Exploring and comparing the experience, and coping behaviour, of men and women with colorectal cancer: A qualitative longitudinal study

EXECUTIVE SUMMARY

2011

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ULSTER Cancer Foundation
From Care to Cure
Exploring and comparing the experience, and coping behaviour, of men and women with colorectal cancer: A qualitative longitudinal study

CONTENTS

1 Contents ................................................................................................................................ 1

2 Forward .................................................................................................................................. 3

3 Research Team ....................................................................................................................... 4

4 Acknowledgements ................................................................................................................ 5

5 Executive Summary ................................................................................................................ 7

   Introduction and Background .............................................................................................. 7

   Aim of Study .......................................................................................................................... 7

   Methodology .......................................................................................................................... 7

   Ethics ....................................................................................................................................... 8

   Findings ................................................................................................................................... 8

   Recommendations .................................................................................................................. 13

   Further Research Priorities .................................................................................................... 15
The Ulster Cancer Foundation is very pleased to have been able to fund this research into how men and women cope with a diagnosis of bowel cancer. Every year over 1,000 people in Northern Ireland receive a diagnosis of bowel cancer. There is a slightly higher prevalence among men. This report looks at how men and women deal with that diagnosis, their experiences and strategies for coping. The report reinforces earlier studies showing men to be less ready to seek information and support.

Through an approach that was both sensitive and academically sound, Dr Eilís McCaughan and her research team at the University of Ulster have produced findings and recommendations that will enable practitioners to develop support and information interventions tailored to the expressed needs of men and women living with a bowel cancer diagnosis. There are clear messages for the Ulster Cancer Foundation and other healthcare organisations in the priority times for offering support, the type of support and information required and the priority groups who are in most need of support. Participants are very clear about the information they need and how and when it should be available.

This research has been funded by people who have made donations to the Ulster Cancer Foundation. We are delighted that we can demonstrate to the public that their donation has been well used to improve the support offered to men and women living with a diagnosis of bowel cancer, now and in the future.

Roisin Foster
Chief Executive of Ulster Cancer Foundation 2011
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We would also like to thank the Cancer Centre, Belfast City Hospital for their support in facilitating this research.

We are grateful to the Ulster Cancer Foundation for funding this project.

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The full Report can be accessed at: http://www.science.ulster.ac.uk/inr/mcireports
Exploring and comparing the experience, and coping behaviour, of men and women with colorectal cancer: A qualitative longitudinal study
EXECUTIVE SUMMARY

INTRODUCTION AND BACKGROUND

• The literature shows that men with cancer are less likely than women to utilise health services and psychological support services and to express distress and emotions openly.

• There is some evidence to suggest that men and women may cope differently with a diagnosis of colorectal cancer (CRC); however these studies are limited in number and frequently present conflicting findings.

• Many of the studies on men’s health behaviour are quantitative in nature and have collected data at one point in time.

• It is important to understand similarities and differences in how men and women experience, and cope with, colorectal cancer and its treatment over a length of time, from their own perspectives.

• Understanding the context and the factors which influence the health related behaviour of men and women with colorectal cancer has the potential to influence the provision of effective, person-centred information and support services.

AIM OF STUDY

• The aim of this study was to explore and compare the experience, and coping behaviour, of men and women with CRC and its treatment over an 18-month period, post-diagnosis.

METHODOLOGY

• A longitudinal qualitative study was conducted. A convenience sample of thirty eight individuals (24 men, 14 women) with a diagnosis of CRC were interviewed at four time points, over an 18-month period. The four interviews were conducted post-surgery, post-chemotherapy (if indicated), six months post-chemotherapy and 12 months post-chemotherapy. Participants were recruited from the Cancer Center in Northern Ireland.
Executive Summary

- Interview tapes were transcribed and analysed using the techniques of labelling, coding, categorising and theme development.
- Data from the same participants collected at the 4 time-points were tracked in order to reveal changes and trends in the evolving experience and coping strategies.

Ethics

- Ethical Approval was obtained from the Office of Research Ethics Committees in Northern Ireland (ORECNI).

Findings

Experience of Participants

Diagnosis

- Males in the sample tended to delay in presenting to their GP. This was not the case for women.
- Receiving a diagnosis of CRC was a traumatic experience for the participants.
- Most men in the sample reported that they were not emotionally affected when told they had cancer although some reported that they showed more emotion towards their diagnosis in private than in public. Most, but not all, female respondents reported being emotional about their diagnosis.

Surgery

- The surgical experience seemed to be similar for male and female participants.
- Some participants desired more acknowledgements from medical staff that they had undergone surgery to remove a cancerous tumour, that it was more than ‘routine’ surgery.
Some felt that doctors only dealt with the physical sequelae of the surgery, and did not address their psychological issues.

- Many felt they were left with the uncertainty regarding the need (or not) of a laparoscopy, open surgery or a stoma.
- Those participants who did not need adjuvant chemotherapy felt ‘abandoned’ after their surgery. They had minimal contact with doctors who they considered to be ‘cancer’ specialists.
- Women experiencing difficulties due to new unpredictable bowel habits or those fitted with a stoma bag tended to reduce their social activities. Most men, however, tended to maintain their social activities.

Chemotherapy

- Prior to chemotherapy, participants reported experiencing anxiety as they did not know what to expect, although male participants did not appear as anxious (from their self reports) as their female counterparts.
- The participants experienced a number of side effects associated with undergoing chemotherapy. These were nausea and vomiting, pain, fatigue, diarrhoea, mouth ulcers, watering eyes and dry skin on their hands and feet.
- Tiredness/loss of energy was reported as one of the most severe and limiting side effects of the chemotherapy.
- From their self reports, the physical effect of the treatment seemed to be worse for females than males.
- Symptom prevalence was reported to be the same for men and women, but men reported that symptom distress was lower for them.
- On completion of chemotherapy the participants were attempting to reintegrate into ‘normal’ life.
• Some individuals continued to experience persistent side effects such as tiredness, watering eyes and/or lingering problems with bowel functioning.

• Many individuals felt that although they had finished chemotherapy, they were still ‘cancer patients’ (as they were still suffering from its associated side effects).

• Most participants worried about their cancer returning. The impact of this ranged from total preoccupation to no concerns.

• Uncertainty was experienced in cycles and usually peaked just before review appointments, scans or significant cancer anniversaries.

• Some men presented themselves as having no concerns about the cancer recurring (when asked about it) although in their answers to other questions there was evidence to contradict this.

• Most male and female participants had adjusted to their ‘new normal’ post-chemotherapy. However, some men and women did still feel it was necessary to reduce their social activities.

• Some participants also made positive changes in their lives, such as adopting a healthier lifestyle or deciding to live their life to the fullest.

• Six to twelve months post-chemotherapy, the participants were still living with their altered bowel habits or stoma bag although they did not find them restrictive at this stage. Many were still experiencing the uncertainty that they may suffer a recurrence.

Coping strategies

Information needs and information seeking behaviour

• The type and amount of information required varied in accordance with the participant’s stage on the cancer care continuum. There was no obvious gender difference in information needs and seeking behaviour.
EXECUTIVE SUMMARY

Diagnosis and surgery

- This was the time when the participants desired the most information.
- Some individuals were very proactive in obtaining information. They accessed the Internet and talked to peers about their experience.
- All participants wanted to know they had cancer.
- All participants wanted information that was non-technical, easy to understand and relevant to their circumstances.
- All participants wanted the information as soon as possible after surgery.
- A subgroup of participants adopted a more passive role to information seeking. They had a fear of knowing too much and relied heavily on their doctor for the necessary information.

Chemotherapy

- During chemotherapy attitudes to information were similar to those described above. The group was split – some wanted a lot of information, others did not.
- After chemotherapy, their information needs decreased, although they desired more information on diet and wanted more details on follow-up appointments and scans.
- There was some indication that factors such as socio-economic status and age were related to information seeking behaviour.
- Doctors, other health care professionals and other individuals with cancer were the main sources of informational support during chemotherapy.

Social Support

- Sources of support included doctors and other health care professionals (during treatment), relatives/friends, other individuals with cancer and the Church.
EXECUTIVE SUMMARY

- Family and friends provided emotional support. Many male participants relied on their wives for their emotional support.

- Most female participants appeared to obtain their emotional support from a variety of sources and did not rely on their spouse to the same extent as the male patients.

- Those with a stoma reported receiving valuable support from the stoma nurse. There was however limited support for those without a stoma.

Diagnosis and surgery

- The participants desired more psychological support from the medical staff than they obtained.

- Many reported a void in support from health professionals in the period between surgery and commencing chemotherapy.

- Those who did not require chemotherapy reported a lack of support from health professionals, post surgery.

Chemotherapy

- Participants reported that they received adequate support at this stage through their attendance at the cancer centre for chemotherapy.

- Post-chemotherapy, more women than men reported that they wanted more support than they obtained.

- Interest in formal support groups increased at this stage.

Overall coping strategies

- Most participants coped by adopting positive attitudes.

- Many undertook ‘downward social comparison’ i.e. comparing with someone whose experience was worse than theirs.
EXECUTIVE SUMMARY

• They were thankful that they had been diagnosed with cancer of the bowel, and not another form of cancer which could not be operated on, or would spread more easily.

• They viewed the cancer as a battle/fight to be won.

• They used the experience as an opportunity to make positive changes in their lives. Some re-evaluated their lives and made the decision to become healthier; others felt they wanted to appreciate life more, and not worry about things as much they did before their diagnosis.

• They felt that they had ‘come out’ of the experience better than they had ‘gone in’.

• The participants rarely reported using any negative coping strategies such as alcohol consumption, smoking or anger.

• Both male and female participants coped with potentially difficult situations, such as when they were discussing their diagnosis or treatment options with humour.

• Humour was also used in potentially embarrassing situations, for example if they were in company and needed to go and change their stoma bag, or the stoma bag started making noises.

RECOMMENDATIONS

Priority Times

• Priority times for targeting information and support following a diagnosis of colorectal cancer should be:
  - At the time of diagnosis.
  - Pre-surgery (support regarding the uncertainty of surgical procedure outcome).
  - Post-surgery.
  - If a person is not receiving chemotherapy.
• If a person has a stoma.
• Pre-chemotherapy.
• Immediate post chemotherapy (information on coping with disease and treatment side-effects).

Priority Groups

• Priorities for targeting of information and support on coping with the cancer diagnosis and treatment should be:
  • Patients who display negative coping strategies and so may be high risk for depression or using inappropriate coping mechanisms.
  • Partners or wives of men who have a colorectal cancer diagnosis.
  • Men who may have a tendency to minimise the impact of their cancer and its treatment.
  • Women, who post chemotherapy, appear to need focused support as they feel particularly isolated.

Provision of Information

• Appropriate information needs to be provided at the relevant time-point (i.e. pre surgery, pre chemotherapy).
• Clear and concise ongoing information should be communicated to all patients at the above time-points.
• All patients should have access to a colorectal specialist nurse, not just the patients who have had a stoma.
• Information provision should recognise the individuality of patients and their various coping strategies which may include passive information gathering.
EXECUTIVE SUMMARY

Focused information and support

- Patients should be encouraged to speak to other individuals with CRC, as study participants described them as a useful source of information.

- More information and advice should be provided on diet.

- Post chemotherapy, more information should be provided on follow-up. Each patient should be provided with a written schedule of approximate dates.

- Tiredness is a common symptom for individuals with CRC and may not be well managed. Further investigation into this symptom in this population group is warranted.

- Health care professionals should be aware that patients may suffer from continuing uncertainty and provide ongoing support for this, particularly at the time of significant dates such as scans and anniversaries.

- Patients should be reassured that the physical symptoms are transient, and they should be assisted in finding methods of problem solving to help them adapt to their new normal.

FUTURE RESEARCH PRIORITIES

Future research should focus on:

- Identifying the characteristics of those men who choose to avoid discussing their diagnosis and downplay the impact of their disease.

- The partners of individuals with colorectal cancer to determine their individual information and support needs, if any.

- Tiredness was a prominent symptom for the individuals with CRC. Research should focus on identifying appropriate methods of addressing this, especially for those people who also have a stoma bag fitted and hence tend to lead a more sedentary lifestyle.
• Further research should be undertaken to determine if post-treatment support interventions would have better outcomes for women and men with colorectal cancer in terms of less uncertainty and anxiety.
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The Ulster Cancer Foundation is very pleased to have been able to fund this research into how men and women cope with a diagnosis of bowel cancer. Every year over 1,000 people in Northern Ireland receive a diagnosis of bowel cancer. There is a slightly higher prevalence among men. This report looks at how men and women deal with that diagnosis, their experiences and strategies for coping. The report reinforces earlier studies showing men to be less ready to seek information and support.

Through an approach that was both sensitive and academically sound, Dr Eilís McCaughan and her research team at the University of Ulster have produced findings and recommendations that will enable practitioners to develop support and information interventions tailored to the expressed needs of men and women living with a bowel cancer diagnosis. There are clear messages for the Ulster Cancer Foundation and other healthcare organisations in the priority times for offering support, the type of support and information required and the priority groups who are in most need of support. Participants are very clear about the information they need and how and when it should be available.

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The full Report can be accessed at: http://www.science.ulster.ac.uk/inr/mcireports
REPORT CONTENTS

<table>
<thead>
<tr>
<th>Introduction</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender and Health</td>
<td>1</td>
</tr>
<tr>
<td>Men and Cancer</td>
<td>3</td>
</tr>
<tr>
<td>Colorectal Cancer</td>
<td>4</td>
</tr>
<tr>
<td>The experience of colorectal cancer</td>
<td>5</td>
</tr>
<tr>
<td>Coping with colorectal cancer</td>
<td>5</td>
</tr>
<tr>
<td>Study rationale</td>
<td>8</td>
</tr>
<tr>
<td>Study aims and objectives</td>
<td>9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Methodology</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Study design</td>
<td>10</td>
</tr>
<tr>
<td>Sample</td>
<td>10</td>
</tr>
<tr>
<td>Procedure</td>
<td>11</td>
</tr>
<tr>
<td>Recruitment</td>
<td>11</td>
</tr>
<tr>
<td>Data collection</td>
<td>12</td>
</tr>
<tr>
<td>Data analysis</td>
<td>13</td>
</tr>
<tr>
<td>Credibility of findings</td>
<td>13</td>
</tr>
<tr>
<td>Ethical considerations</td>
<td>14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Findings</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>15</td>
</tr>
<tr>
<td>Interview completion rates</td>
<td>17</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Section 1: The experience of colorectal cancer</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>The experience of being diagnosed with cancer</td>
<td>18</td>
</tr>
<tr>
<td>Delay in initial presentation</td>
<td>19</td>
</tr>
<tr>
<td>Reaction to diagnosis</td>
<td>20</td>
</tr>
<tr>
<td>Specific strategies used to cope with receiving a cancer diagnosis</td>
<td>21</td>
</tr>
<tr>
<td>Acceptance</td>
<td>21</td>
</tr>
</tbody>
</table>
The experience of bowel cancer surgery 24
  Surgery for ‘cancer’ 24
  Being dependent 25
Coping with bowel cancer surgery 26
  Perception of being cured 26
The physical side effects of having bowel cancer and undergoing bowel surgery 27
  Altered bowel habits 27
Specific strategies used by the participants to cope with unpredictable bowel habits/stoma bag 28
  Problem solving 28
Expectations of chemotherapy 32
Physical symptoms and side effects of chemotherapy 33
The psychological experience of chemotherapy 34
Specific coping strategies using during chemotherapy 35
  Detachment/denial/threat minimisation 36
Physical experience after chemotherapy 38
  New normal 38
Psychological experience after chemotherapy 42
  Lingering uncertainty 42
Specific strategies used by participants to cope with the uncertainty 44
  Objective tests 44
  Trust in medical profession 45
  Carpe diem 45
  Pre-occupation with uncertainty 46
Summary of colorectal cancer experience 48
  Physical cancer journey 48
  Psychological cancer journey 49
INDEX OF TABLES

Table 1: Participant demographics 15
Table 2: Treatment received 16

INDEX OF FIGURES

Figure 1: The physical cancer journey 49
Figure 2: The psychological cancer journey 50
Figure 3: Experience of, and coping with, colorectal cancer 71
Figure 4: Gender and illness 73
Figure 5: Reaction to uncertainty 79
INTRODUCTION

Gender and health

The feminist movement in the 1960s focused research on issues related to women and women’s health (White and Cash, 2004). Similar enquiry into men’s health has not followed suit and thus there is minimal data available on the area (White and Johnson, 1998). For this reason, men’s health has recently become an area of concern (White and Cash, 2004), particularly as there is evidence to suggest that men die younger and are more prone to disease than women (White and Johnson, 1998). Men’s health has thus increasingly become a key area of concern for healthcare professionals and policy makers (White and Cash, 2004). In 2007, the Cancer Reform Strategy highlighted inequalities in cancer incidence, uptake of services and outcome according to gender (Department of Health, 2007). In response to this, the National Cancer Equalities Initiative was created to further the understanding of the inequalities that exist in cancer (National Cancer Equalities Initiative, 2010).

