CI) to report changes in outcome variables. Due to the small sample size, measures of significance will not be reported. The statistical package will be IBM SPSS version 26.

An inductive thematic analysis will be performed on the collected qualitative data from the exit interviews. The recorded interview audio will be transcribed using a secure online audio transcription service (TRINT). Data will be cross-checked and analysed by the research team. NVivo will be used in the coding process for all transcripts to generate the themes.

In cases of lost to follow up, if the rate is <20%, missing data will be handled by single imputation method, where the missing value on the continuous variable will be replaced by the mean of the group.

Monitoring

Data monitoring

The research data management plan was completed and reviewed as part of the requirement for this study set out in the Australian Code for the Responsible Conduct of Research and SLHD governance practices.

Adverse events

Adverse events will be recorded and Significant Safety Issues (SSI) notified to the Human Research Ethics Committee (HREC).

Auditing

Trial conduct will be monitored by the Human Research Ethics Committee at Concord Repatriation General Hospital.

Ethics

Research ethics approval

Ethics approval was granted by Sydney Local Health District Human Research Ethics Committee, Concord Repatriation General Hospital (SLHD HREC, CRGH) under the reference number 2019/PID 15308. This study was registered on the Australian and New Zealand Clinical Trials Registry (ANZCTR), ACTRN 12620000821998. The study will be performed in accordance with the "NHMRC National Statement on Ethical Conduct in Human Research" (Commonwealth of Australia 2007, updated 2018) and the ethical principles that have their origin in the World Medical Association Declaration of Helsinki (Helsinki 1964, updated 2016).

Trial registration

Australian and New Zealand Clinical Trials Registry ACTRN 12620000821998. Registered on 17th August 2021.

Protocol amendments

All protocol modifications will be reviewed by the chief investigator and formal amendments approved by the ethics committee at CRGH.

Consent or assent

Patients with symptoms of bowel dysfunction referred to the study will be contacted by one of the research team. Patients will then be assessed against the selection criteria. Information about the

study will be explained by the investigator either in the clinic or over the phone. Interested patients will be given an opportunity to ask questions about the study and allowed time for decision-making. A patient information sheet will be handed to prospective participants or sent by mail or email. The investigator will obtain written signed consent.

Declaration of interests

A Concord Cancer Centre Research Grant was received for this project with the funding contributing to the cost of disposable equipment. There are no other conflicts of interest to declare.

Access to data

The principal investigators will have data access on REDCap and will be obliged to review data prior to submission of publication and presentation.

Dissemination policy

The results for this study will be presented and published in a peer-reviewed journal.

Discussion

Anterior resection surgery with sphincter preservation remains the mainstream treatment for curative CRC, in combination with chemoradiotherapy for locally advanced disease. There is a high prevalence of associated bowel dysfunction (i.e. LARS) amongst cancer survivors, leading to physical-psycho-social well-being problems after treatment [10, 14, 15]. Ongoing bowel disturbance inevitably affects the physical activity level and psycho-social well-being of an individual, placing a substantial restriction on the cancer survivor regaining a normal and healthy lifestyle. This can also impact the carer and the family [34]. LARS is multifactorial and its management requires a step-wise multimodal approach [16, 35].

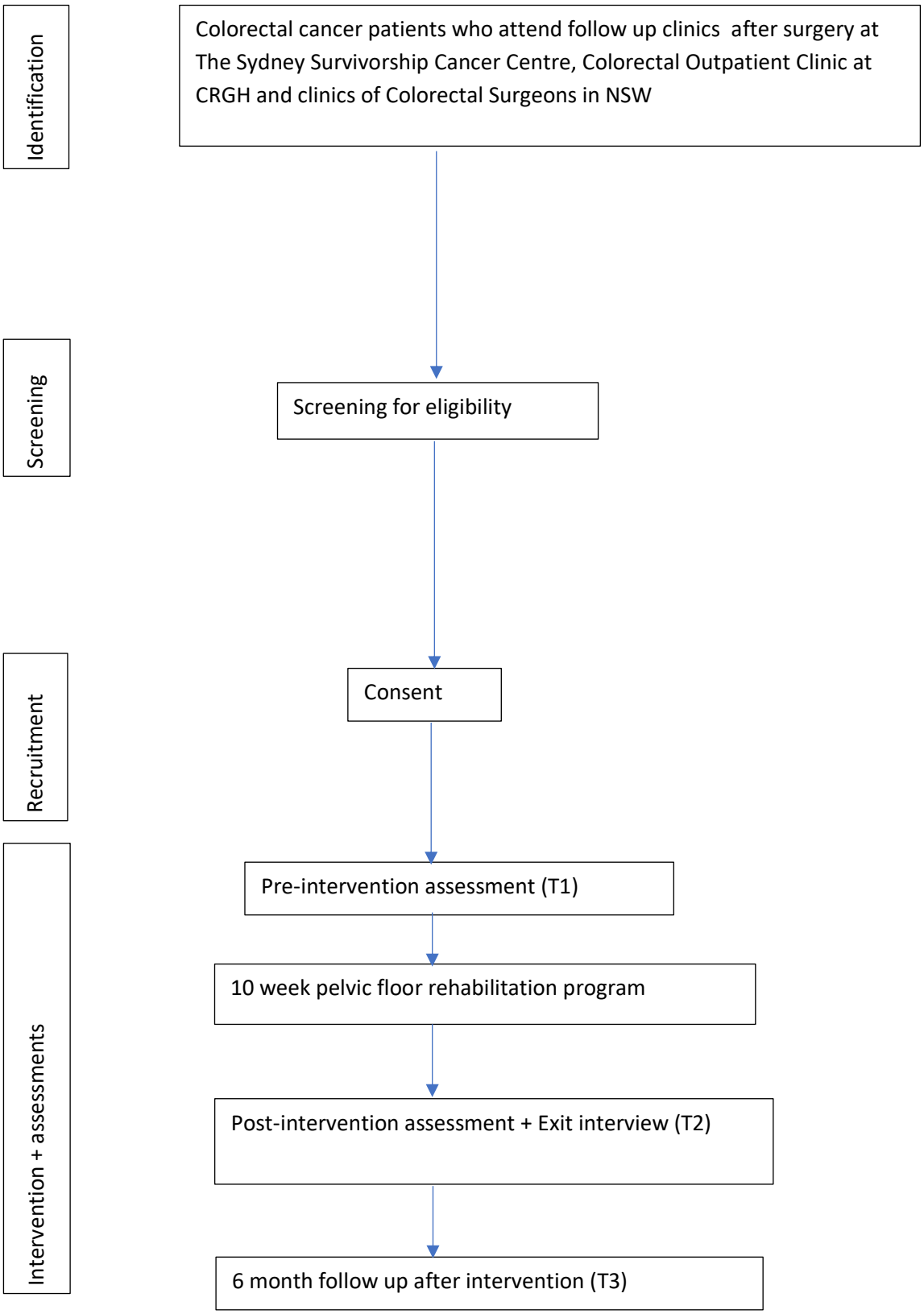
A structured pelvic floor rehabilitation program that consists of patient education and pelvic floor retraining forms part of the LARS treatment algorithm by addressing the physical and psychological impact of the bowel dysfunction. Supportive care education may assist patients to adapt and re-

establish a new bowel routine, and to set-up coping strategies by improving their understanding of permanent changes caused by the surgery and treatment [36], whereas PFM training in promoting functional improvement in anorectum may improve the bowel symptoms. Evidence of the efficacy of pelvic floor muscle training for faecal incontinence and urgency secondary to colorectal resection has been inconsistent due to variability of treatment protocols, patient selection, and outcome assessments [19, 37].

Intervention acceptability and patient compliance are crucial factors to determine the successfulness of service provision in this cohort of patients in a complex health care system [38]. A recent pelvic floor rehabilitation for anterior resection syndrome feasibility study reported difficulties with recruitment, adherence and reduced compliance before surgery and in the early postoperative period, with only 1 out of 9 recruited participants completing the program. Medical complications, low staffing levels, and lack of family available to provide transport, all contributed to the low participation and completion rate [39]. Our intervention is timed for after completion of cancer treatment, which eliminates some other potential external variables (e.g., surgical complications, competing medical appointments) that can affect adherence to the program. This study examines the feasibility of pelvic floor rehabilitation and the outcome will provide information to assist service provision and implementation, and development of a clinical pathway at the organisational level. It will also provide preliminary information on the efficacy of the intervention for bowel, bladder and sexual dysfunction as well as impact on quality of life. If the study finds the pelvic floor rehabilitation program is acceptable to patients, a randomised controlled trial would be required to further evaluate the effectiveness of the rehabilitation program.

Limitations of this study include the impact of COVID on recruitment, and the requirement to modify the protocol to adopt a telehealth component for some of the treatment sessions. Another possible limitation related to the efficacy analysis, is lack of data on pre-existing bowel and pelvic floor dysfunction before the cancer diagnosis, with a reliance on retrospective self-reporting measures.

Figure 1 Study flow chart



Research plan	**Enrolment**	**Study Period**				**Close-out**
		Pre-intervention assessment	10 week intervention	Immediate Post-intervention assessment	6 months post -intervention assessment	
Enrolment:						
Eligibility Screen	X					
Informed consent	X					
Intervention:						
Rehabilitation program (see Table 1 for detail)			X			
Assessment:						
Questionnaires		X		X	X	
Functional assessments		X		X		
Exit interview				X		
Statistical analysis						X

Table 3. SPIRIT Schedule of enrolment, interventions and assessments

(X = Research plan at timepoints)

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Supplementary file 5.1. Exercise diary

Pelvic Floor Rehabilitation Program

Concord Repatriation General Hospital

Exercise and Bowel Symptoms Diary

Study investigator to complete:

Study ID: □□□□□□

Initials: □□□

Instruction:

The exercise and bowel symptom diary is for you to record your exercise practice and keep track of your bowel symptoms **every day** for the next 12 weeks. This diary will help us to monitor your progress and also will remind you to do your pelvic floor exercises.

Every day write down what pelvic floor exercises you have done, the number and types of bowel movements, the number of accidents, and the medications used to stop bowel frequency.

Please bring in this diary with you to each weekly visit.

If you have any questions regarding the diary, please do not hesitate to contact Carol, the pelvic floor physiotherapist on 8084 3831 or email: kcha7376@uni.sydney.edu.au

Week 1

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 2

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 3

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 4

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 5

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 6

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 7

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 8

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 9

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 10

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 11

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Week 12

Exercise instruction:

1. Contract your pelvic floor muscles. Hold for ____ seconds of strong contractions then release; repeat ____ times
2. _____ times fast contractions
3. Repeat _____ times per day
4. Position: Lying Sitting Standing
5. Challenge:

Date							
How many times did you do the exercises?							
How many times did you use your bowel?							
Bowel leakage (Y/N); amount							
I can hold 15 minutes to get to toilet Y/N							
Medicine to stop bowel movement (Y/N)							
Use of supplement fibre (Y/N)							

Bristol Stool Chart

Type 1 Separate hard lumps like nuts (hard to pass)

Type 2 Sausage shaped but lumpy

Type 3 Like a sausage but with cracks on surface

Type 4 Like a sausage or snake, smooth and soft

Type 5 Soft blobs with clear cut edge (passed easily)

Type 6 Fluffy pieces with ragged edges, a mushy stool

Type 7 Watery, no solid pieces (entirely liquid)

Concord Cancer Centre
Concord Repatriation General Hospital

CONCORD REPATRIATION GENERAL HOSPITAL

Diet after Bowel Surgery

Anterior Resection Syndrome

Diet after Bowel Surgery

Change in Bowel Habits.

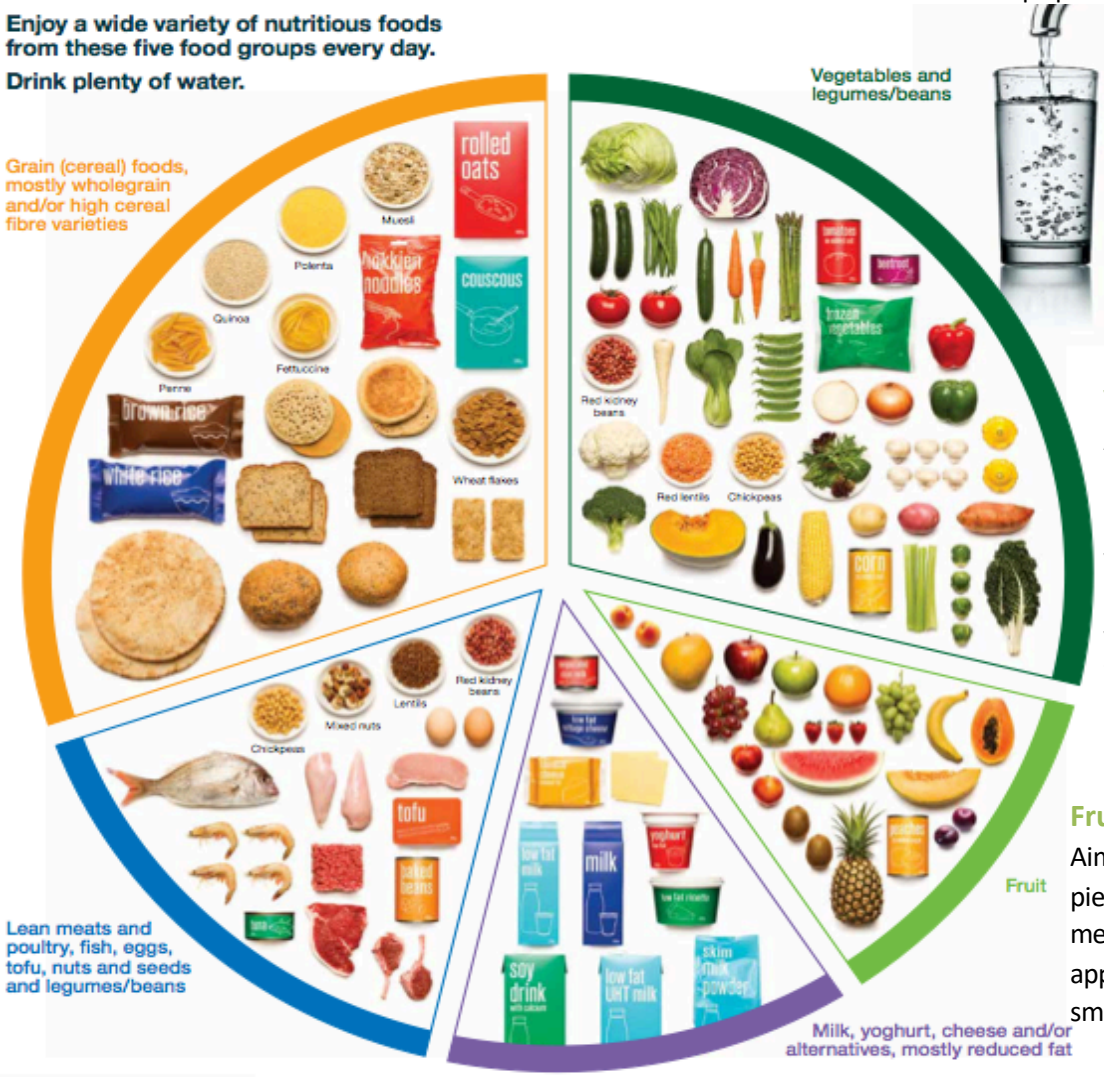
Your bowel habits are likely to have changed and you may be experiencing diarrhoea, constipation and wind. These symptoms can improve over time, however some may have longer-term changes. Dietary changes may assist you in achieving an acceptable bowel function and also adjusting to a 'new normal'.

Healthy Eating:

To stay healthy it is important to follow a balanced diet, choosing a variety of foods from the five food groups illustrated below[1].

Fluid:

It is important to stay hydrated. Aim for 6-8 cups per day.



Vegetables:

Aim for **5** serves per day (½ cup cooked vegetables, 1 cup raw salad vegetables, and ½ potato)

Fruit:

Aim for at least **2** pieces per day (1 medium apple/banana, 2 small apricots)

Dairy:

Aim for **2-3** serves per day i.e. 1 cup milk, 2 pieces of cheese, a tub of yoghurt.

[1]National Health and Medical Research Council. ***Australian Guide to Healthy Eating.*** Canberra: NHMRC; 2013 Jan 13

How can diet help with bowel problems?
Dietary suggestions.

Diarrhoea:

Diarrhoea occurs when your bowel motions are more frequent than usual and become loose; it can often be accompanied by cramping and urgency.

Eat regular meals

Try to eat small, frequent meals (5-6 per day) and chew well**.** Avoid skipping meals as this may worsen watery stools and cause increased gas.

Keep hydrated

Drink plenty of fluids over the day.
Avoid excessive amounts of caffeine, juices and artificially sweetened beverages, this can worsen your bowel habits.
Oral rehydration solutions" such as Gastrolyte™ or Hydralyte to replace the lost electrolytes may be needed.
Always ask your Doctor or pharmacist before trialling.

Eat foods higher in soluble fiber

Soluble fibre can help thicken your stools and slow down digestion. It can be found in:

- White bread, white rice, pasta, noodles, plain crackers and biscuits such as milk arrowroots, bananas, applesauce, cornflakes/puffed rice, oats, crisp chips, and pretzels.

Limit fibrous foods- insoluble fibre

Insoluble fibre adds bulk to the stool and can speed up digestion and stool frequency. This can be found in:

- Wholegrain breads and cereals, nuts and seeds, fruits and vegetable skins. Your may need to peel your fruit and vegetables.

Slowly reintroduce fibrous foods gradually, because any sudden increase may make symptoms worse.

Dietary suggestions.

Limit stimulants:

Some foods may further irritate your bowel. Temporarily avoiding/limiting certain foods may help, such as:

- Spicy, rich or fatty foods such as curries, deep fried foods etc., prunes and prune juice, fruit juice, alcohol, caffeine and artificially sweetened products, carbonated beverages, high fibrous foods such as fruit and vegetable skins, bean/legumes and wholegrains etc.

Try a fibre supplement:

Fibre supplements such as, Benefibre™, ProNourish™ and Metamucil™, etc. can help slow down digestion and add bulk to your stool. Check the product's instruction for correct dosage. If you're increasing the amount of fibre in your diet, make sure you also drink more liquid.

Anti-diarrhoeal medications

Anti-diarrhoeal medications such as loperamide or codeine phosphate slow down bowel motions. Consult your doctor or nurse specialist before taking this medication. If used, its best taken 30 minutes **BEFORE** meals.

Probiotics

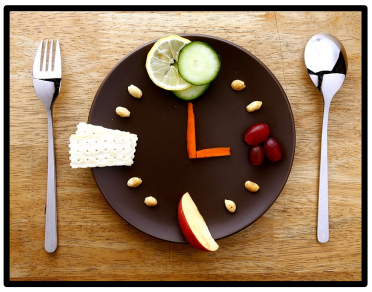
Probiotic supplements may help with diarrhoea. Take the dose recommended by the manufacturer for at least four weeks to see if they are helping. Alternatively try including yoghurt as part of you diet such as. Chobani™, Vaalia™, Jalna™, Yoplait™. Always check with your healthcare team before taking probiotics and don't take them during cancer treatment.

Dietary suggestions.

Wind

Bacteria present in the large bowel produce wind as they break down the food you eat. Swallowing air when you eat or drink can also cause wind.

Eat regular meals



Avoid missing meals. Have a snack and drink if there's a long gap between meals.
Take your time when you're eating and drinking to avoid swallowing too much air .

Limit gas producing food

Foods can sometimes be causing your wind, try eating less of it to see if that helps. Common ones include:

- beans and pulses, like lentils and peas.
- some vegetables, including broccoli, cabbage, cauliflower, Brussels sprouts, onions, asparagus, cucumbers, garlic, leeks, mushrooms.
- Fatty foods
- sparkling water and fizzy drinks
- sorbitol and mannitol, which are sweeteners found in sugar-free sweets, chewing gum and some chocolate.
- wine and beer
- fish, onions, garlic, eggs, cheese, asparagus and baked beans may cause smelly wind but vary from person to person.

Peppermint tea

Drinking peppermint tea can help to reduce wind.
Probiotic supplements may also help with wind and bloating.

Dietary suggestions.

Constipation

Constipation is when your stool is hard, dry and difficult to pass

Eat regular meals

Eat at least three meals each day. Try not to skip meals

Increase your fibre intake

Fibre adds bulk to your stools, holds water and helps soften your stools which can help the bowel to function normally. Gradually increase the amount of fibre in your diet to avoid any further bowel changes by including:

- Wholegrain bread, rice, pasta and breakfast cereals
- Peas, beans and lentils
- Choose more raw fruits and vegetables and eat the skin, if you can. Fresh or tinned fruit that is high in a natural laxative called sorbitol. For example, prunes, raisins, plums, grapes, peaches, raspberries, strawberries, apricots, apples or pears .
- Fruit juices high in sorbitol, such as prune or pear juice

Keep hydrated

If you're increasing the amount of fibre in your diet, make sure you also drink more liquid. Be careful not to overdo it – eating too much fibre can make constipation worse

Keep active

It can take up to four weeks for you to see any change in your bowel habit.

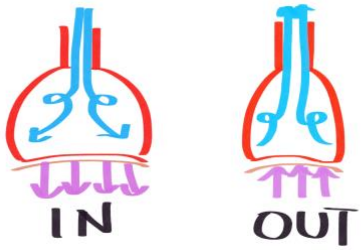
Supplementary file 5.3. Pelvic floor exercises

Pelvic Floor Muscle Exercises

Instructions for pelvic floor muscle exercises

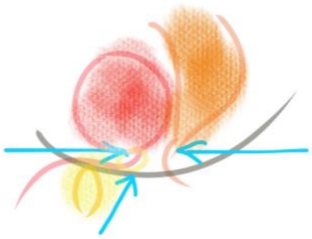
The basics on how to contract and relax your pelvic floor muscles:

1. Find a place where you feel comfortable to lie down, or to sit, or to stand upright.
2. Make sure your pelvis is not tilted forward or backward.
3. Start with some breathing exercises:
   IN through NOSE; OUT through MOUTH.
   RELAX shoulders; Belly OUT as Breathing IN; Belly IN as Breathing OUT.
4. After 3 breathes, on the next breathing OUT, TIGHTEN your pelvic floor by SQUEEZING and LIFTING the FRONT and BACK passages. Continue for 4-5 seconds.
5. LET GO your pelvic floor muscles when you breathe IN.
6. Rest for another 3 breathes.



DO NOT

- Tighten your buttock or your thighs
- Hold your breath
- Contract your tummy or stomach (you may feel light tightening of your lower abdominal muscles)
- Bear down through your pelvic floor

Female	Male
"close the openings and lift up" "lift your pelvic floor off the chair" "bring your anus forward towards the vagina" "sucking from a straw" 	"lift up your nuts to guts" "shorten your penis" "pull your anus toward your nuts" 

May the FORCE be with you

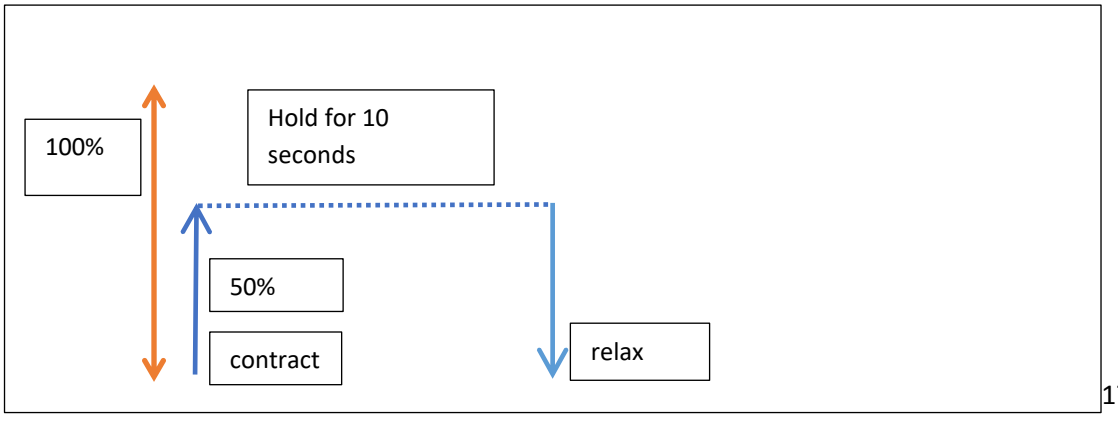
Once you are able to turn on your muscles properly then you should focus on how much FORCE they can generate, this is the STRENGTH. By following the same steps, contract the muscles at 80% -100% effort in various positions until the muscles become fatigue. You should be able to contract a little stronger each time and remember do not use the wrong muscles.

What is your SPEED?

Speed training is essential for accuracy which means turning on your pelvic floor muscles at the right time, in the right place and for the right purpose. Speed training involves repetitive contraction of the pelvic floor muscle closest to your maximal squeeze with short rests in between. Part of your pelvic floor muscle exercises at home should include quick and strong contractions as per the weekly instructions given by your physiotherapist.

Hold on! – ENDURANCE

The pelvic floor muscles contain a lot of slow-twitch fibres which are important to maintain the tone and contraction in order to keep you continent throughout the day. This training is slightly different to the STRENGTH training but same principle applies.



Supplementary file 5.4. Low anterior resection syndrome score

Study ID □□□□□□ Date □□□□□□

The aim of this questionnaire is to assess your bowel function. Please tick only one box for each question. It may be difficult to select only one answer, as we know that for some patients symptoms vary from day to day. We would kindly ask you to choose one answer which best describes your daily life. If you have recently had an infection affecting your bowel function, please do not take this into account and focus on answering questions to reflect your usual daily bowel function.

1. Do you ever have occasions when you cannot control your flatus (wind)?

□ No, never

□ Yes, less than once per week

□ Yes, at least once per week

2. Do you ever have any accidental leakage of liquid stool?

□ No, never

□ Yes, less than once per week

□ Yes, at least once per week

3. How often do you open your bowels?

□ More than 7 times per day (24 hours)

□ 4-7 times per day (24 hours)

□ 1-3 times per day (24 hours)

□ Less than once per day (24 hours)

4. Do you ever have to open your bowels again within one hour of the last bowel opening?

□ No, never

□ Yes, less than once per week

□ Yes, at least once per week

5. Do you ever have such a strong urge to open your bowels that you have to rush to the toilet?

□ No, never

□ Yes, less than once per week

□ Yes, at least once per week

Supplementary file 5.5. Memorial Sloan Kettering Cancer Centre – Bowel Function Instrument

Study ID □□□□□□ Date □□□□□□

As part of the pelvic floor rehabilitation program trial, we are very interested in how your function (bowel, bladder, sexual) and quality of life. Below are 33 questions that should take less than 15 minutes to complete so that we can better understand how your life has been affected by rectal cancer therapy

Over the last 4 weeks….

1. How many bowel movements did you generally have in 24 hours? _____ bowel movements/24 hours

	Always	Most of the time	Sometimes	Rarely	Never
2. Do certain solid foods increase the number of bowel movements in a day?	□	□	□	□	□
3. Do certain liquids that you drink increase the number of bowel movements in a day?	□	□	□	□	□
4. Do you feel like you have totally emptied your bowels after a bowel movement?	□	□	□	□	□
5. Do you get to the toilet on time?	□	□	□	□	□
6. Do you have another bowel movement within 15 minutes of your last bowel movement?	□	□	□	□	□
7. Do you know the difference between having to pass gas (air) and needing to have a bowel movement?	□	□	□	□	□
8. Have you used medicines to decrease the number of bowel movements (drugs like Imodium®, Lomotil®)?	□	□	□	□	□

9. Have you had diarrhea (no form, watery stool)?	□	□	□	□	□
10. Have you had loose stool (slight form, but mushy)?	□	□	□	□	□

	Always	Most of the time	Sometimes	Rarely	Never
11. Have you been able to wait 15 minutes to get to the toilet when you feel like you are going to have a bowel movement?	□	□	□	□	□
12. Have you been able to control the passage of gas (air)?	□	□	□	□	□
13. Have you limited the types of solid food you eat to control your bowel movements?	□	□	□	□	□
14. Have you limited the types of liquids you drink to control your bowel movements?	□	□	□	□	□
15. Have you had soilage (leakage of stool) of your undergarments during the day?	□	□	□	□	□
16. Have you used a tissue, napkin, and/or pad in your undergarments during the day when you go to bed?	□	□	□	□	□
17. Have you had soilage (leakage of stool) of your undergarments when you go to bed?	□	□	□	□	□

18. How often have you had to alter your activities because of your bowel function? ☐ ☐ ☐ ☐ ☐

19. Compared to 4 weeks ago, how would you rate your bowel function now?

- ☐ Much better than 4 weeks ago
- ☐ Somewhat better than 4 weeks ago
- ☐ About the same as 4 weeks ago
- ☐ Somewhat worse than 4 weeks ago
- ☐ Much worse than 4 weeks ago

Supplementary file 5.6. International Consultation on Incontinence Questionnaire

Female Lower Urinary Tract Symptom (ICIQ-FLUTS)

Study ID □□□□□□ Date □□□□□□

Urinary symptoms

Many people experience urinary symptoms some of the time. We are trying to find out how many people experience urinary symptoms, and how much they bother them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

1. Please write in your date of birth: □□□□□□

2. a) During the night, how many times did you have to get up to urinate, on average?

None	□ 0
One	□ 1
Two	□ 2
Three	□ 3
Four or more	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0	1	2	3	4	5	6	7	8	9	10
Not at all										a great deal

3. a) Do you have sudden need to rush to the toilet to urinate?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0	1	2	3	4	5	6	7	8	9	10

Not at all a great deal

4. a) Do you have pain in your bladder?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

5. a) How often do you pass urine during the day?

1 to 6 times	□ 0
7 to 8 times	□ 1
9 to 10 times	□ 2
11 to 12 times	□ 3
13 or more times	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not a great deal a great deal

F score: sum scores 2a-5a □□

6. a) Is there a delay before you can start to urinate?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not a great deal a great deal

7. a) Do you have to strain to urinate?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not a great deal a great deal

8. a) Do you stop and start more than once while you urinate?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not a great deal a great deal

V score: sum scores 6a+7a+8a □□

9. a) Does urine leak before you can get to the toilet?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

10. a) How often do you leak urine?

Never □ 0

1 or less per week □ 1

2 or 3 times per week □ 2

Once per day □ 3

Several times per day □ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

11. a) Does urine leak when you are physically active, exert yourself, cough or sneeze?

Never □ 0

Occasionally □ 1

Sometimes □ 2

Most of the time □ 3

All of the time □ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

12. a) Do you ever leak urine for no obvious reason and without feeling that you want to go?

Never □ 0

Occasionally □ 1

Sometimes □ 2

Most of the time □ 3

All of the time □ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

13. a) Do you leak urine when you are asleep?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

I score: sum scores 9a-13a □□

Thank you very much for answering these questions.

Supplementary file 5.7. International Consultation on Incontinence Questionnaire

Male Lower Urinary Tract Symptom (ICIQ-MLUTS)

Study ID □□□□□□ Date □□□□□□

Urinary symptoms

Many people experience urinary symptoms some of the time. We are trying to find out how many people experience urinary symptoms, and how much they bother them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

1. Please write in your date of birth: □□□□□□

2. a) Is there a delay before you can start to urinate?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

3. a) Do you have to strain to <u>continue</u> urinating?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

4. a) Would you say that the strength of your urinary stream is….

Normal	□ 0
Occasionally reduced	□ 1
Sometimes reduced	□ 2
Most of the time reduced	□ 3
Reduced all of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

5. a) Do you stop and start more than once while you urinate?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

6. a) How often do you feel that your bladder has not emptied properly after you have urinated?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

VS: sum scores 2-6 □□

7. a) Do you have a sudden need to rush to the toilet to urinate?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

8. a) Does urine leak before you can get to the toilet?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

9. a) Do you leak before you can get to the toilet?

Never	□ 0
Occasionally	□ 1
Sometimes	□ 2
Most of the time	□ 3
All of the time	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

10. a) Do you ever leak for no obvious reason and without feeling that you want to go?

Never	☐ 0
Occasionally	☐ 1
Sometimes	☐ 2
Most of the time	☐ 3
All of the time	☐ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

11. a) Do you leak urine when you are asleep?

Never	☐ 0
Occasionally	☐ 1
Sometimes	☐ 2
Most of the time	☐ 3
All of the time	☐ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

12. a) How often have you had a slight wetting of your pants a few minutes after you had finished urinating and had dressed yourself?

Never	☐ 0
Occasionally	☐ 1
Sometimes	☐ 2
Most of the time	☐ 3
All of the time	☐ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

IS: sum scores 7-12 □□

13. a) How often do you pass urine during the day?

1-6 times	□ 0
7 to 8 times	□ 1
9 to 10 times	□ 2
11 to 12 times	□ 3
13 or more times	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

14. a) During the night, how many times do you have to get up to urinate, on average?

Non	□ 0
One	□ 1
Two	□ 2
Three	□ 3
For or more	□ 4

b) How much does this bother you?

Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10

Not at all a great deal

Thank you very much for answering these questions.

Supplementary file 5.8. Female Sexual Function Index (FSFI)

Study ID □□□□□□ Date □□□□□□

Instructions: These questions ask about your sexual feelings and responses during the past 4 weeks. Please answer the following questions as honestly and clearly as possible. Your responses will be kept completely confidential. In answering these questions the following definitions apply.

Sexual activity can include caressing, foreplay, masturbation and vaginal intercourse.

Sexual intercourse is defined as penile penetration (entry) of the vagina.

Sexual stimulation includes situations like foreplay with a partner, self-stimulation (masturbation), or sexual fantasy.

Check ONLY one box per question

Sexual desire or interest is a feeling that includes wanting to have a sexual experience, feeling receptive to a partner's sexual initiation, and thinking or fantasizing about having sex.

1. Over the past 4 weeks, how **often** did you feel sexual desire or interest?
   - □ Almost always or always
   - □ Most times (more than half the time)
   - □ Sometimes (about half the time)
   - □ A few times (less than half the time)
   - □ Almost never or never

2. Over the past 4 weeks, how would you rate your **level** (degree) of sexual desire or interest?
   - □ Very high
   - □ High
   - □ Moderate
   - □ Low
   - □ Very low or none at all

Sexual arousal is a feeling that includes both physical and mental aspects of sexual excitement. It may include feelings of warmth or tingling in the genitals, lubrication (wetness), or muscle contractions.

3. Over the past 4 weeks, how **often** did you feel sexuality aroused ("turned on") during sexual activity or intercourse?

- ☐ No sexual activity
- ☐ Almost always or always
- ☐ Most times (more than half the time)
- ☐ Sometimes (about half the time)
- ☐ A few times (less than half the time)
- ☐ Almost never or never

4. Over the past 4 weeks, how would you rate your **level** of sexual arousal ("turn on") during sexual activity or intercourse?
   - ☐ No sexual activity
   - ☐ Very high
   - ☐ High
   - ☐ Moderate
   - ☐ Low
   - ☐ Very low or none at all

5. Over the past 4 weeks, how **confident** were you about becoming sexually aroused during sexual activity or intercourse?
   - ☐ No sexual activity
   - ☐ Very high confidence
   - ☐ High confidence
   - ☐ Moderate confidence
   - ☐ Low confidence
   - ☐ Very low or no confidence

6. Over the past 4 weeks, how **often** have you been satisfied with your arousal (excitement) during sexual activity or intercourse?
   - ☐ No sexual activity
   - ☐ Almost always or always
   - ☐ Most times (more than half the time)
   - ☐ Sometimes (about half the time)
   - ☐ A few times (less than half the time)
   - ☐ Almost never or never

7. Over the past 4 weeks, how **often** did you become lubricated ("wet") during sexual activity or intercourse?
   - ☐ No sexual activity
   - ☐ Almost always or always
   - ☐ Most times (more than half the time)

- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

8. Over the past 4 weeks, how **difficult** was it to become lubricated ("wet") during sexual activity or intercourse?
   - No sexual activity
   - Extremely difficult or impossible
   - Very difficult
   - Difficult
   - Slightly difficult
   - Not difficult

9. Over the past 4 weeks, how often did you **maintain** your lubrication ("wetness") until completion of sexual activity or intercourse?
   - No sexual activity
   - Almost always or always
   - Most times (more than half the time)
   - Sometimes (about half the time)
   - A few times (less than half the time)
   - Almost never or never

10. Over the past 4 weeks, how **difficult** was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?
    - No sexual activity
    - Extremely difficult or impossible
    - Very difficult
    - Difficult
    - Slightly difficult
    - Not difficult

11. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **often** did you reach orgasm (climax)?
    - No sexual activity
    - Almost always or always
    - Most times (more than half the time)
    - Sometimes (about half the time)
    - A few times (less than half the time)
    - Almost never or never

12. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **difficult** was it for you to reach orgasm (climax)?

    - ☐ No sexual activity
    - ☐ Extremely difficult or impossible
    - ☐ Very difficult
    - ☐ Difficult
    - ☐ Slightly difficult
    - ☐ Not difficult

13. Over the past 4 weeks, how **satisfied** were you with your ability to reach orgasm (climax) during sexual activity or intercourse?
    - ☐ No sexual activity
    - ☐ Very satisfied
    - ☐ Moderately satisfied
    - ☐ About equally satisfied and dissatisfied
    - ☐ Moderately dissatisfied
    - ☐ Very dissatisfied

14. Over the past 4 weeks, how **satisfied** have you been with the amount of emotional closeness during sexual activity between you and your partner?
    - ☐ No sexual activity
    - ☐ Very satisfied
    - ☐ Moderately satisfied
    - ☐ About equally satisfied and dissatisfied
    - ☐ Moderately dissatisfied
    - ☐ Very dissatisfied

15. Over the past 4 weeks, how **satisfied** have you been with your sexual relationship with your partner?
    - ☐ Very satisfied
    - ☐ Moderately satisfied
    - ☐ About equally satisfied and dissatisfied
    - ☐ Moderately dissatisfied
    - ☐ Very dissatisfied

16. Over the past 4 weeks, how **satisfied** have you been with your overall sexual life?
    - ☐ Very satisfied
    - ☐ Moderately satisfied
    - ☐ About equally satisfied and dissatisfied
    - ☐ Moderately dissatisfied
    - ☐ Very dissatisfied

17. Over the past 4 weeks, how o**ften** did you experience discomfort or pain during vaginal penetration?
    - ☐ Did not attempt intercourse
    - ☐ Almost always or always
    - ☐ Most times (more than half the time)
    - ☐ Sometimes (about half the time)
    - ☐ A few times (less than half the time)
    - ☐ Almost never or never

18. Over the past 4 weeks, how **often** did you experience discomfort or pain following vaginal penetration?
    - ☐ Did not attempt intercourse
    - ☐ Almost always or always
    - ☐ Most times (more than half the time)
    - ☐ Sometimes (about half the time)
    - ☐ A few times (less than half the time)
    - ☐ Almost never or never

19. Over the past 4 weeks, how would you rate your **level** (degree) of discomfort or pain during or following vaginal penetration?
    - ☐ Did not attempt intercourse
    - ☐ Very high
    - ☐ High
    - ☐ Moderate
    - ☐ Low
    - ☐ Very low or none at all

Thank you for completing this questionnaire

Supplementary file 5.9. International Index of Erectile Function Questionnaire (IIEF)

Study ID □□□□□□ Date □□□□□□

Please use an X where applicable and be sure to initial and date all corrections

Instructions: these questions ask about the effects your erection problems have had on your sex life, over the past 4 weeks. Please answer the following questions as honestly and clearly as possible. In answering these questions, the following definitions apply:

Definitions:

Sexual activity includes intercourse, caressing, foreplay and masturbation

Sexual intercourse is defined as vaginal penetration of the partner (you entered the partner)

Sexual stimulation includes situations like foreplay with a partner, looking at erotic pictures, etc

Ejaculate is defined as the ejection of semen from the penis (or the feeling of this)

Mark ONLY one circle per question:

1. Over the past 4 weeks, how often were you able to get an erection during sexual activity?
   - □ No sexual activity
   - □ Almost always or always
   - □ Most times (much more than half the time)
   - □ Sometimes (about half the time)
   - □ A few times (much less than half the time)
   - □ Almost never or never

2. Over the past 4 weeks, when you had erections with sexual stimulation, how often were your erections hard enough for penetration?
   - □ No sexual stimulation
   - □ Almost always or always
   - □ Most times (much more than half the time)
   - □ Sometimes (about half the time)
   - □ A few times (much less than half the time)
   - □ Almost never or never

3. Over the past 4 weeks, when you attempted sexual intercourse, how often were you able to penetrate (enter) your partner?
   - □ Did not attempt intercourse
   - □ Almost always or always
   - □ Most times (much more than half the time)
   - □ Sometimes (about half the time)
   - □ A few times (much less than half the time)

- ☐ Almost never or never

4. Over the past 4 weeks, during sexual intercourse, how often were you able to maintain your erection after you had penetrated (entered) your partner?
   - ☐ Did not attempt intercourse
   - ☐ Almost always or always
   - ☐ Most times (much more than half the time)
   - ☐ Sometimes (about half the time)
   - ☐ A few times (much less than half the time)
   - ☐ Almost never or never

5. Over the past 4 weeks, during sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?
   - ☐ Did not attempt intercourse
   - ☐ Almost always or always
   - ☐ Most times (much more than half the time)
   - ☐ Sometimes (about half the time
   - ☐ A few times (much less than half the time)
   - ☐ Almost never or never

6. Over the past 4 weeks, how many times have you attempted sexual intercourse?
   - ☐ No attempts
   - ☐ 1-2 attempts
   - ☐ 3-4 attempts
   - ☐ 5-6 attempts
   - ☐ 7-10 attempts
   - ☐ 11 or more attempts

7. Over the past 4 weeks, when you attempted sexual intercourse how often was it satisfactory for you?
   - ☐ Did not attempt intercourse
   - ☐ Almost always and always
   - ☐ Most times (much more than half the time)
   - ☐ Sometimes (about half the time)
   - ☐ A few times (much less than half the time)
   - ☐ Almost never or never

8. Over the past 4 weeks, how much have you enjoyed sexual intercourse?
   - ☐ No intercourse

- Very highly enjoyable
- Highly enjoyable
- Fairly enjoyable
- Not very enjoyable
- Not enjoyable

9. Over the past 4 weeks, when you had sexual stimulation or intercourse ow often did you ejaculate?
   - Did not attempt intercourse
   - Almost always or always
   - Most times (more than half the time)
   - Sometimes (about half the time)
   - A few times (much less than half the time)
   - Almost never or never

10. Over the past 4 weeks, when you had sexual stimulation or intercourse how often did you have the feeling of orgasm or climax (with or without ejaculation)?
    - No sexual stimulation or intercourse
    - Almost always or always
    - Most times (much more than half the time)
    - Sometimes (about half the time)
    - A few times (much less than half the time)
    - Almost never or never

Question 11 and 12 ask about sexual desire. Let's define sexual desire as a feeling that may include wanting to have a sexual experience (for example, masturbation or intercourse), thinking about having sex or feeling frustrated due to a lack of sex.

