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Exploration of the Lived Experiences of Rectal Cancer Patients

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Declaration

I hereby declare that this thesis is my own work and effort and that it is has not been submitted elsewhere for any award. Where other sources of information have been used, they have been acknowledged.

Acknowledgements

To all the patients I have had the privilege and honour to look after during my career. Special thanks to all of the participants for taking part in this research study and for sharing their experiences with me. Thank you.

To my BFF Anne. For your love, support, guidance and most importantly our friendship over the last thirty-three years. Thank you x

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Finally, I would like to dedicate this dissertation to my beloved Mum & Dad, the best teachers I've ever had, who showed me the true meaning of caring. Loved and missed so much x.

Abstract

Aim: To explore the lived experiences of rectal cancer patients following diagnosis, treatment and surgery.

Background

Patients diagnosed with rectal cancer can have a complex treatment trajectory involving a combination of radiotherapy, chemotherapy and surgery. Patients can now undergo sphincter saving surgery and avoid a permanent colostomy; however more often than not a temporary defunctioning ileostomy is formed to prevent anastomotic dehiscence.

Sample and Setting

A purposive sample of seven individuals were recruited and consented to participate within this study: four females and three males, aged 44 – 71 years old. Five of the participants had a temporary defunctioning ileostomy, one had a temporary colostomy, and one had a permanent colostomy.

Data Collection and Analysis

Semi-structured interviews were utilised, and transcriptions were transcribed verbatim and analysed using interpretative phenomenological analysis.

Findings

Four major themes emerged from the data analysis: consequences of diagnosis, the effects of treatment, communication and outlook on life. Participants reported the shock of their diagnosis and the major challenges they experienced as a consequence of their stoma. Five out of the seven participants stated they would never have chemotherapy again due to the severe nature of the side effects of the treatment. Surviving cancer changed their outlook on life and many discussed how it changed their lives for the better.

Conclusion

This study highlighted the complex trajectory rectal cancer patients endure. Participants reported that stoma formation and living with its unpredictability caused a detrimental effect on their physical and psychological wellbeing more than any other part of the treatment plan. However, the findings highlighted the resilience that colorectal cancer patients possess in order to complete their treatments and survive.

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Chapter 1: Introduction

This chapter will provide an overview of the key factors contributing to the development of this research study. The aim of this study was to explore the lived experiences of patients diagnosed with rectal cancer who had undergone their recommended treatment plan. The prevalence of colorectal cancer will be discussed, along with radiological staging, treatment options, rectal cancer surgery, the consequences that patients endure following surgery and how the study was conducted.

Colorectal cancer (CRC) is the third most common cancer diagnosed within the United Kingdom (UK) with 41,000 people being affected each year (Bowel Cancer UK, 2018). It is the second largest cancer killer in the UK, with 16,200 people dying per annum (Bowel Cancer UK, 2018). Survival rates have doubled over the last four decades from 22% - 57% (Cancer Research United Kingdom [CRUK], 2018); with current five-year cancer survival rates within the UK similar to Europe at 57%, however, America reports 91%, Canada, 82% and Australia 55-65% (Appleton, Goodlad, Irvine, Poole and Wall, 2013). Improvements in CRC survival rates within the UK have been attributed to the bowel cancer-screening programme that was initiated in 2006 utilising the faecal occult blood test (FOBT). However, the flexible sigmoidoscopy-screening tool method (examining the left side of the colon) has demonstrated to be more effective and has proven to reduce colorectal cancer incidence and mortality by detecting CRC's and removing adenomas (precancerous polyps) (Atkin et al., 2010; Holme et al., 2014). Aitken et al. (2010) found that CRC incidence was reduced by 23% and mortality by 31% by adopting this method. This was subsequently supported by Libby et al. (2012) who suggests this could rise further with an increase in participation within the screening programme. Furthermore, the majority of CRC's (67%) originate in the left side of the colon, with 32% of patients' cancers being detected within the rectum (CRUK, 2018).

Rectal cancer patients' treatment trajectory will depend on several factors, including the site of the cancer and the radiological staging results. Both Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) are utilised to provide a prognostic indicator for each patient (Glimelius, Tiret, Crevantes & Arnold, 2013). The CT scan examines the chest, abdomen and pelvis for any sign of spread of the primary cancer (metastatic disease) and estimates the stage of the disease (National Institute for Health and Care Excellence, [NICE] 2011). The MRI scan provides detailed images of the

rectum and will demonstrate if the cancer has penetrated through the layers of the bowel wall and into the surrounding lymph nodes. It is with this information that an individualised treatment plan transpires from the Multi-Disciplinary Team meeting and the decision for neoadjuvant treatment is considered (Moran et al., 2017). If a rectal cancer is large, threatens or breaches the resection margins, encroaches onto the inter-sphincteric plane or with levator involvement downstaging treatment should be considered (NICE, 2011). Treatments can consist of downstaging chemotherapy, followed by chemo-radiation (short course five days or long course five weeks) then a waiting period (eight to twelve weeks) prior to surgery (Moran et al., 2014).

The four notable objectives of rectal cancer surgery are: resection of the primary cancer, avoidance of local recurrence, preservation of the autonomic nervous system and safeguarding of the anal sphincter (Hohenberger & Bittorf, 2003). Total Mesorectal Excision (TME) is widely acknowledged as the optimal surgery for rectal cancers, resulting in a reduction of local recurrence rates and its principles should be applied to all surgical techniques whether by laparoscopic, robotic or open procedures (Heald, Husband & Ryall, 1982; NICE, 2011; Moran et al., 2017). Historically, patients diagnosed with a low rectal cancer had one surgical option – an abdominal perineal excision of rectum, which resulted in formation of a permanent stoma (McCarthy, Pearson, Fulton & Hewitt, 2012). The past three decades have seen rapid advances of surgical techniques, particularly with laparoscopic and robotic surgery (Lirici & Hüscher, 2016). Surgical skills and expertise have facilitated patients now to undergo sphincter saving surgery, thus preventing the necessity of some patients having a permanent stoma. This sphincter saving surgery is known as an “anterior resection” and has revolutionised surgical outcomes for some rectal cancer patients.

However, sphincter saving surgery normally necessitates the formation of a temporary defunctioning ileostomy to protect the newly formed anastomosis, endeavouring to reduce anastomotic dehiscence and pelvic sepsis (Matthiesson et al., 2007; Alves et al., 2008; Wu, Ma, & Yang, 2014). The formation of a defunctioning ileostomy does not completely prevent anastomosis dehiscence but can reduce the consequences of pelvic sepsis and septicaemia developing (Alves et al., 2008; Wu, Ma, & Yang, 2014). Controversy remains over when the actual timing of an ileostomy should be closed. This is attributed to patients requiring adjuvant chemotherapy, postoperative complications

and patients not being given priority for their additional reversal surgery (Lordan et al., 2007; Herrle et al., 2016) which impacts on their overall quality of life.

Furthermore, having a temporary stoma can prevent patients adapting to living life fully due to uncertainties and putting their life on hold until the stoma has been reversed (Danielsen, Soerensen, Burcharth & Rosenburg, 2013). There is a growing body of literature acknowledging that the formation of a stoma also decreases a patients' quality of life (Tsunoda et al., 2008; Health Quality Improvement Partnership, 2018; Hubbard et al., 2017). Additionally, rectal cancer patients can experience long-term health related quality of life issues and concerns impacting on both the patients' and families' quality of life (Tsunoda et al., 2008; Danielsen et al., 2013; Sanoff, Morris, Mitcheltree, Wilson & Lund, 2015). Patients have reported both psychological and physical challenges including altered body image, sexuality issues including lack of libido and erectile dysfunction, high output stomas, leakage, retraction and dehydration (O'Leary, Fide, Foy & Lucarotti, 2001; Lordan et al., 2007; Tsunoda et al., 2008). Jansen et al. (2011) proposed that patients endure symptoms for as long as a decade whereas it has been acknowledged that patients can suffer adverse symptoms up to 15 years after their primary surgery (Department of Health (DH), 2012). Therefore, there is a need for these patients to have access to physical and psychological support in order to manage the consequences of their treatments and reduce the impact on their quality of life (Barnwell, 2015).

The role of a Colorectal Nurse Specialist is predominantly to support a patient from diagnosis, through any necessary neoadjuvant treatments, surgery, postoperative recovery, adjuvant therapy and subsequent follow up care. Throughout my career as a Colorectal Nurse Specialist, I have nursed and cared for many patients who have been diagnosed with rectal cancer, undergone the recommended treatments and have experienced comparable as well as different consequences of treatments. More patients are now undergoing curative treatment, and the provision of survivorship programmes assists patients to adapt to their new normal and address the physical and psychological consequences of their treatments (Maher, Petchey, Greenfield, Levitt & Fraser, 2018).

Rectal cancer patients are frequently subjected to complex treatment care packages after diagnosis and the subsequent recommended treatments can have a detrimental

impact on the patients' and their families' quality of life (Moran et al., 2014). The aim of this research study is to gain a better understanding of the experiences of patients who have undergone colorectal cancer treatment. The research question was guided by the PICO Framework (Table 1). The PICO framework was adapted as within qualitative research it is the participants' experiences that dictate the outcome of the study (Trice & Bloom, 2017).

Table 1: PICO Framework

Population Colorectal cancer patients	**I**ntervention Surgery with stoma formation
Comparison Surgery no stoma formation	**O**utcome ? Quality of Life/lived experience

The research question posed therefore, is:

What is the lived experience of colorectal cancer patients?

Chapter 2 will discuss the literature review that examined and critically appraised the evidence demonstrating the complex journey rectal cancer patients endure following diagnosis, treatment and the consequences of surgery.

Chapter 2: Literature review

2.1 Introduction

This chapter will discuss the literature review that was undertaken for this research study. In order to provide a contextual background to the research study and due to the limited number of qualitative studies demonstrating the lived experience of rectal cancer patients' it was necessary to explore both quantitative and qualitative literature to demonstrate the challenges that patients experience. The PICO framework was adapted to develop the literature search strategy (Trice & Bloom, 2017), in addition to the use of a qualitative critical appraisal skills framework that assisted with a methodical approach to the selection and appraisal of the qualitative articles identified for review (Critical Appraisal Skills Programme, 2018). The literature search strategies and databases used will be described in section 2.2.

2.2 Literature Search and Review

A literature search identifies sources that are relevant to the topic of interest (Burns & Grove, 2010; Creswell & Creswell, 2018). Likewise, Parahoo (2014) proposes that a literature search has several key functions: to offer a reasoning to conduct the study, to identify what is already known about the topic, to appraise comparable or identical research studies that have already been conducted and to consider the theoretical basis for the proposed study.

Prior to conducting the literature search, best practice guidelines and national standards were revised for the management of colorectal cancer (Department of Health (DH), 2011; National Institute for Clinical Excellence and Health (NICE), 2011; Association of Coloproctology of Great Britain & Ireland (ACGBI), 2017).

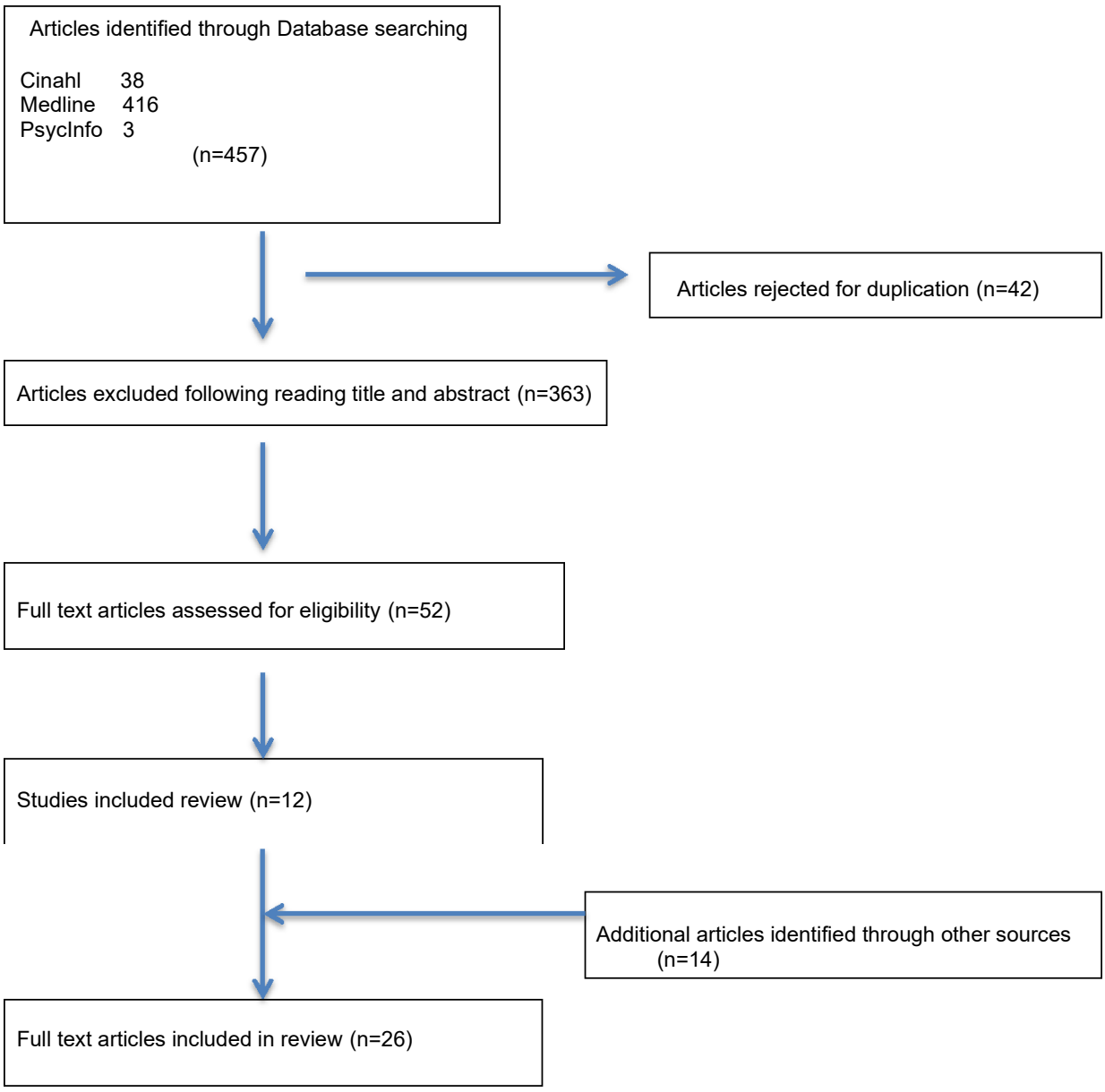
A literature search was conducted accessing several electronic databases via the Elton Bryan Stevens Company (EBSCO) host. These included the Medical Literature Analysis and Retrieval System Online (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO and the Cochrane Library (Boswell & Greene Jackson, 2017). These sources are recognised as reliable resources involving healthcare research (Boswell & Greene Jackson, 2017). "CINAHL headings", "MESH (Medical Subject Headings) 2018" and "Thesaurus" were used then 'exploded'. These headings offer alternative terms for similar concepts and produce a more comprehensive search

