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Bowel symptom management following sphincter-sparing surgery for rectal cancer.

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MSc of Research

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Bowel symptom management following sphincter-sparing surgery for rectal cancer.

Abstract

Aims

The aim of this study is to determine the content, format and mode of delivery of an intervention for patients following sphincter-sparing surgery who have experienced altered bowel function.

Background

The treatment of rectal cancer often causes the development of life-altering bowel symptoms. Healthcare professionals play a pivotal role in supporting patients in their management of symptoms but increasingly it is recognised that care often becomes the patients' sole responsibility. Numerous studies have identified the need to support patients in the self-care of their bowel symptoms and to develop interventions to facilitate same. Yet there is a dearth of literature around interventions to support patients with the symptoms specific to rectal cancer treatment, to self-care for their bowel symptoms, which do not involve the use of invasive techniques or continuous health-care professional input.

Design

A qualitative descriptive design.

Methods

To determine the content, format and mode of delivery of an intervention a purposeful sample of five patients and ten healthcare professionals were interviewed through individual semi-structured, audio-recorded interviews. Participants included those who had undergone sphincter-sparing surgery for rectal cancer and those involved in their care. An initial pilot study was carried out prior to conducting the main study. Data were analysed utilising deductive content analysis and data coded according to pre-determined categories. The research was underpinned by the Symptom Management Theory and also utilised the Medical Research Council Framework Guidance for the Development of Complex Interventions.

Findings

Participants acknowledged the existence and impact of bowel dysfunction following surgery for rectal cancer, often continuing for a number of years post-treatment and varying from frequency, urgency and tenesmus to skin irritation and pain, in addition data analysis revealed multiple symptoms which occurred and in addition the variability of these symptoms in relation to severity, duration and associated degree of bother. The psychological and social impact of symptoms was also evident. All participants (n=15) acknowledged issues within the current practice around educating patients about the incidence, treatment and self-care of bowel symptoms, often resulting in prolonged periods of symptom experience or use of unhelpful or unsafe self-care strategies. Additionally, participants identified the need for the development of an intervention to support patients. Patients and healthcare professionals identified a phone application as a convenient and accessible method but also acknowledged the need for a booklet/written mode to cater for those less able to utilise technological formats. Of interest some healthcare professionals felt that a leaflet format would be preferable as a means of intervention delivery, this contrasted with the views of patients who felt an online or phone application format would allow greater accessibility and convenience. The intervention proposed is a multi-modal format which provided patients with information around medication, diet, skin care, resources, alternative therapies and pelvic floor exercises. Finally, throughout all interviews the need for a human contact, i.e. ability to access a healthcare professional, was highlighted as a pivotal and important feature of any intervention.

Conclusion

This research has provided insights into the bowel symptoms experienced by patients following sphincter-sparing surgery for rectal cancer, the impact of these symptoms, the strategies utilised to manage these symptoms. Importantly, this study identified the need to create an intervention to allow patients to manage their symptoms in a safe and evidence-based manner and determined the appropriate content, format and mode of delivery using the findings of interviews with both affected patients and those involved in their care.

Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

Signed: ___Mairéad O' Sullivan________ Date:___7/4/20_____

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List of Abbreviations

ANP= Advanced Nurse Practitioner

ARS= Anterior Resection Syndrome

CI=Confidence Interval

CNM= Clinical Nurse Manager

CNS= Clinical Nurse Specialist

CRC= Colorectal Cancer

FI=Faecal Incontinence

HCP= Healthcare Professional

IBD=Inflammatory Bowel Disease

IBS=Irritable Bowel Syndrome

LARS= Low Anterior Resection Syndrome

MRC= Medical Research Council

NCHD= Non-Consultant Hospital Doctor

PFE= Pelvic Floor Exercises

RCT= Randomised Control Trial

RGN= Registered General Nurse

SHO= Senior House Officer

SPR= Specialist Registrar

SSS= Sphincter-sparing Surgery

TME=Total Mesorectal Excision

Chapter 1- Introduction and Background to the Study

Introduction

The focus of this study is to explore patients' bowel symptom experiences and symptom management self-care strategies following sphincter-sparing surgery for rectal cancer. In addition to examine the need for an intervention to aid patients in their self-care of bowel symptoms. The rationale for this study came from clinical practice, experience as a nurse within a colorectal setting both as a staff nurse and subsequently a Colorectal Oncology Coordinator and the prevalence of rectal cancer, its treatment, and resultant effects. The researcher had worked within the colorectal setting for over four years and during this time had encountered many patients experiencing persistent bowel dysfunction following treatment for rectal cancer. In 2018, there were over 1.8 million reported cases of colorectal cancer worldwide (GLOBOCAN, 2018). In Ireland, colorectal cancer is one of the most common cancer in both sexes, with rectal cancer accounting for 27% of cases (National Cancer Registry of Ireland, 2013).

According to the most recent evidence, rectal cancer survival rates have improved from 49.9% to 62.6% (NCRI, 2017) and advances have been made in surgical techniques. Bowel cancer survivors account for the third largest group of long-term cancer survivors (Institute of Medicine and National Research Council*,* 2006), however, the treatment of rectal cancer often negatively impacts upon quality of life and causes the development of life-altering bowel symptoms (Bryant *et al.,* 2012). The surgical treatment combined with neoadjuvant and adjuvant therapies commonly results in the development of altered bowel symptoms including “anterior resection syndrome”, an umbrella term used to describe a group of sequelae such as frequency, urgency, incontinence and tenesmus (Sanoff *et al.,* 2015, Wells *et al.,* 2014. Digennaro *et al.,* 2013, Konanz *et al.,* 2013). The resultant symptoms causing patients to report uncertainty as to whether they would have chosen the same treatments had they been aware of the potential side effects (Sanoff *et al.,* 2015).

Whilst the abdominoperineal resection was once considered the gold-standard for treatment of rectal malignancy, sphincter-sparing surgery has now taken its place as it often removes the need to form a permanent stoma (Bryant *et al.,* 2012). Nevertheless, these surgeries often result in the development of adverse bowel function (Schwandner, 2013). There is a plethora of literature exploring the troublesome effects of sphincter-sparing surgery on bowel function, with studies varying in their reports of bowel dysfunction prevalence from 10% (Allgayer *et al.,* 2005) to 90% (Bryant *et al.,* 2012), but little has been published into possible interventions which may be utilised by patients in the non-clinical setting.

Healthcare professionals play a pivotal role in supporting patients in their management of symptoms. However, it is recognised that the patient’s role in the management of care is important, particularly as this care often becomes their sole responsibility. In addition, growing evidence recognises the efficacy of web-based delivery of healthcare interventions. The researcher noted the lack of a formal programme or intervention to address bowel dysfunction post-SSS and limited awareness amongst staff in relation to the issue. Working closely with staff in the colorectal setting presented both opportunity and challenges for the researcher in conducting this research, something which the Methodology Chapter shall explore further.

The aim of this study is to determine the content, format and mode of delivery for inclusion in an intervention for patients following sphincter-sparing surgery who have experienced altered bowel function. The high incidence of rectal cancer in Ireland and extent of surgical intervention for rectal cancer necessitates further research into the management of potential treatment side effects. The following chapter discusses rectal cancer and outlines the prevalence, predisposing risks, diagnosis and treatment of rectal cancer and resultant effects.

1.1 Prevalence of Rectal Cancer

Rectal cancer describes the proliferation of malignant (cancerous) cells within rectal tissue, the final portion of the large intestine. Publications reporting on the incidence of cancer tend to report cancers of the colon and rectum together. However, the focus of this study is upon bowel symptoms following treatment of rectal cancer only. On a global scale, 1,849,518 cases of colorectal cancer were reported in 2018 (GLOBOCAN, 2018). For men, the likelihood of developing colorectal cancer stands at 4.6% versus 4.2% amongst women (Siegel, 2017). Statistics reveal that almost half a million cases of colorectal cancer were reported in Europe (GLOBOCAN, 2018) and that colorectal cancer accounted for 11.9% of deaths from cancer within Europe (European Cancer Statistics, 2012). The incidence of rectal cancer in the European Union is approximately 35% of the total colorectal cancer incidence, i.e. 15–25/100 000 per year (Glynne-Jones *et al.,* 2013). In the U.K, of the 40,000 individuals diagnosed with colorectal cancer every year, 35% receive a diagnosis of rectal primary malignancy (NICE, 2014).

It is the infiltration, extent and height of a patient's tumour which determines their suitability for sphincter-sparing surgery. Distance from anal verge is a deciding factor in the formation of a permanent stoma versus the prospect of anastomosis/ sphincter-sparing surgery. This is a significant influencing factor upon bowel symptoms post- operatively (Walma *et al.,* 2015).

In general, the earlier the stage of rectal cancer at diagnosis, the greater the chance of survival(Haggar & Boushey, 2009, National Cancer Intelligence Network, 2009). The National Cancer Intelligence Service (2009) found, in their comparison of 5-year survival rates, that patients with a Duke A staging at diagnosis had a survival rate of 93.2% in comparison with the 6.6% survival rate seen in patients with Duke D staging at diagnosis.

1.2 Risk Factors Associated with the Development of Rectal Cancer

Traditionally, rectal cancer was predominantly seen in high income countries, linked to the industrialisation and urbanisation (World Cancer Research Fund, 2018).

Haggar and Boushey (2009) note that 63% of all colorectal cancers occur in developed countries. However, one meta-analysis carried out by the World Cancer Research Fund (2018) found that when previously lower income countries such as Japan and Eastern Europe made the transition into high income countries, the cases of colorectal cancer rapidly and significantly increased, sometimes doubling. As Ireland is classified as a high-income country, with an increasing westernisation of diet and urbanisation, the importance of awareness and research into rectal cancer, its treatments, and their outcomes is pivotal. Many studies identified an inverse relationship between a high intake of red meat and dietary fats and increased rates of colorectal cancer (Aykan N., 2015 & WCRF, 2018). The World Cancer Research Fund's analysis of several cohort studies observed that 75% of the papers reviewed (n=12) found an increased incidence of colorectal cancer the higher the intake of red meat. Whilst causative mechanisms for this were not fully determined, high cooking temperatures, the presence of nitrates and large consumption of haem contained within red meat were all found to be potential links to increased rates of rectal and colon cancer (Aykan, 2015, WRCF, 2017,). The Central Statistics Office (2017) publish meat consumption figures within Ireland annually and found that of all meat consumption in

Ireland, 58% was red meat, with 410,000 tonnes of meat production being utilised domestically. As the link between red meat and the development of rectal cancer has been deemed “probable” (WCRF, 2011), Ireland’s high consumption of red meat adds to the rationale for the need further research around rectal cancer. Whilst the current study does not focus upon the risk factors associated with rectal cancer, providing affected patients with education about the risk factors is vital in the context of recurrence risk and to ensure that symptoms experienced post sphincter-sparing surgery are not confused with recurrence or vice versa.

Alcohol and tobacco consumption (Taylor, 2012) are also linked with increased rates of colon and rectal cancer. The most recent figures for tobacco use in Ireland found that 23% of Irish adults smoked (Sheridan *et al.,* 2018). In the 2014 study carried out by the Health Research Board (2013), 50% of Irish individuals interviewed were classified as harmful drinkers according to the WHO Audit C Screening Tool. The incidence of these rectal cancer linked risk factors in Ireland again highlights the necessity into research surrounding rectal cancer and its effects.

Other contributing factors linked to an increased risk of rectal cancer include lack of physical activity and a high Body Mass Index. Men have a slightly higher risk for development of rectal cancer (World Cancer Research Fund, 2011), again the reasons for this have not been identified. Advancing age is another risk - 86% of colorectal cancers occur in those aged 60 years or greater (Taylor, 2012). The 2011 Irish Census revealed that there were 754,179 individuals greater than 60 years of age residing in Ireland, adding to risk factors for rectal cancer development amongst the Irish population.

Whilst there remains uncertainty as to the actual causation of rectal cancer, an increasing body of evidence-based research, as outlined above, points to a link between a high consumption of red meat, alcohol and tobacco and an increased occurrence of rectal cancer. Given the high consumption rates of red meat, alcohol and tobacco use amongst the Irish population, in tandem with the presence of an ageing population, Ireland is a high-risk population for the development of rectal cancer. Therefore, it is imperative that further research is undertaken to explore rectal cancer, its treatments, and the resultant effects.

1.3 Treatment of Rectal Cancer

Rectal cancer treatment has significantly improved in recent decades, due to the development of both adjuvant and surgical treatments (Wells *et al.,* 2014). Currently, the 5-year survival rate following rectal cancer diagnosis in Ireland is 59% (NCRI, 2017). In Ireland, 75% of people diagnosed with rectal cancer underwent surgery, 41% Radiotherapy and 51% Chemotherapy (NCRI, 2015). The following sections outline these treatments.

1.3.1 Surgery for the Treatment of Rectal Cancer

Preservation of sphincter function is the aim of rectal cancer surgery but even when this is successfully achieved, many patients are faced with life-altering, non-desirable and problematic bowel symptoms (Wells *et al.,* 2014). Up to 50% of those who undergo sphincter-sparing surgery will experience a group of symptoms collectively known as Anterior Resection Syndrome (Taylor, 2015).

Typical sphincter-sparing surgeries include, but are not limited to, low and high anterior resection, total mesorectal excisions (TME) and inter-sphincteric proctectomy with colonic pouch to anal anastomosis (Brown *et al.,* 2008). Some patients may require a temporary stoma formation depending of the extent and height of tumour and its invasion.

In a Cochrane systematic review of 35 studies (Pachler & Wille Jorgenson, 2012), the long-held assumption that maintenance of bowel continuity would result in better quality of life outcomes than a permanent stoma was challenged. In this review the authors found that the traditionally held opinion that avoidance of a permanent stoma was beneficial was not supported, as the studies reviewed did not reinforce this assumption of superior quality of life amongst those without a stoma (Pachler & Wille- Jorgenson, 2012, pg.2). However, the authors also recognised that the ability to draw firm conclusions was limited by the fact that none of the studies were randomised control trials, the issue of socio-economic background was not considered as a compounding variable, 29 of the studies failed to assess baseline quality of life and in many studies (n=6) the participants were of an older age.

These factors challenged the validity and reliability of the reviews that did, and did not, propose an improved quality of life amongst those without a permanent stoma. Whilst not scientifically rigorous the study examining this topic seems to indicate that sphincter-sparing surgery does not necessarily point towards improved outcomes for patients in terms of both bowel dysfunction and quality of life. This highlights the potential effects of rectal cancer treatment on patients as they may experience a marked reduction in quality of life like that of those with a permanent stoma due to altered and bothersome bowel symptoms.

1.3.2 Chemotherapy for the Treatment of Rectal Cancer

Patients diagnosed with rectal cancer may also undergo chemotherapy to reduce the likelihood of metastases, shrink tumour size or slow tumour cell proliferation (Das & Crane, 2009). Chemotherapy may be adjuvant (after surgery) or neo-adjuvant (before surgery) (Taylor, 2012). Those receiving palliative treatment may also receive chemotherapy as their primary intervention. Whilst the experience of bowel symptoms post treatment for rectal cancer may be influenced by all elements of treatment this study primarily focuses upon outcomes post-surgical treatment. The following section will discuss factors which influence the development of bowel dysfunction, including radiation therapy, a key treatment for rectal cancer.

1.4 - Risk Factors Influencing the Development of Bowel Symptoms

The incidence of bowel dysfunction following sphincter-sparing surgery is an area increasingly explored by recent research. It is imperative that the factors influencing altered bowel function are examined to ensure that the content, format and delivery of an intervention will respond accordingly. Reports of bowel symptom prevalence vary greatly with a marked dissonance noted between clinician estimation of its impact and occurrence to that of patient experience (Chen *et al.,* 2014). Whilst it is now known that altered bowel function and development of anterior resection syndrome are in part resultant of surgical and adjuvant therapies (Duijvendijk *et al.,* 2002, Walma *et al.,* 2015, Ozgen *et al.,* 2015) their cause is not fully understood. Reduced rectal reservoir, fibrosis of rectal tissue and inadvertent damage to sphincter are just some of the potential causes. However, the significance of patient pre-operative history including pelvic surgery, childbirth, pre-existing continence issues and formation of temporary stomas are all identified as contributing causes and risk factors in the development of altered bowel function following sphincter-sparing surgery (Bryant *et al.,* 2012). The following section seeks to explore the numerous factors which contribute to development of bowel dysfunction identified and explored by the literature. The findings of this section will contribute to the formulation of content for an intervention for management of these symptoms.

1.4.1 Surgery as a Factor Influencing Development of Bowel Symptoms

In Ireland 70% of patients diagnosed with rectal primaries will undergo surgery (NCRI, 2017). As a direct result of surgery, excision of rectal tissue causes a reduction of rectal reservoir volume (Kakodkar *et al.,* 2006). An interventional study carried out by Pucciani *et al.,* (2008) echoed these finding and noted significant differences between the mean anal pressures of those post-sphincter-sparing surgery and that of healthy control subjects (20.5±10.5 versus 47.8 ±6.6). Many surgical developments were developed to improve neorectal configuration (Kye *et al.,* 2016) such as the development of the colonic J- pouch, transverse coloplasty and side-to-end anastomosis. A systematic Cochrane review (n=16 studies) (Brown *et al.,* 2008) found that development of this reservoir did indeed reduce the incidence of faecal incontinence when compared with a straight coloanal anastomosis in the eighteen months following surgery and of the reviewed studies there were “significant advantages in patients with CJP (colonic J-Pouch) reconstruction, particularly in bowel frequency and urgency”. However, for many individuals the symptoms of anterior resection syndrome occur regardless of surgical technique (Bryant *et al.,* 2012). Some studies argued that symptoms largely subside in the 12 months’ post- stoma reversal. Nevertheless, a study carried out by Chen *et al.,* (2015) studied patients for 14 years post-Total Mesorectal Excision and radiation therapy and found many experienced major LARS (low anterior resection syndrome) for many years post-treatment. The prolonged duration of bowel symptoms was echoed in a qualitative study in which patients' bowel symptom experiences were examined and were found to persist even at 42 months following surgery (Landers *et al.,* 2011).

The formation of a temporary diverting ileostomy is another factor seen to increase and contribute to the development of altered bowel function. Many patients undergoing surgery for rectal cancer will have a temporary stoma formed to protect the anastomosis, allowing earlier feeding and recovery (Chand, 2008). Black *et al.,* (2011) estimated that as many as 6,000 stomas are reversed in the U.K every year. Again, the reasons for the negative effects of temporary stoma formation are not fully understood but weakening of pelvic floor muscles, anal sphincter damage intraoperatively and altered pathophysiology caused by stoma formation are all seen as contributory factors (Attene *et al.,* 2008, Walma *et al.,* 2015). Flooden *et al.,* (2014) compared anorectal function five years post-surgery amongst patients who had and had not had temporary stomas formed and found that those who at some point had temporary stomas, experienced a higher median stool frequency (2.5 vs 3, p=0.1). One prospective clinical trial study of 11 patients following TME examined anorectal function and through measurement of rectal compliance and reservoir capacity determined that increased incontinence was resultant of reduced neo-rectal capacity (Van Duijvendijk *et al.,* 2002).

Other contributory factors to Anterior Resection Syndrome (ARS) and altered bowel function following SSS include a history of pelvic or obstetric surgery and chemotherapy. The high number of patients undergoing surgery for rectal cancer in Ireland and well-documented resultant alterations to bowel function further supports the need to develop an intervention which allows management of bowel symptoms.

1.4.2 Radiation Therapy as a Factor Influencing Development of Bowel Symptoms

Important to acknowledge also is the impact which radiation therapy may have upon the development of faecal incontinence as it “diminishes compliance of the rectum due to fibrosis, resulting in a reduced reservoir function” (Lange & Velde, 2008). As many as 52% of patients undergoing treatment for rectal cancer, in Ireland, received radiation therapy during 2012-2014 (NCRI, 2017). Radiation therapy most commonly takes place pre-operatively either as a long or short course (Taylor, 2012). It may also involve a combination of chemotherapy and radiation (chemorads). Post-operative radiation therapy may also be carried out if the risk of local recurrence is deemed to be high (Das & Crane, 2009). The adverse impact which radiation may have on bowel symptoms has been examined by numerous studies (Bregendahl *et al.,* 2013, Liang *et al.,* 2016). Patients who undergo radiation may experience more bowel dysfunction in comparison to those who do not, Chen *et al.,* (2015) outlined this in their randomised trial, with Major LARS occurring in 56% of those who had received pre-operative radiation versus 35% who had undergone surgery alone (99% confidence interval).

In a randomised controlled trial carried out by Bregendahl *et al.,* (2013) it concluded that use of neoadjuvant therapy, regardless of duration, is a strong risk factor for the development of low ARS and altered bowel function. A prospective and comparative study which examined the effects of pelvic floor exercise and biofeedback training amongst both irradiated (n=41) and non-irradiated (n=54) patients following rectal cancer surgery found that irradiated patients had a significantly higher incidence of faecal incontinence, scoring an inferior 7.4 ± 2.2 on the Modified Cleveland Incontinence Score in comparison to 8.7±2.7 (Allgayer *et al.,* 2005). The increased risk of bowel dysfunction caused by radiation therapy, a commonly utilised adjuvant therapy in the treatment of rectal cancer, highlights the importance of actively supporting patients to manage the potential symptoms and issues caused by radiation.

One prospective, non-randomised trial (Allgayer *et al.,* 2005) identified that patients who had undergone radiation (n=41) experienced higher levels of faecal incontinence than those who underwent surgery alone(n=54), patients who had received radiation had an average Modified Cleveland incontinence score of 7.4 whereas patients who were non-radiated scored a better average of 8.6 (*P*= <0.001). In the context of this study, acquiring an accurate history of patients’ neoadjuvant treatment is pivotal as its effect on bowel function post-sphincter-sparing surgery is evident and well documented.

Conclusion

Rectal cancer occurs not only in developed societies but those experiencing developing urbanisation and industrialisation. It affects men and women, those with family history and those without. Constantly evolving treatment is leading to improved survival rates, better outcomes, and reduced recurrence. However, the symptoms caused by developing treatments such as sphincter-sparing surgery and radiation therapy remains costly, both physically and personally, to those affected (Sanoff *et al*. 2015).

Whilst many risk factors and preventative measures have been identified, rates of rectal cancer continue to rise, with the incidence and mortality rates increasing rapidly in many low-income and middle-income countries. Therefore, the level of sphincter-saving surgeries being carried out, have seen an increase, so too have the rates of radiation, another factor closely linked to increased bowel dysfunction. The abdominoperineal excision, once seen as the gold standard of rectal cancer treatment, has seen a decline in popularity and relevance. The resultant effects of rectal cancer treatment are well-documented and the need to develop interventions for the management of bowel dysfunction has been communicated by numerous studies (Laforest *et al.,* 2012, Landers *et al.,*2014), supporting the argument for a review of the empirical literature to guide the development of an intervention to aid patients' self-care of symptoms. The following chapter explores the plethora of physical effects which rectal cancer treatments, including sphincter-sparing surgery, may have upon a patient's bowel function.

1.5- Overview of Thesis

Chapter Two of this thesis will, through an extensive narrative literature review, explore the existing knowledge around the occurrence of bowel symptoms following sphincter-sparing surgery for rectal cancer. This chapter will seek to identify known physical bowel symptoms. In addition, this chapter will examine the psychological and social impact of bowel dysfunction following surgery for rectal cancer. Furthermore, the section will be closely linked to the strategies used to manage bowel dysfunction, a topic which chapter three will further examine.

Chapter Three will examine the concepts of self-care and self-management, in particular self-care as outlined by Humphreys and Dodd (2001). This chapter will also endeavour to identify existing self-care strategies utilised by patients to manage their bowel dysfunction. This will be examined through the undertaking of a narrative review. A systematic review examining interventions aimed at supporting patients to improve or eliminate their bowel symptoms will then be conducted.

Chapter Four will outline the methodology utilised to conduct this study. This chapter will lay out the aims and objective of the study. Moreover, the rationale for selection of a qualitative, descriptive design using individual semi-structured interviews through purposeful sampling will be described. In addition, the application of the MRC Framework (2006) including selection of underpinning theory, the Symptom Management Theory will be discussed. Furthermore, the process of data collection, and a description of the data analysis process using qualitative content analysis whilst maintaining trustworthiness will be outlined. Finally, the means of ensuring ethics and rigour will be discussed, including informed consent, confidentiality, data management and reflexivity, dependability, credibility and transferability.

The findings from the qualitative, descriptive phase of the study will be described in Chapter Five. These will be presented under the findings of the pre-determined categories i) Bowel Symptom Experience ii) Physical Responses to Bowel Symptom Experience iii) Psychological and Social response to bowel symptom experience iv) Symptom Management v) Proposed Intervention to Improve Symptom Outcome.

In addition, Chapter 6 will discuss the study as a whole and its place within current research, healthcare and its potential impact and will provide a conclusion of the thesis.

Finally, Chapter 7 will outline the strengths, limitations and recommendations of this research.

Chapter 2- Bowel Symptom Experience Following Sphincter-Sparing Surgery for Rectal Cancer

Introduction

Research into the symptoms experienced following sphincter saving surgery has increased significantly, with much of the focus given to anterior resection syndrome (ARS), the term given to the sequelae of symptoms experienced post-sphincter-sparing surgery (Liang *et al.,* 2016). A plethora of symptoms, such as faecal incontinence, leakage, urgency, incomplete defecation, evacuatory dysfunction, fragmentation of stools, tenesmus and incontinence of flatus have been reported following sphincter-sparing surgery (Laforest *et al.,* 2012, Pachler & Wille- Jorgensen, 2012). The studies exploring altered bowel function following sphincter-sparing surgery vary in their reports of the prevalence of bowel symptoms, with figures ranging from 10% (Allgayer *et al*, 2005) to 90% (Bryant *et al*, 2012). This chapter explores the alterations to bowel function which can occur following sphincter-sparing surgery including anterior resection syndrome and the responses to bowel symptom experience including the physical, psychological and social impacts which these symptoms may have upon individuals. To fulfil the criteria of anterior resection syndrome (ARS) diagnosis, a clustering of symptoms including incontinence of faeces and flatus, urgency, frequency and tenesmus, although definitions and classification of ARS varied across studies (Chen *et al.,* 2015, Ziv *et al.,* 2013). Due to lack of set definitions of this syndrome the decision to include all bowel symptoms experienced was made.

The Symptom Management Theory was developed by the School of Nursing Centre for Symptom Management at the University of San Francisco (Humphreys et al, 2008, 2018). This theory provides the most comprehensive framework to guide the current study. This theory addresses phenomena of relevance to the study by allowing the researcher to focus on the dimensions of symptom experience, symptom management strategies and symptom outcomes. The use of this theory in conducting this study and its application to this participant group will be addressed in more detail in Chapter 3. At this point the Symptom Management Theory will be utilised to provide focus for the literature review in exploration of symptom experience of participants. Thus, the literature review is structured using the concepts of symptom experience, symptom response and in the next chapter the self-care component of symptom management strategies.

2.1- Search Strategy- A Review of the Current Literature

An initial narrative literature search was carried out to identify the existing body of knowledge. This search sought to examine the bowel symptoms caused by sphincter-sparing surgery for rectal cancer including anterior resection syndrome. Whilst in part the aim of this study is to determine the proposed content for an intervention, an understanding of bowel symptoms experienced by patients is pivotal to aid and inform the formulation of a new intervention. A narrative review was chosen as these reviews are generally comprehensive and allow for coverage of a wide range of issues in a given area (Cronin *et al.,* 2008)

To achieve these aims, a search of the literature was carried out in Cochrane Library, PubMed and CINAHL databases. All randomised, non-randomised, qualitative, quantitative, longitudinal, cross- sectional, cohort, prospective, retrospective and observational studies which examined bowel symptoms post colorectal surgery were reviewed. Exclusion of “Colorectal” as a search term yielded few results, as many studies utilised the terms colorectal and rectal interchangeably even when referring to cancers solely of the rectum. The decision was made, therefore, to include this as a search term. Conference papers, opinion papers or non- peer reviewed papers were excluded. Key search terms utilised included “rectal”, “colorectal”, “malignancy”, “neoplasm”, “faecal incontinence”, soiling, leakage, “anterior resection syndrome”, “bowel symptoms”, “urgency”, “frequency” and “tenesmus”, combined using Boolean terms such as AND/OR as appropriate with all included terms listed in Appendix 1

The literature searches were limited to the years of 2005- May 2018 inclusive, with updates made in May 2019. Although the researcher intended to carry out the search without English language as a limitation, the choice to include it was made due to limited resources in relation to translation services. To ensure inclusion of all relevant data, grey literature was also reviewed through inclusion of any pertinent literature in the reference lists of papers explored.

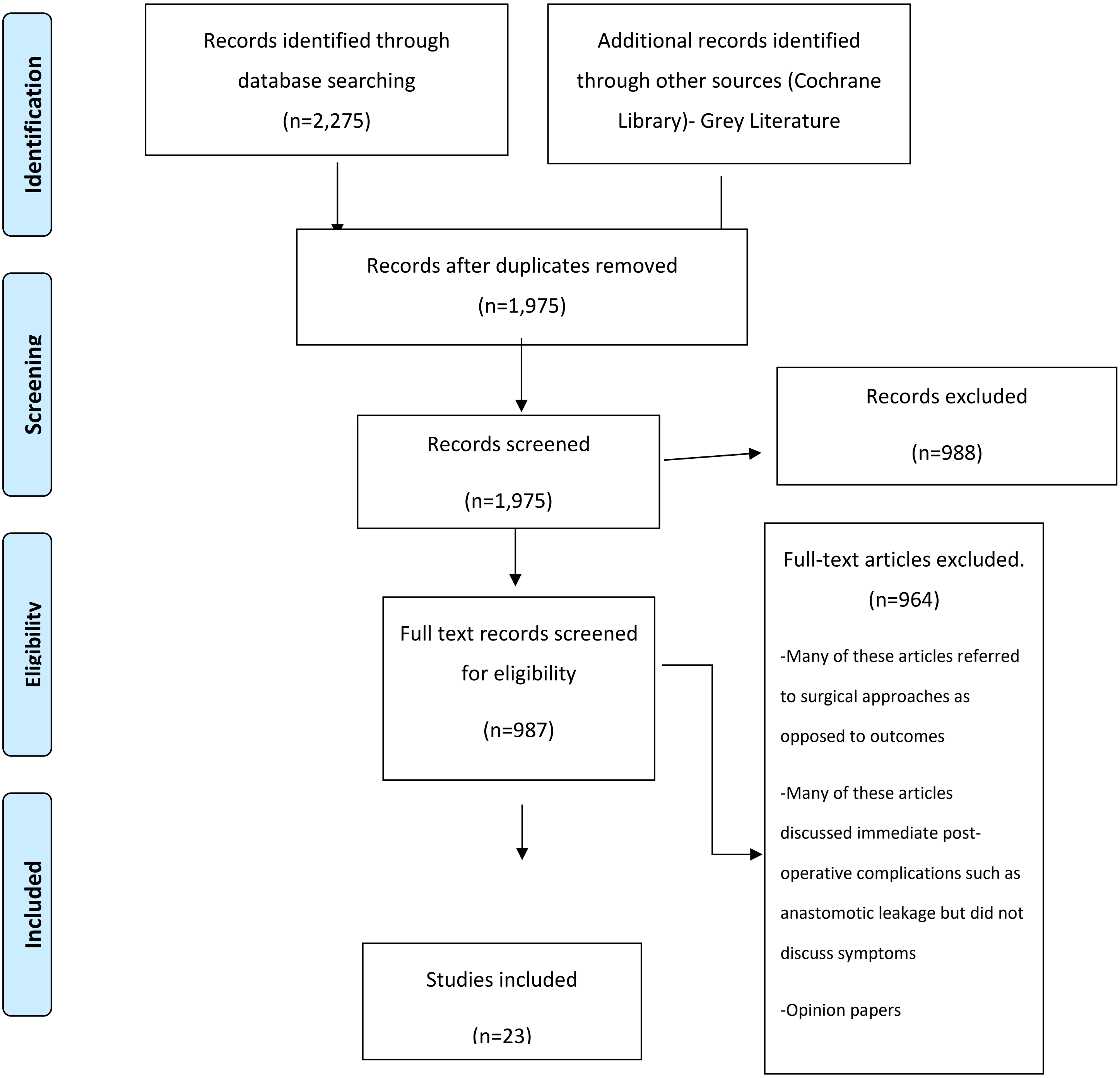
Inclusion criteria were papers which explored or measured the effect of rectal cancer treatment on bowel function amongst patients who no longer had active disease and did not have a stoma. Excluding the verified presence of rectal cancer, being over the age of 18 and having had sphincter-sparing surgery for treatment, there were no exclusion criteria placed on the types of participants included in the literature search. Gender, social status, and race were not used as discriminatory criteria in the studies selected to allow a greater insight and ensure a comprehensive examination of the issue.

Any surgeries in which the patients' bowel continuity was achieved through preservation of the anal sphincter were included in this review. These surgeries included, but were not limited to, anterior resection, total mesothelial excision, pouch formation or straight colo-anal anastomosis. As many of the reviewed studies compared patients with stomas to those with anastomoses, they were not excluded, however, only the results discussing participants without permanent stomas were included in the literature review. The results were then input to a Prisma Flow chart (Liberati *et al.,* 2009) to allow others to identify the strengths and weaknesses of the review, illustrate the review process and facilitate replication should same be attempted by other researchers.

Figure 1- PRISMA 1

PRISMA (2009) Flow Diagram 1.0- CINAHL, PUBMED & Cochrane Library

Bowel Symptoms Post Sphincter-sparing Surgery for Rectal Cancer



Reproduced with the permission of The British Medical Journal- Liberati *et al.,* (2009) The literature review is divided into separate sections. The initial section includes an examination of the individual symptoms which manifest following sphincter-sparing surgery. The subsequent section outlines the physical, social and economic impact which unmanaged bowel symptoms may have upon individuals experiencing same. Again, the symptom management dimension of the Symptom Management Theory will be utilised as it provides a framework for the review of studies focusing upon symptom experience following SSS.

2.2-Literature Review- Bowel Symptoms Following Sphincter-sparing Surgery

This section focuses on the prevalence and manifestations of the most common bowel symptoms experienced by patients, following sphincter-sparing surgery, that emerged following the literature review. These findings will guide the development of the proposed intervention through the identification of the most bothersome and life-altering symptoms experienced by patients. An overview of these symptoms is illustrated in Table 1, which can be found on page 39.

2.3 – Physical Bowel Symptoms

Faecal Incontinence

Faecal incontinence is “the involuntary loss of bowel control, which normally allows the passage of gas or stool at a socially acceptable time and place” (Person *et al.,* 2006). Maintenance of faecal continence is a multifactorial process that relies on correct functioning and integrity of the internal and external anal sphincters, and pelvic floor muscles to contract when rectal distension occurs, or rectal pressure increases (Bartlett *et al.,* 2012). Colonic transit time, stool consistency, cognitive and neurologic factors also contribute to continence (Meyer & Richter, 2015).

Whilst hypotheses exist as to why patients experience faecal incontinence following SSS it is theorised that damage to the sphincter during surgery or previous injury such as childbirth, prolonged periods of reduced activity by the pelvic floor muscles caused by temporary stoma formation and rectal surgery may cause altered bowel function (Allgayer *et al.,* 2005, Kakodkar *et al.,*2006, Attene *et al.,* 2009).

Following sphincter-sparing surgery, faecal incontinence has been identified as one of the most common bowel symptoms with reports on its prevalence varying from 10% (Allgayer *et al.,*2005),to Koyama *et al.,* (2014) reporting that faecal incontinence occurred in almost 84% of participants, resulting in the need for incontinence pad use.

In one prospective, comparative, single centre study 58% of the participants (n=24) reported occasional or frequent soiling following surgery for colorectal cancer (Laforest *et al.,* 2012). Similarly, in a cross-sectional study of Danish individuals carried out by Bregendahl *et al.,* (2013) all eligible patients who had undergone a curative resection for rectal cancer (n=938) were administered a validated questionnaire, 48% reported major bowel dysfunction including faecal incontinence, with 23.6% of those following TME (total mesothelial excision) and neoadjuvant therapy reporting incontinence of liquid stool. Nikoletti *et al.,* (2008) identified “leakage from bowel” amongst almost 38% of participants with 28% of this group reporting incontinence of solid stool.

A clinical trial examining the efficacy of a rehabilitation programme for faecal incontinence found that almost 40% of patients post ileostomy takedown experienced faecal incontinence (Attene *et al.,* 2009). In terms of the duration of faecal incontinence, publications have reported an improvement of such symptoms in the 6 months following surgery (Taylor & Bradshaw, 2013). However, Landers *et al.,* (2012) found that participants reported altered bowel symptoms two to three years following surgery. A finding supported by the retrospective interventional study carried out by Bartlett *et al.,* (2011) where surgery for colorectal cancer had caused bowel dysfunction amongst its participants (n=19) between 12- 24 months post-surgery. Chen *et al.,* (2015) found in their multi- centre randomised trial that amongst participants (n=242), the median time post TME +/- neoadjuvant was 14.6 years, yet 46% reported Major LARS when bowel dysfunction was assessed using the validated LARS tool. A prospective study examining anorectal function following total mesorectal excision found that episodes of daytime incontinence and soiling increased to 73% in the year following surgery when compared to 45% preoperatively (Van Duijvendijk *et al.,* 2002).

The prevalence of faecal incontinence following sphincter-sparing surgery has been thoroughly explored and recent publications have also examined its significant impact upon patients and how they experience such a symptom (Allgayer *et al.,* 2005, Bartlett *et al.,* 2011, De Miguel *et al.,* 2010). These studies (Landers *et al.,* 2012, Chen *et al.,* 2015 & Laforest *et al.,* 2012) highlight the importance of identifying and acknowledging faecal incontinence as a potentially lifelong post-operative symptom and aiding patients to manage it through support and education.

In terms of the economic implications which faecal incontinence may have upon an individual's life, those experiencing this symptom may experience significant economic personal and public losses through reluctance to return to employment, absenteeism, the cost of incontinence supplies and medications, medical fees etc. (Meyer & Richter, 2015).

Quality of life is fast becoming a measurement increasingly relied on by clinicians and researchers alike in measuring the success/ feasibility of an intervention or treatment (Pachler & Wille- Jorgensen, 2012). In terms of faecal incontinence, its effect on quality of life is well documented. Laforest *et al.,* (2012) compared the Faecal Incontinence Quality of Life scores of patients who had undergone rehabilitation for faecal incontinence post-rectal resection(n=22) versus the control group of matched patients who had not (n=24), those in the rehabilitation group scored significantly higher results in terms of depression/self- perception (3.2 ± 0.6 vs 2.6 ± 0.7) (*p*-value = 0.005) and lifestyle (2.6 ±

0.7). This study, based quality of life upon four domains: life style, coping and behaviour, depression/ self- perception and embarrassment. In a prospective single centre study comparing long term quality of life amongst those with a stoma (n=20) versus those with a pouch (n=39), it was noted that when patients undergo pouch formation they experienced disillusionment with the impact which surgery may have upon their continence as many expect a return to “normal” in terms of bowel function, the median time of follow up was 74 months, again highlighting the non- transient nature of this issue (Mrak *et al.,* 2011). This study also found that amongst those who had avoided a permanent stoma the mean EORTC QLQ C30 score was a low 26.1 out of a possible 100 in terms of diarrhoea. The EORTC QLQ C30 measures quality of life based upon function and symptom scales. Whilst quality of life studies cannot be relied upon in isolation due to the varying definitions of social function etc., findings aid clinicians in assessing the effects of illness, treatments and interventions.

Summary

Faecal incontinence is a symptom which effects and pervades all aspects of an individual’s personal, physical, and emotional health. High rates of incontinence were identified amongst individuals following treatment for rectal cancer across the literature and the impact which this bothersome symptom may have upon individuals was highlighted. As shown by the reviewed studies, faecal incontinence is often long-standing and at times its occurrence and impact is underestimated by health care professionals. Whilst the severity of faecal incontinence varies, for many affected patients the use of incontinence wear is lifelong. The high rate of occurrence justifies the argument for further research into supportive interventions and further education for patients experiencing these life-altering symptoms. The next section seeks to explore urgency, a symptom closely linked to episodes of faecal incontinence.

Urgency

Faecal urgency can be described as the need to defecate immediately without the ability to delay for even a short time (MacArthur, Bick & Keighley, 1997). This symptom has been identified amongst patients following sphincter-sparing surgery which appeared frequently amongst the publications reviewed. One such study by Laforest *et al.,* (2015) examined the bowel function amongst patients post total mesorectal excision (TME) (n=46) and the efficacy of a rehabilitation programme, almost 37% of the participants, including the control group, reported faecal urgency. A retrospective study evaluating the use of biofeedback intervention in the treatment of ARS/ altered bowel function found that 24.6% of its participants (n=61) experienced urgency as their primary bowel symptom and found that a sense of urgency and faecal incontinence were closely associated (Liang *et al.,* 2016). Landers *et al.,* (2012) explored the impact of urgency, this qualitative study found that patients often experienced urgency prior to episodes of faecal incontinence, thus social situations were dominated or determined by the proximity of a toilet. This study also found that for others, where the potential for embarrassing episodes caused by urgency, associated with faecal incontinence was conceivable, a complete avoidance or withdrawal from social interactions was undertaken.

A prospective study examining anorectal function of patients following TME identified that 46% ($p<0.05$) of patients continued to experience urgency four months post-operatively (Duijvendijk *et al.,*2002). The duration of urgency was even found to persist 14 years following initial treatment for rectal cancer, with 48% of participants in a multicentre trial reporting urgency more than once per week (Chen *et al.,* 2015), highlighting that altered bowel symptoms may often persist beyond the initial post-operative period with resultant detrimental effects on EORTC-QLQ-C30 and CR29 scores in terms of emotional, cognitive social functioning and financial impacts.

A cross-sectional study in Denmark assessed the presence of low anterior resection syndrome amongst patients (n=938) and found that the most common and burdensome symptom experienced by patients who had undergone curative TME and neoadjuvant therapy was urgency, with 43% experiencing episodes of urgency (Bregendahl *et al.,*2013). A higher incidence was identified amongst patients following sphincter-sparing resection when combined with neoadjuvant therapy, resulting in 77% of participants (n=29) reporting urgency (median time post-operatively was 45.6 months) (Ozgen *et al.,*2015). The same study also identified that individuals with symptoms of urgency scored significantly poorer results in terms of future perspective ($p < 0.01$) and sexual functioning ($p < 0.016$), highlighting the many aspects of life which unmanaged altered bowel symptoms may permeate.

Summary

The prevalence, often-prolonged duration and burden of urgency experienced by patients post- SSS is apparent across the literature. The symptom of urgency pervades many areas of life sometimes resulting in withdrawal from socialising and the development of fear and embarrassment. The close association made by patients between incontinence and urgency was also explored. Furthermore, the literature identified how patients' daily lives were often decided by proximity to toilet facilities. The prevalence of urgency was also explored with many patients highlighting this symptom as non-transient and burdensome.

Evacuatory Dysfunction & Tenesmus

Tenesmus is "the painful sensation of incomplete evacuation of the bowel, resulting in the sensation of needing to defecate many times daily" (Ní Laoire *et al.,* 2017, pg 113). Other literature describes the sensation of needing to pass stool within one hour of a previous bowel motion as "clustering" (Bregendahl et a., 2013). Tenesmus is a symptom commonly reported by patients following sphincter-sparing surgery and is associated with significant levels of distress but was also shown to be underestimated by clinicians in terms of its prevalence (Chen *et al.,* 2014). This section seeks to explore the prevalence, frequency, and impact which evacuatory dysfunction and tenesmus may have upon patients following sphincter-sparing surgery, further illustrated by the content of Table 1.

In a prospective study examining patient (n=11) anorectal dysfunction following total mesorectal excision, 55% reported tenesmus at 4 months post- operatively (Duijvendijk *et al.,* 2002), however anal manometry results returned to pre-operative levels 12-months following surgery. The burden caused by the feeling of incomplete evacuation was echoed in Landers *et al.,* (2011) qualitative study carried out to explore patients' (n=143) self-care strategies and bowel symptom experiences, with participants reporting incomplete evacuation to be "distressing". The effect and prevalence of tenesmus post sphincter-sparing surgery again highlights the need to aid patients in management of their bowel symptoms.

In Bregendahl *et al.,*' (2013) study examining Danish patients (n=938) who had undergone curative resections for cancer, the issues of clustering, incomplete evacuation and obstructive sensation as contributing symptoms of Low Anterior Resection Syndrome were examined. Of the 174 patients who had undergone a TME with neoadjuvant therapy, 56.3% (C.I 48.6-63.8) reported clustering, 54.1% (C.I 46.3-61.7) reported incomplete evacuation and 37.9% (C.I 30.7-45.6) reported a sensation of obstruction upon defecation. This same patient group also reported a high incidence (43.6%) of unproductive call to pass stool. The median time since surgery of participants was 54 months. The prolonged duration of symptoms and high incidence of occurrence further promotes the need for patients to be aided with their management of symptoms. The impact of clustering was explored, with 75.8% experiencing moderate or severe bother resultant of this symptom (Bregendahl *et al.,* 2013).

Chen *et al.,* (2015) further explored clustering amongst Dutch patients (n=242) who had undergone TME more than 14 years before the time of data collection. Of patients who had not received pre-operative short course radiotherapy (n=118), 42.3% reported clustering of bowel motions at least once per week and of those who had received radiotherapy 68% reported clustering at least once per week ($p < 0.01$). This study highlighted not only the significant effect which neoadjuvant therapy may have upon bowel dysfunction but also the non-transient, life altering duration of this dysfunction

Summary

The need to educate patients about interventions which can aid incomplete evacuation, reduce sensations of tenesmus, and prevent clustering of bowel motions is highlighted by these studies, as patients continue to experience burdensome bowel symptoms in the months and often years following sphincter-sparing surgery. The prolonged endurance also demonstrates that patients often face management of evacuatory dysfunction alone with minimal results. Evacuatory dysfunction varied in terms of presentation and severity across the literature but was identified as a prevalent and bothersome symptom. The following section refers to increased frequency of bowel motions, a symptom identified by the literature to be intrinsically linked to both urgency and faecal incontinence.

Frequency of Bowel Motions

Whilst there is no set definition for a normal frequency of bowel motions, once per day to three times per week is widely accepted. One clinical study by Kadokar *et al.,* (2006) found in their healthy control group (n=16) that the average number of bowel motions was 1.3±0.11 per day. This section examines the marked increase in bowel motions experienced by patients following sphincter-sparing surgery.

In a retrospective study exploring the use of biofeedback amongst individuals (n=19) experiencing bowel dysfunction following SSS, the average number of bowel motions per day reported was 5.2 (IQR 2.9-8.6) (Bartlett *et al.,* 2011). This was corroborated by a larger study by Chen *et al., (*2015) examining bowel dysfunction amongst 242 Dutch patients who had undergone total mesorectal excisions and short course radiotherapy for rectal cancer. This study found that 32.5% (p<0.01) of patients had very frequent bowel motions of between 4-7 movements per day. Almost 7% reported more than 7 motions per day. Further detail relating to this can be seen in Table 1.

Kadokar *et al.,* (2006) explored functional outcomes of participants who had undergone low anterior resection and total mesorectal excision (n=18), in the 6 months following stoma closure, participants' daily average bowel motion was 5.6 ±3.2 compared to their preoperative count of 1.3±0.11. A study with a larger sample of 116 estimated that patients following anterior resection had an average number of 3 (range,1-25) bowel motions per day when they received neoadjuvant radiation versus 2.5 (range,0.3-15) per day when they did not (Scheele *et al.,*2015). Again, the significant effect which neoadjuvant therapy can have upon symptoms development was apparent. This serves to emphasise the profound effect which sphincter-sparing surgery may have upon bowel function but also the need to assist patients to manage bowel symptoms.

Constipation

Constipation is a decrease in the frequency or a difficulty in passing bowel movements (National Institute for Health and Care Excellence, 2015). For some patients following sphincter-sparing surgery, bowel dysfunction may manifest itself as difficulty in passing stool and the development of constipation. The prevalence of evacuatory dysfunction, including constipation, varied from 12%-74% (Bryant *et al.,* 2012). The following section will discuss this bowel symptom so as to inform the potential development of an intervention to aid its management.

In a cross-sectional study examining bowel dysfunction amongst patients (n=174) following low anterior resection with adjuvant radiation therapy, 31.8% of participants reported straining upon defecation (95% CI 24.9-39.3) and 18.1% (95% CI 12.7-24.7) required assistance to defecate (Bregendahl *et al.,* 2013). Similarly, a multi-centre trial examining the presence of low anterior resection syndrome (LARS) found that amongst patients reporting Major LARS (N=111) 20% experienced constipation ($p< 0.02$). Another prospective study examining patients’ (n=22) functional disorders following resection for rectal cancer determined that 22% of participants reported dyschezia (difficult or painful bowel motions due to constipation) during a median time of 22 months following ileostomy reversal.