11. Over the past 4 weeks, how often have you felt sexual desire?
    - Almost always or always
    - Most times (much more than half the time)
    - Sometimes (about half the time)
    - A few times (much less than half the time)
    - Almost never or never

12. Over the past 4 weeks, how would you rate your level of sexual desire?
    - Very high

- High
- Moderate
- Low
- Very low or none at all

13. Over the past 4 weeks, how satisfied have you been with you overall sex life?
    - Very satisfied
    - Moderately satisfied
    - About equally satisfied and dissatisfied
    - Moderately dissatisfied
    - Very dissatisfied

14. Over the past 4 weeks, how satisfied have you been with your sexual relationship with your partner?
    - Very satisfied
    - Moderately satisfied
    - About equally satisfied and dissatisfied
    - Moderately dissatisfied
    - Very dissatisfied

15. Over the past 4 weeks, how do you rate your confidence that you can get and keep your erection?
    - Very high
    - High
    - Moderate
    - Low
    - Very low

This is the end of this questionnaire

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.
Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			**I feel as if I am slowed down:**
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			**I get a sort of frightened feeling like 'butterflies' in the stomach:**
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			**I have lost interest in my appearance:**
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			**I feel restless as I have to be on the move:**
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			**I look forward with enjoyment to things:**
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			**I get sudden feelings of panic:**
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			**I can enjoy a good book or radio or TV program:**
	0	Definitely	0		Often
	1	Usually	1		Sometimes
	2	Not Often	2		Not often
	3	Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:

Total score: Depression (D) _____ Anxiety (A) _____

0-7 = Normal

8-10 = Borderline abnormal (borderline case)

11-21 = Abnormal (case)

Supplementary file 5.11. Fecal Incontinence Quality Of Life (FIQOL)

Study ID □□□□□□ Date □□□□□□

1. In general, would you say your health is:
   □ Excellent □ Very good □ Good □ Fair □ Poor

2. For each of the items, please check the appropriate box indicating how much of the time the issue is a concern for you due to accidental bowel leakage. (If it is a concern for you for reasons other than accidental bowel leakage then check the box under Not Apply, N/A.)

Due to accidental bowel leakage:	Most of the time	Some of the time	A little of the time	None of the time	N/A
a. I am afraid to go out	□	□	□	□	□
b. I avoid visiting friends	□	□	□	□	□
c. I avoid staying overnight away from home	□	□	□	□	□
d. It is difficult for me to get out and do things like going to a movie or to church	□	□	□	□	□
e. I cut down how much I eat before I go out	□	□	□	□	□
f. Whenever I am away from home, I try to stay near a restroom as much as possible	□	□	□	□	□
g. It is important to plan my schedule (daily activities) around my bowel pattern	□	□	□	□	□
h. I avoid traveling	□	□	□	□	□
i. I worry about not being able to get to the toilet in time	□	□	□	□	□
j. I feel I have no control over my bowel	□	□	□	□	□
k. I can't hold my bowel movement long enough to get to the bathroom	□	□	□	□	□
l. I leak stool without even knowing it	□	□	□	□	□
m. I try to prevent bowel accidents by staying very near a bathroom	□	□	□	□	□

3. Due to accidental bowel leakage, indicate the extent to which you AGREE or DISAGREE with each of the following items. (If it is a concern for you for reasons other than accidental bowel leakage then check the box under Not Apply, N/A.)

Due to accidental bowel leakage:	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	N/A
a. I feel ashamed	☐	☐	☐	☐	☐
b. I cannot do many of things I want to do	☐	☐	☐	☐	☐
c. I worry about bowel accidents	☐	☐	☐	☐	☐
d. I feel depressed	☐	☐	☐	☐	☐
e. I worry about others smelling stool on me	☐	☐	☐	☐	☐
f. I feel like I am not a healthy person	☐	☐	☐	☐	☐
g. I enjoy life less	☐	☐	☐	☐	☐
h. I have sex less often than I would like to	☐	☐	☐	☐	☐
i. I feel different from other people	☐	☐	☐	☐	☐
j. The possibility of bowel accidents is always on my mind	☐	☐	☐	☐	☐
k. I am afraid to have sex	☐	☐	☐	☐	☐
l. I avoid traveling by plane or train	☐	☐	☐	☐	☐
m. I avoid going out to eat	☐	☐	☐	☐	☐
n. When I go someplace new, I specifically locate where the bathrooms are	☐	☐	☐	☐	☐

4. During the past month, have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile?
   1 □ Extremely so- to the point that I have just about given up
   2 □ Very much so
   3 □ Quite a bit
   4 □ Some -enough to bother me
   5 □ A little bit
   6 □ Not at all

FACT-C (Version 4)

Supplementary file 5.12. Functional Assessment of Cancer Therapy – Colorectal

Study ID □□□□□□ Date □□□□□□

Below is a list of statements that other people with your illness have said are important**. Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4

GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

FACT-C (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

FACT-C (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

	ADDITIONAL CONCERNS	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
C1	I have swelling or cramps in my stomach area	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
C3	I have control of my bowels	0	1	2	3	4
C4	I can digest my food well	0	1	2	3	4
C5	I have diarrhea (diarrhoea)	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
Q2	Do you have an ostomy appliance? (Mark one box)	☐ No		or	☐ Yes	
	If yes, please answer the next two items:					
C8	I am embarrassed by my ostomy appliance	0	1	2	3	4
C9	Caring for my ostomy appliance is difficult	0	1	2	3	4

Supplementary file 5.13. Patient evaluation survey

Patient Evaluation Survey

Pelvic Floor Rehabilitation Program

This survey is an opportunity to provide feedback on your experience with the Pelvic Floor Rehabilitation Program associated with Concord Repatriation General Hospital. The Pelvic Floor Rehabilitation Program aims to improve bowel function after bowel cancer surgery and to assist your recovery in returning to normal activities.

You are asked to complete this survey at the conclusion of your rehabilitation program. Your feedback will help us to evaluate and to make future improvements to the service. We appreciate your participation and comments. This feedback may be given anonymously.

Instruction: Please tick the **ONE** box that is most appropriate and fill in the blanks.

1. What is your age? _____

2. What is your gender? ☐ Male ☐ Female ☐ Intersex

3. What is your main language spoken at home? _____

4. The information given as part of the rehabilitation program was easy to understand.
   ☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

5. The information given during the rehabilitation program was useful.
   ☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

6. The exercise instructions made it easy to continue the exercises at home.
   ☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

7. The information about healthy diet was useful.
   ☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

8. The Pelvic Floor Rehabilitation Program was easy to get to.

□ Strongly agree □ Agree □ Disagree □ Strongly disagree

9. The clinicians were knowledgeable and appropriately answered my questions.

□ Strongly agree □ Agree □ Disagree □ Strongly disagree

10. I was given the opportunity to discuss issues that had never been discussed before with my doctors.

□ Strongly agree □ Agree □ Disagree □ Strongly disagree

11. I received excellent support throughout the program?

□ Strongly agree □ Agree □ Disagree □ Strongly disagree

12. This program has helped me to regain my confidence.

□ Strongly agree □ Agree □ Disagree □ Strongly disagree

13. Overall, how would you rate your experience with the Pelvic Floor Rehabilitation at Concord Hospital?

0	1	2	3	4	5
Very poor	Poor	Average	Good	Very good	Excellent
□	□	□	□	□	□

14. How could we improve the program?

_____

_____

Supplementary file 5.14. Pelvic Floor Rehabilitation Program Questionnaire

Study ID □□□□□□ Date □□□□□□

1. How much do your bowel symptoms bother you?

   0 1 2 3 4 5 6 7 8 9 10
   Not at all Extremely

2. How much do your bowel symptoms affect your daily activity?

   0 1 2 3 4 5 6 7 8 9 10
   Not at all Extremely

3. Which of the following symptoms affect you most? Tick ONE box only
   - □ Faecal incontinence
   - □ Flatus (gas) incontinence
   - □ Unable to defer defecation more than 15 minutes
   - □ Wake up at night for defecation (nocturnal defecation)
   - □ Urgent evacuation
   - □ Frequent defecation
   - □ Anal pain with defecation
   - □ Unable to tell whether going to pass gas or stool
   - □ Other, please specify _____

4. BEFORE your surgery, did you receive any information about possible bowel function problems?

   □ Yes □ No □ Don't remember

5. AFTER your surgery, did you receive any information about bowel function problems?

   □ Yes □ No □ Don't remember

6. Have you discussed your bowel problems and possible treatments with your doctor or health professionals?

   □ Yes □ No

7. Before you participated in this bowel rehabilitation program, what did you do to try and help your bowel problems?

   □ Medications □ Diet □ Exercises □ Pelvic floor exercise

Chapter 6: Structured pelvic floor physiotherapy rehabilitation for low anterior resection syndrome in colorectal cancer: An Australian feasibility study

Overview

This chapter builds on the previous one by evaluating the feasibility and preliminary effectiveness of a structured 10-week pelvic floor rehabilitation program for patients with low anterior resection syndrome after colorectal cancer treatment. The findings indicate that the program is feasible and shows promising outcomes, offering valuable insights into its implementation. These results are useful for guiding future scaling and refinement of the intervention in subsequent trials.

This chapter has been submitted to a peer-reviewed journal and is currently under review. The manuscript is quoted verbatim and formatted according to the requirements of the journal.

Contribution of authors

I, Kin Yin Chan was responsible for study conceptualisation and design, project administration, dataset management and analysis, and drafting and finalising manuscript.

Gemma Collett collected data

Michael Suen was responsible for project administration, performed data analysis and reviewed the manuscript

Susan Coulson reviewed the manuscript

Janindra Warusavitarne reviewed the manuscript

Janette Vardy developed the concept, analysed data and reviewed the manuscript

Abstract

Purpose: Low Anterior Resection Syndrome (LARS) is a common and debilitating outcome of sphincter-preserving surgery for colorectal cancer, severely affecting quality of life. While pelvic floor rehabilitation (PFR) is recommended as a conservative treatment, access to structured care is limited. This study assessed the feasibility and acceptability of a structured, physiotherapist-led PFR program in an Australian outpatient setting, and explored the within-person changes in bowel function and quality-of-life.

Methods: A non-randomised, single-arm prospective study was conducted at Concord Repatriation General Hospital (Sydney, Australia) from September 2020 to April 2024. Colorectal cancer survivors with LARS (score >20) and bowel continuity restored >6 months previously were enrolled. The 10-week PFR program included education, pelvic floor muscle training, rectal balloon biofeedback, and home exercises, with adaptations for telehealth due to COVID-19. Primary outcome was program adherence. Secondary outcomes included bowel, bladder, and sexual function, quality-of-life, and anorectal physiology; measured at baseline, 3- and 9-months.

Results: Fourteen participants (mean age 61; 7 female) completed the program (one dropout with non-clinical reason), with 100% attendance and 95.8% home exercise completion. Bowel function improved significantly (mean LARS score reduction -12.1; $p < 0.001$), with 71.4% achieving meaningful change at 3-months and 63.6% at at 9-months. Quality-of-life significantly improved on validated measures. Anorectal physiology showed increased anal pressures, sensory thresholds, and better defecatory coordination. No adverse events were reported.

Conclusions: A structured, physiotherapist-led PFR program is feasible and acceptable for colorectal cancer survivors with LARS. While improvement in bowel function and quality-of-life were observed over time, these findings should be interpreted as exploratory. The hypothesis-generating findings

support further evaluation of PFR in a controlled trial to evaluate effectiveness and inform integration into multidisciplinary survivorship care.

Keywords: Low Anterior Resection Syndrome, Pelvic Floor Rehabilitation, Colorectal Cancer Survivorship, Bowel Function, Physiotherapy

Introduction

Low Anterior Resection Syndrome (LARS) is a common and often debilitating functional consequence of sphincter-preserving surgery for colorectal cancer (CRC) [1, 2]. It is characterised by a constellation of symptoms, including faecal urgency, increased frequency, incontinence, and difficulties with evacuation [3-5]. The severity of LARS varies; however, patients who undergo temporary stoma formation, radiotherapy, or low anastomosis are at a greater risk of developing symptoms [6]. LARS affects up to 80% of CRC survivors, with 38–62% meeting criteria for major LARS [7-9]. In regional Australian settings, ~55% of patients report LARS, with 37.5% experiencing major LARS [10]. The LARS symptoms can greatly impair physical function, psychosocial well-being and overall quality-of-life (QOL) [11-13].

Various treatment options for LARS management have been identified, including pharmacological methods, conservative management, and surgical intervention [14, 15]. Optimised conservative management (OCM) is recommended as first-line management, and involves lifestyle and behavioural modifications, dietary adjustments, and pelvic floor rehabilitation (PFR) [16, 17]. PFR offers a structured, patient-centred approach that targets bowel function through pelvic floor muscle training (PFMT) and biofeedback (BF), aiming to re-establish anorectal coordination and rectal sensory discrimination and restore pelvic floor function [18-20]. A randomised controlled study demonstrated PFMT initiated early in postoperative recovery was associated with a lower LARS score compared with standard care [19]. PFR, in conjunction with biofeedback, education and lifestyle advice, has been associated with improved QOL [21]. These findings suggest PFR may confer meaningful patient-reported benefits; however, variability in intervention protocols and care settings limits generalisability.

Despite the growing recognition of LARS, and emerging international evidence supporting PFR, a standardised protocol for PFR is lacking, and access to coordinated care remains limited in Australia [20, 22, 23]. Many patients receive fragmented, reactive care instead of proactive, structured

rehabilitation. Evidence regarding the feasibility and implementation of PFR programs in the Australian healthcare system is scarce, particularly given differences in service delivery models compared to Europe and North America. Major gaps include unclear referral pathways, inadequate integration with oncology and surgical services, and a lack of tailored care to address individual patient needs, highlighting the need for localised evidence to inform service feasibility and implementation [24, 25]. This study addresses this gap by evaluating the feasibility and acceptability of a structured physiotherapist-led PFR program delivered in an Australian outpatient CRC care setting, while exploring within-person changes in bowel function and QOL.

Methods

Study Design

This is a non-randomised, single-arm, prospective study evaluating the feasibility of a physiotherapist-led PFR in CRC for patients with LARS after undergoing sphincter-preserving anterior resection for CRC. Recruitment occurred at Concord Repatriation General Hospital (CRGH), a tertiary teaching hospital in Sydney, Australia, from September 2020 to April 2024. The recruitment period was extended due to disruptions caused by the COVID-19 pandemic, and the study protocol was adapted to include a telehealth component. Ethics approval was granted by the Sydney Local Health District Human Research Ethics Committee, Concord Repatriation General Hospital (SLHD HREC, CRGH) under the reference number 2019/PID 15308. This study was registered on the Australian and New Zealand Clinical Trials Registry (ANZCTR), ACTRN 12620000821998. The study was conducted in accordance with the “NHMRC National Statement on Ethical Conduct in Human Research” (Commonwealth of Australia, 2007, updated 2018) and the ethical principles derived from the World Medical Association Declaration of Helsinki (Helsinki, 1964, updated 2016).

Participants

Patients attending The Sydney Cancer Survivorship Clinic, Colorectal Surgery Outpatient Clinics at CRGH, or the clinics of colorectal surgeons in New South Wales, Australia, were invited to participate. Eligibility criteria included: (i) anterior resection with sphincter preservation for CRC +/- neoadjuvant/adjuvant therapy; (ii) onset of bowel dysfunction symptoms post-surgery and treatment, with a LARS Score >20; (iii) bowel continuity restored for at least 6 months; and (iv) no clinical evidence of recurrent CRC or distant metastasis. Assessment at 6-months was selected pragmatically to identify patients whose LARS is unlikely to improve on its own [26]. Exclusion criteria included: (i) age under 18; (ii) inability to give informed consent or follow instructions due to cognitive or English language difficulties; (iii) neurological disorders or acute exacerbation of inflammatory bowel disease. Written consent was obtained from participants before enrolment.

PFR Intervention

PFR intervention was delivered by a single physiotherapist trained in pelvic floor dysfunction and rectal balloon biofeedback. Before PFR, therapists discussed attendance requirements with each participant and provided a schedule and reminder calls. Attendance and completion of home exercise were monitored weekly. PFR began with assessments, including Patient-Reported Outcome Measures (PROMS), a clinical examination, and collection of clinical data. Participants attended one 60-minute session per week for 10 weeks with a physiotherapist trained in pelvic floor dysfunction and rectal balloon biofeedback. Originally conducted in person, the program adapted to telehealth in July 2021 due to COVID-19 restrictions, offering supervised PFM training via secure videoconferencing.

The first session included education on pelvic floor and anorectal anatomy, LARS post-CRC surgery, symptom management strategies (including diet, optimal toileting, and bowel/bladder habits), and correct pelvic floor muscle (PFM) activation. Educational handouts were provided. The 10-week PFR program focused on anorectal coordination, pelvic floor muscle (PFM) training, and overall

functional performance. It involved three key components: 1) Anorectal Coordination with Biofeedback using a rectal balloon catheter to elicit sensations of rectal distension, urge, and maximal volume, with instructions to activate pelvic floor muscles and expel the balloon at maximal volume. 2) PFM Training, including visual feedback with a transperineal ultrasound [27, 28] to ensure proper muscle activation, followed by structured exercises for strength (maximal contraction), endurance (sustained submaximal contraction), and reaction (fast contraction) with a focus on relaxation and breathing. The training also incorporated functional exercises in various static and dynamic positions, including supine, sitting, standing, and during movement, using resistance equipment. 3) Home Exercise Program was prescribed based on pelvic floor muscle training exercise described in the protocol. The intensity, frequency and repetitions were tailored according to the goal achieved and progress made at the end of each weekly training session. A bowel symptom diary to record exercises and bowel symptoms daily was also included. Diaries were reviewed weekly (in person or via telehealth) to monitor progress and guide further exercise prescription.

Outcomes

Outcome measures were selected to evaluate feasibility, acceptability and preliminary clinical signals of benefit associated with the PFR program. Data were collected at three time-points: baseline (0 month), 3-months (post intervention), and 9-months (follow-up), with the first two assessments conducted in person and the final one as a phone interview (PROMS only).

The primary endpoint was feasibility, including adherence, completion and compliance. Adherence was assessed through therapist-recorded attendance at supervised sessions, completion of exercise diaries and exercise frequency, and the overall compliance of the PFR.

Secondary endpoints were 1) participant satisfaction and acceptability assessed at program completion using an investigator-developed survey; 2) exploration of clinical outcomes within-

person changes over time, measured by validated questionnaires. Bowel function was assessed using the Low Anterior Resection Syndrome Score (LARS) and Memorial Sloan Kettering Cancer Centre – Bowel Function Instrument (MSKCC-BFI) which capture symptom severity and functional impact of bowel dysfunction [29, 30]. Bladder function (International Consultation on Incontinence Questionnaire – Lower Urinary Tract Symptoms [ICIQ-LUT)]) [31], and sexual function (International Index of Erectile Function [IIEF], Female Sexual Function Index [FSFI]) [32, 33] were also evaluated. QOL was assessed using condition-specific and cancer-specific instruments [34-36] (Fecal Incontinence Quality of Life FIQOL, Hospital Anxiety and Depression Scale HAD, Functional Assessment of Cancer Therapy – Colorectal FACT-C). PROMS were self-administered by participants at each assessment time-point.

Objective anorectal function, using anorectal physiology assessment was conducted at 0 and 3-months to explore physiological correlates of symptom changes, using high-resolution anorectal manometry and a 24-channel water-perfused manometry and endoanal ultrasound was performed (Hitachi Aloka medical diagnostic ultrasound system).

Feasibility Justification

The sample size was pragmatic, based on the number of eligible CRC patients attending CRGH outpatient clinics and the number of anterior resections performed over the previous two years. Given than 30% of CRC patients were likely to report LARS, the aim was to recruit 15 participants over a 24-month period.

Statistical Analysis

Statistical analyses were conducted using IBM SPSS Statistics 26.0. Feasibility outcomes included adherence, completion and compliance with PFR program. Attendance was recorded by the

treating-therapist and defined as the proportion of scheduled therapy sessions attended by each participant. Exercise adherence was assessed using home exercise diaries, in which participants recorded the frequency and completion of prescribed home exercises (once daily, at the prescribed intensity and repetitions). Exercise adherence was calculated as the proportion of prescribed exercise sessions over the study period, based on the diary records reviewed by the physiotherapist at each session, including during telehealth consultations. Program completion was defined as attendance at ≥80% of scheduled sessions. Overall compliance was defined as meeting ≥80% of both attendance and home exercise adherence requirements. An investigator-developed satisfaction survey was administered at program completion to assess overall satisfaction with the program.

Demographic characteristics were reported using descriptive statistics. Given the small sample size and non-normal distribution of repeated-measures data, non-parametric tests were applied. Changes in LARS, MSKCC-BFI, FIQoL and FACT-C scores across three time points (baseline, 3- and 9-months) were analysed using the Friedman test. Where significant overall effects were found, Conover post hoc tests with Bonferroni correction were used for pairwise comparisons. Effect sizes were calculated using Kendall's W for overall effects and rank-biserial correlation (rrb) for pairwise comparisons, with values interpreted as small (±0.1), moderate (±0.3), and large (±0.5) effects; the sign of the coefficient indicates the direction of the association. Statistical significance was set at $p < 0.05$. To evaluate the clinical relevance of changes in bowel function using the LARS score, we applied an established Minimal Clinically Important Difference (MCID) defined as a 5-point shift on the score [37]. Individual participants were deemed to respond to PFR with changes in bowel function if their LARS score after intervention decreased by 5 points compared to their baseline. This pre-defined threshold allowed differentiation between statistically significant changes and those likely to represent clinically meaningful improvement in the participants' bowel function. This pre-defined metric ensures the reported changes reflect a tangible reduction in LARS severity

over a period of time. Missing data were handled using a single imputation method, in which the mean of the group replaced the missing values in the continuous variables.

Results

Participant recruitment opened in September 2020 but due to COVID-19 restrictions, the first enrolment occurred in May 2021. Of 38 patients assessed for eligibility, 23 did not enrol (including 5 who were ineligible). Reasons for non-enrolment of the eligible patients included lack of interest, competing work or personal commitments, health-related issues, logistical barriers to attendance, COVID-19-related concerns, and lost to follow-up (unable to contact). For the five ineligible patients, three patients were excluded due to a LARS score <20, and two were deemed not clinically suitable for study enrolment (Table 1a). The targeted sample size of 15 participants was achieved in January 2024. Figure 1 provides an overview of study recruitment. Baseline characteristics are shown in Table 1b. One patient withdrew in week 2 due to social circumstances (time commitment due to work). This participant was included in the baseline characteristics and partial adherence data. Fourteen participants completed the program and were included in the final comparative analysis. One participant did not return the home exercise diary, and one did not complete the post-intervention anorectal physiology study. At 9-months (follow-up assessment), outcome data were unavailable for three participants due to: lost to follow-up (n=1), cancer recurrence (n=1), and attending other active medical treatment (n=1). No adverse events were reported.

Adherence and Satisfaction

The program had a 94.7% attendance when including all 15 participants. Excluding the participant who withdrew, attendance was 100% with all remaining participants meeting the predefined completion criterion of attending $\geq$80% of scheduled sessions. Home exercise adherence was high,

with 95.8% completion rate among participants who returned exercise diaries (13/14). The overall compliance met ≥80% of both attendance and home exercise adherence requirements.

Due to COVID-19 restrictions, 8/14 participants completed the program using a hybrid delivery model (adapted protocol). The number of telehealth sessions delivered to the participants ranged from 1-6 sessions. Quantitative satisfaction outcomes indicated high acceptability of the program with 60% rating it “excellent”, 26.7% “very good” and 6.7% “good”. In-depth satisfaction outcomes including qualitative findings from exit interviews will be reported elsewhere.

Figure 1. Study Recruitment

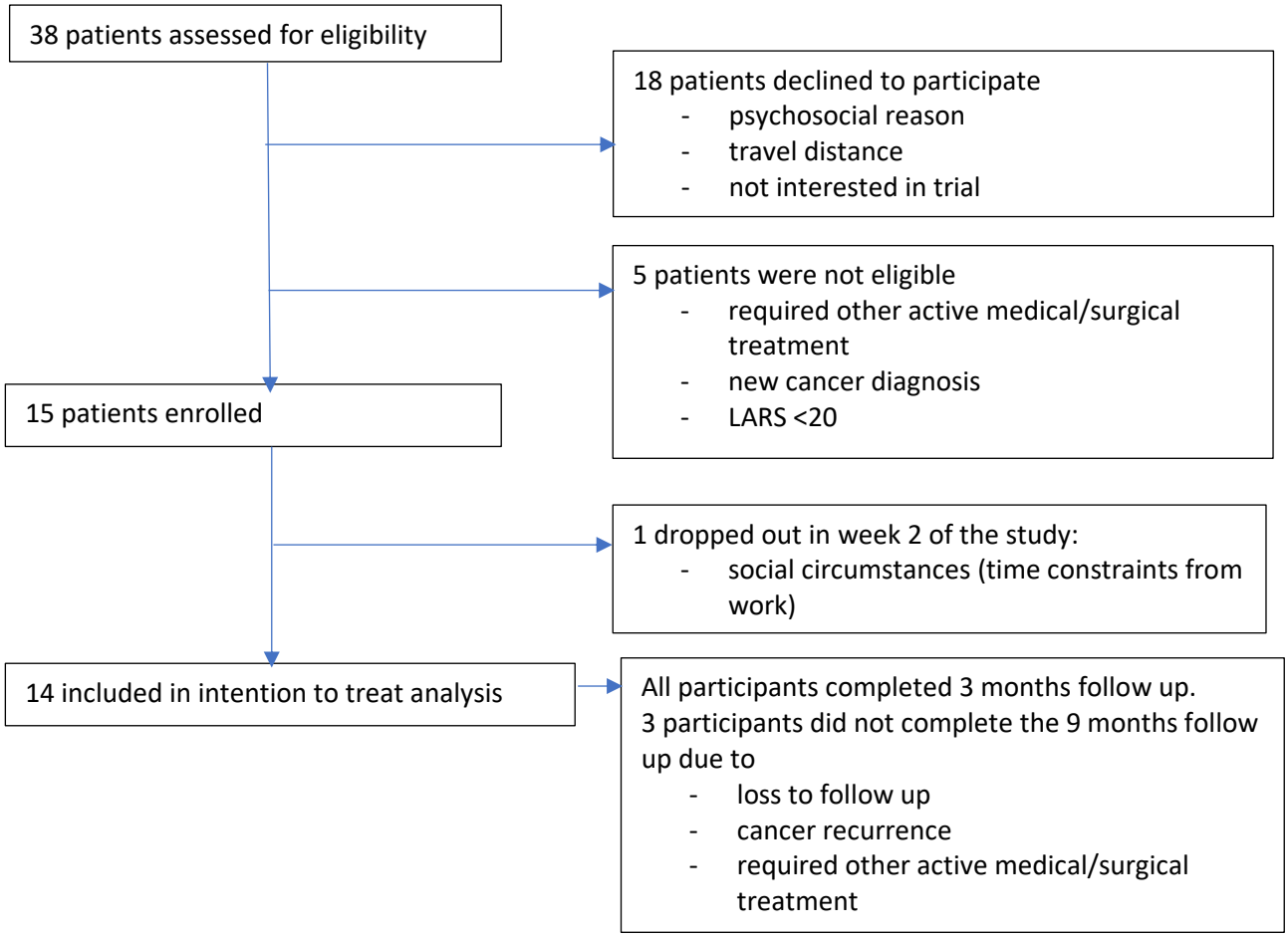


Table 1a. Reasons for non-enrolment

Recruitment flow category	Reason for non-enrolment	n
Declined to participate (n=18)	Not interested/declined participation	6
	Unable to commit due to work or other commitments	5
	Lost to follow-up/unable to contact	3
	Health-related reasons (received other medical advice)	2
	COVID-19 related concerns	1
	Logistical barriers (distance to travel)	1
Not eligible (n=5)	Required other active medical/surgical treatment	1
	New diagnosis of other cancer type	1
	Did not meet LARS eligibility criteria after screening (LARS score <20)	3

Table 1b. Baseline Characteristics (n=15)

Demographics	
Age [mean (range)] (year)	61 (44-81)
Gender [n (%)]	
- Male	8 (53.5)
- Female	7 (46.7)
BMI [mean (range)] (kg/m^2)	26.6 (19.0-36.4)
Childbirth history [n (%)]	
- Female	7 (100)
Smoking [n (%)]	
- Never	8 (53.3)
- Previous	6 (40)
- Current	1 (6.7)
Marital status [n (%)]	
- Married	10 (66.7)
- Divorced	2 (13.3)
- Widow	3 (20)
Employment status [n (%)]	
- Unemployed	1 (6.7)
- Self- employed	4 (26.7)
- Employed full time	3 (20)
- Retired	7 (46.7)
Other medical history [n (%)]	
- Hypertension	6 (40)
- Diabetes Mellitus	1 (6.7)
- Both	1 (6.7)
- None	7 (46.7)
Surgical information	
Cancer stage [n (%)]	
- Stage I	3 (20)
- Stage II	5 (33.3)
- Stage III	7 (46.7)
Cancer location [n (%)]	

- Sigmoid	2 (13.3)
- Rectum	13 (86.7)
Operative approach [n (%)]	
- Open	1 (6.7)
- Laparoscopic	10 (66.7)
- Hand Assisted Laparoscopic	3 (20)
- Robotic	1 (6.7)
Type of surgical procedure [n (%)]	
- High Anterior Resection	1 (6.7)
- Low Anterior Resection	3 (20)
- Ultra-low Anterior Resection	11 (73.3)
Anastomotic height from anal verge [n (%)]	
- ≥11 cm	1 (6.7)
- 6-10.9 cm	3 (20)
- 0-5.9 cm	11 (73.3)
Type of Reconstruction [n (%)]	
- End to end anastomosis	10 (66.7)
- Side to end anastomosis	3 (20)
- Colonic J pouch anastomosis	1 (6.7)
- Coloanal anastomosis	1 (6.7)
Surgical complications [n (%)] (UTI, SBO, Anastomotic leak x2, Adhesiolysis)	
- Yes	6 (40)
○ Anastomotic leak	2
○ SBO	2
○ UTI	2
- No	9 (60)
Stoma [n (%)]	
- Yes	11 (73.3)
- No	4 (26.7)
Stoma duration [mean (range)] (months)	4.82 (2-10)
Time since bowel continuity restored [mean (range)] (months)	19.5 (7-60)
Oncological treatment	
Neoadjuvant therapy [n (%)]	
- Yes	5 (33.3)
- No	10 (66.7)
Neoadjuvant therapy type [n (%)]	
- Long course neoadjuvant chemoradiotherapy	4 (26.7)
- Short course neoadjuvant radiotherapy	1 (6.7)
- None	10 (66.7)
Adjuvant therapy [n (%)]	
- Yes	7 (46.7)
- No	8 (53.3)
Baseline LARS (Total score 42)	
- Minor LARS (21-29)	6 (40)
- Major LARS (30-42)	9 (60)

Bowel Function and Quality of Life

Minimal Clinically Important Difference (MCID) for LARS

The established Minimal Clinically Important Difference (MCID) for the LARS score is 5 points [37]. The mean change in LARS scores from baseline to post-intervention at 3-months was -12.07 (SD = 10.34, 95% CI: -6.1 to -18, $p < 0.001$). At the 3-month (post-intervention), 10/14 participants (71.4%) exhibited a clinically meaningful improvement, defined as a reduction of ≥5 points in their LARS score. Overall, 7/11 (63.6%) participants who completed the 9-month (follow-up assessment), showed a clinically meaningful within-person improvement.

LARS Category

At baseline, 10 participants (71.4%) were classified as experiencing major LARS. Following the intervention, this decreased to 3 participants (21.4%), with 5 participants classified as having no LARS (35.7%). In total, 9/ 14 (64.2%) participants, showed improvement by at least one LARS category. Specifically, 3 participants moved from major LARS to no LARS, 4 from major to minor LARS, and 2 from minor to no LARS. At the 9-month follow-up, 6 /11 participants showed sustained improvement in LARS categories. One participant demonstrated further improvement, transitioning from minor LARS to no LARS (Figure 2).

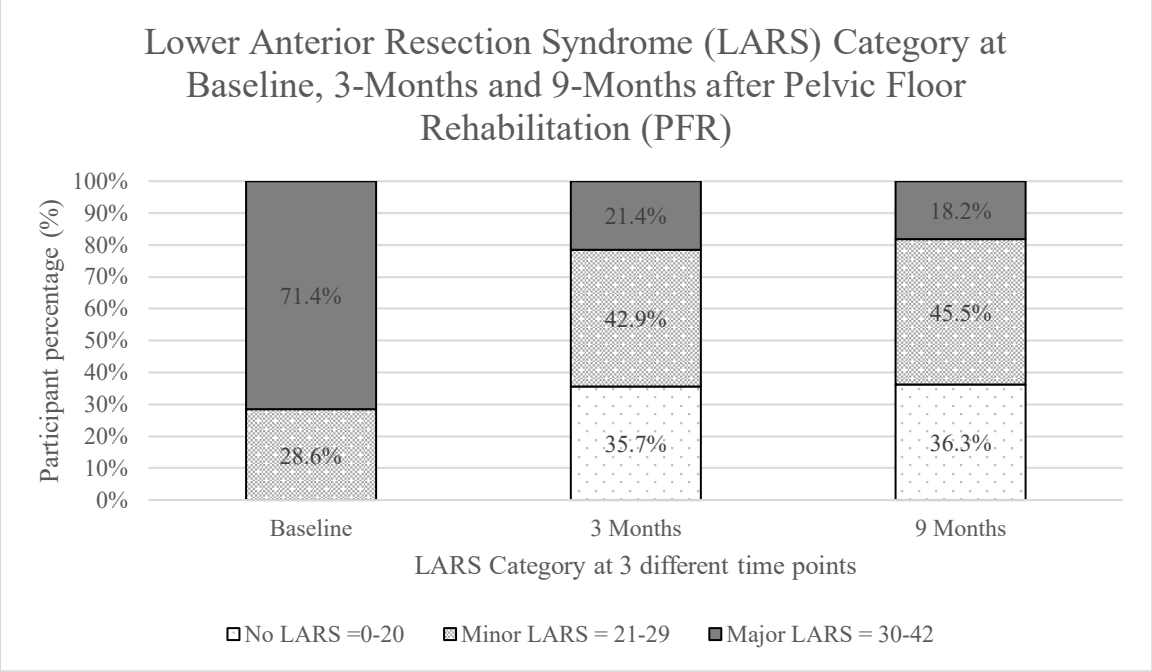


Figure 2. Lower Anterior Resection Syndrome (LARS) category at baseline, 3 months and 9 months after Pelvic Floor Rehabilitation (PFR)

LARS Score and MSKCC Bowel Function Instrument

The mean LARS Score decreased from baseline (M= 34.79, SD = 5.34) to post-intervention (M= 22.71, SD = 11.77) and remained improved at follow-up (M = 24.91, SD = 2.57). A Friedman test revealed a significant change in LARS scores across the three time points—baseline, post-intervention, and 9-month follow-up—$\chi^2(2) = 12.67$, $p = .002$, with a large effect size (Kendall's W = 0.576). Post hoc Conover tests showed significant improvements from baseline to post-intervention ($p < .001$, rrb = 0.945) and from baseline to 9-month ($p = .002$, rrb = 1.000). No significant change was observed between post-intervention and follow-up ($p = 1.000$), indicating gains were maintained. Participants demonstrated improvements in bowel function measured by the MSKCC Bowel Function Instrument, with mean total score increased from 56.3 at baseline to 65.1 post-intervention, indicating an overall improvement of +8.8 points (95%CI 4.2, 13.3, p=0.01). Improvements were observed across all MSKCC subdomains, including frequency (+4.5), urgency (+5.4), soilage (+1.6), and diet (+0.21), suggesting broad-based functional gains. Similarly, MSKCC-BFI scores showed a significant overall difference over time, $\chi^2(2) = 8.00$, $p = .018$, with a moderate

effect size (Kendall's W = 0.333). Post hoc comparisons revealed significant improvements from baseline to both post-intervention and 9-month follow-up (p = .027 for both), with large effect sizes (rrb = –0.859 and –0.872, respectively). No significant difference was found between post-intervention and follow-up (p = 1.000), suggesting sustained benefit (Table 2).

Quality of life (FIQOL and FACT-C)

Participants showed an associated improvement of +0.6 (95%CI -0.9, -0.2, p<0.001) in faecal incontinence–related quality of life (FIQOL) following the intervention. The overall FIQOL scores improved across all four subscales: Lifestyle domain improved from a mean of 2.5 (SD = 0.9) to 3.2 (SD = 0.8), Coping improved from a mean of 2.1 (SD = 0.8) to 2.9 (SD = 0.8),
and Embarrassment increased from 2.6 (SD = 1.1) to 3.0 (SD = 1.1), suggesting reduced negative emotional impact. Improvement in quality-of-life was observed in these findings. The change of FIQOL scores was sustained at the 9-month follow-up.

Participants showed an increase in mean FACT-C scores from baseline (M = 105.04, SD = 18.33) to post-intervention (M = 114.06, SD = 18.10) and remained stable at 9-month follow-up (M = 113.98, SD = 18.26). The associated improvement in quality-of-life was observed following the intervention, as indicated by both the FIQoL and FACT-C.

A Friedman test for FIQoL showed a significant difference across time points, $\chi^2(2) = 14.73$, $p < .001$, with a large effect size (Kendall's W = 0.669). Post hoc Conover tests revealed significant improvements from baseline to post-intervention (p = .014, rrb = –0.848) and from baseline to 9-month follow-up (p < .001, rrb = –0.909), both with very large effect sizes. Notably, FIQoL also improved significantly from post-intervention to follow-up (p = .014, rrb = –0.667), suggesting a continued upward trajectory in quality of life over time. Similarly, the FACT-C scores demonstrated a significant overall improvement, $\chi^2(2) = 8.91$, p = .012, with a moderate effect size (Kendall's W = 0.405). Post hoc tests showed large significant improvements from baseline to post-intervention (p = .008, rrb = –0.788) and baseline to 9-month follow-up (p = .027, rrb = –0.682). No significant

change was observed between post-intervention and follow-up, suggesting that the quality of life gains were maintained over time (Table 2).

Measure	Friedman χ^2(df)	p	Kendall's W	Comparison	P_{bonf}	Rank-Biserial Correlation (rrb)
LARS	12.67 (2)	0.002	0.576	Baseline vs Post	< .001	0.945
				Baseline vs 9M Follow-Up	0.002	1.000
				Post vs 9M Follow-Up	1.000	–0.556
MSKCC-BFI	8.91 (2)	0.012	0.405	Baseline vs Post	0.008	–0.909
				Baseline vs 9M Follow-Up	0.027	–0.848
				Post vs 9M Follow-Up	1.000	0.439
FIQoL	14.73 (2)	< .001	0.669	Baseline vs Post	0.014	–0.848
				Baseline vs 9M Follow-Up	< .001	–0.909
				Post vs 9M Follow-Up	0.014	–0.667
FACT-C	8.91 (2)	0.012	0.405	Baseline vs Post	0.008	–0.788
				Baseline vs 9M Follow-Up	0.027	–0.682
				Post vs 9M Follow-Up	1.000	–0.045
ICIQ-MLUT	3.00 (2)	0.223	0.214	Baseline vs Post	0.651	0.667
				Baseline vs 9M Follow-Up	0.323	0.500
				Post vs 9M Follow-Up	1.000	–0.048
IIEF	4.43 (2)	0.109	0.554	Baseline vs Post	0.412	–1.000
				Baseline vs 9M Follow-Up	1.000	0.200
				Post vs 9M Follow-Up	0.108	1.000
ICIQ-FLUT	2.80 (2)	0.247	0.350	Baseline vs Post	0.852	1.000
				Baseline vs 9M Follow-Up	0.384	0.800
				Post vs 9M Follow-Up	1.000	0.200

Table 2. Changes in LARS, MSKCC Scores, FIQOL, FACT-C, MLUT, IIEF and FLUT across Time Points: Friedman Test and Conover Post Hoc Results with Effect Sizes. (FSFI was not included due to all female participants not being sexually active)

Abbreviations- LARS: Low Anterior Resection Syndrome; MSKCC-BFI: Memorial Sloan Kettering Cancer Centre- Bowel Function Instrument; FIQOL: Fecal Incontinence Quality of Life; FACT-C: Functional Assessment of Cancer Therapy- Colorectal; ICIQ-MLUT: International Consultation on Incontinence Modular Questionnaire- Male Lower Urinary Tract Symptoms; IIEF: International Index of Erectile Function; ICIQ-FLUT: International Consultation on Incontinence Modular Questionnaire- Female Lower Urinary Tract Symptoms.