Men are more at risk of developing and dying from those cancers that should affect men and women equally (non-sex specific cancers) (White, 2009). A recent report indicated that this difference is almost 70% (White et al., 2010), with women therefore having significantly higher survival than men for nearly all cancers (Micheli et al., 2009). While there may be biological and physiological reasons to account for differences in male and female cancer incidence and mortality rates, health behaviours also play an important role in influencing survival (Branney, 2008). There are many sociocultural factors associated with health behaviour and gender is one of these factors (Courtney, 2000). Gender has been defined as ‘a set of socially constructed relationships which are produced and reproduced through peoples actions’ (Gerson and Peiss, 1985). Gender is, therefore, not something we ‘are’, but something we ‘do’ in social situations (Moynihan, 1998). The widespread assumption of the ‘difference’ between men and women has been challenged with the idea that there are similarities between, and diversity within, men and women (Emslie et al., 1999). There are multiple forms of masculinity (and femininity) and therefore variation among men (and women) (Connell and Messerschmidt, 2005).
Hegemonic masculinity describes men who demonstrate aggression, strength, self-reliance and limit their emotional responses. This form of masculinity has come to be viewed as the idealised, socially dominant form of masculinity (Connell, 1995; Wall and Kristjanson, 2005). It has been argued that hegemonic masculinity may only exist as a reference point as men may construct and reconstruct their gender identity from context to context (Speer, 2001). It is possible that many men have a public masculinity which conforms to the hegemonic reference point, and a private masculinity. Social and cultural expectations may prevent many men from demonstrating other forms of masculinity. Males frequently use health behaviours to demonstrate their masculinity, for example, the denial of pain or weakness, the appearance of being strong and the refusal of any need for help (Courtenay, 2000). Thus they maintain a socially acceptable masculine appearance of taking illness ‘like a man’ and being able to cope through not expressing any concerns and fears (Moynihan, 1998). Women have traditionally been stereotyped as emotional, expressive, compassionate and yielding (Moynihan, 1998). It is often assumed (incorrectly) that all men are naturally ‘stoical’ and choose not to cope through emotional disclosure (Emslie et al., 2007). Hilton et al (2009) warned that we should be wary of stereotyping women as ‘expressive’ and man as ‘stoical’. As explained by Paechter (2003) there are many types of masculinity ‘inhabited and enacted variously by different people and by the same people at different times’. The same theory could be applied to femininity. Social expectations may therefore prevent many men from practicing other forms of masculinity. The question to be addressed now is which masculinity (or femininity) we perform and when (Paechter, 2003).

Masculinity as a concept is crucial to understanding men’s health behaviour (George and Fleming, 2004). Little is known about the effect ‘male’ health behaviours have on cancer incidence and mortality rates. White (2004) suggested that there must be a focus on determining which aspects of men’s beliefs and behaviours militate against successful help seeking as well as possible weaknesses in current health care systems to meet the health needs of a man.
A review of the literature examining masculinity and the cancer experience revealed that the majority focused on male only cancers such as prostate cancer (Kelly, 2009; Arrington 2008; Oliffe, 2006; Broom 2004 and Wall and Kristjanson, 2005). Only one study was found that examined the impact of gender in a ‘shared’ cancer (Emslie et al., 2009). They demonstrated a difference in spousal support between men and women with colorectal cancer (CRC), but they also reported diversity among men and women (Emslie et al., 2009). Examining the impact of gender on the cancer experience of a shared cancer provides more opportunity to compare and contrast the male and female experience. It is clear from the literature that there are gaps in studies of men with ‘shared’ cancers, for example CRC.

**Men and cancer**

The literature demonstrates clearly that men with cancer are less likely than women to utilise health services and psychological support services (Courtenay, 2000; Boudioni et al., 2001; George and Fleming, 2004, Manii and Darcy, 2008). It has been suggested that men do not like to access professional counselling, but prefer to deal with their issues independently or in private with their wives or oncologist (Seale et al., 2006). Many men do not like discussing the emotional aspects of their illness openly as they perceive this as a threat to their masculinity; they view sharing emotions as a feminine attribute (Seale et al., 2006)

Boudioni and colleagues (2001) carried out a quantitative study comparing male and female cancer patients’ use of a national cancer information service. As expected, women had more frequent use of the information service. However, their findings also demonstrated the complexity that underlies the information and support seeking behaviour of male cancer patients. No single pattern of information or support seeking was found among male patients. They also found that factors such as age, social class and distance from service did affect how men used the information service. Galdas et al. (2005), in a literature review of men and health help-seeking behaviour, concluded that further research was required in order to gain a greater understanding of the diverse
nature of masculinity among men from different backgrounds and cultures, and explore its role in men’s help seeking behaviour.

George and Fleming (2004), used a qualitative approach to explore factors affecting men’s ‘help-seeking’ in the early detection of prostate cancer. They found that men experience social, psychological and structural barriers to help-seeking including a threat to masculinity, embarrassment, fear and guilt at using an under-resourced health service. However, fear of cancer, the value of early detection, the media and encouragement by their partners were the key cues to action. These findings illustrate the need for services and information provision, to extend through all levels of society through a range of strategies and settings (George and Fleming, 2004).

**Colorectal Cancer**

CRC is the third most common cancer in the UK and US (National Cancer Institute, 2008; Cancer Research UK, 2009). The occurrence of the disease is related to age, with over 80 percent of first diagnoses occurring in the over sixties. Until the age of fifty, there is no gender difference in CRC incidence and mortality rates, but in later life the mortality rate in males is much greater than that in females (National Cancer Institute, 2008; Cancer Research UK, 2009). As with any cancer diagnosis, individuals with CRC face many challenges and concerns during their cancer journey (Northouse et al., 1999). It is a highly traumatic experience (Mills and Sullivan, 1999) and can elicit numerous emotions and psychological demands on an individual for an extended period of time (Taylor, 2001; Ramfelt et al., 2002).

Data is available on the impact of gender on CRC screening uptake (Wardle et al., 2005), CRC survival rates (McArdle et al., 2003) and CRC tumour location (De Cosse et al., 1993). However, very little information exists on the influence of gender on the experience of CRC, for example coping, information need and support use (Rozmovits et al., 2004; Schmidt et al., 2005).
The experience of CRC

Physical and psychological impact of diagnosis and treatment

Individuals with CRC experience difficulties with the physical side effects associated with the disease and its subsequent treatment. This usually involves changes in bowel habits which has obvious implications on quality of life. The unpredictable nature of the problem leads to a loss of control (Mizuno et al., 2007; Wilson et al., 2009). Individuals can experience reduced confidence, embarrassment, and a reduction in social activities, work and sexual relationships (Ness et al., 1998; Northouse et al., 1999; Rozmovits and Ziebland, 2004, Desnoo and Faithfull, 2006; Houldin and Lewis, 2006; Simpson and Whyte, 2006). Having a stoma can lead to added embarrassment and limitation due to the fear of accidents, smell or noises. Those with a stoma often report a loss of independence and privacy which impacts on their sense of adult identity (Rozmovits and Ziebland, 2004). As regards gender, there is some evidence to suggest that men find a stoma more difficult to deal with than women (Rozmovits and Ziebland, 2004). As with all cancer diagnoses; there is an associated psychological impact following a diagnosis of CRC. After treatment individuals are often fearful that their cancer will return and are therefore understandably worried about their future (Northouse et al., 1999; Houldin and Lewis, 2006; Simpson and Whyte, 2006; Wilson et al., 2009).

Coping with CRC

Optimism

Individuals with a diagnosis of CRC appear to cope through ‘positive acceptance’, that is they accept their diagnosis and try to maintain an optimistic, positive attitude towards the disease and its treatment (Taylor, 2001; Dunn et al., 2006; Houldin and Lewis, 2006; Simpson and Whyte, 2006). To help them cope, they attempt to find benefits in their illness and feel lucky when they compare their situation to others (Dunn et al., 2006; Houldin and Lewis, 2006; Simpson and Whyte, 2006). As regards the influence of gender on coping with CRC, a qualitative study involving a heterogeneous sample of individuals with cancer, eleven of whom had a diagnosis of CRC, reported that women were more likely than men to identify positive aspects of their disease. Men were more matter-of-fact about their diagnosis; their cancer appeared to have neither a positive nor a negative
affect on their life (Foley et al., 2006). The authors concluded that individual responses to
cancer and its treatment may stem from personal characteristics such as gender rather
than the nature of the cancer, for example, tumour site or treatment received (Foley et al.,
2006). Three quantitative studies have demonstrated that females with CRC report more
distress than their male counterparts (Baider et al., 1989; Northouse et al., 2000; Tuinstra
et al., 2004). There has also been a suggestion that males adjust better to their illness and
treatment than females (Baider et al., 1989; Northouse et al., 2000). It is therefore
plausible that gender may be influential in how individuals cope with CRC and additional
research is necessary to examine the issue further.

Information seeking
From the literature, it would appear that persons with CRC want information on all
aspects of their disease and treatment. The most commonly requested information can be
summarised under three headings; 1) information on treatment, including complications
and side effects (Galloway and Graydon, 1996; Beaver et al., 1999; Knowles et al., 1999;
Boudini et al., 2001; Salkheld et al., 2004), 2) information on the disease (Beaver et al.,
1999; Boudini et al., 2001) and 3) supportive information, incorporating emotional
support (Boudini et al., 2001) and information on activities of daily living and improving
quality of life (Galloway and Graydon, 1996). They desire this information from
knowledgeable sources such as the medical profession or friends and relatives with past
experience of the disease (Sahay et al., 2000). The amount of information desired varies
from person to person as some require as much information as possible whereas others
are content to leave it in the hands of their doctors (Northouse et al., 1999; Bain et al.,
2002; Wilson, 2005; Dunn et al., 2006; Worster and Holmes, 2008). A recent qualitative
study has demonstrated the complexity of information seeking behaviour. The study
explored the information seeking behaviour of individuals with a diagnosis of breast,
prostate or colorectal cancer. The authors identified five patterns: intense information
seeking, getting ‘good enough’ information, fortuitous information seeking, minimal
information seeking and guarded (avoidance) information seeking (Lambert et al., 2009).
The desire for information is influenced by the stage on the cancer care continuum a
person is at, with the desire for information on what to expect in the long term being high
as individuals with CRC often feel ‘cut adrift’ once their treatment is complete (Sahay et al., 2000; Dunn et al., 2006). A limited number of studies report on the influence of gender on information. A cross-sectional study involving individuals with a diagnosis of CRC or prostate cancer noted similarities and differences in the information needs between men with different diagnoses (CRC versus prostate cancer) and men and women with the same diagnosis (CRC) (Boudini et al., 2001). Men with CRC requested less information on complementary therapies and more on prognosis than females with CRC. However, no single pattern of information or support seeking was found among males, nor were men’s requests consistently different from women’s (Boudini et al., 2001). Qualitative research has suggested that men may be less likely to access additional information services, they instead prefer to ‘maintain hope through silence’ (Leydon et al., 2000). This study examined a heterogeneous sample of cancer patients with only one individual with a diagnosis of CRC, more research in a homogeneous CRC sample is therefore necessary.

**Social Support**

Support is obtained from a variety of sources, for example, from the medical profession for specialist information support (Sahay et al., 2000; Campbell et al., 2001; Rozmovits et al., 2004; Dunn et al., 2006) and from friends and family, the primary source for emotional and instrumental support (Sahay et al., 2000; Campbell et al., 2001; Taylor, 2001; Ross and Johansen, 2002; Dunn et al., 2006; Simpson and Whyte, 2006). It has been reported that individuals with CRC have a low awareness of available support services (Sahay et al., 2000; Rozmovits et al., 2004), for those who do attend, there is a variable response, with some individuals finding support groups beneficial and some not (Campbell et al., 2001; Ross and Johansen, 2002). The role of gender in support use is unclear due to conflicting findings presented in the literature. Four studies have reported no association between gender and support (Boudini et al., 2001; Eakin and Strycker, 2001; Bui et al., 2002; Engel et al., 2003). Two quantitative studies have however reported differences in support use between males and females. The first study reported that male participants relied on their wives support, whereas females appeared to be unaffected by their husbands support and made less use of the support available to them.
(Keller and Henrich, 1999). In the second study, Bui et al. (2002) concluded that attendance at support groups may be gender-related, as males in the study reported that support programmes were too female orientated (Bui et al., 2002).

**Study rationale**

According to Banks (2001), it is a myth to think that men do not care about their health. Men do appear to worry about their health, but feel unable to talk about their concerns or seek help (Banks, 2001). The National Cancer Alliance study (1996) showed that most men were as keen as women to obtain adequate information about their condition and treatment. McCaughan (2002) found that although men did not appear to actively seek information about their cancers, they still had many questions that they wanted answered. They appeared comfortable discussing their medical needs with healthcare professionals, but did not seek information on psychosocial issues. However when these men were in a ‘safe’ environment (in their own home with the researcher), they did open out and shared psychological and emotional concerns. One of the few studies carried out in Northern Ireland on men and cancer (Spiers et al., 1999) has reported similar findings. The authors concluded that if men are given a safe environment in which to meet with their peers, and permission to talk about personal issues, they will make full use of the opportunity (Spiers et al., 1999).

Many of the studies on men’s health behaviour are quantitative in nature and have collected data at one point in time (Boudini et al., 2001). Moreover, the body of research comparing help-seeking behaviour between genders notably lacks qualitative methods of enquiry. There is a need to find out the similarities and differences of information seeking behaviours of men and women over a length of time in order to gain a more meaningful understanding of how they think, what health-related strategies and coping styles they employ, their perceptions of services and other information providers and what methods of health promoting behaviour they adopt. There is some evidence to suggest that men and women may cope differently with a diagnosis of CRC; however the studies are limited in number and frequently present conflicting findings. A study comparing the experience and coping behaviour of men and women with a diagnosis of CRC will
provide data for direct comparison between men and women and will add to the useful insights already revealed by the studies reviewed above.

If information and support services targeted specifically at men are to be effective, understanding the context and the factors which influence the health related behaviour of men with CRC is crucial. The findings of this study can potentially have relevance for men with other types of cancer as well.

**Study aim and objectives**
The aim of this study is to explore and compare the experience and coping behaviour of men and women with colorectal cancer over an 18-months period, post-diagnosis.

The objectives of the study are:
- To compare what the disease means to men and women and how it affects their lives.
- To compare their coping strategies and coping styles.
- To explore how being ‘women’ or ‘men’ affect their coping styles.
METHODOLOGY

Study design
A prospective longitudinal descriptive qualitative study (Sandelowski, 2000) exploring men’s health behaviour with respect to their information and support seeking patterns was conducted. The study compared men and women with CRC. Participants were interviewed on four separate occasions over an 18 month period; 1) after diagnosis and surgery, 2) on completion of chemotherapy, 3) six months after chemotherapy and 4) twelve months after completion of chemotherapy. Those who did not require chemotherapy were interviewed every six months.

Sample
The sampling frame for the study was men and women with a diagnosis of CRC attending the Northern Ireland Cancer Centre for treatment. The non-probability sampling method of purposive sampling was used. Participants were selected based on their ability to provide a wide range of data in accordance with the needs of the study. Factors considered during sampling were gender, age, stages of disease, treatment to be received, and the presence of a stoma.

The exact number of participants needed for the investigation could not be determined before study commencement. In qualitative research each individual is not a unit of analysis; the units identified in the data could be any experience, incident or situation (Ramfelt and Lutzen, 2005). Therefore recruitment continued until no new themes were emerging from the interviews and data saturation had been reached. It was anticipated however that approximately 30 males and 30 females attending the newly diagnosed CRC oncology clinic at the Northern Ireland Cancer Centre would be recruited over a six month period. Through attrition, it was expected that 8 to 10 participants would not complete the study.
**Inclusion criteria**

- Men and women, over the age of 18
- A first diagnosis of CRC
- Aware of this diagnosis
- Physically and mentally able to participate (based on their consultant’s assessment)
- Willing to give informed consent

**Exclusion criteria**

- Patients who were referred to the Palliative Care Team (these patients were excluded as a longitudinal study would be inappropriate and the aim of the study was to explore experiences over a period of time).
- Patients with metastatic disease
- Patients who are unable to speak English (it was felt that the use of an interpreter in qualitative research that requires a trusting relationship between researcher may distort the relationship and thus the quality of the findings).

**Procedure**

**Recruitment**

Potential participants were identified during their first oncology appointment. These individuals were newly diagnosed CRC patients who had been referred to the oncologist following surgery. The consultant screened consecutive patients for inclusion. Prior to study commencement the consultants had been briefed by the researcher and given written information on the study’s inclusion and exclusion criteria and what was required of participants (appendix 1). If the patient’s consultant deemed them suitable for inclusion, he gave preliminary information to the patient about the study and provided a letter of information and a participant information sheet explaining the study in more detail (appendices 2 and 3). If there was an expression of interest, the patient’s phone number was passed from the oncologist to the researcher. The potential participants were then approached by the researcher via the telephone and the study was discussed in more detail. Potential participants were given approximately one week to consider the written
information before written informed consent was sought (appendix 4). It was made clear to the participants that once recruited to the study they could withdraw at any time. The interview was conducted at the participants’ venue of choice at a mutually convenient time. Process consent was used in the study, therefore, prior to subsequent interviews at the 6, 12 and 18 month follow-up stages, the participant was contacted by telephone to obtain informed consent and arrange a suitable and convenient meeting place for the interview. Throughout all of the interviews, the interviewee was reminded of their right to refuse to answer specific questions or terminate the interview at any time.

**Data collection (Interview)**

Interviews focused on each participant’s experience of CRC and the effect it had on their lives, on how gender affected their coping styles and coping strategies, their perceptions of health professionals and services, their reasons for using or not using existing services, their access to information services including lay sources, complementary and alternative therapists and Internet usage. The interview schedule was developed to encourage discussion on these topics (appendix 5). Interviewees were asked to tell their story from the time when they first suspected there was a problem. This provided the opportunity for participants to express unsolicited opinions and describe their own unique experience. Issues raised by participants were explored in more detail using a semi-structured interview technique. The interview schedule was developed and updated as preliminary analysis revealed emergent themes.