Again, it is the prevalence and duration of constipation following rectal surgery that highlights the need for an intervention to aid patients to manage their symptoms. However, it also displays the need for the intervention to cater for those who fit the typical profile of faecal incontinence or urgency following surgery but also those who experience reduced defecation.

Flatulence / Incontinence of Flatus

Another symptom closely linked with faecal incontinence is flatulence or incontinence of flatus. Flatus describing the uncontrollable propulsion of gas via the anus (Chen *et al.,* 2015). The literature reviewed found that many patients experienced increased flatus following sphincter-sparing surgery but decreased ability to control it.

In the cross- sectional study of Danish patients following LAR (n=938) ± neoadjuvant therapy, 67.2% of those who had received neoadjuvant therapy (n=174) experienced incontinence of flatus (Bregendahl *et al.,* 2013). Similarly, in a randomised trial examining bowel function 14 years following TME, 51.8% (n=61) of participants reported incontinence of flatus at least once per week (Chen *et al.,* 2015). Landers *et al.,* (2012) further explored the issue of flatus with one participant noting large volumes of uncontrollable flatus. Desnoo & Faithful (2009) also found in their qualitative study that patients found it difficult to decipher between flatus and stool.

In a retrospective review of biofeedback amongst patients who had undergone surgery for colorectal cancer, prior to the intervention patients reported flatus as a symptom which scored 3.0 on the Jorge & Wexner Continence Grading scale, a score of 4 is severe (Bartlett *et al.,*2011). Excessive flatus was reported by 75.2% (n=76) of participants in the Nikoletti *et al.,* (2008) study of bowel issues following SSS and was found to be the 2nd most commonly reported gastrointestinal problem, with 55.3% of those reporting it as causing significant bother.

Perianal Skin Irritation

Another symptom identified by the literature was the occurrence of perianal skin irritation and perianal discomfort. Whilst studies mentioned the use of skin protection strategies in their initial advice to patients, they did not identify the number of patients experiencing perianal skin irritation (Bartlett *et al.,* 2011).

One retrospective study carried out by Nikoletti *et al.,* (2008) examined patients (n=101) who had undergone sphincter-sparing surgery for colorectal cancer in the preceding 6- 24 months. This study found that almost 50% of patients experienced soreness and itching to their perianal area. This finding was echoed in both Desnoo & Faithful's (2006) report that patients' incontinence required the use of barrier creams or moist toilet wipes to protect their perianal skin. This is further outlined in Table 1. Landers *et al.,* (2012) also highlighted that perianal skin irritation resulted in such pain that participants resorted to showering between bowel motions as they found themselves "sore from using toilet paper" (p.295).

In a retrospective study examining and comparing functional outcomes following sphincter-sparing surgery amongst Japanese patients (n=73), 22% of patients following low anterior resection and 32% of those post-intersphincteric resection reported perianal skin irritation.

Summary

The varying manifestations and degrees of physical symptoms experienced by those following treatment for rectal cancer was closely and commonly explored in the literature. Faecal incontinence, urgency, evacuatory dysfunction, tenesmus, skin irritation, flatulence and constipation were some of the symptoms most commonly identified. Throughout the literature the longstanding duration of these symptoms was acknowledged with reporting of symptoms occurring from weeks to year post-operatively.

Another point clearly identified across the studies was the unmet needs of patients in terms of caring for and coping with the sequelae experienced as a result of treatment. The survivorship of many was tarnished by symptoms and impaired by the lack of information patients received to aid in their self-care. The examination of symptoms experienced following sphincter-sparing surgery clearly highlights the necessity to further explore solutions available to patients to aid in their symptom care. Closely linked to the physical symptoms is their psychological and social impact, which the following section seeks to explore.

Symptom	Definition	Range of incidence	Duration	Comments
Faecal Incontinence	The involuntary loss of bowel control, which normally allows the passage of gas or stool at a sociably acceptable time and place (Person *et al.,* 2006).	25.9% of participants who had not undergone radiation reporting complete incontinence (Allgayer *et al.,* 2005)- 84% (Koyama *et al.,* 2014).	Varied across the literature- 1 month (Ziv *et al.,* 2013) to 14 years (Bregendahl *et al.,* 2013)	Certain foods and fluids exacerbated symptoms. Some patients had involuntary leakage during the day only whereas others experienced incontinence at night time. Incontinence pad use was widespread across all studies. Led to withdrawal from socialising, employment, public transport etc.
Urgency	The need to defecate immediately without the ability to delay for even a short time (MacArthur, Bick & Keighley, 1997).	24.6% (Liang *et al.,* 2016) – 77 % (Ozgen *et al.,* 2015)	Chen *et al.,* (2015), the median period since treatment was 14.6 years, 48 % of patients post TME and neoadjuvant radiation therapy reported urgency at least once per week.	Closely associated to incontinence. Patients expressed the importance of knowing where toilets were located prior to leaving the house. Of 101 participants in the Nikoletti *et al.,* (2008) study, 36.6% reported getting to the toilet on time as a social concern relating to their bowel function.
Frequency	Increase in number of bowel motions per day (Kadokar *et al.,* 2006).	32.5% (Chen *et al.,* 2015)- 57 % (Bregendahl *et al.,* 2013)	6 months (Nikoletti *et al.,* 2008) to 14.6 years (Bregendahl *et al.,* 2013)	Across the literature, an increased number of bowel motions was noted following surgery. With 32.5% of participants in one study reporting 4-7 bowel motions per day and 7 % reporting greater than 7 (Chen *et al.,* 2015).
Evacuatory Dysfunction/ Tenesmus	"The painful sensation of incomplete evacuation of the bowel, resulting in the sensation of needing to defecate many times daily" (Ní Laoire *et al.,* 2017).	Varying degrees of severity and different presentations.	6 months (Kadokar *et al.,* 2006)- 14.6 years (Chen *et al.,* 2015)	Some patients regarded the sensation of tenesmus to be "distressing" and resulted in significant discomfort.
Constipation	Constipation is a decrease in the frequency or a difficulty in passing bowel movements (NICE, 2015).	12% (Bryant *et al.,* 2012) – 31.8% (Bregendahl *et al.,* 2013)	6 months (Nikoletti *et al,* 2005)- 14.6 years (Chen *et al.,* 2015)	Patients reported the use of "defecational assistance" i.e digital evacuation or laxative use (18.1%)(Bregendahl *et al.,*2012). For some patients the occurrence of constipation or other presentations of evacuatory dysfunction mimicked their previous symptoms and caused a fear of recurrence.
Skin Irritation	Perianal skin irritation and perianal discomfort.	Ranging from 22% of 73 participants to 50% (n=50) (Nikoletti *et al.,* 2008).	4 weeks post-operatively – 14.6 weeks (Chen *et al.,* 2015)	Commonly reported across the literature and often a result of frequency, incontinence and use of toilet paper. Many participants utilised moist tissue, wipes and barrier creams to cope with this issue.

Table 1- Bowel Symptoms Following Sphincter-Sparing Surgery

2.4 Response to Bowel Symptom Experience- The Psychological and Social Impact of Bowel Symptoms

Introduction

The physical effects of sphincter-sparing surgery and its resultant bowel dysfunction are well documented. However, the impact which these physical symptoms may have upon daily patient life is increasingly being used to inform treatment decisions, as explored by Wille & Jorgenson's systematic Cochrane review (2012). To inform and provide rationale for the development of a bowel symptom self-care intervention, the resultant quality of life effects must be explored, thus ensuring that the most burdensome symptoms to psychological and social health are identified. A number of studies identified by the researcher's literature search have explored these effects through use of both validated quality of life tools and qualitative methods. This chapter seeks to explore the effects that altered bowel function may have upon psychological and social well-being. Again, the symptom response element of the Symptom Management Theory will be utilised to structure the findings of examined studies.

2.4.1 Psychological Impact of Bowel Symptoms Following Sphincter-Sparing Surgery

In one multi-centre, qualitative study the severe impact which impaired bowel dysfunction had upon a patients' daily life was examined, the fear of faecal incontinence was "intensified in social situations", meaning some participants had to plan any activities in advance whereas others withdrew from or avoided social situations completely (Landers *et al.,* 2012). One cross-sectional analysis explored the psychological impact which altered bowel function may have upon a patient (Ozgen *et al.,* 2015). This study utilised the validated tools (EORTC QLQ -C30, EORTC QLQ CR38 and the Wexner Score) to explore anal sphincter function and its impact on quality of life. Those who experienced faecal urgency reported lower functioning in the Wexner classification in terms of future perspective ($p=0.010$) and reported "sometimes" altering their lifestyle due to bowel functioning. Overall, their findings were consistent with anorectal dysfunction having a direct and negative impact upon quality of life, a finding supported by other studies (Chen *et al.,* 2015, Walma *et al.,* 2015, Scheele *et al.,* 2015). In their discussion, the authors also identified the need for more follow-up and support tailored to a patient's individual experience of altered bowl function (Ozgen *et al.,* 2015). This highlights the importance of identifying bowel symptoms and provides rationale for exploring the need for development of an intervention which would aid patients to manage their symptoms to lessen the negative impact upon their daily lives and future perspectives.

Another area of psychological wellbeing explored in the literature was emotional and cognitive functioning (Chen *et al.,* 2015). In a multi-centre randomised trial, patients who had undergone TME and short course radiotherapy were followed up at a median time of 14.6 years post treatment (Chen *et al.,* 2015). This study founded that 46% of participants (n= 242) continued to experience Major Low Anterior Resection Syndrome (LARS) and its effect resulted in lower EORTC- QLQ C30 scores for emotional functioning (81.8) and cognitive functioning (80.9) compared to those experiencing minor or no LARS. It also identified lower scores in relation to sexual interest amongst men, but this tool does not account for the impact which loss of sexual interest had upon relationships and psychological well-being. Of note, a study carried out exploring quality of life and a comparison of those who had and had not received neoadjuvant radiation, the latter reported better social, emotional and cognitive functioning (80 vs 90, P = 0 .063) (Murata *et al.,* 2008).

From a qualitative perspective Desnoo & Faithful (2006) found that patients with bowel dysfunction were fearful that their symptoms were as result of tumour recurrence. Patients experiencing altered bowel symptoms also communicated feelings of distress and embarrassment, a theme identified by a number of studies (Landers *et al.,* 2011, Digennaro *et al.,* 2013, Walma *et al.,* 2015). Digennaro *et al.,* (2013) identified that patients who had undergone a coloanal anastomosis for rectal cancer scored poorly when administered the Faecal Incontinence Quality of Life Scale in relation to depression (2.1), embarrassment (2) and coping (1.3), where a score of less than 2 indicates lower quality of life. This again serves to highlight the significant psychological implications which altered bowel habits may have upon psychological health and thus rationalises the need to provide patients with evidence-based coping strategies.

Furthermore, a quantitative study carried out amongst colorectal surgeons (n=45) and radiation oncologists (n=13) showed that specialist perception of bowel dysfunction was statistically different to that of the affected individuals who completed the LARS score tool (n= 961) (Chen *et al.,* 2014). Only 1 specialist correctly identified 5 of the correct issues (*p* -value of difference =0.32) (Chen *et al.,* 2014) thus highlighting the marked discrepancies that exist between specialist estimation of and the actual impact which symptoms such as faecal incontinence may have upon a patient's well-being. Thus, emphasising the importance of providing patients with the information and education to actively manage and treat their bowel symptoms post-surgery for rectal cancer.

Finally, the effects of altered bowel symptoms following SSS were explored by Nikoletti *et al.,* (2008) with patients reporting regret about having surgery, sensing a loss of dignity and confidence and experiencing their symptoms as a "handicap" (pg. 394), the most common psychosocial concern expressed was the fear of cancer recurrence (6.9%) (n=7).

Intrinsically linked with the psychological impact is the social response which patients may experience in response to their bowel dysfunction.

2.4.2 Social Impact of Bowel Symptoms Following Sphincter-Sparing Surgery

The impact which bowel dysfunction may have upon social interaction can be significant (Desnoo & Faithful, 2006, Landers *et al.,*2011*,* Scheele *et al.,* 2014). Across the literature the alterations and disruptions to daily life caused by bowel dysfunction were apparent. The following section will discuss the effect which bowel dysfunction may have upon social interaction.

In one qualitative study which utilised a phenomenological approach, patients were interviewed in the 4-6 weeks following their stoma reversal (Taylor & Bradshaw, 2013). Participants of this study described how their bowel dysfunction determined daily activities and restricted their routine. Individuals within this study also highlighted their concerns in relation to returning to work and the need to stop regularly to toilet when leaving the house. One cross–sectional study compared the social functioning of those post- SSS for rectal cancer (n=116) with that of those post-hemicolectomy, a surgical procedure in which a portion of the large colon is removed (n=105) and individuals with no history of cancer (n=103) (Scheele *et al.,* 2014). The findings detailed that the SSS group scored significantly lower QOL scores in relation to social functioning compared to the group with no history of cancer when utilising the EORTC QLQ CR38 tool (77.5 vs 88.5) (*p*= 0.05).

The impact which bowel dysfunction can have upon engagement in social activities was explored by Landers *et al.,* (2011), with participants outlining their reduced participation in social activities and the loss of freedom which their unpredictable bowel symptoms caused them. One participant described themselves as “agoraphobic” in the months following stoma reversal due to the severity of their bowel dysfunction. Similarly, 35.6% of participants in a quantitative, retrospective study exploring bowel problems in patients post-SSS feared emitting odour in social situations, experienced concern about finding toilets when away from home (44.5%) and uncertainty about knowing what foods to eat when away from home (Nikoletti *et al.,* 2008). Desnoo and Faithful (2005) explored the psychological effects of defecatory dysfunction following sphincter-sparing surgery, participants reported that the regular “sensation of needing to go to the toilet” (pg. 248) often resulted in fear, especially if a toilet was not immediately accessible. A non-randomised clinical trial study also identified this occurrence, with all participants (n=14) reporting that their experiences of evacuatory dysfunction had caused them to reduce their human interactions and outings (Attene *et al.,* 2009).

Patients also cited limiting food intake outside of the home setting and avoidance of alcohol as coping strategies (Nikoletti *et al.,* 2008, Landers *et al.,* 2012, Hou *et al.,* 2017), withdrawal from these social activities may also contribute to a reduction in a patient's social engagement and interaction. These studies highlight the burdensome and often socially isolating effects which the inability or lack of information to manage bowel symptoms can often have upon patients.

Desnoo & Faithful (2006) highlighted the withdrawal from socialising reported by patients experiencing bowel dysfunction. However, this study also found that when patients adapted "protective strategies" they increased their social activities, this finding further provides rationale for the development of an intervention that provides strategies to enable patients to take control of their bowel symptoms and would potentially increase their confidence.

Conclusion

The significant ways in which bowel dysfunction following sphincter-sparing surgery may transcend the physical and permeate the psychological and social aspects of patient well-being were explored across the literature. The physical symptoms ranging from flatulence, urgency, frequency and constipation to evacuatory dysfunction and tenesmus. Some of the psychological and social effects of altered bowel function upon individuals included withdrawal from social activities, reduced ability to participate in unplanned activity, impaired sexual function, fear of recurrence, embarrassment, anxiety in relation to employment, limitation of food intake and perceived lack of ability to cope. Much of the literature acknowledged that patient education and information led to improved ability to cope and allowed the development of confidence to re-engage in social activities. The literature also identified the need for interventions which aided patients in their self-care. The following chapter seeks to explore the existing interventions aimed at aiding patients with their self-care of bowel symptoms.

Chapter 3.0- Bowel Symptom Management Strategies

Introduction

The following chapter will examine a number of areas relating to self-care. Firstly, the theoretical perspectives, individual components and the significance of self-care will be reviewed. Secondly through a narrative review, an exploration of self-care strategies utilised by patients to cope with their bowel symptoms following treatment for rectal cancer and their perceived efficacy will be carried out. Finally, a systematic review examining existing targeted interventions used to support patients in the self-care of bowel symptoms in the context of both cancer and chronic bowel disease/ symptoms will be conducted and disseminated. This section aims to examine the existing literature surrounding self-care of bowel symptoms, so as to inform and underpin the potential examination of the need to develop a supportive intervention to aid patients with their management of bowel dysfunction. The next section focuses upon the theory of self-care and its significance in relation to this topic.

3.1.- Self-Care Theoretical Perspectives

This section will discuss the concept of self-care, the individual components which contribute to self-care and the difference between self-care and self-management. This section will also examine why the theoretical concepts of self-care may aid and underpin the development of the proposed intervention. Whilst the focus of this study is to determine the content and delivery of an intervention to aid patients to self-care for their bowel symptoms, when examining the literature, the terms self-care and self-management were often used interchangeably. When discussing self-care and self-management it is important to distinguish differences. To ensure that pertinent information was included neither term was excluded from the search but for this study self-care was the chosen focus.

Self-care is behaviour initiated or performed by individuals on their own behalf to improve their life and promote health using their own resources, including personal attributes (Orem, 1995, Repenning *et al.,* 2003). In addition, self-care strategies are a component of the self-management strategies developed in response to symptom experience, as discussed by Humphreys *et al.,* (2009). Self-care combines the actions individuals carry out to stay fit and maintain good physical and mental health; meet social and psychological needs and prevent illness and cope with long-term conditions and maintain health and well-being after an acute illness or discharge from hospital (UK Department of Health, 2005). For many individuals following medical intervention for a condition, the responsibility of care may become solely theirs. Self- management differs from self-care as it consists of at-home strategies which “are undertaken with the collaboration and guidance of the individual’s physician and other health care providers” (pp.5 Clark *et al.,* 1991).

In health care, self-care refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences, and the lifestyle changes intrinsic in living with a chronic condition (Barlow *et al.,* 2002). Clark *et al.,* (1991) describe self-management as “tasks an individual must undertake to control or reduce the impact of disease on physical health status. Effective self-management involves the ability to monitor one’s condition and to achieve the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. The choice to focus upon self-care was made as many patients who experience and must cope with bowel symptoms do so for years following their surgery, well beyond the period of support and surveillance by their medical teams, but also because this concept focuses upon care of symptoms and well-being following acute illness or admission into hospital. Self-management is a very broad concept, the focus of this thesis was specifically on self-care strategies. The following section will focus upon the self-care strategies initiated by patients to manage their bowels symptoms experienced as a result of SSS and describe the search strategy utilised to identify all pertinent literature.

3.2 Search Strategy- Bowel Symptom Management Strategies Utilised by Patients Following Sphincter-sparing Surgery

Introduction

The following sections present the narrative review used to identify strategies utilised by patient to self-care for their bowel symptoms. Whilst the overall aim of this study is to determine the content and delivery of an intervention to aid patients in their self-care, an understanding of current practices is vital to identify the perceived efficacy of these strategies. It is also important to carry out this search to allow review of potential self-care strategies which may be appropriate for inclusion within a future intervention and also to identify the potentially harmful strategies which patients may use to care for their bowel symptoms when doing so without underpinning evidence.

3.2.1- Search Strategy

To achieve the aforementioned aims, an initial search strategy was carried out across CINAHL, PubMed, the Cochrane Library, and NICE Guidelines between the years 2005-2017, with an update in 2019, in addition to purposively searching the Grey Literature in relation to articles and guidelines supporting, explaining, or discussing self-care strategies for bowel symptoms following sphincter-sparing surgery.

Inclusion criteria were as follows:

Types of participants included any individual who had undergone sphincter-sparing surgery for rectal cancer, no longer had a stoma and was over 18 years of age. Gender, social status, race, or incomes were not used as discriminatory criteria.

Types of papers included studies examining self-care of bowel symptoms including those which subsequently carried out interventions. Randomised Controlled Trials, Non-Randomised Controlled Trials, cross-sectional, prospective, retrospective, qualitative, quantitative, observational and population-based studies which were peer- reviewed were included. All English language or pre-translated papers were included.

Exclusion Criteria were as follows:

Participants who still had a stoma or were less than 18 years of age were excluded. Opinion papers, non- peer reviewed pieces, papers which did not focus on bowel symptoms were excluded as well as articles which included strategies carried out by healthcare professionals upon patients with bowel symptoms which could not be used as self-care strategies e.g sacral nerve stimulation.

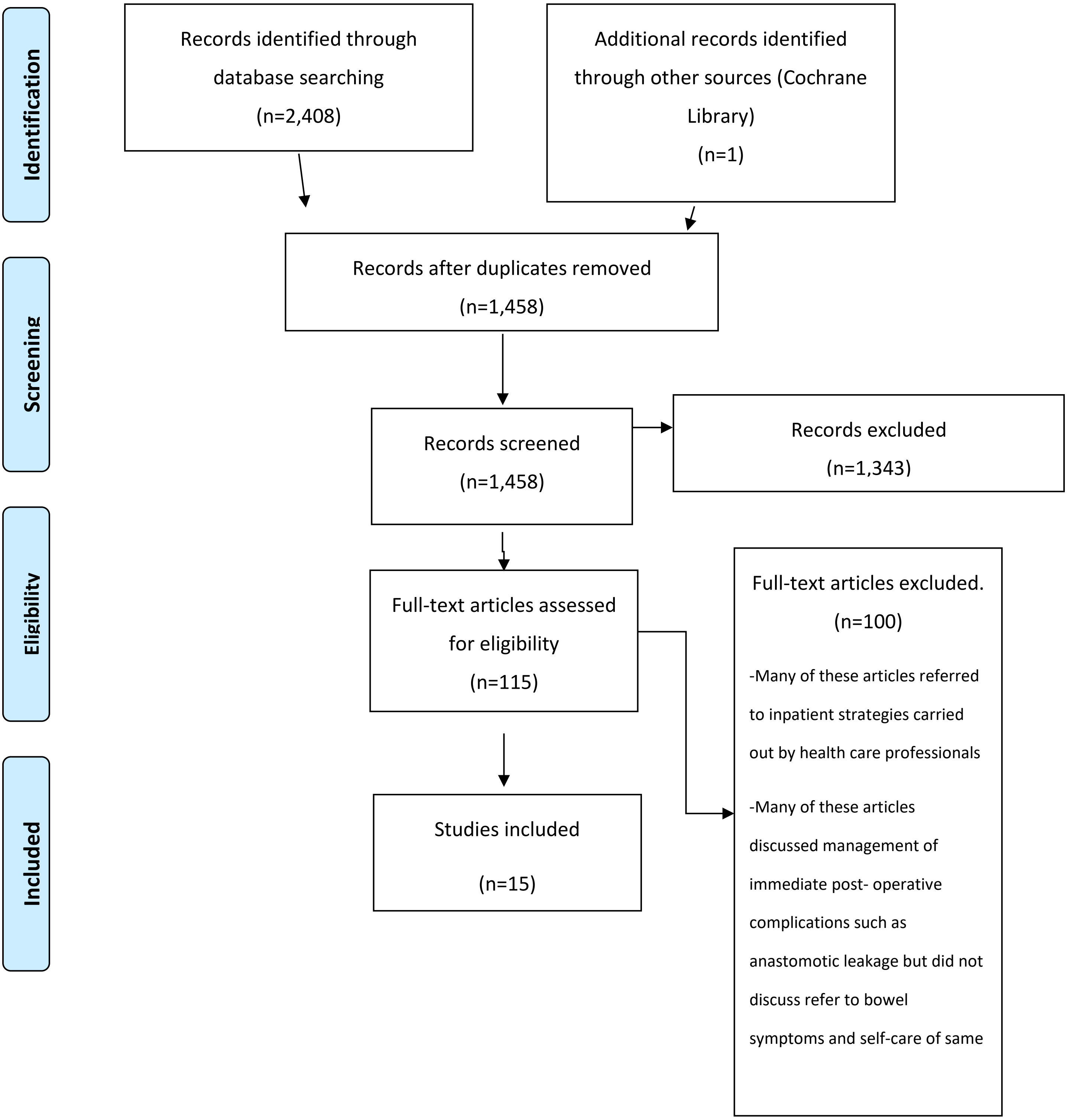
Search Terms

When carrying out this search term such as “self-care”, “self-management”, “patient initiated care”, “self-help”, “bowel symptoms”, “frequency”, “urgency”, and “faecal incontinence” were utilised. A list of all search terms is illustrated in Appendix 2.

The resultant papers were then examined**,** screened for relevance, data input and the process illustrated by the PRISMA chart (Liberatti *et al.,* 2009) (FIG 2). The screening process was examined following data extraction with extracted papers reviewed by two reviewers, ML & JH.

Figure 2- Prisma Flow Chart (Liberati et al., 2009) 2 CINAHL, PUBMED, Cochrane

Bowel Symptom Management Strategies following sphincter-sparing surgery



3.3- Bowel Symptom Management Strategies Utilised by Patients Following Sphincter-sparing Surgery- Literature Findings

This section will discuss the literature which identified some of the self-care strategies utilised to manage bowel symptoms following sphincter-sparing surgery including medication use, dietary alteration, perianal skin management and incontinence product use, and the perceived benefits and potential risks. In terms of origin of relevant studies (n=15), publications included British (n=5), Irish (n=1), French (n=1), Danish (n=1), Australian (n=1), Chinese (n=1), Japanese(n=1), German (n=1) and 3 Cochrane Reviews with multinational input. In terms of research approach, types included prospective (n=2), cross-sectional (n=3), retrospective (n=2), qualitative (n=3), longitudinal, systematic reviews (n=3) and guidelines (n=1). For clarity strategies are divided into the groups of Functional, Activity Related and Alternative as previously described by Landers *et al.,* (2011) and overall findings are presented in Table 2.

3.3.1 Functional Self-Care Strategies for Management of Bowel Symptoms

This section describes functional self-care strategies utilised by patients to manage their bowel symptoms including medication use, dietary strategies and use of incontinence wear. It utilises the definition of “strategies participants use to manage bowel symptoms” as described by Landers *et al.,* (2011). The most common functional care strategies revealed the marked impact which management of bowel symptoms can have upon an individual’s activities of daily living but also how strategies can contribute to improved control, confidence, and the ability to reengage in daily life. Across the literature many functional strategies were identified, this section also examines their perceived effectiveness according to patients.

Medication Use as a Functional Self-Care Strategy for the Management of Bowel Symptoms.

One strategy utilised by patient to cope with bowel dysfunction was the use of medication, including Loperamide. Loperamide (commonly known as Imodium) is a medication which appeared regularly throughout the literature exploring self-care. Loperamide is an anti-diarrhoeal which increases intestinal transit time, reduces propulsion activity and stimulates absorption of electrolytes and water (Regnard *et al.,* 2011). This section examines the incidence of Loperamide use as a self-care strategy, the benefits, perceived efficacy and also the potential risks.

A cross-sectional study examining bowel dysfunction following low anterior resection surgery (n=938) found that 22.5% who had undergone TME and neoadjuvant therapy (n=174) utilised anti-diarrhoeal medication such as Loperamide to manage faecal incontinence, loose stool, and urgency (Bregendahl *et al.,* 2013). Its use was also discussed in Desnoo & Faithful’s (2005) qualitative exploration of anterior resection syndrome, with participants citing Loperamide use as one of their main self-care strategies. Another study examining functional disorders amongst individuals post-TME found that almost 50% of participants (n=24) utilised anti-diarrhoeal medication (Laforest *et al.,* 2012).

From a qualitative perspective, Landers *et al.,* (2012) identified that patients found the use of Loperamide (Loperamide) to be particularly helpful in the management of diarrhoea but also for prophylactic use to prevent it's occurence. Participants noted that this self-care strategy helped them to manage their symptoms in an "effective" way and that it worked "pretty well" (Landers *et al.,* 2012, pp.297). This study also identified the symptom of constipation as an issue, with participants utilising Movicol to aid their bowel motions. Furthermore, the use of Loperamide was noted to be higher amongst patients who underwent radiation therapy (n=41) than those who did not (n=54) ($p< 0.02$) in a prospective study examining the difference in anorectal function following different treatments for rectal cancer (Allgayer *et al.,* 2005). Again, highlighting the effect of radiotherapy upon bowel function following treatment for rectal cancer.

The prevalence of Loperamide use was also examined in a retrospective, descriptive study exploring self-care practices and bowel symptoms of individuals following surgery for colorectal cancer (n=101), where forty seven reported use of bowel medications, 55.3% of which used Loperamide (Nikoletti *et al.,* 2008). The use of bulk-forming agents as a means of managing bowel symptoms was also identified by Desnoo & Faithful (2005). Lomotil as a means of managing increased bowel motions was utilised by 16% of participants in Hou *et al.'s,* (2017) exploration of self-care and bowel symptoms.

In a systematic Cochrane review of 16 studies (Omar & Alexander, 2013), the use of drug treatment to manage faecal incontinence was explored. It was found that when Loperamide versus placebo was administered to patients experiencing faecal incontinence, Loperamide use was associated with higher continence achievement, less faecal incontinence, pad use and faecal urgency. However, it was also acknowledged that when compared with a placebo, Loperamide and other anti-diarrhoeal agents resulted in greater side effects such as constipation. A low dose of Loperamide was the most commonly used anti-diarrhoeal agent used and titration of doses was seen to effectively manage incontinence and consistency.

According to NICE Guidelines the anti-diarrhoeal drug of choice should be Loperamide hydrochloride as it can be used in doses from 0.5 mg to 16 mg per day as required for extended periods of time (NICE 2007). When Loperamide is used, it should be introduced at a very low dose and the dose should be increased, until the desired stool consistency has been achieved (NICE, 2007). However, the guidelines also advise that causation of diarrhoea should be determined to out rule any contraindication to Loperamide use such as acute IBS, gastrointestinal infections, viruses etc and in cases of potential obstruction.

This again serves to highlight the importance of informed self-care to prevent any complications.

In a mixed methods study by Nikoletti *et al.,* (2008) an exploration of self-care strategies for bowel symptoms experienced by patients (n=175) following SSS was examined. A total of 22 participants took medication following a health care professional's advice and in terms of its efficacy, participants rated this as 2.09±0.81 out of a possible 3.0 making it the most effective self-care strategy reported, in comparison to self- initiated medication which scored 1.96 (Nikoletti *et al.,* 2008). Similarly, in a biofeedback study, which sought to improve bowel function following sphincter-sparing surgery using both biofeedback and medication advice, participants were given advice in relation to timing and dosage of anti- diarrhoeal medications (Bartlett *et al.,* 2011). Whilst this was just one element of the programme participants saw improved continence and reduced flatulence as a result.

The use of Loperamide and other bowel function altering medications is a self-care strategy often initiated by patients despite no advice from medical professionals. Whilst the literature and evidence highlighted the potential benefits of these drugs the need for medical guidance is pivotal as Loperamide can have profound effects in term of cardiac function, dependence and constipation and use of laxatives can cause loss of electrolytes etc. (Regnard *et al.,* 2011). Across the literature relating to Loperamide use as a self-care strategy, its potential uses, benefit and perceived efficacy was acknowledged. However, so too was its potential for adverse effects when utilised without evidence-based information.

Diet as a Functional Self-Care Strategy for the Management of Bowel Symptoms

Modification of diet was another self-care strategy frequently explored throughout the literature. In a study carried out by Nikoletti *et al.,* (2008) examining the information needs of patients following sphincter-sparing surgery, diet was reported as the most important information need of patients, with 52.5% of participants reporting it as the type of information they needed. As the following section highlights, this is a coping strategy developed by many patients through trial and error as opposed to informed evidence-based practice and is further illustrated in Table 2, which can be found on page 70.

One cross-sectional study examining self-care strategies amongst patients post SSS, (N=175) identified that 71% of participants found certain foods to increase their number of daily bowel motions (Hou *et al.,* 2017). In addition to this, 86% of patients altered their diet in response to their own bowel symptoms, and almost 76% of participants identified limiting the ingestion of spicy food, caffeine and alcohol to be a helpful self-care strategy in the management of their bowel symptoms. Some participants (94%) also relied upon increased intake of dietary fibre to reduce bowel symptoms (Hou *et al.,* 2017). Similarly, respondents in the study by Nikolletti *et al., (*2008) reported use of a high fibre diet.

However, high fibre intake may in fact exacerbate symptoms of faecal incontinence through the development of softer stool (Bliss *et al.,*2014). High intake of fruit and vegetables may also increase the incidence of nausea, bloating and diarrhoea (Bliss *et al.,* 2014). Hou *et al.,* (2017) acknowledged that often alterations to lifestyle were carried out without the supervision or guidance of a healthcare professional and that some participants (figure not provided) avoided food entirely before social events to prevent episodes of incontinence (Hou *et al.,* 2017). Similar findings were also identified in a retrospective study by Nikoletti *et al.,* (2008) exploring self-care practices of those post-SSS (n=101), with 36.6% of participants (n=37) reporting a change in diet after surgery and 41.5% following a specific diet.

Food limitation was also identified as a self-care strategy in a qualitative study exploring self-care, participants mentioned avoiding pulses, fizzy drinks, sweet foods and increasing their intake of fibre (Landers *et al.,* 2012). However, some worrying practices such as limiting food to being ingested at home or avoiding breakfast were also identified, suggesting that some individuals resort to potentially isolating or unhealthy behaviours to prevent the potential embarrassment of incontinence. The haphazard and often potentially detrimental practices carried out by those experiencing altered bowel symptoms highlights the need for a supportive and evidence-based intervention to aid patients to manage their own symptoms. Whilst some individuals identified improvement in bowel symptoms when observing certain dietary practices, for many symptoms persisted. The following section describes the resultant skin irritation due to bowel dysfunction and the self-care strategies implemented by patients to cope with its occurrence.

Perianal Skin Care as a Functional Self-Care Strategy

A further self-care strategy necessitated by episodes of loose stool and incontinence, which was explored by the literature, was perianal skin care. In their exploration of self-care strategies, Hou *et al.,* (2017) identified that as many as 73% of 175 participants utilised soft toilet paper or non-alcoholic wipes for personal hygiene following bowel motions, this was associated with a high perception of efficacy, with a score of 1.76 ± 0.92 from a potential 3 in the correlation between the MSKCC and the Bowel Symptoms Self-Management Behaviours Questionnaire. Patients also reported utilising barrier creams and protective sprays to prevent perianal irritation with good efficacy and positive effects. As mentioned in the previous chapter the Landers *et al.,* (2012) qualitative exploration of self-care strategies, found that some individuals utilised showering between bowel motions as they found toilet paper to cause sore skin. Comparatively, Hou *et al.,* (2017) found that 35% (n=61) of their participants used warm water to cleanse their perianal skin. This study also found that almost 28% of participants utilised skin creams to protect their perianal skin or prevent discomfort. Desnoo & Faithful (2005) reported that use of moist toilet wipes or barrier cream were amongst the common self-care strategies utilised by participants.

The self-care strategies implemented by individuals relating to skin care were widespread. Some participants cited that implementation of these strategies were as a result of advice received from healthcare professionals (Hou *et al.,* 2017). However, others developed their own strategies (Landers *et al.,* 2012). The potential benefits to patient comfort and perianal skin care through use of barrier creams and continence wipes was identified in a Cochrane systematic review (Beeckman *et al.,* 2016). This acknowledged that repeated episodes of faecal incontinence were associated with incontinence associated dermatitis (IAD), skin infection and increased risk of pressure sores. Whilst it noted that the quality of the reviewed studies (n=13) was low due to small sample size and short duration of trials, the findings overall suggesting that use of a skin protecting cream was of greater benefit than withholding and resulted in lower incidence of IAD (Beeckman *et al.,* 2016). As identified by the literature, skin care as self-care strategy was often based upon patient experience as opposed to evidence based practice. The potential benefit to be gained from evidence-based advice is apparent and the potential risks of poorly managed skin care identified. Again, the need to and benefits of providing patients with education to cope with symptoms resultant of treatment for rectal cancer is evident.

Incontinence Wear as a Functional Self-Care Strategy

Perhaps the most common strategy identified across the literature as a self-care strategy was the use of incontinence wear. Whilst different forms were used, of the included studies 10 noted the use of pads/ napkins/ tissues etc. As outlined by a Cochrane review examining absorbent products for incontinence (Fader *et al.,* 2008), these products may be divided into two categories; i) light, and ii) moderate to heavy incontinence. Whilst pad use was mentioned throughout the literature none of the studies specified which category of absorbent product was utilised.

Use of incontinence pads (protection) was reported by 52% of participants (n=38) in a study examining self-care strategies and bowel symptoms amongst patients following sphincter-sparing surgery (Nikoletti *et al.,* 2008). With 21% of participants having to wear incontinence products “always”. These findings were echoed in a similar study by Hou *et al.,* (2017) with 45% (n=79) of participants reporting the need to wear a napkin or pad in their undergarments in case of leakage throughout the day. In a retrospective study evaluating functional outcomes post treatment for rectal cancer, the need to wear a pad was observed in 84 % of the intersphincteric resection cases and 33% of the LAR cases (Koyama *et al.,* 2014). In Desnoo & Faithful’s (2005) exploration of self-care strategies, the use of pads was cited as one of the most common strategies in management of faecal incontinence due to sphincter-sparing surgery. Similarly, Landers *et al.,* (2012) found the use of protective clothing and incontinence pads to be some of the most common strategies to be utilised by patients following surgery for rectal cancer.

Whilst the efficacy of incontinence wear to allow patients to continue with their activities of daily living is undeniable, the limitations of incontinence wear is evident. Continued incontinence with often little intervention of continence nurse specialists or healthcare professionals, means that use of incontinence pads only masks the problem but does not improve it, and may lead to individuals delaying intervention through fear or embarrassment. The importance of developing an intervention that allows patient to potentially improve their symptoms, as opposed to just mask them, is extremely important.

3.3.2- Alternative Therapies as Self-Care Strategies for Bowel Symptoms.

The use of alternative therapies was also identified as self-care behaviour implemented by patients. Throughout the literature the use of a variety of therapies including yoga, herbalism, massage, spiritualism etc. was identified. This area of self-care also identified many strategies which were not evidence-based, had little effect and had the potential to effect patients detrimentally. The following section discusses the incidence and perceived efficacy of such therapies by patients.

In a qualitative study carried out by Landers *et al.,* (2012) use of vitamins, herbs and bacterial culture were alternative strategies utilised by patients. These findings were similarly explored by the study by Hou *et al.,* (2017), with more that 80% (n=140) citing exercise as a strategy to regulate their mood and participants reporting use of alternative self-care such as massage of the abdomen, drinking yoghurt, sesame oil or honey water. In term of self- medication some patients employed the use of Chinese medicine and microbial ecological agents. However, the study did not report the patients' perceived efficacy of said strategies. Nikoletti *et al.,* (2008) also found that 17% of participants in their study utilised alternative therapies to manage their bowel symptoms. Desnoo & Faithful (2005) too found that a positive mental attitude was one of the main components in managing bowel symptoms and found that when patients developed greater confidence in managing their physical symptoms, the impact that they had upon social aspect of their life was lessened.

In a cross- sectional Beijing survey study, 175 patients following sphincter preserving surgery, were administered the Chinese version of the Memorial Sloan-Kettering Cancer Centre Bowel Function Instrument (MSKCC-BFI), and the Bowel Symptoms Self-Management Behaviours Questionnaire (Hou *et al.,* 2016). This study identified that whilst patients utilised self- management behaviours such as diet alteration and perianal skin management, fewer used therapy self-care such as pelvic floor training, glycerine suppository use and sitz-baths despite it yielding best results (r=-0.232 to -0.580, P < .01), and only those with the most severe symptoms were likely to use therapy. The researcher also identified the need for health care professionals to develop an intervention to aid patients to manage their bowel symptoms. Significantly, it was noted that the greater the frequency of self-care behaviours was noted amongst those experiencing the most severe of symptoms.

The use of alternative therapies was explored by many of the studies however, these were not implemented by health professionals and efficacy and safety of many of the utilised therapies had not been evaluated. This further highlights the need to develop an intervention that not only aids patients to manage their bowel symptoms but does so in a way that is safe, evidence based and effective.

3.3.3 Activity Related Self-Care Strategies for the Management of Bowel Symptoms

Activity related self-care strategies as described by Landers *et al.,* (2012) include actions taken by patients to cope with and manage their bowel dysfunction when it occurs in social interactions/situations. These included identification of toilet facilities, food limitation, reduction of social interaction, alteration to work practices and familial and friend support and engagement.

As discussed in Section 3.1.6, both Hou *et al.,* (2017) and Landers *et al.,* (2011) found that individuals often restrict food when presented with social interactions, with some skipping breakfast before using public transport or limiting food intake when socialising. Other activity related care strategies included clarifying available toilet facilities before attending certain locations or identifying toilet facilities immediately upon arrival (Nikoletti *et al.,* 2008, Landers *et al.,* 2011). Landers *et al.,* (2011) also noted that some individuals removed stressful elements of their daily activities through scheduling and removal of deadlines.

Further activity related self-care strategies included use of emotional coping. Landers *et al.,* 2012) identified participants' use of positive mental attitude, yoga and spirituality as helpful coping mechanisms. In a qualitative study exploring self-care following treatment for rectal cancer, participants voiced that bowel dysfunction was “a small price to pay for their life” (p.248, Desnoo & Faithfull, 2005.) and viewed it as a positive thing. This finding was echoed in another study examining the lived experience of patients following stoma reversal, with participants referring to their bowel symptoms as a “price” to pay for the treatment of their cancer (p. 418, Taylor & Bradshaw, 2013). Adopting this view aided some patients in acceptance of their bowel symptoms and the reality of coping with same. Desnoo & Faithful (2005) also identified that when many individuals developed their own “protection packages” it allowed them to return to social participation.

Activity related self-care strategies were identified across the literature as effective tools in coping with bowel symptoms. Many participants self-initiated these strategies to reduce the anxiety and embarrassment associated with bowel symptoms included faecal incontinence. However, worrying practices such as food restriction or avoidance were noted, highlighting the need for informed and evidence-based guidance for coping with bowel symptoms. Example of these and a summary of findings may be seen in Table 2.

Summary

Self-care strategies utilised by patients were varied in both mode and efficacy. For many patient's these strategies facilitated increased confidence, reduced bowel symptoms and a decrease in the impact which bowel symptoms had upon their daily lives. The myriad of self-care practices identified included functional, alternative and activity related strategies. Use of diet, medication, incontinence wear, skin care products, emotional coping, planning, alternative therapies and stress reduction were just some of the patient-initiated interventions identified. However, uninformed, and self- constructed strategies implemented by patients were commonly identified across the literature reviewed. So too was their limited efficacy and safety, with patients regularly resorting to unusual or unsatisfactory practices to limit the impact which these significant symptoms had upon their daily lives. Whilst practices such as glycerine suppository use and health professional guided medication use were the most effective, very often these were the therapies utilised least.

The long-standing duration of symptoms and lack of improvement highlights the need to develop a supportive intervention that is grounded in evidence-based practice and proven to be efficacious to allow patients to safely care for and potentially improve their symptoms and overall quality of life.

Self-Care Strategies Initiated by Patients	**Description**	**Prevalence**	**Comments**
Functional			
Diet	Increased dietary fibre, avoidance of spicy food, stimulating drinks like caffeine and alcohol. Avoidance of gas yielding food.	Most common self-care behaviour, 94% included appropriate dietary fibre (Hou *et al.,* 2017)	A change in diet was reported by 36.6% of participants (Nikolleti *et al.,*2008). With 41.5% following a specific diet.
Skin Care and Incontinence Wear	Strategies included pads, sitz baths, use of moist wipes, showering instead of using toilet paper and barrier cream use.	43.7%(Hou *et al.,* 2017)-84% (Koyoma *et al.,*2014) of participants reported use of pads, napkins and tissues. Many participants (n=7%)cited use of skin cream to prevent and treat skin discomfort (Hou *et al.,* 2017) or warm water following toileting (47%) (Hou *et al.,* 2017).	Patients reported development of perianal irritation due to frequency and incontinence.
Medication Use	Loperamide, Lomotil, glycerine suppositories, fibre supplements and laxatives (Movicol) (Nikoletti *et al.,* 2008, Landers *et al.,*2012, Hou *et al.,*2017).	25.4% (n=44) (Hou *et al.,*2017)46.5% (Nikoletti *et al.,*2008).	Patients reported efficacy of Loperamide in management of faecal incontinence and frequency (Landers *et al.,*2012)
Activity Related			
Emotional Coping	Family support, use of positive attitude, realisation that symptoms are resultant of life-saving treatment and spirituality were all identified as activity related emotional coping strategies (Hou *et al.,*2017, Landers *et al.,* 2011, Nikoletti *et al.,* 2008, Desnoo & Faithfull, 2005).	More than 53% of patients cited using exercise as a means to regulate mood, almost 40% utilised distraction techniques and 15% sought support and comfort amongst friends and family in a cross-sectional study examining self-care strategies (Hou *et al.,* 2017).	Of note less than 10% of participants went to medical staff for emotional support (Hou *et al.,* 2017). Other strategies used to aid emotional coping included discussing bowel symptoms with other patients, viewing surgery and its resultant symptoms as a “price to pay” for a chance at life (Desnoo & Faithfull, 2005).
Awareness of Facilities	Across a number of studies reviewed, individuals highlighted the importance of knowing the location of toilet facilities prior to or upon arrival to a location (Hou *et al., 2017).*	Hou *et al.,* (2017) found that 47% (n=82) of participants planned their social interactions according to their bowel symptoms and 43.1% knew the location of toilets prior to going out.	Patients acknowledged that awareness of facilities increased their confidence to participate in social activities but Nikoletti *et al.,* (2008) noted that the most frequently reported social concern was finding toilets when away from home (44.5%).
Alternative			
Miscellaneous	Yoga, Chinese medicine, exercise, mindfulness, distraction techniques, bacterial cultures and relaxation breathing.	Varied approaches and usually the least utilised strategy by patient across all studies.	Some strategies cited by patients were initiated with no education or evidence

Table 2-Self-Care Strategies Initiated by Patients

3.4- Existing Interventions to Aid Patients with Care of Bowel Symptoms-Systematic Review

Introduction

The following section, through a systematic review, seeks to examine and describe the current interventions that exist, which support patients to manage their bowel symptoms/dysfunction and evaluate their efficacy. In addition, this review sought to identify elements of the interventions which potentially contributed to improved symptom outcomes.

The choice to conduct a systematic review for this section rather than the narrative approach adopted for the previous section, was made as a systematic review uses explicit and rigorous criteria to identify, critically evaluate and synthesise all of the literature on a topic (Cronin *et al.,* 2008), thereby strengthening the findings and outcomes of the review and the subsequent research carried out as a result of conducting the review. Furthermore, the researcher wished to identify a gap in the current literature through identification and synthesis of research which currently exists around interventions to help self-care of bowel dysfunction. In addition, as the current study seeks to impact upon current clinical practice, the decision to conduct a systematic review was carried out as these are often viewed within research as the most reliable source of evidence to guide clinical practice (Clarke, 2011).

To formulate the research question for this systematic review, the ‘PICO’ (Population, Intervention, Control and Outcome) tool (Centre for Reviews and Dissemination, 2007) was utilised. The following section will examine the PICO framework results used to formulate the research question of this systematic review.

3.4.1- The Population, Intervention, Comparison and Outcome “PICO” Tool.

The population (P) identified for the purpose of this systematic review is participants experiencing altered bowel function as a result of inflammatory bowel disease, treatment for colorectal cancer or irritable bowel disease who do not have a stoma at the time of the intervention. The intervention (I) element of this systematic review is interventions implemented by healthcare professionals with the aim of empowering/enabling patients to self-care for bowel symptoms which did not involve the use of invasive techniques such as sacral nerve stimulation, anorectal manometry etc. The comparison (C) element of PICO is not applicable to this systematic review as no comparison is being made. The outcome (O) observed for this systematic review is improvement in bowel symptoms or perceived improvement of symptoms.

The ‘Preferred Reporting Items for Systematic Reviews and Meta-Analyses’, also referred to as the PRISMA standards for the reporting of systematic reviews (Moher et al 2009) was utilised to ensure this systematic review meets the requirements of quality, to allow others to identify the strengths and weaknesses of the review and facilitate replication should same be attempted by other researchers, this can be found in Appendix 18.

In addition, all potential interventions identified for inclusion were appraised utilising the Joanna Briggs Institute (JBI) Checklist for Quasi-Experimental Studies and the JBI Checklist for Randomised Control Trials, all of which can be seen in Appendix 17.

3.4.2- Aims of Systematic Review

- To critically appraise and discuss evidence from existing, non-invasive interventions designed to aid patients in the self-care of bowel symptoms following surgery for colorectal cancer or bowel symptoms experienced as a result of chronic bowel disease and idiopathic faecal incontinence.
- To identify the effect of interventions upon outcomes relating to improvement of symptoms.
- To ascertain if there is a need to further research or develop an intervention to support patients following sphincter-sparing surgery for rectal cancer to self-care for their bowel symptoms.

3.4.3 Search Strategy

Searches were carried out across the CINAHL, PubMed and Cochrane databases utilising Boolean terms published between 2002-2017, with an update made in May 2019, but this search did not reveal any additional relevant studies. In addition, the author purposively searched the Grey Literature in relation to articles and guidelines supporting, explaining or discussing existing interventions used to manage bowel symptoms. Key words and subject headings/MeSH terms searched in titles and abstracts using various combinations included: “education”, “intervention”, “bowel symptoms”, “inflammatory bowel disease”, “anterior resection syndrome”, “self-care”, “self-led”, “patient-led”.