Variable	t	p	Mean Difference	SE Difference	95% CI for Mean Difference	
					Lower	Upper
Resting Pressure (mean)	1.785	0.100	7.592	4.253	-1.674	16.859
Squeeze Pressure (mean)	2.234	0.045	14.054	6.291	0.347	27.760
Endurance (mean)	1.339	0.205	5.538	4.136	-3.474	14.550
Simulated Defaecation Relaxation (%)	2.884	0.014	17.769	6.161	4.345	31.194
First sensation volume (ml)	0.959	0.356	3.846	4.009	-4.889	12.582
Desire to defaecate volume (ml)	3.425	0.005	21.538	6.289	7.837	35.240
Maximum tolerated volume (ml)	4.815	< .001	26.923	5.591	14.741	39.105
Number of Anal Incontinence per day	2.889	0.014	1.846	0.639	0.454	3.238
Bowel Frequency per day	4.915	< .001	0.920	0.187	0.512	1.328

Table 3. Paired Samples t-Tests of anorectal physiology parameters and stool diary comparing baseline and post-intervention.

Anorectal physiology assessment

Anorectal physiology testing demonstrated improvement in several key parameters following the intervention. Maximal resting anal pressure increased from 55.4 mmHg (SD = 22.3) to 67.1 mmHg (SD = 23.2), while maximal squeeze pressure improved by 8.43 mmHg, suggesting enhanced sphincter function and improvement in voluntary contraction. First sensation volume (from 30ml to 33.9ml), desire to defaecate volume (from 38.5ml to 60ml) and maximum tolerated volume (from 50.8ml to 77.7ml) all increased, indicating improved rectal sensitivity. Simulated defaecation relaxation improved from 7.8% to 25.5%, suggesting improved defaecatory coordination (Table 3).

Other Functional Measures

Anal incontinence and bowel frequency showed statistical improvement (Table 3). Other outcome measures (male and female bladder function, sexual function, Hospital Anxiety and Depression Scale, and Endoanal ultrasound) did not show statistically significant differences.

Discussion

This study supports the feasibility of delivering a structured, outpatient PFR program for CRC survivors with LARS, demonstrating high adherence, completion and acceptability. Exploratory within-participant improvements in LARS symptoms and QOL were observed; however, given the single-arm design, these clinical findings should be interpreted as hypothesis-generating rather than confirmatory of clinical efficacy.

Feasibility and acceptability of PFR

Our primary objective was to evaluate feasibility. High adherence to both supervised sessions and home exercises, as documented through therapist-recorded attendance and completed exercises, supports the feasibility of delivering a structured PFR program in the CRC population, achieving ≥80% with high compliance. Diary review during weekly sessions facilitated individual's motivation and technique reinforcement, which may have contributed to sustained engagement. These findings suggest that structured self-monitoring is an acceptable strategy to support adherence in the cancer rehabilitation model. Several indicators support that the delivery is safe and well-received by participants. Participants' satisfaction was high, likely due to the perceived relevance, supportiveness, and empowering nature of the program, suggesting the value of PFR in CRC care [38]. However, long-term program sustainability should be considered in relation to its costs and implementation within a complex healthcare system. While the adherence rate in our study was high, we acknowledge that this may vary across different healthcare systems due to resource and

accessibility constraints, including the availability of trained staff, regional geographic considerations, and support for minority groups [39-41].

The incorporation of telehealth during COVID-19 disruptions further enhances feasibility, allowing continuity of care when in-person sessions were not possible. This modality provided flexibility without compromising adherence or completion. Our study demonstrated the practical application of this approach specifically to LARS, which is underserved in tele-rehabilitation survivorship care. This approach aligns with broader evidence showing its effectiveness in managing pelvic floor dysfunction symptoms and supporting skill acquisition and retraining through physiotherapy [42, 43]. Telehealth may encounter certain challenges in broader implementation, particularly for individuals with low digital literacy, those with language barriers, in areas with limited internet access, and rehabilitation training elements that require in-person attendance, particularly the rectal biofeedback component in our study [44-46]. Therefore, striking a balance between in-person and virtual care is essential to ensure equity across demographic and geographic groups.

Signal of Clinical Benefit

Exploratory analyses suggested within-person improvement in LARS severity and QOL following PFR, as observed by patient-reported outcome measures (PROMS) and anorectal physiology (ARP) assessments.

Over 70% of participants demonstrated clinically meaningful within-person improvements in LARS scores post-intervention, with 64% maintaining benefit 6-months later. Improvements in PROMS were observed immediately post-intervention, and were generally maintained over time. These improvements occurred alongside favourable changes in ARP measures, including sphincter resting and squeeze pressure, rectal sensation (urge to defaecate and maximal tolerable volume), and defaecatory coordination (anal relaxation), which are physiologically relevant to symptoms such as

urgency, frequency (clustering of bowel motions) and incontinence. The observed within-person physiological changes provide the biological plausibility for the 5-point improvement in LARS score, suggesting that improved anorectal storage and evacuation ability may contribute to a reduction in symptom severity. The parallel changes observed in PROMS and ARP measures suggest a potential mechanistic link between neuromuscular function and symptom improvement. Thus, the convergence of subjective and objective measures supports the physiological plausibility of the intervention, not as a return to “normal” anatomy , but as a functional adaptation that crossed the threshold into a clinically meaningful reduction in symptom burden for the patient. However, given the feasibility design and small sample size, these associations should be interpreted as supportive rather than confirmatory evidence of the mechanisms underlying symptom improvement.

PFR is hypothesised to address the multifactorial nature of LARS, by improving pelvic floor and external anal sphincter muscle function, restoring anorectal coordination and optimising the responses to rectal filling, supporting both evacuation and storage mechanism [17, 18, 47]. This multimodal PFR extended beyond PFM training with exercise and biofeedback, and incorporated education and behavioural strategies including bowel and bladder habits, optimal toileting strategies and dietary advice. These components are intended to reduce maladaptive behaviours such as excessive straining, incomplete emptying, to optimise stool consistency and minimise urgency-triggering behaviours, thereby complementing neuromuscular retraining [48-50]. The integration of biofeedback, education and behavioural strategies may facilitate motor relearning and improve awareness of anorectal function, reduce urgency-related anxiety, and support the re-establishment of effective toileting patterns.

This study contributes to the growing body of evidence of improved LARS symptoms, as measured by PROMS and ARP [51, 52], following PFR, while demonstrating the acceptability of a standardised multimodal PFR approach. PROMS capture patient's experience, and functional impact of symptoms on the health-related quality of life [30, 34, 53]. When paired with ARP data, which offers an

objective measure of bowel function, it provides a more comprehensive understanding of bowel function. The dual assessment approach also informs the design and implementation of individualised rehabilitation programs tailored to specific symptoms and functional needs [54-57]. While this combined assessment method enhances the reliability and specificity of outcome measurements and reduces bias, its implementation may present challenges in resource-limited or rural settings [21]. Variation in individual response observed in this study highlights the need for future controlled trials to examine factors influencing treatment responsiveness, such as the chronicity of LARs, baseline function, comorbidities, psychosocial readiness for behaviour change, durability of benefit and long-term outcomes.

Positioning of PFR within Optimised Conservative Management

This study supports the potential of PFR within the framework of LARS Optimised Conservative Management (OCM) and its integration into standard CRC survivorship care. Current stepwise approaches, such as the MANUEL and BOREAL protocols [20, 58], emphasise conservative treatment but lack standardised integration of structured, multidisciplinary PFR in CRC management. While prior studies by Asnong [19] and Van der Heijden [21] demonstrated benefits of PFR, heterogeneity in the intervention and outcome assessment limits comparability and implementation [59]. This includes variation in the timing of rehabilitation initiation after surgery and treatment, the components and intensity of PFR protocols, and the outcome measures used to evaluate treatment effects. Establishing clear definitions of treatment duration, delivery methods, and outcome assessment will be important for integrating PFR more consistently into OCM pathways. The recent POLARIS RCT protocol compared optimised conservative management with transanal irrigation and sacral neuromodulation [37]. However, the definition of OCM in that study did not include structured and supervised PFR, likely due to resource limitations or disparities in standardised

service access across trial centres. This omission raises important concerns about the standardisation of OCM and need for integrating PFR into the LARS management pathway.

The feasibility demonstrated in this study suggests that supervised, physiotherapist-led PFR could be incorporated consistently within CRC survivorship, However, its successful integration into standard care requires addressing workforce capacity, equitable access, and system readiness. Adherence to treatment protocols and appropriate timing will be essential for achieving meaningful outcomes [60]. Barriers such as a shortage of sufficiently trained physiotherapists and a lack of structured referral systems impede the widespread implementation of PFR in healthcare settings [61]. In Australia, there are no formal rehabilitation models for LARS in contrast to some European countries, where dedicated LARS clinics and structured referral systems are integrated into CRC care [59, 62, 63]. Currently, access to rehabilitation services is often based on *ad hoc* clinician referrals, which rely on individual clinician awareness rather than systematic integration into the care pathway. This fragmented approach can delay care, hinder interdisciplinary collaboration, and contribute to patient disengagement, especially when services are not incorporated into the multidisciplinary cancer care pathways [15]. Addressing these system-level barriers will be essential to scaling PFR beyond research settings.

Strengths

The strengths of this study are its real-world relevance. The intervention consisted of a structured, multimodal rehabilitation program designed to actively engage patients in pelvic floor strengthening, coordination, and functional retraining. This behavioural and functional approach aimed to empower patients and promote sustainable self-management of LARS symptoms. While earlier intervention may benefit selected patients, the 6-month eligibility criteria provided a pragmatic balance between allowing early postoperative recovery and identifying patients with

persistent LARS who may benefit from PFR within routine postoperative recovery pathways [4, 26]. The study included patients with minor and major symptoms, regardless of surgical approach [64]. There was no upper time limit on LARS chronicity, increasing applicability of the findings to both recent and long-standing cases.

Limitations and Future Research

Recruitment was affected by the COVID-19 pandemic, with clinic closures, delays in elective surgeries, restrictions on face-to-face care, and research studies being put on hold, all contributing to the small sample size. However, the extent to which the pandemic directly influenced patients' decisions to enrol was not formally evaluated in this study. Although reasons for non-participation were documented at screening, a more in-depth qualitative investigation of barriers to enrolment was not undertaken. Patient reluctance to participate in the trial may have been influenced by factors such as stigma related to bowel dysfunction, competing personal or work commitments, and concerns about travelling to healthcare facilities during the pandemic. Consequently, important psychosocial, logistical, and health system factors impacting trial participation might not have been fully captured. These factors should be considered when interpreting recruitment feasibility and the generalisability of the findings. Recruitment rates of this nature are not uncommon in feasibility studies, especially interventions containing behavioural elements. Participants' decisions may be affected by time commitments, travel requirements, and individual readiness to actively engage in a supervised program.

All participants were recruited from a single centre and its affiliated clinic, which might limit generalisability due to potential selection bias and participant motivation. The small sample size reflects the feasibility design of the study rather than a trial intended to detect treatment effects. While this cohort number was sufficient to assess the feasibility of PFR and provide preliminary data on bowel function, it was not powered to detect small treatment effects, which precludes causal

inference. The single-arm design, with no control group, further limits the ability to control for non-specific effects, such as increased clinical attention or regression to the mean. Results should be interpreted as hypothesis-generating only.

Future research should address these limitations by conducting a large-scale, multi-centre, adequately powered, longitudinal, randomised controlled trial in varied geographic and clinical contexts. Specifically, comparing structured Pelvic Floor Rehabilitation (PFR) against a 'standard usual care" control group (lifestyle advice, fibre supplementation, and anti-diarrheal medication) will be essential to distinguish the treatment effect from natural recovery or regression to the mean. Based on the 47% recruitment rate observed in this study, future research should also explore clinician-led versus specialist-nurse-led delivery models to improve scalability. Such studies should consider a systematic assessment of recruitment barriers. Furthermore, the observed changes in anorectal physiology provide a foundation for adding secondary mechanistic endpoints in a larger trial to verify the biological plausibility of functional improvements. Incorporating a health economic analysis in the implementation would provide valuable insights into the cost-utility of pelvic floor rehabilitation versus traditional care, helping determine whether the clinical improvements in bowel function justify widespread implementation and sustainability in routine colorectal cancer and survivorship care. Additionally, implementation research could investigate the acceptability, scalability, and sustainability of this intervention in routine clinical practice in diverse settings, supporting its wider adoption if proven effective.

Conclusion

This study demonstrates that structured physiotherapist-led PFR for LARS is feasible and acceptable in an outpatient setting**,** as demonstrated by achieving the target recruitment, high program adherence, and high participant retention. A within-person change in LARS was observed, these

preliminary findings should be interpreted as hypothesis-generating. Nevertheless, they provide a basis for future randomised controlled trials to evaluate the effectiveness of PFR in managing LARS. Overall, this feasibility study confirms that the intervention is safe and logistically feasible to incorporate into routine CRC survivorship care.

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Chapter 7: The experiences of a structured pelvic floor rehabilitation program in colorectal cancer survivors with low anterior resection syndrome: A qualitative study

Overview

The previous chapter provided a quantitative assessment of pelvic floor rehabilitation, highlighting potential benefits and offering valuable insights into its feasibility. However, it did not fully reflect patients' nuanced experiences or the contextual factors influencing engagement and perceived improvement. In this chapter, we gained a deeper understanding of LARS and its impact through thematic analysis of interviews that complemented the quantitative results. A behavioural change model was also introduced, based on lived experiences at PFR, contributing to the existing literature on cancer survivorship care.

This chapter has been submitted to a peer-review journal and is currently under review. The manuscript is quoted verbatim and formatted according to the requirements of the journal.

Contribution of authors

I, Kin Yin Chan was responsible for study conceptualisation and design, project administration, dataset management and analysis, result interpretation, and drafting and finalising manuscript.

Gemma Collett conducted interviews and collected data

Sarah Ratcliffe was responsible for leading data analysis and result interpretation, manuscript revision

Michael Suen reviewed the manuscript

Janindra Warusavitarne reviewed the manuscript

Susan Coulson reviewed the manuscript

Janette Vardy developed the concept and reviewed the manuscript

Abstract

Background: Low anterior resection syndrome (LARS) is a common survivorship challenge after colorectal cancer (CRC), affecting bowel function, psychosocial health, and daily living. Pelvic floor rehabilitation (PFR) is a supportive approach for bowel function recovery, but little is known about survivors' experiences of or behaviour change processes when participating in a structured PFR program.

Aim: This study explored CRC survivors' experiences of LARS and structured PFR with focus on satisfaction, supportive care needs, and behaviour change processes.

Design: This was a cross-sectional qualitative study. Analysis employed a hybrid inductive-deductive approach to theme development and data mapping with Symptom Management Theory (SMT) and the COM-B model.

Setting/Participants: Fourteen participants with LARS who had completed the PFR intervention completed a self-administered paper satisfaction survey and semi-structured telephone interview.

Results: All participants rated their experiences as good to excellent on a 6-point Likert scale. Three themes related to participants' LARS experience and PFR participation were generated: 1. Living with unpredictable LARS; 2. A desire for quality information, timely education, and individualised multimodal support; and 3. Regaining function and control through structured rehabilitation. Processes of behaviour change were: (1) expectation management; (2) gaining ability to manage; (3) self-efficacy and habit consolidation; and (4) re-evaluation and relapse management. Mapping to SMT and COM-B informed development of a new model, the Empowered Behavioural Adaptation Process (EBAP).

Conclusions: LARS imposes considerable physical and psychosocial burdens on CRC survivors, worsened by unmet informational needs and fragmented support. Behaviour change and self-management theories explain how guided, supportive care and individualised multimodal PFR through an Empowered Behavioural Adaptation Process, support self-efficacy and long-term management of LARS in CRC survivors.

Keywords: Survivorship; Colorectal cancer; Low anterior resection syndrome; Pelvic Floor Rehabilitation; symptom management; Behaviour change; Self-management; feasibility; qualitative

Introduction

Colorectal cancer (CRC) is one of the top five most commonly diagnosed cancers in Australia over the past decade [1]. Over half of CRC cases involve sigmoid and rectal cancers. Surgery remains the primary treatment, with 67% of patients undergoing anterior resection [2]. Depending on cancer stage, neoadjuvant and adjuvant therapies are offered to optimise oncological outcomes. Despite advances in management, approximately 40% of CRC survivors persistently experience symptoms of Low Anterior Resection Syndrome (LARS) from curative-intent surgery and chemoradiotherapy [3]. Low Anterior Resection Syndrome (LARS) is characterised by one or more bowel symptoms, such as urgency, incontinence, and frequent or difficult bowel movements after surgery and chemoradiotherapy [4]. Impaired bowel function disrupts daily life and imposes an often underestimated psychological burden on survivors [5-7]. Recurring patterns observed in cancer survivors' experiences include, unpredictability of bowel function affecting both continence and evacuation and unrealistic expectations of full bowel recovery causing ongoing psychological distress [8]. Existing patient-reported outcome measures (PROMS), such as LARS score [9] and Memorial Sloan Kettering Cancer Center – Bowel Function Instrument (MSKCC-BFI) [10], focus on bowel dysfunction symptoms but may underestimate this burden [11-14].

Functional recovery is a complex, prolonged process that requires a multimodal approach to manage the chronic nature of LARS [15, 16]. Yet, many CRC survivors are left to navigate these challenges with limited guidance, fragmented follow-up, and unrealistic expectations about returning to pre-treatment bowel function and social participation [17].

Pelvic floor rehabilitation (PFR), which includes pelvic floor muscle training, biofeedback (sensory, audio, visual), and education, has shown early promise as a treatment option for LARS [18-20]. However, trial variability with different protocols and outcome measures limits the development of effective, targeted LARS management programs [21]. Additionally, feasibility evidence for Australian healthcare system outpatient settings remains limited. Little is known about whether structured and

guided PFR supports CRC survivors with LARS to manage bowel symptoms and improve quality of life (QOL) through behaviour change and self-efficacy.

Symptoms Management Theory (SMT) and the Capability, Opportunity, Motivation – Behaviour (COM-B) model of behaviour change provide insights into understanding the multifaceted impacts of LARS on physical symptoms, psychological readiness, capability, and system-level barriers [22-24]. System-level barriers, including insufficient recovery planning information, low LARS awareness among clinicians, and lack of coordinated pathways for supportive care and rehabilitation, undermine patient preparedness and functional outcomes [25-27]. Need-based supportive strategies, including structured and supervised rehabilitation programs, support cancer survivors through behavioural adaptation essential for self-efficacy and sustainable improvement [28].

This study explored whether outpatient, physiotherapist-led PFR is a practical and supportive approach for CRC survivors living with LARS. By integrating behavioural science into clinical rehabilitation, this study seeks to inform more responsive, patient-centred care in cancer survivorship that goes beyond managing symptoms to promote patient self-efficacy in recovery decisions and support the restoration of life roles. Specific aims included: (1) assess satisfaction of structured PFR in a clinical setting; (2) explore survivors' experiences and understanding of LARS; (3) identify supportive care needs of CRC survivors; and, (4) determine the impact of PFR and its potential to facilitate behaviour change through expectation management, internal adaptation, and ongoing self-management.

Methods

This was a cross-sectional qualitative study conducted as part of a feasibility project for a structured, physiotherapy-led PFR for LARS after CRC surgery and treatment. Reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [29].

Participants were recruited from a PFR feasibility project conducted at a New South Wales outpatient clinic, Australia [30]. Participants were over 18 years old, had undergone sphincter-preserving anterior resection for CRC, experienced new onset of bowel symptoms (LARS score > 20), and at least 6 months post-bowel continuity restoration. Ethics approval was granted by the Sydney Local Health District Human Research Ethics Committee, Concord Repatriation General Hospital (SLHD HREC, CRGH) under the reference number 2019/PID 15308. This study was registered on the Australian and New Zealand Clinical Trials Registry (ANZCTR), ACTRN 12620000821998. The study was conducted in accordance with the "NHMRC National Statement on Ethical Conduct in Human Research" (Commonwealth of Australia, 2007, updated 2018) and the ethical principles derived from the World Medical Association Declaration of Helsinki (Helsinki, 1964, updated 2016).

After completing the PFR intervention, participants were invited to evaluate the program via a self-administered satisfaction survey and semi-structured telephone exit interview (Supplementary file 1). All participants provided written consent. Data collection continued until saturation or all participants completed interviews.

Interviews explored three key areas: (1) impact of LARS on daily lives; (2) perceptions of PFR in alleviating symptoms and improving QOL; and (3) overall satisfaction with PFR (See Supplementary file 1). Lead author (KYC) developed interview questions and flexible prompts guided by Symptom Management Theory (SMT)[23]. An independent researcher (GC), experienced in qualitative interviewing and with no prior involvement in the intervention, conducted the interviews in English. One participant required translation support from a family member with responses paraphrased to preserve the participant's meaning. Interviews were audio-recorded and transcribed verbatim using TRINT audio transcription software [31].

Quantitative data were analysed using SPSS version 26 [32]. Qualitative data were analysed using thematic analysis with a hybrid inductive-deductive approach [33] using NVivo 14 [34], Microsoft

PowerPoint [35], and digital whiteboards. Iterative development and refining of concepts, patterns, and themes continued until consensus on thematic interpretations was reached.

To situate the findings within established theoretical frameworks relevant to symptom management and behaviour change, codes were mapped onto the elements of Symptoms Management Theory (SMT) and the Capability, Opportunity, Motivation – Behaviour (COM-B) model [23, 24] (See Supplementary File 2). While SMT and COM-B models guided interpretation, theme development remained inductive and grounded in participants' accounts. Further explanation of methodological rigour is provided in Supplementary File 3.

Results

All enrolled participants in the feasibility project (n=14), a total of fourteen CRC survivors, completed the 10-week PFR program, including an exit survey and interview.

Mean age was 61 years (range 44-81), 87% had rectal cancer, and 73% had an ultralow anterior resection and a temporary stoma. All participants rated the program as good to excellent. See Table 1 for demographic and satisfaction data.

Table 1. Demographic information and PFR satisfaction of participants

Participants' demographics (n = 14)	**Mean (range) / % (N)**
Age (years)	62.1 (44-81)
Sex	
Female	50.0% (7)
Male	50.0% (7)
Marital status	
Married	64.3% (9)
Widowed	21.4% (3)
Divorced	14.2% (2)
Employment	
Employed full time	14.3% (2)
Self-employed	28.6% (4)
Unemployed	7.1% (1)
Retired	50.0% (7)
Cancer stage	
Stage I	21.4% (3)
Stage II	35.7% (5)
Stage III	42.9% (6)
Cancer location	

Sigmoid	14.3% (2)
Rectum	85.7% (12)
Procedure	
High anterior resection	7.1% (1)
Low anterior resection	21.4% (3)
Ultralow anterior resection	71.4% (10)
Temporary stoma (yes)	71.4% (10)
Stoma duration (months)	4.6 (2-10)
Time since bowel continuity restoration (months)	21.0 (7-60)
Neoadjuvant Therapy	
Long course chemoradiotherapy	21.4% (3)
Short course radiotherapy	7.1% (1)
No neoadjuvant therapy	71.4% (10)
Adjuvant Therapy (yes)	42.9% (6)
LARS score[a]	32.9 (24-41)
LARS category[a]	
Minor	42.9% (6)
Major	57.1% (8)
PFR satisfaction – Overall	
Excellent	64.3% (9)
Very good	28.6% (4)
Good	7.1% (1)
PFR Satisfaction - Psychological impact	
Received support was adequate	
Strongly agree	80% (12)
Agree	13.3% (2)
Confidence regained	
Strongly agree	66.7% (10)
Agree	26.7% (4)
PFR Satisfaction - Knowledge advancement	
Physiotherapist who delivered PFR was knowledgeable in answering questions	
Strongly agree	80% (12)
Agree	13.3% (2)
Opportunity given for discussion	
Strongly agree	66.7% (10)
Agree	26.7% (4)
PFR Satisfaction - Practicality	
Information comprehensibility	
Strongly agree	60% (9)
Agree	33.3% (5)
Information was useful	
Strongly agree	80% (12)
Agree	13.3% (2)
Exercises were clear and useful	
Strongly agree	53.5% (8)
Agree	40% (6)
Dietary advice	
Strongly agree	46.7% (7)
Agree	46.7% (7)

Clinic accessibility	
Strongly agree	53.3% (8)
Agree	40% (6)
[a]LARS symptom severity [ref]: range, 0- 42; 0-20 = No 21-29 = Minor, 30-42 = Major.	

Thematic analysis developed three themes related to participants' experiences with LARS and PFR participation: (1) Living with unpredictable LARS; (2) A desire for quality information, timely education, and individualised multimodal support; and (3) Regaining function and control through structured rehabilitation (Figure 1). Supplementary File 4 presents additional quotes.

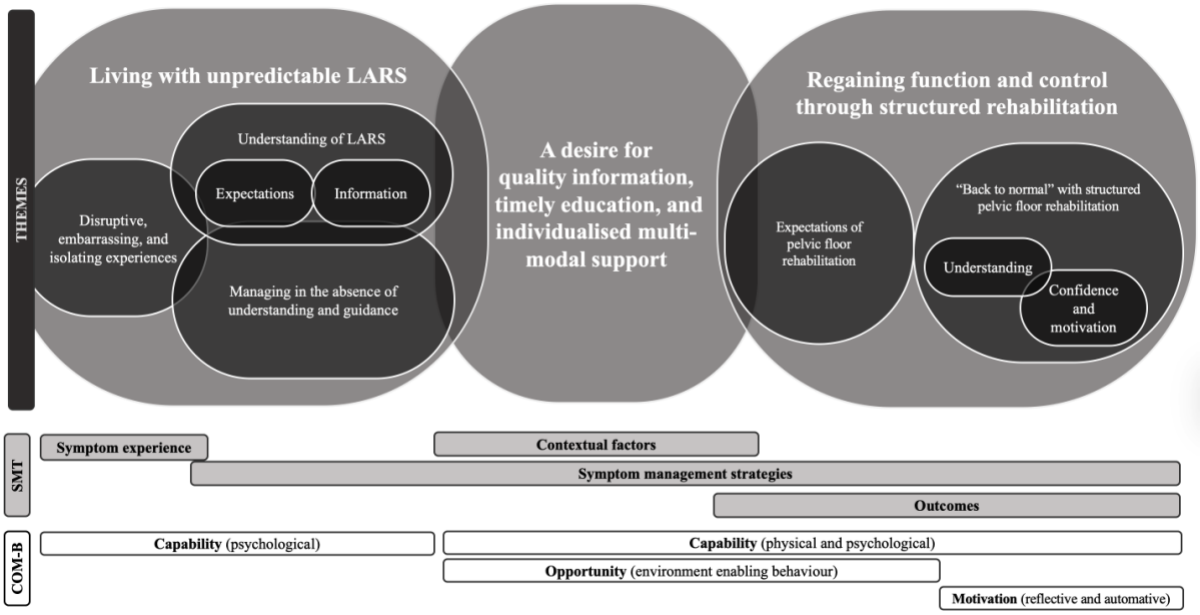

Figure 1. Visualisation of themes developed during analysis, layered with SMT and COM-B
Dark toned ovals represent themes and subthemes developed from this dataset; Grey boxes represent components of SMT; White boxes represent components of COM-B

Theme 1: Living with unpredictable LARS

Participants described living with LARS as difficult and disruptive. They demonstrated varying levels of understanding of LARS, often describing the physical and psychological impacts as more severe than anticipated, prompting adjustments to expectations and modifications in management of persistent LARS symptoms. Knowledge of LARS was linked with experiences and limited information provided by healthcare professionals. This was reported to influence expectations for pelvic floor rehabilitation in aiding bowel function. recovery.

1.1. Disruptive, embarrassing, and isolating experiences

All participants reported experiencing LARS-related symptoms, including increased bowel frequency, urgency, leakage, pain, and change in stool consistency. Bowel routines were frequently described as *"erratic and frequent" [P1],* with some participants needing to use the toilet *"seven to eight times a day" [P8]* or *"missing the toilet many times… [and] soiling my underwear"* [P2]. LARS symptoms also occurred overnight, compounding participants' distress.

The disruptive nature of LARS symptoms was closely tied to emotional and social consequences, including social withdrawal and reluctance to engage in everyday activities. Participants expressed frustration, fear, embarrassment, diminished confidence, and a lack of control. Feeling stigmatised or dismissed by others, including family members, exacerbated their sense of isolation.

> *"embarrassingly enough, I had a couple of accidents… I got to the stage where I was worried about going out, and I would make sure that I was going to a place where there were toilets."*[P5]

1.2. Understanding of LARS

Participants' experiences and knowledge of LARS influenced their initial understanding of recovery. Quality of information received was linked with the perceived impact of LARS. Absent or incomplete information impacted medical decision-making, with one participant sharing, *"I think if you told people the extreme of it, people would be very cautious about having surgery."* [P14].

1.2.1 Expectations and realisations of living with LARS

While participants initially believed that bowel function would return to their pre-surgery state without intervention, some accepted that full recovery was unlikely, acknowledging they were *"never going to be 100%" [P3]. The expectation of recovered bowel function* was often not grounded in a realistic *"understanding of how the bowels work" [P11],* particularly regarding physiological impacts of surgery and treatment. Participants were surprised at the extent of muscle weakness and persistence of symptoms.

"I didn't really appreciate how weak the muscles have become [since surgery]… I just thought, 'oh yes, I'm a perfectly healthy person. I've never had any trouble before. So, you know, why should I be weak [now]?" [P1]

While some participants attributed worsening symptoms to ageing, the lingering impact of cancer treatment was widely considered the primary cause. Several participants indicated the burden of LARS was preferable to a permanent stoma, which was perceived as more stigmatising and psychologically distressing.

"They wanted me to have a stoma bag for life, and I said no… I would rather die than have that." [P9]

1.2.2 Delayed, inconsistent, and absent LARS information

Participants consistently reported limited attention to potential long-term bowel dysfunction and its impact on QOL. Clinical consultations focused on cancer treatment plans and surgical preparation and lacked comprehensive LARS education. Some described information as superficial, overly complex, or generalised, noting clinicians had limited time. Participants felt postoperative bowel issues were a secondary consideration for clinicians, leading to feelings of neglect regarding their ongoing recovery and care needs.

"Before the surgery I didn't know any of this was going to happen. And I don't think he's worried about that. It's about fixing the problem." [P4]

Some encountered prolonged gaps in communication with information on LARS first received months postoperatively. Quality and timing of information was described as *"rude" [P6]* and evoked feelings of frustration, confusion, indignation, and helplessness, largely attributed to the ambiguity, inconsistency, and contradictions in the information offered. A particular concern and source of distress was the lack of clear expectations regarding the recovery timeline and likelihood of functional restoration.

"The information is different depending on who you talk to. It's different from the nurse or from the doctor" [P9]

1.3. Managing in the absence of understanding and guidance

Participants described their experiences with LARS as differing from what they were told to expect. They managed by adjusting their expectations for living with LARS and, in the absence of professional guidance, adopting various passive and short-term solutions to regain control of their lives. Many described feeling helpless and uncertain about how to manage their symptoms; often resulting in inaction.

"I didn't do anything because I didn't know what to do." [P11]

Initially participants were encouraged by healthcare professionals' optimistic predictions but when symptoms did not improve, they adjusted their expectations and adopted pragmatic, symptom-focused management strategies.

"It took quite a few months to get used to [the change]… I realised that it'll never be the same again." [P5]

Most participants relied on self-devised coping strategies for symptom management, often involving trial and error. While sometimes helpful, these approaches often produced inconsistent outcomes. To minimise disruption from unpredictable bowels, personalised routines were developed.

"Before I used to go out, if I have an appointment or anything to do in the morning. Yeah, I didn't used to have any breakfast at all." [P6]

Theme 2: A desire for quality information, timely education, and individualised multi-modal support

In response to a lack of timely, comprehensive, and consistent information about bowel function and cancer treatment, participants expressed desire for more in-depth discussions about bowel function and recovery expectations, alongside adequate time and support to process information.

> *"so preparing somebody for the [stoma] reversal would be a great help. And possibly getting them started on the program like this once the reversal is done, or even before so that people can then become aware." [P5]*

Participants wanted accessible, evidence-based solutions to address symptoms and restore a sense of normalcy and functional control.

> *"I was experiencing, I would say debilitating [LARS] symptoms, and I wanted to try anything possible that could kind of help with that" [P14]*

Participants emphasised the need for extended, multidisciplinary care beyond the acute treatment phase, noting gaps in continuity of care after hospital discharge, advocating for a structured and supportive rehabilitation framework.

> *"I think sometimes a program [like PFR] in extended form would help you understand [LARS]."* [P2]

Theme 3: Regaining function and control through structured rehabilitation

Participants highlighted the contribution of a physiotherapist and the PFR program as central to their recovery experience. Entering the program, they had limited understanding and cautious optimism for PFR. Participation was noted to shift LARS management strategies towards more informed and intentional approaches and prompt sustainable improvements in function and QOL.

3.1 Expectations of PFR

Participants often entered the PFR program with minimal knowledge and vague expectations about its purpose. Many reported PFR had not been discussed previously. Several participants viewed PFR as a final opportunity for improvement, adopting a mindset of, *"nothing to lose." [P1].* Some managed their expectations to avoid disappointment, framing the intervention as a tool for coping rather than a cure.

> *"I don't know what I really expected other than just to learn how to cope better… my surgeon believed it would be a good study for me with the symptoms I am experiencing post-cancer." [P13]*

3.2 "Back to normal" with structured PFR

Participants reported *"dramatic improvement*" *[P3]* in their bowel symptoms, functionality, understanding of LARS, sense of control, and overall well-being as the program progressed. It did not resolve all symptoms, but participants saw it as an important step toward lessening LARS disruption in daily life and supporting their function to, *"come back to normal" [P7],* or be, *"85-90% better than it was" [P5]*. By the end of the PFR program, many participants had resumed activities they had previously avoided, including social outings and travel.

Understanding their body was regarded as key to a more sustainable, confident, and motivated way forward following PFR. Participants emphasised the value of the supervised, multimodal nature of the PFR program, incorporating functional training, biofeedback, and education to gain an understanding of their body, and provide confidence and motivation to move forward

> *"[the physiotherapist] explained a lot of things to me… and made me more realise what the problem I have and what I should do."* [P12]

3.2.1. Understanding my body

All participants highlighted pelvic floor muscle training as key to their functional bowel improvement. With tailored instructions, they gained an understanding of the connection between pelvic floor function and bowel control. The exercises improved body awareness and enabled the strengthening of muscles previously not recognised as relevant.

"Physio gave me a visual of kind of like the cradle kind of thing and like the pelvic floor and the different layers of everything. So, I understand a lot more about how it works," [P13]

Real-time biofeedback was instrumental in helping participants understand and correct their technique. Visual (ultrasound) and sensory (rectal balloon) tools, along with therapist feedback, supported cognitive-motor learning and exposed maladaptive habits participants had unknowingly developed.

“I actually saw the ultrasound and I saw what was happening when I contracted. When I did the pelvic floor exercise, I saw things happening inside of me that spoke major volumes to me.” [P5]

Alongside biofeedback, information about pelvic floor muscles and bowel function anatomy helped simplify complex concepts into understandable details, leading to a better understanding of bowel function. The combination of pelvic floor exercises and bowel retraining supported improved understanding of how diet impacts bowel symptoms. This led to more confident and consistent self-management, such as food choices and meal timing.

"We changed some things in my diet, and it made a big difference. I don’t really have dairy anymore." [P13]

3.2.2. Moving forward sustainably, with confidence and motivation

Participants noted a shift from relying on passive strategies to confidently identifying symptom triggers and using targeted techniques to improve bowel and muscle function. Many reported reduced dependence on incontinence products and medications, along with increased trust in their ability to self-manage.

> *"I feel like I was listening to my body's cues and almost retraining the muscles, to allow me to hold on for longer." [P14]*

Participants shared how addressing functional symptoms and counselling addressed concerns, reducing anxiety and daily uncertainty. The ability to anticipate and manage symptoms reduced stress and anxiety, restored confidence, and provided a sense of control. Social activities and travel became more feasible.

> *"I am today without any pull-ups on, I used to use those pants under underpants, but because I have control after the program, because I didn't have to use them… I feel confident going out now." [P2]*

As participants progressed through the PFR program, many reported *"You are motivated to keep going" [P2]* due to symptom relief, self-efficacy, and personal growth. A trusting relationship with the therapist was key in fostering motivation and adherence, encouraging ownership of their health. This motivation translated into a proactive mindset shift, with some planning long-term wellness strategies, such as continued exercise and integration of pelvic floor routines into daily life.

> *"So the next thing I am going to do is join the gym. I'll be going to start exercising more, and more pelvic exercises at the gym." [P9]*

Mapping thematic results to Symptom Management Theory and COM-B

Table 2 provides a summary of how the inductively developed themes map to Symptom-Management Theory (SMT) [23] and the Capability, Opportunity, Motivation – Behaviour (COM-B) model [24].

SMT domain or COM-B component		**1. Living with unpredictable LARS**	1.1 Disruptive, embarrassing, and isolating experiences	1.2 Understanding of LARS	*1.2.1 Expectations and realisation of living with LARS*	*1.2.2 Delayed inconsistent and absent LARS information*	1.3 Managing in the absence of understanding and guidance	**2. A desire for quality information, timely education, and individualised multi-multimodal support**	**3. Regaining function and control through structured rehabilitation**	3.1 Expectations of pelvic floor rehabilitation	3.2 " Back to normal" with structured Pelvic Floor Rehabilitation	*3.2.1 Understanding my body*	*3.2.2 Moving forward sustainably, with confidence and motivation*
Symptom experience	perception	x	x										
	evaluation	x	x	x	x		x						
	response	x					x	x					
Components of symptom management strategies		x					x	x	x				x
Outcomes		x					x		x		x		
Environment		x		x		x		x	x	x			
Person		x						x	x	x		x	
Health & Illness									x		x		
Adherence									x		x		x
Capability	physical								x		x		x
	psychological	x	x	x	x		x	x	x		x	x	x
Motivation	reflective								x		x		x

	automatic								x		x		x
Opportunity	physical	x		x		x			x	x			
	social	x		x		x			x	x			
Behaviour		x					x		x		x		

Table 2. Matrix of themes and Symptom Management Theory (SMT) and COM-B Models

Theme 1, *Living with unpredictable LARS*, reflects the symptom experience domain of SMT and psychological capability, motivation, and behaviour components of COM-B. Participants perceived and evaluated the impact of LARS on their physical, psychological, and social functions. LARS' disruption to daily routines prompted (COM-B reflective motivation) early adaptive self-management (SMT symptom experience response; COM-B behaviour). Limited understanding of LARS hindered participants' ability to recognise realistic recovery expectations (SMT symptom experience evaluation; COM-B psychological capability) and engage in rehabilitation (SMT symptom experience response).

Theme 2, *A desire for quality information, timely education, individualised multimodal support* maps to the environment domain of SMT and opportunity component of COM-B, emphasising system-level barriers to symptom management. Participants reported inadequate preparation for recovery and insufficient, inconsistent information on LARS during their formal care pathways. Lack of individualised and LARS specific education and delayed coordinated care, limited opportunity to effectively navigate development of LARS management behaviours.

Theme 3, *Regaining Function and Control Through Structured Rehabilitation,* aligns with the symptom management strategies and outcome domains of SMT. As participants progressed through PFR, they developed a proactive plan to re-establish routines and manage unpredictable bowel movements (SMT outcome). This behavioural shift (COM-B behaviour) was supported by skill

acquisition and physiological control (COM-B physical capability), education and informed, guided learning (COM-B psychological capability), and goal-setting and perceived benefits (COM-B reflective motivation). Social reinforcement from established rapport and interaction with a physiotherapist facilitates social opportunities and motivation, leading to long-term behavioural change. Throughout PFR (SMT environment; COM-B opportunity) participants described increasing motivation (SMT personal context; COM-B automatic and reflective motivation) to adopt proactive approaches to managing LARS (SMT symptom management strategies), influenced by automatic and reflective processes during program participation.

Discussion

This study examined the nuances of LARS' impact on people's daily lives and the role of PFR in managing LARS. Our findings further clarify CRC survivors' limited understanding and unrealistic expectations of LARS, and provide new insights into their psychosocial experiences and management of symptoms in the absence of professional guidance. Participants' reflections on PFR demonstrated a structured, continuous, and multidisciplinary model of care encourages behavioural changes for long-term management, supports physical and psychosocial functioning, and is well received by CRC survivors with LARS. This supports the inclusion of PFR in the clinical pathway in survivorship care.

Interpretation of key themes

Our findings align with Keane et al.'s (2020) LARS definition [4], which highlights its complexity in relation to an individual's physical and psychosocial well-being. *Living with unpredictable LARS* highlights how this long-term complication of CRC treatment substantially affects people's daily lives and challenges their psychosocial safety net [6]. As identified in this study and supported by previous research, these effects are often underestimated due to a focus on earlier phase care [5]. Our results demonstrate individuals living with LARS initially face considerable uncertainty and emotional strain trying to cope without professional support. The reactive strategies adopted reflect the underlying

anxiety and uncertainty experienced by participants, particularly the fear of social embarrassment and loss of control in unfamiliar environments, with inconsistent outcomes [36, 37].