During the first interview, participants were invited to describe their experience of being diagnosed with CRC and undergoing surgery. Their current strategies for coping with their illness and their attitudes to information and support were investigated. The second interview focused on the experience of chemotherapy and its associated side effects. The participants’ coping styles were discussed and the strategies described in the first interview were re-examined to identify any change over time. The third and fourth interviews explored the participants’ experience since completion of chemotherapy, issues with review appointments and any persistent symptoms or side-effects. The change in coping strategies over time was also explored.
All but three interviews were conducted in the participants’ home, the remainder taking place in the individuals’ workplace. Participants were asked to choose the venue for the interview to ensure they felt relaxed, comfortable and in control of the situation. The interviewees were interviewed either alone or with their partner in accordance with their own preference. The inclusion of the participants’ partner provided further insight into how the participant was coping with their disease and treatment. Each interview lasted approximately 1 hour, were audio-taped and transcribed verbatim by research support staff. Each transcript was checked for accuracy by the researcher who had conducted the interview. The interviews were carried out by members of the research team who had no connection to the individual’s clinical care.

**Data Analysis**

Interview tapes were transcribed and analysed according to Miles and Huberman’s (1994) techniques of labelling, coding, categorising and theme development. Data collection and analysis were undertaken concurrently; hence analysis began as soon as data became available. Themes were developed throughout the duration of the fieldwork. Recurrent themes were subjected to close scrutiny in subsequent interviews until the development process reached saturation and the theme could not be developed further. Data from the same participants collected at the 4 time-points were tracked in order to reveal changes and trends in the evolving experience and coping strategies.

Each transcript was read and re-read to check for accuracy. Labels were added in the margins to identify important emerging ideas. The transcripts were subsequently imported into the NVIVO computer package to help with data management. Initially a number of free nodes (coding) were created followed by the merging of these free nodes into tree nodes (categorising) where links between emerging nodes became apparent (theme development).

**Credibility of findings**

A number of steps were taken to ensure rigour. During the interview process, the researcher probed and clarified particular points to ensure she understood what the
interviewee was saying. Following verbatim transcription, the interviewer reviewed the transcript for accuracy. Other members of the research team reviewed a selection of the transcripts and hence regular discussion occurred on the emerging themes.

**Ethical considerations**

Ethical approval was obtained from the Office of Research Ethics Committees in Northern Ireland (ORECNI). Site Specific Assessment was undertaken at the Northern Ireland Cancer Centre.

There were two main ethical considerations surrounding the study; informed consent and confidentiality. All potential participants were given the necessary information for informed consent and they had the opportunity to ask questions about the study. Written consent was obtained without any coercion of the study participants and no incentives were offered in return for participation. An assurance of confidentiality was given and participants were made aware that the recorded interviews would be deleted following transcription. Data were protected under the provisions of the Data Protection Act (1998): the data were only used for the purpose of the study, no participant was identifiable in any way: any quotes used were anonymised; all data were stored in a lockable filing cabinet in a lockable office, and access was restricted to those researchers involved in the study and by a password protected computer file.

The researcher also adhered to the principle of non-maleficence (not causing any harm to the participants).

There was the potential for a prolonged discussion (1 hour) on a sensitive topic to cause some distress. Participants were told that they could stop the interview at any time if they found it too distressing or tiring and the researcher would terminate the interview if s/he felt that the participant was becoming distressed. After the interviews debriefing and follow-up support from the clinical support team were offered to participants, if required.
FINDINGS

Participants
Recruitment commenced in November 2006 and ended in June 2007. During this period, 56 individuals were identified as eligible, 38 of them (24 men and 14 women) agreed to take part. Their ages ranged from 24 years to 78 years with a mean age of 60 years (SD 12.15). Participant demographics are presented in Table 1. Most of them were married and not working at the time of their diagnosis. The ratio of male to female of those who declined was the same as the participants: 2 male to 1 female. The main reasons for non-participation were either disinterest in the study or they did not need chemotherapy and therefore did not want to be involved in an 18-month study.

<table>
<thead>
<tr>
<th>Total number of participants</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>38</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>60 (12.15)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>24</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>32</td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment status (at time of diagnosis)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working</td>
<td>18</td>
</tr>
<tr>
<td>Not working</td>
<td>20</td>
</tr>
</tbody>
</table>

Participants received various combinations of cancer treatment, the most common being surgery (with or without the formation of a stoma) followed by adjuvant chemotherapy. The chemotherapy was administered every week for 26 weeks (see Table 2).
**Table 2: Treatment received**

<table>
<thead>
<tr>
<th>Anti-cancer treatment received</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of participants</td>
<td>38</td>
</tr>
<tr>
<td>Surgery</td>
<td>5</td>
</tr>
<tr>
<td>Surgery + stoma</td>
<td>2</td>
</tr>
<tr>
<td>Surgery + chemotherapy</td>
<td>18</td>
</tr>
<tr>
<td>Surgery + stoma + chemotherapy</td>
<td>7</td>
</tr>
<tr>
<td>Pre-op radiotherapy + surgery</td>
<td>1</td>
</tr>
<tr>
<td>Pre-op radiotherapy + surgery + stoma</td>
<td>3</td>
</tr>
<tr>
<td>Pre-op radiotherapy + surgery + stoma + chemotherapy</td>
<td>2</td>
</tr>
</tbody>
</table>
Interview completion rates
The number of participants interviewed at each time point is outlined below.

Interview 1 (baseline – after surgery, before chemotherapy)
Thirty-four participants were interviewed. Four were not interviewed as they had already commenced chemotherapy.

Interview 2 (6 months – after chemotherapy)
Thirty-two participants completed a second interview. Six did not have a second interview. Reasons for non-participation included: One died, two did not require chemotherapy, one was admitted to hospital and one gave no reason for refusal.

Interview 3 (6 months after Interview 2)
Twenty four participants were interviewed. Eight individuals were not interviewed at this stage. Reasons for non-participation included: One had recently had surgery, three withdrew due to disease progression, one individual felt they had nothing more to add to their previous interviews and three provided no reason.

Interview 4 (18 months from baseline)
Sixteen participants completed the final interview. Two of the 16 participants had not been interviewed at time point 3. The researcher made an informed decision not to interview six subjects as it was felt that data saturation had been achieved with these individuals and that no new data would emerge from a further interview. Four participants declined to be interviewed at this stage. Reasons for non-participation included: One individual had suffered a recurrence and was currently receiving further chemotherapy; the remaining three could not be contacted and thus provided no reason for their withdrawal.
SECTION 1

EXPERIENCE OF COLORECTAL CANCER
THE EXPERIENCE OF BEING DIAGNOSED WITH CANCER

Delay in initial presentation

The male narratives indicated that the men were not proactive in presenting to their General Practitioner (GP). These men could be divided into two groups: those who only went to see the doctor as a result of their partners’ insistence; and those who delayed and subsequently mentioned their symptoms whilst attending for another medical problem. The men in the first group were experiencing rectal bleeding for months before eventually confiding in their partner. A male respondent describes how it was ultimately his wife who was the driving force behind him presenting to his doctor.

‘She (wife) nearly went spare because I hadn’t told her before. So she insisted that I go to the doctor.’ (32; Male)

Another male demonstrated how he was conforming to his idea of masculinity.

‘I think men do this...they put off things like going to the doctors...it’s going to fix itself or whatever. I would have had that attitude for a long, long time’. (10; Male)

The second group did not make a specific appointment to discuss their bowel problems. They mentioned problems they had been having while attending for another complaint. They suggested that they would not have sought help for the bowel problems otherwise.

‘Well, probably wouldn’t have been going to the doctors about it if I hadn’t been going for the other.’ (12; Male)

Not all men avoided attending their GP. One man went straight to his doctor when he experienced bleeding, despite his wife suggesting he may have been over-reacting.

‘Funny enough the wife said...I don’t think you have anything to worry about......I said I’ll just go to the doctor and let him check it.’ 36M

Evidence of delaying attending the GP was not as obvious in the female accounts.
Reaction to diagnosis

All participants were shocked when they were first diagnosed with cancer and described it as a very traumatic experience. One man highlighted the impact of the word ‘cancer’.

‘Once I heard ‘cancer’ it was shock’ (21; Male)

Both men and women described feelings of fear and denial. It was at this stage the cancer became ‘real’. Many had concerns before they went to the doctor that they had something serious, but it was only when they had the diagnosis medically confirmed that the psychological cancer journey began.

Some individuals were surprised by their diagnosis as they did not expect to receive such news, especially as they had been feeling well up to that point. One participant described how she had not experienced any bowel cancer symptoms prior to her diagnosis, and therefore felt very fortunate that she had been diagnosed before it was too late.

‘I had no other symptoms or bowel problems because when they were...most people would suffer from diarrhoea or an obstruction and pain and discomfort. I never had anything like that’. (11; Female)

A sense of frustration was noted in some male narratives that the doctor would not say that they had cancer. However others (both male and female) struggled to deal with a doctor who delivered the news bluntly. They felt that the doctor was used to dealing with this type of information, but the participants were not used to receiving such news. One participant described this as the worst experience of his cancer journey.

‘She just came out and said ‘you’ve got cancer’. That was probably the worst.’ (10; Male)

The diagnosis caused the participants to face their own mortality and subsequently reassess their future. One female narrative demonstrated how her diagnosis lead her to think about death.
‘It’s facing your own mortality. It’s the fact that you might not be there in a certain length of time. I know you could walk out and get knocked down by a bus, but it’s very different having to face your own mortality... ’ (13; Female)

In some cases, the idea that they would not survive did not ever enter the participants’ consciousness. One female stated:

‘I did and yet I truthfully never thought of dying. I think if I ever thought of that I think I would just go to pieces.’ (6; Female)

**Specific strategies used to cope with receiving a cancer diagnosis**

Receiving a diagnosis of bowel cancer had a huge psychological impact, leading to feelings of shock, apprehension and fear. The majority of participants coped with this by adopting a positive attitude, hoping that their treatment would be a success. At this stage, participants had a desire for a lot of information on their diagnosis and impending treatment. Social support from a variety of sources such as family and friends and the medical profession was important. These general coping strategies are presented in the section 2 of the report (p72).

**Acceptance**

Some of the men’s narratives suggested that they were unaffected by their diagnosis. These individuals presented themselves as pragmatic towards their cancer. They did not seem to identify any emotional impact that the diagnosis may have had on them. They appeared to be presenting themselves as conforming to the social expectation that men should be ‘matter-of-fact’ about their diagnosis, accept it and move on. For example, one man when describing his feelings towards his diagnosis, discusses how his experience in the Armed Forces influenced his reaction to his diagnosis.

*I’ve probably always been like that, just accept things as they come and if the worst doesn’t happen you think you are lucky. I don't know whether it was my upbringing at home or the life I have led through the forces and the Civil Service. The Civil Service is pretty much regimented as well. I’ve always been like that. Just accept things.* (7, Male)
He also presents very succinctly how society’s perception of how a man should behave played a part in how he reacted.

*It’s just a macho business probably! There is definitely…men are from Mars and women are from Venus, it’s definitely that! ……..If a man shows his feelings he is looked on as a sissy whereas women console each other.* (7, Male)

One female participant was also quite pragmatic and appeared unemotional about her diagnosis.

*You know you are going and getting it sorted and that’s it. There is no point in sitting and crying and getting in a state.* (6, Female)

This account was unusual because an unemotional reaction to the cancer diagnosis was more commonly recounted by the men.

The majority of women’s narratives suggested that they were emotional about their diagnosis. One female described how she could not stop crying upon being told she had CRC.

*He said it was cancer. I just looked at him. When he went outside the door I cried. I cried and cried for nearly an hour. Then (husband) came up and I cried again. I thought that was the end. You hear ‘cancer’ and you think Wow!* (23, Female)

A few men were also emotional about their diagnosis. One man chose to hide this reaction from his family. This was a young man, still living at home with his parents, yet he still felt he could not allow his parents to see his true reaction to having CRC.

*I have cried when there is nobody about. After they told me and after Mum and Dad left I just broke down really and don’t think I really wanted people to see me like that……. I would rather let them know that I’m fine about it.* (22, Male)
Similarly, another male respondent described how he was emotional in response to his diagnosis, but only in front of his family. In the presence of his doctor, his reaction was more stoical.

‘So she (doctor) came in and he just said there is a massive growth on your bowel which will require surgery no matter whether it is malignant or not; we have to get this away.......I said ok, fair enough. So on the way home my wife and I never spoke and then we came in here (house) and both of us broke down’ (32, Male)

Although this shows that some men do react emotionally to the diagnosis, they try not to show emotions in front of others.

There was evidence that traditional views on gender roles influenced the narratives. A male respondent discussed the practical financial implications of having cancer, reflecting the traditional role of men as providers.

*If it is a more serious or evasive type of cancer that shortens your life span, well, there are mortgages and children and financial arrangements to be sorted. You have got to see how the effect of your illness has on all of that. You can’t just turn around and say, ‘Oh that’s it. I’ve got cancer’ and fold.* (1; Male)

In contrast some women spoke in terms of their traditional role as carer. One female emphasised how she desired to live long enough to see her children independent and self sufficient.

‘I lie in bed at night and think if I get five years the children will be.......you know. My one awful fear is that I wouldn’t watch them grow up!’ (13; Female)
Surgery for ‘cancer’

The surgical experience seemed similar for the male and female participants. The initial shock of being diagnosed with a potentially life threatening illness was replaced by relief at the fact the tumour could be operated on and removed, that something physical could be done. One female respondent suggested how she believed that with cancer, physical removal of the tumour through surgery was the solution.

‘With cancer surgery is the answer. Cut it out’ (11; Female)

Many participants indicated that they were undergoing more than routine surgery and that it needed to be acknowledged by the medical staff on the hospital wards that this was surgery for cancer. They experienced the same physical effects of having bowel surgery that all patients endure, but as one female described there was a need for psychological support also.

‘No I think it’s because they just deal with the surgery aspect. They don’t deal with it as being cancer.’ (6; Female)

Surgery appeared to be traumatic for a number of individuals. This was illustrated by those participants who had had previous surgery and were in a position to compare the two. They described bowel surgery as worse than any other surgery they had experienced. One female account reveals that part of the reason for this was the number of ‘unknowns’ associated with the surgery; before the operation it was unclear whether or not they would undergo keyhole (laparoscopic) surgery or ordinary (open) surgery, or wake up with or without a stoma.

‘Although I have had different surgeries and I found this one to be the worst surgery. I wasn’t prepared for it as such. When you are going for appendix or hysterectomy you know exactly what is going to happen, but with this one I wasn’t sure. I was told it could be keyhole, if not it could be ordinary surgery and I may end up with a bag. So I didn’t know what way I was going to come back in.’ (24; Female)
The surgical experience appeared worse for those respondents who felt relatively healthy before their operation, but afterwards they became totally dependent and unable to do anything for themselves. One male narrative described the difficulty:

‘It’s really, really weird because the day before the operation you are running around and able to do all sorts of things and then the day after the operation you need people to actually help you get out of bed. You can’t sit up yourself.’ (22; Male)

Those individuals who had surgery but did not need to have further chemotherapy treatment found the time after their surgery quite difficult. After surgery they were discharged from hospital. However, these individuals still had to deal with the uncertainty that they had had cancer and that it may return. They frequently found themselves worrying about persistent bowel problems, which they rationalised were more than likely normal due to the surgery they had undergone, but they were not completely sure. They felt quite isolated and experienced a lack of information on the duration of their expected recovery, they wondered whether their pain was normal or how long it would take for their bowels to begin to function normally again. They got some information from their General Practitioner, but as they were not a ‘cancer specialist’ they did not have as much confidence in them as they would have had in an oncology consultant.

**Being dependent**

A number of male narratives suggested that they found the experience of being a patient difficult. It was often reported that they felt disempowered, and experienced a loss of dignity and privacy when in the hospital setting. Many men described a loss of independence, with other family members having to do household tasks for them. This was illustrated by one man who became frustrated when he could no longer do what would traditionally be defined as a male task.

‘My biggest problem is that on a Tuesday morning it’s bin morning and I can’t take this out!’ (15; Male)
Similarly, some female respondents emphasised how they too found being dependent at home difficult, but their responses focused on the more traditionally female roles in the house, for example housework and cooking.

Many of the men reported they had difficulty in accepting assistance from their wives in relation to the management of their stoma bag. One male respondent described how he felt humiliated when he had to rely on help from his wife to change his stoma bag.

‘So she would do it for me. Then I got fed up with that because it does degrade you, it really does. It’s humiliating. So I said to hell with this, I’ll do it myself’ (34; Male)

In contrast, one unusual account from a male participant revealed how he was comfortable his wife dealing with his stoma bag until he was able to handle it himself. When speaking about managing his stoma, he spoke in terms of ‘we’ rather than ‘I’.

‘When I first had the bag we had awful trouble......didn’t we love?’ (29; Male)

This approach to managing the stoma bag together was more commonly a female response. For example one female was experiencing difficulty in changing her stoma bag independently, and she was completely comfortable with her husband assisting her with this.