of the databases (Polit & Beck, 2012; Boswell & Greene Jackson, 2017). Truncation was also applied (* and $) to allow for a wider search of the key terms. Key terms were combined with the Boolean operators “AND” and “OR” to assist with a more focussed and productive results. Further inclusions were English language, and dates were set from January 1985 – October 2018. The PICO framework was returned to in order to identify search terms to aid the literature search (Table 1).

The aim of the literature review was to establish the change in management of rectal cancer patients over the last three decades and explore the lived experiences of rectal cancer patients. Historically, patients diagnosed with a low rectal cancer only had one surgical option of an abdominal perineal excision of rectum (APER) and permanent colostomy (McCarthy et al., 2012). Current practice focuses on performing sphincter saving surgery and the avoidance of a permanent stoma. From the literature search 457 articles were identified. Forty-two studies were rejected due to duplication, 363 articles were rejected following reading the title and the abstracts, as they did not focus on rectal cancer treatment specifically and 10 were not available in English language. The full text of the remaining 52 was sought, as it was thought that they would make a valuable contribution to the study (Creswell & Creswell, 2018). All 52 papers were read and critiqued. A further 40 studies were rejected following this process as they were not relevant to the study, leaving 12 studies. The reference lists from the identified papers were also viewed and scrutinised and keywords were harvested to further develop the literature search process. A search of grey literature using Education Resources Information Centre (ERIC) and Google scholar revealed further studies relevant to this study (Grove, Burns & Gray, 2012) that were not retrieved from the electronic database searches. A summary of the literature searches can be found in Appendix 1, and a flow diagram demonstrates the systematic search that was conducted (Diagram 1).

Boswell and Greene Jackson (2017) suggest that the initial title of a study may be altered following and during a literature search as additional evidence may transpire from the search thus allowing the research study to develop further and this occurred following this process.

Diagram 1: Flow Chart of Search Results



2.3 Literature Review

- This literature review will focus on the following themes:
- The need for a defunctioning ileostomy
- Timing of the reversal
- Mortality and morbidity rates
- Quality of life
- Lived experiences.

2.3.1 The Need for a Defunctioning Ileostomy

There is agreement throughout the literature that the formation of a defunctioning ileostomy is to protect the newly formed anastomosis and endeavour to prevent dehiscence and pelvic sepsis (Matthiesson et al., 2007; Alves et al., 2008; Wu, Ma, & Yang, 2014). Anastomotic dehiscence can be predicted in some individuals with existing co-morbidities i.e. diabetes, hypertension and pulmonary disease as well as those requiring technically challenging surgery (Matthiesson et al., 2007). Nonetheless, anastomotic dehiscence can similarly occur in individuals who are classified as low risk (Poon et al., 1999). Whereas the key factors cited for high-risk individuals are considered those who require a low anastomosis (less than 7 cm from the anal verge) and being male (Ruller et al., 1998; Matthiesson et al., 2004).

A randomised controlled trial (RCT) conducted by Matthiesson et al. (2007) with 234 participants compared no ileostomy (n = 118) versus defunctioning ileostomy (n = 116). However, 12 of 116 participants who had a defunctioning ileostomy still experienced an anastomotic dehiscence (10.3%) whereas 33 of 118 participants without an initial defunctioning ileostomy suffered an anastomotic dehiscence (28%). Consequently, this led to 30 of 118 (25.4%) participants requiring emergency surgery and formation of an ileostomy. This study demonstrated that defunctioning ileostomy reduces anastomotic dehiscence, however controversy remains regarding the timing of the reversal of the ileostomy.

2.3.2 Timing of Reversal

Lordan et al. (2007) conducted a retrospective study to determine the actual time that patients waited for reversal of their ileostomy from the initial primary

resection. Fifty patients participated in this study: twenty-four patients received adjuvant chemo-radiotherapy and twenty-six patients did not. Subsequently, the average waiting time for reversal of ileostomy for patients undergoing adjuvant chemotherapy was 197 (35-575) days compared to 133 (75-395) days for those who did not require any adjuvant therapy. Incidentally, sixteen patients did not have their stoma closed at all; three participants had died and no cause was given for the others. Preoperatively, patients are usually informed that their ileostomy will be reversed within six to twelve weeks following their initial surgery (Lordan et al., 2007; Tulchinsky, Shacham-Shmueli, Klausner, Inbar & Geva, 2014; Danielsen et al., 2017). This rarely occurs within this timeframe due to adjuvant chemotherapy being required and priority not being given to the closure of the ileostomy as it is perceived as non-urgent surgery (Lordan et al., 2007; Herrle et al., 2016).

Similarly, Robertson, Puckett, Vather, Jaung, and Bissett (2015) systematic review focused on the early closure of a defunctioning ileostomy. This review incorporated four studies: two retrospective studies, one prospective study and one RCT, with 142 participants. The ileostomy closure varied from eight to fourteen days. Although, 78% of participants in this review had colorectal cancer the remaining 22% had inflammatory bowel disease. Nevertheless, the results showed that postoperative complications were less in early closure in contrast to conventional reversal time of eight to twelve weeks. Alves et al. (2008) also identified that early reversal can reduce postoperative complications but is only possible with selected patients.

A multicentre RCT was conducted on early closure of a defunctioning ileostomy with an intervention group (eight to thirteen days post-surgery) and a control group with routine closure (after twelve weeks or longer) (Danielsen et al., 2017). The aim of the study was to demonstrate if an early closure could lower postoperative complications due to the associated difficulties with a defunctioning ileostomy that affects a patient's quality of life. Fifty-five patients had early closure and fifty-seven had a late closure. A strict inclusion criterion was recognised as a limitation of this study as 418 patients were screened and only 127 patients were initially included. The authors cite that this was to reduce risk and increase patient

safety (Danielsen et al., 2017). However, the strict safety measure nevertheless demonstrated that 30% of the entire sample would benefit from early closure if the radiological contrast enema demonstrated no anastomosis dehiscence. Although ileostomy formation provides anastomotic protection it also has significant risks associated with its creation (Robertson et al., 2015). Stoma related complications including psychological issues, high output and leakage have been cited (Jackson & Barnwell, 2014; Taylor & Morgan, 2011). Lordan et al. (2007) and Danielsen et al. (2017) suggest reducing the morbidity rate associated with defunctioning ileostomy formation early closure should be considered for some patients as the associated morbidity rate is 28-33% (Lordan et al. 2007; Alves 2008).

2.3.3 Mortality and Morbidity Rates

Chow et al. (2009) examined the mortality and morbidity rates of patients following closure of a defunctioning ileostomy in their systematic review. It demonstrated that the effects of an anastomotic breakdown following rectal surgery can be profound. The review incorporated forty-eight studies and involved 6,107 participants. It revealed that there was a 17.3% morbidity rate with the reversal of a defunctioning ileostomy and highlighted a 0.4% - 3.7% mortality rate at the time of reversal. Recently, Danielsen et al. (2017) acknowledged that construction of a defunctioning ileostomy is not without risk citing small bowel obstruction, ileus, as well as dehydration due to a high output stoma as being high risk. Consequently, it should be emphasised that the closure of an ileostomy should not be underestimated to patients, and they should be adequately informed of the post-operative complications that can frequently occur in the same way as their primary rectal resection (Tulchinsky et al., 2014). Patients have frequently acknowledged to health care professionals that they did underestimate the reversal surgery and therefore were not adequately prepared for any major complications that occurred and the altered bowel function, which has a negative impact on their quality of life (Reinwalds, Blixter & Carlsson, 2018).

2.3.4 Quality of Life

Quality of life is frequently cited as an outcome for many quantitative studies. There have been vast improvements in the management of rectal cancers over the last thirty years with downstaging chemotherapy and radiotherapy being utilised prior to surgery. Recent emphasis has been on sphincter saving with a temporary ileostomy and avoiding the formation of a permanent colostomy. The key consequences of this surgery can result in both bowel and sexual dysfunction (Engel et al., 2003). However, Herrle et al. (2016) suggests that data on the impact of a defunctioning ileostomy on quality of life can be contradictory as they found that the formation of an ileostomy did not have a major impact on participants' quality of life; challenging Tsunoda et al. (2008) study.

Tsunoda et al. (2008) conducted a prospective longitudinal study over three years to assess the quality of life in patients undergoing an anterior resection and defunctioning ileostomy for rectal cancer. Twenty-two patients with rectal cancer were assigned to the intervention cohort who had a low anterior resection and defunctioning ileostomy performed. In the control group twenty-five patients had a high anterior resection and no stoma formation. The European Organisation for Research and Treatment of Cancer (EORTC) QLQ-C30 and QLQ-CR38 questionnaires were used to assess quality of life within this study. These questionnaires consist of five functional scales, a global quality of life measure and a symptom assessment that include fatigue, altered bowel function and pain. The study demonstrated that patients who did not have an ileostomy created had an improved quality of life score after their initial surgery. Comparison was made to the intervention group of patients who had a defunctioning ileostomy; they recorded lower scores and described urological, gastrointestinal, sexual dysfunction and body image concerns. Reversal of the ileostomy happened between sixty-one to seventy-nine days postoperatively. Subsequently, following reversal of the ileostomy it was documented that patient's quality of life scores improved from a preoperative score of fifty-four to a post reversal score of seventy-four. Improvement in quality-of-life scores provides an indication of the impact the formation of an ileostomy has on an individual patient but does not

give insight into how these impact on their lived experience and how this can be supported by health care professionals.

Danielsen et al. (2013) explored patients living with a defunctioning ileostomy and its impact on their quality of life. In this study the researchers carried out two focus group interviews with the same seven participants in an attempt to understand the experience on how the patients felt whilst waiting for the reversal of their stoma. The sample consisted of five men and two women with an age range of 40-75 years. This study found that patients felt they lacked control, lived in fear of uncertainty and put their life on hold. This was partially attributed to never knowing for certain when the reversal of the ileostomy would take place. It also highlighted that patients were concerned that stoma formation was a taboo subject, that their altered body image caused them to have feelings of shame and guilt as well as concerns about disclosure. Interestingly, participants suggested it would be beneficial to have stoma patients delivering teaching sessions based on their “real life experiences” post operatively. The authors recommended that nurses should be aware of patients’ uncertainties and feelings and provide the appropriate support and coping strategies to assist them whilst waiting for the reversal.

A further qualitative study with rectal cancer patients who had a temporary ileostomy acknowledged that patients experienced good quality of life despite acknowledging stoma related difficulties (Neuman, Park, Fuzesi and Temple, 2012). A grounded theory approach was adopted with a sample of 26 participants (14 male: 12 female, median age 54). One-to-one in-depth interviews were conducted. Patients described challenges with exercise, sleep, sexuality and social gathering. The authors suggested that the results of this study could assist patients’ preoperative preparation and postoperative expectations of living with an ileostomy.

Further studies have also identified patients experiencing leakage, excoriation, high output stomas, leading to dehydration as well as parastomal hernias, retraction and prolapse (Lordan et al., 2007; O’Leary et al., 2001). Alves et al.

(2008) likewise acknowledges that patients with a temporary ileostomy experience both physical and psychological problems affecting their quality of life. This was attributed to their downstaging and adjuvant treatments in addition to knowing that the ileostomy was not a permanent feature. It was also assumed that the cancer diagnosis enabled a “reconceptualisation” that generated the change in attitude. This indicates that for some patients the experiences with their stomas are not as significant in contrast to their cancer mortality.