Similar to Thomas (2019) we found lack of clinician awareness and insufficient counselling about the long-term implications of LARS were central to the psychological burden of LARS [25]. This knowledge gap leaves many survivors unprepared for their new bowel routine, with physical and psychosocial responses shaped by their subjective experiences of living with these consequences [36, 37].[24, 38] This suggests the need for supportive care that sets realistic expectations to facilitate the psychological internalisation necessary for behavioural change [8, 39].

Although the current survivorship care model promotes an integrated, need-specific, multidisciplinary approach [40, 41], participants did not experience timely and personalised support during bowel function recovery. Communication gaps and dependence on a single clinician were common, limiting access to diverse expertise and restricting participants' ability to make informed decisions about their recovery options. Findings align with existing literature indicating a lack of LARS treatment guidelines, fragmented MDT supportive care, and unmet informational needs lead to suboptimal clinical practice [27, 42-44]. Consequently, the care undermines survivors' preparedness for behavioural change, leaving them to navigate complex and chronic symptoms without evidence-based guidance.

A guided and needs-based care approach is essential for supporting behavioural adaptation in CRC survivors [45]. Results about *Regaining Function and Control Through Structured Rehabilitation* indicate a physiotherapist-led PFR program facilitates physical function and psychosocial recovery by providing education and psychological support. As per SMT [38] and COM-B [24], building physical and psychological capability alongside motivation and providing physical, social, and cultural environments with opportunity, facilitates sustainable behavioural change for adjustment and management of chronic conditions [24, 46].

Empowered Behavioural Adaptation Process Model

Our thematic results highlight the challenges faced by CRC survivors, identifying missed opportunities within the current cancer care model. Results highlight how struggles with physical symptoms and emotional burden are inseparable, and navigating everyday life requires sustainable change through psychosocial adjustment and behavioural adaptation. We propose by integrating behavioural science principles, such as expectation management, self-efficacy, and behavioural change into survivorship care, better support of cancer survivors in moving from uncertainty to confidence and from coping to thriving is possible.

The Empowered Behavioural Adaptation Process (EBAP; Figure 2) addresses the temporal and relational complexities of survivorship in the context of LARS. EBAP emphasises the process of: (1) expectation management, involving psychological preparation for active rehabilitation and rebuilding confidence by setting realistic goals and normalising variability; (2) gaining ability to manage through therapist-guided skill development and meaning-making, offering opportunities and feedback to reinterpret, reframe, and regulate symptoms into manageable experiences; (3) self-efficacy and habit consolidation, where survivors apply skills into sustainable routines through situational cues and self-monitoring; and (4) re-evaluation and relapse management for maintaining long-term adaptation and resilience.

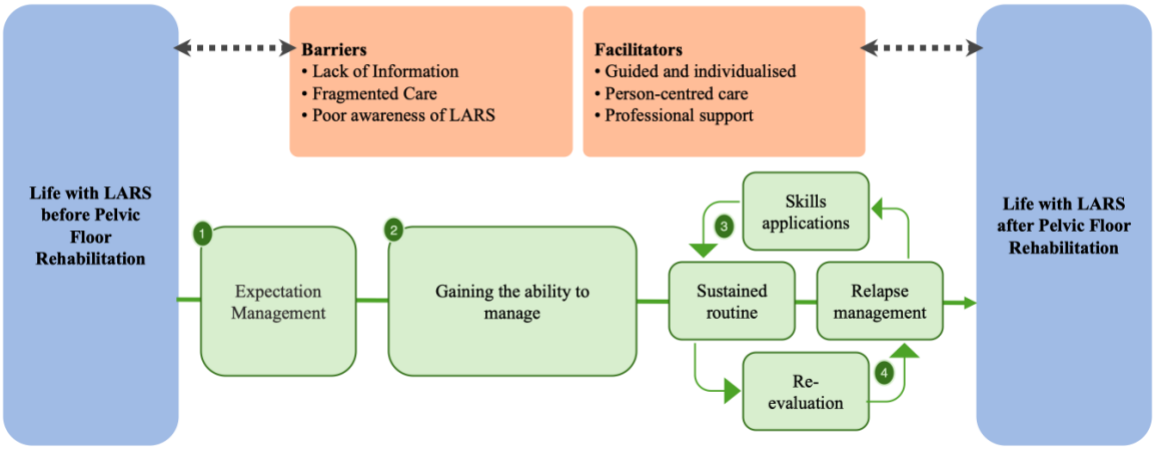

Figure 2. Empowered Behavioural Adaptation Process (EBAP) in the context of PFR for people living with LARS

Green boxes = in stage of process of adapting to live with LARS; Blue = stage of management; Orange = facilitators and barriers of management.

EBAP is grounded in behavioural science principles, integrating key constructs from SMT, COM-B, stress and coping, and self-efficacy. Inadequate information about LARS was a major barrier to functional recovery, and psychological capability and knowledge were closely linked to survivors' ability to manage their recovery journey; hence, the principle of self-efficacy and its role in self-managed recovery [47, 48]. CRC survivors face biopsychosocial challenges from LARS that strain their pre-existing internal coping resources, such as resilience, and the external factors, like limited support or inconsistent professional guidance, that undermine their confidence in resuming normal life [49-51]. The existing model of stress and coping states adaptive coping requires internal resources and external support [52], while social cognitive theory highlights self-efficacy as central to adaptation and behaviour change [53].

While the COM-B model [24] identifies capability, opportunity, and motivation as determinants for behaviour change, it does not fully capture the temporal and relational processes of recovery in survivorship with long-term functional disability. EBAP builds on COM-B by embedding these determinants within a sequential process, highlighting the role of clinician scaffolding and

demonstrating that rebuilding capacity is an ongoing process. Importantly, EBAP provides a prescriptive mechanism to foster post-traumatic growth by sequentially connecting expectation management, proactive coping, and sustained self-efficacy to positive psychological adjustment after adversity [49]. Our findings further indicate that a structured, therapist-supported, patient-centred program is more likely to facilitate a shift from a passive to a proactive mindset, enabling survivors to regain control and confidence in managing their bowel function [27, 54, 55].

EBAP acknowledges the complexity of living with LARS and outlines a process for sustainable change for QOL with LARS. This model is based on empirical data and established behavioural theories. With further testing and validation across a wider cancer population, EBAP offers a model for designing a PFR program that integrates physical recovery, and supports durable psychosocial and behavioural adaptation in CRC survivorship [56, 57].

Strengths and Limitations

This study offers insights into how LARS affects the lives of CRC survivors. It gives voice to survivors' perspectives of LARS and a structured physiotherapist-led PFR intervention and uses established theoretical frameworks to interpret how behavioural change occurs through needs-specific interventions. The experiences captured might reflect a subgroup of more motivated individuals, with clinicians more engaged in the patient's post-treatment recovery and more inclined to refer to PFR. Selection bias might be present in this sample, given their higher health literacy and greater self-advocacy in seeking medical information. Result interpretation could be influenced by their beliefs about the consequences of action and emotional responses after completing PFR, which may differ from those of individuals who have never received similar treatment or from those of people with prior PFR under different protocols and structures. Nonetheless, this bias should be considered when interpreting the findings, as the perspectives captured may differ from those of less-engaged patients. On the other hand, even among highly motivated patients, who are more likely to seek out

information and management strategies, those reporting inadequate supportive care suggest that the “average” patient is likely to face even larger gaps in care, highlighting potential unmet needs in LARS management. Additionally, these participants provided the “rich” data necessary for an in-depth exploration of symptom management and the impact of the specific PFR program used in the study, data that less engaged individuals might not have contributed.

Recruitment from a single metropolitan Australian centre may limit generalisability due to the potential under-representation of the broader population of CRC survivors experiencing LARS. Participants’ experiences might be influenced at various levels, including their demographics (e.g., health literacy, socioeconomic status, ability to access services), self-advocacy for treatment, and clinicians’ level of engagement in PFR, which can extend to health system resources. Although the findings should be interpreted within the context of a single-centre study, they offer a theoretical generalisability, meaning that the insights from SMT and COM-B behavioural framework, along with the proposed theory EBAP, can still inform clinical practice in other hospitals with similar resource constraints, clinical practices, and patient demographics. While this single-centre focus limits statistical generalisability, the consistency of our findings with broader literature [37, 39, 58] suggests that educational gaps are a widespread systemic issue. Consequently, these findings may be transferable to other hospital units with similar clinical practices and counselling protocols.

The research team’s expertise in CRC added valuable clinical context, enriching the interpretation and credibility of results and providing latent meaning and contextual grounding to ensure the theoretical sensitivity and clinical relevance of the themes. We acknowledge the potential for professional bias and assumptions of overlooking unfit data. Collaborative coding and ongoing reflexive discussion during analysis and write-up helped reduce risk of bias; nonetheless, future research could incorporate more interdisciplinary stakeholders, such as behavioural scientists and patient representatives, to enhance interpretation and challenge assumptions. One other limitation

of this study was that the survey's consistently positive phrasing could introduce acquiescence bias. The design choice was prioritised to decrease the cognitive load and prevent confusion for participants whose first language was not English. The standard reverse-code items may increase the risk of confusion among participants from culturally and linguistically diverse backgrounds, potentially leading to mistaken responses and lower data quality. To ensure the credibility of our findings, these quantitative scores were triangulated with in-depth semi-structured interviews, which provided nuanced feedback. These steps strengthen the credibility of the findings despite the methodological trade-off.

Clinical implications and future direction

Findings highlight the need for timely, specific, and consistent LARS education and counselling to support psychological readiness for functional recovery after CRC treatment, recognising the variability and chronicity of LARS. Embedding structured, physiotherapist-led PFR into interdisciplinary and coordinated survivorship care is necessary for sustainable health outcomes. A national guideline for LARS rehabilitation is needed to raise clinicians' awareness, legitimise the resource allocation and ensure equitable access to healthcare for people with LARS. Future implementation research in broader settings, including diverse socioeconomic populations across multiple centres, would further inform the design and implementation of a survivor-centred model of LARS management.

Conclusion

Our results indicate cancer survivors face physical and psychological challenges from LARS, including a loss of control and withdrawal from daily activities. Unmet informational needs, unrealistic recovery expectations, and fragmented support after CRC treatment contribute to the difficulty of living with LARS. Behaviour change and self-management theories help explain how guided, supportive care and individualised multimodal PFR support can enhance self-efficacy and support

long-term management of LARS using an empowered behavioural adaptive process. Practice, policy, and future research should investigate the implementation of interdisciplinary, multimodal LARS management approaches into survivorship care in broader settings within clinical guidelines.

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Supplementary Information

Additional documents are provided as supplementary information for this manuscript, including: 1. Low Anterior Resection Syndrome (LARS) score, study-specific satisfaction survey, interview question guide; 2. Data analysis process example diagrams; 3. Supplementary text on methodological rigour, 4. Additional quotes by subtheme, and 5. Symptom management strategies.

Supplementary 7.1 Survey and interview guide

Supplementary File 1 – Low Anterior Resection Syndrome (LARS) score, study-specific satisfaction survey, interview question guide

The survey was a study-specific satisfaction survey developed by the research team with content validated through expert review. Participants rated PFR for psychological impact, self-reported knowledge advancement, and practicality using a 4-point Likert scale. Demographic information and LARS symptom severity were collected during the feasibility project. LARS symptom severity was assessed using the validated 5-item LARS questionnaire. This document contains the Low Anterior Resection Syndrome Score questionnaire, a patient evaluation survey used to assess satisfaction with pelvic floor rehabilitation (overall, psychological impact, knowledge advancement, and practicality), and the interview guide.

Bowel Function Questionnaire (LARS)

Name: _____

Date: _____

The aim of this questionnaire is to assess your bowel function.

Please tick only **ONE** box for each question.
It may be difficult to select only one answer, as we know the symptoms may vary from day to day. We could kindly ask you to choose one answer which best describes your daily life. If you have recently had an infection or taken any medication that was affecting your bowel function, please do not take this into account and focus on answering questions to reflect your usual daily bowel function.

Do you ever have occasions when you cannot control your flatus (wind)?
□ No, never
□ Yes, less than once per week
□ Yes, at least once per week

Do you ever have any accidental leakage of liquid stool?
□ No, never
□ Yes, less than once per week
□ Yes, at least once per week

How often do you open your bowels?
□ More than 7 times per day (24 hours)
□ 4-7 times per day (24 hours)
□ 1-3 times per day (24 hours)
□ Less than once per day (24 hours)

Do you ever have to open your bowels again within one hour of the last bowel opening?
□ No, never
□ Yes, less than once per week
□ Yes, at least once per week

Do you ever have such a strong urge to open your bowels that you have to rush to the toilet?
□ No, never
□ Yes, less than once per week
□ Yes, at least once per week

Patient Evaluation Survey

Pelvic Floor Rehabilitation Program

This survey is an opportunity to provide feedback on your experience with the Pelvic Floor Rehabilitation Program associated with Concord Repatriation General Hospital. The Pelvic Floor Rehabilitation Program aims to improve bowel function after bowel cancer surgery and to assist your recovery in returning to normal activities.

You are asked to complete this survey at the conclusion of your rehabilitation program. Your feedback will help us to evaluate and to make future improvements to the service. We appreciate your participation and comments. This feedback may be given anonymously.

Instruction: Please tick the **ONE** box that is most appropriate and fill in the blanks.

1. What is your age in? _____

2. What is your gender? ϒ Male ϒ Female ϒ Intersex

3. What is your main language spoken at home? _____

4. The information given as part of the rehabilitation program was easy to understand.
   ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

5. The information given during the rehabilitation program was useful.
   ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

6. The exercise instructions made it easy to continue the exercises at home.
   ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

7. The information about healthy diet was useful.
   ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

8. The Pelvic Floor Rehabilitation Program was easy to get to.
   ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

9. The clinicians were knowledgeable and appropriately answered my questions.

   ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

10. I was given the opportunity to discuss issues that had never been discussed before with my doctors.

    ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

11. I received excellent support throughout the program?

    ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

12. This program has helped me to regain my confidence.

    ϒ Strongly agree ϒ Agree ϒ Disagree ϒ Strongly disagree

13. Overall, how would you rate your experience with the Pelvic Floor Rehabilitation at Concord Hospital?

0	1	2	3	4	5
Very poor ϒ	Poor ϒ	Average ϒ	Good ϒ	Very good ϒ	Excellent ϒ

14. How could we improve the program?

    _____

    _____

Exit interview

Pelvic Floor Rehabilitation Exit Interview Transcript

Exit interview will be conducted within 1 week after completion of the program via telephone.

Introduction:

Hello I am *[first name and last name, role]* from the University of Sydney. May I please speak to *[participant's name]*.

If speaking with the correct person: I am calling you to conduct a phone interview because you have recently completed a pelvic floor rehabilitation program of a research project with Carol Chan, physiotherapist. This exit interview is part of the study for the evaluation purpose. Is now a suitable time to talk? [If NO]: Is there another time I can call you back? [If YES]: I am interviewing you to better understand how the pelvic floor rehabilitation program may have impacted your bowel function and day to day life.

Participation in this interview is voluntary and your decision to participate, or not participate, will not affect your relationship with your doctor or ongoing care you receive. This interview will take approximately 15-20 minutes. With your permission, I would like to audio record the interview because I don't want to miss any of your comments. All information you provide will be kept confidential and only be shared with the research team members. We will ensure the information will not identify you anywhere including in any research reports. You may decline to answer any question or stop the interview at any time and for any reason. Would you have any questions before we start?

May I turn on the recorder?

Just before we begin, do you mind telling me your name.

Interview questions:

First of all, I will start with questions that are related to your bowel symptoms **before** your participation in the pelvic floor rehabilitation program

1. Why did you choose to participate in the Pelvic Floor Rehabilitation Program?
   Prompt: did your surgeon refer you to participate?

2. What did you expect from the Pelvic Floor Rehabilitation Program before you started the program?

3. How did your bowel symptoms impact your day to day life prior to starting the pelvic floor rehabilitation? *(Illness perception and symptom evaluation)*
   Prompt: How would you describe the severity of your symptoms

4. How did you manage your symptoms before you participated in the program?
   Prompt:
   - *i) Functional self-care strategies include: took exercise (describe type), took medication, increased fibre in diet, took extra fluid, took fibre supplement, changing meal times or skipping meals, avoiding certain food or changing diet or others*
   - *ii) Social activity related self-care strategies e.g. knew the location of a toilet all the time, wore protecting clothing or brought extra underwear when out of the house, wore incontinence pads, planned social events to prevent incontinence*
   - *iii) Alternative self-care strategies e.g. complementary therapies, used spirituality (religion), used trial and error*

*Now I am going to ask you a few questions **related to after** your participation in the pelvic floor rehabilitation program*

5. Did you notice any change of bowel symptoms after starting the pelvic floor program? If yes, what were the changes? *(after participant answer the first part of the question)* When did they start to change?

6. Now you have completed the Pelvic Floor Rehabilitation, can you suggest if the program has any impact on your day to day life?
   Prompt: Are you are able to do things that you couldn't do before?

7. How has it impacted your understanding of bowel symptoms?

8. How has it impacted your self- care management?

9. Was it worth the time for what has changed?

10. In your opinion, what possible changes should be made to the advice or support provided before and after your bowel cancer surgery in regards bowel function?

11. Before we finish, is there anything else you would like to tell us about your experience with this program?

Thank you very much for your time and the information you shared today.

Supplementary file 7.2 mapping diagram

Supplementary File 2

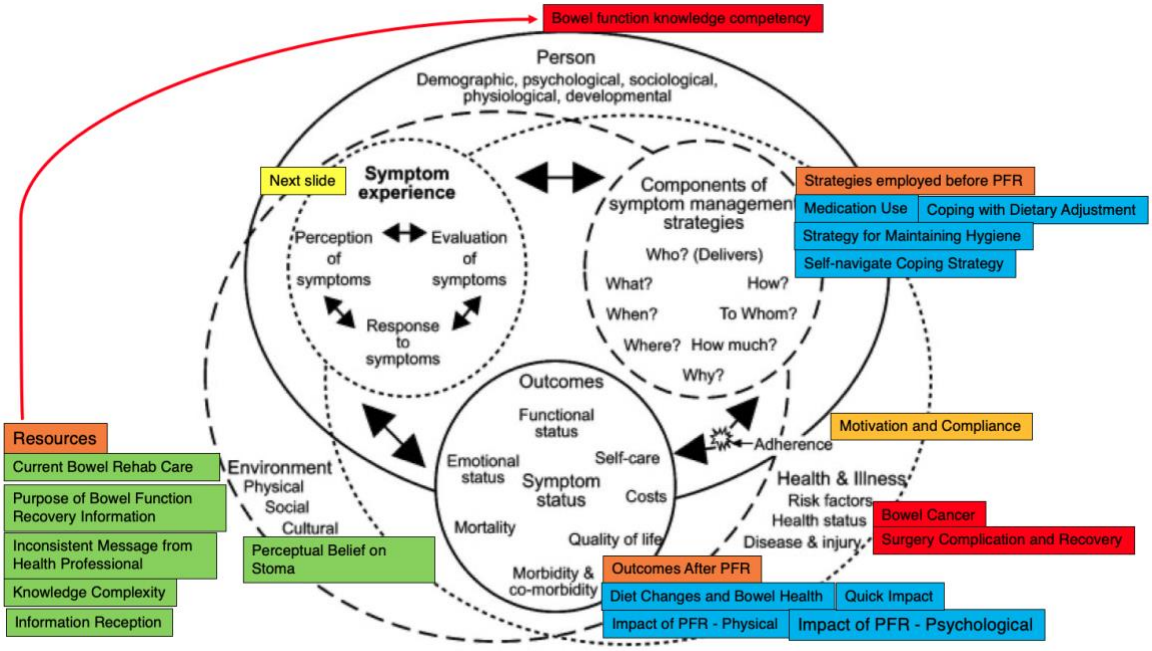


Figure 1. **Symptom Management Theory (SMT)**
Revised Symptom Management Conceptual Model adapted from Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., Lee, K., Miaskowski, C., Puntillo, K., Rankin, S., & Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing*, *33*(5), 668–676. https://doi.org/10.1046/j.1365-2648.2001.01697.x
This is an example of visualisation during data analysis using an existing model SMT overlapping the preliminary codes
The codes are coloured to map the COM-B elements-Red: Capability; Orange: Motivation; Green: Opportunity; Blue: Behaviour

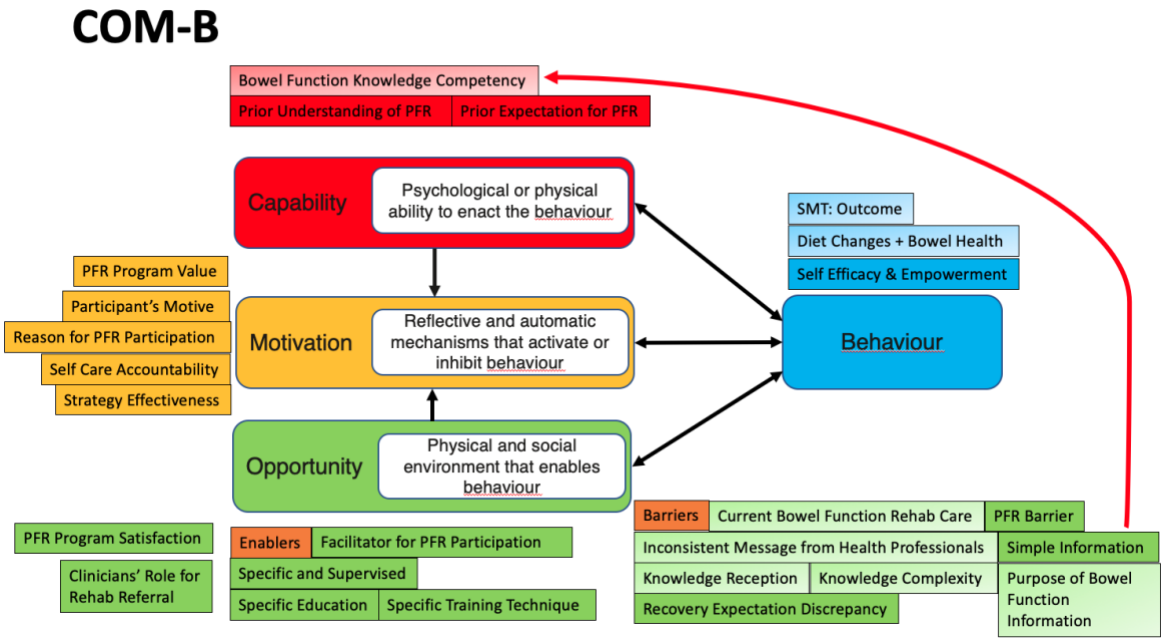
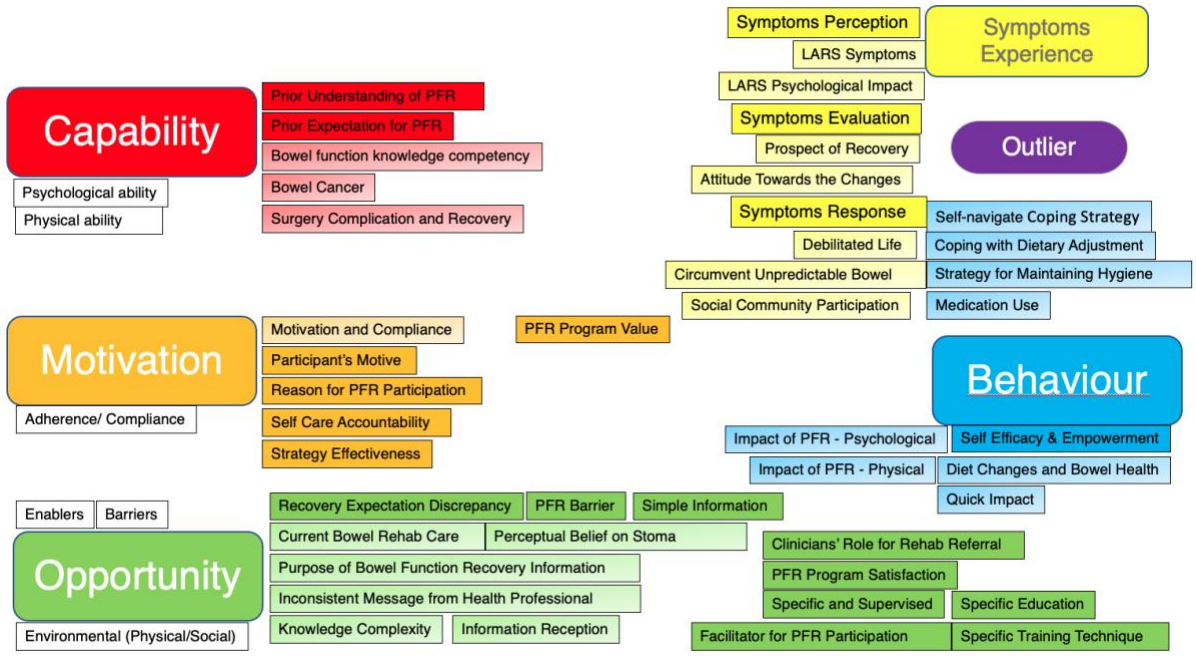


Figure 2. **COM-B Model**
The COM-B system – a framework for understanding behaviour, figure adapted from Michie, S., van Stralen, M.M. & West, R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Sci* **6**, 42 (2011). https://doi.org/10.1186/1748-5908-6-42

This is an example of visualisation during data analysis using an existing model COM-B overlapping the preliminary codes. The codes are coloured to map the COM-B elements- Red: Capability; Orange: Motivation; Green: Opportunity; Blue: Behaviour



Codes with the colour gradient have also appeared in the SMT model

Figure 3. **COM-B + SMT**

The diagram visualised the mapping of preliminary codes, combining with SMT and COM-B.

The codes are coloured to map the COM-B elements- Red: Capability; Orange: Motivation; Green: Opportunity; Blue: Behaviour; Yellow: Symptom experience (SMT)

Codes with the colour gradient have also appeared in the SMT model

Supplementary file 7.3 – Methodological rigour

Supplementary File 3 – Methodological rigour (research team and reflexivity)

Strategies were implemented to minimise potential biases, ensure methodological rigour and support research integrity. An independent researcher experienced in qualitative methods and with no involvement in the PFR intervention conducted the participant interviews. The analysts, KYC and SR, brought topic and methodological expertise respectively, to the interpretation process. Both were actively involved in data analysis, meeting regularly to review coding, interpret findings, and achieve consensus on developing themes. To ensure rigour, both authors (KYC and SR) independently reviewed the codebook and discussed the themes to reach an analytic consensus. The trustworthiness of the analysis and results was established through two types of data sources (surveys and interviews) and adherence to a guiding methodological approach and framework.

Supplementary file 7.4 – additional quotes

Supplementary File 4 – Table 1. Additional quotes by subtheme			
Theme	**Subtheme**		**Illustrative quotations**
Living with Unpredictable LARS	**Disruptive, embarrassing, and isolating experiences**		"bowel movements were quite erratic. [with] frequency was up to eight times a day" [P1] "[I was] missing the toilet many times… [and ended up] soiling my underwear." [P2] "embarrassingly enough, I had a couple of accidents… I got to the stage where I was worried about going out, and I would make sure that I was going to a place where there were toilets." [P5] "[My friends and daughter tell] me it's in my mind, you know, because first thing I [do when I get somewhere is] go in the toilet." [P6] "I would go to the shops, just to get out. And hospital visits and stuff like that. Yeah, but if you are talking about a social life, it was non-existent." [P9]
	Understanding of LARS	**Expectations and realisations of living with LARS**	"I didn't really appreciate how weak the muscles have become [since LARS]… I just thought, 'oh yes, I'm a perfectly healthy person. I've never had any trouble before. So, you know, why should I be weak [now]?" [P1] "After some 18 months, I was still having a lot of problems [with bowel function]." [P2] "Obviously with the condition that I have, [things are] never going to be 100%, [and] assuming at some stage… [I'll] probably end up having a bag permanently; as you get old, you are more likely [to be] incontinent" [P3] "They wanted me to have a stoma bag for life, and I said no… I would rather die than have that." [P9] "I have no understanding of how the bowels work" [P11]
		Delayed, inconsistent, and absent LARS information	"I certainly wasn't [given] much information about the potential for discomfort and the amount of self-care I had to do in order to basically get through every day for quite some time after surgery… it was quite dramatic." [P1] "before the surgery I didn't know any of this was going to happen. And I don't think he's worried about that. It's about fixing the problem…. I don't think you have time to go through [the bowel function] with the busy surgeon to get things… I think that's what he's more in tune with and I understand that" [P4] "I was told at the time by my oncologist it would probably take 3 to 6 months… And that we should get it back. And then hearing the majority of people don't get that, it's, it's a bit to me it's rude and I think they should say, 'all right, this is a percentage of people where it will probably start to work properly, get this larger percentage which you maybe we don't know is an age where your balance won't work properly again." [P6]

			"The information is different depending on who you talk to. It's different from the nurse or from the doctor… Everyone needs to get on the same page with everything, you know what I mean?" [P9] "He just mentioned…it takes some time for the bowel, you know, to get back to normal. But he did say that it will get back to normal." [P11] "They give me some information, but not enough… I realise[d] after surgery it's more complicated than a story [they gave me]." [P12] "I think if you told people, the extreme of it. People would be very cautious about having surgery." [P14]
	Managing in the absence of understanding and guidance		"It took quite a few months to get used to… I realised that it'll never be the same again." [P5]
			"I had those pull up underwear on most of the time, [in case] I don't make it to the loo," [P5] "I didn't do anything because I didn't know what to do." [P11]
			"Before I used to go out, if I have an appointment or anything to do in the morning. Yeah, I didn't used to have any breakfast at all." [P6] "I was taking gastro stop several times a week. Right. Maybe 3 or 4 times a week." [P14] "I tried to watch what I eat; you know, I had good days and bad days. I thought I might be alright for one or two days, but I was all over the place." [P3] "Even my activities like golf, I wouldn't be happy about going—would have to prepare myself and take pads." [P2] "[Mum] does need to change her daily routine to plan when she goes out, and she needs to make sure she feels empty with her stomach before she can go out... So basically it was just making sure [mum] had emptied her bowel" [P8] "I would make sure that I was going to a place where there were toilets," [P5] "I was experiencing, I would say debilitating [LARS] symptoms and, I wanted to try anything possible that could kind of help with that" [P14]

A desire for quality information, timely education, and individualised multimodal support	"And also I think the physio ought to be just part of the process. I don't know in the future whether [PFR] will be covered by health funds or Medicare. I suppose for some people that might be a concern, the whole post operative care package" [P1] "I suppose they had a plan, but I think sometimes a program in extended form would help you understand [about LARS]." [P2] "so preparing somebody for the [stoma] reversal would be a great help. And possibly getting them started on the program like this once the reversal is done, or even before so that people can then become aware of and show what they can do and what potentially is going to happen after the reversal and to prepare them for that." [P5] "I wish [there was] funding to continue with this program because it will help patients in a similar situation.'' [P11]		
Regaining Function and Control through Structured Rehabilitation	**Expectations of pelvic floor rehabilitation**		"I just don't anticipate…I had nothing to lose" [P1] "The surgeon [thought] that a referral to [PFR] would basically retrain my bowel with all these exercises… and will be beneficial."[P3] "I don't know what I really expected other than just to learn how to cope better… my surgeon believed it would be a good study for me with the symptoms I am experiencing post-cancer." [P13]
	"Back to normal" with structured pelvic floor rehabilitation	**Understanding my body**	"On the first couple of [sessions], there's been a dramatic improvement… the pain that was there all the time… it is nowhere near the same kind of horrible intensity that I was going on before this happened. And then eventually [the symptoms] just disappear. So, the first thing you noticed during the lifting the pelvic floor and doing those exercises that take that feeling away a lot quicker." [P3] "I understand I'm able to receive pelvic floor exercises, etc. I'm able to complete [them on] my own in my condition. Whereas before I was unable to accept [life] with[out] medication, and now having done this pelvic floor thing, I know that I can control it. I can control it completely. [Symptoms are] not completely solved everything, but I'd say it's 85-90% better than it was." [P5] "I feel it has come back to certainly not 100%, but come back to normal," [P7]
			Biofeedback and practical exercises "I actually saw the ultrasound and I saw what was happening when I contracted. When I did the pelvic floor exercise, I saw things happening inside of me that spoke major volumes to me." [P5] "But then after that, tell me how to breathe. How to do the motion. Then I found that this I... Less go to the toilet and then each time it's clear." [P7]

			"[I learnt] Not taking care of my diet affects not just my digestion, but also my pelvic floor and muscles. Physio gave me a visual of kind of like the cradle kind of thing and like the pelvic floor and the different layers of everything. So, I understand a lot more about how it works." [P13]
			Informed education “I don’t know how a layperson would be able to get through it as well as I did know. Because after, after the first or second session talking to [therapist], I gained a greater understanding of how it works. After the first session, I sort of learned about the different muscle groups and the different areas of the muscles, and it was quite enlightening.” [P1] “One thing is, [the physiotherapist] explained a lot of things to me… and made me more realise what the problem I have and what I should do.” [P12]
			Tailored information and management strategies "I recognise the things that set me off, like chocolate. Too much, and I have problems. I try to avoid them and only have a little." [P2] "I used to eat at night, around 8 or 9, but now I just eat around 5:00." [P10] "We changed something in my diet, and it made a big difference. I don’t really have dairy anymore." [P13] "I tend to stick to my safe foods when I’m outside the house." [P14]
		More sustainable, confident, and motivated ways forward	**Functional bowel control** “I don’t have to think about wearing pads], I've got a stack of pads." [P1] "I was sure, the muscles get more stronger and more firm because you've been doing those regular exercises, you know, and I'm confident that will go as time goes by." [P3] “I didn’t have to rush on it,” [P4] "Basically, [I] have stopped the tablets [immodium] completely." [P5] "Well, I used to take Movicol every day, but now I hardly use it. Sometimes, I still use it, but I would say maybe once a week." [P12] “I don’t instantly have to drop everything and run to the bathroom, I’m able to hold my bowels a lot longer… I learned to identify urgency a lot differently.” [P13] “I feel like I was listening to my body’s cues and almost retraining the muscles, to allow me to hold on for longer.” [P14]

			Confidence, comfort, and aspirations “I am today without any pull-ups on, I used to use those pants under underpants, but because I have control after the program, because I didn’t have to use them… I feel confident going out now.” [P2] “It’s a very beneficial program, and [the physiotherapist]’s very passionate about it. So that also helps you because you know that they really believe in it's going to make a difference.” [P4] “she is not feeling as anxious as before,” [P8] “Now I can do things more confidently, even plan for travelling to go to travel,” [P11] “I used to panic… I am able to go out in public and not stress so much. Mentally, I do find now knowing that I've got those exercises and those processes in my toolbox, I'm not panicking.",” [P13]
			Motivation “You are motivated to keep going” [P2] “So the next thing I am going to do is join the gym. I’ll be going to start exercising more and more, pelvic exercises at the gym.” [P9] “That exercise made me feel much better. I told [the therapist], You just led me into that program, and before long, I still needed exercise to keep getting much better—even better now.” [P12]

Supplementary file 7.5 – Symptoms management before and after pelvic floor rehabilitation (PFR)

Supplementary File 5 – Symptoms Management Before and After Pelvic Floor Rehabilitation (PFR)

Before PFR	**After PFR**
Over the counter medication such as anti-diarrheal medication	Maintain the practice of pelvic floor muscle exercises
Minimise oral intake: restrict food consumption before going out	Engage in regular functional exercises like running
Dietary adjustment: avoid certain food	Diet monitoring: balanced diet and regular meals
Pre-emptive bowel emptying	Maintain established bowel routine and toilet habit
Planned outings around toilet locations, ensure toilet facility is easily accessible	
Incontinence products such as pull-up underwear, or bring spare clothes	

Chapter 8: Colorectal cancer and work participation: A cross-sectional survey study

Overview

The previous chapters demonstrated that pre-surgery education and PFR could potentially reduce LARS severity and improve functional ability. These findings offer valuable insights into the personal, psychological, and practical aspects of living with LARS, as well as active engagement and behaviour change in rehabilitation and LARS management. They highlight the broader context of survivorship, where functional recovery intersects with social and occupational reintegration. This chapter's study aims to assess the prevalence and timing of returning to work, identify factors influencing work reintegration, and explore unmet vocational needs among cancer survivors. Collectively, these findings complement earlier chapters by situating LARS management within the continuum of survivorship challenges and contributing to the under-explored literature in this area.

This chapter has submitted to a peer-review journal and is currently under review. The manuscript is quoted verbatim and formatted according to the requirements of the journal.

Contribution of authors

I, Kin Yin Chan was responsible for study conceptualisation and design, project administration, dataset management and analysis, result interpretation, and drafting and finalising manuscript.

Michael Suen performed data analysis, and reviewed the manuscript.

Susan Coulson reviewed the manuscript

Janette Vardy developed the concept and reviewed the manuscript

Abstract

Aim: Colorectal cancer survivors often face ongoing physical symptoms that affect their well-being, quality of life, and return to work. This study examines work participation patterns among Australian colorectal survivors, focusing on personal, clinical, and work-related factors influencing their return-to-work.

Method: This cross-sectional study involved colorectal cancer survivors aged 18-65 who were employed at diagnosis and had completed primary treatments for stage I-III cancer. Participants completed a self-administered questionnaire. The primary outcome was return-to-work status, with secondary outcomes including sociodemographic, clinical, and work-related factors relevant to returning to work.

Results: Ninety-three participants completed the survey, mostly aged 51–60 years (43.5%), with 59.1% females and 60.2% rated themselves as from an Australian background. Most were married or in de facto relationships (80.6%) and over half (53.8%) cared for children aged 6–17. Most participants were well educated, with 30.1% holding postgraduate degrees. Occupationally, many were professionals (26.9%) or senior managers (22.6%). Colon cancer was most common (62.4%). Treatments included surgery (95.7%), chemotherapy (77.4%), and radiotherapy (21.5%). The majority had stage III disease (55.9%). The mean time off work after diagnosis was 6 months. Common symptoms impacting work were fatigue, bowel issues, neuropathy, and cognitive problems. Many required work adjustments, like flexible hours, reduced hours, or working from home.

Conclusion: This study explores colorectal cancer survivors' return to work, emphasising physical recovery, psychological readiness, and workplace support. It highlights the need for qualitative research to improve return-to-work policies, communication, and long-term employment sustainability.

Keywords: Colorectal Cancer; Work Participation; Survey; Readiness; Adjustment

Introduction

Colorectal cancer (CRC) ranks among the top five most commonly diagnosed cancers in Australia. The incidence of CRC has demonstrated a declining trend, while the 5-year survival rate has improved from 55% to 71% over the past two decades [1]. This improvement is attributed to early detection, advances in surgical and oncological treatments, and a coordinated model of cancer care [2]. Although CRC remains more common among the older population, a concerning rise in cases among younger people has been observed. Between 2000 and 2023, diagnoses of CRC in individuals under 40 years have tripled, particularly rectal cancer [3-5]. As diagnoses occur earlier and survival rates improve, a growing number of CRC survivors are of working age, bringing emerging survivorship issues, especially regarding work participation, that require attention within integrated cancer care and health service delivery.

Return-to-work (RTW) is a crucial aspect of cancer survivorship, offering financial stability, psychological well-being, and social integration. Work provides income and financial security that support both individuals and families [6, 7], and may help reduce financial toxicity as well as related psychological and emotional distress [8, 9]. Beyond financial needs, work serves as a form of rehabilitation, aiding in the recovery of physical and cognitive functions. This process helps restore a sense of normalcy, control, and purpose through resuming daily routines and role responsibilities for many survivors [10, 11]. The social engagement and self-identity gained through work can rebuild an individual's confidence and combat feelings of isolation and anxiety, ultimately leading to an improved quality of life [12, 13].

Fatigue, decreased physical ability, chemotherapy-induced peripheral neuropathy, cognitive impairment, sleep disturbance, pain, and fear of recurrence are symptoms frequently experienced by CRC survivors after surgery and treatment [14, 15]. Surgery-specific sequelae such as bowel dysfunction, incontinence, and stoma management issues are unique to this group. The collective

physical impairment significantly interferes with work performance and psychosocial interactions in the workplace [16]. Unresolved ongoing symptoms may impact physical and cognitive capacity to meet a demanding work role, and increase anxiety around disclosure and potential stigma. Along with the need to manage medical appointments, these factors put CRC survivors at higher risk of poor work performance, absenteeism, or premature exit from the workforce compared to the general population [17, 18].

The transition from hospital-based recovery to work reintegration is a complex process shaped by personal, clinical, and vocational factors. Survivors with lower education levels, pre-existing co-morbidities, or limited workplace supports and flexibility are less likely to return to work or sustain employment [19, 20]. At the same time, temporary work adjustments such as reduced work hours, change of work location (e.g., working from home), and modification of work duties are usually initial strategies to assist re-entry [6]. These measures are limited in duration and options, often non-individualised, and lack flexibility [10]. Insufficient workplace communication, reduced social acceptance due to poor understanding and awareness of cancer-related challenges, lack of cancer-related chronic illness policies, and legal protections for employees may inadvertently lead to poor work performance and productivity, low job satisfaction, and reduced sustainability for the individual [21]. These factors collectively contribute to poorer employment outcomes, financial strain, and reduced quality of life.