‘It’s (x) my husband who deals with the cleaning of mine. I can’t totally see it............we have even thought it through that if I need to change the bag......my husband will come in (to the disabled toilet) with me’. (33; Female)

Coping with bowel cancer surgery

Perception of being cured

During the first interview, many narratives seemed to indicate a perception of being ‘cured’ after surgery. When the surgeon told them the operation was a ‘success’ many appeared to interpret this to mean that they were cured of cancer. This strategy was used by people who did not need chemotherapy and also by those who did have to go on and have adjuvant chemotherapy. One female who knew she had to have chemotherapy
described it as ‘preventative’/ ‘precautionary’, that it was to stop the cancer returning in the future.

‘They got it all. I have no cancer now. Yes I was a cancer patient but I don’t have it now and it’s (the chemotherapy) just preventative, yes.’ (6; Female)

These individuals seemed to remain positive and believe that surgery had removed their cancer, they did not need any further treatment, and they were determined to believe this until they were told otherwise.

THE PHYSICAL SIDE EFFECTS OF HAVING BOWEL CANCER AND UNDERGOING BOWEL SURGERY

Altered bowel habits

Following surgery, both men and women who did not require a stoma bag described how they experienced a change in their bowel habits.

‘You still have to go back and forward if you know what I mean.......in fact I’m going more now than I ever did.’ (18; Male)

‘I would go to the toilet four times a day now because I’ve lost the majority of my bowel......I would go to the toilet after every meal.’ (27; Female)

Those with a stoma bag reported that it had an effect on intimate relationships. The impact of the stoma bag on sexual relationships was not mentioned by many participants, but those who did feel comfortable discussing it, reported that it did have an effect. Those with the bag reported not feeling attractive, they were worried about the bag leaking or bursting. These feelings appeared the same for both the male and female participants. One participant illustrated the issue well.

‘If you want to have a relationship with your husband or partner because the bag is there and you are forever checking it.’ (35; Female)

The stoma bag appeared to influence many individuals’ diets. They found they could no longer eat everything that they wanted to eat, as certain foods caused the bag to fill up quickly and made it more difficult to manage. They also had to adjust their eating
patterns to ensure the bag would not fill up when they were out, or leak during the night. Some found this very difficult to deal with.

‘I think more than anything............. is having to watch what you eat. You have to peel your apples, you are not allowed grapes because they have a skin on them – unless you feel like peeling a grape! You are not allowed onions, curry...lots and lots of things because they can cause an obstruction because don’t forget you are not doing the full digesting and secreting.’ (33; Female)

Undergoing surgery had an effect on how many individuals perceived themselves. This issue was more prominent in the female narratives than the males. One female described how her body had been altered by surgery and the appearance of a stoma bag.

‘You look at your body and it's different now.’ (33; Female)

In comparison, those male participants who discussed their altered physical appearance, emphasised that they accepted how they looked now as they felt there was no other alternative.

Specific strategies used by the participants to cope with unpredictable bowel habits or stoma bag.

Problem solving
How the individuals chose to manage their bowel habits or stoma bag could be divided into two groups; 1) those that solved the problem by reducing their social activities and 2) those that did not reduce their activities and solved the problem through forward planning. In general, the female participants could be placed in group 1 and the males in group 2. However, there were exceptions noted in both groups.

Problem solving by reducing social activities
In a number of female narratives it became clear that they found their altered bowel habits embarrassing. They frequently described how they got embarrassed in public and did not like having to constantly run to the toilet in social situations. In response to this, many female participants stated that they had reduced their social activities. It appeared women felt it was not ‘feminine’ to have bowel problems. From an early age females are
taught that bodily functions are something to hide, whereas men are taught that their bodily functions do not need to be hidden (Toner and Ackman, 2000). As a result of this, bowel functions become more of a social embarrassment for women than men. One female highlights this belief well.

‘I’m sure you heard my stomach there. It’s really embarrassing because I don’t like to go out anywhere.....Even going to my friends house......I mean to actually get up and go to their loo......you don’t know if you are going to be sitting up there for 10 minutes or 20 minutes at a time......My best friend......I was in her loo for half an hour......It was just gurgling and gurgling and gurgling and the wind is coming out in gushes. You don’t want people listening to you. It’s really embarrassing......’ (8; Female)

For some female respondents the embarrassment was related to context. They found it very embarrassing in public, but their attitude changed when they were with their family. One female participant emphasised how at home she was able to see the humour in the situation.

‘I have terrible flatulence. It’s absolutely terrible......It’s fun in the family now but you have to have a thick skin......’ (27; Female)

This sense of embarrassment was not as apparent in the male narratives. For example, when one man was asked about how he was coping with his altered bowel habits, he responded with:

‘There is nothing really upsetting me at the minute......it doesn’t upset me about going to the toilet if I have to run......’ (16; Male)

The experience of having a stoma bag also lead to feelings of embarrassment and inconvenience and impacted on the social lives of the respondents. Female narratives emphasised greater concerns in relation to adjusting to these experiences than the male accounts. It would appear that at this stage the majority of women coped with a stoma bag by reducing their social activities. One female account demonstrates how she altered her life until she felt she had gained more control over her life.
‘Well I haven’t been going out……I loved going away for trips and all that has stopped……you are waiting to find confidence in having your colostomy bag’ (23; Female)

This attitude was also noted in some male narratives, but they were atypical cases. One man described his feelings towards the prospect of getting a stoma bag. It is important to note that this was not his reaction to having a stoma bag, following his surgery, his bowel was reconnected and he did not need a stoma. One can wonder if his reaction to a stoma would have been the same if he actually had a bag.

‘I think what the big drawback is, is that it’s more embarrassment than anything else. If I have to get a colostomy bag, this will be a big embarrassment too.’ (7; Male)

Another man indicated that he too preferred to stay at home and limit his social activities, similar to the female participants.

‘……but it’s a changed way of life because of the colostomy. I’m happier nearest my own bathroom rather than in strange places…..Oh it ruins your life really, to be honest. It does...because if you step out your door to go anywhere you have to think what is the situation and what are you carrying with you; maybe change the pouch and that sort of thing.’ (19; Male)

This depiction was not reflective of the majority of male participants with a stoma bag.

**Problem solving by planning ahead**

A number of male accounts portrayed them as being unaffected psychologically by their colostomy. For example,

‘Again if it’s necessary, it’s necessary. Nowadays it doesn’t change your lifestyle that much….’ (10; Male)

By being prepared and making a few alterations to their life, they were able to maintain their desired social activities. They described how they carried an emergency kit with them on day trips and familiarised themselves with the location of public conveniences.
One man, a keen fisherman, altered his diet and organised the timing of his meals so his bag would not fill when he was out fishing.

‘I’m fishing and all……but I’ve got to time it……I would have at 8am a light breakfast……And I know that overnight I’ve been fasting and I know I can nearly guarantee myself up to 1 or 2 o’clock. OK I’m hungry, but I’m not looking for a toilet…’ (34; Male)

Another male participant took a very active approach to his stoma bag. He became heavily involved at the planning stages before his surgery, ensuring that the stoma would be placed in a low position to minimise the effect it would have on his life.

‘In my case you have to have a positive attitude and in my case it’s almost like a determination not to beat it but to master it……It also has to suit your body and your lifestyle. I like to go swimming……and I was thinking ok I want this as low as physically possible’ (36; Male)

Temporary stoma
An important variable that appeared to influence coping was whether or not the stoma was permanent. One man who knew he was going to need a permanent stoma began to take steps to help him cope with the stoma before the operation. He was very actively involved in the placing of the stoma to minimise its interference on his life. A number of other participants whose stoma was temporary did not adopt an active coping strategy; they did not appear to have an interest in learning how to cope with having a stoma bag as they hoped it would be reversed in the future. Frequently before their operation, these individuals did not know if they were going to have a stoma. Understandably they hoped that they would avoid one; subsequently they woke up after the operation with a stoma. They were told it was more than likely a temporary stoma, and thus were only accepting of the stoma on a temporary basis. Therefore although they would say they were accepting of the stoma as it saved their life, it would appear that in reality they were not. They did not fully deal with the consequences of having a stoma as they believed it to be a temporary measure. They tended to reduce their social activities, and only took short trips out of the house.
EXPECTATIONS OF CHEMOTHERAPY

During the first interview the participants spoke of their expectations of chemotherapy. This was quite an anxious time for the participants as they did not know what to expect from their treatment. They often had a number of preconceptions about chemotherapy, they presumed it was going to be a very difficult treatment and they would worry that they would be very tired or suffer from severe vomiting.
PHYSICAL SYMPTOMS AND SIDE EFFECTS OF CHEMOTHERAPY

Many participants described a number of side effects that they associated with undergoing chemotherapy. These were nausea and vomiting, pain, fatigue, diarrhoea, mouth ulcers, watering eyes and dry skin on their hands and feet. The reported side effects ranged from a low to a high intensity and appeared to be affected by gender. The physical effect of the treatment appeared worse for females than males. Females described vividly the side effects they experienced. For example:

‘No matter what I took, it didn’t take the sickness away. The nausea.....you felt you wanted to throw up all the time. Everything made you sick....’ (8; Female)

‘I was very, very sick and I had diarrhoea.’ (11; Female)

The male participants did not appear to have the same experience. They reported similar side effects to the females, for example, nausea and vomiting, pain and diarrhoea but their narratives did not reveal a similar impact. It would appear that symptom prevalence was similar to their female counterparts, but their symptom distress was lower. This becomes evident when the two male exemplars provided below are compared with the previous two female quotations.

‘The odd time you got a wee bit nauseous maybe on a Friday evening or a Saturday morning or something like that you would have felt a wee bit gooey but I was never physically sick’ (36; Male)

‘I didn’t have any......... disastrous side effects’ (20; Male)

One particularly severe side effect that appeared to affect both men and women was tiredness and loss of energy. It was reported as one of the most severe and limiting side effects of the chemotherapy. Both male and female narratives highlighted its severity and impact:

‘I got very tired, really exhausting and I wasn’t doing anything like’ (5; Male)

‘I’m absolutely exhausted and can do nothing. I don’t even go out over the door. I just patter about the house because I am really tired with it’ (8; Female)
THE PSYCHOLOGICAL EXPERIENCE OF CHEMOTHERAPY

Undergoing chemotherapy treatment appeared to impact psychologically on some participants. One female narrative revealed how she felt chemotherapy had both a physical and psychological component.

‘The chemotherapy I must say was the ’biggy’. The stoma bag and all related to it were more physical. Chemotherapy is emotional and physical....’ (33; Female)

The narratives of the participants who had weekly treatment revealed how they found the regularity of treatment difficult. One man described how he felt pre-occupied with chemotherapy and would find himself worrying about the next infusion almost immediately after treatment.

‘I dreaded it so much....you were thinking about Friday from about Wednesday’ (14; Male)

One woman gave an insight into how weekly treatment led her into a continuous cycle of chemotherapy.

‘On the Friday I just slept and slept and then Saturday and even into the Sunday and then it was Monday before you were feeling any way well and then maybe you had to go on the Wednesday to get your bloods done again and the thought of another needle.’ (30; Female)

Many interviewees spoke of how they found themselves becoming nervous and anxious before treatment. Both male and female participants seemed to dread treatment, even though they knew it was benefitting them. One female participant experienced anticipatory nausea, feeling physically sick before she had received any drug treatment. Some participants developed psychological cues which triggered memories of attending for chemotherapy. Two women could no longer drink coffee, as they associated the smell with the chemotherapy centre. One man detested the smell of his car as it reminded him of his journey to the cancer centre. One woman explained how she could smell an odour from the chemotherapy drugs which others who were not receiving treatment could not detect.
‘The minute I walked through the hospital I smelled the chemotherapy. My husband didn’t’ (33; Female)

A number of participants indicated that one of the biggest psychological difficulties was the experience of the nurse trying to find a vein for taking blood or administering the chemotherapy. This was a traumatic experience for a number of individuals as highlighted by two female narratives.

‘I just got the impression as soon as I approached (Hospital y) that my veins just disappeared deep into my arm, psychologically, apart from anything else.’ (13; Female)

‘They were in and out and in and out and there was maybe 3 or 4 nurses coming to me...one was trying once or twice and couldn’t get a vein then she would get somebody else and they were trying and then they were getting somebody else......my nerves were absolutely shattered and the sweat beating off me and just feeling absolutely sick.’ (8; Female)

Having a Peripherally Inserted Central Catheter (PICC) line fitted was an acceptable solution for many participants.

‘It was certainly successful from the point of view of the nuisance every time, every week of having to find a suitable vein’. (3; Male)

However some of the female interviewees described a reluctance to have a PICC line fitted as they were concerned with the impact it would have on their day-to-day life. One female described how she felt it would be difficult psychologically as she would never be able to forget about the chemotherapy with a PICC line in situ.

‘But to get a pick line in?......It’s hanging out of your arm. So it’s there 24/7. You can’t even shower. You have to wrap a bag around it or something; don’t get it wet, do this, do that. I thought sure if I can just go home and forget about this even for 2 or 3 days until it’s time to come up again, but with that in your arm you are never going to forget.’ (8; Female)

**Specific coping strategies used during chemotherapy**

Many participants described using the general coping strategies of optimism, information and support seeking to help them cope with chemotherapy treatment. These will be presented in the subsequent section (p72). However many adopted specific coping
strategies to deal with the particular physical and psychological problems associated with chemotherapy treatment.

*Detachment/denial/threat minimisation*

Many male participants seemed to report less symptom distress than the female participants. It is possible that they were coping by minimising the effect the cancer and its associated treatment was having on their lives. They may have been downplaying the side effects of chemotherapy and the impact caused by having a stoma. One male participant’s account revealed that he was determined to not let the treatment have an effect.

‘I didn’t let it affect me. I didn’t want it to’ (22; Male)

Those men who admitted to suffering severe side effects from chemotherapy provided an excuse/reason for them, for example, one stated the chemotherapy commenced too soon following their surgery.

‘It started off badly, although I think it was because it wasn’t long after the surgery.’ (14; Male)

A number of male participants frequently coped through methods of distraction in an attempt to keep their mind off their illness: it was important to them to keep working and maintaining sporting activities. One stressed how he was well enough to socialise.

‘I wasn’t too bad at all and that I still had the energy to do a few things.....and to go out with friends at the weekend.... ’ (3; Male)

Returning to work was important according to some young male and female participants. This made them feel as if their lives were getting back to some degree of normality and therefore ‘they must be better’. This also served as a distraction strategy to help them stop focusing all their thoughts on bowel cancer.

Those that were affected psychologically by the chemotherapy treatment appeared to cope by trying to minimise the psychological impact. They would tell themselves that
what they were experiencing was nothing in comparison to other forms of physical suffering. One man demonstrated his personal unease at his psychological distress by frequently discussing with the interviewer his confusion at being so psychologically affected by his treatment.

‘Why should it disturb me so much?......I did try to make a nonsense of it and maybe that was a help...... ’ (20; Male)

One female participant went to see a psychologist, and found this helped her cope with the difficult treatment. Other participants stayed in bed and slept after their treatment; they wanted to forget about the day, and move on to the next day as soon as possible.
PHYSICAL EXPERIENCE AFTER CHEMOTHERAPY

The physical experience 0 – 6 months post chemotherapy was similar to that 6 – 12 months after chemotherapy, therefore they have been presented in one section. The participants appeared to progressively improve over time.

‘New normal’

On completion of chemotherapy the participants narratives indicated that they were attempting to reintegrate into ‘normal’ life. The time frame for this varied, for some, six months after chemotherapy, they felt completely back to normal. However, one male described a sense of ‘limbo’; he was no longer a cancer patient, but did not feel completely back to normal.

‘I can get integrated again with an ordinary routine and I’m not completely out of things like a patient…..halfway between two worlds...’ (20; Male)

Following surgery and chemotherapy many male and female narratives indicated that they were experiencing persistent side effects such as tiredness, watering eyes and/or lingering problems with bowel functioning. This was seen as something they lived with, their ‘new normal’. Having persistent watering eyes was highlighted as a problem by some of the male respondents. Their narratives revealed an anxiousness that they were being viewed as emotional, something more traditionally associated with women. One man described his embarrassment in public especially during a funeral - a potentially emotional situation.

‘Sometimes the tears can be running and it can be embarrassing. Going to a funeral and people would be thinking you were getting emotional.’ (5; Male)

The symptoms did not interfere with their quality of life, however, many felt that although they had finished chemotherapy, as they were still suffering from its associated side effects, that they were still a ‘cancer patient’ and could not move forward with their lives and get back to health and back to normal. Two participants were suffering symptoms that were specific to their personal situation. One individual was having
problems with a hernia; the other was completely immobile as he had lost functioning in his lower limbs.

Over time the participants attempted to reintegrate into ‘normal’ life. The female respondents indicated that they were living with side effects such as tiredness and either altered bowel habits or a stoma bag, but they were accepting of this. One woman with a stoma bag emphasised that she was able to work, exercise and travel. She found the Internet a great source to allow her to live her life as she wanted.

‘Then there is so much……only that I was lucky and able to get on the Internet. There are so many things you can get from underwear, gadgets to make life easier……and swimwear……everything……To me it’s just an everyday thing and I don’t fuss.’ (6; Female)

Similarly a female who did not receive a stoma, but was still experiencing altered bowel habits, did not define them as a problem.

‘I go a lot oftener. You would maybe go once a day; I would go four times a day.’
Interviewer: And do you find that restrictive?
‘No, no, I just know every toilet in the town. It’s all part and parcel.’ (27; Female)

Some male respondents emphasised in their narratives that they were not experiencing any problems. One man reported that he was living his life as he had prior to his diagnosis.