Inclusion criteria consisted of the following;

Papers including participants greater than 18 years of age experiencing altered bowel function resultant of Inflammatory Bowel Disease, Irritable Bowel Syndrome, or following treatment of colorectal cancer who did not have a stoma at the time of the study/ intervention.

Exclusion Criteria consisted of the following;

Interventions which included invasive/surgical elements which could not be implemented by individuals experiencing altered bowel function following SSS for colorectal cancer or due to IBD/IBS or idiopathic faecal incontinence.

Interventions which focused upon “management” including clinician prescribed regimes, medication use including Imuran, steroids etc., which required regular monitoring and input from healthcare professionals.

3.4.4- Study Selection and Data Extraction

The researcher extracted data from eligible studies using a predefined extraction table (Table 3- pages 85 & 86). Data extraction included: author(s); year; country and setting; study aim(s); study design and theoretical underpinning; data collection method and instruments; and findings relating to the review aims.

Interventions implemented by healthcare professionals with the aim of empowering/enabling patients to self-care for their symptoms which did not involve the use of invasive techniques such as sacral nerve stimulation, anorectal manometry etc and literature comparing the effectiveness of interventions for patients experiencing bowel symptoms. Interventions included had measurable outcomes, pre- and post- intervention results. All relevant English language or pre-translated papers were examined.

In addition, whilst reviewing the literature the researcher identified a lack of research into interventions used specifically to manage symptoms post-SSS and that much of the treatments were based upon individual symptoms. The choice was therefore made to include literature examining interventions for other bowel symptoms resultant of chronic bowel disease (e.g Crohn’s Disease, Ulcerative Collitis, Irritable Bowel Syndrome) and idiopathic faecal incontinence.

3.4.5- Quality Appraisal

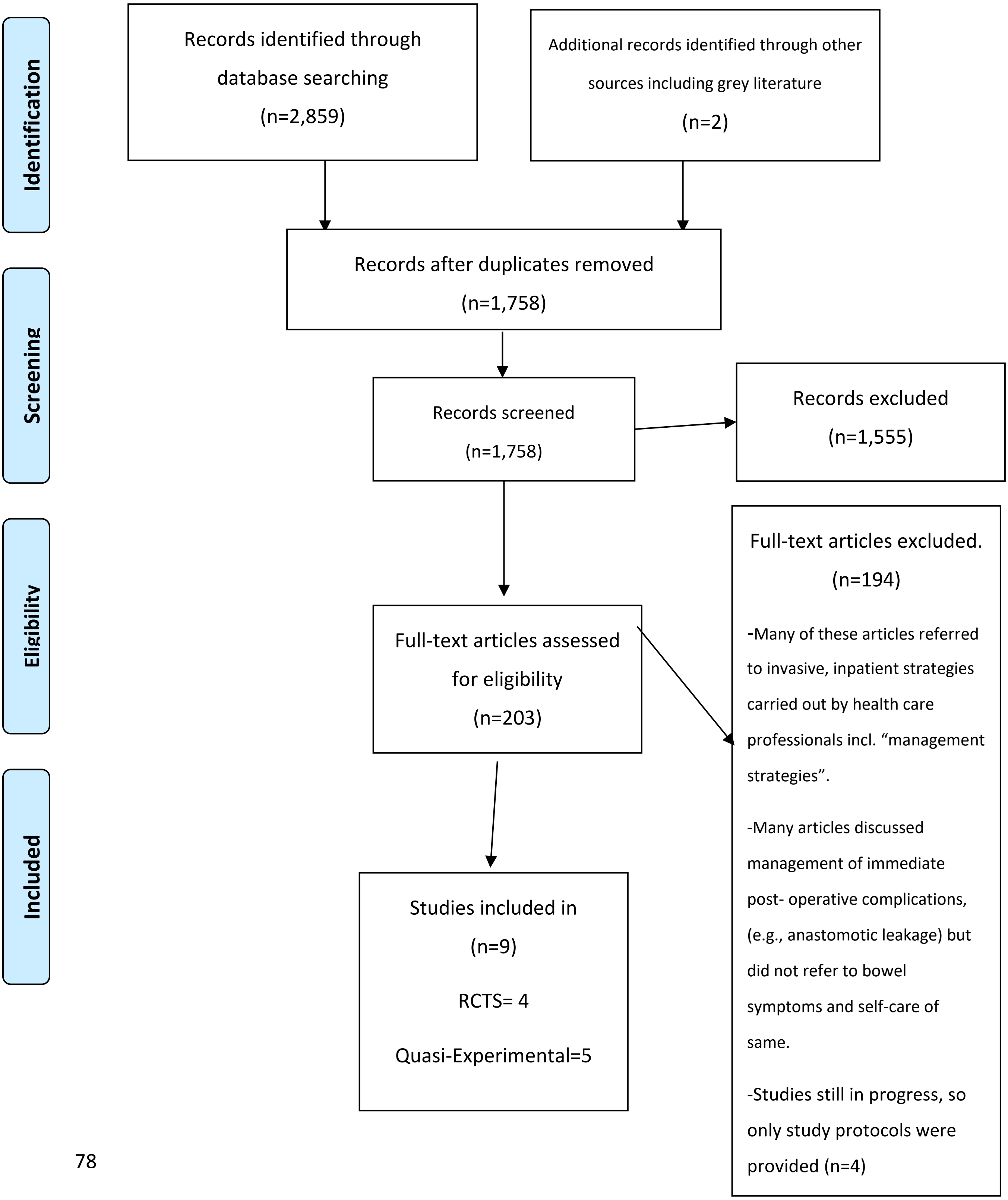
The strength of each study was evaluated using the JBI Checklists for RCTs and Quasi-Experimental Studies. This allowed identification of areas of potential bias and study weakness.

The review examined studies conducted through face-to face interventions at both an individual or group level. Additional factors assessed in the evaluation of studies included (1) Study design including randomisation (2) Intervention type and activities implemented (3) duration and dosage of intervention (4) the use of theory in directing the study's focus.

The following Prisma Flow Chart (Liberatti *et al.,* 2009) 3.0 illustrates the search results;

Figure 3: PRISMA FLOW CHART 3

PRISMA (2009) Flow Diagram 3.0- Interventions to Support Patients in their Self-Care of Bowel Symptoms



-Many of these articles referred to invasive, inpatient strategies carried out by health care professionals incl. "management strategies".

-Many articles discussed management of immediate post- operative complications, (e.g., anastomotic leakage) but did not refer to bowel symptoms and self-care of same.

-Studies still in progress, so only study protocols were provided (n=4)

3.5.- Study Characteristics

Overall, 2,861 titles were identified. Following duplicate deletion, 1,758 records were screened on title and abstract and 1,555 were excluded. The full texts of 204 papers were evaluated and 9 intervention studies were included. In relation to study characteristics four were randomised control trials (Ilnyckyj *et al.,* 2005, Robinson *et al.,* 2006, Jefford *et al.,* 2011, Reusch *et al.,* 2016), and five were quasi-experimental (Smith *et al.,*2002 Nikoletti *et al.,* 2003, Hawkes *et al.,* 2009, Ringstrom *et al*., 2009, Lin *et al.,* 2015). Four studies focused upon bowel symptoms following colorectal cancer (Nikoletti *et al.,* 2003, Hawkes *et al.,* 2009, Jefford *et al.,* 2011, Lin *et al.,* 2015). However, only Nikoletti *et al.,* (2003) focused upon the symptoms experienced specifically following sphincter-sparing surgery for rectal cancer. Amongst the remaining studies, one focused upon idiopathic faecal incontinence (Ilynckyj *et al.,* 2005), three upon inflammatory bowel disease (Smith *et al.,* 2002, Ringstrom *et al.,* 2009, Reusch *et al.,* 2016) and one upon irritable bowel syndrome (Robinson *et al.,* 2006). The interventions reviewed were varied in terms of delivery, duration, outcomes and uses of theory.

Interventions included were Australian (n=3), Chinese (n=1), Taiwanese (n=1), German (n=2), Swedish(n=1) and Canadian (n=1) studies. Intervention characteristics were varied, multimodal, included those delivered directly and indirectly by healthcare professionals. Interventions highlighted the integral role of the patient in self-care. In terms of professions carrying out the identified studies, three were nurse led, three were clinician led, one was carried out by both doctors and nurses, one was carried out by health coaches of no specified profession and 1 was psychologist led. Sample sizes ranged from 10-700 participants. The interventions were delivered in a variety of settings including hospitals, outpatient clinics, G.P surgeries, at home and in lecture facilities.

Intervention approaches included self-help booklets, educational programmes, a tele-based lifestyle intervention, nurse led- survivorship support package, a comparison between education versus biofeedback, medication and pelvic floor exercise programmes, comparison of self-initiated versus healthcare-initiated interventions and DVD delivered intervention.

Tools used to assess symptoms varied and included the Crohn's Disease Activity Index (Smith *et al.,* 2002), the Cleveland Clinic Faecal Incontinence Score (Lin *et al.,* 2015), IBS Severity Scoring System (Ringstrom *et al.,* 2009), the European Organisation for Research and Treatment of Cancer (EORTC) Colorectal Cancer (CRC)-Specific Quality of Life Questionnaire EORTC QLQ-CRC (Jefford *et al.,* 2011), Functional Assessment of Cancer Therapy- Colorectal Tool (Hawkes *et al.,* 2009) and Bowel Function Inventory-Colorectal Surgery (BFI-CRS) (Nikoletti *et al.,* 2003).

In terms of use of theory in guiding the interventions and its impact upon intervention efficacy, only two of the studies utilised an underpinning theory (Ringstrom *et al.,* 2009, Jefford *et al.,* 2016). However, those which utilised theory to underpin their interventions had statistically significant improvements in terms of gastrointestinal symptoms (Ringstrom *et al.,* 2009) (p<0.05) and had a high degree of patient satisfaction (Jefford *et al.,* 2016*).* Theories utilised included the Self-Efficacy Theory (Ringstrom *et al.,* 2009), the Acceptance and Commitment Theory and the Social Cognitive Theory (Hawkes *et al*., 2009). In terms of outcome measures and modes of delivery, Tables 3 and 4 illustrate same further.

The following section discusses the results of interventions seeking to contribute to and improve patient self-care relating to symptoms experienced as a result of colorectal cancer treatment.

3.6-Results of Systematic Review

3.6.1- Bowel Symptoms Due to Colorectal Cancer Treatment

Of the interventions examined only four relating to colorectal cancer which fit the inclusion and criteria were identified (Nikoletti *et al.,* 2003, Hawkes *et al.,* 2009, Ringstrom *et al.,* 2009, Jefford *et al.,* 2011, Lin *et al.,* 2015). Furthermore, only one nurse-led intervention specific to bowel symptoms following sphincter-sparing surgery, that did not exclusively involve use of a biofeedback instrument, sacral nerve stimulation etc., was identified (Nikoletti *et al.,* 2003).

Nikoletti *et al.,* (2003) developed, piloted and evaluated an educational programme which consisted of public seminars, a booklet, pamphlets on public toilets and pelvic floor exercises and a DVD for those living in rural (non-metropolitan) locations. Following this programme, participants were revaluated in terms of bowel function, with statistically significant improvement noted in terms of bloating and overall bowel control (p=0.015) and all had improved scores in terms of bowel knowledge and information. Both the intervention and control groups experienced a statistically significant reduction in leakage. The information provided to patients included dietary information, skin care, pelvic floor exercise, toilet maps and medication advice.

Similarly, an intervention focusing upon colorectal cancer created a bowel cancer survivor support package “Survivor Care” (Jefford *et al.,* 2016) also adopted a multi-modal approach. This provided educational materials including a DVD and booklet, needs assessment, survivorship care plan, end-of-treatment session, and three follow-up telephone calls. Using research and recommendations of the U.K Medical Research Council Framework for Complex Interventions (Medical Research Council, 2006), the Survivor Care package included the use of evidence-based strategies to support patients in the care of post-treatment sequelae, promote patient involvement in care and address the specific information needs of participants. The DVD provided information relating to the late and long-term effects of colorectal cancer treatment, including bowel dysfunction and advice from health care professionals to aid self-care for these effects. Participants expressed that following the intervention their “unmet needs” were reduced from an average of 7 to 3. Participants also cited that information about diet, exercise, and coping with episodes of incontinence were topics explored by the package which participants felt they needed more information about. Whilst the intervention in part consisted of reliance upon nurse involvement in terms of interviewing, telephone follow-up and survivorship care plan development etc., the elements of education which empowered self-care, such as the DVD and booklet were considered “useful, relevant, and convenient” (p9., Jefford *et al.,* 2016). A reduction in bowel frequency was noted amongst the intervention group (CI=95%).In addition, the use of a control group of participants receiving usual care, highlighted that those who had received usual care in addition to the Survivor Change intervention felt greater satisfaction in relation to their survivorship.

A further intervention reviewed was the “CanChange” intervention developed by Hawkes *et al.,* (2009). This intervention was delivered by telephone and the study sought to determine the feasibility of a psychosocial and lifestyle intervention aimed at patients following colorectal cancer treatment. This intervention included strategies such as relaxation training, symptom management, healthy eating, alcohol intake, weight management and physical activities. Participants of the intervention group received 6 telephone sessions with trained health coaches and an interactive handbook. Outcomes measured included colorectal cancer specific outcomes. Following the intervention, a reduction was seen in relation to diarrhoea and incontinence (40% vs 20%, *p*=0.13). This intervention also saw improvement in relation to lifestyle variables, with a reduction in processed meat intake, sedentary behaviour and improved fruit, and vegetable consumption (15% vs 36.8%). This study again highlights the beneficial effects which educational interventions can have upon a patients' self-care.

Similarly, Ringstrom *et al.,* (2009) developed and examined the efficacy of an educational intervention for patients with IBS, which provided patients with information through education sessions. Participants (n=12) were given information by both a GI Specialist Nurse, a physiotherapist, a gastroenterologist and a dietician in relation to GI anatomy and physiology, diet, medical treatment options, relaxation practices and coping strategies. Participants' gastrointestinal symptoms were measured pre-intervention and at 3,6 and 12 months following the intervention, using the IBS- Severity Scoring System. Participants scored significantly reduced severity at 3 and 6 months (*p*<0.05) and Health Related Quality of Life Scores also improved scores at 3 months following the intervention (37 versus 42). The benefits of patient education and increasing patient involvement in care were highlighted by this study.

Lin *et al., (*2015) examined the efficacy of pelvic floor rehabilitation through a demonstration/ education session and an information DVD and leaflet administered upon discharge to patients post-SSS and stoma reversal, the control group did not receive the same education. Continued efficacy was retested at 1,2,3,6 and 9 months post discharge. The Wexner Faecal incontinence score of the exercise group significantly decreased from 8.37 to 2.27 after PFME (pelvic floor muscle exercise) compared with that of the non-exercise group (from 8.54 to 2.58).

The following section will outline the results of interventions focused upon bowel symptoms resultant of IBD, IBS and idiopathic faecal incontinence.

Author & Year & Country	-Design -Aim -Sample	Healthcare Provider Administering the Intervention	-Components of Intervention -Theory Utilised (if applicable)	-Mode of Delivery -Time	-Outcomes Measured	-Impact of Intervention
Hawkes *et al.,* (2009). Australia	-Experimental design -To determine the feasibility and efficacy of a lifestyle intervention for those following treatment for colorectal cancer "CanChange". -20 CRC Survivors drawn from practices of 3 consultants.	Health coaches- qualifications not specified.	-i)Telephone sessions with health coaches relating to relaxation training , fatigue and symptom management, physical activity, healthy eating, alcohol intake, weight management and smoking. -ii) Supported by use of an interactive handbook. -Social Cognitive Theory	-6-Weekly 45minute sessions telephone sessions -Informational and interactive handbook	-Physical activity -Sedentary behaviour -Dietary intake Alcohol consumption -Smoking -QOL and bowel symptoms using the Functional Assessment of Cancer Therapy – Colorectal (FACT-C; Version 4).	Reduction in fatigue (75% vs 50%, *p*=0.06), diarrhoea and incontinence (40% vs 20%, *p*=0.13). 76% of participants gave the programmes a rating of "excellent". Decrease in the consumption of processed meat ((1.0 (3.0) vs 0.0 (1.0))
Lin *et al.,* (2016)	-Longitudinal experimental design. -Aim to examine the effect of PFE on faecal incontinence following stoma reversal -53 participants post-stoma reversal for rectal cancer	Nursing and Medical Staff within the university conducting the study and the hospital in which the study was carried out.	-Consisted of PFE Training at home, initially checked by first author and research assistant and the provision of an educational D.V.D. to the intervention group VS no exercise education amongst the second group. -No theory specified	DVD and single education session Session day before discharge, 1 week post-discharge and DVD continued at home for 9 months following discharge	Cleveland Clinic Faecal Incontinence Score	PFE were shown to improve F.I within the first 6 months following reversal. Mean Cleveland Clinic Continence Scores for the Exercise group @ 6months was 2.67(SD.88) VS 4.54 (SD3.59) amongst the control group.
Jefford *et al.,* (2016). Australia	-Experimental Design - Nurse-led support package for patients following treatment of colorectal cancer. - 110inthE Usual Care control group and 106 in the Survivor Change	Nurse Co-ordinator for GI Service	-Institute of Medicine report "From Cancer Patient to Cancer Survivor: Lost in Transistion" findings were utilised to underpin the intervention along with the UK Medical Research Council Guidelines for the	-DVD, Information booklet, question prompt list, individualised survivorship care plan, 60-90 minute face-to-face nurse led end of treatment session and 3	-Distress- using the Brief Symptom Inventory -The European Organisation for Research and Treatment of Cancer quality of life questionnaire QLQ-C30	-Patients reported that their unmet information needs reduced from a median of 7 (SD 2-19) (of possible 35) to 4 (SD 0-19). -SC group reported greater satisfaction

	Intervention Group all of whom were approaching the end of their treatment or were up to 6 months post-treatment.		Development of Complex Interventions.	follow-up telephone calls.	-EORTC QLQ-CRC to measure disease specific symptoms.	with their survivorship -failed to show an improvement in levels of distress or QOL
Nikoletti *et al.,* (2003). Australia.	-To pilot test an educational intervention for individuals who had undergone sphincter-sparing surgery for CRC (190) so as to reduce or prevent faecal incontinence or bowel symptom and a control group (n=130) of family member of the intervention group who had not undergone treatment for CRC.	Nurse Gastroenterologist Physiotherapist	-National Continence Management Strategy Public Toilet Map and Website -Public Lectures or recorded videos of same relating to GI anatomy, pelvic floor exercises, skin care, medication management, diet, self-care strategies. -Education Booklet- Improving Bowel Function after Surgery for Bowel Cancer.	Seminar-1 day To non-metropolitan participants a video of the education sessions and the same literature as the metropolitan group. Post-test at one week post the seminar and 11 weeks post seminar.	-Bowel function (using the BFI-CRS tool) -Bowel care practices. -Bowel function knowledge	-Reduction in perianal soreness, and substantial decrease in faecal leakage(38 to 22%) and problems with bowel control (60% to 38%).
Ringstrom *et al.,* 2009)	-Experimental, longitudinal design. -To develop and feasibility test an educational intervention for patients with I.B.D -12 participants attending the GI outpatient clinic in a Swedish Hospital	GI Clinical Nurse Specialist GI Consultant Dietician Physiotherapy Psychiatrist	6 Educational sessions outlined GI Anatomy, lifestyle factors, medical treatment, diet, body and min links in relation to breathing stress, relaxation techniques, a discussion session and a course summary session.	-Educational sessions 2hours once per week and self-administered questionnaires before the intervention and at 3 and 6 months post-intervention.	-IBS Severity Scoring System -Short form-36 to assess Health Related Quality of Life. -Course Evaluation form utilising a seven-point grading system	-Increased scores relating to perceived IBS knowledge, reduction of GI Symptom severity @ 3 months ($p<0.05$).

Table 3- Interventions Promoting Self-Care of Bowel Symptoms Following Colorectal Cancer Treatment

3.6.2- Interventions Promoting Self-Care of Bowel Symptoms due to Inflammatory Bowel Disease, Irritable Bowel Disease or Idiopathic Faecal Incontinence.

The following section discusses interventions initiated to aid patients to self-care for their bowel symptoms due to inflammatory bowel disease, irritable bowel syndrome or idiopathic faecal incontinence. A detailed table outlining study characteristics can be found in Table 4 (page 91).

One specialist nursing intervention for IBD by Smith *et al.,* (2002), examined the efficacy of nurse-led counselling upon health-related quality of life, including bowel symptoms. Whilst this study fell outside of the timeline of the search strategy, the decision was made to include it as it provided valuable insight into nurse-led interventions relating to bowel symptoms. The intervention consisted of advice around diet, exercise, drug therapy, physical symptoms, relaxation strategies and coping mechanisms. Participants reported baseline physical symptoms including diarrhoea and abdominal pain, but the researchers did not give figures relating to same following the intervention. However, Crohn's Disease Activity Index scores which included severity of diarrhoea etc., saw improvements from 138.7 at baseline to 113.8 at 12 months ($p<0.05$).

In defecation, the pelvic floor plays a key role in support of the bowel and in closure of the sphincter to prevent incontinence. Several studies included examined the efficacy of pelvic floor rehabilitation programmes in improvement of bowel symptoms and ways in which it can aid patient self-care. In a randomised controlled trial study comparing pelvic floor exercise and education to biofeedback (Ilnyckyj *et al.,* 2005), the potential positive outcomes achieved by non-invasive means was identified amongst participants experiencing faecal incontinence (n=18). Among participants, 61% reported no episodes of faecal incontinence or soiling in the week following the intervention (Ilnyckyj *et al.,* 2005). Prior to the intervention the participants had reported at least one incontinence episode per week. The results of the biofeedback group did not show any greater outcomes in terms of incontinence or complete response. Education provided to the pelvic floor group included perianal skin care, toileting supplies and advice in relation to the correct way to perform pelvic floor exercises.

Robinson *et al.,* (2006) conducted a comparison of interventions aimed at promoting self-help amongst patients diagnosed with irritable bowel syndrome. This intervention consisted of an education guidebook group (n=141), a guidebook and “self-help” meeting group (n=139) and a control group which received no intervention (n=140). The guidebook consisted of information relating to lifestyle, diet, pharmacological interventions, and alternative therapies. Following exposure to this, patients reported a perceived improvement of IBS symptoms (p<0.001), whilst there were no statistically significant improvements in terms of diarrhoea or constipation, all differences noted were in favour of the intervention group. The only issue was that intervention results were potentially limited by the low turn-out of patients (n=59) to the self-help meeting. However, the development of the guidebook resulted in a reduction of G.P visits for IBS issues by 1.56 per year (92% C.I 1.15-1.98) and a reduction in cost per patient of £73 (C.I £43-£103) per year. This study highlighted the marked benefit which increased education and supporting self-care can have upon patient healthcare needs and on potential reduction of healthcare costs.

Reusch *et al.,* (2016) reported improvements following the implementation of their self-management psychoeducational programme for patients diagnosed with Inflammatory Bowel Disease. Participants were placed in the intervention group (newly developed psychosocial intervention as well as medical advice) or a control group which received medical advice and limited psychosocial information only. Both groups attended modules outlining gastrointestinal tract information, IBD specific education, pharmacotherapy advice. The intervention group also attended smaller group meetings focused upon coping strategies, shared experiences, and personal resources. Whereas, the control group received general information in relation to toilet maps, disability pass legislation and access to psychotherapy. Following completion of the intervention no significant superior outcomes were noted in the intervention participants. However, improvements were noted in terms of anxiety, (2.47 vs 2.15), depression (2.45-2.15), disease related knowledge (2.47-3.58) amongst intervention group participants and amongst the control group in relation to disease knowledge (3.12-3.86), skill and technique acquisition (2.59-2.92).

-Author & Year & Country	**Healthcare Professional Providing Intervention**	**-Design -Aim -Sample**	**-Components of Intervention -Theory Used**	**-Mode of Delivery -Dose and Time**	**-Outcomes Measured**	**-Impact of Intervention**
Smith *et al.,* (2002)	RCT carried out by a IBD Clinical Nurse Specialist.	- RCT -To evaluate the impact of specialist nursing interventions on management of inflammatory bowel disease, remission and quality of life. -Identified single study examining the efficacy of a nurse-led IBD counselling programme. -100 participants	100 IBD patients receiving a specialist nurse delivered counselling package (n = 50) or routine outpatient clinic follow-up (n = 50), with assessments at entry and six and 12 months.	-Face-to-face intervention Information was provided in the form of booklets and videos examining physical symptoms, drug therapy, diet and surgery. Psychological intervention involved stress management, relaxation exercises and coping mechanisms. -12 months	-Crohn's Disease Activity Index (CDAI) -Health related quality of life was measured using the SF-36 Short Form -Hospital Anxiety and Depression Scale	Mental health scores at 6 months for patients were higher in patients who received nurse-led counselling compared to patients who received routine follow up. However, these differences were not statistically significant (Crohn's WMD 3.50; 95% CI -2.66 to 9.66; P = 0.27; ulcerative colitis WMD 3.80; 95% CI - 1.71 to 9.31; P = 0.18;). Pooled mean mental health scores at 6 months were higher in patients who received nurse-led counselling compared to patients who received routine follow-up but not statistically significant.
Ilnyckyj *et al.,* (2005)	Gastroenterologist	-RCT -To compare an educational programme alone versus education and biofeedback upon faecal incontinence in women	-Educational intervention included physiology of defecation, skin hygiene advice, toileting supplies, pelvic floor information. VERSUS Biofeedback .	Education sessions with a pelvic floor therapist versus same educational session but addition of biofeedback balloon insertion. -Duration of intervention was 2 months.	-Episodes of faecal incontinence amongst both groups.	-45% of those in the educational intervention group achieved total continence. Whilst 86% in the biofeedback group achieved continence, not statistically different, due in part to the small sample size.
Robinson *et al.,* (2006)	Consultant Gastroenterologist and Doctors from the Gastroenterology Team of the study setting	-To compare self-help interventions for patients experiencing IBS to care for bowel symptoms -Randomised controlled trial -420 patients attending GP with IBS.	-Guidebook detailing lifestyle, diet, pharmacological and alternative therapies. -Self-help group meeting facilitated by a coordinator and the guidebook -A control group who did not receive an intervention but contended to liaise with their primary healthcare provider	-Guidebook -Self-help meeting -Re-assessed at 1 year following the intervention.	-GP Visits -IBS Symptom severity -Quality of Life using the IBS-QOL Instrument -Hospital Visits -Health status was measured using the GHQ-28 and SF-36 Instruments.	Those who received the guidebook saw a marked statistically significant reduction in G.P Visits from 2.75(1.36) to 2.26(2.04). Which was an average reduction in G.P Visits by 1.56. Those who received the handbook also reported a reduction in hospital visits – 40% reduction

-Author & Year & Country	**Healthcare Professional Providing Intervention**	**-Design -Aim -Sample**	**-Components of Intervention -Theory Used**	**-Mode of Delivery -Dose and Time**	**-Outcomes Measured**	**-Impact of Intervention**
Reusch *et al.,* (2016)	Gastroenterologists and Psychologists	-Cluster- randomised control trial -To compare the effect of a psychoeducational programme versus General psychosocial information alone upon IBD related issues including self-care. -Sample consisted of 540 patients suffering form I.B.D.	-Both groups attended lectures relating to GI anatomy and physiology, IBD information, treatment options, medication options, complication and child bearing. The control group then received general psychosocial advice relating to general public resources (public toilet access), social legislation and types of psychotherapy. The intervention group participated in group psychoeducational session.	-Lecture Format- 5 large and 3 small closed lectures. -Assessments took place prior to the interventions, following the lectures and at 3 and 12 months.	-IBD related concerns -Medical disease knowledge -Psychological Disease knowledge -Coping with anxiety -Positive and Active engagement in life -Depression -Physical health -Mental health	-Reduction in IBD related concerns. Bith the intervention group and control group saw an improvement in their Physical health summary scale *p*<0.001.

Table 4- IBD, IBS & Idiopathic Faecal Incontinence Interventions

3.7- Discussion

Recent years have seen a growth in the efficacy and use of, multimodality and multidisciplinary rehabilitative programmes, including nurse-led interventions and educational programmes, dietary interventions, medication use, pelvic floor exercise and perianal skin care interventions for the management of bowel symptoms. Intervention approaches included self-help booklets, educational programmes, a tele-based lifestyle intervention, nurse led- survivorship support package, a comparison between education versus biofeedback, medication and pelvic floor exercise programmes, and a DVD delivered resource programme. Studies' results included improved continence, reduced frequency, urgency and flatus. Throughout the literature the benefits of evidence-based interventions which support patients in their self-care of bowel symptoms was evident, as were the aspects which required further development and research.

The systematic search of the literature identified only one study, greater than 14 years old, which aimed at aiding patients in their self-care of bowel symptoms specifically following rectal cancer surgery (Nikoletti *et al.,* 2003). The potential benefits of such an intervention and others aimed at enabling self-care for bowel dysfunction resultant of other conditions were apparent, with patients being given a heightened awareness of bowel symptoms and means of coping with same. However, its applicability was limited by its time of development. In addition, evaluation of this study using the JBI checklist for quasi-experimental studies (Appendix 17), identified that the short follow-up period following the intervention may have lessened the integrity of the results, as did receipt of funding from a continence product company. The potential for selection bias was also present in this study, as was the limitation presented by the lack of double-blind testing. However, upon completion of this study one of the recommendations made included the need to provide further education and resources for patients to improve their bowel symptoms following surgery for rectal cancer, supporting the need to further explore supportive interventions to aid with bowel symptoms.

Within the colorectal cancer specific interventions, those which adopted a multi-modal approach, blending use of resources such as DVDs, handbooks and telephone calls (Nikoletti *et al.,* 2003, Hawkes *et al.,* 2009, Lin *et al.,* 2015), seemed to result in statistically significant improvements in bowel function, highlighting the potential benefit of providing a number of education modalities to suit different styles of learning, thereby increasing the opportunity to improve bowel symptoms.

However, none of these interventions were easily accessible in the form of a web-based tool. All involved a heavy reliance upon healthcare professional support and a number were delivered in a single setting through a lecture/meeting format. Furthermore, only one intervention was specifically tailored towards helping patients to manage bowel symptom following treatment for rectal cancer, thereby limiting the reviewed studies' applicability to this patient group. In terms of methodological approaches, the majority of the studies had a short follow-up time, thereby limiting the ability to examine the long-term effects of the interventions, the longest follow-up period amongst the studies reviewed was 12 months (Robinson *et al.,* 2005, Ringstrom, 2009, Reusch, 2016).

The benefits of written information resources were noted in a number of the studies (Robinson *et al.,* 2006, Hawkes *et al.,* 2009, Jefford *et al.,* 2011). Interventions which utilised written guidebook/booklet formats saw reductions in bowel symptoms, unmet information needs and GP visits. This illustrates potential usefulness of written information in a future intervention to reiterate and reinforce education and information for patients affected by problematic bowel symptoms.

In the study conducted by Reusch *et al.,* (2016) researchers acknowledged that whilst no significant superior outcomes were noted amongst the intervention group, this study highlighted the benefits which an educational intervention can have upon patient outcomes and their ability to self-care and how the delivery of practical information can have positive effects on the well-being of patients experiencing bowel dysfunction. Similar to the limitations of the study conducted by Smith *et al.,* (2003) which saw a limited sample size, the potential for selection bias and the failure of the researchers to select an effective intervention to improve strategies to manage bowel dysfunction.

In terms of the quality of Ilynckyj and colleagues' study (2005), whilst it met 11 of 13 aspects of the JBI RCT Evaluation checklist (2012) , it was limited by the knowledge of the researchers as to which intervention the participants were receiving so the study was therefore not “double-blind”. In addition, this study only included female participants thereby limiting its applicability to the wider population. However, this study highlighted the potential for non-invasive techniques such as pelvic floor exercise, skin care and toileting advice to improve continence and whilst the biofeedback group of this study achieved greater sphincter strength, their improved continence was not statistically different to that of the education group alone. The relatively inexpensive and effective intervention of pelvic floor exercise to help manage bowel symptoms was explored by a number of the other interventions. The ability for this intervention to be delivered at home at any time also serves to increase its usefulness, accessibility, and potential for inclusion in the development of an intervention for those experiencing altered bowel functions following sphincter-sparing surgery.

The evidence to support the superiority of invasive interventions versus educational programmes and pelvic floor exercise was challenged by Ilnyckyj *et al., (*2005), with no difference between the intervention group versus those that underwent invasive biofeedback. Lin *et al.,* (2015) also identified the potential that pelvic floor exercise seems to accelerate the expected improvement in faecal incontinence occasionally seen following surgery but that this effect was not seen at 9 months. Only one of the studies reviewed focused upon the specific patient group of rectal cancer survivors following sphincter-sparing surgery, and assisting in improvement of bowel symptoms specific to this treatment (Nikoletti *et al.,* 2003). Whilst the evidence in favour of interventions which empower self-care was apparent, all required either lecture format, DVD development and other forms of delivery which had limited accessibility, involved patients attending specific locations for meetings or were costly.

Studies evaluated also served to highlight the potential efficacy which healthcare professional delivered interventions may have upon the empowerment of patients to self-care for their bowel symptoms. Despite the limitation of these studies, the beneficial potential of both nurse-led and other HCP delivered interventions was identified and the marked impact which education and advice may have upon the bowel function and quality of life of patients experiencing altered defecation.

A number of the studies did not have control groups (n=5), thereby increasing the risk of bias. The dearth of non-invasive interventions aimed towards this group highlights the need for the development of an intervention which provides patients with concise, clear, evidence based and accessible information which can aid in self-care, but also contribute to the safety and well-being of those affected by bowel dysfunction following already difficult treatment for rectal cancer.

Of the literature exploring interventions which empowered patients to actively participate and make decisions in their self-care, the benefits and symptom-improvement were identified. However, there is an evident gap in the research in relation to a supportive and up-to-date intervention to empower patients in the self-care of bowel symptoms experienced specifically following surgery for rectal cancer. Much of the literature focused on invasive interventions, which often resulted in patients taking an inactive role in their own care.

Conclusion to Literature Review

Rectal cancer remains one of the most common cancers seen in Ireland and the world today. Advances made have allowed for improved outcomes, maintenance of bowel continuity, better survival rates and avoidance of permanent stomas. Over 70% of individuals who receive a diagnosis of cancer in Ireland will undergo sphincter-sparing surgery (NCRI, 2017). Whilst this development has been widely accepted and attempts made to avoid surgeries such as abdominoperineal resection, for many individuals, treatment of rectal cancer results in the development of life altering and very often physically detrimental outcomes. A number of the articles reviewed by this literature review challenged the assumption that maintenance of bowel continuity automatically results in improved quality of life when compared with a permanent stoma.

A myriad of symptoms may occur, from mild urgency and frequency, to total faecal incontinence (Landers *et al.,* 2012, Chen *et al.,*2015). These bowel symptoms may manifest themselves initially in the post-operative period and resolve over time but for many remain an issue for many years following treatment (Chen *et al.,*2015).

These symptoms often result in detrimental outcomes not only physically but upon the social and psychological well-being of those affected. Whilst patients regularly adopt and develop strategies which allow them to participate in daily life, for many their bowel dysfunction result in a withdrawal from social activity, gainful employment, and personal relationships. Some of the strategies initiated by patients which this literature review identified, included practical functional strategies such as medication use, incontinence wear and skin care, some of which improved patient symptoms and allowed for a degree of confidence. Yet for others, the adoption of uninformed and potentially detrimental strategies such as food restriction or social activity avoidance, places patients at risk of negative side effects and social withdrawal.

In terms of existing interventions for those following treatment for rectal cancer, to aid the self-care of bowel symptoms, there is a dearth of published literature which does not involve the use of invasive interventions such as anorectal manometry, trasanal irrigation and biofeedback. A single study which specifically sought to improve bowel symptoms following sphincter-sparing surgery was identified (Nikoletti *et al.,* 2003) though its findings are limited by its time of publication and the limited scope for reproduction due to the mode of delivery.

Other interventions reviewed which sought to aid self-care of bowel symptoms, resultant of other conditions, provided insight into different modes of delivery and methodological approaches. The efficacy of tele-interventions and lecture-based formats were highlighted, as were the benefits of patient participation in care decision making. The review of the literature also highlighted the lack of interventions which have progressed beyond pilot testing, but also the lack of interventions where outcome measurements are carried out beyond one year following testing. Another gap seen was the absence of an intervention which was universally accessible and did not involve specific recruitment and selection. There was no web-based intervention identified by the literature search and similarly, no intervention which allowed universal patient access. All interventions required healthcare professionals or researchers to access patients via outpatient clinics, GI consultant referrals etc. as opposed to a central system which allowed patients to access self-care advice from their homes.

Furthermore, excluding Nikoletti *et al.,* (2003) all of the interventions reviewed focused upon idiopathic incontinence, bowel symptoms resultant of IBD or IBS, thereby limiting the interventions' potential applicability and usability for those suffering bowel symptoms following sphincter-sparing surgery for rectal cancer due to different physiology and structural anatomy.

The review of the literature revealed not only the extent of bowel dysfunction experienced by patients following sphincter-sparing surgery for rectal cancer bur the varying strategies they utilise to regain some degree of bowel control. This review also highlighted the lack of available interventions for patients which can be utilised solely in their home setting. However, of note was that the approaches and intervention formats utilised provided valuable information regarding which approaches do and do not work in facilitating increased patient self-care. Finally, this literature review allowed the author to identify the existing need to develop an up-to-date, accessible, evidence based targeted intervention which will empower and support patients in their self-care of bowel symptoms specifically experienced following sphincter-sparing surgery.

3.8- Revisiting the Research Question

As identified by the literature review, there is a dearth of existing interventions which focus specifically on the bowel symptoms experienced by patients following sphincter-sparing surgery for rectal cancer (Nikoletti *et al.,* 2003; Chen *et al.,*2015: Landers *et al.,* 2014). The impetus for conducting this study emerged as a result of a number of factors. Firstly, no such intervention existed within the institution of the researcher. Secondly, within the wider sphere of healthcare, the lack of an intervention solely aimed at those experiencing bowel symptoms resultant of SSS was identified. Thirdly, the evident increase and movement of responsibility of management of care from the HCP to the patient in current healthcare which has emerged in recent years purports the need to empower patients in their self-care of chronic conditions. There was but a single study identified within the literature review which focused solely on the bowel symptoms experienced following treatment for colorectal cancer (Nikoletti et al., 2003). This study was of limited use given the length of time since its publication. Also, components of this intervention involved patients and their families making a number of visits to a clinical setting. Such an approach does not proactively support and empower participants in their self-care as such an approach was limited in its potential for sustainability, its cost efficacy and its failure to follow patients up beyond 11 weeks. In addition, the remainder of interventions reviewed focused on bowel symptoms experienced as a result of inflammatory bowel disease, irritable bowel disease and idiopathic faecal incontinence thereby failing to examine the symptoms and issues experienced specifically by those following sphincter-sparing surgery for rectal cancer. Therefore, it is timely to ascertain the strategies which may be of use and benefit to those affected by bowel symptoms specifically experienced following sphincter-sparing surgery for rectal cancer.

Finally, a systematic literature review identified a single intervention which specifically focused upon this patient group i.e those experiencing bowel symptoms due to rectal cancer treatment. Furthermore, an intervention which was delivered through the accessible form of a web-based delivery or leaflet/booklet, application was not identified. Thus, it was proposed that the outlined study be carried out so as to identify helpful interventions for patients following SSS.

Chapter 4.0 Methodology

Introduction

This chapter will describe the proposed methodological process of this study, including the aims and objectives, research design, rationale for selection of design, use of the MRC Framework for Development of Complex Interventions, sample, access and recruitment, ethical considerations, data collection and data analysis.

4.1 Aims and Research Questions

The overall aim of this study, guided by the MRC Framework for the Development and Evaluation of Complex Interventions, was to gather a body of evidence through interviews with both patients and relevant healthcare professionals, which would underpin and inform the design, format and content of an intervention aimed at supporting patients to self-care for their bowel symptoms following surgery for rectal cancer.

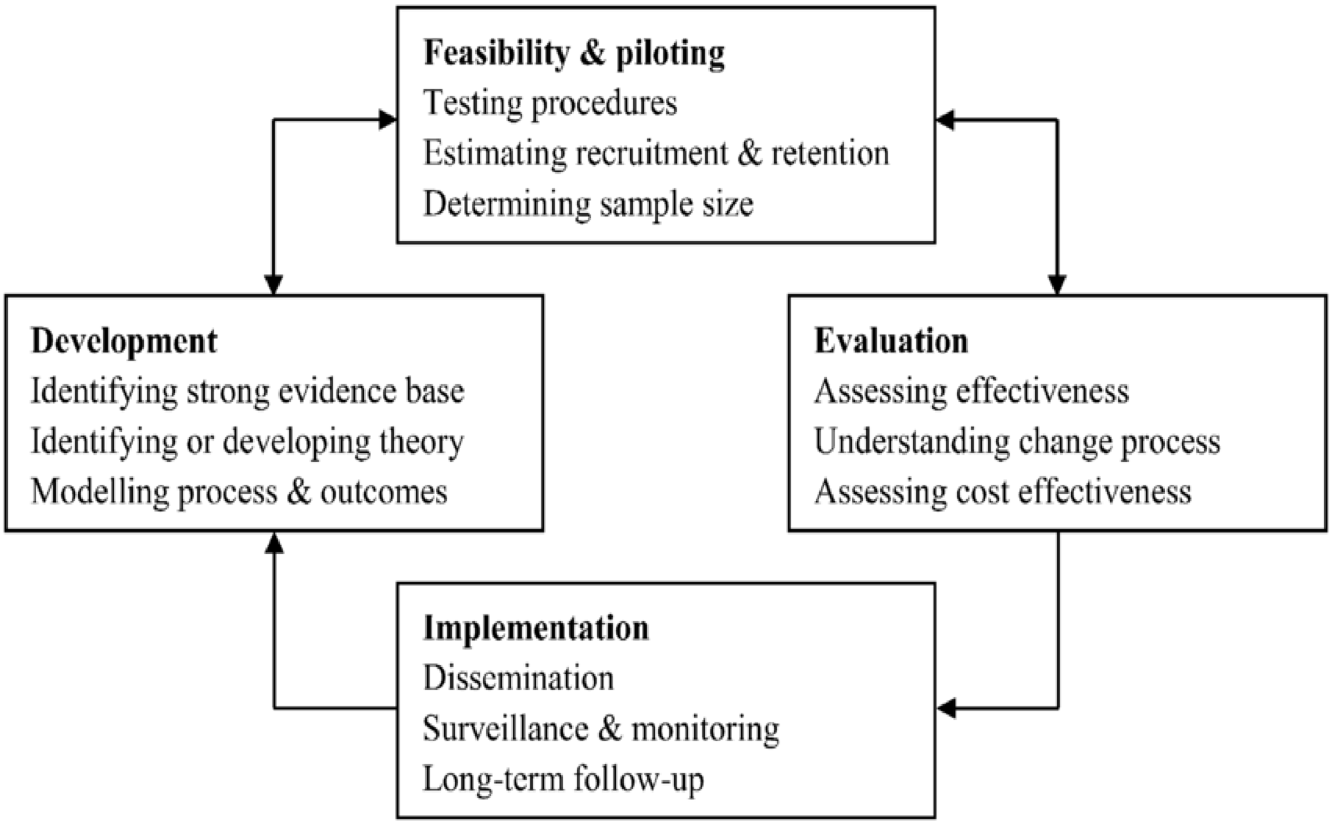
To address the above aim this study sought to identify bowel symptoms, the strategies which patients utilise to manage their bowel symptoms and strategies which may be suitable for inclusion in an intervention. In addition, it was proposed that this information, along with the findings of an extensive systematic review, would be used in the drafting of a framework outlining the proposed content and preferred format of delivery of an intervention to aid patients in the self-care of bowel symptoms. The following objectives were addressed using a qualitative, descriptive approach and one-to-one interviews with patients following sphincter-sparing surgery for rectal cancer and healthcare professionals involved in their treatment journey (CNSs, CNMs, Colorectal RGNs and Colorectal Surgeons):

- Describe the bowel symptoms experienced by patients following SSS, including the types and variability of symptoms.
- Describe the strategies which patients utilise to manage their bowel symptoms and details surrounding same through use of the Symptom Management Theory.
- To identify the information which patients and healthcare professionals involved in their care think should be included in an intervention.
- Outline the preferred content, format, timing and mode of delivery of an intervention to support patients in the self-care care of their bowel symptoms following sphincter-sparing surgery for rectal cancer.

4.2 Medical Research Council Framework

The MRC Framework for Complex Interventions (Medical Research Council, 2009) guided the development of this study. This framework seeks to aid researchers in the selection of appropriate methods of research, the systematic development of interventions and encourages the use of theory and appropriate up-to date evidence (MRC, 2006). This Framework outlines the process of intervention development and Implementation in four stages; Development, Feasibility and Piloting, Evaluation and Implementation. The individual steps of the study’s progression are outlined in Figure 5 below, and this study will focus upon the development stage.

Figure 4- Medical Research Council Framework for the Development of Complex Interventions



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4.2.1- Identifying existing evidence

The MRC (2006) recommends that identification of existing evidence is a pivotal step in the development stage of intervention creation. To identify the relevant and existing evidence around the topic of bowel symptom management following sphincter-sparing surgery, an extensive literature review was conducted. This literature review sought to explore existing rectal cancer statistics, rates of surgery, the subsequent symptoms which occur as a result of rectal cancer, the effects of these upon patients and the strategies/interventions which currently exist to aid patients in their care of these symptoms. The MRC Framework suggests that the systematic review be maintained and updated as the evaluation proceeds (MRC, 2006), throughout the research process the researcher regularly conducted searches and updated the systematic review relating to interventions to ensure the inclusion of all up to date data.

As outlined in Chapter 3, there were few interventions which sought to improve bowel symptoms following sphincter-sparing surgery for rectal cancer through self-care or through the use of non-invasive means (Nikoletti *et al.,* 2003; Hawkes *et al.,* 2009; Jefford *et al.,* 2016). Other interventions examined bowel symptoms and ways to improve same but not symptoms specifically experienced as a result of rectal cancer treatment. This literature thereby provided a rationale for the need to develop an intervention which focuses on this specific patient group and their specific symptoms. This literature review also proved useful as it allowed the researcher to identify the efficacy of certain research designs, the influence of theory/ approaches, appropriate sample sizes, effective/ineffective intervention content and intervention deliveries.

4.2.2 Identifying developing theory

Current evidence suggests that interventions underpinned by theory are the most effective and well designed (Glanz *et al.,* 2010; Bartholomew *et al.,* 2001). The MRC Framework (2006) also recommends that interventions be developed systematically using best evidence and appropriate theory. Theories assist in intervention development as they can help to identify why certain behaviours take place and can also suggest ways in which interventions can help to change or influence behaviour (Glanz, 2015). In relation to theory use, of the 11 interventions reviewed, most (n=7) did not utilise theory to underpin their interventions and where theory was mentioned, it was usually used to “inform” the study as opposed to a number of the theory’s constructs being applied to the intervention’s development. One example of this was an intervention developed by Hawkes *et al.,* (2009) which utilised the core components of the Acceptance and Commitment Theory in the intervention’s development and the Social Cognitive Theory to “ground” the CanChange intervention, resulting in non-significant improvement in relation to colorectal cancer specific symptoms such as diarrhoea and incontinence of faeces (40% vs 20%). In contrast, Ringstrom *et al.,* (2009) utilised Bandura’s theory of Self-

Efficacy (a core concept of the Social Cognitive Theory) to design the delivery of their IBS (Inflammatory Bowel Disease) school the General Theory of Nursing used to frame the IBS School, with the intervention resulting in improved GI symptoms, IBS knowledge and perceived symptoms. The IBS symptom score of participants was significantly reduced at three ($p < 0.05$) and six months ($p < 0.05$) after the IBS school.

Whilst exploring theories best suited to underpin and inform this study, the researcher examined theories which explored symptom experiences, symptoms management strategies and patient involvement in care (self-care). The researcher sought to identify a theory which matched the study's aims and provide guidance to the development of an intervention which sought to affect and improve patients' self-management strategies and ultimately their experience of bowel symptoms. Theories considered to guide the intervention development included the Theory of Unpleasant Symptoms, the Social Cognitive Theory and the Theory of Symptom Management (Humphreys *et al.,*2008, 2018 Dodd *et al.,* 2000*)*. When examining these theories, and their applicability to the topic being explored/significance, the issues of broad relevance, internal consistency, and testability were considered, as recommended by Fawcett (2005).