Health professionals can play an essential role in preparing survivors for RTW by assessing readiness, addressing physical limitations through symptom management strategies, and working with cancer survivors to make informed decisions to meet their needs [22]. However, in practice, there is limited structured support for RTW within survivorship care in Australia. Current models mainly focus on clinical recovery rather than functional reintegration, leaving a gap in service delivery and survivorship policies. Existing RTW research in Australia has focused on other cancer types and populations, mostly breast cancer, with limited understanding of CRC-specific challenges like bowel

dysfunction and treatment side effects. It is necessary to better understand the work experiences of CRC survivors, including their physical challenges, psychological preparedness, and adaptive behaviours for a successful RTW. Gaining these insights will inform the development of integrated survivorship models that support both functional and vocational recovery, ultimately reducing the long-term economic and psychosocial burden of cancer.

This study aims to examine the patterns of work participation among CRC survivors in Australia and identify the personal, clinical, and work-related factors associated with their return to work.

Methods

Study design

This is a cross-sectional survey study. The study design, data collection, statistical analysis and reporting were guided by the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendations and checklist to ensure transparency and completeness [23]. The Sydney Local Health District Human Research Ethics Committee—Concord Repatriation General Hospital, CRGH (2021/PID 00076) approved this study. It was conducted in accordance with the "NHMRC National Statement on Ethical Conduct in Human Research" (Commonwealth of Australia, 2007, updated 2018) and the ethical principles derived from the World Medical Association Declaration of Helsinki (Helsinki, 1964, updated 2016).

Setting and Sampling Strategy

Participants were recruited using a combination of convenience sampling at clinics and voluntary response sampling via social media, both being non-probability sampling methods. Recruitment focus was on Australian CRC survivors who had attempted to RTW after treatment. Potential participants were identified from the colorectal outpatient clinic at Concord Hospital, the Sydney

Cancer Survivorship Clinic, and the Digestive Pelvic Floor Centre, a private clinic. Recruitment also occurred via unpaid online advertisements in bowel cancer support groups on social media, websites, and newsletters, with prior permission from site administrators [24]. Ads were shared through platforms such as Facebook and X via CRC survivor organisations, including Bowel Cancer Australia, Friends of the Sydney Cancer Survivorship Centre, Bowel Cancer Fighters, CanRevive Inc., Cancer Voices South Australia, Cancer Council, Live Work Cancer, and PINC&STEEL Cancer Rehabilitation. Collaborations to promote the study were also established with research institutes such as DIRECT USYD and the University of Sydney Research Support. For participants recruited from clinic settings, medical staff could review electronic medical records only to confirm eligibility for the study, but the data analysed were all patient-reported. Interested, eligible individuals received a flyer containing study information and contact details, along with a hard copy of the study-specific survey for those attending clinics, or an accessible link via REDCap to the electronic survey, which included instructions and self-explanatory eligibility criteria. Hard copies of the survey could be mailed back or given to clinic staff, or the electronic version could be submitted online following prompts at the end of the survey. Contact details for the research team were provided for any questions. Participants demonstrated implied consent by returning their survey.

Participant eligibility

CRC survivors eligible for inclusion were those who had completed all primary and adjuvant treatments for stage I-III cancer, and were aged between 18 and 65 years at diagnosis. Participants must have been employed in the paid labour market at the time of their CRC diagnosis and possess sufficient English language skills to comprehend and complete the questionnaires independently. Individuals were excluded if they experienced difficulties understanding the questionnaires or engaging in conversation due to language barriers or cognitive impairments.

Sample size rationale

This study initially aimed to recruit 300 to 350 CRC survivors using a combination of convenience and voluntary response sampling. National epidemiological data informed the chosen sample size, based on the estimated 5,000 new cases of CRC diagnosed annually among individuals aged 20-64 in Australia in 2014 [4]. Considering 95% confidence intervals and a moderate population proportion, this range was deemed sufficient to generate a reliable descriptive estimate and to capture a diverse range of work participation experiences. However, the COVID-19 pandemic substantially affected recruitment feasibility, due to a reduction in in-person clinic visits and the suspension of clinical trial.

Questionnaire development and survey administration

The survey was specifically developed for this study to explore RTW experiences among CRC survivors. The Cancer and Work Model behavioural model approach guided its conceptual design [11], which enables a systematic analysis of sociodemographic factors, disease-related physical and psychological factors, work-related factors, functional factors, and work demands that impact the work outcomes of cancer survivors, influencing equitable access and providing an understanding of effective access to health services and support [25]. This framework informed the inclusion of individual, social, and system-level factors relevant to work participation during the cancer journey. The development of the survey is based on the Evaluative Linguistic Framework for Questionnaires (ELF-Q), which focuses on optimal comprehensibility and respondent engagement to ensure clarity and accessibility for the general public [26]. The survey underwent review by consumer representatives prior to distribution to ensure the acceptability, face validity, and relevance of the content.

The final survey is a self-administered, anonymous instrument that includes questions on demographics, occupational background, cancer history and treatment details, and work participation experiences during the cancer journey, and is estimated to take 15 minutes. Eligibility

criteria were stated in the survey instructions. Participants completed the survey at their own convenience and returned it either online or via mailed hard copy.

Outcomes & variables

The primary outcome of this study was RTW status following CRC diagnosis and treatment. RTW was self-reported and categorised as a binary variable. Other outcome measures included the following co-variates: (1) sociodemographic factors such as age, gender, ethnic background, marital status, caring responsibilities for dependents, highest education level, occupation and employment type; (2) clinical characteristics such as year of cancer diagnosis, cancer stage, tumour location, surgical details, oncological treatments, presence of a stoma, prolonged hospital stays, and cancer-related side effects; and (3) work participation experiences, including perceptions of work's meaning, RTW readiness, time lost due to treatment and recovery, leave access, the impact of side-effects on work, and RTW adaptive strategies. All variables were measured at a single time point post-treatment, when survivors were either preparing to return to work or had already returned.

Statistical methods

Data were analysed using SPSS (Version 29.0). Demographic characteristics, cancer history and related medical information, occupational background, and work participation data were reported with descriptive statistics presented as frequencies and percentages for categorical variables and means for continuous variables. Participants with missing outcome or covariate data were excluded from the relevant variable analyses. No imputation was performed due to the low proportion of missing data (<10%).

Results

Participant Demographics

Participant recruitment took place from April 2021 to May 2025. Ninety-three participants completed the survey. The majority were aged 51–60 years (43.5%) at the time of the survey. There were 55 (59.1%) females, and 56 (60.2%) were rated themselves as from an Australian background. Educational attainment was high: 30.1% held a postgraduate degree and 26.9% a bachelor's degree. Most were married or in a de facto relationship (80.6%), and over half (53.8%) reported caring responsibilities, mainly for children aged 6–17 years.

Participants worked across diverse sectors, with the most common being health care and social assistance (18.3%), education and training (12.9%), and professional/scientific/technical services (11.8%). Trained professionals (26.9%) and senior managers/executives (22.6%) represented the largest occupational groups. Most had regular daytime jobs (79.6%) and had permanent employment (63.4%), with 62.4% being the primary household income earner. Household income was typically $65,000–$80,000 per annum (67.7%). (Table 1)

Cancer History

Colon cancer was more common (62.4%) than rectal cancer (34.4%). Most underwent laparoscopic surgery (53.8%) for their bowel cancer treatment, with 40% having a stoma at some stage during their cancer journey. A permanent stoma was required in 9.7% of cases. Nearly one-third (28.0%) experienced prolonged hospital stays due to complications. Chemotherapy was received by 77.4%, and radiotherapy by 21.5%. Over half (55.9%) reported stage III disease. Almost all participants were under ongoing surveillance (93.5%). Ongoing cancer-related issues were reported by 46.2%, most commonly bowel dysfunction (n=34) and peripheral neuropathy (n=29). (Table 1)

Return-to-Work Experiences

Work was mainly valued as a source of income (84.9%), but also for societal contribution (53.8%) and career prospects (36.6%) (supp file 1). Most participants stayed in the same job after their diagnosis (79.6%). Time off work was common: 89.2% took leave for surgery and 50.5% for radio/chemotherapy (supp file 2), with a mean absence from work of 6.06 months. Sick leave (66.7%) and leave without pay (36.6%) were the most utilised entitlements.

Decisions to return were mostly self-driven: 34.4% felt physically ready, 30.1% believed they were ready, and 12.9% returned to work based on medical advice. Among those who returned (n=83), three-quarters reported they received no formal preparation (74.7%). Confidence levels on returning to work varied: 31.3% felt confident, 8.4% extremely confident, while 28.9% felt unconfident. The impact of cancer-related issues on participants' work activity was moderate in 43.4% and significant in 15.7%. (Table 2)

Workplace Challenges and Adjustments

Cancer treatment-related symptoms most impacting return to work included fatigue (62.4%), bowel issues (50.5%), peripheral neuropathy (39.8%), memory and concentration problems (39.8%), and psychological distress (37.6%) (Figure 1). Reported challenges involved maintaining concentration (57.0%), physical demands (43.0%), and needing time off for medical appointments (40.9%) (Figure 2). A substantial proportion of participants reported requiring work adjustments to facilitate their return: 36.6% adopted flexible hours, 34.4% reduced their hours, and 22.6% worked from home. Only 31.2% reported no adjustments needed (Figure 3). Most required support, mainly from family (44.1%) and employers (44.1%), although 26.9% never sought help. Notably, 73.1% lacked awareness of workplace rights after a cancer diagnosis. (Table 2)

Table 1. Demographic information, cancer history and relevant surgical and medical information

Demographics		**N (%)**
Age (at time of survey)	18-30 31-40 41-50 51-60 61-65 65 or over	2 (2.2) 17 (18.5) 21 (22.8) 40 (43.5) 5 (5.4) 7 (7.6)
Sex	Female Male	55 (59.1) 38 (40.9)
Ethnic Background	Australia North East Asia (e.g. China, Hong Kong, Korea) Europe and the former USSR South East Asia (e.g. Indonesia, Malaysia, Philippines,) Middle East and North Africa Africa (except North Africa) Oceania Aboriginal and Torres Strait Islanders Northern America Southern Asia (e.g. India, Sri Lanka)	56 (60.2) 10 (10.8) 9 (9.7) 8 (8.6) 3 (3.2) 2 (2.2) 2 (2.2) 1 (1.1) 1 (1.1) 1 (1.1)
Education Level	Secondary Education Certificate Level Advanced Diploma and Diploma Level Graduate Diploma and Graduate Certificate Level Bachelor Degree Level Postgraduate Degree Level	10 (10.8) 8 (8.6) 13 (14.0) 9 (9.7) 25 (26.9) 28 (30.1)
Marital Status	Married/De Facto Divorced Never married Separated Widowed	75 (80.6) 10 (10.8) 5 (5.4) 2 (2.2) 1 (1.1)
Caring Responsibilities to Dependents	No Yes - Children between 6-17 years - Children under the age of 6 - Other	43 (46.2) 50 (53.8) - 33 (35.5%) - 8 (8.6%) - 9 (9.7%)

Field of Work	Health Care and Social Assistance	17 (18.3)
	Education and Training	12 (12.9)
	Professional, Scientific and Technical Services	11 (11.8)
	Financial and Insurance Services	8 (8.6)
	Information Media and Telecommunications	5 (5.4)
	Arts and Recreation Services	4 (4.3)
	Construction	4 (4.3)
	Manufacturing	3 (3.2)
	Public Administration and Safety	3 (3.2)
	Transport, Postal and Warehousing	3 (3.2)
	Retail trade	2 (2.2)
	Wholesale trade	2 (2.2)
	Accommodation and Food Services	1 (1.1)
	Agriculture, Forestry, and Fishing	1 (1.1)
	Electricity, Gas, Water and Waste Services	1 (1.1)
	Rental, Hiring and Real Estate Services	1 (1.1)
	Other	15 (16.1)
Occupation	Trained professional	25 (26.9)
	Senior manager/ Executive	21 (22.6)
	Manager	10 (10.8)
	Clerical and administrative worker	6 (6.5)
	Machinery operator and driver	4 (4.3)
	Technician and trade worker	2 (2.2)
	Community and personal service worker	1 (1.1)
	Labourer	1 (1.1)
	Sales worker	1 (1.1)
	Other	22 (23.7)
Work Schedule	Regular daytime	74 (79.6)
	Shift work	6 (6.5)
	Other	13 (13.9)
Employment Type	Permanent	59 (63.4)
	Self-employed	17 (18.3)
	Casual	4 (4.3)
	Temporary	3 (3.2)
	Currently in transition, looking for a job	2 (2.2)
	Other	8 (8.6)
Main Income Earner in Household	Yes	58 (62.4)
	No	35 (37.6)
Estimated Combined Household Annual Income	$30,000-49,000	5 (5.4)
	$50,000-64,000	3 (3.2)
	$65,000-80,000	10 (10.8)
	>$80,000	63 (67.7)
	prefer not to answer	12 (12.9)
Cancer History		**N (%)**
Cancer Location	Colon	58 (62.4)
	Rectum	32 (34.4)
	Not Sure	3 (3.2)
Cancer Stage	Stage I	17 (18.2)
	Stage II	18 (19.4)
	Stage III	52 (55.9)

	Not Sure	6 (6.5)
Surgical Approach	Laparoscopic Open Robotic Not Sure	50 (53.8) 36 (38.7) 3 (3.2) 4 (4.3)
Stoma	No Yes, but reversed Yes, temporary but not reversed yet Yes, and it is permanent	56 (60.2) 26 (27.9) 2 (2.2) 9 (9.7)
Radiotherapy Treatment	No Yes	73 (78.5) 20 (21.5)
Chemotherapy Treatment	No Yes	21 (22.6) 72 (77.4)
Receiving ongoing bowel cancer surveillance	No Yes	6 (6.5) 87 (93.5)
Ongoing cancer related problems (some patients reported more than one problem)	No Yes - Bowel dysfunction - Peripheral neuropathy - Fatigue - Sexual dysfunction - Bladder dysfunction - Stoma issues - Mouth ulcers - Anxiety - Hearing loss - Chronic pain	50 (53.8) 43 (46.2) - n = 34 - n = 29 - n = 9 - n = 6 - n = 4 - n = 3 - n = 2 - n = 1 - n = 1 - n = 1

Table 2. Experience of returning-to-work

Return to Work Challenges		**N (%)**
Time taken off work for cancer treatment (months, mean)		6.06
Leave entitlement used*	Sick leave Long service leave Annual leave Unpaid personal leave Paid personal leave Leave without pay	62 (66.7) 12 (12.9) 27 (29.0) 19 (20.4) 11 (11.8) 34 (36.6)
How did you make the decision to return to work?	Doctor told me I could go back to work I think I was ready I felt physically well and ready to go back to work I had no choice but to go back to work I have not been able to return to work	12 (12.9) 28 (30.1) 32 (34.4) 12 (12.9) 9 (9.7)

Received any preparation (physical, psychological or environmental) before going back to work (n= 83)	No Yes - Discussed with my employer a return to work plan - Participation in rehabilitation class - Discussed with family - Other	62 (74,7) 21 (25.3) - n = 15 - n = 7 - n = 5 - n = 8
Confidence level when returned to work (n = 83)	Extremely unconfident Unconfident Neither confident or unconfident Confident Extremely confident	3 (3.6) 21 (25.3) 26 (31.3) 26 (31.3) 7 (8.4)
Impact of cancer-related problems to work activity (n= 83)	No impact Small impact Moderate impact Large Impact Unable to participate in work at all	8 (9.6) 24 (28.9) 36 (43.4) 13 (15.7) 2 (2.4)
Seeking help for your work-related issues during cancer journey*	Never asked for help Family support Discussed with health professionals Discussed with employers Cancer support organisation Union representatives Other	25 (26.9) 41 (44.1) 38 (40.9) 41 (44.1) 15 (16.1) 2 (2.2) 2 (2.2)
Knowledge about rights at work entitlements after a cancer diagnosis?	No Yes	68 (73.1) 25 (26.9)

*Could select more than one

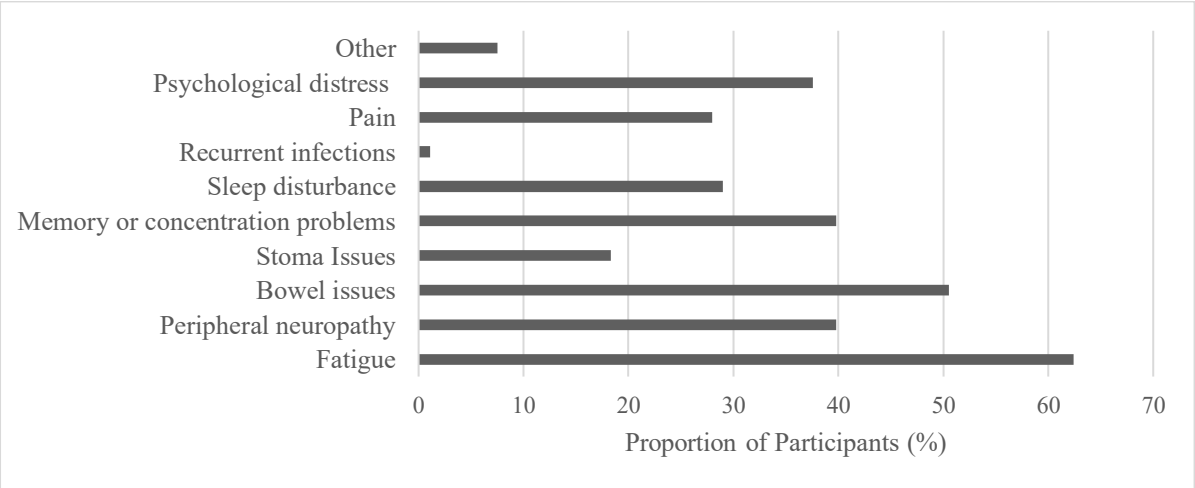


Figure 1. Cancer-related symptoms affecting return to work

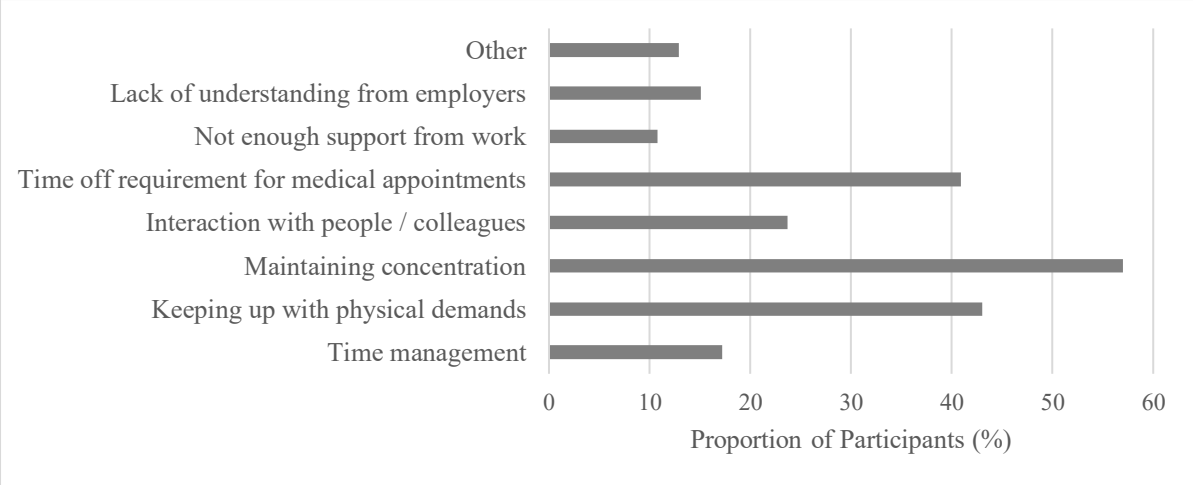


Figure 2. Challenges at work during and after cancer treatment

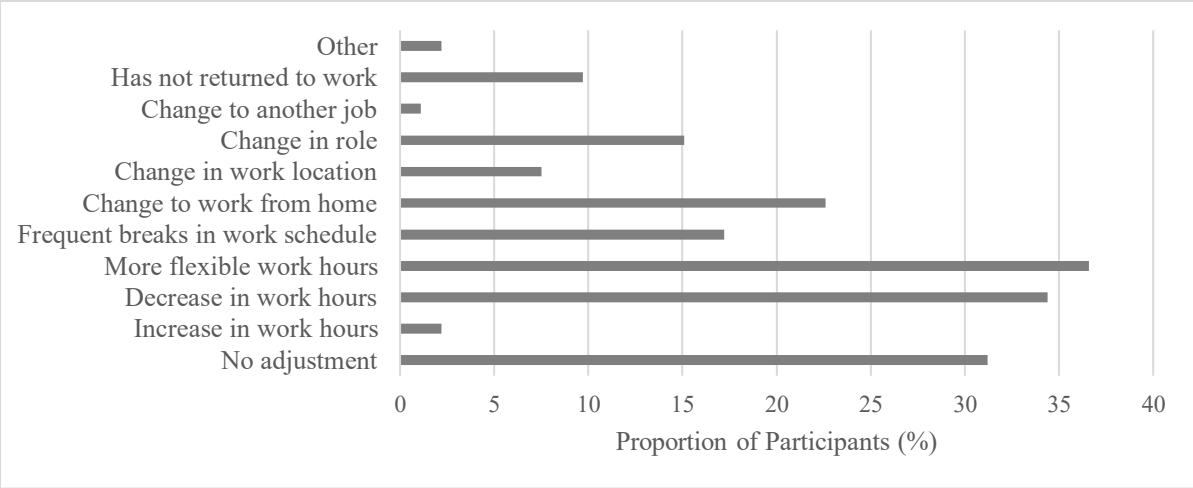


Figure 3. Adjustments made to overcome work challenges

Discussion

The observed patterns in this study offer new insights into the complex process of RTW among CRC survivors; highlighting evolving interactions between physical recovery, psychological preparedness, and the workplace environment. While most survivors resumed their pre-cancer employment, many reported reduced confidence, limited understanding, and difficulty during the transition back to work. This work-reintegration process involves both physical and psychosocial adaptation, shaped by individual capabilities, self-efficacy, and available support systems [22, 27].

Altered physical capability

Persistent treatment-related effects such as bowel dysfunction, fatigue, and chemotherapy-induced neuropathy were common challenges in maintaining employment. Fatigue emerged as the most disruptive symptom, consistent with earlier CRC survivorship studies that identified it as a key factor affecting work participation [9].

Although these late effects are well recognised, our study found that post-treatment rehabilitation services are often fragmented, with a limited RTW-focused approach. The majority of participants received no RTW preparation or support before their return. Long-term functional sequelae, such as cancer-related fatigue, may develop into chronic disabilities, especially when compounded by stigma or insufficient workplace adjustments [10]. An integrated survivorship model that explicitly incorporates occupational rehabilitation is therefore necessary.

Cancer survivors' readiness and adaptation for work reintegration during the transition

RTW readiness among CRC survivors emerged as multifactorial, comprising physical and psychological capability, emotional stability, and self-perceived competence within a social context, aligning with the biopsychosocial (BPS) model of recovery [28]. While the official work resumption is often determined based on medical clearance, it overlooks the psychosocial component and the care needs [14]. However, our findings showed survivors' decisions were primarily made from their perceived readiness, relying on self-assessment or informal advice with minimal structured guidance from health care providers. This self-navigation, through adaptive behaviour, could potentially lead to premature, delayed, or unsuccessful RTW and heighten uncertainty or mismatch expectations [29]. Our findings suggest that the absence of a structured, multidisciplinary RTW readiness

assessment perpetuates communication gaps between health care providers and survivors. Although survivors valued discussing work concerns with clinicians, employers, and family members, these conversations were inconsistent. Common current assessment tools, such as patient-reported outcome measures, capture physical outcomes and quality of life, but lack relevance to RTW readiness specific to CRC [30, 31]. Our findings highlight a communication gap between health care providers and cancer survivors. A consistent approach throughout the cancer journey is needed to guide the establishment of the RTW plan in terms of timing and capacity, and to facilitate informed decisions regarding RTW readiness and transition.

Psychological and Systemic Implications

RTW after CRC should be understood as both an employment outcome and as part of long-term survivorship rehabilitation. For many cancer survivors in our study, work participation functions as a form of rehabilitation, helping them regain control and restore a sense of normalcy, purpose and financial security [6, 32, 33]. However, without a structured, RTW-focused rehabilitation guide, survivors with low self-efficacy, limited resilience, financial strain, fear of progression, and poor health literacy [34] may experience ongoing distress, reduced work confidence, and disengagement from their professional role. This situation illustrates the intersection of financial responsibility, emotional recovery, and identity in their profession and society, where work becomes both a necessity, a coping mechanism, and a source of life's meaning.

Our findings underscore the importance of integrating medical, psychological and vocational support within survivorship care to sustain meaningful work participation. The health care providers play an essential role in facilitating the transition process through structured assessment of work readiness, symptom management, and a biopsychosocial approach to communication that supports informed decision-making. The collaboration among multidisciplinary team members is necessary to identify health-related barriers, support informed RTW decisions with a focus on biopsychosocial

communication, and deliver structured medical input for rehabilitation and work reintegration that aligns with the employer's expectations. However, it is essential to explore perceptions and expectations regarding communication about RTW when preparing for this transition, as this gap warrants further investigation.

Clinical and Research Implications

Our findings offer initial insights into areas where CRC survivors may benefit from additional support in their transition from hospital to work. At the clinical practice level, participants' reported experiences suggested gaps in structured guidance and preparedness for RTW. While causal relationships cannot be inferred, these patterns indicate potential value in exploring multidisciplinary readiness assessment that considers cancer survivors' functional ability, physical symptoms and psychological confidence, which could help identify survivors who may benefit from more tailored rehabilitation or workplace support. Health care providers could play a key role in bridging the current gap by linking physical symptoms to the RTW goal that enhances psychological resilience, self-efficacy and work reintegration, especially as survivors transition from intensive monitoring to less frequent medical surveillance.

At the workplace level, participants' accounts highlighted areas where workplace adjustments and employee-focused accommodations may support RTW, including pacing strategies and modifications that address physical and psychosocial needs. These observations are not generalisable but point to themes that warrant further investigation. This process could involve continuous review, feedback, and information sharing among cancer survivors, health care professionals, and employers.

Future research should prioritise qualitative studies exploring health care professionals' and survivors' perspectives to uncover communication barriers, clarify role boundaries, and understand decision-making processes related to RTW during transitions. These insights can inform a co-design

of structured RTW pathways and aid in developing a valid measurement tool to assess work readiness, rehabilitation progress, and long-term work participation sustainability. More rigorous, prospective studies are needed to determine whether integrating RTW planning into CRC care has measurable benefits for recovery, identity, and wellbeing.

Strengths and Limitations

The study has several strengths. It explores an under-researched area in CRC. It provided quantitative evidence on CRC impact and related employment outcomes, addressing a gap in the survivorship literature. By recruiting participants from multiple Australian states and through various community, hospital, and support group networks, the study reflected real-world variations in work transitions after treatment. The use of a study-specific, self-administered survey enabled detailed data collection on treatment side-effects, work participation challenges, and employment adaptation strategies, offering valuable insights into RTW readiness and barriers in this underserved population with unique needs.

However, several limitations should be acknowledged. The cross-sectional design captures data at a single point in time, so it cannot determine causality between treatment effects and RTW outcomes. The sample size was much smaller than planned. Recruiting through online platforms presumes a certain level of digital literacy, potentially excluding survivors with limited internet access, technological skills, or those not active on social media. Due to the open nature of recruitment (via clinics, social media, and community organisations) it was not possible to determine how many individuals viewed the study invitation; therefore, a response rate could not be calculated, and comparisons between responders and non-responders were not feasible. The use of self-reported data may introduce recall or social desirability biases, and voluntary participation could lead to self-selection bias, favouring more motivated, engaged, health-literate individuals or passionate advocates for work-related cancer survivorship issues. Non-response bias might also result in under-

or over-representing specific work participation experiences. Our sample primarily consisted of professional and managerial workers, which limits the generalisability of the findings to manual, blue-collar sectors where workers may face different challenges.

Conclusion

This investigation examined the impact of CRC and its associated side effects on work participation. Resuming work involves more than just physical recovery; it also requires psychological readiness and adaptive mechanisms, which are influenced by confidence, perceived ability, and the availability of support networks. The findings underscore the need for a structured return-to-work process that incorporates readiness assessments and effective communication strategies to facilitate informed decision-making. Future research should focus on qualitative methods aimed at understanding the perspectives of health care professional and survivors, identifying communication barriers, clarifying roles, and exploring decision-making during transition phases. These insights are vital for developing structured RTW procedures and creating measurable tools to evaluate work readiness, rehabilitation progress, and ongoing employment sustainability.

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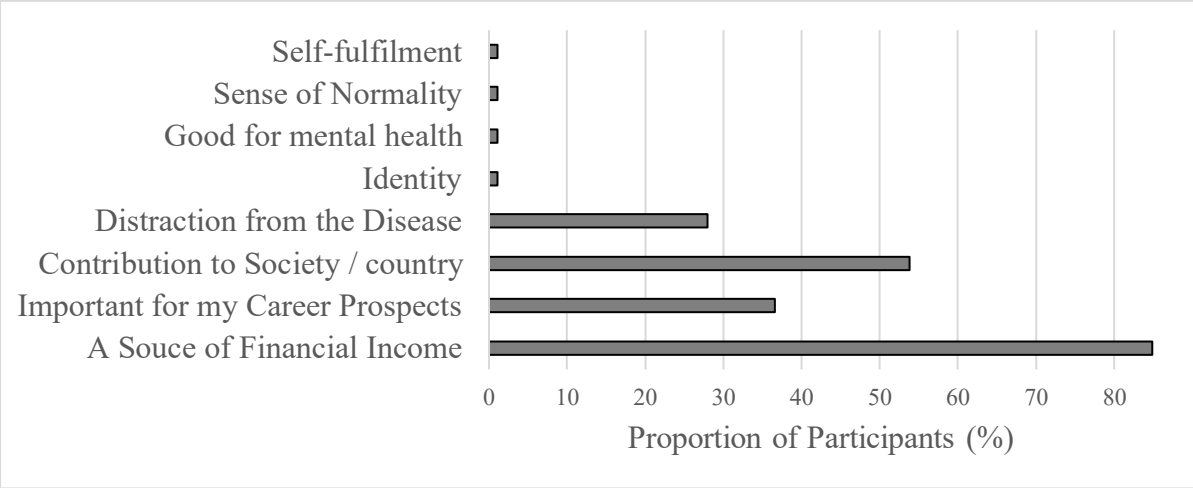
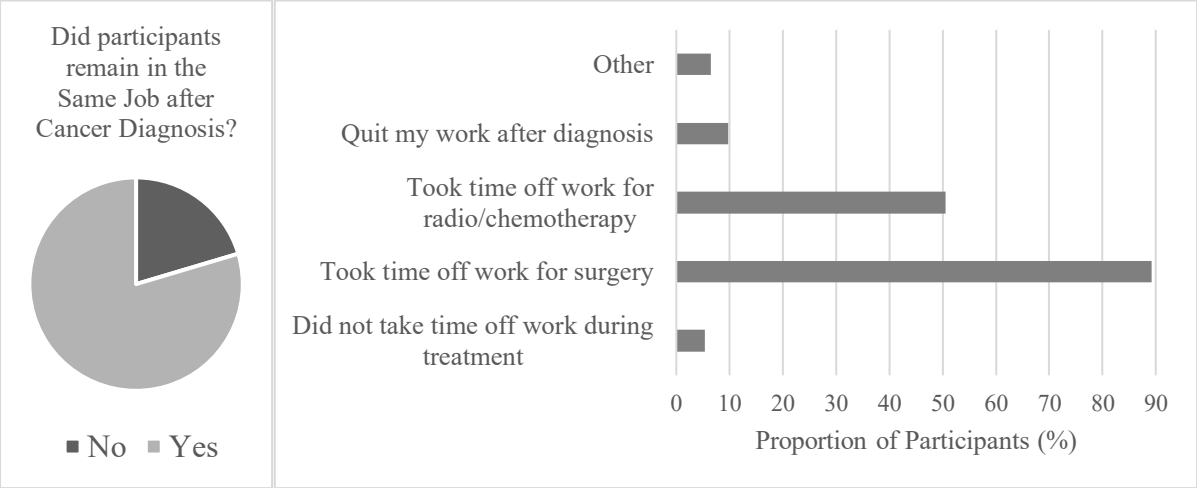
Supplementary file 8.1 additional data



Supp Figure 1. Meaning of work to participants



Supp Figure 2. Participants' work participation during cancer treatment

Supplementary file 8.2 Study survey

Bowel Cancer Survivors' Work Participation Survey

Thank you for participating in the Bowel Cancer Survivors' Work Participation Study conducted by The Sydney Cancer Survivorship Centre at Concord Hospital. The aim of this study is to examine the impact of a bowel cancer diagnosis and treatment side-effects on returning to work. Your information will help us to identify the challenges that bowel cancer survivors have, and assist health professionals to improve advice given regarding getting back to work. Your responses will be anonymous and confidential.
By completing this survey, you are giving consent for us to use your information for research and quality control purposes.
□ I agree
□ I do not agree

You are invited to participate in this survey if you:

(i) are between 18 and 65 years old,
(ii) were diagnosed with stage 1 to 3 bowel cancer within the past 5 years and have no evidence of any cancer after your surgery and other cancer treatment, and
(iii) were in the paid job market at the time of diagnosis (full-time or part-time).

This survey contains questions about you, your cancer diagnosis, work-related questions before or at the time of diagnosis, and after treatment. This survey will take about 15-20 minutes to complete. You can only take this survey once.

Please answer all questions in this survey and return by pressing the submit button at the end; or by sending the form back to the nurse who's given it to you; or by mailing it to Carol Chan at the following address 107/3 Railway Parade Burwood NSW 2134 using the supplied paid envelope. Once your survey response is submitted, you will not be able to withdraw your responses.

We appreciate your participation.

A. About you:

1. What is your **age**?

   □ 18-30 □ 31-40 □ 41-50 □ 51-60 □ 61-64 □ 65 or over

2. Please indicate your **gender**:

   □ Male □ Female □ Intersex

3. What is your ethnic background? (tick one only)

   □ Australia

   □ Aboriginal and Torres Strait Islanders

   □ Oceania (New Zealand, Fiji, Other Oceania)

   □ Europe and the former USSR (e.g. Germany, Netherlands, Greece, Italy, Malta, Spain, Yugoslavia, Poland, UK, Other Europe)

   □ Middle East and North Africa (Lebanon, Arab Republic of Egypt, Other Middle East and North Africa)

   □ South East Asia (Indonesia, Malaysia, Philippines, Other South East Asia)

   □ North East Asia (China, Hong Kong and Macau, Korea, Other North East Asia)

   □ Southern Asia (India, Sri Lanka, Other Southern Asia, Other Asia)

   □ Northern America (USA, Other Northern America)

   □ South America

   □ Africa (South Africa, Other Africa, excluding North Africa)

4. What is your highest <u>completed</u> **level of education**?

   □ Postgraduate Degree Level

   □ Graduate Diploma and Graduate Certificate Level

□ Bachelor Degree Level

□ Advanced Diploma and Diploma Level

□ Certificate Level

□ Secondary Education

□ Primary Education

□ Pre-primary Education

□ Other Education

□ None of the above

5. What is your **marital status**?

□ Never married □ Married/De Facto □ Divorced

□ Widowed □ Separated

6. Do you have **caring responsibilities** to dependent children or a family member?

□ Yes □ No

If yes, what best describes your **caring responsibilities**? Please select all that apply

□ Parent of children under the age of 6

□ Parent of children between 6-17 years

□ Carer of adult with disabilities

□ Carer of elderly parents and/or family member

□ Other

7. What is your **postcode**? □□□□

8. Which field are you currently working in? (tick one only)

□ Agriculture, Forestry, and Fishing

 Mining

 Manufacturing

 Electricity, Gas, Water and Waste Services

 Construction

 Wholesale trade

 Retail trade

 Accommodation and Food Services

 Transport, Postal and Warehousing

 Information Media and Telecommunications

 Financial and Insurance Services

 Rental, Hiring and Real Estate Services

 Professional, Scientific and Technical Services

 Public Administration and Safety

 Education and Training

 Health Care and Social Assistance

 Arts and Recreation Services

 Other, please specify:

9. What is your occupation? (tick one only)

 Senior manager/ Executive

 Manager

 Trained professional

 Technician and trade worker

□ Community and personal service worker

□ Clerical and administrative worker

□ Sales worker

□ Machinery operator and driver

□ Labourer

□ Other, please specify _____

10. What is your usual work schedule? (tick one only)

□ Regular daytime □ Shift work □ other, please describe_____

11. How many **hours do you usually work** per week? □□□

12. What type of contract do you have for your **current employment**? (tick one only)

□ Permanent □ Temporary □ Casual □ Self-employed

□ Currently in transition, looking for a job □ Other, please specify_____

13. Are you the **main income earner in your household**?

□ Yes □ No

14. What is your estimated <u>combined</u> **household income** per year?

□ <$30,000

□ $30,000-49,000

□$50,000-64,000

□ $65,000-80,000

□ >$80,000

□ prefer not to answer

Please continue for next section

B. Cancer History

1. Which **year** was your bowel cancer diagnosed? (tick one only)

   □ 2015 □ 2016 □ 2017 □ 2018

   □ 2019 □ 2020 □ 2021 □ 2022 □2023 □2024

2. Which **part** of your bowel was involved with cancer?

   □ Colon □ Rectum □ Not sure

3. What was the **stage** of cancer?

   □ Stage I □ Stage II □ Stage III □ Not sure

4. What **type of surgery** did you have?

   □ open □ key hole □ robotic □ Not sure

5. Did/ Do you have a **stoma** (bag)?

   □ No, never had a stoma

   □ Yes, I did have a stoma but it's closed now

   □ Yes, I still have a temporary stoma (not yet reversed)

   □ Yes, I have a permanent stoma

6. Did you receive **radiation therapy** as part of your bowel cancer treatment?

   □ Yes □ No

7. Did you receive **chemotherapy** as part of your bowel cancer treatment?

   □ Yes □ No

8. Did you have to stay in hospital longer than expected due to **complications**?

   □ Yes □ No

9. Do you currently see a doctor for monitoring and surveillance of your bowel cancer?

□ Yes □ No

10. Do you still have cancer-related problems?

□ Yes □ No

11. Please describe the cancer-related side effects that you still have.

_____

_____

_____

Please continue for next section

C. Employment and Bowel Cancer Journey:

1. What does work mean to you? (tick all that apply)

   □ It is a source of financial income

   □ It is important for my career prospects

   □ It is a contribution to society/ country

   □ It is a distraction from the disease

   □ Other, please explain _____

2. How long had you worked with your employer at the time of your cancer diagnosis?

   □ _____ weeks □ _____ months □ _____ years

3. Did you remain in the same job after your cancer diagnosis and treatment?

   □ Yes (Go to Q5) □ No (Go to Q4)

4. What is the reason for the job change?

   □ I was not fit for returning to previous job after cancer diagnosis and treatment

   □ I had quit the previous job at the time of cancer diagnosis

   □ Other reason that was not related to my cancer diagnosis and treatment

5. Which of the following describes your work participation during the cancer journey?

   (tick all that apply)

   □ I did not take any time off work after diagnosis or during treatment

   □ I took time off work for surgery

   □ I took time off work for radiation therapy and/or chemotherapy

   □ I quit my previous work as soon as I found out I had bowel cancer

   □ Other, please describe _____

6. How much time **in total** did you take **off** from work for your cancer treatment?

   □ _____ days □ _____ weeks □ _____ months

7. Which leave entitlement(s) did you access for your leave? (Tick all that apply)

   □ Sick leave □ Long service leave □ Annual leave

   □ Unpaid personal leave □ Paid personal leave □ Leave without pay

8. How did you make the decision of **when** to return to work?

   □ My doctor told me I could go back to work

   □ I think I was ready

   □ I felt well physically and ready to go back to work

   □ I had no choice but needed to go back to work

   □ I have not been able to return to work (go to Q12)

9. Did you have any preparation of any kind including physical, psychological and/or environmental before going back to work?

   □ Yes (go to Q10) □ No (go to Q11)

10. If yes, how did you prepare yourself for getting back to work? (tick all that apply)

    □ Discussed with my employer a return to work plan

    □ Participated in rehabilitation classes to build up my strength

    □ Discussed with my family coordinating between work and family

    □ Other, please describe _____

11. How confident were you when you got back to work?

    □ Extremely unconfident □ Unconfident

    □ Neither confident or unconfident □ Confident □ Extremely confident

12. On returning to work during or after treatment (include surgery, radiation therapy and/or chemotherapy), how much did the cancer-related problems **impact** your work activity?