‘Just getting back to normal. I went back to work full again full time……I just do my usual thing. I go to work and organise my social life…….’ (22; Male)

If these men did admit to experiencing symptoms such as tiredness they seemed to play down their experience. When they acknowledged the ‘odd day’ of tiredness they attributed this to work or age not to their ‘physical stamina’ being affected by the illness.

‘Fully back to normal……Well a wee bit of tiredness, but I would say it’s my age.’ (12; Male)
‘I’m tired because I am tired……there has been the odd day at work where I’ve felt knackered but I think that’s more to do with the work and if it’s been a busy week as
opposed to not physically......not having the physical stamina because of the illness.' (1; Male)

One man presented himself as accepting of his illness and having no problems with his altered bowel habits.

‘No I don’t think about that end of it much. Obviously because it’s major surgery and it’s a major operation and it’s a major change to your body so there are the side effects which you just learn to adapt to and live with, etc, etc.’ (3; Male)

In contrast, some male and female respondents still felt restricted by their stoma bag. One man described how he reduced his social activities and did not like to plan ahead.

‘I feel......if we set aside the colostomy I feel as well now as before the operation........Well it’s just managing it......You need to keep looking after it. You have good times and bad times......’ (19; Male)

Similarly, one female participant was still reducing her social activities:

‘I go out, but I don’t go very far. I would be scared to go very far you know, with this (stoma bag) in case anything happens’

One female participant who was managing her stoma bag well decided to have a reversal. As a result of the reversal she experienced protracted bowel symptoms. She felt she needed to have the reversal to bring her cancer journey to an end. She described her bowel symptoms as her new normal and was making the necessary adjustments to her life.

‘But now it’s just when I need to go I need to go and I just work around that’ (33; Female)

Another female was offered a reversal, but as she was coping so well with her stoma bag and had heard reports from other individuals about the possibility of bowel problems after a reversal, she decided to keep her stoma bag.

At this stage, those interviewees who had been in employment before their diagnosis were thinking of returning to work. This was usually done slowly, with the participant
gradually increasing their working hours. One female was worried about the effect her persistent tiredness would have on her ability to work.

‘My boss said to me if you are tired at work just sit, but the work I do is cleaning and working. I just can’t all of a sudden say I’m sitting down. I mean, the other cleaners would be looking at you and saying, look she is sitting doing nothing. I think if you have a broken leg or arm people have more...not that you want sympathy but… ’ (25; Female)
PSYCHOLOGICAL EXPERIENCE AFTER CHEMOTHERAPY

Similar to the physical experience, the psychological experience was similar 0 – 6 months and 6 – 12 months post chemotherapy.

Lingering uncertainty

Immediately after chemotherapy many participants reported a feeling of immense relief. However, over time this progressed to worry about the cancer recurring. This uncertainty had the biggest influence on a number of individuals’ experiences and appeared to be of paramount importance to the participants at this stage. One male participant described how he felt trapped with his cancer.

‘In a way you become a prisoner; you become a prisoner of circumstances. A prisoner because you are shut in with a particular life condition and there is no escape from it, indeed you don’t know if it is a condemned cell or not.’ (20; Male)

The degree to which this uncertainty impacted on the study participants varied from unconcern to total pre-occupation. The participants could be divided into three groups: 1) unconcern towards cancer recurrence; 2) some manageable concern and 3) total pre-occupation with the possibility of cancer recurrence. Only female narratives indicated a preoccupation towards the uncertainty, while evidence of unconcern towards cancer recurrence was only noted in the male narratives. An overlap was noted between the sexes, both men and women reported a moderate response to the uncertainty.

1) Unconcern

Some men presented themselves as having no concerns about their cancer returning. One man, who had also emphasised that he was not having persistent bowel problems, detailed that he was not concerned about the risk of recurrence.

‘Well I don’t worry......I’m not the worrying type. You know the old song que sera sera.’ (3; Male)

Evidence of contradiction in the narratives of these men indicated that this may be a front, their attempt at enacting their masculine beliefs. For example, at the beginning of
his interview one man describes his anxiety at having to attend for a scan sooner than expected and the implications of that.

‘Well I don’t know whether to be ...you know...that it’s so quick that there is something there or not that didn’t show up on the scan’ (31; Male)

However, later in his narrative he goes on to say:

‘As I say......it’s there and there is nothing you can do about it......there is no sense in worrying because there is no alot you can do about it.’ (31; Male)

This quote in isolation would indicate that this man is not worried about his cancer, yet what he said earlier would indicate otherwise.

2) Manageable concern

Many male and female accounts indicated that they were living with the fear that their cancer may recur. One female narrative showed how the uncertainty was something that was always with her, but she tried not to become pre-occupied with it.

‘Now it is always in the back of your mind, there is no doubt about it, but I don’t dwell on it.’ (6; Female)

These individuals appeared to have a determination to not let the uncertainty have an influence on their lives. One man rationalised this by emphasising the precarious nature of life in general.

‘I thought sometimes yes, my life is under threat because if it came back. But if I dwell on it I can’t get on with the rest of my life for whatever length of time is left. You know, I could get run over by a bus’ (1; Male)

The uncertainty was experienced in cycles. Immediately following chemotherapy these individuals described feelings of immense relief. The fear and worry slowly receded as the time from their treatment ending increased, but the worry resurfaced before review appointments, scans or anniversaries such as the date of diagnosis or surgery.
3) Pre-occupation

Some females appeared completely preoccupied at the possibility of recurrence. One female worried that any pain or illness was a sign that her cancer had come back.

‘I had a terrible bout of gastroenteritis which drained the life out of me and I thought oh God this is back again.’ (35; Female)

Another woman described herself as a time bomb, signifying that she believed it was only a matter of time before the bomb went off and her cancer returned.

‘All I say is I still keep thinking I’m a time bomb because there are many people who have this cancer thing and they are not even with us now......’ (4; Female)

Specific strategies used by the participants to cope with the ‘uncertainty’

The participants used certain strategies to help them cope with the fact that their cancer may some day return.

Objective tests

Individuals dealt with this uncertainty in a number of ways. The main boost to their confidence that their cancer was not returning was the objective tests they underwent such as blood tests and scans. The impact of these scans was discussed by one female.

‘I would love to have a scan done of my whole body and pinpoint look...there is nothing here. Just give me a scan of my whole body and tell me go away and enjoy your life.’ (35; Female)

Many individuals placed a lot of emphasis on the scans, and trusted that they would pick up any change. Immediately after chemotherapy, the more frequent the scans, the less fearful the individual was. They felt nothing much could grow in a short time frame, and if it did, it could be removed at an early stage. Interestingly, as time went on and the frequency of the scans decreased, they did not take this as a negative, they took this as a positive, as an indicator they were getting better, and the risk of the cancer returning must be getting lower as they did not need to be seen as much. Great faith was also placed in their consultant. One female described how if her doctor told her that everything was going well she worried less about a recurrence.
‘If they (doctor) tell you that you are alright, then you say right I’m alright...’ (27; Female)

Subsequently one female who did suffer a recurrence was very angry at her doctor who told her initially that she should be ‘ok’. She found the recurrence hard to accept as the doctor had told her she was fine.

‘So I couldn’t understand it and said I don’t understand because you told me I was fine...’ (8; Female)

Trust in medical profession

Many participants often felt that after treatment they were back to the same stage as anyone else who had never had bowel cancer; in fact they felt even better off as the doctor was continuing to monitor their progress.

A number had faith in the medical treatment as well as the medical profession. The fact that they had done all they could by having the chemotherapy treatment, and crucially completing all of the cycles, reduced their fear of a recurrence. Certain individuals who had to have a dose reduction as they found the treatment difficult to tolerate, subsequently worried that the dose may not have been strong enough to prevent the cancer from coming back.

A number of participants used the fact that they had been diagnosed with cancer of the bowel as opposed to another form of cancer as a positive coping mechanism. They believed that bowel cancer had better survival statistics than other tumours; it was contained within the bowel and was a solid mass that could be removed through surgery. They felt this greatly reduced their chances of the cancer returning.

‘If I had another form of cancer, then it might be slightly different. If I had leukaemia where you can’t just go in and slice away the offending piece...’ (1; Male)

‘Carpe diem’

Many participants were motivated to make changes in their lives in order to reduce the chance of the cancer returning. They became more alert to what was going on in their
body so they would be more aware of any early warning signs that they may have missed before their initial diagnosis, and lead more healthy lifestyles by improving their diet and exercising more. Others had a ‘carpe diem’ moment and made a conscious decision to make the most of their lives, and to enjoy every day. For example one male explained how he had become more appreciative of his life and was determined to enjoy whatever time he had left.

‘My outlook has probably changed as regards appreciation of...I’ve always been somebody who enjoys life....... but probably now even more so because you realise that time is limited and you never know from one week to the next what the next week is going to bring so you make the most of what is going on.’ (3; Male)

This helped these persons cope with the uncertainty as they felt that even if their cancer did return, they had not wasted their lives in the interim. Returning to work was important to some interviewees as this made them feel as if their lives were getting back to some degree of normality, therefore they must be better. This also served as a distraction technique to help them stop focusing all their thoughts on bowel cancer.

Pre-occupation with uncertainty

Some individuals found that no matter what they tried to do they could not stop worrying about the cancer returning. One man revealed how he could not express his concerns to his family as he wanted to protect them, and did not want to cause them any distress.

‘I’m scared... I don’t want them ones (his family) to see it.’ (37; Male)

These individuals were referred to a psychologist by their oncologist and this proved helpful. They were able to talk to the psychologist in confidence as they knew the psychologist would not be personally affected by what they were saying. Others who found it difficult to cope with the uncertainty took hope from other people they knew who had had bowel cancer and were still alive many years later. They hoped that their experience would be the same.
Age appears to be an important factor in how the participants coped with the uncertainty. The older generation did not appear to worry as much about their cancer returning. They felt they had had a good life, and thus were accepting of the possibility that their cancer may return and they may not survive it. They frequently said that they did not think they would have coped as well with the uncertainty if they were younger and still had more of their life to live.

‘I mean I’m 77 now and when you get to 77 you think well you’ve had a right...and I’ve had a very good life and I suppose you think to yourself well, there is always something has to go wrong.’ (38; Female)
SUMMARY OF COLORECTAL CANCER EXPERIENCE

The cancer journey

For the participants bowel cancer was an experience, or journey which began at diagnosis, took the individual through treatment and onto survival. There were two strands to this journey: the physical cancer journey, and the psychological cancer journey. The physical cancer journey involved the physical side effects associated with bowel cancer and the effects of surgery, chemotherapy and having a stoma. The psychological cancer journey involved the psychological impact of being diagnosed with cancer, the possibility that the cancer may someday return and the impact on the individuals self esteem and sense of identity, e.g. the stigma associated with cancer and their body image.

The psychological journey was very different to the physical journey. The physical journey ended when the individual felt they were back to health after their treatment, once they had recovered from the side effects of surgery and chemotherapy, and felt physically back to normal or had learnt to adjust to their ‘new normal’. For many however, although physically they felt better, they still experienced a sense of uncertainty that they may not be completely cured of their cancer, and that it may return again some time in the future. This common feeling has become known as the ‘Damocles Syndrome’ (Koocher and O’Malley, 1981):

‘According to Greek legend, Damocles a courtier to the tyrant Dionysius, praised his sovereign, who invited him to a feast. However, during the entertainment, Damocles looked up and saw that Dionysius had seated him directly beneath a sword that was suspended from the ceiling by a thread. For Damocles, this sword was a symbol of the precariousness of life and how one's fortune could shift from being in favour at court to falling out of favour, causing the sword to fall down one's head.’

Physical cancer journey

The impact of the physical side effects changed with time and is summarised in Figure 1. Initially the severity of the symptoms and the impact they had on the individual ran in parallel and peaked around the time of surgery and chemotherapy. At the second interview, the physical problems were mentioned frequently as they were at the forefront of the participants mind. At this stage they were affecting the person’s activities of daily living. By the fourth interview, the individuals had learned to adapt and adjust to their
situation and the physical side effects were no longer being defined as ‘problems’, hence the impact decreased despite the symptoms still being present. This was particularly apparent with the female participants. Initially they appeared more affected by the physical side effects than the men, over time they were still having problems with their bowels, but they no longer allowed it to limit their activities.

Figure 1: The physical cancer journey

Psychological cancer journey
The psychological cancer experience began at the time of diagnosis when the individuals were forced to face their own mortality. The experience continued through treatment due to threats to self esteem. These threats resulted from the stigma associated with having cancer, and its impact on body image, physical abilities and personal attributes such as being healthy and independent. The psychological cancer experience was then prolonged by the uncertainty that some time in the future the cancer may return. The psychological impact of having cancer changed over time (see Figure 2). The worry and anxiety was at its highest around the time of diagnosis, however it decreased during treatment as the individual felt they were doing something proactive to help cure the cancer. The
uncertainty then reappeared in cycles. As time progressed from completion of chemotherapy and they had had no relapse, their fear decreased. The worry recurred just before review appointments, scans or significant cancer anniversaries, such as the date of diagnosis or surgery.

**Figure 2: The psychological cancer journey**
SECTION TWO
GENERAL COPING STRATEGIES
INFORMATION SEEKING

Overall there appeared to be two groups identified with regards to information seeking: those who wanted a significant amount of information from a variety of sources (active information seekers), and those who were satisfied with the information they received from their doctor (passive recipients).

Active information seekers

*Diagnosis and surgery*

These participants were pro-active in gaining information; asking questions of their doctor, seeking out relevant information on the Internet and talking to peers. For some it appeared they wanted the information to facilitate informed decision making.

*They have given you the choice as well, very clearly, having explained to you that in their experience, the best course of action, giving you a very clear choice that you can go with it or walk out the door, it is up to you.*’ (1; Male)

‘I want to know exactly where I am at each stage and all the information because I want to make informed choices’ (13; Female)

A common feature of these individuals was a personal CRC knowledge base. This arose either from their profession, a family member, or as a result of them conducting their own search upon diagnosis. As a result of this they felt empowered to ask questions of the doctor, which were well received.

‘.......because you had done your own research in advance, you could have a conversation with them at my level as opposed to the level they maybe use between themselves.’ (1; Male)

‘.......like I went down sometimes with a list of questions, daft questions and no, they always, always treated it as.....this is great, this is what we want to see.’ (008).

This group still viewed the doctor as the ‘expert’; they placed emphasis on his opinion, and wanted information that was specific to them.

‘You have to realise that every individual is an individual and the answer that I get is based on the consultant’s experience.......and I think that’s what you have to trust in.’ (15; Male)
However, many in this group experienced poor PCC in relation to diet. There was a sense of disappointment that dietary advice was not routinely offered. A great importance was placed on receiving information from someone who was seen as an ‘expert’ in the area.

‘Somebody coming in like a dietician who would give you some idea, even when you left hospital, what you should be eating. Again, I don’t think a doctor knows all that much.’ (10; Male)

Many of these patients were now living with a stoma. Patients expressed dissatisfaction with the information received at the time of surgery. For example, one man described how he felt he was given information on the stoma too close to the operation. He did not feel he had been involved in the decision on stoma placement.

‘The first time I saw the stoma nurse was the day prior to surgery. I don’t think that gave me enough time to take it all in to be honest. It’s the sort of thing you need to talk about because …..it has to suit your body and your life style.’ (36; Male)

In the period between surgery and chemotherapy, a number of respondents in this group were disappointed in the amount of information they were given in relation to chemotherapy. This was an anxious time which was worsened by the lack of information.

‘There needs to be a preliminary (chemotherapy) meeting of some sort or some better knowledge given to the patient and their family much earlier…..there is absolutely no information at all.’ (14; Male)

Some thought they were ‘cured’ following their surgery and did not realise they needed to have chemotherapy treatment. Subsequently at their first oncology appointment, they described how it was like being told they had cancer all over again, and they went through another stressful process.

‘Well he started to talk about chemotherapy but to tell the truth it scared me because I thought I was just more or less going up for a (check up)…..Then he started to talk about 26 weeks and getting chemotherapy and things like that. Here’s me, I thought the operation was…a success.’ (18; Male)
During chemotherapy

The attitudes to information during chemotherapy were similar to those presented above. These participants were very proactive and attended chemotherapy with prepared questions for their doctor.

Passive recipients

Diagnosis and surgery

This group described how they adopted a passive role in information gathering and relied on the doctor providing them with the necessary detail.

‘Yes just what the doctors said. I never researched nothing into it at all, just what the doctors told me.’ (31; Male)

Many in this group found retention of verbal information difficult; they found leaflets and diagrams useful as they could review the information in their own time. They had a desire for retrospective information, as opposed to the ‘active information seekers’ who wanted prospective information.

‘I think you need the information to go back on. I think it helps if you can go back on it and see what they actually did. Sometimes you are told things but are not listening properly.........’ (2; Female)

These individuals did not want to do their own search into CRC, and were satisfied with the level of information they received from the medical profession. However, unlike the ‘active information seekers’, this group had scant knowledge of CRC and were therefore not empowered and unable to be part of the decisions relating to their cancer. The control lay with the medical profession; they informed the patients what they believed the individual with CRC needed to know. However, the individuals in this group had limited insights into their information needs. There was evidence in the narratives that these individuals would have asked more questions, if they had had enough knowledge to know what to ask.
Some respondents were completely satisfied with limited information on their diagnosis and treatment. This minimal information provided by the medical profession met their PCC needs. To illustrate, when asked about information seeking from other sources (not the medical profession), an individual responded:

‘Well in relation to the cancer, no........To be quite frank with you, I just said no look, you are the experts and I’m putting myself in your hands as such and I didn’t have any doubt about that.’ (15; Male)

Within the passive information seekers, there existed some individuals who appeared to completely avoid some information, particularly in relation to chemotherapy treatment. They reported feelings of anger towards the medical profession for giving them what they deemed to be un-necessary information. However, contradiction within the narratives revealed that they would have welcomed more detailed information but appeared unaware of that need.