A literature review performed by Taylor and Morgan (2011) analysed the findings of patients’ lives following reversal of their ileostomy after rectal cancer surgery. Nine studies were included in this review and the authors emphasised that it was the altered bowel function following reversal, which had the biggest impact on the patients’ physical and psychological wellbeing despite the lengthy downstaging treatments (chemotherapy and radiotherapy) prior to the major rectal cancer resection. The findings also implied that patients were not aware of the full extent of the consequences that can occur postoperatively following the primary surgery. The authors suggest how the findings could be attributed to several factors. Patients’ being focussed on becoming cancer free at whatever cost and dealing with the consequences later. Explanation of the proposed treatment plan given with little emphasis being made to the temporary ileostomy and subsequent reversal, information normally given by the surgeon. The authors recommend that it is vital that preoperative counselling prior to surgery and providing realistic expectations post operatively is undertaken to ensure individuals are fully informed of all the possible consequences (Taylor & Morgan, 2011).

2.3.5 Lived Experiences

Appleton et al. (2013) conducted a study exploring how individuals adapted from patient to survivor following a colorectal cancer diagnosis and surgery. They explored the physical and psychological challenges patients encountered as well as identifying how patients adjust to life after cancer. This study revealed that many of the participants benefited from helping others by providing support for other cancer patients who had experienced a similar situation. It also highlighted that rectal cancer patients develop techniques and methods to modify their daily

life due to the consequences of their surgery by modifying their diet and taking precautions for any bowel disturbance, which may occur.

Reinwalds et al. (2018) recently explored the lived experiences of patients twelve to twenty months following rectal cancer surgery and provided an insight into their lives. The authors acknowledged that individuals who had a permanent stoma had been previously studied widely within the literature, but there was a lack of information regarding patients experience following sphincter saving surgery and how the consequences of this technique affected their lives. Ten participants were interviewed to provide insight into their lived experience following their surgery. This study described the challenges which individuals face on a daily basis and how they had adapted to living with the uncertainty of an unpredictable bowel function and developed resilience to their condition. Participants expressed that they were deeply affected with the erratic bowel function following the reversal of their ileostomy on a daily basis. They also highlighted how they abandoned and isolated from health care professionals and that there was a need to provide more information on what to expect post-surgery. Altered bowel function is well documented as the main consequence following sphincter saving surgery (Karanjia, Schache, & Heald, 1992; Desnoo & Faithfull, 2006; Taylor & Morgan, 2011; Clarson, 2018). Symptoms reported are frequency, urgency, incontinence of stool and difficult evacuation of stool. These symptoms lead to patients needing to make changes to their daily life and cause emotional distress.

A phenomenological study undertaken by Lu, Huang and Chen (2017) with sixteen participants revealed three key themes: “living in the restroom”, “never backward” and “rebalancing on a new road”, which affected their overall psychosocial position and family life. Once again, the findings of this study revealed that patients are compelled to develop their own coping strategies, as there was a lack of support from health professionals evident post operatively.

2.4 Summary

This review has demonstrated the improvements in the management of rectal cancer over the last three decades that now focuses on sphincter saving surgery, which usually leads to the formation of a temporary defunctioning ileostomy but

preventing a permanent stoma formation. It has shown the need for patients to have a defunctioning ileostomy to prevent an anastomotic dehiscence. From the review it is also evident that patients are living in a world of uncertainty linked to the lack of information/knowledge of when the ileostomy will be reversed. Furthermore, it is widely acknowledged that an ileostomy formation can have a negative impact on the quality of life of patients with poor outcomes noted both in morbidity and mortality rates. The literature review identified a lack of studies exploring the lived experiences of patients who had undergone rectal cancer surgery and the impact that a diagnosis has had on their life.

Chapter three will discuss the research design and methodology chosen for this research study. Additionally, it will address and focus on the ethical implications that need to be considered for this study.

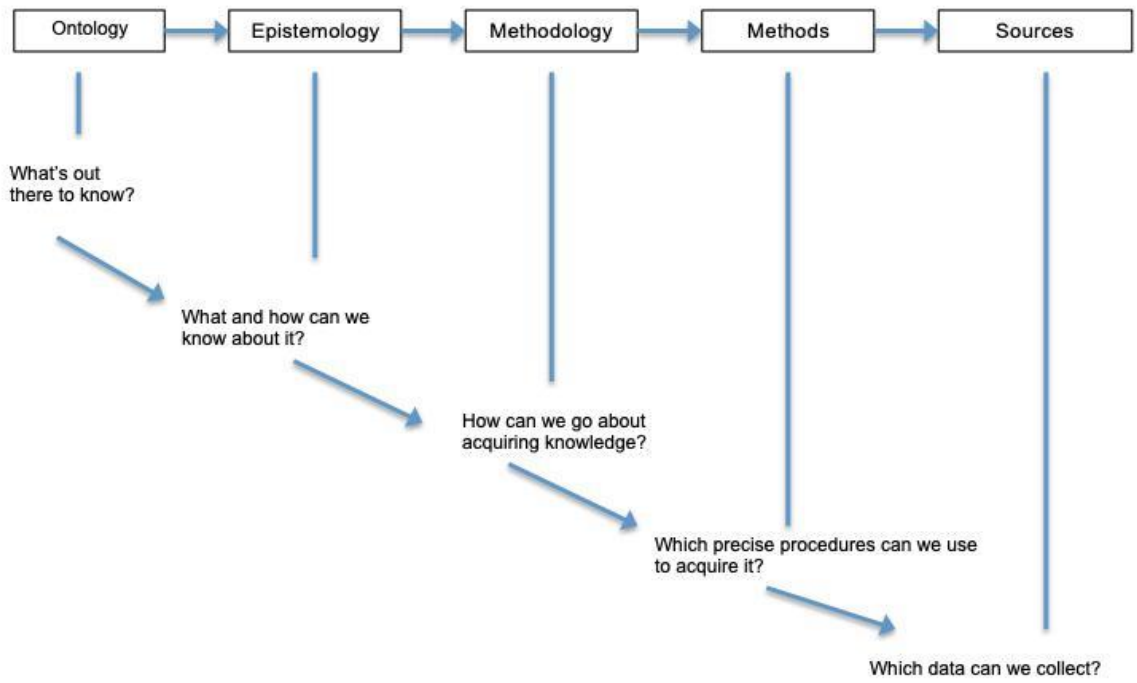
Chapter 3: Research Design

This chapter will outline the research design and rationale for the chosen methodology utilised for this research study. As identified in chapter two there is a paucity of research exploring the lived experience of rectal cancer patients. Within this chapter the study sample, data collection method, data analysis and ethical considerations will be discussed. The research design was driven by the need to explore the lived experiences of rectal cancer patients who had undergone rectal cancer surgery.

3.1 Theoretical Basis & Methods

Research design is a particular mode of inquiry that is adopted for the specific approach within quantitative, qualitative or mixed methods research studies (Creswell & Creswell, 2018). The design of a study must consider the correct approach, the method of data collection, ethical consideration, the time, place and source of the data as well as the methods of analysing it (Parahoo, 2014). Grix (2002) with Ormston, Spencer, Barnard & Snape (2014) inferring that there are fundamental factors that influence the research process. These factors include: ontology (what is out there to know), epistemology (what and how can we know about it), methodology (how can we acquire that knowledge), the methods (the specific data gathering techniques) and the sources (which data can be collected) are all interlinked (Diagram 2). The methodology of a research study is determined by the researchers ontological and epistemological views (Grix, 2002; Killam 2013; Ormston et al., 2014). Ontology is defined as the nature of reality upon which a theory is based (Grix, 2002). However, every researcher will have their own ontological opinion, and this will be reflected in the approach in which the research study is conducted (Grix, 2002). Whereas epistemology centres on issues such as how we can learn about reality and what forms the basis of our knowledge (Ormston, et al, 2014). Collectively, Grix (2002) and Ormston et al (2014) imply that ontology will direct the epistemology, which directs the methodology that will dictate the methods used in research. This methodological coherence is outlined in diagram 2.

Diagram 2: Factors influencing the research process. (Adapted from Grix, 2002)



Kuhn first described the word “paradigm” in 1970 (Parahoo, 2014). Research paradigms can be described as a “school of thought” with a set of philosophical beliefs (Parahoo, 2014) and it is widely acknowledged within health and social research that the two main paradigms referred to are positivism and interpretivism (Ellis, 2010; Parahoo, 2014). These two paradigms are opposing in beliefs and are associated with different methodological approaches (Table 2). However, they can complement each other in nursing practice and are both beneficial to generating different types of knowledge, which is conducive to the delivery of nursing care (Grove et al., 2012).

Quantitative research is grounded in the positivism paradigm: where: a formal, objective and systematic process is embraced (Grove et al., 2012). Quantitative research begins with a hypothesis, and it will seek to confirm or disprove it, therefore, deductive in nature (Ellis, 2010). Quantitative researchers do not deviate in the data collection process as their data collection tools are predetermined and devised in advance of the study e.g. questionnaires (Boswell, 2017; Parahoo, 2014). Qualitative research by contrast, is based on the interpretivism paradigm; where an interactive, subjective and holistic approach is

embraced to explore the lived experiences of individuals to provide meaning (Grove et al., 2012). Qualitative research seeks to explore a phenomenon that cannot be measured. Its focus is concerned with the experience of the individual. Parahoo (2014) suggests that qualitative research can be a collaborative method that can be adaptable and provide an insight into an individual's experience of the phenomena under investigation. Qualitative research starts with a question or statement that needs to be explored but can be adapted to the research study as understanding of the phenomena develops (Boswell & Cannon, 2017).

Table 2. The research paradigms and their major associated methodologies (Adapted from Ellis, 2010)

Research Paradigm	Qualitative Paradigm	Quantitative paradigm
Research methodologies	Phenomenology Grounded theory Ethnography Case study	Randomised controlled trials Cohort study Case control studies Cross sectional studies

The aim of this research study is to explore the lived experiences of rectal cancer patients who have undergone rectal cancer surgery. Therefore, a qualitative methodology was adopted. An interpretative phenomenological approach is commonly used within the qualitative paradigm as well as in the field of nursing and health and social services (Parahoo, 2014). Interpretative phenomenology reflects what it is like to be the individual, providing them with a voice and a platform for them to share their lived experience at a particular time (Newell & Burnard, 2011). This inductive approach acknowledges the importance of the patient's own experiences and allows the participant to explore and make sense of the phenomenon being explored (Smith & Osborn, 2003; Reid, Flowers & Larkin, 2005). The researcher's rationale for this chosen method was influenced by the question set "To explore the lived experience of rectal cancer patients who had undergone rectal cancer surgery". This methodological approach permitted the patients' an opportunity to convey their experience of their cancer trajectory, on how a rectal cancer diagnosis leading to surgery with either a temporary ileostomy or permanent colostomy impacted on their lives (Larkin & Thompson,

2012). Interpretative phenomenological analysis is a combination of "phenomenology" (the experience of the person) with "hermeneutics" (interpretation) (Smith & Osborn, 2003; Smith, 2010). The aim of this approach is to explore the meanings that participants give to their experiences (Reid, Flowers & Larkin, 2005). This is achieved by the researcher immersing themselves in the data by reading and rereading the transcripts in order to familiarise themselves with the data and analysis occurs around the verbatim excerpts from the data (Reid et al., 2005; Smith, Flowers & Larkin 2009). The outcome of this analysis is that themes emerge, and similarities and differences are generated from the participants' experiences, which the researcher then translates into a narrative account (Reid et al., 2005; Smith et al., 2009; McGeechan, McPherson & Roberts, 2018).

3.2.1 Sampling

The sampling strategy for a research study is a fundamental factor of the research design process, as it ensures the effectiveness of the data gathered, the data analysis process, as well as it influencing the findings of the study (Ritchie, Lewis, Elam, Tennant & Rahim, 2014). There are two forms of sampling strategies, probability and non-probability sampling.

Probability sampling strategies are devised to generate an unbiased sample by ensuring that each participant has the possibility of being selected and are chosen by chance (Bloom & Trice, 2017). Probability sampling is regarded as the most rigorous method primarily used in quantitative research, but it is generally unsuitable for qualitative studies (Ritchie et al., 2014). Non-probability sampling is the preferred method used in qualitative research studies as participants are deliberately chosen to reflect specific characteristics of the sampled population (Ritchie, et al., 2014). Due to the nature of this research study a non-probability sampling method was adopted. There are several types of non-probability sampling approaches for qualitative studies including convenience, snowball, quota, theoretic and purposive (Bloom & Trice, 2017; Parahoo, 2014; Ritchie, et al., 2014).

A purposive sample was recognised as the most appropriate strategy for this research study. The purposive sampling technique permits the researcher to intentionally choose individuals who can contribute to the phenomena being investigated (Bloom & Trice, 2017). This method is beneficial, as it allows the participants to contribute to the phenomenon under investigation as they have experienced the phenomena being explored and can reveal their different perspectives of the same phenomena being studied (Ellis, 2010; Polit & Beck, 2012; Parahoo, 2014). A range of perspectives can be accomplished by selecting participants with different characteristics including age, gender, and occupation (Appendix 2) (Newell & Burnard, 2011; Parahoo, 2014). This will enhance the probabilities of identifying a comprehensive range of various perspectives from participants (Ritchie et al, 2014). To ensure this was achieved an inclusion and an exclusion criterion was set (Table 3). This criterion ensures that participants are eligible for the study and excluded if they do not possess the appropriate characteristics from the target population (Burns & Grove, 2010).