□ No impact □ Small Impact □ Moderate Impact

□ Large Impact □ Unable to participate in work at all

13. What <u>cancer-related symptoms</u> have impacted on your work or your ability to go back to work? (tick all that apply)

□ Fatigue

□ Chemotherapy-induced peripheral neuropathy (tingling sensation or numbness in fingers and/or feet)

□ Bowel issues

□ Stoma issues

□ Memory or concentration problems

□ Sleep disturbance

□ Recurrent infections

□ Pain

□ Physical difficulties due to surgery e.g. muscle problem

□ Psychological distress (feeling uncertain or unpredictable)

□ Other, please describe _____

14. What are/were the challenges at work during/ after your cancer journey? (tick all that apply)

□ Time management

□ Keeping up with the physical demands at work

□ Maintaining a high level of concentration at work or keeping my mind on work

□ Having to interact with colleagues or other people constantly

□ Having to take time off work to attend medical appointments

□ Not having enough support from my employer and/or colleagues

□ Employer and/or colleagues did not understand my difficulties due to the cancer and/or treatment side-effects

□ Others, please describe _____

15. What **adjustment** do/did you make to your work in overcoming the challenges? (tick all that apply)

□ No adjustment

□ Change in work hours

□ Increase □ Decrease

□ Change in work schedule

□ more flexible hours □ no shift work

□ frequent breaks □ No change

□ Change in work location/ environment

□ working from home □ workspace

□ Change in role

□ Changed to another job

□ Other, please describe _____

16. Where did you **seek help** for your work-related issues during your cancer journey?

    (tick all that apply)

    □ I never asked for any help

    □ Family support and/or friends

    □ Discussed with health professionals

    □ Discussed with employer

    □ Cancer support organisation

    □ Support from union representative

    □ Other, please describe _____

17. Do you know what **rights** at work you are entitled to after a cancer diagnosis?

    □ Yes □ No

Please continue to the next page

If any of these questions raised issues of concern or distress, please contact Beyond Blue on 1300 22 4636 or Lifeline on 13 11 14 for assistance. This is the end of the survey. Thank you for your participation.

We are also looking for volunteers to participate in an interview on returning to work after cancer to obtain some more detailed information. If you would like to share your experience and participate in the interview, please contact us on the number 1800 778 167 or via email kcha7376@uni.sydney.edu.au

Bowel cancer survivors' work participation survey

What are the barriers and challenges that bowel cancer survivors face when they go back to work?

Help us understand how to improve future bowel cancer management and rehabilitation

Complete a 15-20 minute anonymous survey

We need you if:
1. you are 18-65 years old
2. you were diagnosed with stage 1 to 3 bowel cancer within the last 5 years and have no evidence of any cancer after surgery and treatment
3. you were in the paid job market at the time of diagnosis

How to complete the survey?
Go to XXX or
Scan QR code

Concord Cancer Centre
Concord Repatriation General Hospital

THE UNIVERSITY OF SYDNEY

Carol Chan - Pelvic Floor Physiotherapist
Dr. Michael Suen - Colorectal Surgeon
Sonia Khatri - Colorectal Cancer Nurse
Professor Janette Vardy - Professor of Cancer Medicine
For further information: kcha7376@uni.sydney.edu.au

Chapter 9: Discussion

Overview and aims

Colorectal cancer (CRC) is the fourth most commonly diagnosed cancer in Australia. With advances in surgical techniques and oncological treatments, and early detection and surveillance, the survival rate for CRC has increased by 15% over the past decade. More people are now living in survivorship [1]. Therefore, a paradigm shift in colorectal care is needed, moving from a mainly curative focus to one that also considers long-term functional health outcomes, especially for CRC survivors who face ongoing sequelae of treatment. Bowel dysfunction, known as low anterior resection syndrome (LARS) is common after sphincter-preserving anterior resection surgery for distal CRC. Reported symptoms include unpredictable and variable bowel habits and stool consistency, bowel frequency, urgency, faecal incontinence, and difficulty with bowel emptying [2]. Although the severity of these symptoms varies from moderate to severe among individuals, they can disrupt normal physical function and psychosocial well-being. LARS, along with other debilitating treatment side effects such as chemotherapy-induced peripheral neuropathy and fatigue, constitutes an invisible disability that can make it difficult for affected cancer survivors to fully participate in their community and in society in general. [3].

The overarching questions of this research are to examine how functional recovery and rehabilitation for LARS can be optimised, and how can supportive care for people with CRC be strengthened to improve survivorship outcomes across the cancer journey?

The issue of LARS is under-addressed within Australian clinical practice, and local supporting research evidence is limited. At the system level, there is currently no standardised or consistent screening for LARS in survivorship. The clinical pathway for recovering bowel function is absent.

Structured LARS rehabilitation services are either unavailable or inconsistently provided. Access to ongoing supportive care, provided by various healthcare disciplines, is fragmented across different healthcare settings. This results in unequal service availability and a lack of care continuity. From the patient perspective, education and counselling about bowel function are often disorganised, leaving patients unprepared for the chronic and complex effects of LARS. These impacts extend beyond physical symptoms to affect psychological health, social participation, quality of life, and, in particular, the ability to return to work, which is crucial for regaining normal life. Overall, these issues emphasise the need for a coordinated approach from diagnosis to survivorship in CRC care. To address unmet needs, developing a clinical framework that emphasises a patient-centred, multimodal approach throughout the CRC journey is crucial. An ideal coordinated CRC pathway can be conceptualised as a continuous process of care from diagnosis to survivorship, including several key components. Early identification of patients at higher risk of severe LARS is important for pre-operative education and counselling. Screening for bowel dysfunction using validated tools such as the LARS score is recommended as part of standard care during postoperative follow-up, ideally at multiple time points throughout the first year (e.g., 1, 3, 6 and 12 months) and periodically during survivorship care. Follow-up may involve a combination of in-person consultations, phone follow-ups, and structured patient education resources. Multidisciplinary involvement is crucial across all stages of cancer surgery and may include colorectal surgeons, specialist nurses (colorectal, oncology, survivorship), and allied health professionals like physiotherapists, dietitians, and psychosocial support services. In such a pathway, conservative interventions such as dietary advice, lifestyle modifications, medication optimisation, pelvic floor prehabilitation, and rehabilitation can be gradually introduced based on symptom severity, with referral to specialised services when symptoms persist or survivorship issues affecting life after cancer. There is also an urgent need to identify practical, effective interventions and support systems for this patient group within Australia's limited healthcare resources.

This research addressed these gaps through a mixed-methods approach with a series of interconnected studies. This body of work examines the burden of LARS and opportunities for intervention, using a biopsychosocial approach and increases our understanding of functional recovery and quality of life impacts, by investigating the lived experiences of individuals. This approach filled the gap caused by the absence of an integrated supportive care pathway for CRC patients. The findings were organised around several key themes that met the following objectives.

Objectives:

- To assess the prevalence of LARS in an Australian metropolitan cancer centre. (Chapter 2)
- To develop and evaluate the feasibility and readiness of pre-surgery video-based education aimed at improving patient preparedness, supportive care, and supporting bowel function recovery. (Chapter 3)
- To systematically review existing evidence on pelvic floor rehabilitation (PFR) for patients with bowel symptoms following anterior resection. (Chapter 4)
- To describe the protocol of the structured physiotherapist-led pelvic floor rehabilitation program (Chapter 5)
- To assess the feasibility and efficacy of a structured physiotherapist-led pelvic floor rehabilitation program on bowel function and quality of life. (Chapter 6)
- To explore the experiences of individuals living with LARS and their perceptions of PFR. (Chapter 7)
- To examine return-to-work challenges among CRC survivors. (Chapter 8)

Integrated thematic findings and interpretations

Throughout all the studies in this thesis, several key themes emerged that demonstrate the significant impact of LARS on the physical, psychological, and social aspects of survivorship. The findings highlighted that a multimodal, structured approach to supportive care and rehabilitation

implemented within a clinical pathway using a behaviour change model is feasible and can optimise functional recovery, quality of life, and overall survivorship. These themes include:

1. LARS burden, survivors' lived experience and unmet needs
2. Multimodal structured approach: a feasible intervention in colorectal cancer
3. Promote self-efficacy through behaviour change
4. Broader survivorship

LARS burden, survivors' lived experience and unmet needs

Findings

This thesis reveals that LARS is common, and the persistent bowel symptoms after anterior resection are a debilitating effect on survivors' daily lives. They often experience unmet needs for symptom recognition, information, and structured guidance for recovery. In our long-term, prospective, observational study (Chapter 2), one-third (32.8%) of survivors experienced LARS (both minor and major) after anterior resection at our baseline questionnaire (a mean of 16.8 months since restoration of bowel continuity). Co-existing bladder and sexual dysfunction were also reported by 31% and 24%, respectively. Patients with major LARS were 4.5 times more likely to have sexual dysfunction compared to those without LARS. Current smoking and a low anastomotic resection height were linked to higher odds of severe LARS. Symptoms continued to improve naturally after 12 months post-surgery, but the rate of change in LARS scores was slow (improved by an average of 2.3 points over 12-months). While the LARS score offers quantitative data on severity, the nuanced impact of LARS was explored in a qualitative study in Chapter 7. Cancer survivors described their experiences of LARS as disruptive, embarrassing, and isolating, severely affecting their psychosocial well-being. Their understanding of LARS varied due to delayed and inconsistent information before and after surgery and treatment. In the absence of knowledge and guidance, survivors adopted passive coping strategies, desperately trying to regain control of their lives. This highlights the

importance of professionally guided rehabilitation and management. The findings from these two studies demonstrate the extensive impact on both the physical and psychosocial aspects of CRC survivorship and expose unmet needs in this area.

Interpretation

Chapters 2 & 7 discuss the prevalence of LARS and its clinical implications in colorectal cancer care. LARS is common and often interplays with bladder and sexual dysfunction, which are burdensome sequelae following anterior resection for CRC. Its impact on survivors' quality of life is multifaceted, involving both physical dysfunction and psychosocial disruption. Many survivors in our qualitative study reported feeling unprepared for recovery, with insufficient and inconsistent information on LARS, and the currently existing fragmented care, serving as a major barrier to setting realistic expectations and engaging in rehabilitation. In line with international studies [4, 5], our findings contribute to the global evidence, showing a high prevalence of LARS, especially among rectal cancer patients. Spontaneous recovery of LARS typically happens within 6-12 months [6], and our prospective data from an Australian cohort indicates that improvement tends to stabilise after 18-24 months. Importantly, we found that symptom improvement is often minimal and may not be clinically meaningful [7]. Therefore, our data suggest that the optimal timing for intervention is after spontaneous recovery has plateaued. Smoking was identified as a modifiable risk factor for LARS, probably due to microvascular damage and delayed tissue healing [8]. This highlights the importance of including smoking cessation advice and LARS education in preoperative counselling and prehabilitation to improve bowel function outcomes, especially for those with higher risks of developing LARS [9, 10]. These findings emphasise the need to incorporate LARS supportive care and rehabilitation services into the overall CRC treatment pathway. Routine LARS screening after surgery and treatment, along with timely and structured interventions embedded within cancer care, will assist survivors in adopting appropriate strategies to support functional recovery and lessen the psychosocial impact of chronic and invisible disability. The following section summarises the findings

regarding the potential of preoperative video-based education and pelvic floor rehabilitation, as well as their integration into the colorectal cancer care pathway.

Multimodal structured approach: a feasible intervention in colorectal cancer care

Findings

A structured approach to bowel function recovery, integrating video-based education, multimodal pelvic floor rehabilitation (PFR), and clinician-guided supportive care, has shown potential effectiveness and acceptability, warranting consideration as routine care or integration into the survivorship clinical pathway. In Chapter 3, we assessed a video-based education program designed to meet the informational and psychological needs identified in Chapter 7 for preparation before surgery. Our study showed it was feasible and acceptable. Self-paced individual learning, delivered outside a clinical setting, can improve knowledge and skill acquisition, a prerequisite for LARS recovery. Survivors demonstrated high levels of psychological capabilities, which help them increase their preparedness for behaviour change later in the recovery. In our systematic review (Chapter 4), PFR shows promise in reducing symptoms such as increased bowel frequency and faecal incontinence. However, variability across trials, including different protocols and outcome measures, limits confidence in developing targeted LARS management programs. Therefore, we tested our structured physiotherapist-led PFR using validated outcome measures, which was feasible and the findings suggested clinically meaningful improvements in LARS, with sustained benefits demonstrated in Chapter 6. The multimodal rehabilitation program was specifically tailored for individuals with LARS to engage in for at least six months post-surgery, a period when symptom improvement tends to stabilise, using a LARS score and objective measures to monitor changes over the rehabilitation period. The program focused on education and specific functional training to equip cancer survivors with the knowledge and skills necessary to manage long-term bowel changes (Chapter 5). Overall, a structured, needs-based, and physically and psychosocially informed

intervention delivered under professional guidance via a clear clinical pathway is feasible, and it is crucial for achieving long-term improvements through behavioural change.

Interpretation

The two feasibility studies on interventions have significantly contributed to the current, underexplored literature: video-based education before surgery and the positioning of PFR within optimised conservative management (OCM) for LARS.

First, the feasibility study on clinician-created content emphasises that the timing and amount of reliable information are crucial for engaging patients and building confidence, in contrast to prior research focusing on education after surgery [11-14]. An interesting finding was the minimal impact on anxiety and early behaviour change indicators, suggesting these are influenced by factors beyond bowel and physical function. This highlights the importance of ongoing educational support throughout postoperative recovery to reinforce desired behaviours when survivors experience symptoms.

Second, PFR demonstrates its feasibility and potential efficacy within the LARS optimised conservative management framework and standard CRC survivorship care. Effective LARS management requires a structured, multimodal, stepwise approach [15, 16]. Despite growing recognition of LARS [2, 17] and emerging evidence supporting PFR[18-22], a standardised rehabilitation pathway covering the full range of conservative options has yet to be established [7]. A clear referral pathway and protocol for LARS are necessary, as multidisciplinary team care remains underutilised. Currently, there is no formal rehabilitation model for CRC survivors with LARS in Australia [23]. Our study thus lays the groundwork for future research on implementing PFR and evaluating its effectiveness in the care of CRC survivors.

The feasibility is a key step between clinical trial evidence and widespread implementation. Our work demonstrates that video-based education and PFR can be integrated into existing services, bridging efficacy and real-world practice. Survivors' acceptance further supports the importance of these programs, reinforcing the case for routine use on a broader scale. However, a large-scale study should examine implementation across diverse settings to support wider uptake if proven effective. The following section highlights the effectiveness of a structured multimodal approach through lived experience, adding depth to the quantitative findings on how change occurred.

LARS interventions promote self-efficacy in colorectal cancer care

Findings

Lived experience provides insights to inform patient-centred care. The effective care model for LARS should be multimodal, incorporating a behavioural approach, to ensure sustainable changes that lead to real-world outcome improvements. The survivors' voice in Chapter 7 highlights that a structured, multimodal rehabilitation service and supportive care benefited physical and psychosocial functioning, using a clinician-guided approach for bowel function recovery. The PFR supports the development of proactive LARS management strategies, builds self-efficacy, and promotes sustainable improvements in functional and psychosocial aspects [24-26].

The thematic results guided the development of the Empowered Behavioural Adaptation Process (EBAP), a behaviour change model achieved through a physiotherapist-led rehabilitation program. This adaptation process addresses the temporal and relational complexities faced by survivors in the context of LARS. It consists of four progressive stages: (1) expectation adjustment, which involves psychological preparation for active rehabilitation and rebuilding confidence by setting realistic goals and normalising variability; (2) gaining the ability to manage through therapist-guided skill development and meaning-making, offering opportunities and feedback to reinterpret, reframe, and

regulate symptoms into manageable experiences; (3) self-efficacy and habit consolidation, where survivors apply skills into sustained routines through situational cues and self-monitoring; and (4) long-term adaptation and resilience, maintained through re-evaluation and relapse management.

Interpretation

Behaviour change emerged as a central mechanism for recovery, rather than merely a secondary outcome of rehabilitation. Our model is grounded in behavioural science principles and integrates key constructs from SMT, COM-B, and other psychological and behavioural change frameworks [26-29]. Survivors benefited not only from physical training but also from guided processes that reframed symptoms, built confidence, and established new routines. The EBAP advances understanding by offering a conceptualised model for how behaviour change occurs in colorectal cancer survivorship, directly linking to theories of self-management and behaviour change. This model contributes to existing literature and informs the development of practical guides and tailored interventions, while also providing a platform for future research to evaluate its applicability across diverse cancer populations.

Broader survivorship

Findings

Chapter 8 examined the work participation patterns among colorectal cancer survivors. This study provides new insights into the complex process of return-to-work (RTW), highlighting the evolving interplay between physical recovery, psychological preparedness, and the workplace environment. Fatigue, bowel dysfunction, neuropathy, and cognitive impairment are commonly reported symptoms and challenges affecting work performance. While most survivors resumed their pre-cancer employment, many reported reduced confidence, limited understanding, and feeling under-prepared during the transition back to work.

Interpretation

Return to work is considered a crucial outcome of survivorship. This study emphasises the complexity of survivorship, showing that recovery involves not only symptom reduction but also rebuilding a professional identity and re-engaging socially. Our findings suggest that survivors base their decision to return on their perceived readiness, relying on self-assessment or informal advice, with little structured guidance from healthcare providers. This readiness assessment typically encompasses physical, psychological, and emotional factors, as well as self-perceived competence within the social context, aligning with the biopsychosocial model of recovery [30]. The self-negotiated return-to-work process may increase uncertainty or create mismatched expectations without a structured multidisciplinary team (MDT) assessment, revealing communication gaps between healthcare professionals and survivors. Our results underscore the importance of effective communication and timely information sharing to facilitate informed decisions regarding return-to-work readiness and transition. Future research should explore the perspectives of both healthcare providers and survivors to identify communication barriers, clarify role boundaries, and co-design structured return-to-work pathways. Additionally, developing validated tools for assessing readiness and monitoring rehabilitation progress will be essential for promoting sustainable long-term work participation.

Integrative synthesis

The synthesis of findings across these four emerging themes underscores the disruptive impact of LARS on the physical, psychological, and social well-being of colorectal cancer survivors. By triangulating the prevalence figures with the quantitative data from observational and intervention feasibility studies, as well as survivors' lived experiences, this thesis advances the field from isolated symptom descriptions towards a practical care model that covers the entire colorectal cancer

continuum. This methodological convergence lends credibility and robustness of the evidence, demonstrating consistent patterns across different data sources and study designs.

The integrated findings support the need for routine screening and the implementation of a structured, multimodal care approach using the biopsychosocial framework within the current clinical pathway to address unmet needs in LARS recovery. This thesis also extends the literature by highlighting the underexplored connections between bowel dysfunction, cancer-related side effects, and broader survival outcomes, such as return-to-work challenges. The proposed behavioural change model, Empowered Behavioural Adaptation Process, presents a novel approach to understanding and facilitating behaviour change in LARS management. This signifies a significant conceptual contribution to the field of colorectal cancer rehabilitation research.

By articulating these perspectives, this thesis clarifies research priorities for large-scale implementation research and positions an integrative, behaviourally informed approach to survivorship care as a promising pathway to optimise conservative management of LARS and meet remaining unmet needs.

Strengths & limitations

This mixed-methods thesis investigated LARS from epidemiological, clinical, behavioural, and survivorship perspectives for people with colorectal cancer. Reflecting on the strengths and limitations of this approach clarifies confidence in the evidence and how it can be applied to clinical practice and future research.

Strengths

A key strength of this thesis is its use of a sequential, triangulated mixed-methods design that adopts a patient-focused approach to a common yet under-addressed issue in colorectal cancer survivorship. It combines observational data, feasibility testing, and in-depth narratives from survivors, allowing the thesis to move beyond isolated symptom measurement to a more holistic understanding of real-world patients living with the experience, their potential for functional recovery, and psychosocial consequences. The quantitative findings established scope and patterns, while qualitative data complemented the findings by explaining why and how these patterns affect quality of life and behavioural engagement in rehabilitation.

Another strength of this work is its credibility and validity. The outcomes were assessed using various tools specific to the functional outcomes related to LARS and survivorship. Validated assessment tools were employed to examine the prevalence of LARS and the efficacy of PFR, ensuring comparability with existing literature. A clinical assessment tool was also used to provide objective evidence supporting the findings, parallel with the validated patient-reported outcome measures, to ensure the validity of the results. Additionally, we developed the theory-guided, study-specific survey to address cancer survivorship issues, allowing for a direct examination of these concerns. We also appreciated the prospective nature of data collection, the self-administration of the study, and the involvement of an independent researcher conducting interviews and reflexive analysis in the qualitative research, which minimised potential recall and researcher biases.

An additional and distinctive strength of this research is its conceptual contribution to understanding LARS. The qualitative study employs the established theoretical frameworks to interpret how behaviour change occurs through need-specific interventions. This theoretical foundation ensures internal validity and interpretability. The survivors' voices provide valuable qualitative insights into behaviour change, expectations, and unmet needs that clinicians and policymakers might overlook.

Existing frameworks rarely address the behavioural processes underpinning adaptation to bowel dysfunction. Through the development of the Empowered Behavioural Adaptation Process, this synthesis combines behavioural theory with physiotherapist-led rehabilitation and survivors' lived experiences. More importantly, the model offers a new way of conceptualising conservative management for LARS and addresses a gap in current survivorship and rehabilitation frameworks.

Overall, this body of work provides a unique integration across the colorectal cancer survivorship pathway. This breadth and depth are not reflected in current studies, positioning this thesis as one of the first to investigate LARS throughout the survivorship continuum within the Australian healthcare system.

Limitations

Limitations of individual studies are discussed in their respective chapters; here, we consider the overarching limitations of the thesis as a whole.

First, the clinical studies contributing to this thesis were impacted by the COVID-19 pandemic, which had substantial implications for recruitment timelines and sample sizes. The restricted clinical activity and decreased patient flow attending clinics and elective surgeries resulted in smaller cohorts. Additionally, participants in most studies (except the study in Chapter 8) were recruited from a single centre and its affiliated clinic. This introduces potential selection bias and may limit the generalisability to the broader colorectal cancer population or different healthcare contexts.

Second, using a digital platform for survey administration and intervention delivery assumes a certain level of digital literacy, technological skills, and internet access. This may have excluded individuals with lower digital competence or limited technological resources, leading to potential

accessibility-related sampling bias. While digital delivery promotes flexibility and reflects the modern model of care, it may also influence response behaviour, including recall bias.

Third, we recognise the likely under-representation of cancer survivors from culturally and linguistically diverse backgrounds and those with lower educational attainment who cannot participate in English. All assessments, study materials, and intervention contents (Chapters 3 & 6) were provided in English, which may have created barriers to participation and reduced cultural transferability. As a result, the experiences and needs of groups with limited English proficiency might not be fully captured in the findings.

Nevertheless, the prospective data and the alignment of findings with international data, along with the consistency across quantitative and qualitative findings, strengthen the credibility of the conclusions. The use of validated patient-reported outcome measures and data triangulation with qualitative accounts ensures internal validity and reduces recall bias. Furthermore, the multiphasic study design with temporal measures offers a more reliable assessment of symptom progression and behavioural adaptation than the cross-sectional designs often used in the LARS literature.

While the thesis has limitations typical of mixed-methods research that warrant consideration when evaluating its generalisability, these do not undermine the internal coherence or practical relevance of the findings, particularly regarding intervention feasibility, survivors' experiences, and behavioural processes. These aspects establish the thesis as a strong and novel contribution to functional recovery and rehabilitation for low anterior resection syndrome and supportive care for individuals with colorectal cancer.

Implications and future directions

The collective findings of this thesis have significant implications for colorectal cancer care at various levels, including clinical practice, survivorship care and services, and future research. They highlight that recovery after anterior resection and oncological treatment extends beyond mere survival to include revival through functional restoration, psychosocial adjustment, and social participation, which help rebuild routine and normalcy in life. Incorporating a multimodal approach guided by behaviour change principles into the cancer journey and survivorship care offers a valuable opportunity to better meet survivors' needs and reshape the care model.

Clinical practice

The findings of this thesis have several important implications for clinical practice. Given the high prevalence and debilitating impact of LARS, functional disability can be easily overlooked, particularly in individuals with known risk factors, leading to delayed identification and limited access to timely intervention. Routine screening should therefore be considered as standard care during post-operative recovery and survivorship to support early detection and facilitate appropriate rehabilitation referral. Clinicians need to proactively identify people at higher risk of LARS and anticipate their potential requirement for additional supportive care and later rehabilitation along the survivorship pathway. Several clinical factors identified in Chapter 2 have been associated with increased risk of LARS, including low anastomotic height and smoking, along with previous research indicating neoadjuvant radiotherapy and temporary diverting stoma [17]. Risk prediction tools for bowel dysfunction, such as the POLARS score [31], were found to be unreliable and to have low sensitivity in forecasting major LARS [32]. Ongoing assessments at multiple time points may provide a more reliable way to detect patients with symptoms early.

A key unmet need identified in this work is the inconsistent and delayed LARS information provided to patients, as well as the fragmented nature of care for functional recovery. This thesis provides evidence that prehabilitation, including video-based education, enables psychological readiness for

postoperative bowel recovery. This approach has demonstrated feasibility and acceptability, helping patients develop initial coping strategies, improve understanding of LARS, set realistic expectations, and feel more confident in seeking professional support should symptoms arise. Early supportive care is important for promoting enablement, self-efficacy, and empowerment in self-management. Survivors often rely on self-navigated strategies in the face of uncertainty, reflecting service gaps and limited professional guidance. An additional area for future investigation is whether physiotherapy-based prehabilitation could be introduced earlier in the treatment pathway alongside video-based education, such as before primary colorectal surgery or prior to the closure of a temporary stoma. Early engagement with pelvic floor physiotherapists may help patients better understand changes in bowel function, receive feedback on the skills learnt from the video, establish therapeutic relationships, and potentially facilitate earlier rehabilitation if LARS develops after surgery. Future research should explore the feasibility and effectiveness of integrating physiotherapy within multimodal prehabilitation programs for colorectal cancer patients, with long-term follow-up of function after surgery. Physiotherapist-led pelvic floor rehabilitation offers a promising solution, having shown feasibility and acceptability. A multimodal approach that includes pelvic muscle retraining, education, dietary guidance, and behavioural strategies aligns well with the biopsychosocial nature of LARS, and physiotherapists are well positioned to deliver structured, professionally guided rehabilitation. Integrating such rehabilitation into survivorship care can bridge the gap between surgery and long-term functional recovery, ensuring it becomes a core component of ongoing cancer care rather than an optional extension, positioning PFR as an essential component of optimised conservative management within the LARS treatment algorithm.

Survivorship care and services

The findings of this thesis underscore the significance of survivorship care extending beyond clinical management to deliver need-based support, addressing both physical and psychosocial dimensions of LARS. The Empowered Behavioural Adaptation Process (EBAP) introduced herein presents a novel

intervention design model for highly complex survivorship care. By delineating the stages of expectation adjustment, skill development, habit consolidation, and long-term adaptation, EBAP offers clinicians and survivorship services a structured, process-oriented pathway that facilitates behavioural support change. This represents a substantial progression from fragmented, symptom-focused coping strategies to a more comprehensive model of survivorship care. At the core of this approach is the acknowledgment that post-treatment needs are multimodal and centred around the patient, extending well beyond bowel-related symptoms alone. An essential yet frequently neglected aspect is work reintegration, where colorectal cancer survivors often face unpreparedness due to limited hospital transition-to-work programs, inconsistent guidance from healthcare providers, and difficulties in self-assessing their readiness to resume employment. These observations underscore the importance of multi-level support involving both healthcare professionals and employers to bridge the gap in structured guidance during the transition period. The development of return-to-work assessments that are time-sensitive, contextually appropriate, and aligned with the biopsychosocial impacts of LARS and other cancer-related side effects will be essential to enabling survivors to regain social engagement and meaningful participation in work and daily activities.

Future research

Future research should expand on this thesis by conducting large-scale, randomised multicentre studies on pre-treatment video education and post-treatment pelvic floor rehabilitation for LARS colorectal cancer survivors across various healthcare settings. It should also evaluate culturally and linguistically diverse communities and populations with different levels of health, digital, and academic literacy. Such trials should include long-term follow-up from prehabilitation through rehabilitation, as well as health economic evaluations to assess feasibility and cost-effectiveness within the Australian healthcare system. More work is also needed to explore communication processes between healthcare providers and cancer survivors, especially focusing on role clarity,

shared decision-making, and barriers that prevent cancer survivors from making informed choices about their care and returning to work. Furthermore, developing biopsychosocial-aligned patient-reported outcome measures tailored to work participation, combined with co-design approaches to create a comprehensive return to work readiness pathway, will be vital for guiding responsive, patient-centred rehabilitation throughout the cancer journey.

Conclusion

In conclusion, this research has comprehensively addressed the questions posed at the beginning: how can functional recovery and rehabilitation for LARS be optimised, and how can supportive care for people with colorectal cancer be strengthened to improve survivorship outcomes across the cancer journey? By integrating quantitative and qualitative data, this research systematically examined the burden of LARS, the feasibility and efficacy of prehabilitation and rehabilitation interventions, and the broader survivorship challenges that influence outcomes after colorectal cancer. This multiphase, mixed-methods approach transcends a simple description of LARS, elucidating the causes of this invisible disability on individual physical dysfunction, psychosocial well-being, and vocational challenges, thereby shaping survivors' quality of life.

Across all studies, the emerging evidence offers three key contributions to knowledge in colorectal cancer survivorship. First, it provides the first prospective longitudinal Australian data demonstrating that LARS recovery stabilises after 12 months, signalling a clinically meaningful time point to consider optimised conservative management (OCM) as the next step once spontaneous recovery reaches a plateau. Second, this research advances the field by demonstrating the feasibility and acceptability of video-based pre-surgery education and structured physiotherapist-led pelvic floor rehabilitation within integrated colorectal cancer and survivorship care in the Australian healthcare system. It highlights a multimodal approach that combines physical and psychosocial elements as a

core part of supportive care for people with colorectal cancer. Third, the research introduces a novel behavioural model, the Empowered Behavioural Adaptation Process (EBAP), which explains sustained functional recovery through a guided behaviour change process involving expectation adjustment, knowledge and skill acquisition, habit consolidation, and long-term adaptation. Overall, these contributions position structured and behaviourally guided multimodal intervention as an essential component of OCM and contemporary colorectal and survivorship care.

We recognise certain limitations in this work, including recruitment disruptions during the COVID-19 pandemic, small sample sizes in single-centre studies, and limited cultural and linguistic diversity within cohort studies. Nevertheless, the methodological rigour strengthens the credibility of the findings. Prospective measures, validated patient-reported outcome measures (PROMs), clinical assessment tools, and triangulation across methods that ensure internal consistency and align with international evidence support transferability. The mixed-method design further demonstrates the breadth and depth of the investigation by combining quantitative data with lived experience.

The collective findings have several implications. Clinically, routine LARS screening, a structured referral pathway, and integrated pre- and post-treatment therapeutic interventions should become standard practice. Future research should focus on large-scale, multicentre trials to evaluate prehabilitation and rehabilitation across diverse populations, including long-term follow-up and economic assessments to guide system-level implementation. Further studies are also needed to clarify communication practices between clinicians and survivors, strengthen role clarity in informed decision-making, and co-design return-to-work assessment and rehabilitation pathways grounded in biopsychosocial and vocational principles.

Overall, this thesis reframes LARS as a long-term, invisible disability that needs structured, tailored, and behaviourally guided rehabilitation rather than isolated symptom management. By integrating

prehabilitation with informative education, physiotherapist-led interventions, and structured psychosocial support, this work establishes a foundation for a continuous, patient-centred model of colorectal cancer and survivorship care. Consequently, it advances both theoretical understanding and clinical practice, and establishes service pathways to improve functional recovery, psychological resilience, and social participation among colorectal cancer survivors.

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Chapter 10: Appendices

Contact: Sydney Local Health District Human Research Ethics Committee – CRGH
Concord Repatriation General Hospital (CRGH)
Concord NSW 2139
Telephone: *(02) 9767 5622*
Email: SLHD-ConcordEthics@health.nsw.gov.au
Local Ref: *CH62/6/2019-062*

CONCORD
REPATRIATION GENERAL
HOSPITAL

23 May 2019

Professor Janette Vardy
C/- Carol Chan
Concord Cancer Centre
CONCORD RGH

Dear Professor Vardy,

Re: **Local reference number:** CH62/6/2019-062
REGIS reference number: 2019/ETH09759
Project title: The prevalence of anterior resection syndrome and functional outcome after sphincter-preserving surgery for colorectal cancer at Concord Cancer Centre

Thank you for submitting the above research proposal for single ethical and scientific review. This project was first considered by the Executive Ethical Review Panel of the Sydney Local Health District Human Research Ethics Committee – CRGH at its meeting held on 18 April 2019. This Human Research Ethics Committee (HREC) has been accredited by the NSW Ministry of Health as a lead HREC under the model for single ethical and scientific review.

This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

I am pleased to advise that final ethical approval has been granted on the basis of the following:

- The research project meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

- HREC granted a waiver of the usual requirement for the consent of the individual for the use of their health information in a research project, in accordance with the *Health Records and Information Privacy Act 2002* (NSW) and the NSW Privacy Commissioner's Statutory guidelines on research.

The documents reviewed and approved include:

	IDENTIFICATION NUMBER	**DATE**
Human Research Ethics Application (HREA)	Version 2	01/05/2019
Protocol	Version 2	02/05/2019
Data Collection Form	Version 1	22/03/2019
Bowel Function Questionnaire	Version 1	01/03/2019
Bowel, Bladder and Sexual Function Questionnaire	Version 1	01/03/2019
Privacy Compliance Form		

The HREC has provided ethical and scientific approval for the following sites:

1. Concord Repatriation General Hospital

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at any site until you have submitted a Site Specific Assessment (SSA) Form to the Research Governance Officer (RGO) and received separate authorisation from the Chief Executive or delegate at that site.

Please note the following conditions of approval:

1. HREC approval is valid for five (5) years subject to the supply of an annual progress report. The first report should be sent to the HREC by **31/05/2020.** You must also provide an annual report to the HREC upon completion of the study.

2. You will adhere to the study protocol at all times.

3. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review.

4. You will notify the HREC, giving reasons, if the project is discontinued at a site before the expected date of completion.

5. You will immediately report anything which might warrant review of ethical approval of the project, including unforeseen events that might affect continued ethical acceptability of the project, (including Significant Safety Issues).

6. HREC approval is granted on the assumption that all students and early career researchers are adequately supervised by the principal and senior investigators on a project. This supervision would ensure that all privacy concerns are met (including the completion of confidentiality agreements by participating students) and that both students and participants are supported in the conduct of the study in line with the approved research protocol.

Should you have any queries about the HREC's consideration of your project please contact the Executive Officer - (02) 9767-5622. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the website: https://www.slhd.nsw.gov.au/concord/Ethics/Ethics.html

We wish you every success in your research.

Please quote the local reference number at the top of this letter in all correspondence.

Yours sincerely,

Professor David Le Couteur
Chair
Sydney Local Health District Human Research Ethics Committee – CRGH

Contact: Sydney Local Health District Human Research Ethics Committee – CRGH
Concord Repatriation General Hospital (CRGH)
Concord NSW 2139
Telephone: *(02) 9767 5622*
Email: SLHD-ConcordEthics@health.nsw.gov.au
Local Ref: *CH62/6/2022-093*

CONCORD
REPATRIATION GENERAL
HOSPITAL

This letter constitutes ethical approval only. You must NOT commence this research project at ANY site until you have submitted a Site Specific Assessment Form to the Research Governance Officer and received separate authorisation from the Chief Executive or delegate of that site.

10 August 2022

Professor Janette Vardy
C/- Kin Yin (Carol) Chan
Medical Oncology
Concord Repatriation General Hospital

Dear Professor Vardy,

Re: **Local reference number:** CH62/6/2022-093
REGIS ethics application number: 2022/ETH01083
REGIS project ID number: 2022/PID01226
Project title: Pre-operative video about bowel function and supportive care in colorectal cancer

Thank you for submitting the above research proposal for single ethical and scientific review. This project was first considered by the Sydney Local Health District Human Research Ethics Committee – CRGH at its meeting held on 30 June 2022. This Human Research Ethics Committee (HREC) has been accredited by the NSW Ministry of Health as a lead HREC under the model for single ethical and scientific review.

This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

I am pleased to advise that final ethical approval has been granted on the basis of the following:

- The research project meets the requirements of the *National Statement on Ethical Conduct in Human Research (2007) – updated 2018*.

Special conditions:

- * (If Applicable) In accordance with the National Statement, chapter 4.7; you must seek ethical approval from the HREC of the Aboriginal Health and Medical Research Council (AHMRC) if you intend to use ATSI status in any presentation or publication.

The documents reviewed and approved include:

DOCUMENT	VERSION	DATE
Human Research Ethics Application (HREA)	3	5 July 2022
Protocol*	1.1	8 July 2022
Participant Information Sheet	1.1	8 July 2022
Participant Consent Form	1.1	8 July 2022
Master Code Sheet	1	16 June 2022
Data Collection Form	1	16 June 2022
Flyer	1.1	8 July 2022
Preoperative video script	2	8 July 2022
Referral Form	1	9 February 2022
NCNN Guidelines Distress Management	1.2022	12 June 2021
Questionnaire 1	2	16 June 2022
Questionnaire 2	2.1	8 July 2022
Questionnaire 3	2	16 June 2022
Questionnaire 4	1	9 February 2022
Research Data Management Plan	N/A	16 June 2022

The HREC has provided ethical and scientific approval for the following sites:

1. Concord Repatriation General Hospital

Please note the following conditions of approval:

1. HREC approval is valid for five (5) years subject to the supply of an annual progress report. The first report should be sent to the HREC by **31/08/2023.** You must also provide an annual report to the HREC upon completion of the study.

2. You will adhere to the study protocol at all times.

3. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review.

4. You will notify the HREC, giving reasons, if the project is discontinued at a site before the expected date of completion.

5. You will immediately report anything which might warrant review of ethical approval of the project, including unforeseen events that might affect continued ethical acceptability of the project, (including Significant Safety Issues).

6. It is noted that REDCap will be used for secure research data collection, management and storage in the study. Once the REDCap project has been set-up, using the SLHD Master Code Sheet Project, please provide a copy of the REDCap Project Codesheets with a version number and date to the Ethics Committee for review and approval prior to study commencement. Please note, the SLHD Research Data Manager and REDCap Administrator can be contacted for assistance and bookings via email or online for consultation if necessary.

7. HREC approval is granted on the assumption that all students and early career researchers are adequately supervised by the principal and senior investigators on a project. This supervision would ensure that all privacy concerns are met (including the completion of confidentiality agreements by participating students) and that both students and participants are supported in the conduct of the study in line with the approved research protocol.

8. **Partnering with Consumers:** As per Standard 2 of The National Clinical Trials Governance Framework, you are asked to provide an annual update with your annual progress report (milestone) on the ongoing involvement of consumers in the planning, design, delivery, measurement and evaluation of the trial.

9. It is a condition of approval that the investigators follow the relevant jurisdictional public health guidelines in relation to COVID-19 site requirements.

Should you have any queries about the HREC's consideration of your project please contact the Executive Officer - (02) 9767-5622. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the website: https://www.slhd.nsw.gov.au/concord/Ethics/Ethics.html

We wish you every success in your research.

Please quote the local reference number at the top of this letter in all correspondence.

Yours sincerely,

Sarah Truong
Acting Executive Officer
Sydney Local Health District Human Research Ethics Committee -
Concord Repatriation General Hospital

On behalf of

Dr Janani Thillainadesan
HREC Co-Chair
Sydney Local Health District Human Research Ethics Committee – CRGH

Contact: Sydney Local Health District Human Research Ethics Committee – CRGH
Concord Repatriation General Hospital (CRGH)
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Email: SLHD-ConcordEthics@health.nsw.gov.au
Local Ref: *CH62/6/2019-196*

CONCORD
REPATRIATION GENERAL
HOSPITAL

31 March 2020

Prof Janette Vardy
C/- Ms Kin Yin (Carol) Chan
Concord Cancer Centre
Concord Repatriation General Hospital

Dear Prof Vardy,

Re: **Local reference number:** CH62/6/ 2019-196
REGIS ethics application number: 2019/ETH13665
REGIS project ID number: 2019/PID15308
Project title: A pelvic floor rehabilitation program for patients with bowel dysfunction after sphincter- preserving surgery for colorectal cancer: a feasibility study

Thank you for submitting the above research proposal for single ethical and scientific review. This project was first considered by the Scientific Sub-Committee at its meeting of 03 December 2019 and by the Sydney Local Health District Human Research Ethics Committee – CRGH at its meeting held on 12 December 2019. This Human Research Ethics Committee (HREC) has been accredited by the NSW Ministry of Health as a lead HREC under the model for single ethical and scientific review.

This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

I am pleased to advise that final ethical approval has been granted on the basis of the following:

- The research project meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

The documents reviewed and approved include:

	IDENTIFICATION NUMBER	**DATE**
Human Research Ethics Application (HREA)	Version 4	28/02/2020
Study Protocol	Version 2.1	12/03/2020
Master Participant Information Sheet and Consent Form	Version 2	06/03/2020
Diet after bowel surgery	No version	13/01/2013
Questionnaire Booklet Cover Page	Version 1.1	12/03/2020
Pelvic Floor Rehabilitation Program Questionnaire Booklet	Version 1	17/01/2020
Pelvic Floor Rehabilitation Program Questionnaire	Version 1	07/11/2019
Pelvic Floor Muscle Exercises	Version 1	19/11/2019

Low anterior resection syndrome score	Version 1.1	07/11/2019
Memorial Sloan Kettering Cancer Centre – Bowel Function Instrument	Version 1	07/11/2019
Patient Evaluation Survey	Version 1.1	02/01/2020
Exercise and Bowel Symptoms Diary	Version 1.1	01/01/2020
FACT-C Questionnaire	Version 4	16/11/2007
FIQOL Questionnaire	Version 1	07/11/2019
FSFI Questionnaire	Version 1	07/11/2019
HADS Questionnaire	Version 1	07/11/2019
ICIQ-FLUTS Questionnaire	Version 1	August 2014
ICIQ-MLUTS Questionnaire	Version 1	January 2016
IIEF-Questionnaire	Version 1	07/11/2019
Australian Register of Therapeutic Goods - 132538	No version	25/10/2006
Australian Register of Therapeutic Goods - 136828	No version	28/03/2007
Australian Register of Therapeutic Goods - 226992	No version	18/08/2014
Research Data Management Plan	Version 1.1	12/03/2020

The HREC has provided ethical and scientific approval for the following sites:

1. Concord Repatriation General Hospital
2. Digestive Pelvic Floor Centre, 107/3 Railway Parade Burwood NSW 2134

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at any site until you have submitted a Site Specific Assessment (SSA) Form to the Research Governance Officer (RGO) and received separate authorisation from the Chief Executive or delegate at that site.