‘I just don’t want to know that I’m going to have pain or to be sick. I just want everything over and done with.......I know that you are better knowing at the end of the day because if something did happen.......say you took mouth ulcers or something did happen, you would probably be worrying more because you would be saying, well why am I taking this? (8; Female)

**During chemotherapy**

These participants’ attitudes to information did not change during chemotherapy; they remained passive, allowing the doctor to tell them what he thought they needed to know.

**After chemotherapy**

Whether they were classed as active information seekers or passive recipients, participants indentified a need for more information on follow-up appointments and
scans. This increased anxiety in a number of individuals who placed great importance on their scans to detect any signs of a recurrence.

‘It’s the lack of information........You are left in limbo........ Why don’t they send me for a scan or whatever?........At least I would know they are going to come to me instead of me hanging about and you don’t know whether it’s cured or in remission or still there.’ (30; Male)

Within the data collected, there appears to be no obvious gender difference in information seeking behaviour. It would appear that there are other factors such as socio-economic status and age which were related to individual experience. The older generation frequently felt it was not appropriate to question a doctor, they did not feel they had the ability to ask questions, and were content to accept what the doctor said. In addition, many did not have access to/limited understanding of the Internet, so this hindered their ability to conduct their own search. As a spouse of one of the participants suggested:

‘Probably our age is a factor too. He is 78 and I’m 71 and we don’t have the Internet for a start and we wouldn’t know how to go about doing computers.’ (7; Male)
SEEKING SOCIAL SUPPORT

When individuals were diagnosed with cancer, they encountered a number of problems both physical and psychological. To cope with these difficulties they needed more social support than normal.

Sources of support

Social support was provided by a number of sources including the medical profession, friends and relatives, other individuals with cancer, and the Church. Different sources provided different types of social support. The medical profession provided the participants with informational support, as did other patients. The participants viewed this as an appropriate source for providing them with information on their disease and treatment. They viewed the medical profession as a reliable source as they had great trust in their knowledge and understanding of their condition and therefore they were able to provide them with appropriate, relevant, trustworthy information. They viewed other patients as an appropriate source of informational support as they had been through the experience and could therefore relay valuable ‘real life’ information about the illness and treatment.

Family and friends appeared to be the main sources of emotional support. They provided the support and assistance the individual needed to deal with the difficulty of being diagnosed with a life threatening disease and helped them cope with difficult treatment. This emotional support gave the participants a sense of security and of being loved. Family and friends also provided instrumental support, the tangible support that was necessary to help the individual get through their day, e.g. household chores, accompanying them to treatment etc. Some individuals resented this support as they did not like their loss of independence and disliked being a burden to loved ones. For example one female described her feeling of unease at having to depend on others.

‘Having to rely on other people I don’t like. I’ve never had to rely on others so I don’t like that. I don’t like not being able to do things.’ (6; Female)
Family and friends also provided informational support through their attendance at review appointments with the participant, and using the Internet to glean additional information that they felt would help the participant.

The source of support tended to vary between the male and female participants. The men typically relied on the wife or partner for support. When speaking about their sources of emotional support the men would identify their wife as the main provider. It would seem that they did not need any other support as they did not identify any other sources.

‘I have my wife and she has been my support from day one’ (36; Male)

It would even seem that some of the men did not want any other support:

‘A lot of people crowding me, ……you just don’t want it’ (34; Male)

These men did not seek any peer support from sources at the cancer centre. They did not make an attempt to speak to anyone else who was having chemotherapy (unlike their wives). As illustrated by the response below, they took steps to avoid speaking to others.

‘I tend not to talk to them (other people at the cancer centre). My wife will talk to people. I just sit there! I take a book with me and read it.’ (34; Male)

In contrast, the female participants were more general in their response. They did not specifically identify their husband as their main source of support. They spoke more generally of ‘friends and family’. They were very aware of overburdening their family and therefore had a desire for emotional support from a variety of sources. Unlike the men described above, the female participants found support in attending the cancer centre, meeting other people who were having treatment. This was illustrated by one female who described her peers in the cancer centre as ‘family’

‘I admired these people and they gave me encouragement……I sort of felt a family type thing.’ (33; Female)

As a result of this they missed attending the cancer centre once their treatment was complete. The men did not report experiencing this same loss of support.
Some individuals avoided telling friends that they had been diagnosed with bowel cancer and thus they did not get support from this source. One man discussed how he did not tell people as he did not want any sympathy.

‘I’ve told as little people as possible because I don’t want people running around feeling sorry for me……because people would naturally say ‘Oh that poor man has cancer’. I don’t want people pitying me.’ (7; Male)

This attitude was common in the older generation who felt there was a certain stigma associated with having cancer, especially bowel cancer, an area of the body that is seldom talked about. One man revealed how he worried that the disease implied something bad about the person who had it.

‘You get the impression that people look down their nose at you…like you are like a leper.’ (37; Male)

Some participants found additional support through their faith; this provided them with the strength they needed to cope. The participants spontaneously mentioned their faith as something that helped them cope; the question was not posed by the researcher. Those individuals who mentioned faith as something that was important seemed to be the same ones who were very accepting of their illness as they felt there was nothing they could do about their diagnosis. They believed that the doctors would do all they could and the rest was in God’s hands. These individuals often said that they were not afraid of dying. It would appear that having a sense of faith removed a lot of the anxiety; they were able to be positive and hopeful that another source, a ‘higher being’ in addition to the medical profession was working for them. If He decided that they would not survive their illness then they were accepting of that.

**Colostomy bag and support**

Support was crucial to many of the individuals with a stoma bag. They felt that the support they received from the stoma nurse was invaluable. The support from the stoma nurse was largely practical support such as teaching the individual how to change their bag, helping them with ordering supplies etc. Many also got practical support from family members who helped in the management of the stoma at home. Others did not
want this help; they found it degrading and wanted to be totally independent in managing their stoma. None of the individuals mentioned attending a stoma support group. When asked about this in the interview, interest was minimal; some felt they would be interested to go to be able to offer support to others, but did not feel they needed the support themselves.

**Change in support needs with time**

Individuals need for support changed in accordance with their stage in the cancer journey.

*Diagnosis and surgery*

The experience of having cancer surgery was more than a physical experience; individuals required some form of psychological support also. As one female detailed:

‘No I think it’s because they just deal with the surgery aspect. They don’t deal with it as being cancer.’ (6; Female)

A number of individuals experienced a void in support between their surgery and their first attendance at the cancer centre to discuss their chemotherapy. They found this particularly difficult to deal with as they did not know what to expect from the next stage of treatment. It was felt that at this stage the support of, for example, a specialist nurse who could inform them of what to expect from chemotherapy would reduce their anxiety levels and the fear of the unknown. Interest in attending a formal support group at this stage was minimal. One man described how he felt there was a lack of continuity between his surgery and the cancer centre.

‘If there was something to follow on once it was found that you needed to go further on, at least somebody that knows. Everybody in (Hospital x) says well we don’t know anything about this, it’s nothing to do with us. So you didn’t know anything. If you did, if there was somebody there or you could go somewhere that they could quickly tell you because whenever I went to the (Hospital y), they could tell you in 5 minutes basically what is going to happen. If you only could have that sooner it would help matters.’ (14; Male)

One subgroup of participants who were all under the care of one specific consultant did get to see a specialist nurse after their surgery. These individuals did not appear to have
the same anxiety levels pre chemotherapy as those who did not receive the same level of support.

*During chemotherapy*

During chemotherapy both men and women felt they received adequate support from the medical profession through their attendance for chemotherapy. In addition at this stage they received a lot of support from friends and family. As a result of this, at this stage interest in attending formal support groups was low, and gender did not seem to influence attitudes to support groups.

*After chemotherapy*

On completion of chemotherapy many participants encountered a number of physical and psychological difficulties. A number of female narratives revealed that to cope with these difficulties they needed further support. One female described this as a feeling of abandonment, revealing that she felt she needed more ongoing support.

‘Whenever all the treatment is over and you are sort of...there is almost whilst you want to be cut adrift, there is that feeling that you are being abandoned...’ (13; Female)

Similarly another female participant stated that she would have liked more support at this stage, and felt that a visit from a specialist nurse would prove valuable.

‘Yes there does need to be somebody there to catch you at the end of it all, at the end of the chemo and your visits to the hospital because.......everybody has gone and left you.’ (35; Female)

An account from one male respondent demonstrated that similar to a number of the females, he too missed the support from the hospital.

‘It sounds strange but you start looking forward to your trips there (the cancer centre)......it’s like another family that you have got outside.’ (1; Male)

This was an atypical response, as the majority of male respondents reported that they did not miss attending for chemotherapy and did not appear to have the same desire for ongoing support. For example:
Interviewer: ‘some people find that when they are not going back to hospital, it’s quite difficult to cope……’

‘I was glad to not have to go’ (5; Male)

Interest in support groups increased at this stage for many male and female participants. One female who was attending a support group found it useful, but stressed this was because all attendees were well. She expected she would not find it as beneficial if a member of group suffered a relapse.

‘We have a support group. They are fine. Everybody is on the road to recovery. There is nobody having treatment or anything at the moment. So we are all sort of 4 years or a year or 2 years and seem to be getting on really fine.’ (35; Female)

Similarly one female did not attend a support group for this reason; she was feeling apprehensive that a negative story would bring back her anxiety.

I didn’t go to any support groups. There are support groups that you can go to but I found...I suppose they would have been one thing that I would have been very apprehensive about going because I didn’t want to get any negative stories first hand! ......Everything is going along honky dory here I don’t want to hear any negative stories here first hand. (6; Female)

One man who attended a support group stressed in his narrative that he was attending to help others, he was keen to emphasise that he did not need any support. This was not apparent in the female accounts.

‘I actually go out to them more out of respect and support for the girl that runs it, the stoma sister…….How much I get out of it, I’m not kind of sure’ (1; Male)

Another male respondent, who reported that he was deeply affected psychologically by his illness, indicated that he felt he could not talk to anyone, not even his wife or a counselor. His oncologist suggested he attend a psychologist but did not avail of the service.

‘I couldn’t talk to nobody. See the things that were going through my mind? I couldn’t talk to nobody…….I says I can’t talk to my wife……But I couldn’t even get the courage up to ring anybody (counselor)…. ’ (37; Male)
Through their accounts these men appear to be enacting their masculine beliefs. The first, 1, was anxious to stress that he did not need support; he was attending support groups to support others. Similarly the second male, 37, was not comfortable with showing his emotions in public and wanted to manage them privately. It is possible that his masculine beliefs were preventing him from showing his emotions and opening up and discussing his illness.
OPTIMISM AND POSITIVE THINKING
Receiving a diagnosis of bowel cancer seemed to have a huge psychological impact, leading to feelings of shock, apprehension and fear. The majority of participants coped with this by adopting a positive attitude, telling themselves to be positive and hopeful that their treatment would be successful.

Downward social comparison
Being optimistic led a number of individuals to say that they felt lucky, especially when they compared themselves to other people with the same diagnosis, who were in a different situation to themselves (e.g. those who had received their diagnosis at a later stage; those who were not responding well to treatment; those who were suffering from severe side effects; those who had had to deal with a stoma bag, or those who had not had the same family support). Often a person felt guilty that they had a better prognosis than a peer, and felt bad about feeling fortunate when others were suffering. This ‘downward social comparison’ where an individual in a stressful situation compares themselves with others who they believe are worse than they are was frequently noted in the interviews. Participants made the comments spontaneously, evidencing that they had engaged in some kind of downward comparison with other individuals with cancer. This downward comparison helped the individual cope as it allowed them to feel better about themselves. In most situations, no matter how bad the person’s prognosis was, they always knew of someone else who was worse off. Even if they did not know someone in person, they often speculated that there must be someone in the world worse off than them. In some cases the downward comparison did not help the participant cope positively. For example, one female described how knowing someone who was not doing well caused her to they worry that she would end up in a similar situation.

‘I looked……and people had lost their hair and people really looked ill and I thought…..I’ll never get through this.’ (30; Female)

Many female participants gave more attention to negative experiences. This was not as apparent in the male narratives.
Participants with a stoma bag frequently spoke about other people they knew who had a stoma bag as a way of portraying the fact that having a stoma bag was something that was socially acceptable due to the number of people who are living their day to day life with one. They were doing this as a way of reducing the stigma associated with having a bag by telling themselves that this was a very common and acceptable thing to have. Through this comparison they felt that they were not on their own, and if other people could cope with having a stoma bag, then so could they.

Some individuals who were trying to be positive about their illness, felt surprised by this reaction, and felt that perhaps they were not worrying enough about their diagnosis by not taking it as seriously as they ought. They felt that perhaps they were tempting fate, and that the cancer may return at a later date because they did not take it seriously enough initially.
POSITIVE COGNITIVE RESTRUCTURING

The participants, both male and female, coped with the negative experience of being diagnosed with cancer by attempting to find something positive in the experience. This was done in a number of ways.

Participants:

- Were thankful that they had been diagnosed with cancer of the bowel, and not another form of cancer which could not be operated on or would spread more easily.
- Viewed the cancer as a battle/fight to be won.
- Used the experience as an opportunity to make positive changes in their lives. Some re-evaluated their lives and made the decision to become healthier, others felt they wanted to appreciate life more, and not worry about things as much they did before their diagnosis.
- Found a positive reason for their diagnosis.
- Felt that they had come of the experience better than they had gone in.

Diagnosis and surgery

A number of individuals used the fact that they had been diagnosed with cancer of the bowel as opposed to another form of cancer as a positive coping mechanism. They believed that bowel cancer had better survival statistics than other tumours; it was contained within the bowel and was a solid mass that could be removed through surgery. They felt this greatly reduced their chances of the cancer returning. In addition, one male with a stoma bag restructured his opinions and concluded that having a stoma bag improved his toilet habits.

‘Strange enough in some ways, it is possibly more hygienic and it’s more convenient!’ (1; Male)

During chemotherapy

Some of the participants, both male and female, used words such as ‘fight’ and ‘battle’ in their interviews when they were describing their diagnosis and treatment. They were
attempting to be positive about their experience, it was going to be difficult, but it was something that they could overcome; their cancer was a battle to be won.

‘I was fighting it and that was it and hopefully I’ve won the fight.’ (21; Male)

**After chemotherapy**

Many attempted to find something positive from their diagnosis, a justification for why they were diagnosed. For example, one female stated that her diagnosis and experience meant that her children would be screened and any developing tumour would hopefully be detected at an early stage.

‘So my children, my sister’s and my brother’s children are all being screened which makes you feel a lot better because I don’t want anybody to have to go through what I have. That makes me feel better too. (27; Female)

Many were keen to use their positive experience to help others to cope; usually they expressed a desire to be involved in supporting other patients through the sharing of their own experience. This provided them with a justification for their own illness, by going through the diagnosis and treatment themselves; they could help another individual through their own stressful experience.

The participants often felt that after treatment they were back to the same stage as anyone else who had never had bowel cancer; in fact they felt even better off as the doctor was continuing to monitor their progress.

**Negative Coping**

Negative coping strategies are those which can reduce distress in the short term, but lead to permanent problems. Some examples of negative coping are use of drugs or alcohol, smoking, anger or unhealthy eating.

There was minimal evidence in the narratives of participants using any negative coping strategies. It is possible that they did not want to reveal any to the interviewer. One
female participant, who had stopped smoking upon diagnosis, started again when she suffered a recurrence.

‘And then I started smoking again! I was off them 14 months and I went to the hospital and when they told me the bad news I came home and just said to John go and get me 20 cigarettes. He said no and I said if you don’t I’ll go round myself. I said I need a cigarette. So I started again.’ (8; Female)
HUMOUR

Many male and female participants coped with potentially difficult situations, such as when they were discussing their diagnosis or treatment options with humour. This strategy was also apparent in potentially embarrassing situations, for example one female described how if she was in company and needed to go and change her stoma bag, or the stoma bag started making noises she would try and laugh about it.

‘I try to make casualness of it. I’ll say, you’ll have to excuse me; my bag is calling and things like that and have a bit of a laugh with it.’ (33; Female)

It is likely that individuals used humour as a coping strategy to make themselves feel better, to help them cope with tense, stressful situations. One man revealed how using humour enabled him to view the situation from a different perspective and perhaps find it less threatening; this would in turn lower his fear/anxiety.

‘Even in (Hospital y) the ‘craic’ was fierce with them 2 doctors and x [the specialist nurse] there. It turned from you were being told it was serious then it eased off about telling jokes about losing my hair and all this carry on and it was very good.’ (21; Male)

The majority adopted this coping strategy in front of spouses and children, therefore it could also be viewed as a strategy individuals adopted to make other members of the family feel better and portray the image the situation was not as bad as it seemed and that the individual with cancer was coping well.
SUMMARY

The experience of CRC and the coping strategies used by the participants is summarised in Figure 3. This details the physical and psychological components of the CRC experience, and those that contain both physical and psychological elements. The specific coping strategies that link to certain experiences are also included. As can be noted from the diagram, gender has an influence on all aspects. The general coping strategies used to help the participants manage the entire CRC experience are included at the foot of the diagram.
Figure 3: Experience of, and coping with, colorectal cancer
DISCUSSION

A longitudinal qualitative study exploring and comparing the experience and coping behaviour of men and women with CRC was conducted. Participants were interviewed on four separate occasions over an 18 month period. An 18 month follow up was selected as it was anticipated that this would be a crucial period when the patients’ stability and well-being were threatened.