Table 3: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Participants who have undergone rectal cancer surgery and had a defunctioning ileostomy or colostomy within the last 10 years	Participant's known not to have a rectal cancer
Participants who can understand and speak English fluently	Participants not capable of providing a valid consent
Participant able to provide valid consent	Participants who are unable to speak and understand English

3.2.2 Sample Size

One of the key factors in planning a research study is to have an appropriate sample size. In quantitative studies, sample sizes are normally large, and probability sampling is embraced, whereas, in qualitative studies sample sizes are usually smaller (Parahoo, 2014; Ritchie, et al. 2014). Ritchie et al. (2014) suggest that "symbolic representation" is required in qualitative sampling in order that similar "units" are selected to both "represent" and "symbolise" qualities that are of significance to the study. A small sample will permit the researcher to

undertake a comprehensive exploration of each participant's experience (Parahoo, 2014). Considering this guidance, ten participants were invited to participate as the aim was to maximise the representativeness of the phenomena being investigated (Bloom & Trice, 2017).

3.2.3 Recruitment

Permission was sought from the Clinical Director and Clinical Lead for surgery to access the local CRC database in order to access potential participants for this study (Appendix 3). Participants were then selected from the database that had a confirmed rectal cancer diagnosis, undergone rectal cancer surgery, had formation of defunctioning ileostomy or permanent colostomy and surgery performed within the last ten years.

Ten potential participants were selected who met the inclusion criteria from the database. An invitation letter (Appendix 4) and a participant information sheet (Appendix 5) were sent to all potential participants. Participants were asked to contact the researcher if they wished to take part in the study and if they had any questions or concerns, they wanted answering prior to agreeing. It was also reiterated within the participant information sheet that should the participant decide not to participate their future care would not be compromised.

From the ten invites seven participants agreed to participate. Participants either left messages on the voicemail facility or emailed the researcher direct. Participants were contacted by telephone to arrange the interview at a suitable date and time that was convenient to them. Prior to undertaking the interview participants were asked to re-read the information sheet, ask any questions or concerns they may have prior to signing the consent form (Appendix 6).

3.3 Data Collection

Qualitative research depends on various approaches by the researcher to enter into individuals' inner thoughts (Parahoo, 2014). The collection of data can be gathered via different methods: interviews, focus groups, video recording and scrutinising written text (Burns, & Grove, 2010, Ellis, 2010). Semi structured interviews were identified and utilised as the data collection tool for this study.

This method was recognised as most favourable due to the qualitative nature of the study and semi structured interviews are frequently used with IPA (Reid et al., 2005; McGeechan et al., 2018). This method allowed the researcher to gain a deeper understanding of the phenomena being explored by permitting the researcher to prompt the participant to share their lived experiences (Ellis, 2010). Prior to the interviews being conducted a proposed interview schedule was devised to ensure the researcher had a level of consistency whilst collecting the data but still permitting a degree of flexibility for the participants to reveal their meaningful experience (Arthur, Mitchell, Lewis & McNaughton Nicholls, 2014). As this study was exploratory in nature, it was vital that an open approach be adopted to allow the participants to speak freely and recall their lived experience of the phenomena being explored. However, this was a retrospective study, and recall can sometimes be less accurate depending on the length of time from the event (Grove et al., 2012). It is also helpful to have a plan on how the interview could proceed.

Arthur et al. (2014) suggest that formulating a staged plan for your interview can also assist the data collection process, which was undertaken (Table 4). A proposed list of questions was devised from a combination of the literature and clinical expertise prior to commencing the interviews (Appendix 7). (Newell & Burnard, 2011).

Table 4: Staged Interview Plan (Adapted from Arthur et al., 2014)

Stage 1: Introduction & context
Stage 2: Ease participants gently into the topic
Stage 3: Core part of the interview
Stage 4: Winding down, summarising and checking key issues.

Data was collected from the interview via a digital recorder, and this was transcribed verbatim. The researcher undertook the transcription acknowledging it to be time consuming (ranging from six to fifteen hours per interview) secretarial support was declined due to confidentiality concerns, financial implications and becoming detached from the data (Newell & Burnard, 2011; Polit & Beck 2012).

Field notes were also taken throughout the interview and were written up after the interview occurred. The interviews were scheduled to last approximately an hour; however, this was guided by the participants' responses. Interviews lasted from 23.12-61.21 minutes.

The researcher was aware that by asking the participants to revisit and give an account of what could have been a traumatic time for them both physically and psychologically throughout their cancer trajectory could evoke emotional distress, therefore it was necessary to be able to deal with the unexpected (Webster, Lewis & Brown, 2014; Black et al., 2018). The natural process of qualitative interviews often involves probing (Webster et al., 2014). The ability of the researcher to ask probing questions in a proficient manner can often lead to participants reflecting on their experience effectively (Webster et al., 2014). This can often lead to increase anxiety, distress and misrepresentation (Richards & Schwartz, 2002). During three of the interviews, the interviews were stopped due to emotional distress displayed by the participants. Time was given to participants to compose themselves. Each participant was asked if they wished to stop the interview or if they wished to continue. Consensus was given by all participants to proceed. The following day a telephone call was placed by the researcher to the three participants, to check their wellbeing and ensure no adverse effects from the interview were reported.

3.4 Rigour

Denscombe (2014) implies that it is vital that a qualitative researcher demonstrates accuracy of the data collected and be able to verify it, as qualitative results are unlikely to be replicated, unlike quantitative research findings. Subsequently, qualitative researchers therefore discarded the use of this terminology and exchanged these terms for: dependability, credibility and transferability (Lincoln & Guba, 1985; Glaser & Straus, 1967). Therefore, it was vital that the researcher ensured that the study was designed soundly and conducted in a rigorous manner in order to generate trustworthy findings (Ormston et al., 2014). This was achieved by adopting a methodological and rigorous approach across the whole study and discussing early coding with the

researcher's supervisor and using verbatim quotes from participants throughout the analysis (Smith et al., 2009).

3.5 Data Analysis

Data analysis is an integral part of qualitative research that actually commences before all data has been collected (Spencer, Ritchie, Ormston, O'Connor & Barnard, 2014; Black, McGlinchey, Gambles, Ellershaw & Mayland, 2018). Data analysis can be a thought provoking and inspiring point of the research process where one moves from the raw data to interpreting it (Burns & Grove, 2010). Interpretative phenomenological Analysis (IPA) was utilised for this study as a fundamental element of IPA is the 'participants voice' and 'their interpretation of the phenomena' being investigated (Reid et al., 2005). With IPA the researcher is required to take account of the participants perspective, as well as attempting to interpret the participants experiences and concerns, in order to answer the research question (Reid et al., 2005). The analysis of data in an IPA study is developed from the key components of the verbatim transcriptions and field notes from the primary interviews of the participants (Reid et al., 2005; Ellis, 2010). Prior to this process the researcher attempted to remove any preconceived ideas about the possible experiences of participants, a process known as bracketing. This allowed the researcher to avoid misinterpreting the lived experiences of the participants (Burns & Grove, 2010). It is imperative that the researcher becomes fully acquainted with all the data (Burns & Grove, 2010). This analytical process required the researcher to immerse oneself in the data by reading and rereading the transcripts as well as listening and relistening to the audio recordings and revisiting the field notes which recorded the participants emotional responses and feelings displayed throughout the interview (Burns & Grove, 2010; Polit & Beck, 2012; Black et al., 2018; Spiers, Smith, Simpson & Nicholls, 2016; McGeechan et al., 2018).

During any research study a vast amount of data can be collected (Parahoo, 2014). The transcriptions from the interviews produced over 47,000 words and it is part of the analysis process to reduce the volume (Burns & Grove, 2010). During data reduction, the researcher attempts to discover the key themes from

the field notes and the digital recordings from the interviews (Burns & Grove, 2010; Black et al., 2018). The researcher re-listened to the digital recordings concurrently whilst viewing the transcriptions. Notes were written in the margins of the transcripts recording observations, interpretations, and emerging themes (Burns & Grove 2010; Black et al., 2018).

Coding each transcript allowed the researcher a method of retrieving the relevant data from each interview in a methodical manner (Burns & Grove, 2010). Each transcript was initially reviewed and coded individually before all transcripts were scrutinised for similarities and differences between participants and themes began to emerge (Burns & Grove 2010; Spiers et al., 2016; Black et al., 2018; McGeechan et al., 2018). Themes can signify the similarities between participants' experiences aside from their individual experiences (Reid et al., 2005).

3.6 Pilot Study

A pilot study prior to the main study can enhance the methodology of a research study (Burns & Grove, 2010). Undertaking a pilot study assisted in refining the research design and data collection tools (Grove et al., 2012) and allowed the the opportunity to gain confidence in undertaking the one-to-one interviews. It also provided an opportunity to ensure that the processes and environment was conducive for participants to feel relaxed and at ease thus facilitating them to speak openly and freely (Marshall & Rossman, 2016). Minor adjustments were made following the pilot study such as refining the proposed questions, "Do Not Disturb" notice for the door, office phone transferred to reception area, and the provision of water and paper tissues in the room.

3.7 Reflexivity and Researcher Positioning

Parahoo (2014) suggests that it should be recognised that there could be a blurring of roles when participants know the researcher in another position Similarly, Alvesson (2003) recognised that some uncertainties could arise from the transition of nurse to researcher for participants possibly leading to the participant feeling obliged to participate within the research study as they may

feel that any future care could be compromised if they did not (Parahoo, 2014). It was explained to participants that the researcher's role during the interview was that of a researcher and not of the colorectal nurse specialist. However, there are advantages of participants knowing and trusting the researcher around easier access to participants and an established trust and rapport (Marshall & Rossman, 2016). Toma (2000) proposes that having an established familiarity and rapport with the participants can improve the quality of the data collection and the data generated. The active role of the researcher in recruitment, data collection and interpretation is consistent with IPA.

My positionality as an insider researcher provided opportunities but also challenges. I already had a rapport with the participants, given my role as their Clinical Nurse Specialist, and this may have meant they felt more comfortable talking to me about their experiences. This can enrich the data. However, it also brings potential biases. My personal and experience and the tacit knowledge from many years in the role, makes it challenging to avoid pre-existing assumptions. This could influence interpretation of the data and prioritising of themes. While complete objectivity is not an objective of IPA, it is important to minimise risks of overlooking taken for granted experiences by being too close to the participant experiences. Through a reflexive process of ensuring ongoing self-awareness, attempting ot maintain critical distance and remaining attentive to the participants' experiences rather than having any pre-existing interpretations, the double hermeneutic of IPA is engaged with.

3.8 Ethical Considerations

It is widely acknowledged that research contributes to improving the delivery of health and social care to patients (Department of Health [DH], 2005). However, it can also tentatively cause harm to both the participant and the researcher (DH, 2005; Royal College of Nursing (RCN), 2009). It is therefore vital that the appropriate research governance is adhered to in order to safeguard the general public and for them to benefit from the research that's been undertaken (DH, 2005). Therefore, ethical considerations should always be considered at the

beginning of any research design and be maintained throughout the whole study and beyond (Webster et al., 2014).

This research study is part of a Masters in Advance Practice programme at University of Chester. It is a component of any research study within the National Health Service (NHS) or similar organisations that involves patients' or service users to seek ethical approval from the Local Research Ethics Committee (LREC) and the university ethics committee if appropriate (DH, 2005; RCN, 2009; DH, 2011; Newell & Burnard, 2011). For the purpose of this study approval was obtained from the Chair of the Jersey Research Ethics Committee following a scientific review by the Faculty Health Research Ethics Committee at the University of Chester (Appendix 8).

Research ethics committees can provide constructive feedback to the applicant as it allows discussion of the research with the committee in order to clarify any concerns they may have regarding the study, which was adopted by the researcher (Parahoo, 2014; Webster et al., 2014. The committee provided recommendations and these were adhered to and following a second resubmission, approval was granted to proceed with the study.

The Nuremberg Code (1947), a key document in medical ethics, is instrumental to ensuring that all human participants in any research studies provide informed consent, have the mental capacity to do so and partakes in a study without coercion (DH, 2005b; Cannon, Delahoyde & Summer, 2017).

Key ethical principles are consistently recorded as guidance for researchers throughout the literature (Table 3) (Webster et al., 2014; Ellis, 2010; Parahoo, 2014). These principles are reflected and protected by the Declaration of Helsinki (2013) where the ethos remains that no harm should come to any participant and it should be a voluntary process (World Medical Association, 2013). These are mirrored in the Humans Rights Act (1998), Data Protection Act (1998) and Data Protection (Jersey) Act 2018.

This study involves participants who have had a rectal cancer diagnosis, who have undergone neo-adjuvant chemotherapy, radiotherapy (some a combination of both) and subsequently surgery. Key ethical principles were adopted in this research study in order to ensure and protect participants from harm (Table 5).

Table 5: Key Ethical Principles

Beneficence: The research should benefit society	**Non-maleficence:** No harm to participants.
Justice: Researchers must ensure participants are treated equally	**Autonomy:** Respect individuals right to exercise their freedom

Beneficence, one of the key ethical principles indicates that the research study should potentially benefit society and that participants may benefit from sharing their experience (Parahoo, 2014). Due to the paucity of literature on the lived experience of rectal cancer patients, it is anticipated that this study may help other patients going through a similar experience. It may also be cathartic for participants to share their experience. Non-maleficence suggests that research should cause no harm to the participant (Parahoo, 2014). Although, it is envisaged that no physical harm may occur there is the likelihood that some psychological distress may be displayed by participants by asking them to recall what could have been a traumatic time in their life (Webster et al., 2014). Due to the semi structured interview process and the researcher adhering to the interview schedule, justice and fairness was maintained for all participants (Parahoo, 2014; Canon et al., 2017). Autonomy, the fourth ethical principle to consider lends itself to three fundamental components: decision-making, the ability to act on your decision and regard for the individual (Canon et al., 2017). Within the research process this leads to informed consent.