The Theory of Unpleasant Symptoms is a middle-range nursing theory developed in 1995 by Lenz and colleagues (Lenz *et al.*, 1995). This theory was developed to allow those examining symptom experience to garner a greater general understanding of the similarities of symptoms experienced by a number of populations. This theory also seeks to give an increased understanding of symptom experience, thereby assisting the development of interventions seeking to improve, reduce or lessen the effect of symptom experience (Lenz & Pugh, 2018). The three major concepts of this theory include the symptom, influencing factors and performance outcomes. It also asserts that influencing factors (psychological, physical and situational) influence an individual's or population's predisposition to/risk of symptoms, experience and response.

This theory was considered as it acknowledged that symptoms may occur in isolation or in cluster, as outlined in Chapter 2, but also provided a structured conceptual focus allowing for the identification of symptoms, influencing factors and performance outcomes, thereby providing structure and guidance for the development of an intervention focusing upon symptom management. However, this theory was not chosen due to its limitations, including applicability. As the theory asserts that symptoms are ""the perceived indicators of change in normal functioning as experienced by patients" i.e. subjective, this suggests that objective signs are not explicitly dealt with by the theory. By potentially excluding objective signs, this theory limits its applicability relating to those who may be unable to describe their symptom. This theory was also not chosen as it does not specifically focus upon symptom management, a major component of this study, and also focuses more upon symptoms clusters as opposed to individual symptoms. Furthermore, this theory is limited by its generalisability i.e. its lack of detail, which may be required whilst working with a particular clinical population i.e. those experiencing altered bowel habit following SSS. It focuses on symptoms clusters and therefore the interaction the physiological and doesn’t deal with symptom experience on its own. In addition, it fails to capture the concept of symptom management.

Another theory considered was the Social Cognitive Theory (SCT). This theory was utilised by Hawkes *et al.,* (2009), as discussed in the literature review. This theory emanates from the hypothesis that human behaviour is a dynamic process by which humans learn through their own experiences, but also through observing the experiences of others and their subsequent outcomes (Bandura, 1998). This theory was originally developed in 1986 by psychologist Albert Bandura. This theory also asserts that behaviour is a dynamic phenomenon influenced by personal factors, behaviour, and environmental factors. A key concept of this theory is the idea of reciprocal determinism, this purports that a person may be both an agent of change and responder to change (Bandura, 1997), thereby suggesting that role models and changes to environment can be used to promote health, manage symptoms and within self-care.

This theory also suggests that behaviour (i.e., actions) and personal factors (i.e. cognitive, affective, and biological events) can all dynamically influence each other (Bandura, 1997). This theory also identifies self-efficacy (an individual’s confidence in their own ability to carry out a task/behaviour) as a key element influencing health interventions (Bandura, 2001). This theory was considered as it afforded insights into potential barriers to learning via an intervention and concepts which assist in the development of interventions such as goal setting and self-control and acknowledges the influence of past experience on behaviour implementation (Bandura, 1997). The choice was made not to use this theory as it lacks applicability to this area of study in that it does not specifically assist in the assessment of symptoms in addition to its date since publication. This theory also fails to focus specifically upon symptom management and subsequent symptom outcomes. In addition, the structure of this theory purports that changes in environment will automatically lead to change in behaviour of people which is not necessarily true (Biglan, 1987). However, throughout the study, influential elements of this theory, especially the concept of self-efficacy, were considered and used as guidance during patient interviews. The concept of self-efficacy, that individuals' level of confidence in his or her ability to successfully perform a behaviour, can impact upon them implementing certain behaviours was very applicable to this study, and something which the researcher considered when discussing strategies and a future intervention with participants. The researcher did this by asking patients about the strategies they used and why they used them but also in asking why the avoided certain strategies. This theory was also considered for its potential influence in the success/failure of a future intervention as it takes into account the 4 main contributory sources to people's belief in their self-efficacy: mastery experience i.e. previous successes and failures, vicarious experiences i.e. seeing others similar to one's self-carrying out behaviours, social persuasion i.e. having doubts about one's own ability reduced and finally reduction in their stress responses (Bandura, 1998). The importance of reassuring those with bowel symptoms of their ability to cope, the potential of showing how an intervention has worked amongst people with similar issues and showing individuals how implementing certain behaviours has impacted their own symptoms were all aspects of the SCT applicable to this study. Furthermore, Bandura (2001) discusses how behaviours which fulfil social norms gain positive social reactions, this matches the aim of this study in that strategies which result in a reduction of embarrassing and potentially “abnormal” social reactions resultant of bowel symptoms might contribute to positive social reactions and thereby be appealing to individuals experiencing their effects.

The Theory of Symptom Management (SMT) was chosen to underpin the intervention development. Originally developed by the USCF School of Nursing, to allow greater understanding of symptom experience, it has been continuously utilised to allow the measurement of symptom management outcomes. The theory has subsequently undergone a number of revisions and developments by Dodd *et al.,* (2001) and Humphreys *et al.,* (2008 & 2018). The main components in the model are symptom experience, components of symptom management strategies and symptom outcomes (Dodd et al. 2001). In addition, this theory addresses the concepts of the metaparadigm of nursing, person, environment and health. In Humphreys *et al's.,* (2013) discussion of the direct relationships identified by this theory, they assert that symptom experience, management strategies and outcomes of symptom management are all intrinsically linked. Dynamic relationships among these concepts are placed within a three-dimensional sphere of person, environment, and health/illness (Shin, 2014). This theory was chosen as it outlines 3 clear concepts of symptom experience, symptom management strategies, and symptom status outcomes. This theory purports than when an individual notices (perceives) an unusual sensation, they will assess this sensation's (symptom) manifestation i.e location, severity, frequency, duration etc. Finally, the individual will seek to ameliorate or manage this symptom through self-care strategies or seek more effective interventions through healthcare (Shin, 2014). This theory also provides a clear framework through which a patient's symptoms can be assessed and allows insight into the way symptoms can be managed, thereby assisting in the development of useful and structured symptom management interventions (Humphreys *et al.,* 2008). The SMT also provides a structure for understanding the connections among these concepts and provides a framework for considering interventions and outcomes (Bender *et al.,* 2018), as illustrated in Figure 5.

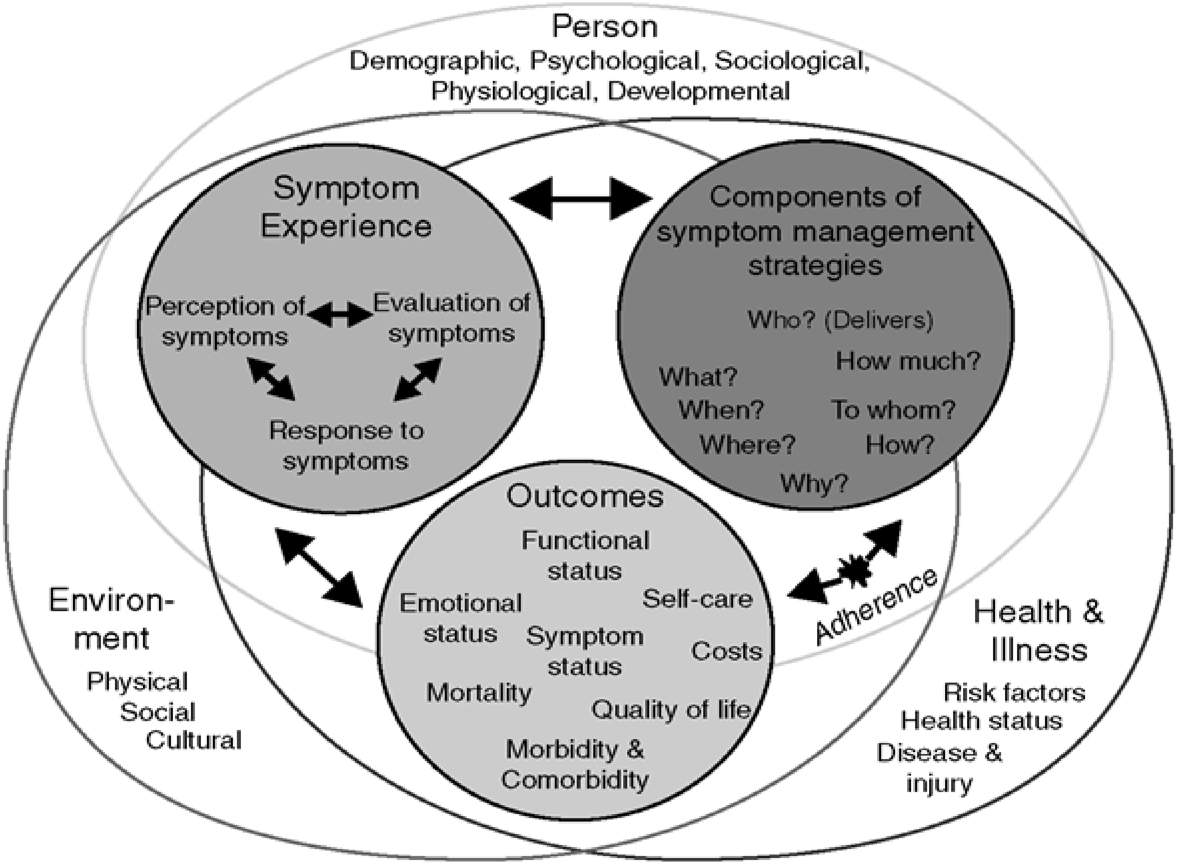


FIGURE 5- Revised UCSF symptom management model. Reproduced with permission of the publisher Dodd *et al.,* (2008)

This theory matched and informed the aims of this study as it provides insight into what may be included in an intervention i.e. processes which may “avert, delay or minimise symptom experience” (page 143, Humphreys *et al.,* 2008). As identified by Landers *et al.,* (2012), this theory also provides structure through its clearly defined concepts for presenting and discussing study findings and offers guidance and focus for research question formulation. This theory also acknowledges that there is a relationship between patients’ experience of symptoms and the self-care strategies they choose to manage them (Humphreys *et al.,*2008). The efficacy of underpinning an intervention with the SMT was highlighted in a study by Barnason *et al.,* (2016), in which individuals who underwent coronary artery bypass surgery were provided with a 6-week post-operative symptoms management intervention connected to their hand-held mobile devices. This telemonitoring intervention used in conjunction with SMT led to significant improvements in physical activity when compared with the control group(F[1,209] = 4.66, $p<0.05$) (Barnason *et al.,* 2016) . The efficacy of underpinning an intervention with the SMT was also seen in a home-care exercise intervention carried out by Hoffman *et al.,* (2012) to combat cancer-related fatigue. This intervention utilised WiiFit software to increase exercise carried out by patients following treatment for lung cancer, and resulted in increased exercise, patients’ self-perceived efficacy relating to balance and decreased levels of fatigue.

In the current study the individual aspects of each component guided not only the research design and the SMT, but the content of interviews with patients, describing their symptoms experience, and was especially useful when probing into what a future intervention might look like- following the framework provided by this theory. The author examined where, why, who, when, and by whom an intervention should be delivered.

Throughout the planning, interviewing and dissemination of data this theory was used to guide and support the study. A graphical representation highlighting an example of how findings of this study relate to the SMT diagram can be found in Appendix 19.

4.3 Research Design

To achieve the aims and outcomes of the study, a qualitative descriptive design was adopted. When conducting research, it is pivotal that the researcher selects the most suitable research design (Struebert & Carpenter, 2007, Cresswell & Poth, 2017). The research design selection determines how sampling is conducted and how data is collected and potentially analysed (Streubert & Carpenter, 2011). The following section will discuss the rationale for selection of a qualitative descriptive design.

Descriptive studies facilitate exploration about phenomena around which there is a paucity of knowledge (Burns & Grove, 2011, English & Pengelly, 2016). In addition, descriptive studies facilitate a "comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000). In a healthcare setting, qualitative, descriptive research increases the understanding of the experiences of participants, identifies what is important to healthcare providers and patients and assists in identifying barriers to change (Quick & Hall, 2015). Some defining attributes and characteristics of a qualitative descriptive approach include use of purposeful sampling, conducting open-ended individual or focus-group interviews and utilisation of qualitative content data analysis (Sandelowski, 2000). A qualitative approach was utilised, as this method allows the researcher to explore the experiences, behaviours and perspectives of both patients and healthcare professionals and to evaluate interventions (English & Pengelly, 2016). Furthermore, as purported by Sandelowski (2010), qualitative descriptive design should be utilised when straight descriptions of phenomena are required. Therefore, the qualitative descriptive design used facilitated exploration and description of the bowel symptoms experienced by patients and current strategies utilised to self-care for bowel dysfunction. In addition, this method allowed for identification of what would be beneficial for inclusion in an intervention, seeking to improve bowel symptom self-care, from the perspective of involved stakeholders. A descriptive design was chosen to explore the perspectives of patients and relevant healthcare professionals relating to the potential content of an intervention to manage bowel symptoms. Whilst a quantitative design could have been considered, the researcher determined that a qualitative descriptive design would allow the voice of patient participants and insights of healthcare professional participants to be heard, thereby facilitating identification of core views and needs.

The majority of studies in the literature review (n=5), around interventions to manage bowel symptoms, adopted a quantitative approach (Robinson *et al.,* 2006, Belling *et al.,* 2009, Hawkes *et al.,* 2009., Ringstrom *et al.,* 2009, Reusch *et al.,* 2016). Whilst a number of interventions resulted in improved bowel symptoms, many were not deemed to be of statistical significance. Importantly, this quantitative approach failed to capture the significance of improvements to the patients and did not fully explore the impact which reduction of symptoms had upon their quality of life. This approach also did not identify the individual components of the interventions which participants found to be of most benefit. A qualitative design was adopted by a number of the included studies (Nikoletti *et al.,*2004, Jefford *et al.,* 2016, Hou *et al.,* 2017). This qualitative approach provided insight into the efficacy of individual strategies upon individual symptoms and identified this from both a patient perspective and a symptom measurement view. The researcher therefore made the choice to adopt a qualitative approach to the design.

In addition, descriptive studies allow researchers to examine phenomena about which there is little knowledge (English, 2016). This method was chosen as the literature has clearly identified a scarcity of existing interventions to aid patients with the bowel symptoms experienced, specifically following surgical treatment for rectal cancer. Furthermore, descriptive studies should be utilised when straight descriptions of phenomena are required (Sandelowski, 2010), thereby in keeping with the objective of this study. As discussed by Sandelowski (2010) researchers conducting qualitative-descriptive studies stay closer to their data and to the surface of words and events than researchers conducting grounded theory, phenomenological, ethnographic, or narrative studies. As this study sought to capture the experiences of patients so as to fully understand the impact of bowel symptoms and what they and HCPs considered would be of benefit in the management of these bowel symptoms, this method of study was chosen.

4.4 Sample

A purposeful sample was utilised for the purpose of this study. Purposeful sampling consists of the deliberate inclusion of participants who can help to provide the necessary data (English & Pengelly, 2016). This form of sampling was utilised as it can allow “for the identification and selection of information-rich cases related to the phenomenon of interest” (pg. 533, Palinkas *et al.,* 2015). Non-probability, purposeful sampling was used in this study to intentionally recruit participants who would provide appropriate, meaningful insights about the phenomena being studied (Sandelowski, 2010; Nicholls, 2009; Parahoo, 2006, Burns & Grove 2005). In relation to HCP (healthcare professional) participants, the purposeful selection of project location employees with professional or clinical knowledge, experience or expertise pertinent to the research project was carried out. To reduce risk of bias in sample selection and decrease the risk a strict inclusion and exclusion criteria were adopted.

As illustrated by the inclusion and exclusion criteria, patient participants were adults who had undergone sphincter-sparing surgery for the treatment of rectal cancer and were experiencing altered bowel function as a result.

Sampling in qualitative studies is based on quality as opposed to quantity (Nichols, 2009). The sample size is said to be accurate once data saturation has occurred which should clearly reflect the findings of the study (Cleary *et al.,* 2014; Lambert & Lambert, 2012; Burns & Grove, 2005). A typical sample size for a qualitative descriptive study may be as few as three to five persons, ranging up to about 20 participants (Magilvy & Thomas, 2009).

In relation to data saturation, in qualitative data this may often be difficult to define or decide upon but in relation to sample size, it should ensure that the research question being asked is confidently and accurately answered (Krippendorf, 2004; Bengtsson, 2016). Furthermore, in a study carried out by Guest *et al.,* (2006) the degree of data saturation during interviews with women in relation to sexual behaviours and self-reporting of same in Western Africa found that despite having carried out 60 interviews, data saturation had almost fully occurred by their 12th interview and the majority of themes had emerged by the 6th interview. The following section outlines the inclusion and exclusion criteria of the sample for the current study.

4.4.1 Inclusion and Exclusion Criteria

Patient Inclusion criteria:

- Individuals who have undergone sphincter-sparing surgery for rectal cancer
- Greater than 6 weeks following surgery
- Experiencing altered bowel function
- Greater than 18 years of age
- Restoration of bowel continuity present

Patient Exclusion Criteria

- Less than 18 years of age
- Presence of a stoma at the time of data collection
- Presence of active disease
- Currently undergoing radiation therapy
- Individuals who required the use of an interpreter in the pre-operative setting

Healthcare Professional Inclusion criteria;

- Registered General Nurses working within a colorectal setting for a period greater than 2 years
- Colorectal Ward Clinical Nurse Managers
- Clinical Nurse Specialists practicing within a colorectal setting
- Specialist Registrar and Consultant Colorectal Surgeons

Healthcare Professional Exclusion Criteria

- Student or agency nurses
- Locum clinicians
- Nurses working outside of the colorectal setting

Those with confirmed active disease will be excluded due to the impact which active rectal disease may have upon bowel symptoms. The choice to exclude agency and student nurse and locum colorectal clinicians was made as their interaction and experience of working with patients with bowel symptoms may be limited. A total of 19 participants were included in the study, however only 15 participants completed an interview with the researcher.

Reasons for withdrawal of these four participants included recurrence of disease (n=1), death of a participant's relative (n=1), time constraints (n=1) and scheduling issues (n=1).

4.5 Access and Recruitment

Permission to access both staff and patients was sought from the Ethics Committee of the hospital (Appendix 4), the Director of Nursing, the Clinical Director and Consultant Colorectal Surgeons (Appendices 6 & 7). This will be discussed in more detail in the Ethical Considerations section of this chapter. In terms of accessing participants, a purposeful sample of RGNs, CNMs, CNSs, Colorectal Consultants and NCHDs was chosen from the colorectal ward, with consideration given to time of experience in the colorectal setting amongst the RGNs. Patient participants were invited to participate in the study through a letter of invitation, Information leaflets and attached consent forms (all of which may be viewed in appendices 8-11) which were administered by the Colorectal Clinical Nurse Specialists in the colorectal clinic or by the Colorectal Surgeons conducting outpatient appointments. Healthcare professionals were approached face-to face and those who expressed an interest in participating in the study received a participant information leaflet (Appendix 10) and consent form (Appendix 11) via the hospital’s internal mail or directly from the lead researcher.

Completed consent forms were returned to the researcher’s work address by internal mail. A one week ‘cooling off’ period was afforded, to allow potential participants time to think about whether they wished to take part in the research study or not. Within that one-week period, potential participants were encouraged to contact the researcher should they have any concerns or queries regarding participation. After this period has elapsed, potential participants who had not returned completed consent forms were contacted by the researcher to ascertain whether they wished to participate or not. The researcher also liaised with the Colorectal CNSs to identify potential participants with known bowel dysfunction following sphincter-sparing surgery as the CNSs had vast experience of working with this group and were able to identify participants willing to discuss their symptoms and experience. Access and recruitment were carried out in accordance with the hospital's research policy.

4.6 Setting

A large, acute, public-sector university teaching hospital in Leinster was chosen as the research site. This hospital includes a 31-bed colorectal ward catering for the patients of 4 colorectal surgeons; it also houses a colorectal liaison service of 3 Colorectal Clinical Nurse Specialists. As many as 80 sphincter-sparing surgeries are carried out in this hospital every year according to the hospital's information system (HIS). The potential of bias introduction due to the study being carried out in an hospital setting is acknowledged and its potential impact was addressed by the carrying out of the interviews in a non-clinical area of the hospital.

4.7 Data Collection

Data collection in qualitative descriptive studies is described as the orderly, accurate collection of information with the aim of discovering the “who”, “what” and “where” of events and experience (Sandelowski, 2000; Sandelowski, 2010), in this case the experiences of patients facing bowel symptoms and the perspectives of those involved in their care. Data collection occurred over a 2-month period. Semi-structured interviews were conducted with patients, consisting of a pre-determined list of questions which evolved from a review of the literature on bowel symptoms, self-care strategies and existing interventions but also the existing categories identified by the researcher. Semi-structured interviews are a common method of data collection in qualitative studies, they consist of open-ended, pre-determined questions but allow for deviation from same should new information/ discussion emerge (Sandelowski, 2010; Nicholls, 2009). In addition, semi-structured interviews enable reciprocity between the interviewer and participant (Galletta, 2012). Questions utilised involved the careful use of follow-up cues/probes but with flexibility relating to both the phrasing and order as recommended by English & Pengelly (2016), with same further illustrated in Appendices 12 and 13. Audio recording of interviews was used as it was considered necessary to ensure that the data collected was accurate. The audio-recorded content was then transcribed by the researcher at the study location after each meeting; it is recommended that the researcher perform this procedure, as transcripts need to be detailed to capture verbal content and cadence (Bailey, 2008). These interviews are useful research techniques as they allow both the researcher and participant to expand upon their questions and answers. Individual qualitative semi-structured interviews were carried out with participants to allow for the emergence of topics and perspectives (English, 2016). Socio-demographic data were also collected from all participants. Demographic detail requested from patient participants included age, time since surgery, employment status, marital status and gender. In relation to healthcare professional participants data were collected relating to gender, age, time working in area and education including specialist qualifications. The findings of same are outlined in Chapter 6.

The main research questions posed by this study were formulated both through the extensive literature review carried out, the theoretical evidence underpinning the study (The Theory of Symptom Management) and the existing evidence. The questions sought to determine the most common bowel symptoms experienced by patients, which symptoms were most problematic, which strategies they utilised to manage bowel symptoms, and should an intervention be developed what content and mode of delivery would be most acceptable. These questions also broadly addressed the severity, frequency, timing and degree of bother attributed to symptoms. These questions also sought to determine the views of HCPs in relation to bowel symptoms, strategies and the development of an intervention. These questions are outlined in appendices and were used to guide the formulation of questions posed to both HCP and patient participants.

In relation to individual interviews with the healthcare professionals, a similar but HCP focused interview prompt list was utilised, same is illustrated in Appendix 13. The interviews were carried out with the aim of ascertaining the perspectives of healthcare professional into the bowel symptoms which they perceive to be prevalent and most bothersome but also to identify which strategies they perceive to be most useful, usable for patients. These findings were then compared with the findings of the individual patient interviews and used to guide the further development of content of a future intervention through identification of both similarities and differences. The pre-determined categories included bowel symptom experience, physical responses to bowel symptoms, psychological and social response to bowel symptoms, symptom management strategies and proposed intervention to improve symptom outcome. Any disparities between the views of the patients and healthcare professionals were noted and are discussed further in Chapter 6.

The development of this study was guided by the extensive literature review carried out, the MRC Framework for the Development of Complex Interventions (2006) and the Theory of Symptom Management.

Data Collection Procedure

Recruitment for the study was carried out as outlined by the access and recruitment section. Individual interviews were conducted with participants at the agreed time and venue. For many of the HCP participants meetings were cancelled last minute due to their work commitments. This proved to be one of the most challenging aspects of the data collection process as the researcher often booked an interview room many weeks in advance only to have the slot unfilled. Prior to commencing the interviews, the details of the information leaflet and consent form were re iterated. Participants were reminded that their participation was completely voluntary and that there would be absolutely no negative consequences should they withdraw. Participants were also reminded that the interviews would be audio recorded and consent was gained for this. The researcher then began to record, and the aims and purpose of the study were read aloud. Initial introductory questions were utilised to put the participants at ease. Participants were encouraged to seek clarification if required. The researcher utilised the interview scheduled to guide the interview but also used prompts to facilitate elaboration and the emergence of new information. Interview lengths varied greatly, lasting between 17 minutes to one and a half hours. Of note the majority of short interviews were with doctors participating in the study. Following completion of the interviews all participants were provided with the contact details of the researcher should they wish to add anything to their interviews or withdraw their participation. Data analysis then commenced as described in the data analysis section.

Pertinent literature purports that when carrying out research which explores topics of a sensitive and personal nature, it is important that interviews should take place in a quiet environment with no distractions (Whiting, 2013; McGrath *et al.,* 2018). Ideally, the researcher should sit across from the participant with a tape recorder between the two to capture both voices equally (Al-Yateem, 2012). This positioning also enables the researcher to note nonverbal cues (latent content), such as eye contact, crying, laughing, or hand gestures (Al- Yateem, 2012). Thus, in line with current evidence-based practice all interviews for this study were carried out in a quiet, private meeting room which had been booked, required swipe access, therefore preventing any unwanted distractions and allowing for privacy and confidentiality. Participants were seated across from the researcher, provided with a glass of water and both written and verbal consent was gained prior to commencing audio recording.

4.8 Ethical Considerations

The welfare of any research participant should take precedence over achieving any research objectives (Greaney *et al.,* 2012). To ensure same, the Ethical Conduct in Research Guidelines by the Irish Nursing and Midwifery Board (NMBI, 2015), and the ethical principles outlined in the Declaration of Helsinki (World Medical Association, 2013) were adhered to. These principles include beneficence and non- maleficence, justice, veracity, fidelity and confidentiality. To conduct this research, approval was sought from the Clinical Research Ethics Committee of the hospital setting chosen for this study. The role of any ethics committee in healthcare is to ensure that ethical principles are being adhered to and that the rights of the study participants are being observed (Burns & Grove, 2005).

The researcher is a colleague of all healthcare professional participants employed at the study location. Therefore posing the potential risk of research coercion. Maintenance of clear communication, clear portrayal of the researcher role from the workplace role and regular reflection by the researcher was carried out to prevent this issue from occurring. Participants were invited to withdraw from the research at any time if they did not wish to continue their participation. Participation in the study was voluntary and participants would be aware of this from the outset. Participants could decline to participate or exit the project at any time and without giving a reason; they were reassured that withdrawal or non-participation would not affect their working status. Those who choose to participate were expected to engage in a single interview with the researcher.

The patient participants in this study may be receiving ongoing care and input from the Colorectal Services of the hospital, of which the researcher is an employee. Patients were informed that refusal to participate/withdraw from the study would not in any way affect their treatment/care. Those who participated were also ensured of their confidentiality. In relation to confidentiality, the research study participants were informed that their contributions would be anonymised. Code names such as Patient 1,2,3 were used for patients and HCP (Healthcare Professional) 1, 2,3 used for healthcare professionals to protect participant identity. This applied while transcribing the audio recordings, recording notes during interviews and throughout data analysis. The researcher alone retained the original identifiers.

The researcher recognised that as an employee of the institution and with an established role in the organisation in which the project would take place, 'Insider knowledge', in the form of pre-understanding (denoting both explicit and tacit knowledge of the research context and setting) is advantageous in this regard to gain access, build trust and foster close collaboration (Coghlan, 2005). However, role duality between the researcher's professional role and research role may cause a degree of confusion and ambiguity for the researcher and those with whom they work and collaborate (Coghlan, 2014).

Additionally, the researcher identified that she may find it difficult to question their pre-existing assumptions and maintain a critical perspective (Coghlan, 2014). The challenge was to build on closeness and foster distance by occupying 'the space between' both roles; negotiating relational closeness whilst insuring analytical distance (Gray *et al.*, 2016, Coghlan, 2014). The researcher acknowledged that her position as a senior Staff Nurse and familiarity with some of the participants could inhibit open discourse or influence the study's outcomes (Coghlan, 2014).

4.8.1 Data Management

The researcher was the sole individual with access to the raw data. Project participants would have access to hard copies of transcripts if they so wished. Audio-recorded participant contributions were anonymised, via the application of code names (e.g.

participant 1, 2, 3 etc.) and by the removal of any potentially identifying details during the transcription process. All data collected were stored electronically on a password protected laptop computer. The laptop computer and the audio-recording device used to record the interviews were secured in a locked filing cabinet at the project location, to which the researcher retained the key. Recordings of meetings were erased from the audio-recording device once transcribed. All project data was retained as per hospital policy and in keeping with GDPR (General Data Protection Regulation) legislation (HSE, 2018).

4.9 Pilot Study

A pilot study is, a small-scale test of the methods and procedures to be used on a larger scale (Leon *et al.,* 2010). The fundamental purpose of conducting a pilot study is to examine the feasibility of an approach that is intended to ultimately be used in a larger scale study (Leon *et al.,* 2010). In her discussion of pilot studies, Perry (2001) highlights the benefits of conduction pilots, it allows for identification of barriers, ascertaining details of participant recruitment and also allows the researcher to determine the suitability of the data collection instrument. To ascertain the above, a pilot study was conducted with one HCP and one Patient participant separately. This allowed the researcher to examine the efficacy of interview techniques, research questions, ascertain if use of cues and probes were appropriate and also to ensure that no leading or inane questions were utilised (Westlund & Stuart, 2017). Following the pilot study, the researcher made a number of adjustments: participants were given more time to read through the information sheet again to refamiliarize themselves with the aim of the study, a glass of water was provided and the interview setting was changed to a different room that had less noise outside so as to not interrupt the discussion between the researcher and participant. The researcher was also given insight into the waiting times for access to private interview rooms and the importance of sending reminders to interview participants.

4.10 Data Analysis

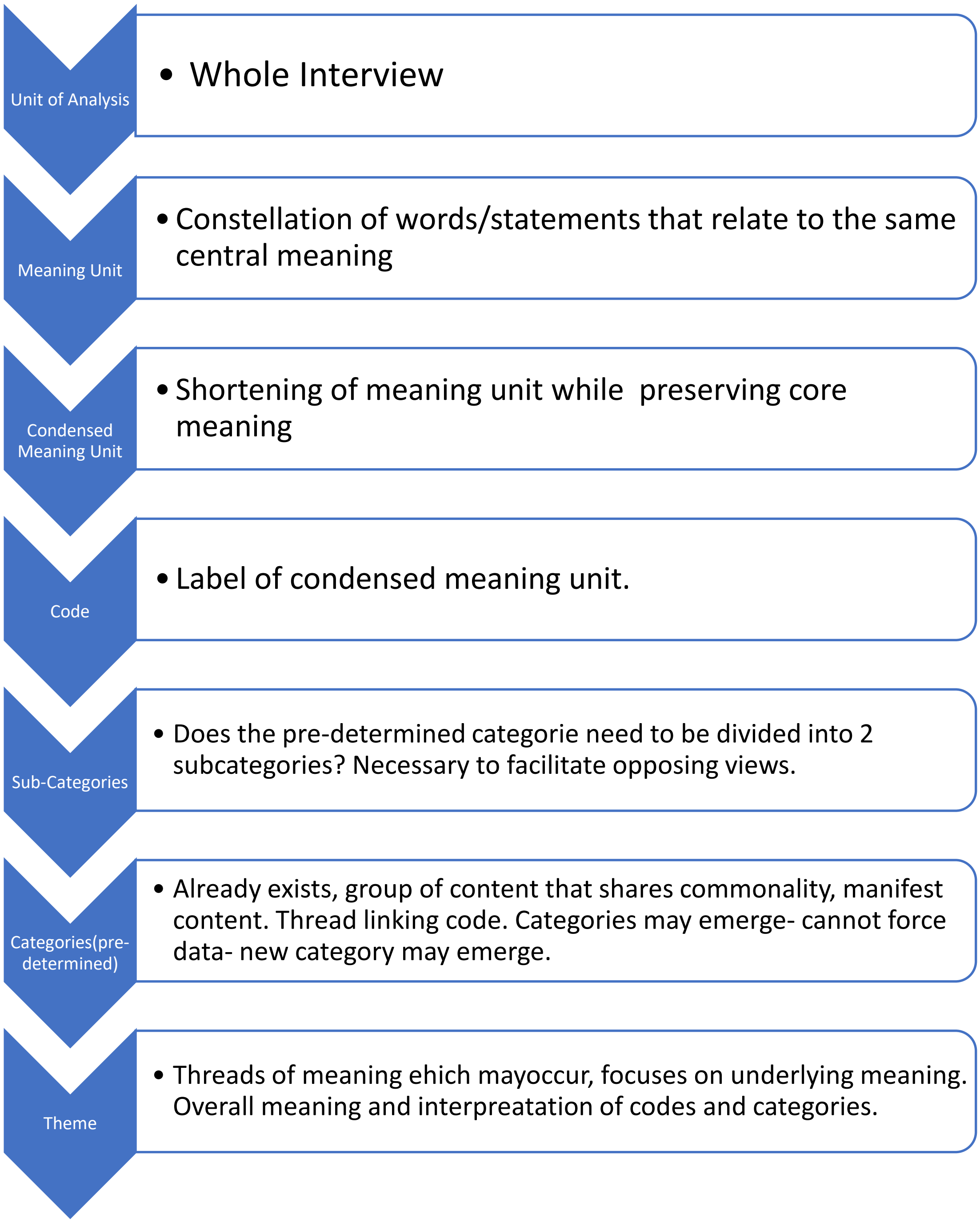
In qualitative research, data analysis is a complex, non-linear and often challenging process which results in raw data being transformed into themes, categories or description (Granheim & Lundman, 2004; Elo & Kyngas, 2008). The objective of qualitative data analysis is to transform large volumes of text, such as transcribed interviews, into organised and concise summaries of results without losing the true meaning of the text (Erlingsson & Brysiewicz, 2017). The data analysis which was undertaken by the researcher was underpinned and informed by the selected method of deductive content analysis. The following section will describe this process and rationale for using same.

Content analysis is defined as method for the “systematic and objective means of describing and quantifying phenomena” (Sandelowski, 1995) and may be either deductive or inductive. Content analysis has also been described as a “systematic coding and categorizing approach used for exploring large amounts of textual information unobtrusively to determine trends and patterns of words used, their frequency, their relationships, and the structures and discourses of communication (Mayring, 2000; Pope et al., 2000; Gbrich, 2007, Vaismoradi *et al.,* 2013). This form of data analysis matched the aims of the study as it facilitated the transformation of the large volumes of qualitative, sensitive text garnered through interviews with participants into a concise and organised summary of results (Granheim & Lundman, 2004, Erlingsson & Brysiewicz, 2007). Furthermore, content analysis was chosen as it is useful in the exploration of sensitive phenomena, the topic of this study being bowel symptoms, an area many may be reticent to discuss and allows the analysis of narrative accounts (Vaismoradi *et al.,* 2013) whilst also allowing for the emergence of new knowledge and insights (Elo & Kyngas, 2008). According to Elo & Kyngas (2008), deductive content analysis is useful when prior research on a phenomenon (e.g. bowel symptoms) would benefit from further description again in keeping with the aims of this study.

To undertake effective content analysis, three stages must be carried out, planning, organising and reporting, this was done following the guidance of Elo & Kyngas (2008).

This method of data analysis was chosen as its aim is to systematically take and transform large volumes of text into a concise, organised and categorised summary of key ideas in such a way that facilitates new insights, representation of facts and submitting them to descriptive treatment (Elo & Kyngas, 2008,Erlingsson & Brysiewicz 2017). As outlined by Braun *et al.,* (2018) content analysis provides a qualitative and detailed account of the data. It minimally organizes and describes the data set in (rich) detail. This form of analysis also provides new insights by increasing understanding of particular phenomena and can inform practical actions (Krippendorff, 2018). Again corresponding to the aims of this study, to identify the delivery and content of an intervention to aid patients to self-care for bowel symptoms following SSS for rectal cancer.

Large bodies of text are broken down into smaller meaning units. A meaning unit is a constellation of words or statements that relate to a common meaning through either content or context (Krippendorff, 2018; Bengtsson, 2016). Meaning units are assigned codes, codes are consigned to categories and then themes and inferences are made (Krippendorff, 2018). This process is illustrated in the below Figure 6;



- Whole Interview

- Constellation of words/statements that relate to the same central meaning

- Shortening of meaning unit while preserving core meaning

- Label of condensed meaning unit.

- Does the pre-determined categorie need to be divided into 2 subcategories? Necessary to facilitate opposing views.

- Already exists, group of content that shares commonality, manifest content. Thread linking code. Categories may emerge- cannot force data- new category may emerge.

- Threads of meaning ehich mayoccur, focuses on underlying meaning. Overall meaning and interpreatation of codes and categories.

Figure 6 Adapted from Krippendorff (2018)

In this type of analysis, data were coded according to pre-determined categories, which were constructed from prior knowledge. In this instance the pre-determined categories included bowel symptom experience, the psychological and social impact of bowel symptoms, the symptom management strategies initiated by both patients and HCPs for bowel symptoms and finally the proposed content and delivery of an intervention.

As purported by Elo & Kyngas (2008) content analysis is well-suited to analyse the multifaceted, important, and sensitive phenomena of nursing, and in this case the sensitive topic of bowel dysfunction being discussed with participants. The intention was that content analysis of the study's data would inform the content and design elements, mode of delivery and format of the potential future intervention. In descriptive, qualitative approaches, gathering and analysing data are conducted simultaneously, and according to Vaismoradi and colleagues (2013) this adds to the depth and quality of data analysis. This was in keeping with the aims of the study as the semi-structured interviews sought to gain data and insights into the experiences of those affected by altered bowel symptoms and those involved in their care, presenting large volumes of data to be coded and categorised to give meaning, both latent and literal. It was also chosen as this study is underpinned and guided by theory (Symptom Management Theory), and a deductive approach can be used when the structure of analysis is carried out based upon a theory or model (Elo & Kyngas, 2008).

Data analysis commenced following the first interview and continued throughout the data collection phase, thereby ensuring that sufficient data were collected throughout the remainder of the interviews. Demographic details were collected and input into tables (5 and 6). The gathering of demographic data allowed for the description of the population being studied and also was necessary to ensure the transferability of the study's findings (Graneheim & Lundman, 2003; Burns & Grove, 2005).

Following semi-structured interviews with individuals, audio-transcripts were transcribed. The audio-recorded content was transcribed by the researcher at the study location after each meeting; it is recommended that the researcher perform this procedure, as transcripts need to be detailed to capture verbal content and cadence (Bailey, 2008). Transcribed data was then read and re-read, to allow a general understanding and insight into what is being communicated by participants (Erlingsson & Brysiewicz, 2017). Both manifest (words, phrases, etc.) and latent (vocal cadence and emphasis, silence, laughter, etc.) content was taken into account during analysis of audio-recordings. The process of ascertaining "meaning units" was then undertaken, whilst always referring to the research question and study aims. Continuous analysis of the text progressed from meaning units, to codes, categories, themes and finally, overarching theme identification (Elo & Kyngas 2008, Erlingsson & Brysiewicz, 2017). Throughout this process, the researcher consistently ensured that the core meaning of the transcribed interviews was not lost, through regular re-reading of the text and referral to the audio-recordings, whilst bearing in mind the potential influence which previous knowledge and experience may have upon interpretation of results (Erlingsson & Brysiewicz. 2017). An example of this process and analysis can be seen in Appendix 16.

Data were analysed according to pre-determined categories as outlined above, which were based on a review of the literature and the theory guiding the study's development.

4.11 Management of Rigour and Quality

In qualitative research demonstrating methodological rigour establishes trust and confidence in the findings of the study and should be evident during all stages of the research process (Thomas & Maglivy, 2011; McBrien, 2008; Ryan *et al.,* 2007). Trustworthiness is an alternative term often used in the literature to describe methodological rigour.

Credibility, dependability, confirmability, and transferability are the most common measures to achieve trustworthiness in qualitative studies (Lincoln & Guba, 1985). These were considered throughout the study and shall be outlined in the following sections.

Credibility

In order for a qualitative study to be credible, the findings must be an accurate representation of the participants' experiences (Thomas & Maglivy, 2011; McBrien, 2008). Credibility is ensured by confirming that all findings are strongly grounded in the data

(Koch, 2006). A strategy to ensure credibility throughout this study included regular debriefing with supervisors to discuss interpretations and the process of data analysis from meaning unit to themes. In addition, the use of semi-structured interviews can allow for participants to seek clarity on what is been asked which can enhance the credibility of findings (Burns & Grove, 2018). The researcher also studied and examined participant transcripts individually, as well as identifying any similarities across interviews with participants, healthcare professionals and patient participants alike. Additionally, all findings were peer reviewed by both of the researcher's supervisors (JH &ML) to ensure that the process of data analysis was carried out in a structured and logical fashion, to prevent the omission or alteration of the data's meaning.

Dependability

The dependability of a study describes when a researcher's decision-making process is clear for another researcher to see (Grossoehme, 2014; Ryan *et al.,* 2007; Koch, 2006; Sandelowski, 1986) and is pivotal as it establishes that a study's findings are consistent and repeatable. One method to ensure dependability is to undertake an external audit also known as an inquiry audit, that is, allowing an outside researcher (in this case the researcher's supervisors) to examine, explore, and challenge how data analysis and its interpretation were carried out.

To ensure dependability of this study’s findings, extracts from conducted interviews were presented and the method through which data was analysed was presented throughout the study and to the researcher’s supervisors. Additionally, the processes within the study were reported in detail, thereby enabling a future researcher to repeat the study as recommended by Shenton (2004). An example of this is discussed and illustrated in the next chapter. Therefore, the researcher provided evidence and clearly outlined how decisions were made at each point of the research process.

Transferability

The transferability of a study is the ability to transfer the findings of the study or the methods used to conduct the study from one setting to a different setting (Graneheim & Lundman, 2003) or when readers can relate their experiences to the findings from the study (Shenton, 2004). Within this study, transferability was facilitated through provision of clear descriptions of the research process, the context in which the study was carried out and through outlining the selection and characteristics of participants, data collection and analysis, in keeping with the recommendations made by Graneheim & Lundman (2003) and Shenton (2004).

Reflexivity

Reflexivity involves reflection upon one’s own values, opinion and how they could potentially influence the outcome and findings of research (McBrien, 2008). Reflexivity is pivotal to ensure the credibility and trustworthiness of any qualitative study (McBrien, 2008). To ensure reflexivity was maintained throughout this study, the researcher regularly met with experienced nurse researchers (i.e. research supervisors) and also maintained a private reflective journal so as to facilitate regular self-critique and appraisal in keeping with the guidance provided by Koch (2006) and McBrien (2004).

Conclusion

From the extensive literature review carried out, a number of issues arose that warranted further attention. Conflicting findings, coupled with the fact that no interventions focused specifically upon aiding patients in their self-care of bowel symptoms experienced following SSS, provided the impetus for this study.

The aims of this study were to identify the symptoms experienced by patients, the strategies they utilise to self-care, their information needs and also the strategies which would be beneficial for inclusion in an intervention. In addition to exploring the perspectives of those involved in the care of these patients and what they deem useful/helpful for inclusion within an intervention.

Finally, this study aimed to determine what content, mode of delivery and format would be most beneficial for patients. In keeping with the aims and objectives of this study a qualitative, descriptive design, underpinned by the Theory of Symptom Management (Humphreys *et al.,* 2008, 2018), was adopted in order to facilitate an exploration of this topic and allow insight into the relationships which exist between symptoms experienced and symptom management. In addition,the MRC Framework (2006) was utilised to provide guidance for the way in which this methodology was conducted. The study was at all times guided by the core ethical principles as outlined by the Irish Nursing and Midwifery Board (2015), the ethical principles outlined in the Declaration of Helsinki (2013), and obligations as set out in the hospital’s policy on research. Finally, deductive analysis was undertaken following collection of data through semi-structured interviews. This led to the emergence of the study’s findings which the following chapter will present.

Chapter 5.0- Findings

Introduction

In this chapter, the findings from the qualitative, descriptive phase of the study, using semi-structured individual interviews (n=15), are presented. The sample and demographic characteristics of the participants are outlined. The findings will be presented according to five pre-determined categories and subcategories which emerged from analysis of the data.

5.1-Sample Characteristics

Eight patient participants who had experienced bowel dysfunction following sphincter-sparing surgery and fourteen healthcare professionals involved in their care returned consent forms. Of the patient participants, three withdrew from the study, due to recurrence (n=1), death of a family member (n=1) and no reason provided (n=1). Whilst time constraints (n=2), illness (n=1) and commencement of employment in a different facility (n=1), were cited as reasons for non-participation by four healthcare professionals. Thus, fifteen participants were interviewed for this study: ten healthcare professionals and five patients.

5.2- Demographic Characteristics

5.2.1 Healthcare Professionals

Ten healthcare professionals (HCPs), involved in the care of patients following surgery for rectal cancer, participated in semi-structured interviews, aged from 24-63 years, with a mean of 39 years. In relation to years of employment, length of time working with this cohort of patients varied from 3-30 years, with a mean of 8.5 years and time since qualification varied between 3- 42 years. The majority of HCP participants (n=7, 70%) had completed further education to either a Higher Diploma, Masters or Doctorate level. In relation to the gender of HCP participants six females and four males were interviewed. In terms of employment roles there was a variety of job titles, with 70% (n=7) of participants being nurses, and the remainder working as medical practitioners. In terms of specific job titles, 50% (n=5) of participants were Clinical Nurse Specialists working within the colorectal setting, including Coordinators, Continence and Pain specialists.

Table 5- Demographic Characteristics of Healthcare Professionals

Variables	**N(%)** **Total=10**
Age (years)	
25-30	2 (20)
31-35	2 (20)
36-40	3 (30)
41-45	1 (10)
55-60	2 (20)
Gender	
Male	4 (40)
Female	6 (60)
Current Job Title	
Clinical Nurse Specialist/Co-ordinator	5 (50)
Clinical Nurse Manager	1 (10)
Staff Nurse	1 (10)
NCHD Colorectal Surgeon	2 (20)
Consultant Colorectal Surgeon	1 (10)
Highest Level of Education	
Undergraduate	2 (20)
Postgraduate/HDip	1 (10)
Masters	4 (40)
Doctorate	3 (30)
Time Since Qualification (years)	
<5	1 (10)
5-10	2 (20)
11-15	3 (30)
16-30	2 (20)
31-40	2 (20)

5.2.2 Patients

The demographic details of patient participants (n=5) following SSS (sphincter-sparing surgery) for rectal cancer are presented in the below Table 6. All patients were greater than 60 years of age, with the oldest patient being 81 years of age, in keeping with the national average age group affected by rectal cancer (NCRI, 2019). In terms of marital status, the majority of patients were married (n=3), one participant single and one divorced. Only one participant had 3rd level education, two had secondary education and two primary level education only. The time elapsed since their surgery (either reversal or direct anastomosis) varied from 12-26 months. Two of the patients had adjuvant chemotherapy and one patient had neoadjuvant chemoradiation therapy.

Table 6- Demographic Characteristics of Patient Participants

Variable	N(%)
Age(Years)	
60-65	2 (20)
66-70	2 (40)
81-85	1 (20)
Gender	
Male	4 (80)
Female	1 (20)
Education Level	
Primary	2 (40)
Secondary	2 (40)
Third-Level	1 (20)
Time Since Surgery	
6-12 months	1 (20)
>1 year	2 (40)
>2 years	2 (40)
Marital Status	
Single	1 (20)
Married	3 (60)
Divorced	1 (20)
Adjuvant Therapy	
Yes	2 (40)
No	3 (60)
Neoadjuvant Therapy	
Yes	1 (20)
No	4 (80)

5.3 Qualitative Data Findings

The pre-determined categories which emerged as a result of the extensive literature review and were explored by the semi-structured interviews are as follows: 1) Bowel Symptom Experience 2) Physical Responses to Bowel Symptoms 3) Psychological and Social Response to Bowel Symptoms 4) Symptom Management 5) Proposed Intervention to Improve Symptom Outcomes. A summary of the main categories and their subcategories are presented in Figure 7 and will be discussed in detail in the following sections.