CRC was selected as it is a disease that affects both men and women; therefore it facilitated the examination of the influence of gender on the CRC experience. Other studies have been conducted that focus on the experience and coping of individuals with CRC, but few follow the participants longitudinally and are therefore limited in their ability to draw conclusions on how the experience changes with time. There is also a paucity of literature focusing on the impact of gender on the CRC experience. The longitudinal nature of this study and the inclusion of a gender examination set this research apart from similar investigations in the area.

Gender

A diagnosis of CRC led to physical and psychological changes for the participants. The majority of respondents attempted to be optimistic about their diagnosis. In general the men appeared more accepting of their diagnosis, and the women seemed more open to discussing the emotional aspects of their cancer diagnosis and experienced more of an impact from the physical side effects of the disease. The impact of the disease led to a reluctance to socialise, and many found it necessary to reduce their social activities. These findings corroborate previous literature on the experience of CRC. It has previously been reported that CRC is a physical and psychological experience, which can impact on lifestyle and which men are more stoical towards (Wilson et al., 2009; Mizuno et al., 2007; Foley et al., 2006). What this study adds is an in-depth insight into the impact of gender on the CRC experience. The study demonstrated that there is a variation between men and women, within men (and women) and that there are also similarities among men and women. It has shown how gender is practiced differs from
individual to individual. Men and women should not be stereotyped as coping in accordance with traditional views of masculinity and femininity, that is, men as stoical and women as emotional (Hilton et al., 2009).

The majority of men in this study portrayed the ‘typical’ male gender traits. However some men in certain environments revealed more traditionally female traits, for example, emotion and/or dependence. Similarly while the majority of female participants presented themselves as aligning with the traditional views of the female gender, a minority in certain situations presented a more masculine appearance. Figure 4 illustrates how in the acute stage of illness, the majority of men and women react as would be expected in accordance with the traditional gender beliefs. However, in certain situations, for example, at the time of diagnosis, in a certain environment, for example, in private, some men can adopt more feminine traits and vice versa.

**Figure 4: Gender and illness**

HCPs should be aware that how men choose to react to a cancer diagnosis will differ from individual to individual and that not all men will align with the traditional view of masculinity. Many men may tend to minimise the impact of their cancer and its treatment. They may be suffering from physical symptoms or psychological distress that they are reluctant to discuss; however, other males may be comfortable discussing their
emotional reaction to their diagnosis, while others may only be comfortable expressing those emotions in private. HCPs need to determine how men wish to deal with their diagnosis and not make assumptions based on traditional gender beliefs. Encouraging men to ‘open up’ about their illness will not suit all men.

**Longitudinal qualitative research**

Conducting a longitudinal qualitative survey allowed a rapport to develop between the interviewer and the participant. This may have led to the respondent providing a deeper insight into their CRC experience. Findings from the study demonstrate how longitudinal studies can reveal more about men’s emotions and ways of coping than a cross-sectional interview or a quantitative questionnaire. It allowed the identification of ‘gaps’ or inconsistencies in the male narrative which lead to the detection of the male ‘facade’. For example, the positive image portrayed by many male participants in the current study that they were accepting of their diagnosis could have been how they wanted to be viewed by outsiders as how they were coping to maintain the masculine appearance. They could have also been ‘putting on a front’ for family members. During the first interview these male participants presented themselves as accepting of their diagnosis, but this was a transient feeling as in subsequent interviews after chemotherapy, they experienced the lingering doubts about their cancer returning, worrying that certain bowel symptoms may be another tumour developing. Accepting the initial diagnosis could have been the male participants way of getting over that first difficult hurdle of receiving a potentially life threatening diagnosis, and coping with difficult surgery and treatment. This strategy was hard for the male participants to maintain long term. Chemotherapy acted as a distraction, during treatment they coped well as they felt they were doing something positive to get rid of the cancer, but after treatment, when they no longer had something specific to focus on, they began to worry about the chance of a recurrence, despite the fact they had initially presented themselves as someone who was not worried about the fact they had cancer.

In some cases the spouse was present during the interview, usually the female spouse of the male patient. Furthermore, all interviews (except one) were conducted by a female
researcher. This may have enhanced the male patients’ needs to enact their masculinity. Research interviews provide a context for the performance of gender, and may not reflect ‘actual’ gender practices (O’Brien et al., 2007).

**Participant experience**

Similar to previous research, following their diagnosis of CRC, the study participants reported changes in both their physical and psychological experiences (Wilson et al., 2009; Kidd et al., 2008). The physical experience involved the physical side effects associated with bowel cancer and the effects of surgery, chemotherapy and having a stoma. The psychological experience involved the psychological impact of being diagnosed with cancer, the possibility that the cancer may recur and the impact on the individuals’ self esteem and sense of identity (e.g. the stigma associated with cancer, their body image).

Initially the severity of the symptoms and the impact they had on the individual ran in parallel and peaked around the time of surgery and chemotherapy. By the final interview, many individuals had adjusted to their situation and the physical side effects were no longer being defined as ‘problems’. This finding is in contrast to previous work by Rozmovits and Ziebland (2004) who reported that some individuals experience a long term negative impact on their ability to socialise. A small number of individuals in the current study did report a reduction in social activities. In a number of studies psychological distress has been shown to decrease as the individual recovers from the distress caused by physical symptoms and side effects (Ulander et al., 1997; Stommel et al., 2004). This was not found in the current study although by the fourth interview (18 months post diagnosis) both male and female participants, had adapted to their physical symptoms and had learnt to accept them, they were still reporting a degree of psychological distress. The uncertainty that their cancer may recur some time in the future prolonged the psychological distress. This finding corroborates previous research; fear of cancer recurrence is often stated as one of the greatest concerns of individuals with CRC (Northhouse et al., 1999; Sahay et al., 2000; Dunn et al., 2006; Houldin and Lewis, 2006; Simpson and Whyte, 2006).
Coping
The new physical and psychological experiences disrupted the participants’ daily lives and sense of normality. The participants had to go through a process of transition, which has been described in the literature as a movement and adaptation to change, rather than a return to a pre-existing state, a ‘new normal’ (Kralik et al., 2006). In order to cope with their cancer the participants had to let go of familiar ways of being and gradually separate themselves from old behaviours (Kralik et al., 2006). The coping strategies used by the participants could therefore be viewed as techniques in this transition or adaptation process. They used strategies to reconstruct their sense of self, to prevent the cancer from dominating their life and to maintain a sense of normality. The normality was however a ‘new normal’ as the participants would not be the same physically and/or psychologically after their cancer.

It has frequently been stated that individuals with CRC and cancer in general, attempt to maintain a positive optimistic attitude (Mazanec et al., 2010; Dunn et al., 2006; Houldin and Lewis, 2006; Simpson and Whyte, 2006, Carver et al., 2005). They make a determined effort to find something positive in their experience and feel lucky when they compare their situation to others (Dunn et al., 2006; Houldin and Lewis, 2006; Simpson and Whyte, 2006). This is not unique to individuals with CRC, as individuals with other cancer diagnoses frequently make reference to the experiences of people they know when discussing their own experience (Bellizzi et al., 2006). This social comparison is a coping method frequently used by individuals to help them evaluate their own situation by comparing themselves to others (Buunk and Gibbons, 1997). The individual had an affiliation with other patients who had been through the same experience; this affiliation helped them cope through reducing the stressfulness and uncertainty of their situation. The comparison usually revolved around their stoma bag, the side effects of chemotherapy and their chances of their cancer returning. Individuals used social comparison for motivation – ‘if he can do it, I can do it’ and for encouragement and confidence: they used the positive experience of others e.g. someone they knew who had been through surgery and survived it.
On the whole, the majority of men appeared more pragmatic towards their cancer diagnosis and presented themselves as being unaffected by surgery. This corroborates previous work conducted by Foley et al. (2006) whose study concluded that men with CRC reflected upon their cancer experience in a very matter-of-fact way. They acknowledged and respected that cancer was part of their lives, but they indicated that the diagnosis had had neither a positive nor a negative impact on their life (Foley et al., 2006). The female participants appeared to be emotional about their diagnosis and were more affected by the physical side effects of the disease and its treatment. Females with CRC have often been shown to be more emotionally affected and distressed than men (Ernstmann et al., 2009; Hagedoorn et al., 2008; Tuinstra et al., 2004; Northouse et al., 2000). It should be noted that studies have suggested that female sex is a predictor of high overall toxicity from chemotherapy, the reason for this is unknown (Diaz et al., 2006; Wiser and Berger, 2005).

This response has been detected in other chronic illnesses. Men with heart disease have been shown to delay seeking help for heart symptoms, and have been shown to be determined to return to a ‘normal’ life after diagnosis, rather than adapting to the consequences of their illness and accepting the limitations imposed on them (Emslie and Hunt, 2009). However, in the current study there was variation within sexes and individual variation in relation to context. It has been suggested that men may adopt masculinity dynamically, in accordance with context (Wall and Kristjanson, 2005). This was illustrated in the current study by the man who chose to hide his emotional response to his diagnosis in front of his doctor. In addition Emslie et al. (2009) in a study comparing men and women’s accounts of spousal support during CRC demonstrated a difference in men and women with CRC, but they also reported diversity among men and women. They reported some evidence of traditional gender roles having some influence on support, for example, women focused on domestic and childcare, whereas men focused more on finances and ‘protecting’ partners. The majority of men discussed how they valued their wives ‘practical’ support and did not mention ‘emotional’ support. However, a difference within men was detected, with some men valuing emotional
support from their wives (Emslie et al., 2009). The divergent findings in this study provide support for the fact that gender practices differ on an individual basis.

Immediately after surgery the study participants commonly found that some aspects of their lives were beyond their control, particularly in relation to bowel and stomal activity. They frequently reported physical side effects that led to feelings of embarrassment and reluctance to socialise. This appears to be a common feeling in the CRC literature (Rozmovits and Ziebland, 2004; Persson and Hellstrom, 2002; Taylor, 2001). The participants sought to take control of their lives through problem solving coping strategies. Generally, gender beliefs appeared to influence how they chose to resolve the unpredictable bowel problems: the majority of female participants reduced their social activities, whereas the men appeared to maintain their activities by planning ahead and taking action, for example, knowing the location of public conveniences. This problem solving coping is demonstrated in the literature, but the gender influence has not previously been highlighted. It has been reported that the main social concern for individuals with CRC is the location of public toilets (Nikoletti et al., 2008) and individuals frequently restrict themselves to places where toilet facilities were familiar (Wilson et al., 2009). It is however important to note the variation that existed within the group, with some men choosing to reduce their social activities, a response that was typically noted in the female narratives.

As time progressed, many men and women reacted similarly, however there was some variation evident between and within sexes. With regards to the long term physical side effects of the disease and treatment, many women admitted to still experiencing side effects, but they did not have a great impact on their lives. In contrast many men either indicated that they had no problems, or if they were suffering from a symptom, for example, tiredness, they stressed that it was not necessarily due to their illness. It must be noted that some men and women were still experiencing an impact on their life. Although the majority of respondents had adapted physically, many were still psychologically affected. How the individuals reacted to this uncertainty could be placed on a spectrum
from no concern, through some concern with minimal impact to total preoccupation (see Figure 5).

Figure 5: Reaction to uncertainty

Gender may have an influence on the extreme reactions as only men reported having no concerns and only women experienced total preoccupation. It is possible that many men were enacting the traditional view of masculinity that men should be unaffected by disease, be strong, unemotional and in control. Admitting to suffering physical side effects or worrying about cancer returning could threaten their sense of masculinity. Some contradiction in their narrative would provide evidence to suggest this was an attempt to portray a masculine image.

This study has added to the current knowledge by demonstrating similarities and differences in how men and women adjust to CRC and how gender practice differs from person to person and from context to context on an individual level. Individuals with CRC engage in a range of gender practices, which as alluded to earlier, has been described as ‘doing’ gender (West and Zimmerman, 1991). Many female participants in the current study took longer than the male participants to adapt to their new normal. Initially the female participants appeared more affected by the physical side effects than men, however over time even though they were still having problems with their bowels; they no longer allowed it to limit their activities. In contrast, the men appeared accepting of their ‘new normal’ almost instantly, they did not have the same prolonged period of adjustment. Traditionally women are responsible for juggling multiple roles (mother,
partner) and it has been proposed that their sense of identity is greatly affected by a cancer diagnosis and therefore they experience more disruption than their male counterparts. The impact may not be as obvious in men as they don’t have the same roles to fulfil in the family (Emslie et al., 2007; Northouse et al., 2000). In contrast many men believe they must show strength, stoicism, control and success. They must demonstrate that they can cope and adapt quickly. This may lead them to have a shorter transition process (Emslie et al., 2009). Another argument is that women are more open about talking about their emotions and are more comfortable than men about discussing their emotional distress (Northouse et al., 2000). It is plausible therefore that both men and women are suffering from the same distress, but the male participants are not willing to share that experience for fear of portraying themselves as less of a man. Women may be more aware of their distress and may be more honest in their responses than men (Ernstmann et al., 2009). This avoidance (or blunting) from men, should not necessarily be viewed as a suboptimal coping strategy. It has been demonstrated in the literature that blusters cope well (Miller, 1995). A study examining the influence of correspondence between spouses coping styles revealed that males with cancer who were blusters had a better psychological reaction when their wives were also blusters (Barnoy et al., 2006). Men should therefore be ‘allowed’ to cope in the manner that suits them, and do not necessarily need to be encouraged to ‘open up’. In the current study, there was variation noted between the men, and not all men chose to avoid discussing their illness.

**Information**

‘We must not assume that everyone wants to know everything’ (Worster and Holmes, 2008) is an excellent way of describing the participants’ attitude to information on their illness. The dichotomy presented in the findings is corroborated by recent literature. It has frequently been reported that individuals with CRC are divided between those who want information and those who attempt to avoid too much information (Lambert et al., 2009; Worster and Holmes, 2008; Dunn et al., 2006; Bain et al., 2002). Those individuals who desired a lot of information achieved some degree of control over their treatment, something which was probably removed from them upon diagnosis. Being diagnosed with a life threatening disease such as cancer could make a person feel quite
disempowered, they may feel they have lost control over their lives, thus by seeking out
information, they feel they are gaining some of the control back. It is possible that the
participants who did not have the same desire for information coped by not facing the
reality of their condition; it is possible they were in denial and may have felt
overwhelmed by too much information. This may lead them to not coming to terms with
their illness. Alternatively, it may allow them to adjust or accept their diagnosis more
slowly, at a pace that they can cope with. It is therefore vital that individuals with CRC
receive information that is individually tailored to their own needs.

Participants frequently reported that they had received minimal information on diet.
Dietary advice has recently been highlighted as a topic with the highest rank in terms of
importance of information needed since bowel surgery (Nikoletti et al., 2008); moreover,
other individuals with CRC reported receiving conflicting advice on diet (Campbell et al.,
2001). This is obviously an area that needs addressing, particularly given the nature of the
disease.

The present study highlighted two time points in the cancer experience where information
was lacking: immediately after surgery before chemotherapy and on completion of
chemotherapy. Previous studies have also reported these two time points as periods of
anxiety for individuals with CRC as a result of minimal information and/or support
(Dunn et al., 2006; Rozmovits et al., 2004; Sahay et al., 2000; Knowles et al., 1999). A
number of participants assumed incorrectly that their treatment was complete after
surgery. Subsequently at their first oncology appointment when they were told that they
needed chemotherapy, it was like being told they had cancer all over again, and they went
through another grieving process. This information gap between surgery and attending
the cancer centre is something that needs improved, as it was evident that some
individuals misinterpreted the situation regarding their treatment.

No association was found in the current study between gender and information
preference. Three earlier studies on individuals with CRC arrived at a similar conclusion,
reporting no difference in information needs with respect to gender (Boudini et al., 2001;
Knowles et al., 1999; Galloway and Graydon, 1996; Meredith et al., 1996). In contrast three studies reported that women have a stronger desire for information than men. One study concluded that male CRC patients appeared to be more willing to allow paternalism in treatment decision-making, indicating that they did not have a strong desire for information to inform treatment choice (Salkhead et al., 2004). Moreover, in a large (n = 2331) heterogeneous study including CRC participants, both sexes wanted detailed information, but women wanted to know the name of the illness and information on all available treatments. Covariates such as tumour site were ruled out statistically as causing this difference. Leydon and colleagues (2000) reported that men with CRC were less likely than women to access additional information services. This male attitude to information could be a method of avoidance coping; they are detaching themselves from the situation and the fact that they have cancer.

Support
It has been reported that accessing social support is a common form of coping for individuals with CRC (Deimling et al., 2006). Consistent with previously published research, the study participants accessed social support from a number of sources such as the medical profession, friends and family, peers and the Church (Dunn et al., 2006; Beaver et al., 2005; Campbell et al., 2001; Sahay et al., 2000). There were instances were the participants in the current study did not want support from family and friends as they did not want to become a burden and were embarrassed by their loss of independence. This finding has been reported by Dunn and colleagues (2006). In their study of CRC patients they reported occasions were participants did not welcome the support from family and friends. They stated this was an important finding as it had not previously emerged in other qualitative research (Dunn et al., 2006). This current research corroborates this finding and underscores its importance.