Informed consent should be seen as a process and not a solitary episode (Webster et al, 2014; Canon et al., 2017). Participants in provided with various opportunities to ask questions before providing their informed consent (Table 6). Burkhardt & Nathaniel (2014) suggest that informed consent implies that participants have not been coerced into a particular situation, consequently choosing to participate of their own accord.

Table 6: Opportunities to ask Questions

1. Invitation letter to participate in the research study.
2. Provision of participant information sheet.
3. Follow-up call and answer any questions or concerns.
4. Appointment for the interview if willing to participate.
5. Confirmation letter regarding appointment and reiterating key points.
6. Re reading participant information leaflet prior to signing consent form prior to interview.

There is always the possibility that a prospective participant may decide not to participate after reading and considering the information sheet. All participants were reassured that their future care would not be compromised if they decided not to participate. Additionally, if the participant decided to take part and then changed their mind that would also be acceptable.

3.9 Confidentiality

A vital component of research ethics is maintaining the confidence of all research participants (Ellis, 2010). The researcher-maintained participants confidentiality by ensuring that participants were assigned an individualised number prior to undertaking the interview and no other form of identification was utilised during or following their interview (Webster et al., 2014). All data collected from the one-to-one interviews, including the digital recordings and transcriptions of the interviews were uploaded to a password-protected computer. All field notes were stored securely in a locked cabinet that only the researcher had access to via a key. The researcher abided by the Data Protection Act, 1998 and Data Protection (Jersey) Law 2018.

3.10 Summary

Having discussed the research design and outlined the methodology underpinning the study, this has been considered in relation to how best to answer the research question. The research design is aligned to the study's aim of exploring the lived experiences of individuals with rectal cancer. Consideration has been given to issues

of quality, including credibility and reflexivity. In the following chapter, the findings will be discussed.

Chapter 4: Findings

This chapter will discuss the findings and data analysed from this study. Seven participants agreed to participate within this study: four females and three males, aged from 44-71 years old. Five of the participants had a temporary defunctioning ileostomy, one had a temporary colostomy, and one had a permanent colostomy (Appendix 2). Length of time waiting for reversal of stoma ranged from six weeks to eighteen months.

Four overarching themes emerged from the transcripts of the participants: consequences of diagnosis, effects of treatments, communication and outlook on future; from those further sub themes developed described in the table below (Table 7).

Table 7: Main Themes & Emerging Themes

Main Themes	**Emerging themes**				
1.Consequences of diagnosis	Cancer diagnosis	Reaction to stoma formation	Fear of mishaps	Sexuality Dysfunction & Altered Body Image	Reversal of stoma
2. Effects of Treatments	Suicidal thoughts	Radiotherapy	Chemotherapy		
3. Communication	Negative	Positive	Role of the Clinical Nurse Specialist		
4. Outlook on life					

4.1 Consequences of Diagnosis

From this theme several sub themes emerged from the data: reaction to cancer diagnosis, stoma formation, reaction to stoma formation, fear of mishaps, body image and sexuality and reversal of stoma.

4.1.1 Cancer Diagnosis

A cancer diagnosis can have a deep psychological effect on an individual (McCaughan & McKenna, 2007; Beech, Arber & Faithfull, 2012).

P4 *"As soon as you mention the word cancer, it kind of scares you a bit and I was a bit scared".*

P7 *"It was a shock ..I couldn't believe it at first. As soon as you are diagnosed, that's it, your normal life is taken away from you …".*

4.1.2. Reaction to Stoma Formation

However, the narratives from some of the transcripts revealed that the stoma formation had a more overwhelming negative effect on them than their cancer diagnosis.

P2 *"The cancer didn't come into it…. I didn't even realise that's why I had THIS stoma bag. I can honestly say, I was. "D E V A S T A T E D" Really devastated… it sounds really dramatic and I promise you it's NOT. I actually thought this is my life OVER …. I wouldn't be able to do anything ever again.. having the bag".*

P6 *"I know cancer should be your biggest fear but having a stoma bag is such a traumatic thing. And so that was probably one of the hardest things to deal with".*

Preoperative assessment and counselling from the colorectal nurse specialist for major colorectal resection and stoma formation is standard practice following the introduction of the Enhance Recovery After Surgery (ERAS) programme (Kehlet, 2009; Younis et al., 2012). However, it was evident from the participants' narratives that the reality of seeing the stoma for the first time post operatively was overwhelming despite the preoperative preparation, as they expressed feelings of shock and disbelief.

P3 ***"…****that was the thing (shaking her head), I just couldn't cope with this like piece of flesh, which was hanging out your stomach (shaking her head).".*

P4 *"…. but having that (pointing to ileostomy site) going all the time no."*

P6 *"… coz it's like a live piece of your bowel that's on your stomach... it felt alien, it was moving and it was on the outside of me. oh my God…it "GROSSED ME" to be honest. When its active, its producing something terribly smelly and not very nice and so I was "GROSSED OUT" with it".*

One participant who had initially refused surgery, as it would result in a permanent stoma changed his opinion after he was diagnosed with recurrent disease.

P7 *"…. there was no way in a million years, I was having that on there (pointing to his colostomy site). …. Look the way I feel now, it doesn't bother me at all. In fact, I don't give a monkeys on what people think or know".*

One participant did not have the routine preoperative explanation because she presented as an emergency admission and described the horror of viewing the stoma for the first time.

P2: *"...it was the most DISGUSTING thing. I was disgusted at myself… it was on me, ...it REPULSED ME.*

Prior to surgery participants were reviewed in clinic by the consultant and colorectal nurse specialist. Preoperative explanation of the proposed surgery and the rationale for stoma formation was given. One participant recalled her reply to the consultant.

P5 ***"****…you will probably have a stoma!…. And he saw my face "No, No No I don't want a stoma bag its awful".*

No stoma was created at the initial primary surgery. The participant was very relieved. However, three days post operatively an anastomotic leak occurred and the patient had to return to theatre for emergency surgery and an ileostomy was created.

P4 *… "When I saw it in the mirror… this is what I called a little willy sticking out of my stomach. I was H O R R I F I E D".*

4.1.3. Fear of Mishaps

Participants expressed their fear living with their stoma, the trepidation of its unpredictability of the appliance leaking, being noisy and the impact this had on their lives. This led to many of the participants socially isolating themselves from family, friends and social activities.

> **P2** *"…not going out... I would eat early on in the day, hoping that everything that was going to happen would...before I left the house. … I constantly thought I smelt... I was living on my nerves I wouldn't go very far from home".*

> **P3** *"... I couldn't cope. I didn't want to go out anywhere or do anything. I had visions that everybody was looking at me and it was gonnae burst…. I went into the kitchen and thought it's a mess and I have just come home… and it was my bag that had leaked and I was hysterical".*

> **P4** *"But having that (pointing to ileostomy site) and having it bursting and having a bag of shit running down your leg and just going aw the time... always leaking…The skin was burnt ...It just burst all the time… I couldn't do it myself".*

4.1.4. Body image and Sexuality

Body image and sexuality have been widely acknowledged as having an impact on an individual's physical and psychological well-being following a diagnosis of CRC and stoma formation (Robinson & Lounsberry, 2011; Taylor & Morgan, 2011). From this study participants cited diminished feelings of masculinity and femininity within their relationships during and after their treatments.

> **P2** *"NEVER in a million years Oh my goodness gracious, never in a million years…No No, No No chance No. I physically would never ever put myself in that situation".*

> **P4** *"No, no still haven't at all. Nope and still quite bad…. It's not good. I like a cuddle….".*

P5 *"No, no never did…Ahh cuddles, but nothing more…".*

P6 *"I didn't want him to see the stoma bag… I felt less feminine …I didn't want him to see it, touch it, know it was there …I did find having any kind of intimacy with my husband difficult …. I think in my mind this was all going to be reversed and so I didn't want to get use to it".*

One of the major consequences following rectal cancer surgery is urological and/or sexual dysfunction. Participants did not recall being informed of this preoperatively.

P4 *"I don't remember being told it might happen…but that probably was the last thing on my mind".*

P7 *"…I've got it now (3 years later) ... well lack of libido, the penis has gone smaller, the skin around the penis swells and still quite tight …. It's fortunate that my wife has had her problems, and she doesn't feel like anything at all. …I haven't even tried Viagra; it's no use coz (wife) doesn't feel anything …she is on these tablets to take away the hormones (diagnosed with breast cancer). So, it's a waste of time and to be honest with you I cannae be bothered".*

4.1.5 Reversal of Stoma

Rectal cancer patients undergoing surgery are usually informed that the stoma will be reversed in 6-8 weeks following their primary surgery. However, this does not always follow suit if adjuvant chemotherapy is required following histological results or an anastomotic leak occurs. This can lead to disappointment, psychological distress and a delay in returning to their place of employment. However, the narratives from the transcripts indicate the reversal of the stoma was the highlight for some participants. None of the participants involved in this study had their stoma reversed within the 6-8 weeks indicated preoperatively.

P2 *"… Over a year.… And I can honestly say it was like winning the lottery. I think it was like being born again... being able to think I can live like a normal*

person…. Go to work, go to the pictures, go shopping, eat any time of the day, … It was like a prison sentence that was never ending. …".

P3 *"Ten months…I did think I would go back to normal then …".*

P4 *"It was for 3 months, the doctor said "..., come back in 6 weeks".*

P5 *"He said you will have stoma for 6-8 weeks…it was 14 months. I think what kept me going as well was that there was a chance of it being reversed"?*

P6 *"I thought probably for 6-8 weeks… it ended up being more 8 months. … I constantly thought of that reversal date".*

4.2 Effects of Treatments

Colorectal cancer patients can experience significant physical, psychological and social stress following their diagnosis and treatments (Shaheen Al Ahwal, Al Zaben, Khalifa, Sehlo, Ahmad, Koenig, 2015). Several participants made profound statements reflecting back on the various treatments that they had encountered and how having the stoma and chemotherapy impacted on their life.

4.2.1. Suicidal Thoughts

One participant described how the combination of trying to deal with her stoma and complete her adjuvant chemotherapy left her at the lowest psychological point she had ever been.

P2 *"It got to the stage…., I don't really care now, I can't go on…. I don't mean I was depressed, I mean I was suicidal … but I think I should just go to sleep just like that. That sounds really strong and that's how I felt about it... I… remember thinking, I can't do this anymore…. I remember at that stage thinking (crying) I'm sorry, I would do anything for you, but I can't carry on with this, even if it was for you. And that's when you know you are at rock bottom …. coz you are at the lowest level of life you will ever be".*

The constant leakage of this participant's ileostomy appliance and needing to depend on his wife to assist with managing and changing his appliance left him feeling depressed and considering taking his own life.

> **P4** *"You wouldn't want to know what I thought…I wanted to commit suicide when I had that…. I really did. I would have quite easily switched off, if there were a switch, without a doubt".*

Participant expressed her gratitude to the colorectal team in supporting her through a traumatic post-operative period.

> **P5** *"…without people like you where would we be, we wouldn't be here, we would be dead or committed suicide".*

4.2.2. Radiotherapy

Preoperative radiotherapy is prescribed to reduce the size of the rectal tumour and improve oncological and surgical outcomes. Radiotherapy can be administered in two forms: external (short or long course) or internal (3-4 sessions). Participant 1 had short course radiotherapy (5 days).

> **P1** *"The radio stuff didn't bother me".*

Participant 4 described the accumulative effects that the long course had on them physically.

> **P4** *"….6 weeks of radiotherapy…. The way I tried to get through it all was making little goals... it was only the last week that I couldn't get up the stairs. I had to get the lift from the 5th floor".*

Participant 7 had a long course radiotherapy as well as papillon therapy. Papillon therapy is also known as contact radiotherapy which involves inserting radioactive pellets or seeds directly into the tumour (interstitial brachytherapy) or placing an endorectal treatment applicator near the tumour to deliver radiation from within the rectum (NICE, 2015).

P7 *"The normal radiotherapy was easy, very easy".*

However, he describes how he felt violated and unprepared for the papillon therapy he was also recommended to undertake.

P7 *"…. He said like it doesn't hurt... Oh my God, for a week later I was shaking my head cos I felt, I don't want to say, I felt I had been raped…. you are hung upside down… gel is put in your bottom, this rod of 8 -12 inches long, thrust in your bottom, wide awake. I just felt like I had been raped. I had no idea it was like that. But what you do, you recollect the pain it's the in and out that hurts…It bloody hurts…I wouldn't do it again. I found that the most traumatic thing I've ever had. Everything, everything, that's the chemotherapy, the ordinary radiotherapy, the stoma, my bottom been taking away that's the most traumatic thing I had through the whole thing".*

4.2.3 Chemotherapy

Chemotherapy can be prescribed neoadjuvant or adjuvant for rectal cancer patients. Participants experienced various degrees of side effects and the subsequent consequences on their lives.

P1 **"…** *the first lot of chemo was the roughest..., The sensitivity in your hands and feet... … I coughed or sneezed which caused me to go into some sort of reflex… I couldn't breathe... The second lot, coz it was on the PICC line …. I didn't find the side effects as severe as the first lot…… I couldn't work at all"….If I was to think back about one thing ..if I had to have chemo again that's the one think that really gets me up here (pointing to his head and tears in his eyes)…having to contemplate going though all that again the chemo. No."*

Participants described the effect the chemotherapy had on their stoma output and general wellbeing.