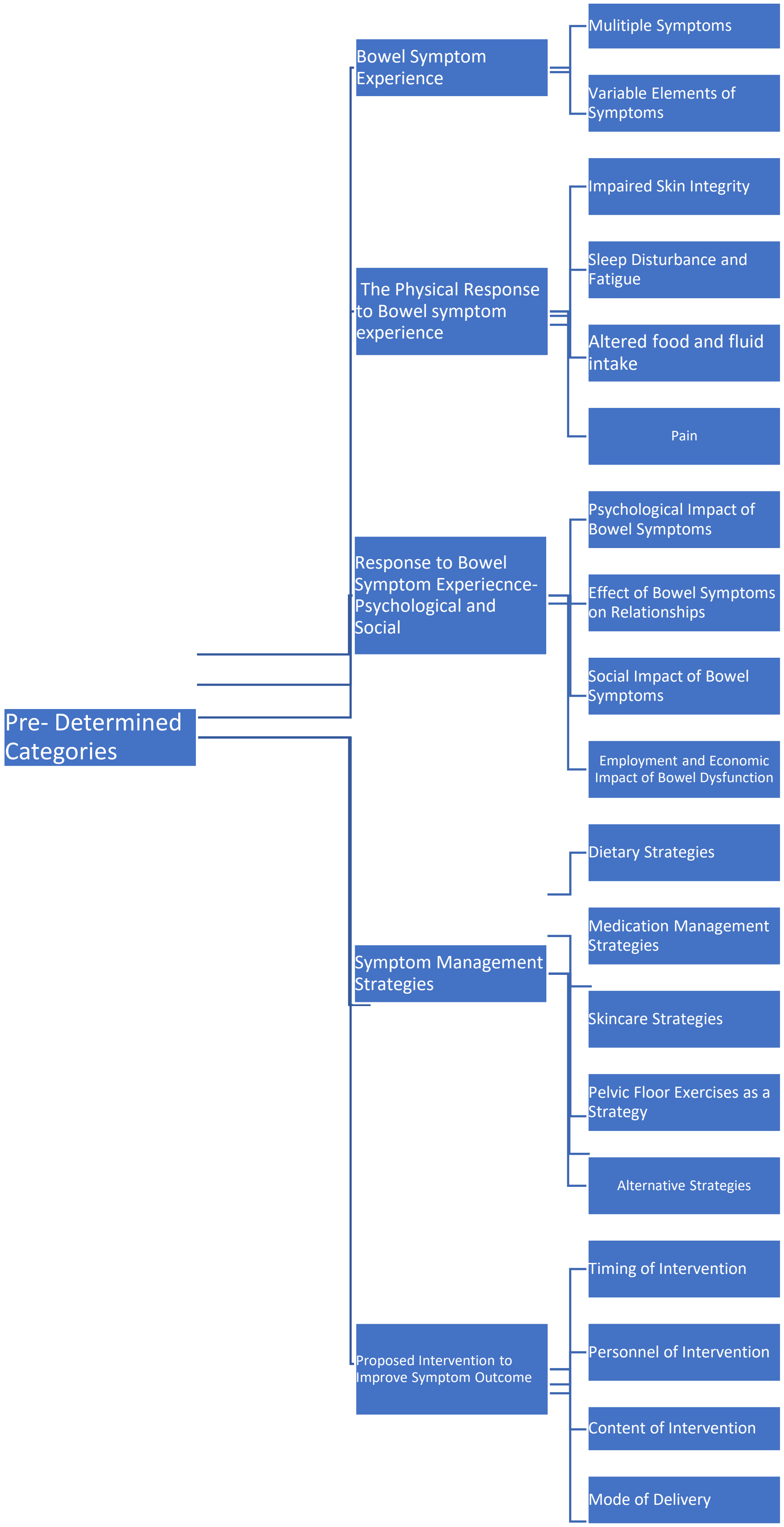


Figure 7: Summary of data analysis findings: Categories and Sub-categories

5.4- Bowel Symptom Experience

The first pre-determined category which was explored by interviews was Bowel Symptom Experience. Analysis of the participants' interviews resulted in the emergence of sub-categories including i) multiple symptoms and ii) variable symptom experience, each describing patients' experience of bowel symptoms as outlined by patients themselves and HCPs involved in this cohort of patients' care. Interviews with participants provided a glimpse into the lives of those post sphincter-sparing surgery and how their new functioning was "a price to pay" (HCP2) for the surgical resection of their cancer. The following section discusses the multiple symptoms experienced by patients following sphincter-sparing surgery for rectal cancer

5.4.1- Multiple Bowel Symptoms

During an exploration of the bowel symptoms experienced by patients, the first obvious sub-category to emerge was the occurrence of multiple types of bowel symptoms. Discussion of bowel symptoms with participants highlighted the varying degrees to which healthcare professionals were aware of the incidence and impact of bowel symptoms, and also the variability to which patients were affected. However, all participants voiced similar views in relation to the most common symptoms experienced by patients following SSS for rectal cancer. Types of symptoms experienced varied from frequency, urgency, incontinence and tenesmus to incomplete emptying, post-defecatory soiling and flatus.

Patients’ reported symptoms were similar to those identified by HCP participants, including discussion of urgency, frequency, clustering, incomplete emptying, tenesmus and incontinence. However, these responses also served to identify symptoms which were experienced by patients regularly but seen by HCPs as issues experienced by few. The following sections discuss the participants’ experience around physical bowel symptoms.

Frequency of Bowel Motions

The issue of frequency was a bowel symptom discussed throughout interviews with all participants (n=17). The term frequency describes an increase in bowel motions. In this context, this refers to the fact that the number of visits to the toilet was within a short timeframe in most descriptions, with reference to the need to move quickly in response to the desire to go to the toilet also mentioned very often. This symptom was amongst the most recurrently mentioned symptoms across both patient and HCP interviews. Whilst the term “frequency” was not always used, every participant described increased bowel motions, sometimes a significant number of bowel motions, amongst this cohort of patients. For many affected patients, frequency varied from three to thirty bowel motions a day or a number of bowel motions within a short period of time. One Clinical Nurse

Specialist reported a patient passing more than five bowel motions within a two-hour period. Another Clinical Nurse Specialist working closely with this cohort of patients outlined the extent of frequency amongst some patients:

"You're talking about bowel movements upwards of twenty to thirty times per day" (HCP5)

All patients interviewed voiced significant bowel dysfunction following sphincter-sparing surgery, whilst one participant had undergone neoadjuvant chemoradiation, a common cause of altered bowel function, he denied any significant changes in bowel motion following same prior to surgery, thereby indicating that his bowel dysfunction began following surgery. Frequency of bowel motions was the symptom most often cited by patients and this was seen in every patient (n=5), with frequency of bowel motions varying from 3- 12 per day, sometimes higher before the implementation of strategies:

"I was going a lot. I was going maybe 11 or 12 times a day" (P1)

These interviews highlighted the varying degrees and subjective nature of symptoms which patients experienced and also their awareness of the issue through their counting of daily defecation. One patient acknowledged that surgery and his desire to forgo the formation of a stoma had contributed to the development of frequency:

> *"This isn't, it wasn't a problem in that I had been warned and I had asked on the day of the operation not to have a stoma, so I had to accept the consequences of my wish and the surgeon's actions"* (P2)

Whilst this section discusses the physical symptoms, the significant impact which frequency can have upon daily life was evident amongst interviewees. The distress associated with frequency was also marked. The impact of frequency illustrated by the following remark describing a car journey, during which this participant was experiencing frequency of bowel motions:

> *"It wouldn't happen a lot, but it has happened Jesus. It was hell on earth on the way home. We had to stop the car so many times like. And he said, "this couldn't be possible". I said, "this is possible" (P2)*

The degree of severity to which some patients experience frequency following SSS was also highlighted by one HCP:

> *"A patient recently who had a very rocky road or whatever and when he came to me first and he was LARS (low anterior resection syndrome) and having 15 bowel movements a day" (P5)*

The impact of frequency was discussed by all participants and was the most common symptom mentioned. Frequency's impact and occurrence was made evident throughout interviews. The researcher also noted that this symptom was closely associated with urgency of bowel motions, which the following section will discuss.

Urgency

All participants also cited urgency as a significant issue, urgency being the need to defecate immediately without the ability to delay for even a short time (MacArthur, Bick & Keighley, 1997). Interviews illustrated urgency as a symptom impacting upon ability to leave home, perform daily activities of living and socialise, something which will be further discussed and is highlighted by the following quotes. One gentleman described urgency as giving him *"not a second"* to delay defecation. And another as *"immediate" (P3).*

Participants' description of urgency illuminated the well-known symptom following SSS, but also illustrated its potential severity and impact upon patients' ability to leave known/familiar environments where toilet facilities were readily available. As illustrated by the following patient quote:

> *"had left the house to go to a sporting event and I had walked 100 metres and I needed to use the toilet" (P3)*

Furthermore, the potential of urgency to place patients in distressing and embarrassing situations was an issue outlined by participants. The degree of urgency experienced by one participant was illustrated when he described the potential circumstances he faced as a result of urgency, *"cos when you have to go, you have to find somewhere, you might have to go to the nearest ditch" (P1).* In addition, the impact of urgency upon daily life was further outlined in one patient's description of its occurrence whilst travelling:

“But like when we were driving home the motorway one day and it was just hell until we got to (names hometown) until we could pull off the motorway.” (P2)

When discussing the symptoms which patients found to be most bothersome, one patient perceived urgency to be the most impactful upon daily life. The bothersome nature of urgency was further acknowledged by another patient who describes the associated panic of realising the urgent need to defecate:

“Absolutely, a complete panic. I’ve got to find a loo and have to find it now” (P3)

The degree to which urgency was experienced was also illustrated by a participant when describing a discussion with a HCP assessing bowel dysfunction:

“One of your colleagues asked one day if I opened the hall door could I switch off the alarm and walk to the loo. Are ya (sic) joking! If I need to go and I open the door the coats are thrown and I’m running in someone else is putting off the alarm.” (P3)

This quote provided insight into the degree to which this participant was affected by urgency, in so far as the seconds taken to key in an alarm were too long to permit delay of defecation.

The impact of urgency was also well-acknowledged by HCPs interviewed, with one surgeon outlining urgency’s impact upon a patient’s ability to hold and delay defecation. When asked to describe the most bothersome symptoms for patients, urgency was selected by one HCP, due to its impact upon daily life, echoing the views of patients in the following quote:

"But it's the incomplete emptying having to go to the loo a number of times and the urgency that often occurs." (HCP9)

Urgency was an issue discussed by every patient and HCP participant, with same occurring in both the initial post-operative period weeks and the years following surgery for rectal cancer. Its impact meant patients were often faced with the need to defecate at inopportune times, including whilst travelling or when there were no toilet facilities available. The descriptions by participants also serve to demonstrate the potential severity of urgency, when defecation cannot even be delayed by seconds. Furthermore, interviews with participants highlighted the impact of urgency, with it being viewed as a symptom which causes panic and also being described by one participant as the most bothersome symptom experienced.

Incontinence

The issue of incontinence and passive soiling was also discussed by participants. Incontinence being "the involuntary loss of bowel control, which normally allows the passage of gas or stool at a sociably acceptable time and place" (Person *et al.,* 2006, pg 972). During discussion with patients, this symptom presented in a number of ways, involuntary passage of formed stool, post-defecatory soiling, small volumes of leakage, staining and sometime incontinence of flatus, or passing stool when passing flatus. Whilst this section does not focus upon the psychological impact of these bowel symptoms, when discussing incontinence, the associated shame and desire to conceal are inextricably linked and discussed:

“it was just the awfulness of it. You know I was running to the bin with all my clothes and whatnot.” (P3)

“I did have a few problems but luckily I live alone, and I was able to clean up my own mess, there was no one that would’ve felt obliged to clean up my mess.” (P4)

This distress and associated shame were echoed in an interview with a continence nurse specialist who described her interactions with individuals experiencing faecal incontinence, with patients stating they felt *“unclean…dirty”.*

The issue of incontinence amongst this cohort of patients was another symptom frequently discussed by HCP participants. Whilst not viewed as a common problem, only seen in more severe cases, this issue had been noted amongst all HCP participants (n=10). Thereby possibly suggesting that the severity to which some patients are affected may be underestimated by HCPs:

“impaired continence and leakage. Although that’s not normally the dominant symptom.” (HCP 9)

These sentiments were resonated amongst the descriptions by patients. Two patients described how they were no longer able to pass flatus outside of the toilet for fear of incontinence and another man refusing to pass gas unless in *“a safe place” (P4).*

The experience of incontinence was further described by one HCP participant as the most bothersome symptom experienced by patients following SSS for rectal cancer:

> *"Oh, the incontinence. The urgency is not nice, but it's this thing of you're fine one minute and then you suddenly realise…they have a lot of passive leakage. And it's coming out and they don't have….. it's so, distressing." (HCP5)*

During interviews with participants, the desire to avoid the formation of a permanent stoma was discussed by both HCPs and patients. For many affected, after the desire to have their cancer removed, stoma avoidance was a key issue. However, patients' perceptions of incontinence were also discussed by one HCP participant, who describes the initial desire for reversal of stoma being marred by debilitating faecal incontinence:

> *"And a lot of patients will have a stoma after surgery and they say, "oh I cannot wait to get rid of this" and then they do, and they realise it is actually worse and the realise they can't manage the incontinence" (HCP5)*

Furthermore, the impact of faecal incontinence upon patient wellbeing was described extensively by one HCP, who compares her experience of caring for those with urinary versus faecal incontinence. This CNS described faecal incontinence being viewed as more distressing, a finding also voiced by one female patient, due to the associated odours and the fact that urinary incontinence pads absorb urine whereas pads to absorb faeces were still in development:

> *"with urinary incontinence, people can tell you they can live with it. But you cannot deal with faecal incontinence" (HCP5)*

In relation to the incidence of incontinence, all patient participants voiced that they had at some point in their post-operative journey experienced incontinence. However, of five patients interviewed, two patients still experienced ongoing incontinence, even at 18-24 months post-operatively. The following quote highlights one participant's continued experience of incontinence despite utilising pelvic floor exercises:

> *"even now I could do then and you're trying to clench your guts together and your guts turn to water but it's almost impossible, you are going to soil yourself" (P4)*

The occurrence of faecal incontinence following surgery for rectal cancer was discussed by all participants (n=15), with its impact and occurrence acknowledged but potentially underestimated. For all patient participants, faecal incontinence had featured both during and beyond their immediate post-operative period and meant use of incontinence wear. For others faecal incontinence no longer occurred but incomplete defecation persisted, as outlined by the following section.

Incomplete Defecation & Clustering of Bowel Motions

The issue of incomplete defecation and clustering was also voiced by almost all of the patients (n=4). Incomplete defection describes the need to pass a bowel motion within a short space of time following previous defecation and also includes tenesmus ""the painful sensation of incomplete evacuation of the bowel, resulting in the sensation of needing to defecate many times daily" (Ní Laoire *et al.,* 2017).

This symptom was particularly problematic and for participants it often meant spending a number of hours of their day being based upon toileting and for some was an issue that occurred every 1-3 days. One participant voiced that his clustering was so severe that at times following defecation he would get as far as the toilet door only to realise he needed to pass another bowel motion. Another gentleman described the process of incomplete defecation, as one which lasted over 5-6 hours until a large volume of diarrhoea occurred, marking completion of the cycle. Another gentleman described his bowel *"turn around system":*

> *"I work on a three day turn around system, but I know every third day I'm going to need to use the bowel. I try and work my life around that." (P2)*

Patient participants also frequently discussed the unpredictable nature of their bowel motions, very often ranging from diarrhoea to constipation and vice versa. For more than half of the patients (n=3), this erratic bowel habit was an issue with one man describing stools varying from small to large. Stool consistency also varied, as highlighted by one man:

> *"but you might one day do nuts and bolts and another you might do a slightly bigger stool" (HCP3)*

Many other manifestations of bowel dysfunction were voiced by HCPs, with a number of participants (n=6) voicing the issue of cluster defecation and the associated time spent toileting as a result until they became, what one Clinical Nurse Specialist described as *"clear".* This process and its associated issues were outlined by a colorectal oncology nurse specialist:

> "*they start going to the toilet and they pass a little and they think they are finished and then they have to go back in again and back in again and back in again. And this can go on for a couple of hours in the morning until they feel…. It may begin with constipated stool and they end up with profuse diarrhoea until the bowel has emptied"* (HCP3)

Summary

The multiple symptoms experienced by patients following sphincter- sparing surgery were explored and well-described by participants. These symptoms were diverse, but commonalities were seen across patient groups. Issues such as faecal incontinence, urgency, frequency, evacuatory dysfunction and tenesmus were described by all patients and discussed by health care professionals. For patients their lives were markedly different from the lives led prior to surgery. The following section describes some of the variable elements of symptoms.

5.4.2- Variable Symptom Experience

This section discusses some of the variable elements of symptom experience, including severity, duration, degree of bother, sensitivity, temporal nature and timing. This sub-category emerged as analysis of data demonstrated that whilst symptoms were often shared by all patients, their nature and presentation varied.

Severity

Amongst participants the varying degrees to which patients were affected was discussed. Interviews highlighted that whilst some patients were far more markedly impacted by symptoms than others, the potential underestimation of HCPs in relation to the impact of symptoms was also a potential issue. All HCP participants (n=10) mentioned frequency of bowel motions, urgency and incontinence and also the extent to which these symptoms were common or uncommon. The following excerpt details the nature of bowel dysfunction from the perspective of a HCP:

> *"a lot of patients would report that they experience frequency of bowel motions, loose bowels, an urgency to go, some faecal incontinence" (HCP 1)*

This quote highlights that many patients experience erratic bowel function following surgery and that it is not a rare occurrence but seen in "a lot" of patients.

Of note, the most awareness of this issue and acknowledgement of the prevalence of bowel issues was noted in the responses amongst the CNS participants:

> *"I would have come across a reasonably large selection of patients following anterior resection. And some of them would have been very mildly affected by it and some much more severely." (HCP3)*

Amongst the medical or ward-based staff the nature and prevalence of this issue was viewed as an uncommon problem, as illustrated by the following quotes:

> *"So, I think most of the time they do well, and they will be doing fine." (HCP8)*

> *"Yeah cos do they come back with an issue after a reversal. It could be something else a surgical issue and this could be an ongoing thing and we don't know." (HCP9)*

The severity of bowel dysfunction was also quantitatively evident in the number of bowel motions experienced by patients, with some reporting 3 per day to the 30 bowel motions per day which one Clinical Nurse Specialist had noted in a patient she had treated. Whilst the severity of bowel dysfunction was most prevalent for patient in the initial weeks post-operatively, one patient acknowledged that very intense faecal frequency still occurred on occasion following ingestion of problematic foods, this was also noted by another gentleman following consumption of a particular sauce.

The severity of skin irritation was also varying. Some patients reported some redness and itch and others bleeding and cracked skin due to perianal skin irritation. The more severe the symptom the more strategies the patients seemed to implement. With one patient who experienced 12 bowel motions per day utilising diet, medication and skin care strategies. Whereas the gentleman experiencing 3 bowel motions per day just used medication.

The varying severity of urgency was also noted. Some participants were able to hold for a car journey, or for the duration of a shopping trip, whereas other did not have enough time to turn off their house alarms or were even faced with defecating in the *"closest ditch"* as earlier described by one gentleman.

In conclusion, patients experienced varying degrees of severity and healthcare professionals recognised that whilst some patients will experience mild dysfunction following surgery, others are faced with life-altering and often all-consuming symptoms.

Duration of Bowel Symptoms

Duration of symptoms amongst those following sphincter-sparing surgery was a topic in which views differed. Many participants acknowledged the possible improvement of symptoms over time, whereas other recognised the potential of symptoms to persist. HCP participants discussed the plethora of physical bowel symptoms experienced by patients and also recognised the sometimes-prolonged duration and severity of these symptoms. All patients interviewed were greater than one year following reversal of ileostomy or restorative sphincter-sparing surgery. Interviews with HCPs provided insight into the potential for duration of symptoms to be underestimated or under-explored after the immediate post-operative period. For patients, their belief that reversal of their stoma or removal of their cancer would result in return to normal bowel function was often challenged, when faced with the long-standing duration of persistent bowel dysfunction. The following section describes their varying duration of bowel symptoms and the duration as perceived by healthcare professionals.

In relation to the duration of the symptoms, there were alternating views amongst HCPs with some viewing bowel dysfunction as an issue seen within the initial post-operative stage, and others acknowledging the potential for these symptoms to develop into a chronic problem. This occurrence was noted by one Clinical Nurse Specialist's experience of the timeline of patient's symptoms:

> *"we do anticipate in the first month to 6 weeks kind of I suppose erratic bowel habit and it can take a while to settle down but what I notice some of the patients complaining of is that after this period is that we would expect it to settle down and is that they're coming back " (HCP2)*

During an interview with one colorectal surgeon, he voiced that symptoms would usually reduce or resolve but *"at about 24 months these will generally plateau."*

These responses serve to highlight the significant disruption which bowel dysfunction following SSS can have upon the daily lives of affected patients and also the varying duration of symptoms experienced by patients.

Patient participants interviewed had differing timelines since their surgeries, but all were greater than one-year post-operation and continued to experience altered bowel function. One patient describes the continuing experience of bowel dysfunction despite being greater than 18 months post-operation and this degree of dysfunction being assessed by a healthcare professional:

> *"there was kind of a lull then recently it came back, and I went to a doctor examined me and then gave me, filled out a questionnaire and eh which, an incontinence questionnaire and I got a very high score, which wasn't the best" (P3)*

The cyclical nature of certain symptoms was also highlighted by one patient, who discussed the symptom of frequency and its tendency to occur for a certain duration then subside:

> *"It would go on for maybe two days and it would just run out of me and I'd have to keep going to the toilet" (P1)*

In relation to duration of bowel dysfunction the same patient also described a period of one week having to pass before his bowel dysfunction improved following "a flare".

In relation to HCP perspectives of the issues of obstructed defecation, constipation and incomplete emptying as symptoms, whilst viewed as less prominent than frequency and urgency, the impact of these symptoms were still acknowledged, including potential readmission to hospital:

"patients are saying that they find it very difficult to go and it's causing them discomfort and pain and they have readmissions to hospital due to this problem" (HCP1)

"kind of not emptying properly of feeling the pressure to go and not anything passing" (HCP2)

On analysis of HCP responses relating to physical bowel symptoms, the issue of bowel dysfunction and its impact was overall well understood and acknowledged, albeit at times underestimated. The potential failure of HCPs to investigate for or ask about physical bowel symptoms was acknowledged by less than half of participants (40%), thereby indicating that one of the causes of underestimation of bowel symptoms amongst HCPs may be due to inadequate assessment. One colorectal registrar attributed the failure to explore this issue to the focus of the healthcare team upon surveillance and oncological follow up. One nurse specialist felt this was not adequately assessed due to time and resource constraints. A colorectal consultant outlined his views of current under investigation:

"I think we are not…we don't look for this problem enough and unless the patient is upfront and maybe they are struggling. We need to look for it more proactively and then you can engage patients in any strategies about it" (HCP 9)

As highlighted by this section, the physical bowel symptoms experienced by patients are diverse and vary in terms of severity, duration and frequency. However, across all interviews, the significant changes from previous function was apparent and the impact which these symptoms had upon daily life. The following sections will now discuss the second subcategory, that is the variable elements of symptoms experienced, including the degree of bother relating to specific symptoms.

Degree of Bother Relating to Specific Symptoms

The symptoms which patients found to be most bothersome were discussed. Bothersome in this context referred to the symptoms which had the biggest impact upon patients' daily lives and well-being. Varying and diverse findings including incomplete evacuation, clustering, frequency and urgency. The degree to which patients perceived certain symptoms as bothersome was quite similar, of note when discussed with healthcare professionals, many gave very contrasting opinions.

When asked in relation to the symptom found to be most bothersome, one patient discussed frequency and the associated physical response:

> *"It was the biggest problem of the whole lot. You wouldn't believe how weak and dizzy you get" (P2)*

This quote serves to highlight that these symptoms can result in potentially harmful physical deficits.

The view of frequency as the most bothersome symptoms was echoed in the views of a number of healthcare professionals as communicated by the following quote:

> *"suppose the frequency of bowel motions is probably more bothersome for people as like obviously it would affect their ability to live their lives because they are very conscious of the fact that they need to have a toilet nearby." (HCP1)*

The desire for normal bowel motions was expressed by one patient, who outlined his bowel function when compared to that of the perceived "normal human", further illustrating the unpredictable nature of bowel dysfunction:

> *"I'd love to go to the loo and just go, but you might one day do nuts and bolts and another you might do a slightly bigger stool, but you never use the loo like a normal human. You can't! So I could go twelve times a day, when it starts" (P3)*

One healthcare professional cited faecal incontinence as the symptoms which they believed to be most bothersome to patients, discussing associated distress and its sudden nature:

> *"Oh, the incontinence. The urgency is not nice, but it's this thing of you're fine one minute and then you suddenly realise…they have a lot of passive leakage. And it's coming out and they don't have(...) it's so, distressing" (HCP5)*

During discussion with healthcare professionals in relation to degree of bother, one concept to emerge was the difference between genders and the bother they associated with bowel symptoms. Amongst three of the Clinical Nurse Specialists, this topic emerged. One colorectal nurse thought that women coped better, as for them the occurrence of *"leaky bodies"*, relating to menstruation and urinary incontinence post-partum, was a fact of life. However, the same nurse specialist, thought men were more likely to discuss their bowel issues. This was noted by two other nurse specialists.

The degree of bother which patients attributed to individual symptoms was often not as a result of the symptom itself, but its impact on their ability to participant and experience their day to day life. Two HCPs, a nurse specialist and a consultant surgeon discussed incomplete emptying as bothersome due to it necessitating prolonged periods of the day being totally devoting and based around toileting. Another doctor reported flatulence as the most bothersome due to the associated embarrassment and shame.

Summary

As illustrated by participants, the degree of bother which patients attribute to different symptoms is varied and often individual to the person. Also noted was that the degree of bother experienced was usually resultant of how much it impacted the daily lives of those affected. For patients, frequency was generally seen as the most bothersome issue and for others, urgency and incomplete evacuation. Discussion of this issue also led to the identification of another closely linked issue, the physical effect of bowel symptoms, which is discussed in the following section.

5.5 The Physical Response to Bowel Symptom Experience

During interviews with both patient and HCP participant, another sub-category which emerged was the physical responses which the experience of bowel symptoms elicited for patients. This included impaired skin integrity, sleep disturbance and fatigue and finally altered fluid and food intake. This was not something which the researcher had expected to emerge so clearly from the data, and again served to highlight the profound impact which bowel symptoms may have upon the lives of those effected and illustrated their new lives as “the price to pay” (HCP2) for the treatment of their rectal cancer. The findings within this sub-category will now be presented.

Impaired Skin Integrity

Perhaps the most significant physical effect of bowel symptoms to emerge from the interviews with patient participants was that of impaired skin integrity. This describes the breakdown and irritation of skin of the perianal area. Some patients were so adversely affected it resulted in bleeding and pain. Patients described severe excoriation and perianal discomfort resultant of frequency, loose stool and consistent use of toilet paper. Participants outlined some of the causes but also the impact of this issue. One of the most notable elements was the degree to which it was underestimated by healthcare professionals, of those interviewed (n=10), only one identified this as a significant issue. Whereas all patient participants discussed this as a significant issue they faced as a result of altered bowel function following treatment for rectal cancer.

Participants described the extent of impaired skin integrity due to bowel dysfunction. One patient describes in graphic detail the severity of his impaired skin integrity in the following quotes: so much so that he enlisted the help of his spouse to assess the area:

> *“my whole anus was inflamed, it was burning, the skin was cracked and cut …. I had my wife take a photo one day….. and it was just oozing blood.” (P1)*

Furthermore, the same patient described how this impaired skin integrity was resultant of faecal frequency and was so severe it manifested as cut skin and perianal tenderness. Two other patients also reported having experienced perianal skin irritation and soreness. This issue of impaired skin integrity and its causes were echoed in an interview with one HCP who described skin irritation as a result of faecal frequency, consistency and use of toilet paper:

"Well patients are using toilet paper and they are excoriated. Faeces on the skin will burn in a minute, they don't have any time to leave it on the skin." (HCP5)

When healthcare professionals discussed the impact of bowel symptoms, one nurse specialist identified impaired skin integrity as a prominent issue, perhaps influenced by the nature of her role working closely with this cohort of affected patients. As outlined by the above section, perianal skin irritation was a problem noted frequently amongst the patients interviewed but amongst the healthcare professional group the majority viewed it as *"not a common problem",* as voiced by one CNS or non-existent problem, highlighting again the potential underestimation of its occurrence:

"Most of these patients will have a formed stool so it's not like it's a small bowel…output, which would be more likely to cause a perineal skin irritation." (HCP 9)

Summary

For patients affected, perianal skin irritation became so problematic that it resulted in infection, pain and bleeding from the area. As acknowledged by the literature, many patients who receive neo-adjuvant chemoradiation for rectal cancer will already experience impaired skin integrity, a painful and uncomfortable symptom response which can then be further compounded by the issues of faecal urgency, frequency and incontinence experienced due to surgery. This significant issue was often underestimated by clinicians, therefore potentially limiting its recognition and treatment. Skin irritation was often as a result of faecal urgency, closely linked with disturbance of sleep, which the following section shall outline.

Sleep Disturbance and Fatigue

The impact of bowel dysfunction upon the sleep quality was another physical impact of bowel symptoms which emerged during discussion with patients. Both healthcare professional and patient participants described broken sleep due to faecal frequency and urgency and the resultant fatigue experienced by patients.

For some participants this issue emerged when discussing the use of Loperamide. This patient described the broken sleep he had experienced due to the need to defecate during the night and how Loperamide use had been commenced to prevent this, *"so that it doesn't affect me at night so I don't wake up" (P1).*

Both healthcare professional participants and patients outlined the impact of bowel symptoms upon sleep including the frequency of waking, with one discussing the occurrence of broken sleep occurring "*Oh yeah twice a night" (P1)* and another outlining his experience of being prescribed sleeping tablets by his GP *"Because I wasn't sleeping great" (P2)* due to nocturnal faecal frequency.

This finding was echoed during discussions with healthcare professionals who outlined broken sleep amongst this cohort of patients due to faecal frequency and urgency and the associated anxiety.

For participants, the impact of bowel dysfunction transcended the physical response, and impacted their personal lives. One man described leaving the bed which he shared with his wife so as not to disturb his family by using the toilet facilities at night when they slept. Affected by late night frequency which woke him from sleep, he outlines his symptom-imposed sleep disturbance and social withdrawal:

> *"when I go to bed I normally try, and if I'm unlucky enough and I get a later in the evening I would take myself away from the rest of the family and would sleep downstairs. And that means I'm not waking everyone up" (P4)*

The impact of sleep disturbance and continued bowel dysfunction was outlined by participants. The associated fatigue and exhaustion were an issue which both HCPs and patients discussed. One woman reported weakness following the occurrence of faecal frequency and one gentleman stating the same symptom, *"it just wore you out"*. The continuous and notable impact is outlined by the following patient quotes, with one patient so markedly physically affected, that the journey from toilet to place of sleep was traversed by crawling:

> *"I may need to go 5 or 6 times (overnight). But I'll crawl back to the settee and fall back asleep" (P3)*

This participant's experience illustrates the extent of exhaustion and fatigued experienced as a result of altered bowel function.

Summary

Perhaps not an immediately evident impact of bowel symptoms, but an obviously prominent physical effect of bowel dysfunction was its impact upon sleep and resultant fatigue. Participants described their exhaustion, separation from their family at night and the broken nature of sleep associated with nocturnal frequency and urgency. For patients this issue often led to fatigue, further compounded by altered dietary and fluid intake, as outlined in the following section. Whilst individual patients modified their diet to manage their symptoms it is also important to highlight the negative impact of inadequate dietary modification upon patients' function.

Altered Food and Fluid Intake

A change to dietary and fluid intake was a physical impact discussed by participants. For the majority of patients (n=4) the development of bowel dysfunction following surgery for rectal cancer often necessitated changes to dietary habits and fluid consumption. This finding was echoed in the perspective of healthcare professional participants. Increased bowel sensitivity meant that, for many patients, certain food types were avoided or restricted and that timing of oral intake was often adjusted. Participants discussed a range of dietary practices, from those endorsed by healthcare professionals such as low residue low fibre, to more harmful practices such as fasting and skipping meals.

The physical impact of bowel symptoms also meant for some participants the development of dehydration. The following section describes the experience of one patient relating to increased bowel sensitivity and its impact upon diet:

> *"I used to be that I could eat all things, but since the surgery I've found that it's gone really, really sensitive" (P1)*

This quote also serves to highlight the impact of SSS upon changing the participant's bowel function. For other patients the challenges of newfound bowel sensitivity meant new dietary intakes and often the avoidance of certain foods. This sensitivity is illustrated by the following quote in which one participant described the food she can and cannot tolerate:

> *"I eat an awful lot of potatoes and cauliflower. Turnips I won't touch them. Carrots, very little. Peas very little. Brown bread no no…. I would risk oranges the odd time. But any other fruit peaches, plums, pears...out of the question" (P3)*

This same patient also described how the symptoms resultant of intake of certain foods, pears in particular, resulted in frequency of bowel motions and in turn dehydration.

The avoidance of certain foods was also described by one participant and how this impacted on their meals in comparison to those consumed by family members. Therein highlighting the potentially isolating impact of new bowel dysfunction and having to adopt a different diet to that of family or peers:

> *“Even eating at home. Whatever everyone else is having I may have to have something which would be bland” (P2)*

The need to alter timing of food and fluid consumption was also voiced by a number of participants both HCPs and patients alike. For a number of participants self-imposed fasting prior to travel or social events was practiced, potentially allowing for increased risk of malnutrition and dehydration. Another patient went so far as to *“starve”* herself in an attempt to manage bowel symptoms. The following quote highlights this practice:

> *“If they are coming in for the outpatient appointment they might say “look I just had a cup of tea this morning” or “I didn’t chance eating anything”, or “I had a cup of tea and a slice of toast” rather than having a big heavy meal” HCP 3*

One continence nurse specialist outlined her concern relating to this practice and its potentially adverse effects:

> *“So, people will say “oh if I’m going out, if I have a morning meeting I won’t have a breakfast” and then “when the meeting is over I’ll go and eat something”. Because straight away you think you know this is a really bad habit, they need to get their nutrition.” (HCP5)*

Patients also cited that avoidance of food types often led to recognition by others that they had adopted different diets. One participant described her experience at a family wedding when her inability to eat certain foods was noted by other guests at the table:

> *“I just wanted beef and a spud. I can’t eat lettuce either for instance, I can eat tomatoes but then everyone is looking at you and asking “oh are you not? Would you be sick.” (P3)*

Adoption of certain diets was also carried out to effect a change in bowel motions, an often-effective symptom management strategy, including tailored fibre intake or avoidance of problematic foods. However, participants expressed concern in relation to potentially unhealthy dietary practices and their potential to negatively impact upon patient health:

*"also people cutting out certain foods or adopting an unhealthy diet. Like kind of a fatty diet cos they find that like *sic*, it kind of like bulk up or whatever and it's probably not the best…")(HCP1*

For many patients, the ingestion of certain foods or fluid intake was closely associated with the occurrence of bowel dysfunction.

Of note, some patients avoided high fibre foods, a food group known to aid in the prevention of colorectal neoplasms, as discussed in Chapter 1. This potentially problematic response is outlined by these participants:

"a low residue, low fibre diet to try and more constipate themselves" (HCP 6)

"and lots of patients would say that they avoid certain foods, so people report that they avoid high fibre foods or caffeine like coffee and caffeinated drinks as they find that they increase their bowel symptoms like loose bowel motions and urgency to go to the toilet" (HCP 1)

However, of note, a number of participants cited a worrying practice of complete food avoidance and fluid restriction in an attempt to alleviate or prevent symptoms, thereby placing themselves at increased risk of inadequate nutrition or dehydration:

"they'll try and maybe reduce their diet if they're going somewhere" (HCP2)

“Nothing to drink until I was nearly at my destination because I find that if you drink, immediately after you eat that is a big problem” (P3)

For one participant the ingestion of a pear resulted in significant frequency and loose stool, leading to dehydration. Experiences such as these resulted in the same individual adopted an almost complete cessation of dietary intake which had a marked impact upon her well-being:

“…eating desert and all those things. And it was only I realised I couldn’t hold it down, hold it in. Then I was getting really anxious that I couldn’t go anywhere. I thought that I had to starve myself.” (P3)

Another response to bowel symptoms relating to dietary intake was highlighted by one participant, who described his struggle as a diabetic in choosing foods which improved his bowel function without negatively impacting upon his diet-controlled blood sugar management. This patient discussed the challenges presented by trying to manage both these issues with little formal dietary advice, thereby often resulting in management of neither issue, having marked impacts upon him quality of life and potential future health.

Summary

The potential physical impact of bowel symptoms was seen by the impaired fluid intake and food restriction which patients sometimes felt forced to make in an attempt to alleviate symptoms. Participants described the dehydration, the increased risk of malnutrition and an inability to consume foods as they had done before their surgeries. The foods closely linked to the prevention of bowel cancer were avoided due to their significant negative impact on bowel function. This further outlined the marked impact which bowel dysfunction following SSS can have upon affected individuals. Some participants described pain resultant of consumption of certain foods and also pain associated with imminent bowel motions or lack thereof, which the following section will present.

Pain

Another physical impact of bowel symptom experience, which emerged from the data, was that the experience of pain relating to bowel function or lack thereof. Participants described the crampy abdominal pain experienced prior to defecation. For others it was failure to have a bowel motion which resulted in much discomfort.

During an interview, the pain associated with constipation was described by one healthcare professional, who noted this sometimes contributed to hospital readmission. This was seen to occur even in the period beyond the initial post-operative stage:

> *"Patients are saying that they find it very difficult to go and it's causing them discomfort and pain and they have readmissions to hospital due to this problem." (HCP1)*

For other patients the experience of pain was seen as a warning or precursor to problematic defecation including urgency. This experience was so distressing to one individual he likens it to the experience of gout or childbirth:

> *"It may give you a warning it's on the way. The warning it gives you is a stomach cramp. I'm not a female. Obviously never had a baby but I have had gout as a man and*

it’s not too far off the gout pain…. it’s severe and really sharp and now its short but it lets you know it’s on the way.” (P2)

The pain experienced by those affected resulted not just in the unpleasant sensation but also knock-on effects including lethargy, a topic already emergent from the data. The impact of this pain was further described by one participant who voiced the resultant fatigue experienced due to pain:

“And then I would get pain and cramps, and I would take painkillers It just wore you out” (P1)

Summary

What became apparent throughout the analysis of data was the link between bowel dysfunction and pain. Many of the healthcare professionals acknowledged the possible experience of pain due to altered bowel function but it was the patients who described best its severity and impact. Already faced with the diagnosis of cancer, it’s often gruelling treatment and recovery, those affected then struggle with life altering bowel symptoms, only to experience associated pain. For some this occurred as a result of sudden bowel motions without much warning or for others signified failure to defecate.

Conclusion

The physical impacts of bowel symptoms were varied and often significant. All patient participants described the effect of bowel dysfunction upon skin integrity and also discussed the altered fluid and food intake which they experienced in attempting to alleviate symptoms. For others pain was problematic as was the often-interlinked fatigue. These along with the experience of the bowel symptoms themselves meant that for many their lives were very different than prior to their surgical resection. The shame embarrassment, frustration and anxiety which occurred as a result of these physical responses became apparent, something which the next section and category acknowledges and illustrates.

5.6 The Psychological and Social Response to Bowel Symptom Experience

Patients interviewed highlighted the impact which symptoms had upon their psychological health. Bowel symptom experience impacted upon confidence, personal relationships, ability to participant in gainful employment and also to participate in certain social aspects including meals out, sporting events, weddings and even sharing a bed with their partner. These findings were echoed in the interviews conducted with those involved in their care. For those affected, the degree to which they were impacted varied from mild frustration to anxiety requiring pharmacological intervention. The following section discusses the pre-determined category of the psychological and social impact of bowel symptoms. The sub-categories which emerged included psychological impact, social impact, impact upon relationships and the impact upon financial well-being and employment. The following section describes the plethora of psychological effects of bowel dysfunction upon patients following sphincter-sparing surgery.

Psychological Impact of Bowel Symptom Experience

All participants interviewed described some degree of psychological impact attributable to bowel symptom experience. Whilst the severity and manifestation of this impact varied, it was discussed by all patients and noted by all healthcare professionals. Psychologically, the ways in which patients respond to continued bowel symptoms ranged from frustration, anxiety and withdrawal.

Interestingly, both healthcare and patient participants discussed the existence of mind-gut or brain-bowel connection. Participants discussed the close link between psychological well-being, its impact upon bowel symptoms and vice versa. This feedback process was illustrated by one Clinical Nurse Specialist who acknowledged that those experiencing heightening anxiety in turn experienced exacerbation of their physical symptoms. Even amongst the patient participants who had not heard the term mind-gut link, an awareness of emotional well-being upon bowel symptoms was acknowledged, one patient stating:

> *"I'm convinced that that area of your stomach down around your bowel and your brain that there's a connection with your brain. There's definitely a connection….but there is a link in there somewhere, even if is it in my nervous system, I don't know where it is" (P3)*

Participants also acknowledge the potential for this link to result in a negative cycle from which the affected patient found it difficult to emerge:

> *"The more erratic the bowels become the more the symptoms can occur. The more anxious the patient is the more the symptoms. And I suppose the gut is the second brain." (HCP 2)*

> *"And as many people will say if you sort whatever is troubling their mind the physical stuff will sort themselves out…there's such a huge brain-bowel link." (HCP 5)*

Whilst many acknowledged the link between bowel and brain, one healthcare participant hypothesised that those prone to anxiety before their diagnosis were more likely to experience bowel symptoms:

> *"Patients I would find that are more symptomatic I find are the ones are more anxious (sic), are the ones that suffer from a degree of anxiety anyway. If you are of a more anxious nature you are probably going to find this more problematic…. I think if you are anxious by nature, I think this is going to further aggravate your problem. I don't think it's just that, that anxious people are the only ones that suffer but I do think they are going to suffer more than the average person" (HCP 3)*

The researcher found this to be an interesting view but also one with the potential to contribute to the possible dismissal or disregard of the severity or perhaps true cause of bowel dysfunction. Whilst acknowledging that the impact of psychological distress upon the digestive system is a known phenomenon, the degree to which it was deemed as responsible for bowel dysfunction in these of patients was one which should be considered with caution.

The significant distress and frustration experienced by patients permeated much of their life, particularly in the initial months following surgery, during which they struggled to cope with or manage their bowel dysfunction. For some this meant the development of uncharacteristic responses to stress or the development of anxiety as illustrated by these participants:

> *“Yeah, I got very irritable, very short fuse and would normally I would handle things very well…. I went to me doctor and she put me on some medication for anxiety, not anxiety but I suppose it was a short-term thing to calm me down. Because I wasn’t sleeping great” (P1)*

Other participants voiced embarrassment and anxiety experienced as a result of their bowel dysfunction. For others, the desire to return to their pre-operative selves, or to return to normal life and function, was tangible. Those affected longed for a life not ruled by their bowel function and felt this so acutely they expressed a desire for a cure but felt it did not exist. Expressed eloquently by both patients and a healthcare participant, acknowledging bowel dysfunction as a burden to shoulder in payment for treatment of their cancer:

> *“I suppose not their life as they were living before they got diagnosed with this cancer. And I suppose maybe feeling a certain resentment, you know from the from the surgery, not that there was ever a hesitancy to have the surgery but it’s just a very big price to pay” (HCP2)*

> *“I always hoped that there would be a miracle intervention drug, and someone would “say here you go, try this, this will guarantee that you go in one motion, everyday like a normal person does” (P3)*

Furthermore, one participant stated; *“My life had to change” (P3),* as a result of his experience of bowel dysfunction.

For others, symptoms such as urgency and frequency meant fear of associated faecal incontinence, especially when away from home or within company. The fear meant many withdrew socially, in turn becoming a “prisoner” to their symptoms. This fear of incontinence was described by one participant:

> *“The psychological component, if it gets in on you and it can get in on you very, very easily you will become a prisoner and you won’t go out because you’re afraid to go out in case you soil yourself or soil somewhere else” (P4)*

Moreover, the fear associated with potential faecal incontinence was outlined by one participant stating, “*there is a fear, not a blind fear but that I’m going to soil myself here” (P3)*, again illustrating the far-reaching impact of bowel symptoms not just upon physical wellbeing but the psychological health of those affected**.**

Healthcare professional participants caring for these affected patients described their perspectives of patient symptom experience and the psychological effects, acknowledging the frustration and low mood resultant of continued bowel problem. When describing working with these patients, a continence nurse specialist discussed the marked psychological impact of bowel symptoms, associated anxiety and how difficult it was following on from the already challenging road of cancer diagnosis and treatment to being thrust into the role of managing for themselves:

> *“they (patients) are already traumatised because they have had a cancer diagnosis and they have been through hell and they now feel that they are coming to the end of a very long road. They are bit at this stage that they are feeling a little bit let loose cos they were so cossetted through treatment and they say they have this problem” (HCP 5)*

For many patients faced with this issue, the expectation that reversal of their stoma or resection of their cancer would be the end to their issues was prevalent but when the realities of altered bowel function persisted beyond the initial post-operative phase this often led to frustration, anxiety and at times anger. This was experienced by patient participants and often witnessed by the HCPs involved in their care. For some, symptoms resulted in anger and frustration, *"Era yeah it pissed me off sometimes" (P5)*, amongst others, HCPs identified the potential for symptoms to result in, "(…) *anxiety and maybe low mood and a loss of confidence" (HCP2).*

This observation was made by other HCPs, a nurse manager and colorectal nurse specialist, and highlighted the effect of unmanaged symptoms, especially over a prolonged period of time, and the potential for this to be seen as untreatable by patients:

> *"they can feel exasperated because it is not settling, it's the return to clinic and trying different thing and exasperation is something that we see quite frequently" (HCP2)*
>
> *"Very stressful filled with anxiety, thinking it's never going to end" (HCP10)*

For many, the unknown duration of symptoms and often the lack of clarity relating to potential symptoms proved problematic and impacted upon their daily lives. Furthermore, many described the anxiety and low mood which they attributed to their physical symptoms. For those affected, embarrassment in relation to discussing this issue was recognised. Reluctance to do so potentially contributed to under-diagnosis and delay in intervention:

> *“For male patients especially in Ireland, especially the older population, they might find it embarrassing and they wouldn’t’ want to talk about it and unless its brought up in the right environment” (HCP 6)*

> *“It’s definitely not something that’s broached enough and not something that patients volunteer. Because its busy and the focus is on the cancer more so.” (HCP6)*

The fear of recurrence was an issue which understandably emerged following interviews with participants. For patients the changes in bowel habit experiences preceding cancer diagnosis were mimicked by the bowel symptoms which occurred as a result of treatment.

One participant outlined this issue which occurred to him, following a prolonged duration of faecal urgency, which he related back to a previous discussion with his physician:

> *“And in the back of your mind to, “is it going to come back?” and as Dr ******* said “we don’t know what has been going on in your body previous to this and it could have some from somewhere else and go somewhere else and mask itself in another part of your body” and he said it goes into your lymph nodes and then it spread to….I think two or three lymph nodes were removed and I suppose you would be thinking about that too.”(P1)*

For this patient too, the occurrence of mild pain had also evoked thoughts and fear relating to the recurrence of cancer. Whilst awaiting an MRI this man recounted his apprehension and anxiety relating to what they, the healthcare providers, might find. For patients experiencing bowel dysfunction, it is another issue and pressure placed upon the plethora of existing worries lived by those following diagnosis and treatment of cancer.

This was articulated by another gentleman describing his fear of metastases:

"And when your survival instinct sticks in … you're worried it's (cancer) gonna peak through somewhere and go somewhere else" (P3)

This again illustrates the significant worry and distress experienced due to bowel symptoms, so much so that patients relate its occurrence to the potential return of their cancer.

The understandable and rational fear of recurrence experienced by patient following treatment for cancer is often elevated and exacerbated by the occurrence of bowel dysfunction post sphincter-sparing surgery. Symptoms such as frequency and urgency imitate the bowel symptoms which initially indicated to patients that they had colorectal cancer. This again highlights the importance of providing patients with the information around the occurrence of post-operative bowel symptoms and general education around this topic. The occurrence of such fear, anxiety and the existence of bowel dysfunction often so markedly affected patients it resulted in their withdrawal from or alterations to their employment. An issue which the following section will explore.

In addition to the individual's mood and well-being, the development of symptoms also impacted upon social and personal relationships, as outlined by the following section.