Please note the following conditions of approval:

1. HREC approval is valid for five (5) years subject to the supply of an annual progress report. The first report should be sent to the HREC by **31/03/2021.** You must also provide an annual report to the HREC upon completion of the study.

2. You will adhere to the study protocol at all times.

3. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review.

4. You will notify the HREC, giving reasons, if the project is discontinued at a site before the expected date of completion.

5. You will immediately report anything which might warrant review of ethical approval of the project, including unforeseen events that might affect continued ethical acceptability of the project, (including Significant Safety Issues).

6. The researchers are asked to consider how the current advice relating to COVID-19 will impact on the study design/procedures.
    a. In addition, please provide a COVID-19 specific protocol with appropriate methodology to align with the current guidance.
    b. Please outline how the impacts of COVID-19 will be addressed at an ethics and governance level.

7. Please provide the summary of results that will be provided to participants for review and approval prior to distributing.

8. It is noted that an External Entity Agreement was executed between the Sydney Local Health District and Gastrointestinal and Pelvic Floor Specialists Group Sydney Pty Ltd.

Should you have any queries about the HREC's consideration of your project please contact the Executive Officer - (02) 9767-5622. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the website: https://www.slhd.nsw.gov.au/concord/Ethics/Ethics.html

We wish you every success in your research.

Please quote the local reference number at the top of this letter in all correspondence.

Yours sincerely,

Professor David Le Couteur
Chair
Sydney Local Health District Human Research Ethics Committee – CRGH

Contact: Sydney Local Health District Human Research Ethics Committee
Concord Repatriation General Hospital
Concord NSW 2139
Telephone: (02) 9767 5622
Email: SLHD-ConcordEthics@health.nsw.gov.au
Local Ref: *CH62/6/2021-004*

CONCORD
REPATRIATION GENERAL
HOSPITAL

18 March 2021

Prof Janette Vardy
C/- Ms Kin Yin Carol Chan
Sydney Cancer Centre
Concord Repatriation General Hospital

Dear Professor Vardy,

Re: **Local reference number:** CH62/6/2021-004
REGIS ethics application number: 2021/ETH00067
REGIS project ID number: 2021/PID00076
Project title: Colorectal cancer survivors in work participation: Perspective of cancer survivors and health care providers

Thank you for submitting the above research proposal for single ethical and scientific review. This project was first considered by the Executive Ethical Review Panel of the Sydney Local Health District Human Research Ethics Committee – CRGH at its meeting held on 28 January 2021. This Human Research Ethics Committee (HREC) has been accredited by the NSW Ministry of Health as a lead HREC under the model for single ethical and scientific review.

This lead HREC is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research* and the *CPMP/ICH Note for Guidance on Good Clinical Practice.*

I am pleased to advise that final ethical approval has been granted on the basis of the following:

- The research project meets the requirements of the *National Statement on Ethical Conduct in Human Research (2007) – updated 2018*.

The documents reviewed and approved include:

	VERSION	DATE
Human Research Ethics Application (HREA)	2	05 February 2021
Protocol	1.1	15 February 2021
Participant Information Sheet & Consent Form – Cancer Survivor	1.1	18 February 2021
Participant Information Sheet & Consent Form – Health Professional	1.1	18 February 2021
Interview Guidelines	1	18 December 2020
Invitation HP	1	27 February 2021
Social Media Advertising	1	16 February 2021
Survey Poster	No version	No date
Survey	1.1	16 February 2021
Interview Flyer	1	17 February 2021
Survey Flyer	1	16 February 2021

The HREC has provided ethical and scientific approval for the following sites:

1. Concord Repatriation General Hospital
2. Digestive Pelvic Floor Centre

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at any site until you have submitted a Site Specific Assessment (SSA) Form to the Research Governance Officer (RGO) and received separate authorisation from the Chief Executive or delegate at that site.

Please note the following conditions of approval:

1. HREC approval is valid for five (5) years subject to the supply of an annual progress report. The first report should be sent to the HREC by **18/03/2022.** You must also provide an annual report to the HREC upon completion of the study.

2. You will adhere to the study protocol at all times.

3. Proposed changes to the research protocol, conduct of the research, or length of HREC approval will be provided to the HREC for review.

4. You will notify the HREC, giving reasons, if the project is discontinued at a site before the expected date of completion.

5. You will immediately report anything which might warrant review of ethical approval of the project, including unforeseen events that might affect continued ethical acceptability of the project, (including Significant Safety Issues).

6. It is noted that REDCap will be used for secure research data collection, management and storage in the study. Once the REDCap project has been set-up, using the SLHD Master Code Sheet Project, please provide a copy of the REDCap Project Code Sheets with a version number and date to the Ethics Committee for review and approval prior to study commencement. Please note, the SLHD Research Data Manager and REDCap Administrator can be contacted for assistance and bookings online for consultation if necessary.

Should you have any queries about the HREC's consideration of your project please contact the Executive Officer - (02) 9767-5622. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the website: https://www.slhd.nsw.gov.au/concord/Ethics/Ethics.html

We wish you every success in your research.

Please quote the local reference number at the top of this letter in all correspondence.

Yours sincerely,

Professor David Le Couteur
Chair
Sydney Local Health District Human Research Ethics Committee – CRGH

Pre-operative video about bowel function and supportive care in colorectal cancer

PARTICIPANT CONSENT FORM

I,_____ *[full name]*

Of_____ *[address]*

have read and understood the Participant Information Sheet on the abovenamed research study

and have discussed the study with _____
[investigator responsible for conducting informed consent].

- I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

- I understand that my participation in this study will allow the researchers and others, as described in the Information for Participants, to have access to my medical record, and I agree to this.

- I would like to receive a copy of the study results when they become available. My email address is: _____

- I understand that, during the course of this study, my medical records may be accessed by the Ethics Committee approving the research in order to verify results and determine that the study is being carried out correctly.

- I understand that the SLHD software license for REDCap (Research Electronic Data Capture) will be used to manage the collection and storage of my research data.

- I have had an opportunity to ask questions and I am satisfied with the answers I have received.

- I freely choose to participate in this study and understand that I can withdraw at any time.
- I also understand that the research study is strictly confidential.

- I hereby agree to participate in this research study.
- I consent to the storage and use of my information collected from me for use, as described in the relevant section of the Participant Information Sheet, for:
  -This specific research project

Participant Name:_____

Participant Signature:_____

Date:_____

Name of Person conducting informed consent:_____

Signature of Person conducting informed consent: _____

Date:_____
_____

Pre-operative video about bowel function and supportive care in colorectal cancer

PARTICIPANT INFORMATION SHEET

Title	Pre-operative video about bowel function and supportive care in colorectal cancer
Short Title	
Protocol Number	1
Project Sponsor	Sydney Local Health District
Coordinating Principal Investigator/ Principal Investigator	Professor Janette Vardy – CPI Ms. Kin Yin Carol Chan – PI Dr. Michael Suen – PI
Associate Investigator(s)	Ms. Sonia Khatri Mr. Janindra Waruvitarne Dr. Susan Coulson
Location	Concord Repatriation General Hospital

1. Introduction

This research study looks at patient education and support on bowel health before and after surgery. You have been invited to take part in this research study because you have bowel cancer and will be going for surgery. In this study, we would like to find out whether watching a prepared video is useful to help patients learn about how the bowel works and how surgery could affect the bowel. We would like to see if watching the video will help you to prepare for recovery after your surgery, and information on how to seek help if you require it. You will learn some skills on how to improve your bowel after surgery and pelvic floor muscle exercises that you may wish to practice before the surgery.

The study is being conducted within this institution by Professor Janette Vardy, Medical Oncologist at The Sydney Cancer Survivorship Centre; Kin Yin Carol Chan, Physiotherapist and PhD Candidate, Sydney Medical School of The University of Sydney; and Dr. Michael Suen, Colorectal Surgeon Consultant, Colorectal Unit, Concord Hospital. All of the above investigators are affiliated with the Sydney Local Health District (SLHD) and The University of Sydney. None of the above investigators have any conflict of interest in the study participation. The results from this project will form part of Kin Yin Carol's PhD study under the supervision of Prof Janette Vardy.

This Participant Information Sheet (PIS) will tell you what is involved in the study and help you decide whether or not you wish to take part. Please read this information carefully. If

there is anything you do not understand or if you feel you need more information about anything, please ask. Before you make a decision, please feel free to talk things over with a relative, a friend or your doctor.

2. Study Procedures

If you agree to participate in this study, you will be asked to sign the Participant Consent Form at the end of this document. You will then be asked to undergo the following study activities:

1. Complete the first set of questionnaires about your understanding of bowel and pelvic floor function and your current bladder, bowel and sexual health function. In the questionnaires, you will also be asked questions about your background including education level and marital status. There are 3 questionnaires in the first set of questionnaires. It will take about 5-10 minutes to complete all 3 questionnaires. You may complete the questionnaires either online via a survey link or paper copy if you prefer. If you are using paper copies, please keep and return them with the second set of questionnaires that you complete after watching the videos. You will be asked to return all the completed questionnaires immediately after the study via post. A reply-paid envelope will be given to you.

2. Watch 4 pre-recorded videos on bowel function and support care for bowel cancer surgery. This link will be given to you after you have enrolled into the study. This video will include information about normal bladder and bowel health and possible bladder and bowel issues some people have after surgery. The video will include a demonstration of pelvic floor exercises and ways to improve bowel function after surgery. It will take you about 40 minutes to watch all 4 videos. You can watch them on any electronic device (e.g., phone or computer) that has an internet connection. You can choose to watch them anywhere and anytime that suits you. However, you need to complete the viewing 3-5 days before your surgery.

3. Complete the second set of questionnaires about your understanding of bowel and pelvic floor function after watching the videos. We will also ask for your feedback about your experience watching the videos. There are 4 questionnaires in the second set of questionnaires. It will take you about 10-15 minutes to complete all 4 questionnaires. You may complete the questionnaires either online via a survey link or paper copy at your request.

4. Return the questionnaires if you use paper copies. There are 7 questionnaires in total. Please return all of them in the reply-paid envelope provided.

5. The researcher will call and remind you 5 days before your surgery to see how you are going with your video viewing and questionnaire completion.

If you agree to participate in this study, we ask you to sign the Participant Consent Form before participating. Also, the researchers would like to collect information from your medical record that is relevant to this study. This information will include your age, gender, past medical history and the medical information about your current bowel cancer treatment. We will be linking this information to the answers of your questionnaires.

3. Risks

The whole study will take about 55-65 minutes. As described in the above section, you will have access to questionnaires and video via a link given by one of the researchers after enrolment or paper questionnaires will be given on request. Information such as age, gender and medical history will be collected from your medical record.

This study does not involve any medical procedure, however it is important for you to understand what are the potential risks for this study.

The risks of participating in this study are very low. The possible risks are the time inconvenience of completing the questionnaires or it may cause a feeling of fear related to a past medical or personal experience.

If you wish to talk to someone outside the research team due to any distress caused to you by the assessment and procedure you can contact Beyond Blue 1300 22 4636. Alternatively, you may give consent to the research team to inform your treating doctor to discuss arranging a follow-up consultation if your distress is related to the cancer and treatment.

4. Benefits

We intend that this research study furthers medical knowledge and may improve treatment of bowel dysfunction associated with bowel cancer surgery in the future. You may benefit from gaining additional information about pelvic floor and bowel health from this video.

5. Costs

Participation in this study will not cost you anything, nor will you be paid.

6. Voluntary Participation

Participation in this study is entirely voluntary. You do not have to take part in it. If you do take part, you can withdraw at any time without having to give a reason by contacting Carol Chan on 8084 3831 and informing us about your decision. Whatever your decision, please be assured that it will not affect your medical treatment or your relationship with the staff who are caring for you. Of the people treating you, only the nursing staff will be aware of your participation or non-participation.

If you decide to withdraw from the study, we will not collect any more study-related information from you and no further information will be collected from that time point however previously collected data will be kept as part of the analysis on the completion of the study.

7. Confidentiality

All the information collected from you for the study will be treated confidentially. All identifying information will be de-identified with a unique ID code. De-identified data will be stored on an online secure password protected research database accessed within REDCap at Concord Repatriation General Hospital supported by Sydney Local Health District Information Technology Department. Any identifiable hardcopy data will be stored in a locked cabinet in a locked office of Professor Janette Vardy, Oncology Department at Concord Repatriation General Hospital.

The identifiable data such as name, email and contact number will be stored on REDCap-SLHD in a separate file. Only the investigators named above will have access to your data. REDCap-SLHD is a secured database system with strict access only by authorised persons.

The data will be analysed by the researchers at the Concord Repatriation General Hospital. All data for use in journal publications and presentations will be de-identified (de-identified data means that you/your information will not be identifiable). The files will be retained for 7 years from the day the study is completed. After this time the files will be disposed of using secure means.

The study results will be used in a higher research degree project and will be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such a presentation or in any publication. In addition, your data will not be stored outside the SLHD database system.

8. Storage of Data

The SLHD software licence for REDCap (Research Electronic Data Capture) will be used for to manage the collection and storage of research data. REDCap is a secure, web-based, non-commercial, data management tool designed for research purposes. Data collected by REDCap is stored on servers in the SLHD data centre. Data is secured, and back-up, privacy and confidentiality.

9. Future use of Data

The data collected in this project will not be used in future research studies. The results of this study and de-identified data will not be shared in the future with national and international collaborators.

10. Further Information

When you have read this information, Carol Chan will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact them on Carol Chan (02) 8084 3831 or email: kcha7376@uni.sydney.edu.au

This information sheet is for you to keep.

11. Ethics Approval and Complaints

This study has been approved by the Human Research Ethics Committee - CRGH of the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study should contact the Executive Officer on 02 9767 5622 or email SLHD-ConcordEthics@health.nsw.gov.au and quote reference number *2022/ETH01083*

The conduct of this study at the Concord Repatriation General Hospital has been authorised by the Sydney Local Health District. Any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer on 9767 5622 and quote protocol number *[insert local protocol number].*

PARTICIPANT INFORMATION SHEET & CONSENT FORM

STUDY TITLE: A pelvic floor rehabilitation program for patients with bowel dysfunction after sphincter- preserving surgery for colorectal cancer: a feasibility study

INVESTIGATORS:

1. Professor Janette Vardy, Medical Oncologist, The Sydney Survivorship Centre, Concord Hospital
2. Dr. Michael Suen, Colorectal Surgeon Consultant, Colorectal Unit, Concord Hospital
3. Ms Kin Yin (Carol) Chan, Physiotherapist PhD Candidate, Sydney Medical School, The University of Sydney

All of the above investigators are affiliated with The University of Sydney and Concord Repatriation General Hospital. None of the above investigators have any conflict of interest in the study participation. This project is being conducted as part of Kin Yin (Carol) Chan's PhD study.

SPONSOR OF THIS PROJECT:
Sydney Local Health District (SLHD)

INTRODUCTION:
You are invited to take part in a research study into a pelvic floor rehabilitation program for bowel dysfunction after colorectal cancer surgery. The aim of the study is to determine how surgery and curative treatment affect bowel function and quality of life; and to examine how effective the pelvic floor exercise program is in improving bowel function for people who have issues with this caused by the cancer and surgery. You have been invited to take part in this research because you have been treated for bowel cancer and have ongoing bowel dysfunction.

This Participant Information Sheet (PIS) will tell you what is involved in the study and help you decide whether or not you wish to take part. Please read this information carefully. If there is anything you do not understand or if you feel you need more information about anything, please ask. Before you make a decision, please feel free to talk things over with a relative, a friend or your own doctor.

HOW MANY PEOPLE WILL TAKE PART?
About 15 people like you will take part in this study. All of the people taking part in the study will be recruited from Concord Repatriation General Hospital and the procedure and exercise treatment will be performed at Digestive Pelvic Floor Centre in Burwood.

WHERE DO THE ASSESSMENTS AND TREATMENT TAKE PLACE?
The pelvic floor rehabilitation program and assessments will take place at the Digestive Pelvic Floor Centre, at 107/3 Railway Parade in Burwood. This will enable us to use new equipment not available at Concord Repatriation General Hospital.

You will have to make your own way to the Centre and the cost of your travel will not be covered by the study.

STUDY PROCEDURES:
If you agree to participate in this study, you will be asked to sign the Participant Consent Form. You will then be asked to undergo the following procedures:

1. Bowel and pelvic floor function assessment – approximately one hour.
    (a) You will be asked to complete a set of questionnaires about your bowel and pelvic floor symptoms, and how are these symptoms are affecting your daily activities. It will take about 30 minutes to complete the questionnaires.
    Two medical studies will be done to assess how well your bowel and pelvic muscles work. The two tests will altogether take about 30 minutes.
        a) Anorectal manometry physiology study. This involves insertion of a catheter, which is a piece of tubing no thicker than a human finger, through the back passage into the lower bowel (rectum). This catheter is connected to a monitor that measures the pressures of the back passage and pelvic floor muscles. This procedure does not require any sedation. During the test, you will be asked to squeeze and relax your muscles around the back passage, and to cough and push with the catheter inserted. There is a small balloon at the tip of the catheter which will be inflated during the test. This is used to test the reflex and the sensation of the lower bowel.
        b) An endoanal ultrasound. This involves insertion of a probe (approximately the width of your little finger) into the back passage to take images of the muscles. It is used to assess the shape of the back passage and whether the muscles are working. A trained physiotherapist (Carol) and a colorectal surgeon (Dr. Michael Suen) will perform this. Both are trained and experienced in using this machine.

2. Pelvic floor rehabilitation program
    The rehabilitation program will commence the week after the assessment and go for 10 weeks. Each weekly session will last approximately one hour. The rehabilitation program includes:
    (a) Bladder and bowel education. Information sheet on diet and bowel medication use will be given and explained to you. Carol will also go through information on how to maintain a good bladder and bowel habit.
    (b) Pelvic floor muscle strength training. Carol will provide instruction and supervision when performing exercises with the aid of ultrasound images. An ultrasound probe is placed on the surface of your genital area during scanning. This will provide visual feedback for your pelvic floor muscle movements which can help to correct your exercise technique. This ultrasound machine is registered for use in Australia and is standard for viewing pelvic floor activity.
    (c) Bowel sensation and coordination training. This aims to improve the urge sensation, the coordination and control between lower bowel and back passage for defecation. A single use rectal balloon catheter will be used during the training session by the treating therapist.

(d) You will be asked to do some of the exercises at home between sessions (approximately 15 minutes/day). You will be asked to record your daily exercise times in on the exercise diary.

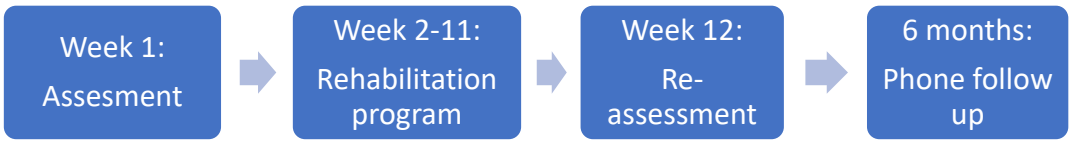
This rehabilitation program is an individual session with no other participant presence at the time of treatment. We will record the number of sessions you attend and obtain your exercise dairy for evaluation at the end of the program.

3. Bowel and pelvic floor function re-assessment
   (a) An evaluation will be performed after the completion of the 10- week program. This includes filling out questionnaires and performing an anorectal physiology study as you did at the first assessment (explained above). You will also be asked to complete a program satisfaction survey.
   (b) Carol will contact you by phone or in person for an interview 6 months after the program to follow up your progress. At this time you will be asked about your bladder, bowel and sexual function using the same set of questionnaires.

4. Exit interview
   You will be asked to participate in an interview one week after you complete the program. You will be asked a number of questions to gain feedback about your bowel function management and experience with the program. This will be completed with a research staff member who is not directly involved in this study. The interview will be conducted via telephone and it will take approximately 15-20 minutes. The interview will be recorded and transcribed by the researchers of this project for analysis. Direct quotes may be used in a research publication, but all quotes will be labelled with an assigned study ID only, therefore your identity will be un-identifiable.

HOW LONG WILL YOU BE INVOLVED IN THE RESEARCH?

The bowel and pelvic floor function assessment and treatment will be conducted in a consultation room located in Burwood (Digestive Pelvic Floor Centre) where the special equipment used for the tests is located and currently Concord Hospital does not have this equipment at present. The Digestive Pelvic Floor Centre is about 15 minutes drive from Concord Hospital. The assessment will take place the week before the exercise program starts. This assessment will take 60 minutes to complete the questionnaires and to perform the assessment.
Participation in the pelvic floor rehabilitation program will require you to attend a 1-hour exercise session at the Digestive Pelvic Floor Centre where it is set up for pelvic floor treatment and training, for once per week for 10 weeks. A follow up visit will re-assess your bowel and pelvic floor function the week after you complete the exercise program. This assessment is the same as the first assessment: you will be asked to complete questionnaires and to re-assess your bowel function with anorectal physiology study by the same person. This assessment will take 60 minutes.
Participants will be given the option of telehealth consultation to replace some face-to-face training sessions, particularly during COVID-19 restrictions. However, you must complete 5 mandatory in-person bowel sensation and coordination training sessions during the program. This entire assessment and rehabilitation program will take 12 weeks. In addition, Carol will contact you at 6 months after the program to follow up your bowel symptoms and function which will take 15 minutes.



EQUIPMENT USED IN THE RESEARCH STUDY

The equipment used (explained above) are all registered for use in Australia and are standard for assessing complex bowel function disorders such as constipation and bowel leakage. All catheters used for the assessment and exercise training are disposed of after each session. The ultrasound equipment will be cleaned using a standard disinfection procedure, so the risk of infection is very low.

STUDY INFORMATION

Most information for this study will be obtained from the questionnaires and the assessments. However, some medical information that is relevant to the study such as surgery details will require access to your medical record by the researchers. All of the information collected as part of the study will remain at Concord Repatriation General Hospital. The written or recorded information and the statistical analysis of the study results, whether they are collected at Concord Hospital or Digestive Pelvic Floor Centre, will be entered and kept in a centralised electronic study database with security login (Research Electronic Data Capture REDCap). While you are participating in the study we will keep your name and contact details to allow us to contact you for follow up visits. All your identification will be removed from data entry, result analysis and publication. All collected information will be kept for fifteen years. After this period of time, the information will be destroyed using secure destruction methods. The data will not be re-used for any study in future.

COSTS

If you are participating in this study, the consultation and exercise sessions, equipment for investigation and training will be supplied at no cost to you. You will not be paid for taking part in this study and should not incur any costs from participating in it. The members of your treatment team are not being paid to participate in this study.

VOLUNTARY PARTICIPATION

This is entirely your own decision to take part in this study. Your decision of whether to participate or not, will not influence the care or treatment you receive in any way. Please be assured that, whatever your decision, it will not affect your relationship with your doctors and other health professionals who are treating you, or your relationship with Concord Hospital.

If you change your mind and want to withdraw from the study, you can let us know at any time. This decision will not affect the care you receive or your relationship with your doctors, health professionals and the Hospital. You can contact Carol on (02) 8084 3831 or via email kcha7376@uni.sydney.edu.au for discussion. Please let us know if you decide to withdraw from the study and do not wish any of your information to be used in the study analysis. In this case your information will be destroyed in a secure manner. If you are unable attend the exercise sessions due to

medical reasons, we would still encourage you to attend another follow up assessment if possible unless you request a formal withdrawal from the study.

WHAT ARE THE BENEFITS OF TAKING PART?

While we intend that this research study furthers medical knowledge and may improve treatment of bowel dysfunction after colorectal cancer surgery in the future, it may or may not be of direct benefit to you. All people participating in this study will receive the same cancer care they would have received if they decided not to take part.

WHAT ARE THE RISKS OF TAKING PART?

The anal manometry test and pelvic floor training with rectal balloon catheter are low risk procedures and unlikely to cause any pain. Complications are rare but it is possible the following may occur:

- Minor bleeding from back passage (spotting on the toilet paper) due to irritation from the catheter or balloon
- Bowel perforation (tearing). The chance of this occurring is very low with a risk of 0.13% (that is one in a thousand) quoted in one case report.
- Equipment failure however the risk is minimal as the equipment will be tested each time before use.

The balloon attached to the catheter usually contains latex. Please inform and discuss with the research team if you have a latex allergy.

COMPENSATION FOR INJURIES OR COMPLICATIONS

If you suffer any injuries or complications as a result of this study, you should contact the study team as soon as possible. They will assist you in arranging appropriate medical treatment. If you are eligible for Medicare, you can receive any medical treatment required to treat the injury or complication, free of charge, as a public patient in any Australian public hospital. In no way does signing the Participant Consent Form waive your legal rights nor does it relieve the investigators or Concord Repatriation General Hospital from their legal and professional responsibilities.

CONFIDENTIALITY

All the information collected about you for the study will be treated confidentially. The information will be identified using a study code assigned to you at the start of the study and your initials. The completed questionnaires will be stored in a locked cabinet in the Oncology department. All collected information will be de-identified and transferred into a database system with password security on a hospital computer. Only people who are directly involved in this study will have access to the information. The recorded audio data from the exit interview will be de-identified, transferred and stored on REDCap. This will ensure data are securely stored with regular back-up. Audio recordings will be deleted from the recording device once it is transferred to a secured serve. The recordings will be transcribed by investigators and will then be deleted from the storage system.

If you consent to take part in this study your hospital medical records may be inspected by regulatory authorities, or by the Human Research Ethics Committee to check that the research has been carried out appropriately. By signing the consent form you are giving permission for this to be done. In addition, a photographic identification is required to ensure verification of your identify and to confirm your identify to validate the consent. All details obtained by those named will remain confidential. A report of this study may be submitted for publication but individual

participants will not be identifiable. The collected information will be kept for 15 years and will be destroyed in a secure manner after this period.

HOW TO GET TO THE DIGESTIVE PELVIC FLOOR CENTRE?

You can drive to the centre or go by public transport. There is metered street parking and a community carpark outside the centre. There is also 2-hour free parking in Burwood Plaza which is 3 minutes walking distance to the Centre. The Burwood train station and bus stops are only 150 metres from the Centre. Any travel costs will not be covered by the study

FURTHER INFORMATION

If you would like to know more about the study; or if you feel concern or experience distress at any stage of the assessment and exercise; or if you wish to receive a copy of any publication or presentations that are directly related to the research, please feel free to contact Carol Chan, the Pelvic Floor Physiotherapist running this study on (02) 8084 3831 or kcha7376@uni.sydney.edu.au This information sheet is for you to keep.

This study has been approved by the Human Research Ethics Committee - CRGH of the Sydney Local Health District. If you have any concerns or complaints about the conduct of the research study, you may contact the Executive Officer of the Ethics Committee, on (02) 9767 5622.

The conduct of this study at Concord Repatriation General Hospital has been authorised by SLHD Human Research Ethics Committee Concord Repatriation General Hospital. Any person with concerns or complaints about the conduct of this study may contact the Research Governance Officer on (02) 9767 5622 and quote protocol number STE17783. The conduct of this study at Digestive Pelvic Floor Centre has been approved by the management of the Centre. If you have any concerns or complaints about the conduct of the study at the Centre, you may contact the team on (02) 8084 3831.

A pelvic floor rehabilitation program for patients with bowel dysfunction after sphincter- preserving surgery for colorectal cancer: a feasibility study

PARTICIPANT CONSENT FORM

I, ..……..……[name]

of…….[address]

have read and understood the Information for Participants for the above named research study and have discussed the study with

…… ……...

I have been made aware of the procedures involved in the study, including any known or expected inconvenience, risk, discomfort or potential side effect and of their implications as far as they are currently known by the researchers.

I understand that, during the course of this study, my medical records may be accessed by regulatory authorities or by the Ethics Committee approving the research in order to verify results and determine that the study is being carried out correctly.

I understand that the interview will be audio-recorded, and will then be transcribed and be kept in a manner in which I cannot be identified for analysis and I agree to this.

I freely choose to participate in this study and understand that I can withdraw at any time.

I hereby agree to participate in this research study.

Name (Please Print):.....

Signature:..... **Date:** .....

Name of Person who conducted informed consent discussion (Please Print):

……

Signature of Person who conducted informed consent discussion:

Signature:..... **Date:** .....

This section should be completed if informed consent is obtained via telephone

For The protocol was discussed with _____[Participant's name] via telephone on _____ [DD/MMM/YYYY]. I received the Participant's signed consent form on _____ [DDMMMYYYY].

□ Consent was obtained using telehealth with "Name of Investigator" whose photographic identification was sighted by Participant who observed the Investigator's signature being written

□ Consent was obtained using telehealth with "Name of Participant" whose photographic identification was sighted by Investigator who observed the Participant's signature being written

□ Consent was obtained via telephone with "Name of Investigator", on _____[DD/MM/YYYY].

□ Consent was obtained via telephone with "Name of Participant", on _____[DD/MM/YYYY].

□Participant's signed consent form received by the Investigator on [DD/MM/YYYY].

□ Discussed with _____[Participant] via telephone on _____[DD/MM/YYYY], and received signed consent form on _____[date]. Signed by [Investigator]

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REVIEW ARTICLE

Efficacy of pelvic floor rehabilitation for bowel dysfunction after anterior resection for colorectal cancer: a systematic review

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Abstract

Purpose Bowel dysfunction is common after anterior resection for colorectal cancer (CRC). Pelvic floor rehabilitation (PFR) may improve functional outcomes after surgery. This review aimed to evaluate the efficacy of PFR for patients with bowel symptoms after anterior resection.

Methods MEDLINE, CINHAL, PUBMED, EMBASE, Scopus, PsycINFO, Web of Science, PEDRO and Cochrane Library were searched from inception to June 2019. A final search was performed on 11 July 2020. Randomised controlled trials (RCTs), cohort studies, case-control studies and case series of bowel dysfunction after CRC surgery and PFR were eligible for review. Outcome measures were bowel function changes measured by patient-reported outcomes and manometric measurement. Risk of bias assessments using Methodological Index for Non-Randomized Studies (MINORS) tool and Newcastle Ottawa Scale (NOS) were conducted.

Results Eleven trials met eligibility criteria: four retrospective studies and seven prospective, non-randomised controlled studies. A total of 516 participants were included, of which 455 received PFR. Functional outcomes were measured by bowel functional outcome questionnaires, patient diary, anorectal manometry and three studies measured quality of life. Faecal incontinence was improved in seven studies, and bowel frequency also decreased in five studies. The mean MINORS score was 10 (8–13) out of 16 in non-comparative groups and 18 (16–22) out of 24 in comparative groups; the NOS was 4.2 (3–7) out of 9. The overall risk of bias was high in most studies.

Conclusions PFR appears to be beneficial for improving bowel function after anterior resection for CRC. However, the studies included had methodological limitations, so further investigation on the effectiveness of PFR is warranted.

Keywords Colorectal cancer · Bowel dysfunction · Anterior resection · Pelvic floor · Rehabilitation · Biofeedback

Introduction

Colorectal cancer (CRC) is the third most commonly diagnosed cancer and accounts for 10% of all cancers worldwide [1]. There has been a shift in CRC management paradigms in the past two decades which has resulted in decreased mortality. Prevention, screening, surveillance measures and a multimodal treatment approach to CRC have improved survival, achieving a 5-year survival rate between 60 and 70% internationally [2]. The evolution of diagnostic technology and surgical techniques, together with advancements in chemoradiotherapy, has contributed to these dramatic improvements in CRC oncological outcomes [3, 4]. Total mesorectal excision (TME) with anal sphincter preservation has been widely performed for distal colon and rectal cancer in the last 20 years to minimise the need for a permanent colostomy as it is believed that the health-related quality of life is poorer in patients with a stoma [5, 6].

Although sphincter-preserving surgery allows the restoration of bowel continuity, bowel function is often

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compromised due to alterations in anatomy and physiology in the anorectum after surgery. Up to 80% of CRC survivors experience bowel habit changes, including incontinence, frequency, urgency and emptying difficulties [7] with 40% reporting severe symptoms [8]. An international consensus has defined low anterior resection syndrome (LARS) as symptoms of variable, unpredictable bowel function; emptying difficulties; altered stool consistency; urgency; increased stool frequency; incontinence; repeated painful stool; and soiling [9]. Some spontaneous recovery usually occurs in the first 6–12 months after bowel reconstruction, but improvement often then plateaus, with symptoms frequently persisting beyond 10 years [10, 11]. The ongoing bowel disturbance often leads to physical and psycho-social health consequences, placing substantial restrictions on the cancer survivor's daily activities and impacting their quality of life [9, 12].

Anterior resection syndrome is multifactorial in aetiology. Currently, LARS is hypothesised to be caused by damage to the neuromuscular structures leading to alteration of anorectal physiology and anal sphincter function, lumbosacral neuropathy from chemoradiotherapy and reduced capacity of the neorectum [10]. Risk factors for LARS include substantial involvement of the anorectum in resection surgery, administration of neoadjuvant therapy and prolonged duration of a temporary defunctioning stoma [8, 11, 13]. Systematic reviews and narrative reviews have summarised the management of LARS including medication, dietary adjustment, anal and colonic irrigation, pelvic floor rehabilitation and sacral nerve modulation [14–19]. The primary goals are to restore anorectal function using minimally invasive approaches and to optimise overall physical function after surgery to improve quality of life. Pelvic floor rehabilitation (PFR) consists of pelvic floor muscle exercises, biofeedback, rectal balloon retraining and electrostimulation that aim to improve pelvic floor muscle strength, rectal sensation and coordination [14]. Although PFR has been reported to be easy to deliver and inexpensive, with sustainable outcomes and minimal adverse effects, most of the studies have been non-randomised controlled trials and reviews limited by the poor quality of the study trials available [20, 21]. Lin et al. gave a general overview of the efficacy of pelvic floor muscle training on bowel dysfunction following all types of colorectal cancer surgery. Another systematic review by Visser et al. evaluated the effectiveness of PFR in improving functional outcome after a low anterior resection, concluding that pelvic floor rehabilitation has a beneficial effect on bowel dysfunction after anterior resection [20].

The aim of this current systematic review is to update the literature with the inclusion of additional studies that specifically evaluate PFR after anterior resection surgery for CRC, as well as examining in more depth the design of the PFR programs, and their effectiveness in treating bowel dysfunction after anterior resection surgery for CRC. This review extends the extant literature by including four recently published trials with an additional 169 subjects and two relevant older trials to assess the efficacy of PFR on bowel function after anterior resection and examining the design of PFR programs in an attempt to identify discrepancies in current practice and gaps between evidence and application.

Methods

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [22]. No protocol for this review has been registered or published.

Eligibility criteria

Eligible studies were selected according to the criteria outlined below:

Study design Quantitative study designs including randomised controlled trials (RCTs), cohort studies, case-control studies and case series were eligible for inclusion. Case reports, systematic reviews, commentaries, letters and editorials were excluded.

Participants Participants in the studies were aged over 18, had undergone anterior resection for sigmoid or rectal cancer and did not have a temporary or permanent ostomy at the time of the trial. Studies with mixed cohorts of participants with non-anterior resection and/or non-CRC were included if more than 80% of participants had an anterior resection for CRC, or if data were able to be reported separately.

Intervention PFR consists of various components of training for regaining bowel function. Of interest were interventions focussing on pelvic floor muscle strength, anorectal coordination and rectal sensation. Studies that explicitly described the intervention with pelvic floor muscle exercises alone, or in combination with biofeedback, and/or electrical stimulation, were eligible for inclusion in the review. Electrical stimulation alone (interventions involving transcutaneous, percutaneous, intra-anal electrical stimulation or sacral neuromodulation) and behavioural education alone were excluded. Pelvic floor muscle exercise was defined as any strength training to the pelvic floor muscle complex including external anal sphincter, puborectalis, as well as Kegel exercises. Types of biofeedback included visual, audio and sensory with the use of devices such as electromyography, ultrasound, digital guidance, anorectal manometry and anorectal balloon catheter [23].

Outcomes Studies were eligible for inclusion if the primary endpoint was bowel function measured by a validated

questionnaire, patient-reported symptoms, bowel diary and/or anorectal manometry.

Timing There was no restriction on time from surgery to start of PFR.

Setting There was no restriction by the type of clinical setting.

Language Studies in languages other than English were included only if they were adequately translated.

Search strategy

Both qualitative and quantitative studies were sought. No restrictions on the date of publication or study designs were imposed. Eight electronic databases: MEDLINE (1946–2019), CINHAL (1982–2019), PUBMED (1996–2019), EMBASE (1947–2019), Scopus (1823–2019), PsycINFO (1806–2019), Web of Science (1900–2019), PEDRO (1999–2019) and Cochrane Library (2019) were searched in June 2019 by one reviewer (KYC) with assistance of an academic librarian. The following Medical Subject Heading (MeSH) terms were used: colorectal cancer, colorectal neoplasm, rectal cancer, rectal neoplasms, anterior resection, bowel function, faecal incontinence, anterior resection syndrome, pelvic floor, training, rehabilitation, biofeedback and exercise (Appendix). Reference lists of identified articles were also checked. A final search was performed on 11 July 2020.

Study selection

Two of the authors (KYC, MS) independently screened the titles, and abstracts generated by the search after duplications were removed. Full texts were obtained for all titles that met inclusion criteria. The review authors then screened and selected the full text against the eligibility criteria for inclusion of qualitative synthesis. Disagreement was resolved through discussion or with the assistance of a third reviewer (JV).

Data collection process

A data collection form was designed and utilised. Data were extracted from the included studies by one reviewer (KYC) and checked by a second reviewer (MS). Disagreement was resolved through discussion or with involvement of a third reviewer (JV). Data items for extraction included study methodology (author's name, year, study design, country, inclusion criteria, trial size), demographic information (gender, age), surgery details (stage of tumour, surgery technique, level of anastomosis, diverting stoma, neoadjuvant/adjuvant therapy, duration of bowel symptoms, time since surgery), pelvic floor rehabilitation intervention details (protocol details including duration, intensity, frequency, time, type and setting) and reported outcomes (bowel function scores, patient-reported outcomes, quality of life, anal manometry and duration of follow-up) of the reviewed studies.

Risk of bias in individual studies

The risk of bias was assessed by two reviewers independently using both the Methodological Index for Non-Randomized Studies (MINORS) tool and Newcastle Ottawa Scale (NOS). MINORS is a validated instrument consisting of 8 items (aim, inclusion criteria, data collection, endpoints, blinding of assessment, follow-up period, drop-out rate and study size calculation) with an extra 4 items (control group, contemporary group, baseline equivalence of group and statistical analyses) for comparative studies. Each item is allocated a score from 0 to 2 with a maximum score of 16 (or 24 for a comparative study) [24]. The Newcastle Ottawa Scale (NOS) is an 8-item instrument divided into three categories (selection, comparability, outcome). Both cohort and case-control scales were used. The total score of the instrument is 9. For both tools, a higher score indicates lower risk of bias. The included studies were assigned an overall quality of "poor", "fair" or "good" based on the calculated score. A third reviewer was available to resolve any disagreement between the two independent reviewers. Both tools were used as they examined different perspectives of risk of bias in non-randomised controlled trials. A NHMRC hierarchy ranking was used to determine the level of evidence [25].

Data analysis

Cohen's kappa statistic on IBM SPSS statistics (Version 26 2019) was used to measure inter-rater reliability for risk of bias in the methodology assessment. Values > 0.8 indicated a strong level of agreement [26].

Results

Study selection

A total of 580 studies were identified following the electronic database search, and a further three studies were found through reference list checks. After removing the duplicated titles, initial screening by title and abstract, 32 full text articles were obtained to be assessed for eligibility. Twenty-one studies were excluded after review: nine were narrative reviews, two examined PFR in patients with an ileostomy, two consisted of non-colorectal cancer participants, two examined cases other than anterior resection, one examined electrical stimulation alone, one used the same data set from another included study, and the remaining four studies were an editorial, observational study, conference abstract and trial protocol

respectively. Email contact was attempted on two occasions to one study author [27] to clarify the participant's characteristics, but no response was received after 2 months. Eleven studies that met the eligibility criteria were included in the review (Fig. 1). Seven studies were published in the past 10 years, and two studies were published over two decades ago [28, 29]. There was minor disagreement between the two independent reviewers that was resolved after discussion with 100% consensus.

Study characteristics

Study designs

No randomised controlled trials were found. Four retrospective studies, and seven prospective, non-randomised controlled studies were included.