P2 *"Oh God that was awful. It made the stoma uncontrollable... the impact was* ***horrendous…****I really was not well…. I had no energy, was feeling nauseous…it*

made me very depressed.... I couldn't eat... I couldn't even smile. ... I was so not well, I was crying, I had no energy, I was sick all the time I just couldn't cope with it".

P3 *"… as they went on, I had lots of side effects…. It was scary …, that breathing thing and you can't breathe and that really frightened me… it happened every …I slept on the sofa … I was frightened I wasn't going to wake up, … It was like you breathe in and you were going to stop breathing, then you started to cough and then it got tight you. I… spent all the time in bed, the whole time I had chemo I hardly ever went out … I had no energy, I felt sick all the time. I couldn't eat. "While I was having the chemo my bag kept filling up with fluid… I had to keep going to the loo. …. I nearly fainted and I had liked a reaction …I just found, I just found the chemo part of it hard". … I would probably never have chemo again if I needed it"*

P5 *"I couldn't do anything. I had terrible heartburn; … everything I was eating was coming up. I kept having to empty the stoma bag '.*

Participant 4 experienced fewer side effects but still has residual effects 7 years following completion of his treatment.

P4 *"…. really the only side effects I had with chemo was my numbness in my fingers and toes…. I still have the same things in my toes".*

Participant 5 described the immediate effect of the chemotherapy following their first cycle.

P5 *"I was supposed to have 6 months of chemo… "...you might get pins and needles in your fingers" he said (Oncologist) it could last forever but it usually goes. I went to use my phone and I couldn't touch anything; it was like electric shocks…".*

As a result of the side effects of cycle 1, Participant 5 decided against any further chemotherapy.

P5 *"I said to him (oncologist) I'm not having any more. He said, "we could adjust the dose". I said you know I'm not an experiment here…so I said well I know you have my interest at heart but well no more, I will take my chances".*

Participant 6 described the roller-coaster effect of the chemotherapy cycle.

P6 *"It was hard going. …for the first week you are completely zapped of your normal energies and you feel quite tired, low in mood and everything… then you start to bounce back up and by the third week you feel great and that's when you have to start all over again and go back down to your low point"*

4.3 Communication

For some participants the mode of communication was not always ideal when delivered by some health care professionals. Some participants had a negative experience where others reported a more positive one.

4.3.1 Negative Experience

This participant was told in the endoscopy theatre that he had rectal cancer.

P1 *"I think the guy was a locum……. I said to him "is that cancer" and he said "yes" and I went "ok…. … I was still in the room where they do the emm endoscopy thing".*

No preparation, warning shots, privacy or nurse specialist was present for these participants when informed of their diagnosis.

P2 **"***I remember them coming round the curtains and saying, "yes it was cancer, but we think we have removed it all". And to tell you the truth I don't even think I was compos mentis that it might have been cancer …".*

P4 "*They pulled me in and some guy who I had never met before sat me down and said, "you've got ... umm an operable cancer".*

4.3.2 Positive Experience

When bad news was delivered well the participants were reassured and felt that they would be safe and looked after during their complex treatment.

> **P1** *"When I came to see the surgeon …he said, "Don't forget for one minute...this is very treatable". …I didn't feel like this is all a big thing to panic about... I was completely relaxed about everything after that".*

> **P2** *"I wanted her to be there with me... I think it was only then that it really dawned on me the cancer, because they mentioned the word chemotherapy….*

The provision of ongoing support is reassuring to participants.

> **P7** *"... I'm happy with the team I've got. I can pick up the phone anytime I want, and I know people will ring me back as soon as they are free. So, I, eh I think the back-up is absolutely superb".*

4.3.3 The Role of the Colorectal Cancer Nurse Specialist

The colorectal nurse specialist role was highlighted to be pivotal for most participants, offering both physical and psychological support when needed from diagnosis through surgery and onto follow-up care.

> **P1** *"I remember the nurse specialist saying "one of my colleagues has just told me that you have been bombarded with a lot of information…, let me just rewind some of that and explain the processes and in what order they might happen so that is what she did.. So, I was quite calm to hear all of that".*

> ***P2*** *"I would come and see the nurse (specialist), and I don't know what I would have done without her... she definitely got me through…… I know for a fact that I wouldn't have got through it …I know I could phone... to make an appointment to come and see you…you listened to me; you got to know me".*

> ***P3*** *"I was here all the time…. I felt like I was imposing …if I had a problem, oh golly I'm there again, but then I knew that the nurse (CNS) didn't mind yeh".*

P6 *"I think everyone can take a leaf out of your (CNS) book and give that special care…I know I would sometimes have been asking you questions, that I knew I should have been asking oncology, but I wasn't always satisfied I would get the right answer from them.. ".*

4.4 Outlook on Life

A rectal cancer diagnosis and undergoing the subsequent treatments can be a challenging and time-consuming process for both the patient and their families. Most of the participants involved in this study had to endure complex treatments lasting almost a year. Despite their diagnosis and their impending treatment trajectory participants displayed positive acts towards families.

P1 "I didn't want to talk about it all the time… I didn't want to bore them all to death…We needed a different subject to talk about…".

P6 "*… … I wasn't able to say for sure I'm not going to die, but that's what you relay to the kids. Cos you don't want them to worry... it's highly likely that I would be fine after surgery…*"

This "lived experience" has changed participants' perspective and outlook in life. Some participants believe their cancer has gone and do not fear the cancer returning. Others are enjoying life to the full just in case it may return and they need to have a stoma again.

P2 *"... I enjoy life…I am a bit more selfish …., I did too much for other people first…. …I live life as much as I can now... just in case I have to have it back (stoma) at least I have done everything I wanted to, I know in my heart that I will revert back to the old way". I have had a relationship with somebody a younger person by the way (big smile and laugh) my love life has increased tenfold. I think I am so lucky not to have it now".*

P3 "*… I'm one of these… positive people…I have had all that done and its gone. … if it comes back, it comes back".*

P4 *"I am a lot more relaxed than what I was...* I'm *pleased to be here…I'm thinking well maybe I shouldn't be here. Maybe I should be dead, and "He" has given me another wee chance so just make the most of it… that's why I jacked in work and well you don't need money coz it doesn't matter*".

P5 *"Touch wood I'm feeling fine, the only thing I would say now is that I appreciate every day you don't know what's round the corner. … I don't worry about it (cancer) …if it comes back, it comes back. There is no good in worrying about it, if worrying about it coming back stopped it coming back then I would worry but it doesn't".*

P6 *"…. Far more positive not to sweat over small stuff and if you don't like something change it, if you're not happy, do something about it. You put far more emphasis on enjoying life… especially with jobs and stuff. Money is not everything".*

P7 *"obviously better, coz I haven't got a major worry about cancer".*

4.5 Summary

This chapter has analysed, generated and highlighted key information from the perspective of the patient who has "lived" through the experience of a CRC diagnosis and subsequent treatment packages. No two patients experienced the same journey, but they did have similar themes connecting them. Challenges were highlighted on the impact on which a stoma has on an individual. Despite, current evidence supporting formation of a stoma to protect the anastomosis and allow healing, most patients stated that the stoma formation was the worse and the most "horrendous" part of their cancer trajectory. Additionally, five out of the seven participants stated they would not have chemotherapy again.

Chapter five will critically discuss the findings from the participants' experiences and the literature review that was undertaken prior to the research study.

Chapter 5: Discussion

This chapter discusses the findings of the study. The aim of the study was to explore the lived experiences of rectal cancer patients following diagnosis, treatment and surgery. This study has provided a valuable insight into the lived experience of colorectal cancer patients by the use of Interpretative Phenomenological Analysis. Hearing the participants' own interpretation of what treatments they had undergone, what they experienced and how they coped allowed the researcher to interpret the phenomena being investigated further (Reid et al, 2005).

The study has generated further evidence that CRC patients undergo a complex and prolonged treatment trajectory, which can impact on all aspects of their lives (Moran et al., 2017). Some of the findings from this study replicate previous studies that have been conducted (Taylor & Morgan, 2011; Danielson et al., 2013; Ceylan & Vural, 2017). However, several other themes emerged and that provides a greater insight into the lived experience of colorectal cancer patients building on previous evidence from the literature.

5.1 Consequences of Diagnosis

5.1.1 Cancer Diagnosis

The data generated from this study was similar to others in that participants described feelings of both being shocked and scared following their cancer diagnosis (Worster & Holmes, 2009; McCaughan, Parahoo & Prue 2011; Beech et al., 2012). It is acknowledged that a cancer diagnosis can have a major psychological impact on both the patient and their families (McCaughan et al., 2011). However, participants stated that they coped relatively well with their diagnosis despite evidence suggesting that patients suffer both physically and psychologically following this news (Sun, Lin, Hsu & Kao, 2018). This could be potentially attributed to a change in the public perception of cancer and the resilience often shown by cancer patients (Appleton et al., 2013; Reinwalds et al., 2018). Due to improved cancer treatments 75% of individuals diagnosed with cancer, even patients with a poor prognosis are living longer (Maher & O'Connell, 2011). Cancer survival rates continue to improve and now much more emphasis

within the media is on cancer survivorship (Maher et al., 2018; CRUK, 2018). Currently in the UK there are over 2.5 million people living with and beyond cancer. It is now recognised that patients can continue to experience physical and psychological problems following their cancer treatments for decades (Maher et al., 2018). The National Cancer Survivorship Initiative in 2008 provided a platform to improving cancer services following treatments for patients (National Cancer Survivorship Initiative, 2013). Participants from this study acknowledged that they all continue to experience some consequences of their cancer treatments despite several years passing for most of them but feel lucky to have survived their diagnosis.

5.1.2 Reaction to Stoma Formation

The formation of a stoma and having to live with it caused participants more distress than their actual cancer diagnosis and subsequent treatments. There could be various factors that could contribute to this distress. Participants were informed preoperatively of the technical challenges and complications that may be involved with the proposed sphincter saving surgery. However, it was simply introduced to the participant that a temporary ileostomy would be “pulled out” to allow the join to heal for 6-8 weeks and “put back in” with a small surgery to prevent the likelihood of an anastomotic dehiscence (Lordan, et al., 2007). Emphasis was on avoiding a permanent stoma, good oncological outcome and preventing anastomotic dehiscence (Klose et al., 2017) with little focus on the management of the ileostomy and that adjuvant chemotherapy maybe required. It appeared that most participants readily accepted the need for a temporary stoma preoperatively to prevent the consequences of an anastomotic dehiscence. However, one participant refused to consent to have an ileostomy at the primary surgery stage and the surgeons respected this decision; three days postoperatively an anastomotic leak developed, and she had to return to theatre for emergency surgery and ileostomy formation. Tulchinsky et al. 2014 states that an ileostomy is easy to manage; however, the findings of this study do not support this claim. It is therefore necessary to provide clear, realistic, honest and accurate information at the outset and throughout the cancer trajectory (Rutten, Arora, Bakos, Aziz & Rowland, 2005). This will assist the patient to adapt, cope

and manage their stoma care accordingly and avoid disappointment if adjuvant chemotherapy is required which would cause a delay in the reversal of their stoma.

Despite preoperative preparation five participants reported they were still "traumatised" and "devastated" with the sight and management of the ileostomy post operatively. This finding was similar to previous qualitative studies undertaken which reported that although preoperative teaching was provided, participants were not fully prepared psychologically for viewing their ileostomy and managing it post operatively (Persson, Gustavsson, Hellström, Lappas, & Hultén, 2005; Jonsson, Stenberg & Frisman, 2011; Ceylan & Vural, 2017). One participant presented with an emergency bowel obstruction and had no psychological or physical preparation whatsoever. This had a catastrophic effect and led to a longer hospital stay due to the participant being unable to accept and manage the stoma initially. This can be a common reaction for individuals who are unfortunate to present in this way and the principles of the enhance recovery programme are not adopted (Lohsiriwat, 2014).

From this study it is apparent that participants who had routine surgery did not fully understand the extent of what they had to endure following their sphincter saving surgery and temporary ileostomy formation. However, they did cope significantly better than the participant who had no preparation. Nevertheless, it should not be assumed that individuals fully understand what has been told following a cancer diagnosis consultation (Worster & Holmes, 2009). This is supported by Kessels (2003) who states that 40-80% of medical information is forgotten instantly and most patients retain only a quarter of the information following a cancer diagnosis (Jansen et al., 2008). It is therefore paramount to check patients understanding frequently to ensure they are understanding what is involved in their treatment (Nursing & Midwifery Council, 2015).

5.1.3 Fears of Mishaps

Regardless of the preoperative counselling, practical preparation, postoperative teaching and ongoing support from the colorectal nurse specialist participants still lived in fear of mishaps with the appliance e.g. leakage, smell, flatus and noise.

Many of the participants were afraid to go out of their home with the fear of the appliance leaking and not being able to cope with the consequences (Lordan et al., 2007; Neuman et al., 2012). This led to social isolation for most of the participants. Tsunoda et al. (2008) similarly reported that the formation of a stoma resulted in participants restricting their social activities until the stoma was reversed, subsequently participants putting their life on hold until closure of their stoma (Wilson, Birks & Alexander, 2010). Six of the seven participants did not return to work until after the reversal of their stoma, which for some was over one year. This had a financial implication for all participants and their families as many went onto half pay after six months from their diagnosis and two of them were self-employed. Financial impact of cancer is supported similarly with Fenn et al. (2014) and Zafar, McNeil, Thomas, Lathan, Ayanian & Provenzale (2014) studies who found that cancer patients had an increase economic burden following their diagnosis and necessary treatments resulting in a further deterioration in their quality of life.