Effect of Bowel Dysfunction on Relationships

The impact of bowel dysfunction upon personal relationships manifested itself within this cohort of patients in a myriad of ways. From altered body image, changes in sexual activity, the movement of relationship from partner to carer. Participants outlined the effect which symptoms potentially had not only upon the affected individual but also their partner. One healthcare professional illustrated this impact in a general sense:

> *"I think certainly from talking to them (the patients) the impression you get is that It can affect their marriage their relationships with their wives, their husbands." (HCP 2)*

For others affected their bowel dysfunction meant that the social withdrawal they resorted to often impact upon the social lives of their spouse. This was discussed by a number of HCPs but most vividly captured when described by one affected gentleman and echoed by one Clinical Nurse Specialist:

> *"So, I just got sick of it and I didn't want to go anywhere, and it wasn't fair on (wife's name), cos she loves to go places" (P1)*

This impact was recognised by one Clinical Nurse Specialist who outlined her experience of speaking with the spouses of those effected by bowel dysfunction:

> *"And what the wife or the husband might say is that "it's really impacting on our lives, we can't meet our friends, we can't go on our holidays. We were due to go to this gig and something happened. You know the bowels went all erratic again and my husband refused to leave the house. Or you know this kind of business or often they'll get so fed up, they won't leave the house, they won't go out with friends, they'll change their plans to suit the new lifestyle them seem to be experiencing so yeah" (HCP 2)*

The extent of this impact was noted by one HCP to be a contributing factor to relationship breakdown, stating *"marriage breakdown, family breakdown"* (HCP5) sometimes occurs as a consequence of untreated bowel dysfunction, something which the researcher had not expected to be so evident. Another point which emerged was the altered body image which emerged resultant of bowel dysfunction which markedly impacted upon sexuality. The following quote illustrate the far-reaching influence of bowel dysfunction upon relationship, with one man describing his own withdrawal from the bed which he shared with his partner and from the floor on which his family slept:

> *"Some patient I suppose because here body image changes….. then obviously sexuality if they are married or have a partner" (HCP 8)*

> *"and I get a later in the evening I would take myself away from the rest of the family and would sleep downstairs. And that means I'm not waking everyone up" (P3)*

One participant discussed living alone as a beneficial situation, preventing others from witnessing or dealing with his incontinence. This, to the researcher, highlighted again the problem of social isolation. That in an attempt to prevent embarrassment avoidance of others was seen as an acceptable strategy. The first quote illustrates this gentleman's experience and the next the recognised social impact as outlined by HCPs:

> *"I did have a few problems but luckily I live alone and I was able to clean up my own mess. There was no one that would've felt obliged to clean up my mess. I try to look after myself as independently as possible even though I have a sister and a sister in law who are very good" (P2)*
> *"But most of them just become very withdrawn. Don't make plans. Don't make themselves got out or put themselves in a situation where they will be caught out." (HCP 4)*

For affected patients, the experience of bowel dysfunction meant associated embarrassment and shame, especially when this occurred in front of family or friends. For others the experience of a cancer diagnosis and the resultant symptoms proved to isolate and alienate as described by one nurse specialist:

> *"And some of them can get quite upset if something happened whilst their family was there. Either that they had an accident while their family was there and they can be upset about that, just coming to terms with anybody after anything after surgery…. And if this is for cancer and they have had treatment prior to, or they will have chemotherapy and what's going to happen, and it can be quite an alienating experience for them." (HCP 8)*

In relation to qualifying the degree to which patients are psychologically affected by their bowel dysfunction, one HCP working closely with this cohort of patients, as a continence specialist, discussed use of a validated quality of life assessment tool relating to impaired continence and outlines the depth of distress experienced by these patients:

> *"…. often use the continence QOL scale, the smiley faces. And invariably they are a 5, they are totally miserable when they get to me." (HCP5)*

Summary

Those who experience bowel dysfunction following sphincter-sparing surgery are not only faced with life altering physical symptoms but far-reaching psychological issues. Varying degrees of impact were noted from mild to severe. For patients and those involved in their care the associated shame, embarrassment and frustration often resulted in the development of anxiety and withdrawal. This symptom-imposed withdrawal often saw the social aspect of patients' lives severely affected, which the following section outlines.

Social Impact of Bowel Symptoms

For many, these unrelenting symptoms resulted in a withdrawal from socialising and affected their ability to participate in activities with both family and friends. Again, the experience of bowel symptoms transcended the physical and extended to the social. Already faced with the gruelling nature of cancer treatment and often it's effect on social life, patients were now presented with negative effects following treatment completion. The following section describes the resultant social effects of bowel dysfunction. These effects varied from reluctance to attend unfamiliar areas to complete social isolation. For patients, especially in the immediate period following sphincter-sparing surgery, or before the introduction of any symptom management strategies, the experience of bowel dysfunction meant symptom-imposed house arrest. These individuals were so significantly affected they felt unable to leave familiar home surroundings, as illustrated by the perspectives of nurses closely involved in caring for these patients:

> *"A lady said to me recently that she felt she was unable to leave the house, that she doesn't really go out anymore because she's very conscious that people would be, would notice she's going to the toilet a lot more." (HCP 1)*
>
> *"they become very withdrawn, not leaving the house until they know that their bowel is clear." (HCP 4)*

For others, the concept of leaving home was associated with anxiety, frustration and fear, relating to the potential occurrence of bowel dysfunction, thus impacting upon their confidence to leave their homes:

"So, I just got sick of it and I didn't want to go anywhere" (P1)

"Then I was getting really anxious that I couldn't go anywhere." (P2)

For others specific social events provoked fear or a reluctance to attend, especially events in which patients were eating in front of others. One participant described her experience of attending a family wedding and the scrutiny with which other guests brought her under relating to meal choices:

> *"And you go to a wedding and you say you know I can't eat this I can't eat that, and they ask, "would you be sick?" and you just say yeah. Because you can't tell them it's the other thing {diarrhoea}" (P2)*

This patient was so impacted by bowel dysfunction she admitted to missing a number of family weddings and events at which there would be a crowd. Furthermore, she described a complete withdrawal from attending her weekly mass.

The concept of missing out on events was not an isolated one, for others this meant avoidance of social events such as matches or concerts. For another participant, attendance at a sporting event was marred and then cancelled due to the sudden occurrence of urgency. The following quote describes his withdrawal from a sporting event he intended to join with friends:

> *"… at one particular occasion 4 of us had left the house to go to a sporting event and I had walked 100 metres and I needed to use the toilet. So, I just said to the boys take my ticket, give it to someone along the way I can't do it." (P3)*

This incident illustrates the impact of unpredictable bowel function upon affected individuals' ability to participate not only in unplanned but planned outings with those around them. The issue was further illustrated by participants discussing the need to have prior knowledge of all toileting facilities before attending events and also to avoid events with crowds. One participant outlined a hypothetical situation which influenced his choice of venue and event:

> *" … if we are going to a concert I'll see where is it on? Okay there are plenty of loos there I can go there…..I would rather come down on the side of safety here. I'm not gonna *sic* chance this. I just won't. I don't think it's right. Because if we do get to the sporting venue and the back of all of our minds is, we are getting up two flights of stairs or get the escalator somewhere and the toilets blocked. What do I do then?" (P3)*

This quote serves to highlight the thought processes of patients affected by bowel dysfunction when contemplating social outings. This was in keeping with the experiences of all patient participants and was noted by many HCP participants.

For some even the home environment was not seen as a safe place for socialising. One participant described the embarrassment she experienced when friends and family visited her home. This participant was forced to regularly excuse herself to use the toilet. This event was further compounded when a young grandchild commented upon same in the company of others.

Summary

Participants faced with bowel dysfunction often experienced symptom imposed social withdrawal. Patients reported reduced ability to participate in enjoyable social activities such as sporting events, weddings, religious practice, dining out amongst others. The impact of bowel symptoms upon social life was evident and often resultant of fear, fear of incontinence in a public place, fear of the attention of others and fear of “being caught out” (P3). The emotion of fear was further linked to the anxiety of patients relating to return to employment, which the following section will discuss.

Employment and Economic Impacts of Bowel Dysfunction

For many patients throughout their treatment and initial recovery, participation in employment is paused or reduced to some extent. However, for those faced with potentially significant bowel dysfunction following SSS, return to employment is often hindered or adversely affect. This in hand with the considerable cost associated with managing bowel symptoms was noted to play a potentially problematic part in the economic well-being of participants. Discussion with both HCPs and patients revealed a number of economic issues, from feeling unable to return to work, to changing jobs, to financial pressure due to cost of products etc.

In the patient participant group the majority (n=3) had been in gainful employment at the time of their diagnosis. However, following treatment only one patient continued to work. For one patient it was a choice he made following diagnosis to forgo reduced hours or the offer of sick leave and instead take early retirement to focus upon getting better. However, for another participant, the decision to leave work was made due to her experience of bowel dysfunction. So great was her feeling of embarrassment and fear of being discovered to have continence products and the extent of her frequency, she felt incapable of returning to work at a cattle market, as illustrated by the following quote:

> *"But I couldn't because I would have to go walk back that way through a whole bunch of famers to the ladies. Because I couldn't be running in and out. And in case my bag fell over and everyone saw all the paraphernalia in their bag" (P2)*

For some affected individuals, it is the nature of work which contributes to the influence which bowel dysfunction may have. One CNS working closely with patients with incontinence issues acknowledged that many patients were forced to change their jobs completely as a result of bowel dysfunction, finding it *"too hard to manage"* (HCP5). Those travelling for work also faced significant issues in terms of coping with their bowel dysfunction, as acknowledged by a number of participants (n=3). A number of other HCP participants voiced that those working in office settings, with convenient toilet facilities would find it more feasible to return to work. However, this view was challenged by one Clinical Nurse Specialist, when describing clients' experiences of working within an office:

> *"These are people trying to go to work, these are executives trying to go to a board meeting and they are afraid they are going to be incontinent and smell the room" (HCP5)*

The view of the Clinical Nurse Specialist was shared by one patient who viewed himself as "lucky" to work alone at home for a significant portion of his day. This patient also described the challenges faced by those in certain forms of employment including in shop and office settings:

> *"I'm lucky but if you are working where you have to be standing behind a counter or working in a food shop or an office situation you are in big trouble…. but if you're in a rather large organisation and you're in a building and you are affected by this I don't know how you would cope" (P3)*

Another economic impact of bowel dysfunction was the costs of the products and medications utilised to manage bowel symptoms and their impact. For some patients use of certain medication proved costly and so too did the skin care regimes patients were forced to adhere to, in order to protect or heal their perianal skin. One participant outlined the cost of ordering a specific skin care product, with his pharmacist being unable to provide a single unit, the patient was forced to buy a box of the product at a significant cost. During this discussion, the patient acknowledged that these products often *"would cost quite a bit because when you add it all up, you have to get these pads, the creams".* The economic impact of bowel dysfunction was acknowledged as significant by one Clinical Nurse Specialist:

> *"Because it (bowel dysfunction) financially it can impact them again. Even again the amount they have to spend on products! And the amount it costs a fortune" (HCP5)*

Summary

So significant is the impact of bowel dysfunction, those affected faced alteration, amendment and sometimes complete cessation of employment. The role played by bowel dysfunction in blocking return to work was articulated by participants. So too were the challenges faced by those who chose to return to employment. Jobs which facilitated easier management of the occurrence of bowel dysfunction were difficult to identify as only one participant, who works primarily from home alone, felt able to return to employment. This again serves to highlight the significant impact of bowel dysfunction upon the lives of those affected. Furthermore, the burden of bowel dysfunction was furthered by the cost associated with its management, from medication to skin care.

Conclusion

For those experiencing bowel dysfunction following surgery, it does not just impact upon them physically but has sweeping influence upon their psychological and social well-being. Participants interviewed discussed and illustrated the impact which bowel dysfunction had upon their sense of self, their personal relationships, their emotional health, their economic and employment capabilities and also upon the ways in which they interacted with the world outside of their immediate environment. This plethora of symptoms often resulted in social withdrawal, reduced confidence, altered body image and also affected the people in their lives. Patients found themselves living a life drastically different to that previously experienced, often somewhat more limited or cautious. For many, these issues occurred not just as a result of the bowel symptoms themselves but as a result of the strategies they implemented to manage their symptoms, which the following section will discuss.

5.7 Symptom Management Strategies

The next pre-determined category explored with participants, was an examination of the management strategies implemented by both patients and HCPs in an attempt to alleviate the impact, severity and frequency of bowel symptoms. These varied from straightforward medication use and modified diet to the more unusual strategies including coffee enemas, fluid restriction and anal plugs. The main sub-categories which emerged during data analysis was use of dietary, medication, skin care, pelvic floor and alternative strategies. The most prevalent strategies utilised was the use of dietary strategies which the following section will discuss.

Dietary Strategies

The most evident and widespread symptom management strategy utilised by patients and implemented by HCPs was dietary modification. This varied from food restriction, fibre alteration, and altering timing of meals to fasting and portion control. What was evident from discussion with participants was that no structured or formal dietary advice for the management of bowel dysfunction existed and it varied from person to person and institution to institution. For some patients, diet was considered the most efficacious strategy for others a continuing process of trial and error.

Within the HCP group, altered fibre intake was viewed as a key dietary strategy, with many recommending a low-residue, low-fibre diet amongst this group of patients, especially in the initial weeks following sphincter-sparing surgery. However notably, even amongst the healthcare professional group some seemed uncertain of whether to offer patients a high or low fibre diet, with this uncertainty illustrated by the following quotes from both a nurse specialist and a colorectal registrar surgeon:

> *"you say try the high fibre they are running still I don't know that high fibre or a low fibre are working. One type of diet might work for one group of patients or might work for another patient." (HCP3)*

> *"…wouldn't have massive experience of this. But we would kind of dietary advice- low fibre, high fibre." (HCP7)*

This uncertainty was also evident amongst the patient participant group, with many highlighting the lack of clarity relating to diet often leading to exacerbation of bowel dysfunction and prolonged periods of time adopting unhelpful diets. A number of patients described their initial use of a high-fibre diet including bran, grains and seeds, in attempt to effect normal bowel motions, only to discover this markedly increased the frequency and loosened the consistency of their bowel motions. One patient describes the relief experienced upon receiving a FODMAPS (Fermentable Oligo-, Di-, Monosaccharides And Polyols) diet sheet from a dietician after ten months of significant faecal frequency and urgency:

> *"she (the dieticican) gave me a list of all the foods that would cause a reaction. Soluble and insoluble fibres. So, I had a list of the foods that I could eat and a list of the foods … that would cause a reaction, like broccoli or muesli or Weetabix or linseed. Some things with skins. So, I worked on that list that she gave me and I couldn't believe the difference. And it was the first time in 10 months that I had some relief" (P1)*

The efficacy of the FODMAPs diet was one endorsed by one Clinical Nurse Specialist who worked closely with patients experiencing low anterior resection syndrome. This diet was seen as a strategy which *"improves their stool consistency and their evacuation" (HCP4).* Other participants outlined use of gradual food introduction as a strategy to manage bowel dysfunction. With participants utilising plain, low fibre diets initially and gradually introducing other food types. For some this process proved effective, for others a protracted process requiring numerous attempts. One CNS outlined her own advice to patients experiencing bowel dysfunction post SSs:

> *"So, they would be advised about low fibre diet. So, when the stoma is reversed give them the low fibre and give them 6-8 weeks and gradually introduce one new food a day and every couple of days and see how they are reacting to that." (HCP5)*

From a patient perspective this process of gradual food introduction was fraught with adverse reactions and exacerbation of bowel symptoms. For one patient (P1) examination of his food diary brought about the realisation that even small items such as parsley within a sauce had resulted in extensive faecal frequency. So too had foods he thought would assist in his bowel function like Weetabix and linseed. Also outlined by one participant was his difficulty in balancing his blood sugar control as a diabetic, whilst attempting to introduce more fibre through introduction of more fruit into his diet (P3). Other dietary strategies highlighted by participants including calculated timing of food intake depending on their plans. For some patients when they were due to travel or attend an event, large meals or certain food types were restricted. However, concerningly, as discussed in a previous chapter, some patients voiced total elimination of oral intake in attempt to control their bowel dysfunction, with one patient stating she felt the need to *"starve myself" (P5).* This practice was also noted by a number of the healthcare professionals as a worrying strategy implemented by patients:

> *"So, people will say "oh if I'm going out, if I have a morning meeting I won't have a breakfast" and then "when the meeting is over I'll go and eat something". Because straight away you think you know this is a really bad habit, they need to get their nutrition." (HCP5)*

Some healthcare participants gave advice to patients relating to the timing of meals and their portion size. One CNS advised patients to eat lightly before travel and eat their larger meal early in the day to avoid nocturnal faecal frequency. Another HCP, a colorectal surgeon, reported patients avoiding foods known to cause frequency and urgency such as caffeine and chocolate. A number of HCPs also advised avoidance of certain food types including spices and alcohol.

The lack of a uniform, structured approach to diet was acknowledged by participants, HCPs and patient alike. From interviews with participants the recurring theme of a seeming "information minefield" (HCP5) emerged from the data. A number of participants outlined the lack of clarity and guidance given to patients in relation to diet. This, for two patients, had resulted in a number of months of severe issues with incontinence only to find symptoms almost fully alleviated upon receipt of diet sheets.

Amongst healthcare professionals it was acknowledged that the information and advice given to patients was very much influenced by the institution or team member providing this guidance, as illustrated by one Clinical Nurse Specialist:

> *"patients will always tell you, and I have sensed a bit of a minefield myself, they get such conflicting advice from everything. The dietician says one thing, the doctors say one thing, the nurse another and their friends will say "no that doesn't work"" (HCP5)*

Despite issues relating to the dietary strategies utilised, this was cited by many as the most efficacious strategy in affecting an improvement in bowel function. Three patients reported it as the strategy they felt was most effective.

Summary

The dietary strategies enlisted to manage bowel dysfunction following SSS were diverse and often individualised. Patients and healthcare professionals often initiating similar strategies. However, potentially harmful strategies such as food and fluid restriction were noted, placing patients at potential risk of malnutrition and dehydration. For many, dietary modification proved to be one of the most successful strategies, especially use of the FODMAPs diet. Whilst patients benefited from HCP initiated dietary strategies, also acknowledged was the lack of a standardised delivery and contact and at times the delayed nature in which it was provided. This meant for many patients a prolonged period of bowel dysfunction or uncertainty relating to what food products would and would not improve bowel symptoms. This lack of clarity often resulted in patients resorting to other strategies outside of diet, including medication, which will be presented in the following section.

Medication as a Symptom Management Strategy

For many affected by bowel dysfunction, medication was the first port of call and choice for both HCPs and patients. Discussion with participants illustrated a number of medication strategies including glycerine suppositories, codeine phosphate, psyllium husk but primarily the widespread use of Loperamide. From the author’s own experience of working within this setting, Loperamide was most certainly the most common medication used in the management of loose stool, frequency and urgency following sphincter-sparing surgery. Analysis of the data allowed the emergence of a number of findings around medication use. Influencing factors included patients’ willingness to use same, the education given to patients around medication management, especially relating to timing, efficacy of medication management and again the lack of a structured approach to medication to deal with this specific issue.

The participants outlined a number of medications used for the management of bowel dysfunction, with the most common definitely being Loperamide, an oral medication used to reduce diarrhoea, increase intestinal transit time, increase sphincter tone, thereby preventing symptoms such as incontinence and frequency (Regnard *et al.,* 2011). The use of this medication was often healthcare professional initiated but sometimes patient initiated. This, along with diet was seen as one of the most efficacious strategies in the management of bowel dysfunction. Reasons for choosing this medication amongst professionals included its safety, fast acting nature, and relative lack of side effects. When discussing the use of Loperamide, both healthcare professionals and patients cited the importance of timing same before food. This, for many patients contributed to its efficacy, one HCP cited lack of understanding and education around medication use had contributed to patients not utilising it correctly. Another patient outlined his routine of taking Loperamide forty minutes before meals had contributed to improvement of his faecal frequency (P1). For others, Loperamide was only used prior to travel or important events. One CNS outlined patients prophylactic use of Loperamide as a preventative strategy as opposed to a strategy utilised when experiencing bowel symptoms:

> *"… if they know they are going on a bus trip somewhere they can't stop themselves and go to a toilet somewhere then they might take Loperamide as a precautionary measure." (HCP3)*

Another CNS reported a patient using Loperamide prior to a wedding (HCP3). The issue of education and patient knowledge was again discussed by one of the Clinical Nurse Specialists around incorrect and unsafe use of codeine, for some patients within this healthcare setting, codeine was used to reduce loose stool and frequency as a short-term measure. During outpatient review, patients had reported to the CNS self-initiated use of codeine and subsequent illness due to sudden cessation of same:

> *"And I've had patient tell me I took codeine to slow down my bowel…. And I was having a lot of loose bowel motions and I ask them you know did you talk to your GP or nurse specialist? And they said no. And then they stop it abruptly and they become unwell…. we use codeine phosphate in the hospital setting to slow it down but nobody explained the rationale and this is not something we do long term and it's certainly not to be done at home." (HCP8)*

Another interesting finding which emerged from analysis of the data was the reluctance of some patients to utilise medication to manage their bowel dysfunction despite being encouraged to do so by their medical and nursing team. One woman reported reluctance to take medication in favour of a diet-controlled approach to management of her bowel dysfunction but did not provide a reason for this. The author noted patient understanding of the mechanism and use of certain medications was very limited, perhaps due to lack of information being provided by their healthcare team. One patient described this reticence and its emanating from previous long-term use of medication for mental health issues:

> *"I could take Loperamide (Loperamide), well I could take an Loperamide 3 times each day over the weekend …. maybe it's psychological …. but I would like to have enough knowledge to have the best possible outcome without being a slave to a tablet" (P2)*

Some patients voiced issues with Loperamide such as the development of constipation, which they then treated with laxatives, resulting in a see-saw effect upon patients' stool consistency and never the desired effect of "normal" stool. For other patients, application of Loperamide use included use at night, use of liquid Loperamide for easier titration and Loperamide use only for events. Many reported that use of Loperamide had provided them with increased confidence and a heightened sense of control over their symptoms.

One patient voiced use of Loperamide whilst at work as a *"crutch"* which allowed him to feel calmer. This was echoed in the view of healthcare professionals. Another patient described his view of Loperamide as a strategy allowing him the opportunity to leave his home and carry out daily activities:

> *"Imodium, I think it's a great tablet and if you are going out for the day and you feel it and you can just take one. And you could go for hours and hours and then come home and you go to the toilet." (P3)*

Another medication strategy voiced by participants included the use of mini-irrigation enemas and glycerine suppository use. This was used as a strategy, implemented by healthcare professionals, in patients experiencing incomplete defecation and resultant tenesmus. This allowed patients to have a bowel motion in one sitting as opposed to prolonged periods of small ineffectual bowel motions. It's application and efficacy were discussed by two Clinical Nurse Specialists, the healthcare professionals who worked most closely with the cohort of patients experiencing anterior resection syndrome. The use of irrigation systems, the instillation of sterile water into the anus and rectum via a medical device, was noted by HCPs to be an extremely effective but invasive strategy used in the management of bowel dysfunction. This strategy was cited by one patient as an approach he had utilised effectively but ceased due to its invasive and inconvenient nature:

> *"but it wasn't for me, but I said listen girls I can't be bringing this around with me I feel like a plumber." (P2)*

One patient also discussed the prescribing of Fybrogel by one HCP in attempt to bulk his stool, only to find it hugely exacerbated his faecal frequency and diarrhoea. This again highlights the potential mismanagement of bowel dysfunction post-SSS due to poor understanding by HCPs.

Psyllium husk was another supplement which a number of HCPs acknowledged as a potentially helpful and is well documented as having a role in the management of bowel dysfunction amongst this group of patients. However, none of the patient participants had ever received information in relation to Psyllium Husk despite the interviewed HCPs having treated all of the interviewed patients. The use of laxatives by patient affected with constipation was also noted by a number of healthcare professionals.

Finally, the anxiety relating to bowel dysfunction, was another resultant symptom which for two patients had required the commencement of anti- anxiolytic medication Alprazolam (Xanax). One patient described visiting his GP to discuss the anxiety he experienced due to faecal frequency and being prescribed Xanax to aid with sleep. Another gentleman gave detailed insight into his use of Xanax resulting in decreased anxiety and thereby decreased bowel motions, again purporting the concept of the bowel-brain link:

> *"I would always keep at home a Xanax or two. Because I find that if I'm gonna going out and I'm going into a large crowd. And if I'm any way unsure, I take one of them which it calms me down. And once I'm calm and it (the bowel dysfunction) goes out of me head, I move around for a while because I'm not thinking about it (the bowel*

dysfunction). And I haven't thought about it in a few hours. But if I go in cold sober, nothing going on and I get tense thinking and if I get a cramp, I'm like "oh no" (P2)

Summary

The medication management strategies utilised to reduce, prevent or decrease the impact of bowel dysfunction varied from attempts to change stool consistency, reduce diarrhoea, alleviate incomplete emptying to reduce the associated anxiety. Loperamide was evidently the most common medication used to alleviate bowel dysfunction. Both patients and healthcare professionals displayed differing degrees of knowledge around medication use. Some patients expressed reluctance to use medication emanating from past experience or at times apparent lack of understanding. Again, evident was a lack of a structured approach or algorithmic structure to medically manage bowel dysfunction. This at times lead the prolonged failure to treat altered bowel function and in turn potentially leading to the necessity of treating the associated anxiety with medication. Patients use of medication was often noted to be not "as prescribed", especially when relating to codeine and failure to currently time Loperamide, again highlighting the need to provide patients with education and information around medication and current failures. The failure to treat bowel dysfunction with medication often resulted in skin issues such as excoriation and tenderness, the strategies to manage same will now be discussed in the following section.

Skincare Strategies

For patients, the bowel dysfunction they experienced often led to impaired skin integrity of their perianal area. This varied in degrees of severity, from mild discomfort to ulceration and bleeding. Many patients did not disclose this to their healthcare professionals, and healthcare professionals were often unaware of this issue, thereby resulting in its mismanagement and underdiagnosis. Many adopted their own strategies to cope with this issue and some healthcare professionals provided affected individuals with guidance and product information to protect and prevent skin irritation. Strategies varied from Sudocream application and barrier spray to showering following bowel motions or use of toilet wipes to use of incontinence wear or self-made pads. The following section describes some of the strategies utilised by participants.

All patient participants interviewed by the author described some extent of impaired skin integrity as a result of their bowel dysfunction. However, only four of the healthcare professional participants listed skin integrity as a physical issue occurring due to bowel dysfunction. Therefore, of the skincare strategies noted amongst HCPs, it was in interviews with two Clinical Nurse Specialists which revealed the most, perhaps as both of these CNSs worked very closely with patients experiencing bowel dysfunction and resultant affected continence. The most common strategy noted was the use of skin creams such as Sudocream, Vaseline and Bepanthen. Many patients utilised these to treat developed skin integrity as opposed to preventing it. One patient described the use of Bepanthen as a strategy emanating not from HCP advice but of his own experience as a father in treating the nappy rash of his children. Two patients utilised Sudocream to treat excoriation and found it to have moderate efficacy, one stating it "*helps but sometimes not"*.

TENA Wash was a wash cream utilised by patients and endorsed by healthcare professionals, which acted both to cleanse and protect their perianal skin and thereby prevent incontinence associated dermatitis. Participants noted the overuse of toilet paper by patients only resulted in further excoriated and irritation of skin.

Other strategies utilised included use of toilet wipes to cleanse the area following defecation. One Continence specialist outlined this strategy, including use of wipes infused with aloe vera to reduce irritation, dryness and inflammation and also described the process of utilising same:

> *"actual toilet wipes, not baby wipes, they would have aloe vera or camomile, and they are flushable. So they should wipe with that and let it air dry." (HCP5)*

However, one female patient reported that continued use of toilet wipes had resulted in fungal infections. She then returned to showering following toilet use as a skincare strategy, a time-consuming affair that impacted upon her daily life.

Other healthcare professionals cited use of barrier sprays as effective and economical strategies to prevent skin breakdown. The author noted that none of the patients interviewed were aware of barrier creams such as Cavilon or Askina despite their efficacy and awareness of same by healthcare professionals treating them.

Participants utilised incontinence pads too, but some fashioned their own from toilet paper or placed pads upon pads, which one HCP noted as further negatively impacting upon their skin integrity:

"And it's the skin, you explain that the skin can't breathe, and it is (use of double pads and toilet paper) false economy." (HCP5)

Of the patients interviewed, four described use of pads at some point of their post-operative journey, with two patients continuing to utilise same. Three participants described their own creation of continence care pack, which they had developed. These consisted of pads, wipes, bags and sometimes fresh underpants. One patient brought this pack and showed the author the contents.

Other patients utilised post-defecatory showering as a means of cleansing their skin, so as to avoid continued use of toilet paper and its negative effect upon skin integrity. The frustration relating to this time-consuming method of cleansing was voiced by one patient, the continuous nature of her frequency meant she *"was continually in the shower or bath".* This same patient also wore cotton underwear as a means of preventing irritation and stated she had always brought a spare pair of underwear and pads. This was something noted by all of the patient participants and noted by a number of the healthcare professionals, i.e the pre-preparation of skin and continence "packs" which they brought whenever they left the house. Two patients had brought these packs to the interview venue and showed them to the author. Both consistent of toilet wipes, incontinence pads, skin care cream and toilet bags. These patients reported that bringing this kit was a strategy which they incorporated into their everyday lives, to give them confidence to leave their homes or familiar environments. Discussion around this subject contributed to the emergence of the theme of ”living a new normal” from the data, with patients describing the new ways of living which they had to adopt in order to cope with their bowel symptoms.

Further strategies which healthcare professionals gave to patients included use of talcum powder and patting the perianal area dry with a soft clean towel. One of the more unusual strategies to prevent skin irritation which two health care professionals had noted, was the use of anal plugs. Whilst a number of appliances designed for passive leakage exist, these healthcare professionals reported anal plugs had been fashioned by patient themselves or sometimes tampons were utilised as a means to manage this issue. Again, pointing to the potential for adverse strategies to be implemented where formal and evidence-based interventions are not implemented.

Summary

The strategies used by patients to manage impaired skin integrity were diverse, innovative and at times, of an adverse nature. Patients adopted a number of strategies which they had garnered from their times as parents, learned as a result of necessity, been informed of by healthcare professionals or resorted to due to desperation. Skin care creams were the most common skin care utilised but often sub-optimal or failed to prevent skin irritation. Only one patient had utilised the barrier cream wash Tena whilst the other utilised creams to react to as opposed to prevent incontinence associated dermatitis and skin irritation. This meant for some patients with such poor skin integrity, their perianal area became cracked and bled. The lack of information provided to patients by healthcare professionals was evident and potentially impacted by lack of awareness amongst healthcare professionals of this issue.

Pelvic Floor Exercises as a Symptom Management Strategy

The use of pelvic exercises is a strategy with proven efficacy and one which should commence immediately following sphincter-sparing surgery, including post-ileostomy formation (Kye *et al.,* 2016). Participants outlined pelvic floor as a strategy implemented formally by referral to physiotherapy, exercise education sheets and self-initiated exercises carried out without professional instruction. Despite the known benefits, only two patients utilised this as a strategy. Awareness of this strategy to improve bowel function was noted by all healthcare professionals excluding one. The following section describes the use of pelvic floors exercise and also allows insight into the limited education given to patients in relation to these.

Amongst the healthcare professionals, the benefits of pelvic floor physiotherapy were widely acknowledged and all HCP participants, but one discussed the importance of pelvic floor exercises. Pelvic floor exercises were viewed by one colorectal surgeon as *“part and parcel”* of the treatment following surgery for rectal cancer. One consultant surgeon accepted, that for patients experiencing bowel dysfunction, pelvic floor exercise provided reassurance through retraining and strengthening their pelvic floor but also in their assessment of bowel dysfunction severity. This role played by pelvic floor exercise in reassuring patients was articulated by one gentleman who described the contribution which it played in managing his bowel dysfunction:

> *“Very, very helpful…. My advice is do them…. once you do them you do strengthen the muscles around your pelvis …. once you put those PFE in your armoury that does help, you’re able to clench your guts and you’re able to hold on” (P2)*

These sentiments were echoed by another participant, the lady described the role which formal physiotherapy for pelvic floor had played in her recovery. This lady outlined the increased confidence, control and reduced urgency she experienced as a result.

The experience of another gentleman differed as he described his own strategy of tensing him pelvic muscle to prevent defecation when shopping and stated that this was a strategy he had used regularly. Despite not having received any instruction or education relating to pelvic floor exercise, this gentleman utilised his own version of pelvic floor exercise to improve bowel function.

As discussed, the awareness amongst healthcare professionals was evident, but also much discussed was the lack of information afforded to patients in relation to pelvic floor, often only initiated amongst the most severely affected patients. Concern that patients were not aware of PFE (pelvic floor exercise) as a strategy was discussed by one healthcare professionals, a staff nurse on a colorectal ward:

> *"I think a lot of people aren't aware that it can help with the symptoms….. they would see an improvement but I don't think a lot of people are aware that it can something that can be done easily yourself." (HCP1)*

Furthermore, amongst the healthcare professional group some seemed to view pelvic floor physiotherapy as a last resort, or something to be implemented much further down the line rather than immediately after surgery. One Clinical Nurse Specialist viewed pelvic floor physiotherapy referrals as their *"last hope" (HCP3).* The issue of impaired pelvic floor function was also acknowledged by another Clinical Nurse Specialist as *"an issue we don't have time to address…. they come back…. and we don't discuss their bowel function",* again highlighting the potential to miss out on providing patients with the useful strategy of pelvic floor exercise. This CNS also outlined that when referred to pelvic floor clinics, waiting lists and understaffing had further impeded patients' ability to access this strategy.

One nurse specialist working closely with patients experiencing anterior resection syndrome outlined the use of pelvic floor applications as an extremely useful and convenient way of encouraging and reminding patients to complete their exercises. The was echoed by another CNS. Despite this, none of the patients interviewed were aware of the existence of such technology.

Summary

The use of pelvic floor exercise to alleviate the effects of bowel dysfunction was widely acknowledged by healthcare participants and utilised by 60% (n=3) of the patient participants. However, only 40% (n=2) of patients had received formal training in pelvic floor exercises. Pelvic floor exercises were viewed by patients as something to increase confidence and add to their *"armoury" (P2).* Many healthcare professional participants voiced issues for patients in accessing pelvic floor education due to waiting times and understaffing, potentially delaying treatment and facilitating the further weakening of patients' pelvic floor. The use of pelvic floor exercise facilitated patients' improved control and allowing them to delay defecation. The use of pelvic floor exercise application was also recognised by two Clinical Nurse Specialists as a helpful means of encouraging and informing patients on how to utilise Pelvic Floor Exercises as a strategy. Where more mainstream strategies failed or were not provided, many patients affected with bowel dysfunction gravitated towards more alternative strategies which the following section shall discuss.

Alternative Strategies for the Management of Bowel Symptoms

For many patients the strategies which they adopted were utilised in an attempt to alleviate reduce or prevent their bowel dysfunction. Where conventional strategies such as medication use and diet failed or were not provided by healthcare professionals, many patients sought relief or cure in more alternative approaches. These varied from mindfulness, positive mental attitude and herbal remedies to more extreme and potentially harmful approaches such as coffee enemas, digital rectal evacuation and Cannabidiol oil use. The following section outlines some of the strategies utilised by interviewed patients and the experiences of healthcare professionals caring for those with bowel dysfunction.

For many patients, coping with bowel dysfunction was often an emotionally and psychologically challenging experience, often resulting in anxiety, frustration and at times sadness. In light of this, a number of interviewed patients discussed their use of positive mental attitude as a strategy and at times the use of mindfulness and Cognitive Behavioural Therapy to fortify this strategy. For some participants this was an inherent quality which had pre-dated their rectal cancer treatment, with one lady articulating same:

> *"I'd be kind of come day, go day, God sent Sunday…You know today is today, tomorrow will take care of itself." (P4)*

For other, development of a positive mental attitude was acquired through use of techniques including mindfulness and formal cognitive behavioural therapy to reduce the anxiety and fear associated with bowel dysfunction. The views of healthcare participants in relation to mindfulness as a strategy was mixed, with some recognising its role in cancer survivorship and others viewing same as potentially diminishing or dismissing patients' bowel symptom experience, as outlined by the following quote during discussion with one Clinical Nurse Specialist:

"I suppose this is a genuine symptom and condition, and I suppose I don't want to be saying to them that you're saying this is something in your head. I know the two are related. I don't want them to feel like this is all in your head." (HCP3)

Another patient described his regular use of mindfulness as a strategy allowing him to return to the present moment and to prevent being consumed by the experience of bowel dysfunction. Other healthcare professionals acknowledged the importance of counselling and psycho-oncology as an important part of the patient journey and a strategy which was severely impacted by lack of resources and staffing. In fact, the setting in which these interviews were carried out did not have any psycho-oncology resources and instead relied on voluntary/charitable organisations such as ARC and Daffodil Centres to provide patients with emotional support, a role often meant for the Clinical Nurse Specialist but affected by workload and time constraints.

Another Clinical Nurse Specialist who regularly cared for patients experiencing bowel dysfunction described the use of alternative herbal remedies with varying degrees of safety. This HCP acknowledged the limited evidence but relative harmlessness of remedies such as peppermint tea and water for abdominal cramping and bloating but also recounted patient use of unprescribed herbal remedies with potentially harmful effects:

> *"And I suppose there are forums that would suggest different types of herbal remedies…… but various ones that are liver enzyme inducers that may interact with medications and that. So a degree of caution." (HCP8)*

The same professional reported an increase in patients utilising Cannibidol oil for the reduction in abdominal cramping and bloating despite limited evidence and potential for interaction with other medications.

In relation to the management of incomplete emptying, a number of alternative/unusual strategies were noted. Two Clinical Nurse Specialists who had spent a number of years caring specifically for patients affected with low anterior resection syndrome described the use of coffee enemas or shower hoses. Both had seen this implemented a number of times and outlined lack of patient awareness relating to potential adverse effects including perforation and infection. Homemade irrigation sets with smaller volumes using old enema bottles was also noted by one CNS as a very effective strategy but again the safety was brought into question in relation to the cleanliness/ hygiene of using old rectal enema bottles.

One colorectal surgeon also discussed patients resorting to digital evacuation of faeces when they were unable to effectively empty their bowel.

Other alternative strategies which patients had resorted to around toileting habits were discussed by one of the colorectal Clinical Nurse Specialists. Prolonged habitual toilet times, toileting 30-40 times per day, often without result and watching movies or reading books whilst sitting on the toilet for hours waiting for complete evacuation were all mentioned as patient initiated strategies. Again, these strategies were potentially harmful to patients' bowel health and significantly impacting upon their daily lives, as hours were spent around toileting as opposed to providing patients with a means of managing their bowel symptoms in a practical and evidence-based way. This CNS also reported that this toileting strategy often became a behaviour as opposed to a strategy implemented when defecation was required.

Other alternative strategies mentioned by the healthcare professionals and patients included acupuncture and reiki. One CNS expressed concern in relation to some of these in patients who had lymph node involvement of their cancer, but perhaps to a lesser extent applicable in patients with colorectal cancer:

> *"Some will say visualisation reiki, I'd be careful about recommending acupuncture, or massage that might have a bad effect on the cancer. So, if these patients are within the danger zone so you know you wouldn't be doing a lot of effleurage there, they are pushing the lymph around. We steer clear of that" (HCP5)*

One of the more unusual strategies was noted by this CNS, she described an unconventional method used by one patient to deal with flatus odours:

> *"one lady told me her husband follows her around with an aerosol. Out in the shops and everything" (HCP5)*

This strategy potentially embarrassing and highlighting the shame which bowel symptoms can evoke in both patients and their families. The same CNS recommended lighting a match post-flatus to mask or eliminate odours when outside of the home.

In addition, going for walks was a strategy used by one patient (P2) as a way to *“clear the head”* and take her mind off the impact of effects of her bowel dysfunction.

Summary

The alternative symptoms management strategies utilising by patients and initiated by healthcare professionals were diverse and varied from the harmless, helpful to harmful and at times unusual. Mindfulness and psychological support were noted to be of particular help to some patients and an important element in the journey post cancer diagnosis and treatment, albeit under-resourced and accessed. For many patients, desperation resulted in the use of ineffective and potentially unsafe and harmful strategies such as home-made irrigation sets. So too existed strategies which significantly impacted upon patients’ day-today activities such as hours spent around toileting and its development into a behaviour.

Conclusion

The symptom management strategies utilised by patients and initiated by healthcare professional were diverse, had varying levels of objective success and illuminated the lengths which patients were willing to go to, to deal with their bowel dysfunction. The most common and seemingly efficacious strategies utilised appeared to be the use of diet and medication to deal with bowel symptoms. Failure to acknowledge the impact or perhaps even to be aware or investigate this problem amongst healthcare professionals often led patients to attempt their own management of strategies. Focus upon their oncological follow up often meant a failure to assess their bowel function and thereby implement strategies for its management. Analysis of the data also revealed a failure to refer patients on for pelvic floor physiotherapy at an early stage and to provide psychological support, the bowel-brain link potentially being underestimated. For many patients the strategies used emanated from current failures within the treatment of altered bowel function and from the experience of bowel dysfunction forcing patients to live a new normal. The varying degrees of success and lack of uniform treatment strategies further highlight the need for an exploration of what patients and those involved in their care would like to see in an intervention aimed at the management of bowel dysfunction. The following section seeks to discuss same.

5.8 Proposed Intervention to Improve Symptom Outcomes

The aim of this study was not only to identify the symptoms and utilised strategies of patients and those involved in their care, but also to explore what these participants would like to see in an intervention which sought to aid patients experiencing bowel symptoms following sphincter-sparing surgery in their self-care. The final pre-determined category adopted for the study was the proposed intervention for improved symptom outcomes. An analysis of data relating to this category resulted in the emergence of a number of sub-categories including; i) content of intervention ii) timing of intervention iii) healthcare professional proposed to deliver intervention and iv) mode of delivery of intervention. Interviews with participants varied greatly with some purporting immediate implementation, other delayed, some supporting leaflet form to others voicing the benefits of a multi-modal interactive approach. The following section explores the proposed timing of an intervention as discussed by participants.

5.8.1-Timing of Intervention Delivery

The timing of intervention delivery was a sub-category which emerged clearly following analysis of the date. Participants throughout the interviews expressed and acknowledged frustration around the potential delay in symptom treatment, resulting in many being faced with bowel dysfunction over a number of months, naturally leading to discussion around when they would like to see support/intervention implemented. Opinions around when an intervention should be commenced varied from the pre-operative period to 3 days post op and even 6 months following surgery.

Amongst all participants, the importance of early provision of information around the potential occurrence of symptoms following surgery was discussed. So too were the detrimental effects of failure to inform patients of these symptoms. For many, the occurrence of symptoms had elicited fear due to lack of understanding, as discussed in the previous section. One gentleman discussed the importance of pre-operative preparation and what information should be given:

"You should be told in a non-conditional sense that this will happen no mays or might." (P3)

For another gentleman, the importance of explaining symptoms was highlighted as something important as for many patients, *"they could be frightened".* One Specialist Registrar surgeon discussed the potential place of providing patients with information around potential symptoms in the preoperative setting so that *"when they come back, they can say yeah this (bowel dysfunction) is happening. And if they are looking out for it, they can say it."*

A number of participants (n=4), healthcare professionals and patients alike, communicated that the initial period post-operatively would be the best time to commence and introduce the existence of an intervention, some even suggesting that an intervention be commenced in the initial 2-5 days post-operation. The rationale for this included ensuring patients were prepared, whilst one Clinical Nurse Manager suggested that an intervention be introduced a few days following reversal as patients are beginning to eat again and the initial day post-operation would be unsuitable due to pain, anaesthetic and anxiety.

For one staff nurse working in a colorectal setting, the premature introduction of an intervention in the immediate post-operative period was not considered to be beneficial and suggested instead the first outpatient visit for introduction of the intervention. In the setting of this study, the first surgical outpatient appointment usually took place between three to six weeks following discharge:

> *"they might not have a true sense of the symptoms they're experiencing in the long-term. So probably in an outpatient facility…. 4-weeks after they've had their procedure to give them this information would probably be a good idea." (HCP 1)*

Others thought the initial post-op period would be suited to the delivery of general advice as opposed to a focused intervention. This was echoed by an earlier quote by one Clinical Nurse Specialist's experience of initial symptom duration:

> *"we do anticipate in the first month to 6 weeks kind of I suppose erratic bowel habit and it can take a while to settle down but what I notice some of the patients complaining of is that after this period is that we would expect it to settle down and is that they're coming back " (HCP2)*

One Colorectal Clinical Nurse Specialist gave reference to the specific timeframe for commencement of pelvic floor exercises, stating the time for this discussion was when planning commenced for ileostomy reversal. The concept of a step-by step approach to intervention introduction was discussed by two patients and a colorectal registrar. The participants felt the provision of general information in the initial phase would facilitate and support the deliver the application of a more focused intervention later on.

Participants felt this would benefit patients initially as provision of more specific information immediately post-operatively may not yet be applicable or applicable to all:

> *"Probably at the start you don't know what symptoms they're going to get so I suppose a General leaflet on some symptoms what to expect and how to manage each one…. But I suppose a general one at the start I imagine that would be the best" (HCP 6)*

The most popular period of time for intervention introduction amongst participants was a combination of either their postoperative outpatient review or 3 months post operation. One gentleman outlined his opinion in relation to timing of an intervention as something impacted by a person's limited ability to take in information at a time of huge stress, time of diagnosis:

> *"I think when you come back because there is so much to take in. It's that whole thing how do you eat an elephant- one bit at a time. But when you get the initial diagnosis you can't think of anything else." (P3)*

This view was supported by another patient who again highlighted the importance of general information but also the need to rest and recover before seeing and discussing the implementation of an intervention:

> *"Well definitely after the surgery. Give yourself a little bit of time to recover and maybe talk about it. Start off with the basics first after, before you're sent home. To get you started and maybe a few weeks after that talk more about it because you need that bit of time to recover" (P1)*

One patient discussed his reason for supporting a 3-month post-operative timing for intervention, being that a number of patients are usually being assessed for the need for chemotherapy or are potentially receiving chemotherapy. However, in this setting most patients following surgery for rectal cancer, with a TNM (Tumour, Node, Metastases) staging of T3 or nodal involvement requiring chemotherapy, will receive adjuvant chemotherapy for 6 months.

Across interviews with participants, it was acknowledged that the passing of time, for many, meant a resolution or improvement of their bowel symptoms. However, a recurring issue which emerged was current failures within practice relating to the provision of information and making patients aware of this information both in the pre-operative and post-operative stage. This seemed to demonstrate not only lack of awareness amongst healthcare professionals relating to this issue but also potentially in relation to potential solutions. What seemed to emerge overall is that information should be given to patients about the potential occurrence of bowel dysfunction, how to manage their symptoms immediately post-operation and then re-examine them in the post-operative setting to determine the severity/ extent of their bowel dysfunction and the need to implement/ include them within an intervention. In addition, the Continence Nurse Specialist spoke of her own experience of cancer diagnosis and the ability to process information, she described the pre-operative setting as a time unsuitable for large volumes of information:

> *"speaking from a personal point of view you are handed *Shows large volume of documents* you are handed an information overload. You are in a stunned state. You hear the word cancer and it is so true, because I know it, everything else goes over*

your head. So, the minute you hear that diagnosis you lose any information behind it." (HCP5)

In relation to the actual delivery of an intervention, only a single participant, a Colorectal Registrar, believed that an intervention should be implemented 6 months following surgery. This contrasted enormously with both the views of all other participants and with the experience of patients who outlined the hugely distressing impact of symptoms lasting just 4 weeks had on them.

Summary

For patients experiencing bowel symptoms the initial and potentially most severe period of symptom experience, is in the initial post-discharge period upon return of bowel function. Occurrence of bowel dysfunction was highlighted in the previous chapter as having the potential to cause fear of recurrence. This importance of armouring patients with information in relation to the possibility of symptoms occurring and the tools to manage them was acknowledged by participants. For the majority, it was voiced that information should be given in a general sense in the immediate post-operative period and a focused intervention not implemented or introduced until symptoms occurring for patients are established. This, for many, meant implementation of an intervention in the early weeks or months post-operatively. Only one participant suggested anything beyond 3 months for introduction of an intervention. The timing of an intervention's introduction was closely linked to the personnel who would deliver it, which will be explored in the next section.

5.8.2- Personnel to Deliver Proposed Intervention

When discussing the potential intervention, one of the main subcategories which emerged was around the personnel to deliver this intervention. Opinions varied, but amongst the patient group a clearly identified healthcare professional, the nurse, was identified as the most appropriate person. Others suggested trained volunteers, a multi-disciplinary approach, the colorectal surgeons, staff nurses or the Colorectal Nurse Specialists. However, throughout all interviews, what became evident was the importance of a human point of contact being available, especially where other mediums such as technology failed to resolve issues. The following section discusses the opinions of participants and also their rationale for selecting chosen individuals.

When discussing the person they would like to see delivering an intervention, all patients discussed the importance of experience. Experience around the issue of bowel dysfunction and dealing with patients who were faced with same. One gentleman discussed the importance of this person having dealt with this issue over a prolonged period of time:

> *"Somebody that has experience, that they are dealing with this problem in an ongoing basis, not somebody that is filling it maybe. Just someone that has the knowledge and the expertise… Yes of course they are dealing with these patients on a regular basis and you can't buy this experience. You get it over years, you earn it." (P1)*

In relation to specific roles of healthcare professionals delivering this intervention, amongst the patient group, the most commonly mentioned professional was the Colorectal Clinical Nurse Specialist, all five patients suggested this group as the most appropriate people to deliver the intervention. Perhaps influenced by how closely these nurses had worked with the interviewed patients during their initial diagnosis, post-operative period and finally in their coping with bowel dysfunction. For one lady the Clinical Nurse Specialists/ Coordinators were viewed as the appropriate person for the following reasons:

> *"I think the nurse, like (CNS Name). She did say it to me that day she was explaining but before my operation I wanted to hear nothing…I think she was great like. I'd say somebody like that… They are more caring, I think. And I think the consultants deal with the bigger issue of they are going to operate on you." (P4)*

For others, the CNS was seen as the best choice due to their experience. This view was echoed by a number of the healthcare professionals who viewed nurses as the group working more closely with this cohort of patients. Whilst a number had suggested the staff nurses, the limited time available due to workload was acknowledged, as was the regular turnover of staff upon colorectal wards. One Clinical Nurse Specialist articulated same and why she felt Clinical Nurse Specialists were best placed to deliver an intervention:

> *"I think also we are working with them (the patients) all the time; we see them all the time in the outpatients, so we are probably best place to talk about it. And the staff nurses on the ward they come, and they go, and they leave. I mean the vast majority of*

> *the nurses are new to the ward, they are there for 12 months and they are gone." (HCP2)*

For another Clinical Nurse Specialist, the importance and practicality of a nurse-led intervention was discussed. This healthcare professional felt that this was a key issue as for patients faced with issues seeking advice, the HCP most often present and available at all times was a member of nursing staff, whilst doctors were less accessible due to time in surgery, clinics etc. One Continence Nurse Specialist outlined how she believed it was important for the Clinical Nurse Specialist to deliver this intervention and commence survivorship as a whole to this cohort of patients, due to their close working relationship with patients.