Participants' characteristics

A total of 522 participants were included across all studies. Six were excluded due to unmet criteria [28], leaving 516 participants for the review: 61 subjects were in control groups [30–32]. The mean age of the participants ranged from 55 to 67 years. One participant had an anterior resection for radiation proctocolitis as a result of previous cervical cancer, and all others had rectal cancer. In total, 443 participants had undergone a sphincter preserving anterior resection and 73 had an intersphincteric resection. Eight of the 11 studies reported the mean distance of the anastomosis from the anal verge in centimetres: [30, 31, 33–38] 185 had the anastomosis at > 5 cm and 290 at ≤ 5 cm. Overall, 238 participants had radiotherapy alone or both radiotherapy and chemotherapy [28–31, 33–38]. Seven studies reported that 161 participants had a diverting stoma reversed prior to the PFR intervention [30–32, 34–37]. Faecal incontinence and frequency were the most commonly reported bowel symptoms. The duration of symptoms varied from 1 month to greater than 1 year (Table 1).

Intervention

The PFR intervention protocols were very variable (Table 2). Most studies were carried out in an outpatient setting, with the exception of Liu et al. and Lin et al. who conducted home-based exercise programs. Biofeedback was used in 9 studies but varied in type. Electromyography biofeedback or rectal balloon biofeedback alone or in combination were used. Kuo et al. performed electromyography biofeedback in adjunction with neuromuscular electrical stimulation for strength and coordination training. Allgayer et al. applied electromyography biofeedback for strength and sensory training with

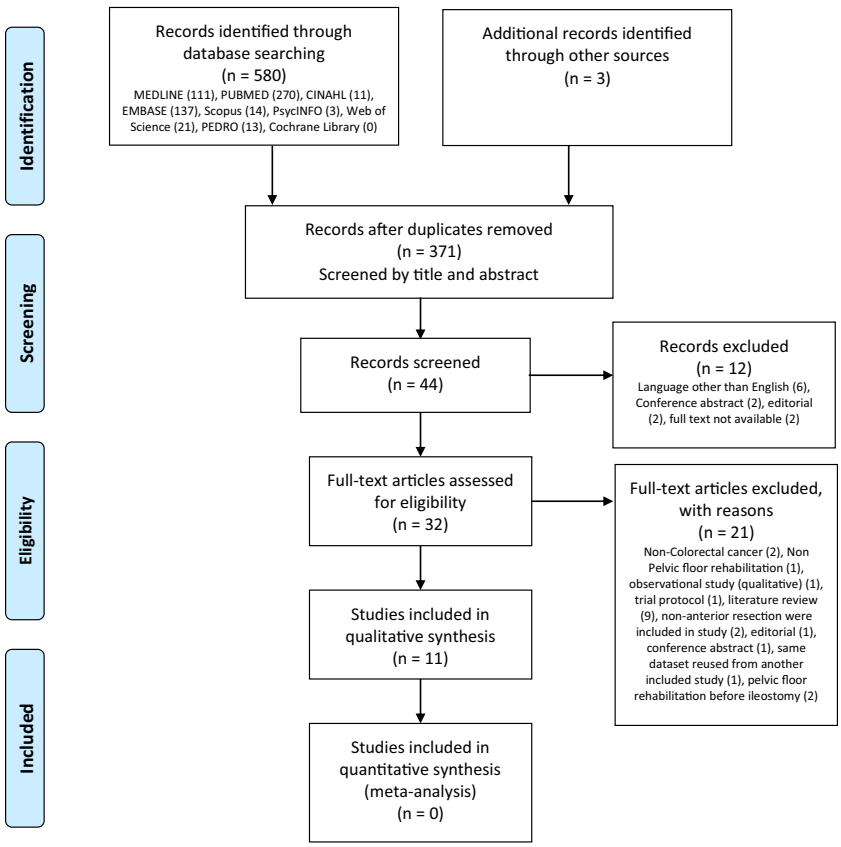

Fig. 1 PRISMA flow diagram of study selection

Table 1 Participant characteristics

Author and year	Participants (*n*)	Gender M/F	Age: mean ± SD (range)	Stage of tumour *n* (%)	Surgery details
Nishigori et al. 2018	30 LAR 20 ISR 10	23M;7F LAR 16M;4F ISR 7M;3F	67 LAR 66.7 ± 9.5 ISR 67.4 ± 8.0	Not recorded	All straight anastomosis LAR 20 ISR 10
Lin et al. 2016	54	42M; 11F Ex 18M; 9F NEx 24M; 2F	64.1 ± 12.6 (27–79)	Stage I 15 (28.3%) 9:5 (Ex:NEx) Stage II 22 (41.5%) 10:12 (Ex:NEx) Stage III 22 (22.6%) 7:5 (Ex:Nex) Stage IV 4 (7.5%) 1:3 (Ex:Nex)	All AR TME 17: 15 (Ex:NEx) PME 10:11 (Ex:NEx)
Liang et al. 2016	61	40M; 21F	63.1 ± 10.5	Stage I + II 22 (36.1%) Stage III + IV 39 (49.2%)	All AR TME 100%
Kuo et al. 2015	32	17M; 15F	56.5 ± 9.75* (31–70)	Stage I 3 (9.4%) Stage II 3 (9.4%) Stage III 23 (71.9%) Stage IV 1 (3.1%)	Radical proctectomy ISR with hand-sewn CAA Laparoscopic 4.12.5% Robotic 28, 87.3%
Laforest et al. 2012	46 Rehab 22 Control 24	26M; 20 F	Rehab 55.0 ± 11.25* (33–78) Control 60.0 ± 11.25* (35–80)	Stage I + II Rehab 8 (36.4%) Control 8 (33.3%) Stage III + IV Rehab 14 (6.6%) Control 16 (66.7%)	Laparoscopic TME 1. Conventional, low, stapled colorectal anastomosis or hand-sewn CAA with side to end anastomosis. Rehab 7, 31.81% Control 8, 33.33% 2. Partial/ Total ISR Rehab 15, 68.18% Control 16, 66.67%
Kim et al. 2011	70	49M; 21F	58.1 ± 10.1 (31–79)	Not recorded	ARS TME 100%
Liu et al. 2011	22	12M; 10F Ex 4 (36.4%) M; 7 (63.6%) F NEx 8 (72.7%) M;3 (27.3%) F	Ex 55.27 ± 14.26 (27–82) NEx 65.73 ± 8.73 (45–73)	Not recorded	Not recorded
Pucciani et al. 2008	88	34M; 54F	59.6 ± 6.75* (46–73)	Not recorded	LAR 69, 79.4%, CAA 19, 21.5%
Allgayer et al. 2005	95 Irradiated 41, 43.15%, non-irradiated 54, 56.84%	61M; 34F Irradiated 28 (68.3%) M; 13 (31.7%) F Non-irradiated 33 (61%) M; 21 (38.8%) F	Irradiated 58.5 ± 11.25* (31–76) Non-irradiated 67.0 ± 8.75* (48–83)	Stage II/III	AR 100%
Ho and Tan 1997	11	5 M;6F	64.8 ± 10.94*	Stage I 6 Stage II 1 Stage III 2 Stage IV 1	AR TME stapled anastomosis and colonic J pouch
Ho et al. 1996	13	10 M;3F	62.1 ± 16.59*	Not recorded	AR TME colorectal anastomosis cross-stapling 7, 53.85% Total colectomy 4, 46.15%

Author and year	Mean distance of anastomosis from anal verge (cm)	Oncological treatment *n* (%)	Diverting stoma *n* (%) and mean duration (months)	Symptom characteristics	Duration of symptoms (months)
Nishigori et al. 2018	LAR 4.1 ± 2.3 ISR 2 ± 0	Neoadjuvant radiotherapy LAR 0 ISR 0 Neoadjuvant	LAR 13 (65%) ISR 10 (100%) Duration not specified	Faecal incontinence Frequency defaecation	LAR 10.2 ± 12.3 ISR 12 ± 12.2

Table 1 (continued)

		chemotherapy LAR 6 (30%) ISR 4 (40%)		Faecal urgency	
Lin et al. 2016	≤ 5 cm 11:13 (Ex:NEx) > 5 cm 16:13 (Ex:NEx)	Neoadjuvant radiotherapy 3 (11.1%):5 (8.5%)(Ex:NEx)	27 (100%) 5.3 ± 3.7	Not recorded	0
Liang et al. 2016	5.2 ± 3.1	Radiotherapy 14 (23%) chemotherapy 13 (21.3%)	33 (54.1%) Duration not specified	Faecal incontinence Frequency defaecation Faecal urgency	7.7 ± 2.9
Kuo et al. 2015	Not recorded. The distance from the AV to the lowest border of the tumour 3.89 ± 0.875 (1.5–5)	Neoadjuvant chemoradiation 25 (78.1%)	5 (15.6%) 7 (3–8)**	Faecal incontinence Frequency defecation Faecal urgency Incomplete evacuation Stool fragmentation	8.2 ± 12.1**
Laforest et al. 2012	Not recorded. The distance from dentate line to the tumour: Rehab 3 (0.5–9) Control 2.5 (1–9) Anastomosis located at or below 30 mm from dentate line	Neoadjuvant radiochemotherapy Rehab 15 (68.2%) Control 17 (70.8%)	T3/T4 30 1.5–2	not recorded	1
Kim et al. 2011	4.1 ± 1.8 (1.0–9.0)	Radiation therapy 49 (70%), neoadjuvant 30 (61.2%), adjuvant 19 (38.8%), chemotherapy 57 (81.4%), neoadjuvant 1 (1.8%), adjuvant 25 (43.9%), both 31 (54.4%)	21 (30%) 7 (3–8)**	Faecal incontinence, frequency defaecation, faecal urgency, incomplete evacuation, stool fragmentation	25.5 ± 21.2
Liu et al. 2011	Not recorded	Not recorded	22 (100%) 6–10	Faecal incontinence, frequency defaecation	1 to > 12
Pucciani et al. 2008	LAR 4.5 ± 1, CAA 2.6 ± 0.8	Neoadjuvant radiotherapy 19 (21.5%), adjuvant radiotherapy 34 (38.6%)	Not recorded	Faecal incontinence	22.4 ± 7.8*
Allgayer et al. 2005	Irradiated 7.6 ± 3.1, non-irradiated 10.3 ± 4.2	41 (43.2%)	Not recorded	Faecal incontinence	1.5 (1–10)**
Ho and Tan 1997	Not recorded	Adjuvant radiotherapy 2 (18.2%)	Not recorded	Faecal incontinence, Frequency defaecation, Faecal urgency, Incomplete evacuation	33.3 ± 20.2*
Ho et al. 1996	Not recorded	Adjuvant radiotherapy 4 (30.8%)	Not recorded	Faecal incontinence, Frequency defaecation	27.0 ± 22.7*

LAR low anterior resection, *ISR* intersphincteric resection, *M* male, *F* female, *Ex* exercise, *NEx* non-exercise, *AR* anterior resection, *TME* total mesorectal excision, *CAA* coloanal anastomosis, *AV* anal verge

*SD = range/4 or SEM/square root of *n*

**Median

Table 2 Intervention

Author and year	Intervention details	Frequency	Duration	Intensity	Time	Type	Setting
Nishigori et al. 2018	1. EAS strength training with EMG visual biofeedback and home exercise 2. Coordination and sensory training with rectal balloon biofeedback	1 every 2–3 weeks	6 months	Not specified	Not recorded	Strength, coordination and sensory with EMG and rectal balloon biofeedback	Supervised OP. Self-monitored home exercise
Lin et al. 2016	1. Routine postop care with information pamphlet for diet and wound care. 2. PFM exercise with instruction for anal sphincter contraction. 3. Participants were educated on self-assessing muscle contraction and informational DVD and pamphlet were given.	4 sessions/day	9 months (based on the time of evaluation)	20 contractions/session	Not recorded	EAS strength training	Home; unsupervised
Liang et al. 2016	Use of rectal balloon biofeedback and EMG biofeedback. EAS contraction without balloon for 30 min ×2/day at home.	Home exercise 2/day. Rectal balloon training either < 15 or > 15	Not recorded	Not recorded	30 min (home)	Strength, coordination and sensory with EMG biofeedback and rectal balloon biofeedback	Home and supervised OP
Kuo et al. 2015	NMES for muscle re-education and contraction. After 2 sessions of NMES, EMG biofeedback was used.	NMES 2–3/week EMG biofeedback 2–3/week	NMES 12 sessions EMG BF 2–3 months	NMES: ramp up and down 2 s with duration of 8 s, frequency 30 Hz on/off 1:3 pulse. EMG biofeedback: 30–40-s hold each contraction	NMES 20 min. EMG biofeedback not specified	Strength and coordination of PFM during voluntary contraction	Supervised OP
Laforest et al. 2012	Rectal balloon biofeedback: PFME with emphasis on maintaining relaxed abdominal muscle while squeezing the perineal muscle with maximum effort in order to achieve 150 ml rectal capacity, 3/5 on perineal strength and the ability to perform perineal muscular locking.	1/week	15 sessions	Not recorded	1 h	Strength and sensory	Supervised OP
Kim et al. 2011	Rectal balloon biofeedback with 3 protocols for strength, coordination and sensory training. Participants were asked to practice EAS contraction without RBBF at home	1/week	10 weeks	Not recorded	Several times for each component in each session.	Strength, coordination and sensory with EMG biofeedback and rectal balloon biofeedback	Supervised OP and home
Liu et al. 2011	Education. Use of hand out and demonstration for Kegel's exercise. Self-monitoring exercise technique. PFM contraction exercise. Non-PF specific exercise.	3–4/day	12–29 months (20 ± 47)	Not recorded	10 min	Strength	Home. Unsupervised
Pucciani et al. 2008	Multimodal rehabilitation based on manometry findings. Pelviperineal kinesitherapy (PK), biofeedback (BF), columetric rehabilitation (VR), electrostimulation (ES). Using visual or verbal feedback, tepid water enema and portable device.	PK 2/week BF 2/day VR 2/day ES 1/day	PK 7 sessions ES 3 months	121 ± 34 days	BF 20 min	Strength, coordination and sensory	Supervised OP and home
Allgayer et al. 2005	PFE. Routine rehabilitation program include information, psychological support, light aerobic exercise. EMG biofeedback with intra-anal EMG device. Home exercise with EMG biofeedback.	1/day	3 weeks	Not recorded	30–40 min PFE. Home 1-h training	Strength and sensory	Supervised OP and home
Ho and Tan 1997	Rectal balloon biofeedback with visual display.	1/day	4 sessions	Not recorded	1 h	Strength, coordination and sensory	Supervised OP and home

Table 2 (continued)

Author and year	Intervention details	Frequency	Duration	Intensity	Time	Type	Setting
Ho et al. 1996	Rectal balloon biofeedback with visual display.	1/ day	4 sessions	Not recorded	1 h	Strength, coordination and sensation	Supervised OP and home

EAS external anal sphincter, *EMG* electromyography, *NMES* neuromuscular electrical stimulation, *OP* outpatient, *PF* pelvic floor, *PFM* pelvic floor muscle, *PFE* pelvic floor exercise

additional psychological support and light aerobic exercise. Two studies did not use any instrument but emphasised correct pelvic floor exercise technique with the use of educational material for strength training [31, 32]. Six studies used rectal balloon biofeedback for strength, sensory and coordination pelvic floor training [28–30, 34, 36, 37]. One study used a tailored multimodal program with four regimes [38]. The duration of the rehabilitation program varied from 3 weeks to 29 months. The frequency of training for each study differed from a daily session to once every 2–3 weeks and the duration for each session from 10 min to 1 h.

Outcome measures

Bowel function outcome measures were most commonly faecal incontinence episodes and bowel frequency. Wexner Faecal Incontinence Score (WIS) [30, 34–38], Modified Cleveland Incontinence Score (MCIS) [33], Vaizey Incontinence Score, [36] Gastrointestinal Standardized Questionnaire [30], patient report [32, 34–38] and a bowel diary [28, 29] were used. Two studies used anterior resection-specific bowel function questionnaires [37, 38]. Three studies measured quality of life with questionnaires which included the Faecal Incontinence Quality of Life Scale, Short Form 36 and Functional Assessment of Cancer Therapy-Colorectal Cancer (FACT-C) [30, 32, 37]. Manometry investigations were used to measure anorectal function outcomes in 8 studies [28, 29, 33–38].

Study quality and risk of bias assessment

Risk of bias of studies were assessed with MINORS and NOS and are presented in Tables 3 and 4. The inter-rater agreement of quality assessment was determined by Cohen's kappa statistic. The kappa coefficient was 0.838 for MINORS and 0.959 for NOS. Minor disagreements occurred (10 of 192 items), but 100% consensus was reached with discussion. The studies were limited by lack of blinded assessment, adequate study size and long-term follow-up [30–38]. Due to these limitations, most studies were rated "fair" with less than 80% of the total score achieved in MINORS and less than 7 (out of 9) on NOS. Only two studies achieved a high score in both assessments [31, 32]. Based on the risk of bias assessment, the level of evidence of all studies was rated between level III and IV on the NHMRC hierarchy ranking [25].

Results of the functional outcomes

Faecal incontinence

Faecal incontinence severity was reported based on questionnaire administration [30–38], patient bowel diary [28, 29] and verbal report [32]. Seven studies used WIS ($n = 381$), and one study used MCIS ($n = 95$). There was substantial score improvement at the end of the PFR ($p < 0.05$) in most studies (Table 4). However, one study did not show a significant difference in WIS after the intervention compared with the control group [30]. Two studies reported that the number of episodes of faecal incontinence had decreased after four sessions of treatment ($p < 0.05$). One study found the improvement continued after 1 year ($p < 0.001$) (Tables 5).

Bowel frequency

Bowel frequency per 24 h was reported in nine studies ($n = 367$). Five studies showed that the number of bowel movements decreased after the intervention ($p < 0.05$) [28, 34–37]. One study also showed a significant improvement after rehabilitation compared with case-matched controls ($p = 0.025$) [30]. Only one study reported no significant difference in bowel frequency before and after the intervention [38]. One study reported the number of weekly bowel motions [29] and another study the number of participants who had > 3 defaecations per day [32]. Due to the difference in reporting, the findings of these two studies were not included.

Quality of life

Quality of life was examined in three studies ($n = 98$) with the use of FIQL, SF36 and FACT-C [30, 32, 37]. A significant difference was found in the total score for CRC-specific quality of life in the intervention group compared with controls ($p = 0.038$) [32]. One study demonstrated some improvement

Table 3 Risk of bias assessment: Methodological Index for Non-Randomized Studies (MINORS)

Reference	Year	Country	Study design	MINORS score (total)	Quality assessment
Nishigori et al.	2018	Japan	Retrospective analysis (case series)	8/16	Fair
Lin et al.	2016	Taiwan	Longitudinal experimental (cohort)	22/24	Good
Liang et al.	2016	China	Retrospective (case series)	9/16	Fair
Kuo et al.	2015	Taiwan	Prospective observational (case series)	8/16	Fair
Laforest et al.	2012	France	Prospective case control (case control)	16/24	Fair
Kim et al.	2011	Korea	Retrospective cohort (case series)	12/16	Fair
Liu et al.	2011	Taiwan	Retrospective cohort (cohort)	13/16	Good
Pucciani et al.	2008	Italy	Prospective non-randomized (case control)	17/24	Fair
Allgayer et al.	2005	Germany	Prospective case control (case series)	11/16	Fair
Ho and Tan	1997	Singapore	Prospective (case series)	10/16	Fair
Ho et al.	1996	Singapore	Prospective (case series)	10/16	Fair

The items are scored 0 (not reported), 1 (reported but inadequate) or 2 (reported and adequate). The ideal score being 16 for non-comparative studies and 24 for comparative studies. < 50% Poor, 51–80% fair, > 80% good

in two domains (vitality and mental functioning) of SF36 [30]. A contradictory finding was shown in two studies where FIQL was used to assess the impact of faecal incontinence on quality of life [30, 37]. One study showed a significant improvement in the three domains except depression/self-perception after the intervention in the LAR group [37]. In contrast, another study found significant improvement in depression/self-perception ($p = 0.005$) but not in the other three domains [30].

Anal manometry

Bowel function was measured by anorectal manometry (Table 6). Eight studies ($n = 394$) examined the changes on resting pressure, squeeze pressure and maximum tolerable volume (MTV). Two studies showed significant improvement in resting pressure ($p \leq 0.001$) and in MTV ($p < 0.05$) after the intervention [34, 36]. A significant change in squeeze pressures was demonstrated in three studies ($p < 0.05$) [34–36]. However, three studies showed lack of significance in the change of all measures [28, 29, 37]. The outcome results in two studies did not compare patients' outcomes pre and post intervention but rather compared the intervention against the control group [33, 38].

Discussion

The aim of this systematic review was to critically evaluate the available evidence on the efficacy of PFR for bowel dysfunction after anterior resection for CRC. Bowel dysfunction and anterior resection syndrome were interchangeably used in the existing studies. These two terms were used to describe faecal incontinence, urgency, frequency, incomplete evacuation and stool fragmentation associated with anterior resection. This systematic review of 11 non-randomised controlled trials, in which seven studies were published within the past 10 years, demonstrated that PRF can improve functional outcome after anterior resection for CRC. Most included studies produced a favourable result in achieving continence and reducing bowel frequency with the use of patient-reported outcomes and manometry assessments. Quality of life was measured in three studies; however, there was only scant evidence for improvement in quality of life. A meta-analysis was not performed due to heterogeneity of treatment protocols and outcome measures, and limited methodology quality. Therefore, this review could not draw any valid conclusion on the size of effect of PFR for bowel dysfunction after CRC surgery.

PFR was demonstrated to be effective for managing faecal incontinence after anterior resection in 9 out of 11 studies based on the improved score of WIS, MCIS and number of incontinent episodes. However, Laforest et al. showed a contrasting result where PFR did not improve the WIS score, i.e., faecal incontinence. The differing outcome in this study could possibly be explained by the presence of associating factors for anterior resection syndrome. Firstly, subjects in this study were recruited 1 month after stoma closure. The post intervention (15 weeks) functional outcomes measuring period was within the first 6 months after bowel reconstruction. Previous studies have shown that bowel function recovery occurs in the first 6–12 months after restoration of bowel continuity [39, 40]. Assessing bowel function in the early stages of bowel adaptation may lead to false-negative results, which may explain the insignificant improvement of faecal incontinence after PFR found in this study. Secondly, participants in the study had had a mix of surgical techniques for anterior resection: coloanal

Table 4 Risk of bias assessment: Newcastle Ottawa Scale (NOS)

		Selection				Comparability	Outcome			
Reference	Year	Representativeness of the exposed cohort	Selection of the non-exposed cohort	Ascertainment of exposure	Demonstration that outcome of interest was not present at start of study	Comparability of cohorts on the basis of the design or analysis	Assessment of outcome	Was follow-up long enough for outcomes to occur	Adequacy of follow-up of cohorts	Total Score
Nishigori et al.	2018	*	(−)	(−)	*	(−) (−)	(−)	*	(−)	3
Liang et al	2016	*	(−)	*	(−)	(−) (−)	(−)	*	(−)	3
Kuo et al	2015	*	(−)	(−)	*	(−) (−)	(−)	*	(−)	3
Kim et al	2011	*	(−)	*	*	(−) (−)	(−)	*	*	5
Allgayer et al	2005	*	(−)	*	*	(−) (−)	*	*	*	6
Ho & Tan	1997	*	(−)	(−)	*	(−) (−)	*	*	*	5
Ho et al.	1996	*	(−)	(−)	*	(−) (−)	*	*	*	5
		Selection				Comparability	Exposure			
Reference	Year	Is the case definition adequate?	Representativeness of the cases	Selection of controls	Definition of controls	Comparability of cases and controls on the basis of the design or analysis	Ascertainment of exposure	Same method of ascertainment for cases and controls	Non-response rate	Total
Lin et al	2016	*	*	*	*	* (−)	(−)	*	*	7
Laforest et al	2012	*	*	(−)	(−)	* *	(−)	(−)	(−)	4
Liu et al	2011	*	*	*	*	* (−)	(−)	*	*	7
Pucciani et al.	2008	*	*	(−)	(−)	* (−)	(−)	*	*	5

*Is allocated if the criteria is satisfied whereas (−) if criteria is not satisfied. Total of 9

Table 5 Functional outcome: patient-reported outcome

Author and year	Functional outcome tool	Before intervention		After intervention		*p* value
		Group 1	Group 2	Group 1	Group 2	
Nishigori et al. 2018*	Wexner Faecal Incontinence Score†	10.7	13.1	5.7	12.6	Group 1 0.01; group 2 0.73
	Faecal Incontinence Severity Index†	28	35	11	30	Group 1 0.04; group 2 0.38
	LARS score†	33	35	26	29	Group 1 0.02; group 2 0.05
	Number of defaecations per 24 h	10.1 ± 3.0	12 ± 5.2	2.7 ± 1.2	3.7 ± 1.8	Group 1 < 0.01; group 2 0.02
	Bristol stool scale	5 ± 1.0	5.1 ± 0.5	4 ± 1.1	3.2 ± 1.0	Group 1 NS; group 2 0.02
	Anti-diarrheal medication (*n*)	15	10	7	5	Group 1 0.02; group 2 0.03
Lin et al. 2016	Wexner Faecal Incontinence Score			3.3 ± 2.4 (T3)	6.19 ± 4.03 (T3)	0.006 (other T NS)
Liang et al. 2016	Wexner Faecal Incontinence Score	10.3 ± 2.0		7.8 ± 2.6		< 0.001
	Vaizey Incontinence Score	13.1 ± 2.2		10.6 ± 2.3		< 0.001
	Number of defaecations per 24 h	8.7 ± 3.8		6.2 ± 3.8		< 0.001
Kuo et al. 2015	Wexner Faecal Incontinence Score	17.74 ± 3.03		12.93 ± 4.73		< 0.001
	Number of defaecations per 24 h	18.77 ± 8.52		7.83 ± 4.27		< 0.001
	Stool urgency	30		25		0.063
	Stool fragmentation	31		24		0.016
	Anti-diarrheal medication (*n*)	27		9		< 0.001
	Nocturnal defaecation	9		6		0.125
Laforest et al. 2012	Wexner Faecal Incontinence Score			8.3 ± 3	9.9 ± 3	0.1
	Kirwan's classification (type I–V)			4,6,8,4,0	3,7,11,3,0	1
	Number of defaecation per 24 h^			2.6 ± 1.25	4 ± 2.25	0.025
	Stool urgency^			8	9	1
	Stool fragmentation (> 2 evacuations in 1 h)^			15	19	0.5
	Dyschezia (stretching to evacuate)^			5	15	0.008
	Anti-diarrheal medication (n)^			12	12	0.77
	Ailmentary restriction^			8	10	0.88
	SF36-Vitality			47.3 ± 9.9	39.3 ± 8.2	0.004
	SF36-Mental Functioning			48.3 ± 7.1	42.7 ± 8.6	0.02
	FIQL-Depression/Self-Perception			3.2 ± 0.6	2.6 ± 0.7	0.005
Kim et al. 2011	Wexner Faecal Incontinence Score	13.0 ± 5.2		8.4 ± 6.0		< 0.001
	Number of defaecation per 24 h	9.4 ± 4.5		5.8 ± 3.3		< 0.001
	Anti-diarrheal medication (*n*)	24		9		NR
	Patient satisfaction VAS			61.9 ± 27.6		
Liu et al. 2011	Defaecation > 3#			4	5	1
	Faecal incontinence or faecal seepage			5	5	1
	FACT-C			66.27 ± 11.98	49.06 ± 19.28	0.038
Pucciani et al. 2008**	Wexner Faecal Incontinence Score	11.8 ± 5.09	12.52 ± 4.45	6.4 ± 3.71	5.81 ± 3.6	< 0.05; < 0.02
	MSKCC (1: LAR 2: CAA)†	32.8 ± 5.4	26.6 ± 4.1	16.6 ± 6.3	14.6 ± 3.1	NS
	Number of defaecation per 24 h	2.9 ± 0.7	4.4 ± 0.8	1.8 ± 0.6	3.4 ± 0.7	NS
Allgayer et al. 2005***	Modified Cleveland Incontinence Score‡	7.4 ± 2.2	8.6 ± 2.8	(9.3 ± 2.5) 8.1 ± 3.6	(11.5 ± 2.6) 10.5 ± 4.4	Both groups 0.001
Ho and Tan 1997****	Number of defaecation per week	37.3	3	14.4	8.9	Group 2 < 0.05
	Number of incontinent episodes	14.8		1.8		< 0.05
	Pad wearing (*n*)	5		0		
	Straining at defaecation		5		1	
	Sensation of incomplete emptying		3		0	
	Anti-diarrheal/laxative medication (*n*)	6	5	0	2	Group 1 < 0.005
Ho et al. 1996	Number of defaecations per 24 h	8.7		4.6		< 0.05
	Number of incontinence episodes	2.7		0.4		< 0.05
	Anti-diarrheal medication (*n*)	6		1		< 0.05

*Group 1 = CAA (coloanal anastomosis), group 2 = ISR (intersphincteric resection)

**Group 1 = LAR (low anterior resection), group 2 = CAA

***Group 1 = irradiated, group 2 = non-irradiation

****Group 1 = faecal incontinence, group 2 = constipation

^Gastrointestinal standardized questionnaire

This outcome measured number of participants who had > 3 defaecation

† Low score indicates better outcome

‡ High score indicates better outcome

anastomosis or intersphincteric resection. Low anastomotic height is a major risk factor for LARS [8]. An anastomosis with intersphincteric resection indicated that partial removal of the anal sphincter was required to try and achieve a good oncological outcome due to a low-lying rectal cancer. This is more likely to result in permanent muscle damage leading to poorer faecal continence outcomes. Other reasons such as radiotherapy and chemotherapy, presence and the duration of a defunctioning stoma and the duration of bowel symptoms have been found

Table 6 Functional outcome: manometric measures

Author and year	Group	Resting pressure (max) (mean ± SD) Before	After	*p* value	Squeeze pressure (max) (mean ± SD) Before	After	*p* value	Rectal capacity (MTV) (mean ± SD) Before	After	*p* value
Nishigori et al. 2018	LAR	NR	NR	NR	NR	NR	NR	NR	NR	NR
	ISR	35	44	0.39	188	275	0.14	110	131	0.43
Liang et al. 2016		25.8 ± 12.3	37.0 ± 12.8	< 0.001	120.2 ± 42.0	146.5 ± 40.9	0.001	119.0 ± 50.7	143.6 ± 52.8	0.015
Kuo et al. 2015		(−)4.21 ± 7.29*	(−)4.08 ± 3.80*	0.061	34.43 ± 35.37*	37.08 ± 22.42*	0.014	NR	NR	NR
Kim et al. 2011		39.1 ± 11.1	44.9 ± 18.1	0.01	136.4 ± 45.2	162.7 ± 56.1	0.006	102.3 ± 42.3	120.3 ± 30.6	0.003
Pucciani et al. 2008	LAR	47.6 ± 21.4	69.1 ± 21.6	NR	88.3 ± 49.1	107.1 ± 79.8	NR	133.8 ± 51.2	131 ± 42.8	NR
	CAA	46.0 ± 18.9	63.3 ± 20.7	NR	86.9 ± 56.1	98.8 ± 37.7	NR	124 ± 52.9	143.1 ± 34.6	NR
Allgayer et al. 2005	Irradiated	27.3 ± 17.2	NR	NR	79.5 ± 34.0	NR	NR	91.2 ± 36.8	NR	NR
	Non-irradiated	33.3 ± 17.8	NR	NR	79.5 ± 34.1	NR	NR	103.0 ± 29.5	NR	NR
Ho and Tan 1997	Incontinent	52.3	57.6	NS	89.3	108.2	NS	130.5	123	NS
	Constipation	50.4	71.3	NS	109.8	118.5	NS	89.5	148.5	NS
Ho et al. 1996	AR	53.3	73.3	NS	134.7	171.7	NS	192	110	NS

NR not reported, *NS* not significant, *LAR* low anterior resection, *ISR* intersphincteric resection, *CAA* coloanal anastomosis, *AR* anterior resection

*Unit measures: hPa

to predict bowel function outcomes and responsiveness to PFR [8, 13]. The inadequate participant characteristics reported for a number of these factors in many of the reviewed studies could affect the generalisability of the studies on the efficacy of PFR for patients with bowel dysfunction. A checklist of associated factors would be beneficial if it was included in future trials.

The goal of PFR is to improve storage and evacuatory function of the neorectum by carrying out specific training on sphincter and pelvic floor muscle strength, rectal sensation and anorectal coordination. Muscle contraction and relaxation exercise and biofeedback therapy are often key components in the rehabilitation program. In this review, nine studies used a combination of sphincter muscle and pelvic floor strengthening exercise and biofeedback therapy in the form of either electromyography biofeedback, rectal balloon catheter or both. One study incorporated neuromuscular electrical stimulation as additional treatment in the program. Two studies used pelvic floor muscle exercise alone. A previous Cochrane review suggested biofeedback ± electrical stimulation in conjunction with pelvic floor exercise may be useful for benign faecal incontinence [41], and there was supporting evidence of biofeedback for dyssynergic defaecation [42]. ARS is multifactorial in aetiology and requires a progressive escalation of management to regain optimal bowel function. PFR should be considered in patients that do not respond to dietary adjustment or medications, before considering surgical options [19]. Although most studies in this review used similar PFR modalities, there was a wide variation of protocols used across studies. In addition, the reporting of interventions showed a lack of tailoring, modification and detailed information on frequency, intensity, time and type (FITT), and information on the intervention, adherence and fidelity according to the Template for Intervention Description and Replication (TIDieR) checklist (Table 7) [43]. This information is particularly important to determine if the protocol is suitable, viable and can be replicated in other clinical settings. Hence, it would be beneficial for future PFR studies to establish a standardised protocol with comprehensive intervention reporting in order to investigate the efficacy, appropriateness and feasibility.

Bowel functional outcomes were measured by a variety of assessment tools across studies. The most commonly used was WIS, but MCIS, Vaizey Incontinence score and patient diaries were also utilised for outcome evaluations.

Table 7 Template for Intervention Description and Replication Checklist (TIDieR)

Study	Brief name	Why	What (materials)	What (procedures)	Who provided	How	Where	When and How much	Tailoring	Modifications	How well (planned)	How well (actual)
Nishigori et al. 2018	Y	Y	Y	Y	Y	Y	Y	P	N	N	N	N
Lin et al. 2016	Y	Y	Y	Y	Y	Y	Y	P	N	N	N	N
Liang et al. 2016	Y	Y	Y	Y	N	Y	N	P	N	N	N	N
Kuo et al. 2015	Y	Y	Y	Y	N	N	N	Y	Y	N	N	N
Laforest et al. 2012	Y	Y	Y	Y	Y	Y	Y	P	Y	N	N	N
Kim et al. 2011	Y	Y	Y	Y	Y	Y	Y	P	N	N	N	N
Liu et al. 2011	Y	Y	Y	Y	N	N	N	P	N	N	N	N
Pucciani et al. 2008	Y	Y	Y	Y	N	Y	N	Y	Y	N	N	N
Allgayer et al. 2005	Y	Y	Y	Y	Y	Y	Y	P	N	N	N	N
Ho and Tan 1997	Y	Y	Y	Y	N	Y	Y	P	N	N	N	N
Ho et al. 1996	Y	Y	Y	Y	N	Y	Y	P	N	N	N	N

Y yes, *N* no, *P* partial

Three studies examined the impact of bowel dysfunction on quality of life with the use of FIQL, SF36 and FACT-C. Due to the heterogeneity of assessing tools used, a meta-analysis was not possible to determine the effect size of PFR on bowel dysfunction. Faecal incontinence is the major symptom of ARS; however, high prevalence of faecal urgency and evacuation difficulty have also been reported [10]. Indeed, in a recent international consensus, ARS was defined as experiencing at least one of the following symptoms after sphincter-preserving rectal resection: emptying difficulties, urgency, incontinence, soiling, variable and unpredictable bowel function, altered stool consistency, increased stool frequency and repeated painful stools [9]. Thus, a validated patient-reported outcome assessment tool that covers these attributes should be implemented in the evaluation process. Low Anterior Resection Syndrome (LARS) score [44] and Memorial Sloan Kettering Cancer Centre Bowel Function Instrument (MSKCC-BFI) were developed for the purpose of assessing bowel function in this specific population. In this review, only two studies used these questionnaires [37, 38]. The lack of consistency in using meaningful assessment tools has led to inaccurate measures of bowel functional outcome. Manometric measures have been used in eight studies. Three studies showed significant improvement in maximal squeeze pressure, and two studies showed improvement in rectal capacity with an improved WIS. The findings of these studies demonstrated an association between physiological changes and faecal incontinence. The sustainability of any treatment effect is unknown due to insufficient long-term follow-up. There is an urgent need to standardise the selected bowel function outcome and quality-of-life measures in future studies, preferably with longer-term follow-up, in order to provide more robust evidence concerning the efficacy of PFR for bowel dysfunction after anterior resection.

Strengths and limitations

The main strength of this review is that it included a comprehensive literature search which yielded an additional four studies compared with previous systematic review [20]. There are several limitations, including low quality across all studies due to small sample sizes, insufficient long-term follow-up and lack of randomisation and blinding assessment, leading to a high risk of bias. The heterogeneity of outcome

measures, variations in intervention protocols and absence of training adherence reporting, meant pooling of data was not possible.

Conclusion

In conclusion, this systematic review found that patients with bowel dysfunction symptoms after anterior resection for colorectal cancer may benefit from PFR. The findings of this review should be interpreted with caution due to several methodological limitations of the reviewed studies. Further well-designed PFR trials that include detailed description of participants' characteristics, a comprehensive protocol to allow examination on its efficacy, appropriateness and feasibility and use of standardised and validated outcome measures specifically for ARS evaluation should be considered in order to produce valid and relevant evidence for future care pathway development in colorectal cancer management.

Author contributions JV is the guarantor. KYC drafted the manuscript. KYC, MS and JV contributed to the development of the selection, the risk of bias assessment strategy and data extraction criteria. KYC developed the search strategy. MS provided expertise on anterior resection. SC and all authors read, provided feedback and approved the final manuscript.

Data availability Not applicable.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethics approval This review article does not have human participation trials conducted by any of the authors.

Consent to participate Not applicable.

Consent for publication Not applicable.

Code availability Not applicable.

Appendix. An example of search strategy

Database: Ovid MEDLINE(R) ALL <1946 to June 26, 2019>
Search Strategy:

1 Colorectal cancer.mp. or Colorectal Neoplasms/ (116527)
2 rectal cancer.mp. or Rectal Neoplasms/ (46607)
3 anterior resection.mp. (4289)
4 bowel function.mp. (3320)
5 Fecal Incontinence/ or faecal incontinence.mp. (10106)
6 anterior resection syndrome.mp. (158)
7 pelvic floor.mp. or Pelvic Floor/ (10236)
8 training.mp. (404940)
9 rehabilitation.mp. or Rehabilitation/ (301618)
10 biofeedback.mp. or Biofeedback, Psychology/ (9837)
11 Exercise/ or exercise.mp. (327634)
12 1 or 2 or 3 (155700)
13 4 or 5 or 6 (13166)
14 7 or 8 or 9 or 10 or 11 (935614)
15 12 and 13 and 14 (111)

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DATA SHARING STATEMENT

Pre-operative video about bowel function and supportive care in colorectal cancer: feasibility study

Registration number:	ACTRN12624000931572
Date registered:	1/08/2024
Date this registration last updated:	1/08/2024
Type of registration:	Retrospectively registered
Date this document generated:	10/07/2025

Will the study consider sharing individual participant data?

No

No IPD sharing reason/comment: Under the SLHD ethics committee privacy act, individual participant data will not be disclosed and shared.

How or where can supporting documents be obtained?

DATA SHARING STATEMENT

A pelvic floor rehabilitation program for patients with bowel dysfunction after sphincter- preserving surgery for colorectal cancer: a feasibility study

Registration number:	ACTRN12620000821998
Date registered:	17/08/2020
Date this registration last updated:	16/02/2023
Type of registration:	Prospectively registered
Date this document generated:	10/07/2025

Will the study consider sharing individual participant data?

No

No IPD sharing reason/comment: Under the SLHD ethics committee privacy act, individual participant data will not be disclosed and shared.

How or where can supporting documents be obtained?

The behaviour change wheel: A new method for characterising and designing behaviour change interventions

Author: Susan Michie et al

Publication: Implementation Science

Publisher: Springer Nature

Date: Apr 23, 2011

Order Date	30-Nov-2025	**Type of Use**	Republish in a thesis/dissertation
Order License ID	1676451-1		
ISSN	1365-2648	**Publisher**	BLACKWELL PUBLISHING
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LICENSED CONTENT

Publication Title	Journal of advanced nursing	**Publication Type**	e-Journal
Article Title	Advancing the science of symptom management.	**Start Page**	668
		End Page	676
Date	01/01/1976	**Issue**	5
Language	English	**Volume**	33
Country	United Kingdom of Great Britain and Northern Ireland	**URL**	http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1365-2648
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Lifetime Unit Quantity	Up to 499		
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NEW WORK DETAILS

Title	The experiences of a structured pelvic floor rehab program in colorectal cancer survivors with low anterior resection syndrome: A qualitative study	**Institution Name**	University of Sydney
		Expected Presentation Date	2025-12-31
Instructor Name	Kin Yin Chan		

ADDITIONAL DETAILS

The Requesting Person / Organization to Appear on the License	Kin Yin Chan

REQUESTED CONTENT DETAILS

Title, Description or Numeric Reference of the Portion(s)	Figure 1 Revised symptom management conceptual model	**Title of the Article / Chapter the Portion Is From**	Advancing the science of symptom management.
Editor of Portion(s)	Debra Jackson	**Author of Portion(s)**	Marilyn Dodd, Susan Janson, Noreen Facione, Julia Faucett
Volume / Edition	33		
Page or Page Range of Portion	668-676	**Publication Date of Portion**	2008-07-07

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Last updated October 2022