5.1.4 Body Image & Sexuality

Colorectal cancer patients can experience sexual and urinary symptoms following their treatments and surgery (Pucciani, Ringressi, Redditi, Masi & Giani, 2008; Knowles, Haigh, McLean, Philips, Dunlop, Din, 2013). Similarly, this study found that male participants experienced sexual impairment and dysfunction, including lack of libido and unable to maintain an erection. Female participants could not contemplate any sort of intimacy whilst having a stoma, as they felt less feminine and did not feel physically attractive to their partner; stating they did not want their partner to see their stoma or appliance. The findings of this study are similar to Ceylan & Vural (2017) were participants also avoided sexual intimacy as they were afraid of the unpredictability of stoma activity and found themselves less attractive to their partners. However, it was found from this study that following reversal of stomas female participants felt a return of their femininity and intimacy with their partner, an increase in their love life, together with the feeling of being “lucky” for not having a stoma.

The findings of this study suggest that participants had either not received or declined support for their altered body image, sexual impairment and dysfunction following surgery. From this study there seemed to be an acceptance of these consequences in order to be cancer free and sexuality needs were less important (Horden & Street, 2007). Although health care professionals discuss quality of life issues with cancer patients seemingly there is a reluctance to discuss sexual concerns with them routinely (Robinson & Lounsberry, 2011). Unresolved sexuality dysfunction can have a destructive effect on the lives of both the patient and their partners (Robinson & Lounsberry, 2011; Ceylan & Vural, 2017). However, sexuality and body image concerns should be addressed by health care professionals routinely both pre and post operatively. The use of a sexual function tool can offer specific guidance to health care professionals in initiating conversations around sexuality and intimacy and providing appropriate interventions as necessary. The PLISSIT model offers four stages of escalating intervention: Permission, Limited Information, Specific Suggestion and Intensive Therapy (Appendix 9) (Albaugh & Kellogg-Spadt, 2003).

5.1.5 Reversal of Stoma & Altered Bowel Function

From this study the highlight for participants was the reversal of their stoma. Participants all reported that they were aware of the consequences that may occur post reversal but were willing to accept them as long as their stoma was reversed. Participants described major disappointments when they were initially informed that the stoma would be for 6-8 weeks only, but the actual time ranged from twelve weeks to fourteen months. There is still no consensus of opinion on when the ideal time for reversal of the ileostomy should occur (Jackson & Barnwell, 2014). However, if adjuvant chemotherapy is required and it is safe to do so, early reversal of the ileostomy should be considered prior to commencing chemotherapy. This would provide a psychological boost as well as reduce the psychological distress of caring for an ileostomy for CRC patients (Alves et al., 2008; Danielsen et al., 2017).

From this study participants did not report any long-term symptoms following reversal of their stoma. This was similar to the studies of both Camilleri-Brennan

& Steele (2002) and Taylor and Morgan (2011). Anterior resection syndrome is a condition that is widely reported following reversal of an ileostomy after sphincter saving surgery that results in altered bowel function (Desnoo & Faithfull, 2006; Taylor & Morgan, 2011; Clarson, 2018). From the literature there is a plethora of evidence documenting the consequences of rectal cancer surgery (Herrle et al., 2016; Danielsen et al., 2017; Klose et al., 2017), with approximately 90% of patients suffering from faecal urgency, frequency and incontinence (Clarson, 2018). These symptoms reported having a major impact on an individual's quality of life (Desnoo & Faithfull, 2006). However, five of the seven participants in this study stated that they had no issues adapting to a new bowel function, as it was a relief to have the stoma reversed, return to normal bowel evacuation and be cancer free.

5.2 Effects of Treatments

5.2.1 Suicidal Thoughts

The risk of suicide amongst recently diagnosed cancer patients has been widely reported within the literature (Misono, Weis, Fann, Redman & Yueh, 2008; Robson, Scrutton, Wilkinson & MacLeod, 2010). It has been suggested that people living with cancer may think of committing suicide as a way of regaining control of their lives (Macmillan, 2018). A study conducted by Misono et al. (2008) found that the risk of suicide with colorectal cancer patients was higher than the general population. However, Samawi et al. (2017) suggest that there is a lack of evidence-based studies to support this claim. A study conducted by Fang et al. (2012) found the risk of suicidal ideation or attempt occurred within the first three months following diagnosis, suggesting that suicidal thoughts was linked to the psychological impact of diagnosis and not the morbidity or side effects of surgery. One of the findings from this study was that some participants experienced suicidal thoughts. However, it was not the cancer diagnosis that triggered the suicidal thoughts but not being able to accept and manage the unpredictability of the stoma output appropriately, together with the side effects of the chemotherapy that resulted in these feelings. This finding is supported by Ceylan & Vural (2017) who found that stoma formation, led to participants experiencing severe depression and suicidal ideation. Additionally, Samawi et al. (2017) found

that stoma formation and postoperative complications following rectal cancer surgery had attributed to increase morbidity rates with rectal cancer patients more than colon cancer patients.

5.2.2. Chemotherapy & Radiotherapy

All seven participants were referred for neoadjuvant or adjuvant chemotherapy. Participants experienced various degrees of side effects during and following chemotherapy. Three participants did not complete the recommended sessions due to side effects and all seven participants said they would never want to have chemotherapy ever again. Three participants were also referred for radiotherapy and all had similar experiences and coped relatively well with the side effects of tiredness and frequent bowel motions. However, one participant also had papillon therapy, as he was initially averse to having a permanent stoma. This treatment is now being offered to individuals who have an early rectal cancer or have significant co-morbidities to avoid surgical intervention (The Clatterbridge Cancer Centre, 2018). Based on the findings from this study, clinicians are going to have to be mindful of the traumatic impact this treatment may have on individuals and that patients need to be prepared psychologically and supported throughout the treatment process.

5.3 Communication

Participants appreciated the professional relationship developed between themselves and members of the multidisciplinary team. When significant news was delivered in a safe and conducive environment participants felt safe and supported. Effective communication was a significant part of most participants' experience (Black et al., 2018). However, participants recalled feeling vulnerable when being informed of their cancer diagnosis within the ward environment without any specialist support being present which was similar to the study conducted by Worster & Homes (2009). The colorectal nurse specialist is the patients' advocate and can assist to transform the patients' experiences of cancer care (Jackson & Barnwell, 2014; Moran et al., 2017). Throughout this study participants described their struggle of trying to live their life with their stoma. They explained that the physical and psychological support from the colorectal

nurse specialist was pivotal to assisting them through this difficult post operatively time.

Participants stated they were reluctant or did not have the opportunity to discuss psychological and physical needs with health care professionals fully during their treatments. From these findings it was apparent that participants could have benefited from more regular physical and psychological assessments from health care professionals. The introduction of a health care assessment tool (Appendix 10) following diagnosis and at regular intervals throughout treatment and beyond could be beneficial to both the patient and health care professionals (MacMillan, 2018). These tools can provide ongoing holistic assessments for the patient. This would allow health care professionals to address concerns and signpost individuals to the appropriate services if required.

5.4 Outlook on Life

Participants acknowledged that their cancer could return but they did not live in fear of this occurring. This is in contrast to numerous studies that revealed patients living beyond their cancer diagnosis and treatment are susceptible to fearing that their cancer may reoccur (Baker, Denniston, Smith, & West, 2005; Simard et al., 2013). Maheu et al. (2016) reported that this fear affects 49% of cancer patients. However, participants were philosophical about recurrent disease and stated that their priorities and outlook in life had changed. There was more emphasis in enjoying life and being grateful for having a second chance.

Participants from this study acknowledged that they all continue to experience some consequences of their cancer treatments despite several years passing for most of them but feel lucky to have survived their diagnosis. Therefore, regular follow up appointments and assessments will allow individuals to have access to health care professionals and address any long-term and ongoing issues affecting their quality of life (Maher et al. 2018). This data has highlighted that participants were supported after diagnosis and throughout their treatment however, there was a perceived lack of support in the follow up phase after completion of treatment.

5.5 Limitations

Study results need to be considered in light of the limitations inherent within the study. As a qualitative study using IPA, depth is prioritised over breadth, and the intention was not to produce generalisable knowledge. Therefore, the experiences of my participants may not be reflective of all patients with rectal cancer. My study did not consider different cultural experiences. Being set in a small geographical area, socioeconomic factors may not have been considered.

While subjectivity is central to IPA, this does increase the risk of bias. My study relied on self-reported experiences, and these could have been subject to recall bias. As the participants were purposively selected from an existing cohort of patients who had already undergone surgery, their recall of their experiences may have been influenced by the outcome of their treatment. It is a possibility that their experiences were influenced by their current emotional status. While participants were purposively selected, and selection bias cannot be ruled out, all had a right to decide to participate, and it is possible that those who chose to participate could have different experiences and engagement with services or differing severity of stage in their cancer journey.

5.6 Summary

The findings have been discussed in relation to existing literature, and the research aim to understand the lived experiences of rectal cancer patients. Through IPA, it was possible to analyse the data to provide an in-depth understanding of how these patients make sense of their experiences. In situating their experiences within the broader literature, the study contributes to an understanding of the complexities of a rectal cancer diagnosis and surgery. These findings have implications for clinical practice. A greater insight into patients' lived experiences can support more person-centred approached to support. The following chapter will conclude the dissertation with recommendations for practice and future research.

Chapter 6: Conclusion & Recommendations

The narratives of the participants described the complex trajectory that rectal cancer patients endure following their diagnosis, subsequent treatments, surgeries and recovery. The findings highlight the resilience that rectal cancer patients possess in order to complete their treatment plan.

This study has found that stoma formation and living with its unpredictability caused a detrimental effect on participants physical and psychological wellbeing than any other part of the treatment plan. However, the reversal of the stoma was seen as the end of their cancer treatment and returning to a new normal. It was evident that stoma formation still had a major psychological effect on participants despite the passing of time from their reversal surgery. This could be the fear that a further stoma may be required in the future if the disease recurred.

The need for effective communication is vital for patients throughout their whole treatment trajectory and postoperative follow up. The Colorectal Nurse Specialist was pivotal in coordinating and contributing to the effectiveness of the patients' cancer management by having access to the different clinicians and services required.

With the improvements in survival rates and more emphasis on survivorship the provision of ongoing holistic follow up care will allow for regular assessments of individuals who can continue to experience the consequences of rectal cancer surgery indefinitely. By 2030 it is forecasted there could be over 4 million people living beyond cancer (MacMillan, 2018) and this will have a financial implication for health service provision in the future. It is projected that by 2020 it could cost the healthcare system one billion pounds a year for the long-term management of cancer treatments (Maher & Connell, 2011).

6.1 Recommendations

This study has generated significant information on the "lived experience" which the researcher can utilise to inform future care delivery for colorectal cancer patients.

1. The introduction of the “Holistic Needs Assessment” at regular intervals throughout the patients’ pathway will assist in providing ongoing. It will support in identifying, preventing and resolving issues for patients, which were identified in this study that had not been addressed. It will also focus on the needs of the individual and support them to develop their own coping strategies. These assessments will be utilised by the multidisciplinary team to inform the holistic needs of patients.
2. Early reversal of ileostomy should be considered prior to adjuvant chemotherapy if at all possible. This will involve working collaboratively with specific members of the multidisciplinary team to enable the logistics of this to happen within the recommended times.
3. Bowel cancer screening to be offered to all individuals at 50 years old.
4. Further research is required into the correlation between suicide ideation and stoma formation with rectal cancer patients.

Word Count: 16,204

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Appendices

Appendix 1: Literature Search

LITERATURE SEARCH: CINAHL, MEDLINE, PSYCINFO

Date searched: 26th October 2018

Dates searched: January 1985 – October 2018

Inclusion: English language Full Text

Search ID	Search Terms	Search Option	Cinahl Results	Medline Results	PsycINFO Results
S1	(MH "Colorectal neoplasms+")	Boolean operator/Phrase	35,542	183,914	1,332
S2	"colorectal neoplasm"	Boolean operator/Phrase	53	551	4
S3	colorectal tum$r	Boolean operator/Phrase	13,850	4,574	1,332
S4	colorectal surger*	Boolean operator/Phrase	877	15,139	157
S5	anterior resection	Boolean operator/Phrase	284	4,345	150
S6	ileostom*	Boolean operator/Phrase	1,481	9,257	66
S7	colostom*	Boolean operator/Phrase	2,032	12,601	151
S8	(MH "Quality of life+")	Boolean operator/Phrase	95,245	167,442	88,200
S9	(MH "Life Experiences+")	Boolean operator/Phrase	30,560	21,909	45,067
S10	S1 OR S2 OR S3	Boolean operator/Phrase	32,650	184,954	1,332
S11	S4 OR S5	Boolean operator/Phrase	1,130	18,861	307
S12	S10 AND S11	Boolean operator/Phrase	396	8,003	53
S13	S5 AND S6	Boolean operator/Phrase	38	416	3
S14	S8 AND S12 AND S13	Boolean operator/Phrase	2	25	0

Appendix 2: Participant Demographics

Participant Number	Gender	Age at Diagnosis	Type of Surgery and Tumour Level	Neoadjuvant/	Date of Primary Surgey	Months Before Reversal of Ileostomy	Marital Status	Occupation
1	M	53	A R & Ileo	Chemo/rad Adjuvant	June 2016	6 months	M	Builder
2	F	44	Hartmanns	Adjuvant	Sept 2015	9 months	S	Trust Administrator
3	F	59	A R & Ileo	Adjuvant	April 2015	13 months	M	Support Worker
4	M	55	A R & Ileo	Neo chemo/rad	Dec 2011	2 months	M	Janitor
5	F	71	A R & Ileo	Adjuvant	April 2015	19 months	M	Housewife
6	F	44	A R & Ileo	Adjuvant	Sept 2015	10 months	M	Trust Administrator
7	M	60	APER	Neo chemo/rad	April 2018	Permanent colostomy	M	Hairdresser

Key

M – Male

F – Female

AR & Ileo - Anterior Resection & Ileostomy

APER – Abdominal Perineal Excision of Rectum

M - Married

S – Single

Appendix 3: Permission Letter for Study

Faculty of Health & Social Care

Research Ethics Sub-Committee (FRESC)
University of Chester

4th June 2018

To whom it may concern

Proposed Research Study: An exploration of the "lived" experiences of rectal cancer patients who have undergone rectal cancer surgery

I am writing to confirm that the above proposed research has been discussed with myself and as Clinical Lead for Surgery and as Clinical Director of the Health & Social Services Department permission has been granted for student [redacted] **on the MSc Advanced Practice (Clinical Pathway)** with the University of Chester to use HSSD facilities to conduct the reserarch and to access participants via the colorectal database. [redacted] will be responsible for identifying and contacting participants for this propsosed research study

Yours sincerely

[redacted]
Clinical Director

Appendix 4: Invitation Letter

18th April 2018

Dear Sir/Madam

I am a student undertaking an MSc in Advanced Practice (Clinical Pathway) through the University of Chester. As part of my course, I am undertaking a research study titled:

An exploration of the "lived" experiences of rectal cancer patients who have undergone rectal cancer surgery

I am inviting you to participate in this study, which will provide you with an opportunity to share your experiences of how you dealt with your rectal cancer surgery.