Other healthcare professionals cited the importance of a multidisciplinary approach, including dieticians, physiotherapists, psychologists, continence nurse specialists, colorectal nurse specialists and member of the colorectal surgery team. One colorectal surgeon discussed the importance of including dieticians in an intervention when discussing food as a strategy and then physiotherapists when dealing with the pelvic floor strategies for patients. Seven of the ten healthcare professionals interviewed considered an MDM approach would be most suitable when developing an intervention, with one colorectal registrar discussing the team but also the importance of a link person:

> *"You have your colorectal nurse specialist your teams, dietician department, incontinence nurse…Your nurse specialists and then the team and then if you had the link." (HCP9)*

One Colorectal Nurse Specialist was of the view that a dedicated clinician be it a nurse or other healthcare professional, with specific responsibility for this issue, should be in place. This CNS along with a number of other healthcare professionals and patients considered that at present the focus was more so upon oncological surveillance and that this limited time given to potential functional issues and dealing with bowel dysfunction.

Of note, one colorectal registrar presented the idea of putting affected patients in contact with previous patients who had faced similar issues, in an almost peer-support format. Similarly, one male patient felt a volunteer with specific training would be an acceptable alternative to a healthcare professional delivering the intervention. In addition, the same man discussed attending a workshop, delivered by two nurses, relating to diabetes and how the use of two individuals, rather than one was viewed as a positive in order for a range of experiences and opinions to be communicated.

Outside of the specific profession of the person leading the intervention, a key issue which emerged was the desire amongst patients and professionals alike to ensure that a human link or contact was maintained regardless of the mode of delivery or format of an intervention. For many patients, information they had received or strategies they had developed sometimes failed to resolve an issue, and when this occurred it was those involved in their care whom they sought help from. One gentleman outlined that whilst an intervention to support and inform patients was something that was needed, it was not something that could replace the ability to pick up the phone and contact someone for practical advice.

> *"we spoke about the app which going forward I think would be good and it's in addition to what we are doing already. But I have met the staff in here and they have told me every single thing that I have needed to know…So important, I've told *names a healthcare professional) and it goes up the course to Dr (Name) and we think "no we need to get him back again" and that point of contact with another human . And that's so important I mean you lift up the phone "Eugh option 3 option 6" and you're losing the will to live. And then when you get through to a human, "here the glue is lifting" "I'll sort you out". (P2)*

Another man highlighted the trust which he had in those involved in his care and how access to these individuals had played a key part in both his recovery and management of his bowel dysfunction.

Summary

Throughout analysis of data, it became evident that the majority of patients determined that an intervention developed should be nurse-led. From a HCP perspective, multidisciplinary input was viewed with importance, especially from nurse specialists, dieticians and physiotherapists and this even more so when relating to the intervention's actual development. The potential development of a role for a clinician focusing solely on this issue was discussed, as was the potential training of volunteers or peer-support. However, one universal finding amongst the data, was how vital human contact was in the management of this issue by participants. Whilst all acknowledged the need for and access to an intervention, all reiterated the importance of being able to speak to another human being when faced with certain problems or personal issues. Exploration of the personnel involved in a potential intervention was closely linked to the content which participants cited as important for inclusion, which the following section will explore.

5.8.3- Proposed Content of an Intervention

When discussing the potential development of an intervention, the most apparent subcategory to emerge was the content for inclusion in this intervention. When discussing the intervention with patients, elements of the intervention were considered with guidance from the TIDier Checklist (Hoffmann *et al.,* 2014). This, provides a template for intervention description consisting of 12 items; name, why what materials, what procedures, who to provide, how, where, when, how much, tailoring, modifications, how well planned and how well actually carried out, only some of which is relevant to the stage of intervention explored by this study. This is illustrated further in Chapter 6. Participants presented an array of views as to what an intervention should consist of. Much of the content proposed mirrored the strategies which patients themselves had eventually implemented or garnered from healthcare professionals to manage their bowel symptoms. This included diet, medication, pelvic floor exercises and skincare. However, analysis of interviews also revealed the importance of including open discussion, increased information provision, multi-lingual options, focus on the general versus specific, use of mindfulness, counselling and more. This section examines the content which patients and those involved in their care deemed as beneficial for inclusion in a potential future intervention.

Perhaps the most common item of content which participants expressed desire for inclusion in an intervention was information and advice around diet. Many patients had utilised diet as a means of symptom management and found this of huge benefit, but the majority had discovered this intervention through much trial and error or following a prolonged period of symptom experience. Therefore, those interviewed expressed desire for dietary information to be provided and presented in a timely fashion to prevent or alleviate adverse symptoms. One lady described having gone home *"in the dark"* and that dietary intervention should be initiated from *"the get-go".* Additionally, this lady outlined the importance of dietary advice and how it would be presented:

> *"So, if they could just say okay this is what you eat, this is what's going to drive your bowel mad, this is going to help you, and these are the foods that you stick with until your whole insides settle down." (P1)*

This need to include dietary advice was echoed by all (n=15) participants. For one participant inclusion of a list of the FODMAPs diet was seen as a key element for inclusion in the intervention. For one staff nurse, dietician developed advice when reintroducing food was noted as potentially useful content. Information around timing of reintroduction of food was discussed by one female participant as vital information for inclusion.

Another element of content which emerged as having importance amongst the interviewed participants was advice around skin care. Patient participants had experienced skin excoriation and maceration as a result of faecal frequency and loose stool. Lack of awareness amongst many of the healthcare participants had also in turn meant lack of knowledge relating to treatment of this issue.

One male patient participant voiced his desire to see practical skincare advice, around cleansing and protection. Another man highlighted that advice relating to creams which could be utilised to protect perineal skin should be included in an intervention's content. Another Continence Nurse Specialist voiced the importance of teaching patients about correct use of incontinence wear and use of toilet wipes etc for skin care. This Continence Nurse Specialist stated, *"they need to understand that skin care is vital".* All patient participants (n=5) expressed a desire for the inclusion of skin care advice.

For all patient participants and many of the healthcare professionals, medication advice in relation to Loperamide, laxatives and other pharmaceutical aids for bowel dysfunction was deemed as important. The importance of offering patients structured and evidence-based information around medication was noted by one pain nurse specialist, to prevent patients adopting unsafe self-initiated medication strategies. Another Colorectal Nurse Specialist discussed the provision of an algorithm by which patients matched their symptoms to the appropriate medication strategy:

"That they might have an algorithm for pharmaceutical interventions that they may need to manage their symptoms like Loperamide to slow them down or some might need some form of laxatives." (HCP10)

In relation to the impact of physical symptoms, one continence nurse specialist interviewed, gave particular focus to dealing with the mental impact of bowel dysfunction. This nurse specialist outlined the importance of making an intervention holistic and outlined one way to achieve this as illustrated by the following quote:

"So that you are giving them the resources, if you wanna (sic) talk to you physio, your doctor, your nurse. And you might find relevant info in support groups? Are there any local support groups?...And we were happy to direct them so if there was extra help, and Arc House, have you thought about relaxation? "If you did the relaxation therapies would you be less anxious?" (HCP5)

The same nurse specialist outlined the importance of mindfulness, CBT and counselling in managing the psychological stress of bowel dysfunction and something which she felt would be beneficial within an intervention. This was mentioned by a number of other participants. One colorectal surgeon acknowledged that the lack of psycho oncology support and was a huge issue and deficit within the current system. Some purported the benefits of counselling and support groups which they had accessed following treatment for rectal cancer. One gentleman outlined his view of a psychological element for an intervention:

"I would believe there is a place for CBT, there is a place for philosophy, for mindfulness. Just for yourself, not to be so hard on yourself. Because sometime what happens to you sometimes is rumination, kicks in… So, any of those mindfulness things that…. helps you in way" (P3)

However, when discussing certain alternative therapies for inclusion in an intervention, two healthcare professionals, a colorectal nurse specialist and the continence nurse specialist expressed concern in relation to certain content. The first expressing caution when discussing psychological support, and the potential for patients to see this as a healthcare professional viewing their bowel dysfunction as a manifestation of solely psychological issues:

> *"I suppose this is a genuine symptom and condition, and I suppose I don't want to be saying to them that you're saying this is something in your head. I know the two are related. I don't want them to feel like "this is all in your head". I suppose it's getting it right" (HCP2)*

The other nurse specialist expressing concern in relation to use of massage and acupuncture where there had been lymph node invasion in the patient's cancer. Healthcare professionals and patients alike also acknowledged that willingness to access and utilise more alternative therapies and psychological supports was a very individual-specific preference and that not everyone would find them beneficial. However, all participants accepted that information relating to these supports including the likes of ARC house should be made available within an intervention and its use at patient discretion. Another patient wished to see the inclusion of alternative strategies but specifically mentioned he would not wish to see any religious elements included when relating to mindfulness.

Pelvic floor exercise was another commonly cited item for inclusion within an interventions content. One colorectal consultant discussed the importance of pelvic floor advice and other elements of the intervention being delivered for the following reason:

> *"So, you know those are the things that patients want to have at home and they can go through in a step wise fashion before having to resort to coming back" (HCP10)*

One gentleman discussed the initial pelvic floor assessment which the intervention could then support through reiterating and reinforcing the information provided during this formal assessment. Another woman discussed the benefits of including pelvic floor exercise in an intervention as a mean to increase the confidence of those utilising it and aiding their continence and control. One colorectal consultant described the importance of including pelvic floor exercises as a means of reassuring patients and retraining their pelvic floor, again to improve control and in turn quality of life.

Amongst all patient participants, the importance of the intervention providing patients with information outlining potential side-effects was cited as a vital element for inclusion within an intervention. One gentleman discussed the importance of making patients aware of potential bowel dysfunction to prevent unnecessary fear and anxiety for patients. This was supported by the sentiments of the continence nurse specialists who acknowledged that many patients had presumed their bowel function would return to normal following stoma reversal only to find themselves with significant bowel dysfunction. One lady discussed the need to provide this information as a means of preparing patents for what was ahead:

> *"But there is life at the end of the tunnel and light at the end of the tunnel but be prepared for going home with information and diet and hygiene." (P2)*

One staff nurse working within the colorectal surgery setting discussed the possibility of including a toilet passport within the scope of an intervention. This being the provision of a toilet pass to all patients experiencing bowel dysfunction which they could present to public toilets and business similar to those utilised by individuals with stomas or IBD. Many participants discuss the importance of utilising simple language and non-medical terms throughout the intervention. With one gentleman and a Clinical Nurse Manager both discussing the importance of using *"big-lettering"* and appropriate literacy level friendly language, especially taking into account the area in which this study was set, an inner-city and disadvantaged area with varying degrees of education. Another male participant also discussed the importance of making the intervention multi-lingual, based upon his experience of working with a number of nationalities. In addition, one gentleman expressed the importance of utilising non-medical terms to ensure comprehension and clarity:

> *"Well I'd like it to be simplified that everyone can understand and that they are not getting bogged down with big spiels and elongated words…We don't know what they are these medical terms. Basic stuff that everyone can understand and that everyone can put into practice." (P1)*

In relation to the content's focus, there was much discussion as to whether an intervention should be general or specific and varied hugely across participants. One colorectal registrar was of the view that initially the focus of an intervention should be general and then progress to more specific information based upon the symptoms experienced by the individual patient. An alternating view was presented by one Clinical Nurse Manager and communicated further by a female patient participant discussing the potential issues around a generalised intervention, stating; *"I don't know if you can generalise it because what might work for one wont for another".* Moreover, when discussing specific versus general approach OF the intervention, one staff nurse communicated her uncertainty relating to the delivery of general information:

> *"I think symptoms specific would be a better way to go than a general information…and I'd say if you specified for different symptoms, different procedures, different lifestyles, different age groups that it would be more specific, tailored to them." (HCP1)*

Furthermore, one gentleman suggested that general information be provided but that specifics topics be explored within an intervention using modules.

Finally, the importance of providing patients with information around access to supports, resources and information was discussed. One man highlighted that prior to his diagnosis he had been unaware of a link between alcohol and cancer and that this was information he wished he had known before. Highlighting the importance of making patients aware of risk factors for cancer development to allow them to make more informed choices to reduce risk of recurrence etc. Another nurse specialist discussed patients use of old enemas for irrigation, and the lack of awareness amongst patients of existing sterile tools specifically designed for irrigation. One colorectal nurse discussed the importance of making patients aware of psychological supports like ARC house.

Summary

When discussing content for inclusion in an intervention four main topics were universally mentioned by participants, medication, pelvic floor exercises, diet and alternative therapies. Interesting insights into the need to make an intervention universally accessible in terms of literacy and language were garnered. The varying opinions when relating to providing specific versus general information was the issue which participants differed most upon, but all highlighted the importance of keeping an intervention geared towards the individual. All participants noted the importance of maintaining a human element within an intervention by delivery through paper, electronic or face-to-face format. The mode of delivery for a potential future intervention is explored in the following section.

5.8.4-Proposed Mode of Delivery

The proposed mode of delivery of the intervention was a key piece of date to emerge during analysis. Throughout discussion of an intervention's development all participants discussed the current failures in the delivery of strategies to aid patients experiencing bowel dysfunction and the need to address this. Potential modes of delivery discussed included websites, applications, leaflets, flowcharts, booklets, a specific clinic, video format or podcast. Rationale for mode selection included accessibility, age, language, ease of use, previous experience, technological literacy and background. Age of participants within the healthcare professional group seemed to influence the mode of delivery they deemed preferable; this was less notable amongst patient participants. The following sections outline the modes of delivery discussed and the rationale for same. One proposed mode of delivery discussed by a number of participants was a leaflet format. Many of the healthcare professionals initially suggested this as a mode of delivery suitable for the older population and a means of supporting verbal information and discussion. Only one patient participant viewed a leaflet version of an intervention as the most appropriate mode of delivery. One Clinical Nurse Manager felt this would be a suitable mode as he himself had utilised it during his own research and another Clinical Nurse Specialist agreed as it was the format she utilised especially when communicating with older adults, the cohort of patients most commonly affected by rectal cancer. When describing the rationale for selecting this mode the same colorectal nurse specialist stated the following:

"Yeah that would probably be a bridge too far for older people. Of course, there is an exception to in every case. But older people don't tend to go on google." (HCP 3)

One patient participant discussed her preference for a leaflet format due to her limited IT skills. This was echoed by another gentleman who felt his limited IT skills would hinder him accessing an application, but also acknowledged the benefits of an online intervention. In addition, the same gentleman voiced that should he be given instruction on the use of an online intervention, he would be open to utilising it. Another patient discussed the potential drawbacks of the leaflet format, such as the easily conceivable possibility of losing, damaging or throwing it away, then leading him to discuss the merits of a web-based/online format. A format discussed by a number of other participants. For one staff nurse the use of written leaflets presented drawback in relation to patient engagement:

> *"A lot of patients don't engage with written material because obviously in the postop period they have a lot of information given to them, and they don't always read it very carefully and they don't pay attention to what's on it and also they lose them" (HCP 1)*

For many participants the benefits of an online or web-based intervention were discussed. Many participants discussed accessibility as a key issue around considering an interventions format. A number of participants acknowledged the fact that almost all adults have access to a mobile phone. With one male gentleman discussing the possibility of using his tablet to access an intervention. In addition, participants outlined a phone-based intervention as useful, due to the privacy it affords users. Furthermore, two participants felt an online intervention meant easier translation of material for non-national patients. One gentleman discussed the benefit of an app-based version facilitating access through one’s phone:

“I suppose your phone is the thing you use most. If you get a piece of paper, you might just throw it away or maybe lose it. If it’s your laptop or computer, you leave it down. But your phone you’re bringing it with you and if you feel like somethings not going right and you’re thinking can I eat this. You can look at your phone and see.” (P1)

A number of the healthcare professionals shared this view including all of the medical doctors interviewed (n=3) and four of the nursing participants. One of the colorectal surgeons felt that a web-based format would be suitable but also purported the benefits of a multi-modal intervention. Further analysis of data revealed this to be a recurring theme. Responding to individuals’ capabilities, knowledge around technology and literacy were elements which supported the need for a variety of modes being available. The accessibility of an application-based intervention was outlined by one consultant:

“I think probably some sort of digital platform, that’s the way everyone is interacting now and if they have access to information and steps they can take in their day to day life. Whether it be an app that’s prob going to be the most useful.” (HCP 10)

One Clinical Nurse Specialist furthered this view, suggesting an online version of the website also containing access to PDF versions of the information provided which patients themselves or healthcare professional could print, for those not wishing to utilise the online version. For one male patient, the concept of utilising a variety of media was illustrated using the example of pelvic floor exercises. This gentleman discusses having an application-based instruction outlining a “how-to” on pelvic floor exercises, supported by access to videos demonstrating same. In addition, a Pain Nurse Specialist outlined the possibility of showing patients instructional videos within a clinic setting, again when relating to pelvic floor exercises. Participants, again seemed to attribute certain modes more suited to certain elements of the intervention, with written lists cited for dietary advice, pelvic floor exercises using videos or illustration.

One patient participant suggested a format by which a patient application relayed information back to clinicians to allow them to examine the degree of bowel dysfunction and the dietary intake of participants, through a food diary, allowing clinicians to examine which foods resulted in exacerbation of bowel dysfunction. In addition, the same gentleman suggested that patients could communicate with healthcare professionals relating to their bowel function through instant messaging. Similarly, one registrar suggested a very similar format:

> *"Bowel diaries could be on an app. That they can log in…it's handy and if you go home and say "I never wrote up my diary" but if they had the phone it's a little click, "actually you know I went to the toilet 10 times today, why is that? Oh, I had the curry last night." (HCP 5)*

Two colorectal surgeons who had experience of working with this cohort of patients in different countries and hospital setting suggested the benefits of an intervention being delivered in a dedicated outpatient clinic setting. This included what one consultant entitled *"a one stop shop",* allowing access to radiology for assessment of pelvic floor, physiotherapy, dieticians, Colorectal Nurse Specialists and Continence Nurse Specialists all in the one visit. For one registrar, examination of existing European clinics and the outpatient format which they utilised to deal with this cohort of patients was recommended. Finally, the importance of access to healthcare professionals regardless of intervention mode of delivery was highlighted by one colorectal nurse specialist, outlining her experience:

> *"I think if they have a problem they want to come in and discuss it that want to come and get practical in terms of a change of diet or medication in relation to their specific problem***….***I think talking with someone face-to-face, that's the way, I don't think you can say to someone go home and read that, look it up on google, I think If people have a problem they want to talk to someone…. And I suppose because they have built up a relationship with you the individual. They don't want a stranger talking on the computer." (HCP3)*

Summary

Analysis of data revealed a number of possible modes of delivery acceptable amongst both patients and healthcare professionals. The variety of modes discussed, and the direct discussion of a multimodal format suggest that this would be the method which would allow greatest engagement across ages, abilities and nationalities. An intervention which consists of varied content but gave access to a number of formats including phone based, website based, leaflet format and the alteration of languages. Participants directly discussed and considered format which they themselves had utilised or seen in use in other settings/circumstances. The author noted that many healthcare professionals did not see web-based/application versions as something acceptable to older adults but this was challenged by the response of patient participants and their willingness to them.

Conclusion

The findings of this study spanned a number of topics, from bowel symptoms, their impact upon patients, the strategies which they and their healthcare providers utilise, the current failures in management of symptoms and what those interviewed would wish to see in an intervention. Patients following SSS are faced with a myriad of symptoms fluctuating from the inconvenient to life-altering. The strategies utilised to manage these symptoms vary from effective to unsafe and at times were stumbled upon through trial and error. Duration of symptoms was individual but often underestimated. In relation to current practices, the strengths, limitations and at times failures were recognised and acknowledged by both patients and professionals. Participants expressed a desire for further sharing of information, more informed decision making, structured assistance, early intervention and accessible means of accessing same. All voiced the need for an intervention's development. Whilst a number of suggested modalities were presented all were in favour of an intervention which utilises simple terminology, allows access to healthcare professionals and not is not solely one format such as computer based or leaflet formats. Age was acknowledged as a barrier to some but having an online or web-based mode of delivery was identified as a useful component. The personnel suggested to contribute to an intervention also varied but a number were mentioned consistently i.e nurse specialists, staff nurses, physiotherapists and dieticians. In terms of those to lead an intervention, the nurse specialist was viewed as the strongest contender. Finally, what became most apparent from the data was the need to create an intervention which caters for all ages, languages and literacy levels. Therefore, what emerged relating to preferred intervention format was that of a multi-modal, multi-disciplinary and multilingual tool. The following chapter will seek discuss the findings

Chapter 6.0- Discussion

Introduction

The aim of this study was to utilise the MRC Framework for the Development of Complex Interventions (2006) and the Symptom Management Theory as a guide to explore the symptom experience of patients following sphincter-sparing surgery for rectal cancer, their responses to symptoms experience, the strategies utilised to manage these symptoms and review the need for an intervention and determine the potential format and content of an intervention to aid this cohort of patients in the self-care of their bowel symptoms. The principal findings of this study with reference to existing literature and previous research will be discussed. In addition, these findings will be presented under the pre-determined category headings selected and also present the overarching theme found to emerge from data analysis.

Colorectal cancer remains the second most common cancer in women worldwide, and the third most common cancer amongst men. From an Irish perspective, colorectal cancer is the second most common cause of cancer death (Irish Cancer Society, 2019). For those diagnosed with rectal cancer, surgery is a mainstay of treatment, with 79% of people with a diagnosis of rectal cancer receiving surgical treatment (NCRI, 2013). Whilst survival rates have improved, those who undergo SSS are often faced with significant changes to their bowel function which can markedly impact their quality of life.

Despite a large volume of studies acknowledging and exploring the symptoms experienced following sphincter-sparing surgery (Desnoo & Faithful, 2005, Nikoletti *et al.,* 2008, Bregnedahl *et al.,* 2013, Landers *et al.,* 2014, Chen *et al.,* 2015, Hou *et al.,* 2017) , to date there have been no studies nationally or internationally exploring the development of an intervention to manage these symptoms or a study which sought to develop an intervention which would allow patients to self-care and manage their symptoms in a non-clinical setting using non-invasive techniques.

Therefore, this study has taken the initial step to address this need. It is anticipated that discussions with patients at whom this intervention is aimed at and those involved in their care, would identify what is required from an intervention, relating to content, timing, personnel and mode of delivery. It is also hypothesised that this body of information will potentially contribute to the development of an intervention for this cohort of patients, both through its exploration of existing evidence and its analysis of new data garnered through this study.

6.1- Sample

When discussing the findings of this study it is important to compare and contrast the sample included to that from a national and international perspective. All patient participants (n=5) were greater than 65 years of age, with 67% of those diagnosed with colorectal cancer in Ireland being greater than 65 years of age (NCRI, 2013). All patient participants in the current study had undergone surgery for rectal cancer, the national figures in Ireland for rectal surgery is 70%. Only one female participant was interviewed for the study, with the remaining participants being male (n=4), this is slightly different to the national proportion of those diagnosed with colorectal cancer, with women representing 40% of all diagnosed (NCRI, 2018).

In relation to the healthcare professional sample, this study was unique in that it sought information not from one discipline alone but from staff nurses, nurse managers, nurse specialists, registrars, colorectal specialist registrars and a colorectal consultant surgeon to facilitate a range of opinions and views.

6.2- Discussion

6.2.1-Bowel Symptom Experience

The findings of this study demonstrate both the prevalence and impact of bowel symptoms. Whilst sphincter-sparing surgery enables individuals to avoid the impact of a permanent stoma, their significant bowel dysfunction has the potential to cancel out the benefits of maintaining bowel continuity (Desnoo & Faithful, 2006). Identification of symptoms was facilitated and acknowledged by all participants including faecal incontinence, frequency, urgency, clustering of bowel motions diarrhoea and constipation, similar to the findings of a number of studies (Landers *et al.,* (2014), Hou *et al., (*2015). The findings of Hou et al., (2017) explored the frequency of symptoms.

However, the current study differed, as outside of the identification and description of symptoms, a qualitative description of their potential variability was provided in relation to severity, duration, associated degree of bother and sensitivity. In addition, the current study uniquely identified the physical impact of bowel symptoms, including the issues of pain, impaired skin integrity, altered fluid and food intake. One notable finding to emerge was the impact of bowel symptoms upon sleep and the resultant fatigue, this was due to both anxiety experienced as a result of symptoms but also related to nocturnal defecation. This saw patients already wearied by treatment, bowel symptoms and reduced food intake impacted further by poor quality of sleep. This is an important issue to consider as a potential barrier to learning and engaging meaningfully with an intervention, due to fatigue or impaired cognitive function resultant of sleep deprivation. Of note, there often seemed to exist a discrepancy and difference in the views of healthcare professionals and patients in relation to the incidence or impact of symptoms, this finding is similar to that of Chen *et al.,* (2014) who found that radiation oncologists and colorectal surgeons' perceptions of symptom bother often differed to that of patients'. The most awareness of this issue and acknowledgement of the prevalence of bowel issues in this study was noted in the responses amongst the CNS participants. Amongst the medical or ward-based staff the nature and prevalence of this issue was viewed as an uncommon problem, a number of the healthcare professionals, especially within the doctor group, seemed to view these bowel symptoms as a rare occurrence. This was another finding which this study uniquely identified. This is important, when considering an intervention and how pivotal education of healthcare professionals is to ensure patients, who may benefit from inclusion within an intervention, are identified in a timely fashion. In addition, many of the healthcare professionals also acknowledged the current failures of practice, including their potential underestimation of the issue or their failure to broach it as a topic with patients following surgery. Moreover, healthcare professionals acknowledged that identification of the issue was often dependent on the patients raising the issues or being forthcoming in relation to their difficulty with bowel dysfunction. Highlighting another issue to emerge from the data, the current failures within practice.

The long-standing nature of bowel symptoms which this study identified, echo the findings of Chen *et al.,* (2015) and the findings of the narrative review, in that symptoms often lasted far beyond the initial post-operative period, with all patient participants being greater than a year post-surgery. However, the current study provided a unique perspective into bowel symptoms experience as it not only identified the long-standing duration of symptoms but also the duration of the cyclical nature of certain symptoms including clustering of bowel motions or the "turn-around" of bowel symptoms described by both patients and HCPs. This study provided a long-term perspective of bowel symptoms, longer that that provided by other studies examining bowel dysfunction, such as Taylor’s 2014 study which explored dysfunction only 4-6 weeks post reversal. In addition, the lack of understanding amongst healthcare participants that bowel dysfunction following sphincter-sparing surgery often lasted far beyond the initial post-operative period became apparent. This has implications for practice and healthcare professionals’ education needs.

The psychological element of bowel dysfunction also became a topic discussed by both patients and healthcare professionals, and one concept which became apparent was that of the “mind-gut link”. This was a phrase utilised by a number of the healthcare professionals and two of the patient participants. The close link between emotions, be it stress, anxiety or fear and the bowel function of affected participants was identified. The occurrence of anxiety and its negative feedback into exacerbation of symptoms was noted amongst healthcare professionals. With a number providing anecdotes of patients relating to their heightened anxiety around certain events such as weddings, plane travel and sport events. Whilst Hou *et al.,* (2017) had identified individuals basing and planning activities around bowel function, the current study further explored this and examined specific incidents or events in which this became particularly problematic. This finding impactful as it suggests the potential need to provide patients with coping strategies to deal with specific events such as travel etc.

Other studies examining psychological issues due to bowel function were identified. Landers *et al.,* (2014) thoroughly explored the experience of bowel symptoms by patients following surgery for rectal cancer. This study too acknowledged the potential for bowel symptom to impact upon the psychological and social well-being of participants. The current study provided an additional perspective, that of the healthcare professional. The current study was also unique in its examination of potential elements for inclusion in an intervention aimed at supporting patients in their self-care. In addition, the current study sought the perspective of patients in relation to content, mode of delivery and personnel involvement within such an intervention.

For patients, and amongst the healthcare professionals who dealt with this cohort, one issue highlighted was the notion of symptoms as a “price to pay” for the cure or chance of cure of their cancer. Whilst individuals acknowledged that they expected some changes they had not envisioned the marked changes in bowel function which they experience. Furthermore, the impact of these symptoms was noted upon their psychological and social well-being, often more in what was unsaid than said. This is a unique perspective provided by this study and gives insight into the experiences of patients facing bowel dysfunction, it has important implications for an intervention to ensure it addresses not only the physical but psychological issues relating to patients’ bowel dysfunction.

The incidence of bowel symptoms has the potential to permeate a myriad of areas of patients' lives, including their work lives, marriages, friendships, ability to attend social events, family events, travel, sleep, dining out, clothing and more. The current study echoes the findings of a study by Nikoletti *et al.,* (2008) which examined bowel dysfunction and self-care following surgery for rectal cancer, with many patients reporting fear in social situations relating to the occurrence of bowel symptoms such as flatulence, incontinence and fear of dietary intake when eating outside of the home. However, Nikolleti *et al.,* provided patients with a set of 12 items to discuss, as opposed to allowing patients to describe and expand upon their experiences which the current study facilitated.

This study provided a qualitative insight into the psychological and social impact of bowel dysfunction. Already faced with the life-altering diagnosis of rectal cancer, patients were then faced with further challenges resultant of bowel issues. Participants discussed the close link between psychological well-being, its impact upon bowel symptoms and vice versa. This mind-gut feedback process was illustrated by this study which acknowledged that those experiencing heightening anxiety in turn experienced exacerbation of their physical symptoms. This link was illustrated too by patients describing the anxiety which they experienced as a result of bowel dysfunction exacerbating their symptoms. This issue was also outlined as being linked to certain activities such as travel, with patients describing reluctance to use public transport and go to the airport without the immediate occurrence of faecal urgency. This served to highlight not only the impact of bowel dysfunction on psychological well-being, but also the importance of addressing psychological needs when treating these patients or considering an intervention.

Throughout this study participants repeatedly acknowledged the need for but lack of psychological support for patients within the service. This again served to highlight the importance of exploring the need for and nature of an intervention aimed at supporting patients not only with their physical symptoms but the resultant psychological impacts and strategies to alleviate same.

In addition, patients and healthcare professionals acknowledged the time constraints placed upon the personnel involved in their care, with clinics and interactions with professional primarily focused upon the treatment and the subsequent surveillance of their cancer as opposed to the impact of that treatment. Clinic meetings with patients focused upon delivery of results, review of scans and arrangement of future investigations. This highlights the need for a supportive intervention which could be provided to patients to give them information on not only the occurrence of symptoms but how to ameliorate or eliminate their impact without the restrictions imposed by staffing, resources and time-restrictions. The current strategies utilised was also explored and will be discussed in the following section.

6.2.2- Strategies for Symptom Management

Discussion of strategies used to manage symptoms revealed a myriad of approaches, varying from the evidence-based to the unconventional. Patients often implemented strategies provided to them by healthcare professionals including Loperamide use and dietary alternatives. However, other strategies identified included food restriction, avoidance, social isolation, cessation of employment, homemade irrigation devices and anal plugs. Some of these findings were similar to those identified in Hou *et al.,* (2017) and Landers *et al.,* (2014) including use of unconventional and often unhelpful or detrimental strategies such as fasting and use of tissue paper instead of appropriate incontinence wear. Whilst Landers *et al.,* (2014) had found the most common strategies utilised to be use of toilet location awareness, medication use, protective clothing and incontinence pads, the participants in this study primarily cited diet, medication use and skin care strategies as their key strategies similar to the findings of Hou *et al.,* (2017). One unique concept, which emerged specifically during discussions with healthcare professional participants, was the concept of gender and its impact upon the self-care strategies and coping mechanisms of patients. Some highlighted that women coped better with “leaky bodies” as they were used to the discharges associated with menstruation, or stress incontinence or incontinence post-partum. The viewpoint was conflicting, with other healthcare professionals viewing men as the group who coped better due to their willingness to be upfront with healthcare professionals and in seeking help. This illustrated the importance of considering the individual rather than the impact of gender upon willingness to engage with an intervention or its role in the identification and assessment of bowel dysfunction for healthcare participants.

A common theme which emerged from the data was the concept of "living a new normal", something which bowel symptoms necessitated amongst affected individuals. This theme of "living a new normal" emerged from the data throughout a number of the pre-determined categories, from physical symptoms to psychological and social. This, for many meant adopting a new way of life through either strategies or behaviours in response to their symptoms or in order to improve or eliminate the impact of strategies upon daily life. Many participants, healthcare professionals and patients alike, voiced that when they discovered a strategy which worked for them it allowed them a greater sense of control or confidence and allowed them to live their lives, not as they had once done but in a new way. For some this included altered diet, timing of food, Loperamide use, changes in their work routine or use of incontinence wear. For some patients this new normal consisted of bringing a pre-prepared continence pack when they left the house to allow them security should they have an episode of incontinence. Interestingly, two of these patients had never had an episode of incontinence but felt "safer" as a result of having these items with them.

However, a notable finding was the reluctance of individuals to utilise strategies despite their known efficacy, such as use of Loperamide. This emanated from previous experience of polypharmacy for treatment of a psychological illness and a reluctance to “rely” upon medication, despite significant issues amongst these patients with incontinence. In addition, lack of knowledge around the current use of Loperamide and therefore its limited efficacy when used incorrectly was highlighted. Whilst Hou *et al.,* (2017) and Landers *et al.,* (2014) had noted that patients often utilised strategies in response to bowel symptoms, these were often passive and of limited efficacy. Whereas the more effective strategies such as Loperamide use and pelvic floor exercises were not as frequently adopted. This brings to light the importance of acknowledgement and awareness of the individual experiences and preferences as a potential barrier to effective treatment but also in relation to the importance of providing adequate information to patients to allow them to make informed and educated decisions about their self-care of bowel symptoms.

Furthermore, the use of dietary strategies were often noted to include low-fibre diets or use of foods which patients felt were less likely to cause problems such as highly processed foods or avoidance of fruit and veg. This practice highlighted the potential for patients to adopt diets which limited the use of foods known to reduce cancer risk such as high fibre, high folate diets. In addition, it places patients at risk of other comorbidities such as high cholesterol, diabetes or malnutrition. Food avoidance also seemed to be something which patients initiated long-term rather than tapering the reintroduction of foods. For some, once a reaction was noted to a certain food, they chose to eliminate this completely rather than attempt it at a later date. This unique finding illustrates the importance of comprehensive dietary advice being provided to both patients and those involved in their care.

Participants also described knowledge of toilet facilities as an important strategy but limited public toilet availability in Ireland potentially pose a challenge, thereby forcing patients to request use of toilets in businesses and restaurants, many of whom may operate a “for customers only” approach.

In relation to existing interventions explored by the literature review, only a single study existed which sought to aid patients in the self-care of their bowel symptoms which specifically focused on the post-rectal cancer surgery group, conducted by Nikoletti *et al.,* (2006). However, this was an intervention which was carried out with both patients and their families and was delivered in a lecture format and consisted of many patients attending a facility far from their homes but did provide a video format of lectures for those in a non-metropolitan setting.

The current study sought to examine an intervention which provided patients with strategies they could utilise in their own homes and refer to on an ongoing basis. Other studies reviewed focused on the bowel dysfunction experienced following general colorectal cancer surgery and helpful elements noted included use of multiple modalities such as telephone session, interactive handbooks and information leaflets (Hawkes *et al.,* 2009) whereas Jefford *et al.,* (2016) purported the use of a nurse-led survivorship programme which utilised a DVD, information booklet, individualised survivorship care plans and face-to-face sessions but did not focus specifically upon bowel symptoms but general symptoms experienced following bowel cancer treatment. The dearth of existing interventions which gave specific focus to the bowel symptoms experienced following sphincter-sparing surgery and the acknowledgement amongst participants for the need for a formal, evidence-based intervention paved the way for exploration of the format, content, mode of delivery, and personnel for such an intervention

6.2.3-Proposed Intervention for the Improvement of Symptom Management

Discussion of symptoms and the strategies utilised to manage such symptoms led to the exploration of intervention development, which the researcher has entitled “Colosymprove”. Within the context of the current study, it is evident that there is a need for an educational intervention geared towards aiding patients with self-care of their bowel symptom following sphincter-sparing surgery. Patients and healthcare professionals expressed their desire for improved outcomes, information and symptom management throughout the interviews and communicated the need and desire for an intervention to be developed to facilitate same. In addition, participants provided much insight into the modes, personnel, content and timing which they thought should be considered in the development of an intervention. This is illustrated further by Figure 8 and input into the TiDieR Checklist seen in Table 7. In the current study all participants acknowledged the current failings of the existing approach to manage bowel symptoms following- SSS and every participant voiced the need to develop such an intervention. Factors which seemed to influence choice of modality included patient age, literacy, technological ability and healthcare professionals voiced the importance of acknowledging the preferences of the individual.

In relation to mode of delivery many discussed leaflets, videos, applications for phones, websites, booklets and group information sessions. However, on further exploration of these topics, many recognised the fact that in modern life, one of the most universal elements was society’s use of and reliance upon phones and the potential usability of a phone-based intervention. However, also acknowledged was the usefulness and accessibility of other formats such as leaflets, especially for the older adult. In addition, the communication of certain information through different methods was acknowledged such as use of videos to demonstrate pelvic floor exercise, or diet sheets for information in relation to food.

In relation to content, patients and healthcare professionals expressed the need for information which would allow patients to cope with their bowel symptoms without significant impact or disruption of their daily lives. All recognised the importance of information relating to diet, skin care, pelvic floor exercises and medication. Unique to this study was the recognition of the importance of providing patients with information around coping with psychological issues including mindfulness and access to information regarding counselling and available resources. This study also recognised the importance of maintained a human element and component to the intervention, thus ensuring open lines of communication with healthcare professionals.

This was further explored when discussing those who should contribute to or deliver an intervention. Many felt a multi-disciplinary contribution should be facilitated but the majority of participants were of the view that this intervention should be nurse-led and in particular the nurse specialists or co-ordinators involved in patient care. This seemed to be influenced by the impression amongst patients that these nurses had more time to spend with patient and their focus was upon the holistic needs of patients whereas doctors/surgeons were more focused upon their surgery. In addition, this was potentially influenced, amongst the patients, by the fact that the nurse coordinators/specialists were the most consistent/familiar person in their cancer journey, usually meeting them at diagnosis, pre-operatively and in their clinics post-operatively. This finding was a development upon the findings of Nikoletti *et al.,* (2008) exploration of self-care practices and information needs had identified specialist nurses as the preferred person and main source of information for patients. Furthermore, these healthcare professionals were thought to have the most knowledge of the individual patients and most experience of working with this cohort. The benefits of a nurse-led intervention were also noted by Jefford *et al.,* (2016) with their nurse-led support package resulting in reduction in unmet educational needs. The current study was unique as it provided patients with a voice to contribute to the development of an intervention which was specifically for their use and benefit. Other interventions explored were developed by healthcare professionals only. In relation to timing, the current study was the only intervention identified which sought both healthcare professionals and patient opinions in relation to the timing of an intervention. Whilst this aspect of the intervention varied most amongst participants all acknowledged the importance of giving patients adequate information prior to surgery and not commencing an intervention in the immediate post-operative period due to the already challenging impact of surgery upon ability to adequately process information. In addition, also allowing time enough for bowel symptoms to present themselves following initial normal post-operative changes.

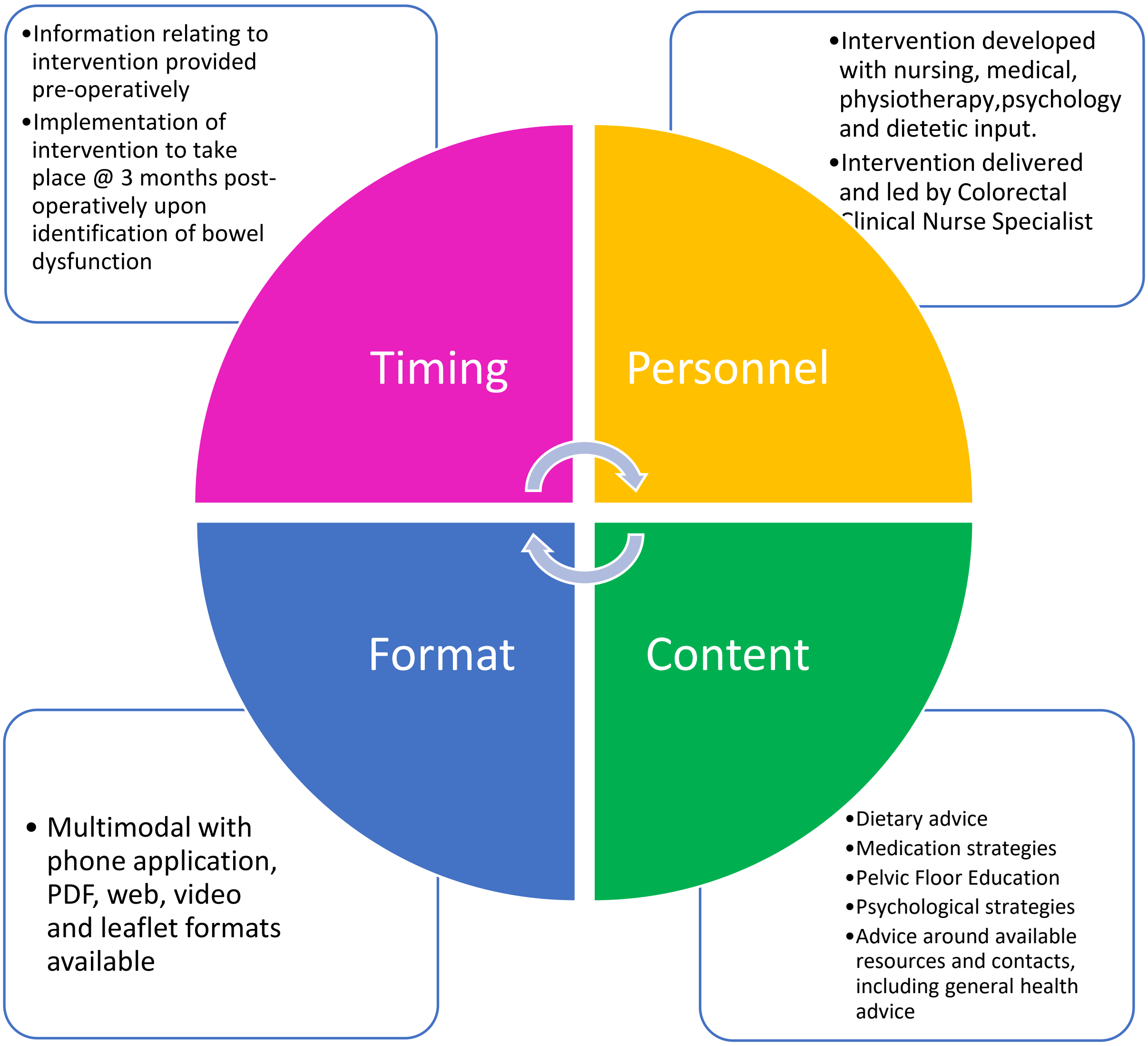
6.3- Proposed Intervention- TIDier Checklist

The TIDier checklist (Hoffman *et al.,* 2014) is utilised for the description of studies in such detail which facilitates the replication of a study by others. The potential format, timing, personnel and delivery of the proposed intervention will be illustrated in Figure 8 and the checklist laid out in Table 7.

Conclusion

In summary, in this chapter the key qualitative findings of this study within the context of the current literature and previous research were discussed. Additionally, the content, delivery, timing and personnel for underpinning a potential intervention were discussed. In the context of the previous literature, the current study has illustrated the need for an intervention to aid patients with the self-care of their bowel symptoms following sphincter-sparing surgery. In addition, this study recognised the need for improved awareness of the issue of bowel dysfunction post-SSS amongst healthcare professionals and the need for assessment of the issue and also adequate information being provided to patients to ensure they are prepared for the potential occurrence of bowel dysfunction post-SSS The participants of this study communicated the need for evidence-based guidance on strategies to manage bowel symptoms and also the importance of retaining a human link regardless of the modality of an intervention.

Finally, the intervention itself envisioned by participants was explored, a multi-modal intervention catering for all ages, literacy levels and languages was proposed. Content of the intervention desired by participants was information around potential symptoms, appropriate strategies, both specific and general information, access to resources and information. The individuals best placed to deliver an intervention were identified as being the nurse specialists involved in the patient journey from diagnosis to survivorship. The proposed intervention has the potential to provide patients experiencing life-altering bowel dysfunction with the information skills and support to aid and empower them to manage their bowel symptoms, and to do so in an evidence-based and safe way, whilst potentially limiting or removing the impact of symptoms upon daily life. A summary of the proposed intervention is presented in Figure 8 and its generation illustrated by the TIDier Checklist, Table 7.



- Information relating to intervention provided pre-operatively
- Implementation of intervention to take place @ 3 months post-operatively upon identification of bowel dysfunction

- Intervention developed with nursing, medical, physiotherapy,psychology and dietetic input.
- Intervention delivered and led by Colorectal Clinical Nurse Specialist

- Multimodal with phone application, PDF, web, video and leaflet formats available

- Dietary advice
- Medication strategies
- Pelvic Floor Education
- Psychological strategies
- Advice around available resources and contacts, including general health advice

Figure 8- Elements of Proposed Intervention for the Management of Bowel Dysfunction

Following Sphincter Sparing Surgery for Rectal Cancer

Table 7- COLOSYMPROVE-Intervention for the Management of Bowel Dysfunction Following Sphincter Sparing Surgery for Rectal Cancer (Adapted From TiDieR Checklist, Hoffman *et al.,* 2014)

Why?	Intervention to aid patients in their self-care of bowel symptoms following sphincter sparing surgery with the aim of treating, improving or reducing symptoms underpinned by the Symptom Management Theory and the MRC Framework. This intervention will be utilised by patient in the home setting to help them manage their bowel symptoms without needing to re-attend or continuously attend a hospital setting or utilise invasive techniques.
What?(materials)	This intervention will provide patients with advice and evidence-based information around medication, diet, skincare, alternative therapies, available supports, lifestyle guidance and resources. All information will be evidence based and formulated based upon the findings of previous study and developed with guidance from nursing, doctors, physiotherapy and dietician healthcare professionals. This intervention will be delivered via multiple modalities based upon the preference or ability of the participants- an application format with web and video-links will be made available to all, but a printable PDF version also available for those not wishing to or able to utilise I.T.
What? **(Procedures)**	Patients will receive general information relating to this intervention in the post-operative period and the need for its implementation will be assessed at their surgical OPD visit. This intervention will be available to patients as an application or a printable PDF version administered to those who prefer paper format. An initial assessment of bowel dysfunction will be carried out upon all patient who have undergone sphincter sparing surgery without a permanent stoma by the clinicians and Clinical Nurse Specialists in the surgical Colorectal Outpatients Clinic. Upon identification of those experiencing bowel dysfunction, selected patients will be referred for the intervention, if agreeable.
Who?	Whilst this intervention may be suggested by all members of the MDT, it will be explained and outlined to patients by the Colorectal

	Clinical Nurse Specialist assigned to them. As mentioned above, need for intervention inclusion will be assessed by Clinicians and CNSs in the CRC OPD Clinic. The development of the intervention will be collaborative project by the MDT including physiotherapists, nursing staff, doctors, psychologists and dieticians. All of those involved in the delivery of the intervention will receive training from the Clinical Nurse Specialists leading the intervention.
How? (mode of delivery; individual or group):	One face-to face interview to introduce the intervention will be delivered in the clinic setting by the Nurse Specialist. Subsequent to this, patients may opt for an application/online version of the intervention or may avail of the PDF printable version. This will be provided to patients individually. Participants will be invited to contact the CNS should they have any queries or questions and all time reminded to contact their GP, medical team or Emergency Department if they become unwell or symptoms become worse.
Where?	Intervention will be introduced to patients post-operatively but implemented in clinic and then conducted by patients at home.
When and how much?	Patients will be assessed at three months post-surgery for the need for inclusion within the intervention. Upon commencement of intervention patients will be encouraged to adhere to the advice of the intervention for 12 weeks, at which time reassessment of bowel symptoms will take place and the need for further intervention or action determined
Tailoring?	Whilst the intervention will provide general information for patients experiencing a myriad of bowel symptoms, sections specific to particular symptoms will be available within the app/ PDF leaflet. This means patients will all have access to the same information but dependent on their symptoms, may utilise same in a different way. Baseline symptoms and issues will be assessed, and areas accessed by patient will also be captured during reassessment.
Modification?	N/A
How well? (Planned)	N/A
How well? (Actual)	N/A

Table 7- Adapted TiDier Checklist-reproduced with Permission.