Please see the enclosed "Participant Information Sheet" for you to read. Should you wish to take part in this research study, you will be required to complete and sign a "Consent Form" prior to the study. A copy of the consent form is enclosed. If you wish to participate within this study please can you contact at me at your convenience and I will arrange a suitable date, time and venue for you to attend.

Your participation within this research study is voluntary and it is your choice whether to participate or not. If you choose not to participate you will not be asked why. Your decision will not affect your follow up care in any way. If you require any further information, please do not hesitate to contact me.

Thank you for considering participating within this study,

Yours sincerely

MSc student

Appendix 5: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

An exploration of the "lived" experiences of rectal cancer patients who have undergone rectal cancer surgery

Invitation
You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

Thank you for reading this.

About the researcher
For the purpose of this research study the researcher is a student undertaking her Master's dissertation and will not be performing the role of the Clinical Nurse Specialist. It is important that you are informed and aware that the interview is not a medical consultation but an interview to explore the "lived" experiences of rectal cancer patients who have undergone rectal cancer surgery. If you have any medical concerns, I will signpost you to the appropriate medical personnel if required.

What is the purpose of the study?
The study has been designed to explore the experiences of patients who have been diagnosed with rectal cancer and have undergone rectal cancer surgery. The aims of the study are to discover how you coped with your cancer diagnosis, your surgery, what it is/was like for you having a stoma formed and what impact this has had on your family and friends.

Why have I been chosen?
You have been chosen because you are a patient who has undergone rectal cancer surgery.

Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part and then change your mind that is okay. You can change your mind right up until after the interview. You will not have to give a reason. After the interviews it will be more difficult to change your mind as I will have anonymised the information collected and it may not be easy to work out which words are yours. Therefore, you will have 2 weeks following your interview to whether you decide to take part or not, this will not affect any care you receive at any time.

What will happen to me if I take part?
If you decide to take part, you will be given this information sheet to keep and asked to sign the consent form. Signing the consent form will mean that you have read and understood this information and agree to take part.

I will then contact you to invite you to meet with me for an interview meeting about your experiences. The interview will be at your convenience, and you will be able to choose the date and time. Allocated car parking can be arranged if required. The meeting will take place within Newgate Street Clinic at the General Hospital in a private room and every attempt will be made to protect your privacy and insofar as possible against any interruptions from occurring during the interview. Light refreshments will be provided e.g. water, tea or coffee.

At this meeting, you will have the opportunity to talk about your experiences following your rectal cancer surgery. The meeting will last about an hour. With your permission the meeting will be recorded. I will not use your name and anything that we talk about will not have your name on it.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks foreseen in taking part in the study.

What are the possible benefits of taking part?

As a patient it is possible that you may welcome the opportunity to share and discuss your views and experiences. By taking part, you may be able to help make other patients experiences better.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact: Professor Angela Simpson, Executive Dean, Faculty of Health and Social Care, University of Chester, Riverside Campus, Castle Drive, Chester, Cheshire, CH1 1SL. Tel: 01244 513380. Email:angela.simpson@chester.ac.uk

Will my taking part in the study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential so that only myself as the researcher carrying out the research will have access to the information. The data collected from the interview will be stored securely for 10 years as per the University of Chester Research Governance Handbook.

What will happen to the results of the research study?

After the research is completed, I will write this up as a report and I will share it with the university and my colleagues. However, your name will not be included in this. The results will be written up into a report and discussed at the colorectal multidisciplinary team meeting. It is hoped that the findings may be used to improve the colorectal service provided to patients.

Who is organising and funding the research?

The research study will be undertaken by me, Catherine Goode as part of my Master's degree course.

Who may I contact for further information?

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact:

Tel: Email:

Appendix 6: Participant Consent Form

Participant Consent Form

Study Title: An exploration of the "lived" experiences of rectal cancer patients who have undergone rectal cancer surgery

Ethics Ref No:

Name of Researcher: Catherine Goode

Please read each statement and sign in the box provided

	Initial box
I have read the participant information sheet and it is in a language, which I understand.	
I have been given the opportunity to ask questions either face to face, via telephone or email.	
I have voluntarily agreed to participate within the research study and attend a one-to-one interview with the researcher.	
I understand that I am free to withdraw at any time without having to give a reason and my future care will not be compromised.	
I agree to the one-to-one interviews being digitally recorded.	
I understand that the researcher will respect confidentiality and that every effort will be made to maintain confidentiality through changing identifying details for the final report and dissertation. My name will not be used in any report following the research.	
I agree to the researcher and research supervisor having access to my interview information and using this for the research.	
I understand that I will be given a copy of this document to keep.	

Name of Participant	**Participant's Signature**	**Date of Consent**
_____	_____	_____
Name of Researcher	**Researcher's Signature**	**Date of Consent**

Appendix 7: Proposed List of Questions/Prompts

1. Perhaps we could begin by talking about how your cancer was first diagnosed.
2. What treatments have you had for your cancer?
3. What was it like for you to undergo the treatments?
4. Tell me what it has been like for you adjusting to living with an ileostomy?
5. Has the ileostomy restricted you in any way?
6. Tell me about the information you received about having an ileostomy.
7. Tell me about any challenges you had about caring for your ileostomy?
8. Tell me about your support network.
9. Tell me about your experience with from your stoma nurse?
10. Is there anything you would like to tell me concerning living with your ileostomy?
11. How long did you wait for your reversal?
12. What has it been like for you to talk about this?

Appendix 8: Ethics Outcome Letters

University of Chester

REF: BH/CG

25 June 2018

Faculty of Health and Social Care

Tel 01244 512600
Fax 01244 511270

Catherine Goode
Newgreen
Eureka Avenue
St. Clement
Jersey
JE2 6PA

Dear Catherine

REC Reference:	RESC0418-918
Project title:	An exploration of the "lived" experiences of rectal cancer patients who have undergone rectal cancer surgery.
Chief Investigator:	Catherine Goode
Educational Supervisor:	Moyra Journeaux

I am pleased to confirm that the above research project has been subject to an independent scientific critique carried out by the Research Ethics Committee of the University of Chester Faculty of Health& Social Care. The review included consideration of the research question, methodology, target group and plans for the recruitment of participants.

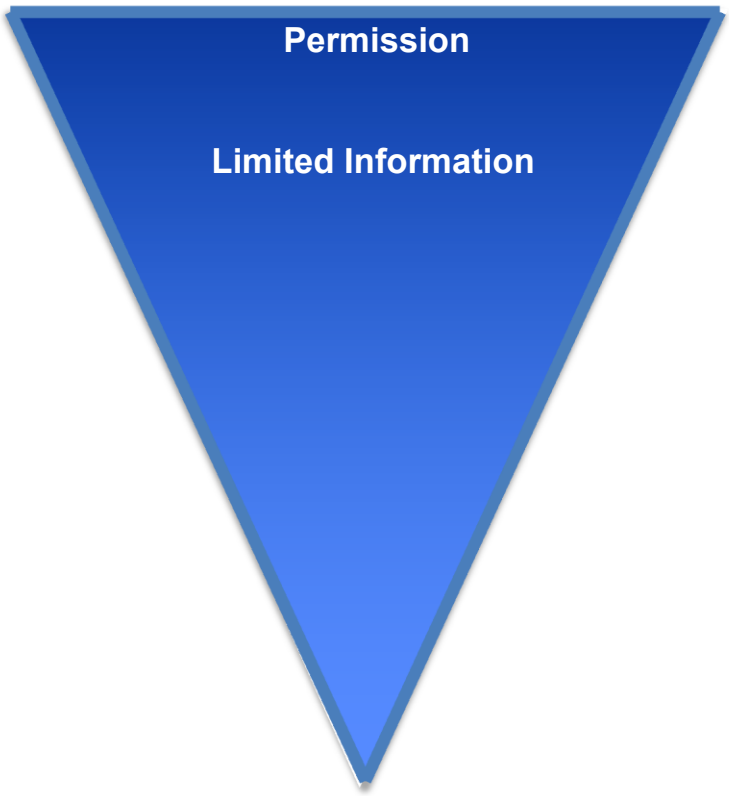
Overall, the reviewers considered the project worthwhile and of scientific merit, and that the protocol describes appropriate plans for the successful completion of the research.

Yours sincerely

Angela Simpson

Professor Angela Simpson
Executive Dean of the Faculty of Health & Social Care
University of Chester

Appendix 9: Plissit Model



Giving patients permission to discuss sexual issues

Giving patients limited information about sexual side effects of treatment

Making specific suggestion based on a full evaluation of presenting problems

Referral to intensive therapy includes psychological interventions, sex therapy and/or biomedical approaches.

Appendix 10: Health Care Assessment Needs Chart

National Cancer Survivorship Initiative – Your Holistic Needs Assessement

Concerns checklist
0001

Living with and beyond cancer – identifying your concerns

Patient's name or label

Completed by:

Date:

Designation:

Contact details:

This self assessment is optional, however it will help us understand the concerns and feelings you have. It will also help us identify any information and support you may need in the future.

If any of the problems below have caused you concern in the past week and if you wish to discuss them with a health care professional, please tick the box. Leave the box blank if it doesn't apply to you or you don't want to discuss it now.

☐ **I have questions about my diagnosis/treatment that I would like to discuss.**

Physical concerns
- ☐ Breathing difficulties
- ☐ Passing urine
- ☐ Constipation
- ☐ Diarrhoea
- ☐ Eating or appetite
- ☐ Indigestion
- ☐ Sore or dry mouth
- ☐ Nausea or vomiting
- ☐ Sleep problems/nightmares
- ☐ Tired/exhausted or fatigued
- ☐ Swollen tummy or limb
- ☐ High temperature or fever
- ☐ Getting around (walking)
- ☐ Tingling in hands/feet
- ☐ Pain
- ☐ Hot flushes/sweating
- ☐ Dry, itchy or sore skin
- ☐ Wound care after surgery
- ☐ Memory or concentration
- ☐ Taste/sight/hearing
- ☐ Speech problems
- ☐ My appearance
- ☐ Sexuality

Practical concerns
- ☐ Caring responsibilities
- ☐ Work and education
- ☐ Money or housing
- ☐ Insurance and travel
- ☐ Transport or parking
- ☐ Contact/communication with NHS staff
- ☐ Housework or shopping
- ☐ Washing and dressing
- ☐ Preparing meals/drinks

Family/relationship concerns
- ☐ Partner
- ☐ Children
- ☐ Other relatives/friends

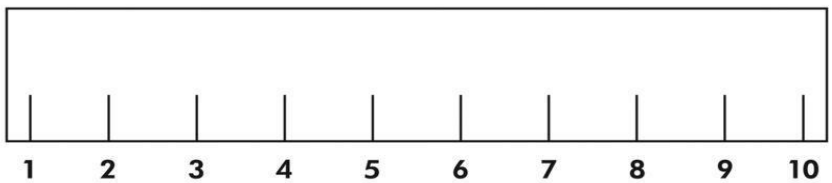
Emotional concerns
- ☐ Difficulty making plans
- ☐ Loss of interest/activities
- ☐ Unable to express feelings
- ☐ Anger or frustration
- ☐ Guilt
- ☐ Hopelessness
- ☐ Loneliness or isolation
- ☐ Sadness or depression
- ☐ Worry, fear or anxiety

Spiritual or religious concerns
- ☐ Loss of faith or other spiritual concern
- ☐ Loss of meaning or purpose of life
- ☐ Not being at peace with or feeling regret about the past

Lifestyle or information needs
- ☐ Support groups
- ☐ Complementary therapies
- ☐ Diet and nutrition
- ☐ Exercise and activity
- ☐ Smoking
- ☐ Alcohol or drugs
- ☐ Sun protection
- ☐ Hobbies
- ☐ Other

Please mark the scale to show the overall level of concern you've felt over the past week.

You may also wish to score the concerns you have ticked from 1 to 10.



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