The following chapter will provide an overview of the thesis along with the strengths and limitations of this study and its potential recommendations and implications for education, research and practice.

Chapter 7.0- Conclusion and Recommendations

Introduction

The following chapter will outline the strengths and weaknesses of this study. In addition, recommendations for practice, education and research will be delineated. This is one of the only studies which has sought to determine the format of an intervention which patients could utilise in a non-clinical setting and one which sought to determine the mode of delivery most acceptable and useful for patents as determined by patients and those involved in their care.

7.1-Strengths and Limitations of Study

The key strengths of this study are the inclusion of the patient voice in the examination of bowel symptoms, where they feel an intervention would be beneficial, how they feel an intervention should be delivered, presented and the content it should include. An additional strength of this study was the inclusion of both nursing and medical perspectives, across a variety of roles to facilitate a balanced and multi-faceted viewpoint. Although not a large sample, this sample provided a variety of perspectives around symptoms, strategies and what should be included to best aid patients in their care of their bowel symptoms. Furthermore, use and underpinning by the guidelines of the Medical Research Council Framework ensured the study was conducted in a logical, step-by step process in which theory was linked to practice. The use of the Symptom

Management Theory to underpin this study also served to strengthen its findings as its use facilitated identification of the clear concepts of symptom experience, symptom management strategies, and the resultant physical, emotional and social responses. thereby providing a clear framework through which a patient's symptoms can be assessed and facilitating insight into the way symptoms can be managed.

In relation to the study's limitations, its small purposeful sample, although deemed to be the most appropriate sample for the purpose of this study, may be viewed as a limitation. In addition, conducting the study in one healthcare facility, a national centre for colorectal cancer surgery, may limit the transferability of findings and its application to smaller centres. Furthermore, the use of a purposeful sample may have resulted in the selection of more severely impacted patents being selected, potentially preventing the experience of more moderately affected patients being explored. In the current study, an established instrument was not utilised to assess the self-care strategies used by patients to manage their bowel symptoms as it was felt a less constricted approach would facilitate a wider discussion around symptom experience.

Finally, another potential weakness of the study was that the researcher worked alongside all of the healthcare professional participants, however, all attempts were made to eliminate the risk of coercion the potential of participants. The steps taken to manage this were as described in the Methodology chapter. An examination of this strengths and weaknesses of this study played a key part in the development of this study’s recommendations for research, which the following section will explore.

7.2-Recommendations for Research

- The development of a multi-modal, nurse-led intervention to aid patients in the self-care of their bowel symptoms following sphincter-sparing surgery for rectal cancer. This should also be available in both online and hard copy versions to patients of varying technological abilities. An application format available for phones is recommended.
- The content of the intervention should include description of potential symptoms, advice on diet, medication, skin care, pelvic floor exercise, available resources, health promotion and healthcare professional contact.
- Development of an intervention should include input from nursing, doctors, dietetics, physiotherapy, psychology and patients.
- The existence of an intervention should be introduced to patients in the post-operative period but not implemented until after their initial outpatient appointment.
- A pilot study of the intervention should be carried out to ensure its feasibility, effectiveness, usability, compliance with NALA (National Adult Literacy Agency) guidelines.
- A longitudinal study with a larger sample from a number of institutions should be carried out to assess the sustainability of the intervention, the long-term impact upon bowel

symptoms and whether such an intervention has measurable impact upon patient quality of life outcomes.

7.3- Recommendations for Practice

- Development of clear protocols and referral pathways for patients experiencing bowel dysfunction should be established to ensure prompt and effective recognition and management.
- Ensure information around the development of bowel dysfunction and colorectal cancer treatment and prevention are more readily available for healthcare professionals.

7.4- Recommendations for Education

- Increased awareness amongst healthcare professionals relating to the issue of bowel dysfunction following-SSS should be fostered through education and training.
- Following rectal cancer surgery patients should be assessed for the occurrence of bowel dysfunction.
- All healthcare professionals working with this cohort of patients should receive education relating to the potential side-effects of rectal cancer treatment and potential strategies which can be utilised to improve or eliminate these issues.

To ensure the findings of this study are communicated and shared, they will be disseminated in journals, at conferences and also delivered by the researcher to colleagues and participants in this setting. It is hoped that a template of this proposed intervention will be developed in the researcher's place of work and piloted. The findings of this study will and have already informed current practice in the setting in which the study was conducted and also will through dissemination inform current practice on a national and international level and facilitate a heightened level of awareness in relation to the issue of bowel dysfunction following-SSS for rectal cancer.

Conclusion

This study emanated from a dearth within current research and practice around interventions for those experiencing altered bowel function following sphincter-sparing surgery for rectal cancer. Whilst studies have extensively acknowledged the existence of bowel dysfunction and its often life-altering impact, few sought to take this knowledge and utilise both it and the views of patients and healthcare professionals to formulate something useful, helpful, accessible, convenient and effective, to aid patient in their management and care of bowel symptoms. Existing interventions focused upon bowel symptoms resultant of idiopathic faecal incontinence, IBD or IBS as opposed to the very specific symptoms experience by those following SSS for rectal cancer. For those interventions which did focus upon cancer survivors they often only gave brief reference to bowel symptoms or were often delivered in a format which limited accessibility such as hospital-based lectures.

This study was unique in its inclusion of both HCPs and patient but also in its goal to develop an intervention which could be accessed by the many, not the few. In addition, the use of the Symptom Management Theory, guided this study from the literature review, structure of interviews, the presentation of findings, to its use in underpinning the potential intervention. A key and unique finding of this study in relation to symptom experience was its marked impact upon not only the physical aspects such as sleep and skin integrity but also upon affected patients' social, psychological and economic well-being. This study also ascertained what is important for information in the views of patients as opposed to what we as healthcare professionals believe they will find helpful. This study also uniquely sought to determine and did identify which modes of delivery and personnel would be most appropriate. One of the key findings of this study explored was the importance of timing. Through exploration of this topic the current failings of practice were also recognised, this emanated not just from the ignorance of healthcare professionals but also the continuous challenges presented by limited resources and timing within outpatient facilities. This highlights the need to develop an intervention which patients themselves can utilise at home without having to continuously attend clinical setting but also removes strain and stress upon the healthcare professional trying to arrange and ensure the oncological surveillance of patients being further imbued with the task of trying to resolve functional issues within a 2 minute outpatient meeting. This intervention, if developed, would allow patients already faced with the life-altering diagnosis of cancer and its resultant effects, with a lifeline or tool which allows them access to information, guidance and support which is evidence-based, developed with HCPs as opposed to the sporadic, trial-and-error, time-constrained approach which currently exists. This study has shown the symptom experience, strategies utilised and desired solution in a form of an intervention as outlined by patients and those involved in their care. This intervention should be delivered in a timely fashion, focus initially on the general, then specific, be formulated by the MDT, be initiated by the Nurse specialist and provide information around general health, dietary interventions, skin care, medication advice, alternative therapies and available resources with the view of improving the lives of patients following sphincter-sparing surgery for rectal cancer. As care of chronic issues moves from the clinical to the community and professional to the patient, it is hoped that the findings of this study will facilitate an intervention to allow patients to manage their bowel dysfunction in a safe and evidence-based manner. This study uniquely included the voice of the patient and the professional and it is hoped that this will contribute to the existing body of evidence around this issue and lead to the development of an intervention which could potentially change the lives of affected patients.

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Appendices

Appendix 1

Search Strategy 1- Bowel Symptoms Following SSS for Rectal Cancer

S1= rect* OR colorect* OR “large intestine” OR “large bowel” **84,270 results**

S2= canc* OR neoplasm* OR tumour OR tumor OR malignanc* **596,941 results**

S3= “anterior resection” OR “sphincter-sparing” OR surg* OR “sphincter saving” OR sphincter preserving* OR “rectal surgery” OR “total mesorectal excision” **715,103 results**

S4= “anterior resection syndrome” OR “bowel symptoms” OR “symptom bother” OR “symptom burden” OR “bowel problems” OR incontinence OR urgency OR frequency OR tenesmus OR leakage **228,464 results**

S1 + S2 = **48,947 results**

S1 + S2 + S3 = **21,920 results**

S1 + S2 + S3 +S4 = **7,247 results**

Above + Limits YEARS (2006- 2016) = **3,851 results**

Above + English Language =**3,844 results**

Above + Research Article = **1,559 results**

Above + Peer Reviewed = **1,552 results**

Above + Human = **1,480 results**

Appendix 2

Search Strategy 2- Search Terms-Self-Care Strategies for bowel symptoms Following SSS for Rectal Cancer

CINAHL Search

S1= rect* OR colorect* OR “large intestine” OR “large bowel” **84,270 results**

S2= canc* OR neoplasm* OR tumour OR tumor OR malignanc* **596,941 results**

S3= “anterior resection” OR “sphincter-sparing” OR surg* OR “sphincter saving” OR sphincter preserving* OR “rectal surgery” OR “total mesorectal excision” **715,103 results**

S4= “anterior resection syndrome” OR “bowel symptoms” OR “symptom bother” OR “symptom burden” OR “bowel problems” OR incontinence OR urgency OR frequency OR tenesmus OR leakage **228,464 results**

S5= management OR “self- management” or “patient interventions” OR “self-care” OR “self-care strategies” OR “coping strategies” OR “symptom management” **730,807 results**

S1 + S2 = **48,947 results**

S1 + S2 + S3 = **21,920 results**

S1 + S2 + S3 +S4 = **7,247 results**

S1 + S2+ S3+ S4+ S5 = **5,175 results**

Above + Limits YEARS (2006- 2016) = **3,851 results**

Above + English Language =**3,844 results**

Above + Research Article = **1,559 results**

Above + Peer Reviewed = **1,552 results**

Above + Human = **1,480 results**

Above + Adult (>18 years) = **774 results**

PubMed Search

S1= rect* OR colorect* OR “large intestine” OR “large bowel” **277,056 results**

S2= canc* OR neoplasm* OR tumour OR tumor OR malignanc* **3,795,759 results**

S3= “anterior resection” OR “sphincter-sparing” OR “sphincter saving” OR sphincter preserving* OR “rectal surgery” OR “total mesorectal excision” **3,049,851 results**

S4= “anterior resection syndrome” OR “bowel symptoms” OR “symptom bother” OR “symptom burden” OR “bowel problems” OR incontinence OR urgency OR frequency OR tenesmus **2,635,021 results**

S5= management OR “self- management” or “patient interventions” OR “self-care” OR “self-care strategies” OR “coping strategies” OR “symptom management” **2,247,003 results**

S1 +S2 = **166,559 results**

S1+ S2 +S3 = **67,510 results**

S1+ S2+ S3+ S4 = **17,947 results**

S1 +S2 + S3 + S4 + S5 =**3,314 results**

Above + LIMIT Years (2006-2016) **= 2,074 results**

Above + English Language = **1,987 results**

Above + Human = **1,916 results**

Above + Adult aged >19 years = **1,501**

Medline Search Strategy

S1= rect* OR colorect* OR bowel* OR “large bowel”= **442,402 results**

S2= neoplasm* OR malignanc* OR canc* OR tumor* OR tumour* OR adenocarcinoma* OR carcinoma = **3,631,856 results**

S3= “colorectal surgery” OR “bowel surgery” OR “rectal surgery” OR “anterior resection” OR “total mesorectal excision” OR “TME” OR “bowel resection” OR “ileostomy formation” OR “ileostomy reversal” OR “sphincter-sparing” OR “sphincter saving” OR “sphincter preserving”= **27,203 results**

S4 = "anterior resection syndrome" OR "bowel symptoms" OR "bowel problems" OR incontinence OR urgency OR frequency OR tenesmus OR leakage OR soiling **= 848,548 results**

S1 + S2= 210,583 results

S1 + S2 + S3= 13,639 results

S1 + S2 + S3 + S4 = 1,615 results

S1 + S2 + S3 + S4 + LIMIT 2006-2017= 1,303 Results

S1 + S2 + S3 + S4 + LIMIT 2006-2017 + English Language = 1,174 results

S1 + S2 + S3 + S4 + LIMIT 2006-2017 + English Language + Human = 907 Results

Appendix 3

Search Terms – Interventions Search Strategy

S1- "bowel symptoms" OR "bowel dysfunction" OR "faecal incontinence" OR "fecal incontinence" OR leakage OR urgency OR frequency OR tenesmus OR bowel OR "skin irritation" OR "perianal irritation" OR symptoms = 572,027 results

S2- education OR intervention OR "web-based intervention" OR "education programme" OR management OR tool OR programme OR information OR guide=2,328,070 results

S3- "irritable bowel" OR" inflammatory bowel disease" OR "crohns" OR "ulcerative collitis" OR rectal cancer" OR "sphincter-sparing surgery" OR "anterior resection"=13,782 results

S4- nurse OR nurs* OR “nurse led” = 1,516,118 results

S1 & S2 = 385,043 Results

S1 & S2 & S3= 8,511 Results

S1 & S2 & S3 & S4 = 4,195 Results

S1 & S2 & S3 & S4 & Limitation 2005-2017= 3,538 Results

S1 & S2 & S3 & Limitation 2005-2017 & Academic Journals = 2,938 Results

Appendix 4- Ethics Committee Approval Letter

Professor Tanya [redacted]
Director of Nursing
[redacted]

23rd July 2018 Institutional Review Board Reference: 1/378/2000

RE: Bowel symptom management following sphincter-sparing surgery for rectal cancer Research Study Protocol
Letter of Invitation — Patient, 05/07/18 Version 2
Participant Information Leaflet (Healthcare Professional) — 05/07/18 Version 2
Participant Information Leaflet (Patient) — 05107118 Version 2
Healthcare Professional Consent Form — 05/07/18 Version 2
Patient Consent Form — 05/07/18 Version 2

Dear Professor [redacted] (Principal Investigator)

I acknowledge receipt of your correspondence addressing points of clarification and enclosing a revised Letter of Invitation — Patient (05/07/18 Version 2), revised Participant Information Leaflet (Healthcare Professional 05/07/18 Version 2), revised Participant Information Leaflet (Patient 05/07/18 Version 2), revised Healthcare Professional Consent Form (05/07/18 Version 2) and revised Patient Consent Form (05/07/18 Version 2) as requested by the [redacted] Hospital and [redacted] Hospital Institutional Review Board (IRB) for the above research study to be carried out at the [redacted]).

This correspondence has been noted and the above listed documents have been approved. Approval to proceed with this research study at the [redacted] is granted; this approval is valid until 27th June 2020.

It is your responsibility to adhere to the approved study protocol and ensure that all researchers involved with the research only use the approved documents without deviation (unless they have been approved by the IRB), to submit annual reports setting out the progress of the research (giving details of the number of participants who have been recruited, the number who have completed the study and details of any adverse events etc.) and to notify the IRB when the research is concluded.

The [redacted] Hospital and [redacted] Hospital IRB would like to remind all investigators involved in research of their legal obligations under the law on Data Protection.

Yours sincerely,

[redacted]

Prof [redacted]
Chairman
Institutional Review Board

Appendix 5- Clinical Director Letter of Permission

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Letter of Permission

Dear Prof. [redacted],

My name is Mairéad O' Sullivan, a staff nurse on [redacted] Ward and I am currently undertaking a Masters by Research with University College of Cork School of Nursing. I am writing to you to seek permission to interview patients whom you have operated upon for the treatment of rectal cancer.

I am hoping to conduct a study examining the bowel symptoms experienced by patients following sphincter-sparing surgery for rectal cancer, the self-care strategies utilised, and the information needs of patients to inform the development of an intervention to aid patients in the self-care of their bowel symptoms.

For this study I wish to interview approximately 15 patients who have undergone these surgeries, including patients in whose care you have been involved. Using a semi-structured interviews I will be interviewing patients in relation to their bowel symptoms, the strategies they use to manage these bowel symptoms and also asking them to evaluate information for proposed inclusion within a web-based intervention.

I hope to recruit these patients through their outpatient appointments or their outpatient interactions with the Colorectal Clinical Nurse Specialists.

I would really appreciate any help you could give me in relation to this and if you have any further questions please, do not hesitate to contact me.

Kind regards,

Mairéad O' Sullivan

Appendix 6- Letter of Permission Colorectal Surgeons-Example 1

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Letter of Permission

Dear Professor [redacted],

My name is Mairéad O' Sullivan, a staff nurse on St. *****'s Ward and I am currently undertaking a Masters by Research with University College of Cork School of Nursing. I am writing to you to seek permission to interview patients whom you have operated upon for the treatment of rectal cancer.

I am hoping to conduct a study examining the bowel symptoms experienced by patients following sphincter-sparing surgery for rectal cancer, the self-care strategies utilised, and the information needs of patients to inform the development of an intervention to aid patients in the self-care of their bowel symptoms.

For this study I wish to interview approximately 15 patients who have undergone these surgeries, including patients in whose care you have been involved. Using a semi-structured format I will be interviewing patients in relation to their bowel symptoms, the strategies they use to manage these bowel symptoms and also asking them to evaluate information for proposed inclusion within a web-based intervention.

I hope to recruit these patients through their outpatient appointments or their outpatient interactions with the Colorectal Clinical Nurse Specialists.

I would really appreciate any help you could give me in relation to this and if you have any further questions please, do not hesitate to contact me.

Kind regards,

Mairéad O' Sullivan

If you give permission for inclusion of your patients within this study please sign below and return to [redacted] Ward, F.A.O Staff Nurse Mairéad O' Sullivan or Email; [redacted]@gmail.com

I hereby give consent for patients, upon whom I have performed sphincter-sparing surgery for rectal cancer, to be included in the research study **"Bowel Symptom Management Following sphincter-sparing surgery for Rectal Cancer",** being carried out by Ms. Mairéad O' Sullivan as part of fulfilment of an academic dissertation.

Signed……… ………………………………..

Date…2/05/2018……………………………………

Appendix 7- Letter of Invitation-Patient

Ms. Mairéad O' Sullivan,

[redacted]

Email; [redacted]

Dear ……….,

I would like to invite you to participate in the study "Bowel symptom management following sphincter-sparing surgery for rectal cancer". I, Mairéad O' Sullivan, am undertaking this study as part of a Masters by Research with University College of Cork School of Nursing and Midwifery.

The proposed study is described in the information leaflet you have been given by your Clinical Nurse Specialist or Colorectal Consultant. Colorectal cancer is the second most common cancer in men and women in Ireland. Of individuals diagnosed with rectal cancer, 70% will undergo surgery, which can result in the development of altered bowel symptoms. The proposed study will seek to identify strategies which may be useful for patients to self-care for their bowel symptoms following surgery for rectal cancer through interviews with both patients and healthcare professionals. Secondly, it is proposed that this information will be used in the drafting of a plan/framework outlining the proposed content, preferred format of delivery of an intervention.

If you would like to participate in this research study, please carefully read the participant information leaflet included herein for further information. Do not hesitate to contact me via the above e-mail address or phone number should you have any concerns or queries that are not addressed by the participant information leaflet. If you decide to take part in this research study, please complete the enclosed consent form and return it to me at the above address by mail at your earliest convenience or return it to your Colorectal Clinical Nurse Specialist or Colorectal Consultant.

Kind regards,

Mairead O' Sullivan (BSc, RGN)

Appendix 8- PARTICIPANT INFORMATION LEAFLET (Patient)

Research Study Title: "Bowel Symptom Management following sphincter-sparing surgery for rectal cancer".

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

What does this mean?

This study aims to identify the bowel symptoms experienced by patients following surgery for rectal cancer, the strategies they use to manage these and what they would like to see included in an intervention aimed at helping them to care for their bowel symptoms at home.

What is the purpose of the research study?

To identify the symptoms experienced by patients after surgery for rectal cancer

To examine the strategies patients use to manage their bowel symptoms

To identify the information which both patients and those involved in their care think need to be included in the proposed intervention.

To determine the content, format and mode of delivery of an intervention to help patients in the self-care of their bowel symptoms following sphincter-sparing surgery for rectal cancer.

Why have I been chosen?

You have been chosen for this study as you have recently had surgery in the [redacted] for treatment of rectal cancer and reported altered bowel function following this surgery. Fifteen participants in total who recently had surgery for rectal cancer in the MMUH have been chosen.

Who is organising the research study?

Ms. Mairéad O' Sullivan, Staff Nurse on [redacted] Ward in the [redacted] Hopsital, is organising the research study as part of an academic dissertation in affiliation with University College Cork (UCC). The anticipated duration of this study is 6 weeks.

As a participant in this study your input is required for one interview the researcher, Ms. Mairéad O' Sullivan.

How will participants be recruited and selected?

Subsequent to ethical approval, potential participants will provided with an information leaflet about the study by your Colorectal Clinical Nurse Specialist or Colorectal Surgeon. The researcher, Ms. Mairéad O' Sullivan, the lead researcher will also be available to answer any questions you might have about the study. Attached to this leaflet is a consent form, individuals who express an interest in participating in the study can either agree to participate immediately and sign same or can take a 1 week period to consider same. You may also receive one reminder from the lead researcher Mairéad to make sur eyou still want to participate before the application closing date. Upon agreement to participate, participants will receive a formal letter of invitation and confidentiality agreement.

A confidentiality agreement will be used to protect the identity of all participants involved in this study and will be an agreement that no participant will disclose any information discussed during this study. For those who wish to avail of it a one-week "cooling off" period will be offered to decide about their participation.

Within that period of 'cooling off ', potential participants will be encouraged to contact the researcher if they have any concerns or questions regarding participating in this study.

The potential patient participants will be approached by the researcher via telephone to finalise whether they wish to partake or not. The consent form will then be signed with the patient participant . The researcher aims to conduct the interview within 2 weeks of the consent forms being completed but will work around the availability of participants.

What is expected of your participation?

As a participant in this study you will be required to attend one interview with the researcher, Ms. Mairéad O' Sullivan. The interview will last approximately one hour. As a participant you will be required to sign a consent and confidentiality agreement prior to commencing this study. As a participant you will be required to openly discuss and share your experience of altered bowel function following surgery for rectal cancer and strategies you have utilised to manage same.

The interviews will be audio recorded and typed notes will be kept ensuring that the information collected from these meetings is accurate. Your identity will be anonymised on the recordings and kept strictly confidential. A summary of the study will be made available to you following completion. You will not be required to give any identifying information during the audio recording of the meeting.

Are there any disadvantages in taking part in this research study?

No.

What are the possible risks of taking part in this research study?

There are no risks associated with taking part in this research study.

What are the possible benefits of taking part in this study?

It is hoped that this research will benefit patients by contributing to the existing knowledge around the self-care of bowel symptoms experienced following surgery for rectal cancer.

It is also hoped that this research will give health care professionals further insight into strategies which could aid patients in the management of their bowel symptoms

Finally, it is hoped that by participating in this study, participants may gain insight into strategies which are safe and evidence based which could help them to manage their bowel symptoms.

Confidentiality – who will know I am taking part in the research study?

The Colorectal Clinical Nurse Specialist involved in you care and the surgical consultant who performed your surgery will be aware of your participation. If you choose not to participate in this study or choose to withdraw from the study at any stage, this will not have any effect on your future healthcare treatment. The meeting you required to attend will be audio recorded to ensure the information that is collected is accurate. The information you will provide will be strictly confidential and will be anonymised at all times during this study. Ms. Mairéad O’ Sullivan will be the individual who will be transcribing the audio-recorded interviews. All data collected from study will be securely stored by the lead investigator, Ms. Mairéad O’ Sullivan, and she will be the individual who will destroy the information collected.

What will happen to the results of the research study

Results will be used as part of an academic dissertation by Ms. Mairéad O' Sullivan. In the future, the results of the research study may be submitted for publication to an academic journal and/or used to help other patients who have experienced altered bowel function following surgery for rectal cancer. Again, all patient details will be anonymous.

Procedure to be used if assistance or advice is required

If you require any further information please contact, Ms. Mairéad O' Sullivan Staff Nurse, [redacted]

Telephone: (0[redacted]/ 087[redacted] or E-mail: [redacted]@gmail.com

Voluntary Participation

Your decision to participate in this research study is voluntary (your choice). You may leave the study at any point and you do not have to give a reason. Your non-participation or withdrawal in this study will not impact on your healthcare circumstances. If you are interested in participating in this study, please read and complete the consent form included.

Thank you for taking the time to consider taking part in this research study.

Appendix 9 PATIENT CONSENT FORM

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Study Title:

“Bowel Symptom Management following sphincter-sparing surgery for rectal cancer”

I……………………………………agree to participate in Ms. Mairead O’ Sullivan’s research study.

- The purpose and nature of the study has been explained to me in writing.

- I am participating voluntarily.

- I give permission for my interview with Ms. Mairead O’ Sullivan to be audio-recorded.

- I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

- I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

- I understand that anonymity will be ensured in the write-up by disguising my identity.
- I understand that I can seek a summary of the study upon request.☐
- I understand that my surgeon will be informed that I am taking part in this research study.
- I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed: ……………………………………. Date: ………………..

PRINT NAME: …………………………………….

Appendix 10- PARTICIPANT INFORMATION LEAFLET (Healthcare Professional)

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Research Study Title

"Bowel symptom management following sphincter-sparing surgery for rectal cancer"

What does this mean?

In 2012, there were almost 1.4 million reported cases of colorectal cancer (GLOBOCAN, 2012). In Ireland, colorectal cancer one of the most common cancer in both sexes, with rectal cancer accounting for 27% of cases (National Cancer Registry of Ireland, 2013). The treatment of rectal cancer often negatively impacts upon quality of life and causes the development of life-altering bowel symptoms (Bryant et al., 2012). Studies vary in their reports of bowel dysfunction prevalence from 10% (Allgayer et al., 2005) to 90% (Bryant et al., 2012). A plethora of symptoms, such as faecal incontinence, leakage, urgency, incomplete defecation, evacuatory dysfunction, fragmentation of stools, tenesmus and incontinence of flatus have been reported following sphincter sparing surgery (Laforest et al., 2012, Pachler & Wille- Jorgensen, 2012).

Some of the psychological and social effects of altered bowel function upon individuals included withdrawal from social activities, reduced ability to participate in unplanned activity, impaired sexual function, fear of recurrence, embarrassment, anxiety in relation to employment, limitation of food intake and perceived lack of ability to cope (Nikoletti et al., 2008, Landers et al., 2012, Hou et al., 2016).

Little has been published into possible interventions which may be utilised by patients in the non-clinical setting. There is an evident gap in the research in relation to a supportive and up-to-date intervention to enable patients in the self-care of bowel symptoms experienced specifically following surgery for rectal cancer.Prior to developing an intervention, it is important to ascertain the information needs of patients, the symptoms most commonly experienced, the strategies which they deem most practical/ useful and the perspectives of the professionals involved in their care.

What is the purpose of the research study?

The proposed study will seek to identify strategies which may be useful for patients to self-care for their bowel symptoms following surgery for rectal cancer through interviews with both patients and healthcare professionals.

Secondly, it is proposed that this information, along with the findings of an extensive literature review, will be used in the drafting of a plan/framework outlining the proposed content, preferred format of delivery of an intervention.

Why have I been chosen?

You have been chosen for this study as your knowledge, professional background, expertise and clinical experience is required to achieve the aim of this research study. Ten participants in total from nursing and medical backgrounds have been chosen. Fifteen patients who have undergone surgery for rectal cancer surgery in the [redacted] will also be interviewed.

Who is organising the research study?

Ms Mairéad O' Sullivan, Staff Nurse on [redacted], is organising the research study as part of an academic dissertation in affiliation with University College Cork (UCC) and is the Lead Researcher. The Principal Investigator of this study is [redacted]). The anticipated duration of data collection for this study is 2 months. As a participant in this study your input is required for a single interview with the Lead Researcher Mairéad O'Sullivan.

How will participants be recruited and selected?

Subsequent to ethical approval, potential participants will be approached verbally by the researcher, Ms. Mairéad O' Sullivan, to inform them of the aim and objectives of this study. Individuals who express an interest in participating in the study will receive a formal letter of invitation, participant information leaflet, confidentiality agreement and consent form. A confidentiality agreement will be used to protect the identity of all participants involved in this study and will be an agreement that no participant will disclose any information discussed during this study. Completed consent forms and confidentiality agreements will be returned to the researcher's work address by mail. [redacted] employees can return their signed consent forms and confidentiality agreement via internal mail. A 'cooling off' period of one week will be given to potential participants, so they will have time to think about whether they wish to take part in the research study or not. Within that week period, potential participants will be encouraged to contact the researcher if they have any concerns or questions regarding participating in the study. After the week has passed the participants will be approached verbally by the researcher in [redacted] to finalise whether they wish to partake or not.

What is the commitment expected of participants?

Participants will be required to participate in a single interview with the Lead Researcher Ms. Mairéad O' Sullivan. Each meeting will last approximately one hour. Meetings will be audio recorded to ensure that the data collected from these meetings is accurate. As a participant you will be required to sign a consent form and confidentiality agreement prior to commencing the study. If you are unable to attend the scheduled interview date then an alternative date may be rearranged. After individual interviews the audio recorded data will be analysed by Ms. Mairéad O' Sullivan.

What type of research will be used?

The research study design that will be used is qualitative descriptive. This is a form of research that enables the researcher to describe phenomena in a straight-forward manner, uninfluenced and unencumbered by pre-existed theoretical constraints and philosophical commitment (Lambert, 2012 & Sandelowski, 2010).

A qualitative approach will allow the researcher to explore the experiences and potential behaviours of both patients and healthcare professionals and to evaluate interventions (Parahoo, 2006). A descriptive method has been chosen to explore the perspectives of patients and applicable healthcare professionals relating to the potential usability and helpfulness of a number of strategies to manage bowel symptoms. Descriptive studies facilitate exploration about phenomena about which there is a dearth of knowledge (Burns & Grove, 2011, Parahoo, 2006).

Are there any disadvantages in taking part in this research study?

No, however, your participation in this project my pose time consuming due to the commitment required for this project as outlined above. Participant awareness of voluntary participation will be helpful in this regard.

What are the possible risks of taking part in this research study?

There are no risks associated with taking part in this research study.

What are the possible benefits of taking part in this research study?

1) The symptoms most commonly experienced by patients following sphincter sparing surgery for rectal cancer may will be identified, which will potentially have a positive impact upon informing the interventions development and therefore its potential to aid patient in the self-care of their bowel symptoms.

2) The development of content for a potential web-based intervention to aid patients in the self-care of their bowel symptoms experienced following SSS for rectal cancer

3) Potential associated positive effects on nurse and clinician knowledge relating to bowel symptoms experienced and strategies which may be utilised, which could therefore improve patient care/satisfaction/experience.

4) Generation of new knowledge on the development of an intervention to aid patients in their self-care of bowel symptoms for use in colorectal services across the healthcare system.

5) This study may impact and influence the further development of interventions which seek to support patients in their self-care outside of the clinical setting.

Confidentiality – who will know I am taking part in the research study?

Your supervisor/department head will be aware that you are taking part in the research study. All data from the research group meetings will be made anonymous and strictly confidential. Ms. Mairéad O' Sullivan will be the individual who will be transcribing the audio-recorded interviews. All data collected from study will be securely stored by the lead investigator, Mr. Robert Lynch, and she will be the individual who will appropriately destroy the information collected from this study.

Hospital Research Ethics Committee Approval

Approval from the [redacted] Institutional Review Board has been granted prior to commencing this study.

What will happen to the results of the research study?

Once the research study is complete, a summary of the study's results will be made available to all participants, both patients and healthcare professionals. Results will also be used as part of an academic dissertation by Ms. Mairéad O' Sullivan. In the future, the results of the research study may be submitted for publication to an academic journal and/or made available to the [redacted] Centre of Nurse Education.

Procedure to be used if assistance or advice is required

If you require any further information please contact, Ms. Mairéad O’ Sullivan Staff Nurse, [redacted] at:

Telephone: [redacted] or E-mail:

Voluntary Participation

Your decision to participate in this research study is voluntary (your choice). You may leave the study at any point and you do not have to give a reason. Your non-participation or withdrawal will not impact on your working status. If you are interested in participating in this study, please read and complete the consent form included.

Thank you for taking the time to consider taking part in this research study.

Appendix 11- Healthcare Professional CONSENT FORM

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Study Title:

"Bowel Symptom Management following sphincter-sparing surgery for rectal cancer"

I…………………………………….agree to participate in Ms. Mairead O' Sullivan's research study.

- The purpose and nature of the study has been explained to me in writing.
- I am participating voluntarily.
- I give permission for my participation in the interview with Ms. Mairéad O' Sullivan to be audio-recorded.
- I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.
- I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.
- I understand that anonymity will be ensured in the write-up by disguising my identity.

- I understand that I can seek a summary of the study upon request.

- I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview ☐

I do not agree to quotation/publication of extracts from my interview ☐

Signed: ………………………………….. Date: ………………..

PRINT NAME: …………………………………..

Appendix 12- Patient Interview Prompts

1)Can you talk to be about to me about your bowel symptoms following your surgery?

2)Are there symptoms you find more bothersome than others, can you tell me about these?

3)Can you tell me about the ways, if any, your bowel habits have affected your daily life? What has been the biggest change?

4)You talk about a number of symptoms, for you are what are some of the ore bothersome symptoms?Can you talk about how frequently these symptoms occur?

5)Do you have any ways/ strategies you use to cope with your bowel habits? Can you tell me more about these?

6)Are there particular strategies you use for specific symptoms? Can you tell me about these?

7)Are there some strategies you find more useful than others?

8)Can you tell me about any skin care strategies you utilise?

9)Have you made any changes to your diet following surgery to manage your bowel symptoms and if so can you tell me about them?

10) Have you used any strategies suggested to you by a healthcare professional? Can you tell me about these?

11)If given the option to design an intervention for patients who have had surgery like you what information would you like it to include?

12)Given the option of a booklet, leaflet, application, or website for information which would you prefer and why?

13)Can you tell me about information you would most like to see included in an intervention and why?

14)Would you like to receive information about skin care in an intervention and why?

15) Is information about diet something you would like included in an intervention and why?

16) Is information relating to pelvic floor exercises something you would like to receive and why? How would you like to receive this information?

17) Can you tell me about how an intervention to cope with bowel symptoms might affect you?

18) Is there anything else in relation to your experience of bowel symptoms you would like to share?

19)Can you tell me anything about your strategies for coping with altered bowel habits which we have not discussed?

20) What strategies have best worked for you in coping with your bowel symptoms and why?

21) Are there times that your symptoms are worse than others and can you tell me about this?

22)In what ways do you find bowel symptoms problematic?

Appendix 13- Healthcare Professional Interview Prompts

1)In your experience what bowel symptoms are most often seen following sphincter-sparing surgery?

2)Talk to me about the symptoms to encounter most often?

3)Can you tell me about some of the self-care strategies you have noted patients self-initiating?

4)What strategies do you think are most beneficial for patients?

5)What are the most common questions asked by patients in relation to their bowel symptoms?

6)What are the most common questions asked by patients about strategies to cope with bowel symptoms?

7)Can you discuss information you would like to see included in an intervention seeking to aid patients in their self-care?

8)How would you like to see this intervention delivered and why would you pick this format i.e what format? e.g mobile application, website, leaflet.

9) Do you think individual strategies should be given for individual symptoms and why?

10)Would you prefer to see general information in relation to strategies following surgery for rectal cancer and if so, what information?

11)Would you like to see information in relation to possible over the counter medication management of symptoms and if so what information?

12)Would you like to see pelvic floor exercise information included and if so in what format or delivery would you propose? Why this format?

13)Is information relating to dietary advice something you would like to see included in an intervention and why?

14)Do you think information relating to perianal skin care would be useful and why?

15)How do you think a structured intervention which aids patients in their self-care could benefit patients?

16)What do you think about information relating to pelvic floor exercises being included in an intervention?

17)What are the main topics you think should be included in an intervention and why?

18)In relation to the time period during which an intervention should be suggested to/ initiated with patients, do you think the pre-operative or post-operative period would be most beneficial and why?

Appendix 14- Demographic Leaflet for Patient Participants

Age

-18-34 years old ☐

-35-54 years old☐

-55-64 years old☐

-65-74 years old☐

-75-84 years old☐

-85-94 years old☐

-95-104 years old☐

Gender

Male ☐

Female☐

Other ☐

Employment Status

Employed☐

Unemployed☐

Retired☐

Student☐

What is your marital status?

Single (never married)☐

Married, or in a domestic partnership☐

Widowed☐

Divorced☐

Separated☐

What is the highest level of education you have completed?

No formal education/ Primary ☐

Junior Cert☐

Leaving Cert☐

Third Level (non-degree)☐

Third Level (degree)☐

Postgraduate ☐

Time since surgery

-6 weeks-2 months☐

-2-6 months☐

-6 months-1 year☐

-1-2 years☐

-2-4 years☐

-4-6 years☐

-Greater than 6 years☐

Appendix 15- Healthcare Professional Demographic Leaflet

Age

-18-34 years old ☐

-35-54 years old☐

-55-64 years old☐

-65-74 years old☐

Gender

Male ☐

Female☐

Other ☐

Education

Third Level (non- degree)☐

Third Level (degree)☐

Postgraduate ☐

Doctorate☐

If you have a specialist qualification, please outline same below;

………

………

Years since qualification

-Less than 1 year☐

-1-2 years☐

-2-5 years☐

-5-10 years☐

-Greater than 10 years☐

Appendix 16-Excerpt of Data Extraction Process-Guided by Elo & Kyngas (2017)

Unit of analysis	Meaning Unit	Condensed meaning Unit	Code	? Subcategory	Category (i.e. pre-determined category	Overall themes
Whole interview/ transcript.	Quotation relevant to the 'category' minus unnecessary words/remarks that from part of normal conversation	A reduced version of the meaning unit without losing the meaning of the data.	Two to three words/concepts that capture the essence of the meaning unit.	Does the pre-determined category need to be broken into two 'subcategories' i.e. one or two subcategories may be necessary where there are varying views (n=14)	All ready identified (NB it is important not to force the data A new category may emerge not pre-determined). 6-7	Overall meaning or interpretation of categories and subcategories (usually 1-2 themes) What is the overall theme (s) coming through
HCP 1	"they (patients) would develop their own strategies, So, probably being aware of toilet facilities, bringing kind of like supplies with them when they go out. So, they might bring a bag of pads or wet wipes.	Patients develop strategies to manage bowel symptoms including knowledge of toilet facilities and bringing toiletries like pads and wet wipes.	Knowledge of where toilet is when socialising and skincare to prevent skin irritation.	Patient Initiated Strategies to Self-Care For Bowel Symptoms	Strategies used to Manage Bowel Symptoms.	*Living a New Normal?*

Appendix 17- JBI Checklists

JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

Author Hawkes *et al.,* (2009) Year 2009

		Yes	No	Unclear	Not applicable
1.	Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	YES			
2.	Were the participants included in any comparisons similar?				N/A=NO CONTROL GROUP
3.	Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?		NO		
4.	Was there a control group?		NO		
5.	Were there multiple measurements of the outcome both pre and post the intervention/exposure?	YES			
6.	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	YES			
7.	Were the outcomes of participants included in any comparisons measured in the same way?				N/A
8.	Were outcomes measured in a reliable way?	YES			
9.	Was appropriate statistical analysis used?	YES	☐	☐	☐

Overall appraisal: Include - YES

JBI Critical Appraisal Checklist for Quasi-Experimental Studies
(non-randomized experimental studies)

Author Ringstrom *et al.* 2009

	Yes	No	Unclear	Not applicable
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	YES	☐	☐	☐
2. Were the participants included in any comparisons similar?	☐	☐	☐	N/A
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	☐	☐	☐	N/A
4. Was there a control group?	☐	NO	☐	☐
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	YES	☐	☐	☐
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	YES	☐	☐	☐
7. Were the outcomes of participants included in any comparisons measured in the same way?	☐	NO	☐	☐
8. Were outcomes measured in a reliable way?	YES	☐	☐	☐
9. Was appropriate statistical analysis used?	YES	☐	☐	☐

Overall appraisal: Include yes Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

Wilcoxon Signed Ranks Test

JBI Critical Appraisal Checklist for Quasi-Experimental Studies
(non-randomized experimental studies)

Author <u>Nikoletti *et al.,*</u>

	Yes	No	Unclear	Not applicable
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Yes	☐	☐	☐
2. Were the participants included in any comparisons similar?	Yes	☐	☐	☐
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Yes	☐	☐	☐
4. Was there a control group?	Yes	☐	☐	☐
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	Yes	☐	☐	☐
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Yes	☐	☐	☐
7. Were the outcomes of participants included in any comparisons measured in the same way?	☐	No	☐	☐
8. Were outcomes measured in a reliable way?	Yes	☐	☐	☐
9. Was appropriate statistical analysis used?	Yes	☐	☐	☐

Overall appraisal: Include

Comments (Including reason for exclusion)

<u>Limitation of this study in that whilst conducted like a quasi-experimental study, findings only published in Government report as opposed to complete findings being included in accredited publication.</u>

JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

Author Smith *et al.,* 2002.

	Yes	No	Unclear	Not applicable
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Yes	☐	☐	☐
2. Were the participants included in any comparisons similar?	Yes	☐	☐	☐
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Yes	☐	☐	☐
4. Was there a control group?	Yes	☐	☐	☐
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	Yes	☐	☐	☐
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Yes	☐	☐	☐
7. Were the outcomes of participants included in any comparisons measured in the same way?	Yes	☐	☐	☐
8. Were outcomes measured in a reliable way?	Yes	☐	☐	☐
9. Was appropriate statistical analysis used?	Yes	☐	☐	☐

Overall appraisal: Include

JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

Author; Lin *et al.,* 2016

	Yes	No	Unclear	Not applicable
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Yes	☐	☐	☐
2. Were the participants included in any comparisons similar?	Yes	☐	☐	☐
3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Yes	☐	☐	☐
4. Was there a control group?	Yes	☐	☐	☐
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	Yes	☐	☐	☐
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Yes	☐	☐	☐
7. Were the outcomes of participants included in any comparisons measured in the same way?	yes	☐	☐	☐
8. Were outcomes measured in a reliable way?	Yes	☐	☐	☐
9. Was appropriate statistical analysis used?	Yes	☐	☐	☐

Overall appraisal: Include

JBI Critical Appraisal Checklist for Randomized Controlled Trials

Author Jefford *et* al., 2016

		Yes	No	Unclear	NA
1.	Was true randomization used for assignment of participants to treatment groups?	yes	☐	☐	☐
2.	Was allocation to treatment groups concealed?	Yes			☐
3.	Were treatment groups similar at the baseline?	yes	☐	☐	☐
4.	Were participants blind to treatment assignment?	yes	☐	☐	☐
5.	Were those delivering treatment blind to treatment assignment?	yes	☐	☐	☐
6.	Were outcomes assessors blind to treatment assignment?	☐	no	☐	☐
7.	Were treatment groups treated identically other than the intervention of interest?	yes	☐	☐	☐
8.	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	yes	☐	☐	☐
9.	Were participants analyzed in the groups to which they were randomized?	yes	☐	☐	☐
10.	Were outcomes measured in the same way for treatment groups?	yes	☐	☐	☐
11.	Were outcomes measured in a reliable way?	yes	☐	☐	☐
12.	Was appropriate statistical analysis used?	yes	☐	☐	☐
13.	Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	yes	☐	☐	☐

Overall appraisal: Include

JBI Critical Appraisal Checklist for Randomized Controlled Trials

Author Reusch *et al.*, 2016

	Yes	No	Unclear	NA
1. Was true randomization used for assignment of participants to treatment groups?	Yes	☐	☐	☐
2. Was allocation to treatment groups concealed?	Yes	☐	☐	☐
3. Were treatment groups similar at the baseline?	Yes	☐	☐	☐
4. Were participants blind to treatment assignment?	Yes	☐	☐	☐
5. Were those delivering treatment blind to treatment assignment?	☐	No	☐	☐
6. Were outcomes assessors blind to treatment assignment?	☐	No	☐	☐
7. Were treatment groups treated identically other than the intervention of interest?	Yes	☐	☐	☐
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Yes	☐	☐	☐
9. Were participants analyzed in the groups to which they were randomized?	Yes	☐	☐	☐
10. Were outcomes measured in the same way for treatment groups?	Yes	☐	☐	☐
11. Were outcomes measured in a reliable way?	Yes	☐	☐	☐
12. Was appropriate statistical analysis used?	Yes	☐	☐	☐
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	Yes	☐	☐	☐

Overall appraisal: Include

Comments (Including reason for exclusion)

Researchers acknowledged small, closed groups may have facilitated sharing of illness experiences by participants in an informal way. In addition, treatment integrity might have suffered, as the same psychologists led both psychosocial interventions. Moreover, in both groups inpatients received several further psychosocial treatments as part of the usual rehabilitation program.

JBI Critical Appraisal Checklist for Randomized Controlled Trials

Author Robinson *et al.,* 2006

	Yes	No	Unclear	NA
14. Was true randomization used for assignment of participants to treatment groups?	Yes	☐	☐	☐
15. Was allocation to treatment groups concealed?	Yes	☐	☐	☐
16. Were treatment groups similar at the baseline?	Yes	☐	☐	☐
17. Were participants blind to treatment assignment?	☐	No	☐	☐
18. Were those delivering treatment blind to treatment assignment?	☐	No	☐	☐
19. Were outcomes assessors blind to treatment assignment?	☐	☐	Unclear	☐
20. Were treatment groups treated identically other than the intervention of interest?	Yes	☐	☐	☐
21. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Yes	☐	☐	☐
22. Were participants analyzed in the groups to which they were randomized?	Yes	☐	☐	☐
23. Were outcomes measured in the same way for treatment groups?	Yes	☐	☐	☐
24. Were outcomes measured in a reliable way?	Yes	☐	☐	☐
25. Was appropriate statistical analysis used?	Yes	☐	☐	☐
26. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	Yes	☐	☐	☐

Overall appraisal: Include

JBI Critical Appraisal Checklist for Randomized Controlled Trials

Author Ilnyckyj *et al.,* 2005

	Yes	No	Unclear	NA
1. Was true randomization used for assignment of participants to treatment groups?	Yes	☐	☐	☐
2. Was allocation to treatment groups concealed?	Yes	☐	☐	☐
3. Were treatment groups similar at the baseline?	Yes	☐	☐	☐
4. Were participants blind to treatment assignment?	☐	No	☐	☐
5. Were those delivering treatment blind to treatment assignment?	☐	No	☐	☐
6. Were outcomes assessors blind to treatment assignment?	Yes	☐	☐	☐
7. Were treatment groups treated identically other than the intervention of interest?	Yes	☐	☐	☐
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Yes	☐	☐	☐
9. Were participants analyzed in the groups to which they were randomized?	Yes	☐	☐	☐
10. Were outcomes measured in the same way for treatment groups?	Yes	☐	☐	☐
11. Were outcomes measured in a reliable way?	Yes	☐	☐	☐
12. Was appropriate statistical analysis used?	Yes	☐	☐	☐
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	Yes	☐	☐	☐

Overall appraisal: Include

Appendix 18- PRISMA Checklist for Systematic Review- Interventions to Aid Patients in Self-Care of Bowel Symptoms

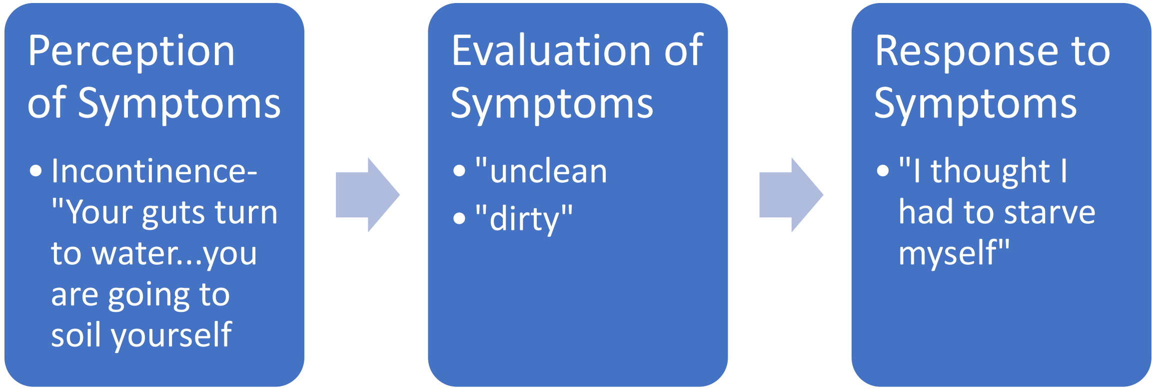
Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	72
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	72-93
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	72
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	73
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	n/a
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	87 & 92
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Not reported
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	310
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	75
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	87 &92

Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	73
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	341-349
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	n/a
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	n/a

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	341-349
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	78
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	79
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	341-349
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	341-349
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	341-349
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	94

Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	90-3
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	94
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097



Appendix 19- Graphical Representation of Findings Relating to SMT Diagram