A number of female participants experienced distress on the removal of the support provided by the healthcare system, whereas many men did not feel the need for long term support. A desire for long term support has been noted in previous studies (Ross and Johansen, 2002; Rozmovits et al., 2004) but any gender influence as not been highlighted.
Keller and Henrich (1999) suggested that men with CRC rely on their wives support in contrast to females who are unaffected by their husbands support. This could explain why the male participants in the current study were not as distressed on completion of chemotherapy. They relied mostly on their wives for support; so on completion of chemotherapy, their support mechanism remained unchanged.

As previously stated the interim period between surgery and chemotherapy and the time after chemotherapy was particularly difficult for the participants. Many desired more support at this stage. During chemotherapy, the treatment acted as a distraction, it was a positive coping mechanism as they were actively doing something to prevent the cancer from returning. Once chemotherapy was over friends and family presumed the individual was back to normal, but some participants did not feel they were back to normal physically or psychologically. Rather than a sudden removal of support at the end of chemotherapy, a gradual decrease in support may prove more beneficial, especially as a number of side effects still persist. Those individuals who had surgery but did not need to have further chemotherapy treatment also experienced a lack of support. This desire for long term support has been reflected in the literature (Rozmovits et al., 2004). Participants’ interest in attending support groups was minimal; therefore support from a specialist nurse between surgery and chemotherapy and after chemotherapy could prove valuable, particularly as the subgroup of participants who did receive support from a specialist nurse did not suffer the same stress and anxiety before chemotherapy as those who did not receive such support. The benefits of a specialist nurse in CRC have been highlighted in the literature. Individuals with CRC have stated that they considered the specialist nurse their main source of support (Broughton et al., 2004). In addition, Worster and Holmes (2008) examined the experience of individuals with CRC who had and had not received support from a specialist nurse. Similar to the outcome of the current study, those individuals who were not seen by the specialist nurse experienced feelings of isolation.

The study participants did not indicate a strong desire to attend formal support groups. Individuals worried about attending support groups in case another attendee suffered a
relapse. This was particularly apparent with the female participants, who gave more attention to negative experiences than the male participants. This corroborates previous literature which has found that CRC patients are sceptical about dealing with other sick people, although the influence of gender was not examined by the authors (Ross and Johansen, 2002). A similar finding has been reported with women with breast cancer who declined to enrol in a group intervention study because they did not want to interact with others who were dying or not coping well (Helgeson et al., 2001). The suggestion that some females do not want to attend support groups challenges the stereotypical view that females cope through expressing their emotions. Previous literature has also shown that the ‘last thing’ some females with breast cancer wanted to do was talk about cancer (Emslie et al., 2007). A common theme running through the conversations on support was that attending support groups could not remove the anxiety or uncertainty that their cancer may return in the future. The only thing that could help with the anxiety was the objective tests such as scans and blood tests. The authors have not found another published study in CRC that reports a similar finding. This finding is important and provides further insight into attitudes towards support group attendance.

Wishful thinking

Frequently the participants (both male and female) reported that they did not realise they had to have chemotherapy post surgery, they thought the surgery had ‘cured’ them of their cancer. This mistaken perception of cure after surgery had been reported in the CRC literature (Wright et al., 2006). The study participants coped by remaining positive and believing that the surgery had removed their cancer, they did not need any further treatment, and they were determined to believe this until they were told otherwise. Further along in the cancer journey, some of the individuals who felt they were cured after their surgery still worried about their cancer returning. Believing that they were cured after surgery was a temporary coping strategy they used to help them cope emotionally with the very difficult operation they had undergone – they had had a lot of bowel removed, their bowels may not have been functioning properly, they may have had to deal with a stoma bag – what was the point in all of this if it had not cured their cancer?
Many participants in the current study hoped that they would not need to have a stoma. They were reluctant to face the possibility, and did not deal with the situation until it became a reality. Subsequently they woke up after their operation with a stoma and had to deal with it then. They were told it was more then likely a temporary stoma, and thus were only accepting of the stoma on a temporary basis. Therefore although they would say they were accepting of the stoma as it saved their life, it would appear that in reality they were not. They did not fully deal with the consequences of having a stoma as they believed it to be a temporary measure. This finding is reflected in the literature. It has been reported that patients with a permanent stoma are quick to adapt to their new normal. However those individuals with a temporary stoma were more inclined to put their life on hold until the reversal (Wilson et al., 2009).

**Age**

Although the aim of the study was to focus on the influence of gender on the CRC experience, another demographic variable appeared to influence the participants’ experience and coping.

Age was an important variable in how individuals coped with their stoma. The older generation felt they would not have coped as well with their stoma if they had been younger. They felt it would interfere more in a young person’s social life and relationships. They did not feel they had much of a social life for it to interfere with. Age was also an important variable in how the participants coped with the uncertainty. The older generation did not appear to worry as much about their cancer returning. They felt they had had a good life, and thus were accepting of the possibility that their cancer may return and they may not survive it. They frequently said that they did not think they would have coped as well with the uncertainty if they were younger and still had more of their life to live. Age also influenced attitudes to information. The older generation frequently felt it was not appropriate to question a doctor, they did not feel they had the ability to ask questions, and were content to accept what the doctor said. In addition, many did not have access to/limited understanding of the Internet, so this limited their
ability to do their own research. The influence of age on coping with CRC has been highlighted in the literature. A number of studies have demonstrated that the older generation tend to adopt more non-participatory role in managing their CRC, using less coping strategies and having a reduced desire for information (Deimling et al., 2006; Dunn et al., 2006; Salkheld et al., 2004; Leydon et al., 2000). However it must be noted that some studies have suggested that age does not influence coping with cancer. Both Ong and colleagues (1999) and Meredith and colleagues (1996) reported that coping styles and information needs were unaffected by age.

Limitations
The strength of this study lies in the use of a qualitative methodology, which enabled the precise experiences of the participants to be obtained without the constraints of a quantitative questionnaire. Nevertheless there are some limitations inherent to a qualitative research study. Qualitative research can be criticised for the analysis being subjective or researcher biased. In an attempt to overcome this, the interviews were conducted by a researcher with limited knowledge of the CRC experience. Other members of the research team peer reviewed a selection of the transcripts and regular discussions were held on the emerging themes.

The sample may not be representative of the views of all individuals with CRC attending the Northern Ireland Cancer Centre. Due to the nature of the study, many potential participants may not have felt comfortable discussing their experience, study volunteers may have been innately more optimistic than those who chose not to participate; furthermore those individuals with particularly high levels of distress may also have declined participation. In addition, the participants were Caucasians and English speaking, therefore the results cannot be generalised to individuals from other cultures.

Although the participants ranged in age from 24 – 78, most of the respondents were in their sixties and tended to occupy traditional gender roles. A study of younger participants with more varied gender roles might produce different findings.
It is possible that the sexual concerns of the participants were not fully explored. It was felt that a number of participants were reluctant to discuss sexual issues with the researcher. The interviewer often had to instigate the conversation and was frequently met with short one word answers.
RECOMMENDATIONS

Priority Times

- Priority times for targeting information and support following a diagnosis of colorectal cancer should be:
  - At the time of diagnosis
  - Pre-surgery (support regarding the uncertainty of surgical procedure outcome)
  - Post-surgery
  - If a person is not receiving chemotherapy
  - If a person has a stoma
  - Pre-chemotherapy
  - Immediate post chemotherapy (information on coping with disease and treatment side-effects)

Priority Groups

- Priorities for targeting of information and support on coping with the cancer diagnosis and treatment should be:
  - Patients who display negative coping strategies and so may be high risk for depression or using inappropriate coping mechanisms.
  - Partners or wives of men who have a colorectal cancer diagnosis.
  - Men who may have a tendency to minimise the impact of their cancer and its treatment.
  - Women, who post chemotherapy, appear to need focused support as they feel particularly isolated.

Provision of Information

- Appropriate information needs to be provided at the relevant time-point (i.e. pre surgery, pre chemotherapy).
- Clear and concise ongoing information should be communicated to all patients at the above time-points.
• All patients should have access to a colorectal specialist nurse, not just the patients who have had a stoma.
• Information provision should recognise the individuality of patients and their various coping strategies which may include passive information gathering.

**Focused information and support**

• Patients should be encouraged to speak to other individuals with CRC, as study participants described them as a useful source of information.
• More information and advice should be provided on diet.
• Post chemotherapy, more information should be provided on follow-up. Each patient should be provided with a written schedule of approximate dates.
• Tiredness is a common symptom for individuals with CRC and may not be well managed. Further investigation into this symptom in this population group is warranted.
• Healthcare professionals should be aware that patients may suffer from continuing uncertainty and provide ongoing support for this, particularly at the time of significant dates such as scans and anniversaries.
• Patients should be reassured that the physical symptoms are transient, and they should be assisted in finding methods of problem solving to help them adapt to their new normal.

**Future Research Priorities**

Future research should focus on:

• Identifying the characteristics of those men who choose to avoid discussing their diagnosis and downplay the impact of their disease.
• The partners of individuals with colorectal cancer to determine their individual information and support needs, if any.
• Tiredness, which was a prominent symptom for the individuals with CRC. Research should focus on identifying appropriate methods of amelioration, especially for those people who also have a stoma bag fitted and hence tend to lead a more sedentary lifestyle.
REFERENCES


Baider L Perez T De-Nour AK 1989 Gender and adjustment to chronic disease: a study of couples with colon cancer. General Hospital Psychiatry 11: 1 – 8


Barnoy S Bar-Tal Y Zisser B 2006 Correspondence in informational coping styles: how important is it for cancer patients and their spouses. Personality and Individual Differences 41: 105 – 115


Beaver K Jones D Susnerwala S Craven O Tomlinson M Witham G Luker KA 2005 Exploring the decision making preferences of people with colorectal cancer. Health Expectations 8: 103 – 113


Boudioni M McPherson K Moynihan C Melia J Boulton M Leydon G Mossman J 2001 Do men with prostate or colorectal cancer seek different information and support from women with cancer? British Journal of Cancer 85: 641 – 648


Campbell MK Meier A Carr C Engh Z James AS Reedy J Zheng B 2001 Health behaviour changes after colon cancer: a comparison of findings from face-to-face and on-line focus groups. Family and Community Health 24: 88 – 103


Desnoo L Faithfull S 2006 A qualitative study of anterior resection syndrome: the experiences of cancer survivors who have undergone resection surgery. European Journal of Cancer Care 15: 244 – 251


Eakin EG Strycker LA 2001 Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: patient and provider perspectives. Psycho-Oncology 10: 103 – 113

Emslie C Browne S MacLeod U Rozmovits L Mitchell E Ziebland S 2009 ‘Getting through’ not ‘going under’: a qualitative study of gender and spousal support after a diagnosis of colorectal cancer. Social Science and Medicine 68: 1169 – 1175


Ernstmann N Neumann M Ommen O Golushka M Wirtz M Voltz R Hallek M Pfaff H 2009 Determinants and implications of cancer patients’ psycho-social needs. Supportive Care in Cancer [Epub Ahead of Print]


Houldin AD Lewis FM 2006 Salvaging their normal lives: a qualitative study of patients with recently diagnosed advanced colorectal cancer. Oncology Nursing Forum 33: 719 – 725


Miller S 1995 Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their diagnosis: implications for cancer screening and management. Cancer 76: 167 – 177


Ong Lm Visser MR van Zuuren KJ Rietbroek RC Lammes FB de Haes JC 1999 Cancer patients’ coping styles and doctor-patient communication. Psycho-oncology 155 – 166


Ramfelt E Lutzen K 2005 Patients with cancer: their approaches to participation in treatment plan decisions. Nursing Ethics 12: 143 – 155

Ramfelt E Severinsson E Lutzen K 2002 Attempting to find meaning in illness to achieve emotional coherence: the experience of patients with colorectal cancer. Cancer Nursing 25: 141 – 149


Seale C Ziebland S Charteris-Black J 2006 Gender, cancer experience and Internet use. Social Science and Medicine 62: 2577 – 2590

Speer S 2001 Reconsidering the concept of hegemonic masculinity: discursive psychology, conversation analysis and participants’ orientations. Feminism and Psychology 11: 107 – 135


Stommel M Kurtz ME Kurtz JC Given CW Given BA 2004 a longitudinal analysis of the course of depressive symptamology in geriatric patients with cancer of the breast, colon, lung or prostate. Health Psychology 23: 564 – 573


Toner BB Ackman D 2000 Gender role and irritable bowel syndrome: literature review and hypothesis. American Journal of Gastroenterology 95: 11 – 16

Ulander K Jeppsson B Grahn G 1997 Quality of life and independence in activities of daily living pre-operatively and at follow-up in patients with colorectal cancer. Supportive Care in Cancer 5: 402 – 409

Wall D Kristjanson L 2005 Men, culture and hegemonic masculinity: understanding the experience of prostate cancer. Nursing Inquiry 12: 87 – 97


White A Cash K 2004 The state of men’s health in Western Europe. Journal of Men’s Health and Gender 1: 60 – 66


Wilson S 2005 Patients and relatives tell us what they need to know through their narratives: an exploratory qualitative study. The British Journal of Healthcare Computing and Information Management 22: 21 – 22


Wiser W Berger A 2005 Practical management of chemotherapy-induced nausea and vomiting. Oncology 19: 5


Appendices
Appendix 1: Instructions to Consultant

Project title: Exploring and comparing the experience and coping behaviour of men and women with colorectal cancer: a qualitative longitudinal study.

Chief Investigator: Dr Eilis McCaughan

Inclusion Criteria:
- Men and women over the age of 18 years
- First diagnosis of colon or rectal cancer
- First appointment with the oncologist
- Disease stage: Duke’s A, B or C *(Richard, should we say up to C1 – we want to include as big a population as possible but as this is an 18month longitudinal study we need to ensure that most of the sample will be able for such participation).*
- Aware of their diagnosis
- Physically and mentally able (based on consultant assessment) to participate
- Able to communicate about their condition (based on consultant assessment)
- Able to communicate in English
- Willing to give informed process consent

Exclusion Criteria:
- Patients referred to the Palliative Care Team
- Patients with evidence of widespread metastatic disease
- Patients unable to speak English

What will be required of participants?

Participants will be interviewed on four separate occasions over an 18 month period. The first (baseline) interview will be after surgery, before they commence any further anti-cancer treatment. Interviews 2, 3 and 4 will be at 6 months, 12 months and 18 months respectively from baseline.

The interview will be semi-structured, focusing on each participant’s personal experience of colorectal cancer.

What is required of the Consultant?

Once an appropriate potential participant has been identified:
- Give preliminary information about the study
- If there is an expression of interest give them the letter of invitation, participant information sheet and consent form
- Take a contact telephone number and advise that a member of the research team (Gillian Prue) will contact them to discuss the study in more detail
Appendix 2: Letter of invitation

Gillian Prue
Research Associate
Institute of Nursing Research
Room 12J05B
University of Ulster
Shore Road
Newtownabbey
BT37 0QB

You are being invited to take part in a research study that will explore the experience and coping behaviour of men and women with a diagnosis of colorectal cancer.

It is up to you whether or not you participate in this research project. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part, will not affect in any way the standard of care you receive.

If you do decide to take part you will be invited to participate in a discussion about your personal experience of having colorectal cancer on four occasions over the next 18 months. These discussions will be completely private and will only involve you and one of the researchers. If you agree to take part in the study, you are still not obliged to take part in all four discussions. The researcher will meet you in a place that is convenient to you.

Before you decide, it is important for you to understand why the research is being done and what it will involve. In the next few days you will be contacted by one of the researchers involved in the study that will explain the study to you in more detail, letting you know what you will be asked to do if you agree to take part.

Please feel free to look through the pack that comes with this letter, and read through the Participant Information Sheet. This will provide you with all the information you need.

If you need any more information, please do not hesitate to contact Gillian Prue at the contact details provided below.

Yours Sincerely

Gillian Prue

University of Ulster
Tel: 028 9036 8542
E-mail: ge.prue@ulster.ac.uk
Appendix 3: Participant information sheet

Exploring the experience of men and women with colorectal cancer

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of the study and what will happen if you take part.
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The experience of having cancer can vary from person to person, and it is possible that men and women may deal with having cancer differently. If the help and advice provided by the health care system is to be effective, it must suit the needs of both men and women. Colorectal cancer is a disease that affects both genders. Thus exploring the experience and coping behaviour of those with colorectal cancer permits a comparison between the reactions of men and the reactions of women to the same disease. This will help us determine whether or not men and women deal with having cancer differently. The study will follow both men and women for a period of 18 months following diagnosis to determine how they cope with and adjust to the disease with time.

Why have I been chosen?

The aim of this study is to record the experience of having colorectal cancer from the time of diagnosis for an 18-month period. You have been chosen as you have not yet started your treatment and therefore your experience can be recorded from the start. In total, over a six-month period, around 30 men and 30 women, in the same position as yourself, will be invited to take part in the study.
Do I have to take part?

No. It is up to you whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

If you become distressed during the study and feel that it may help to talk to someone in confidence, just let us know and we can refer you to a trained counsellor.

What will happen to me if I take part?

Over the next 18 months, on four separate occasions, you will be invited to take part in a discussion about your personal experience of having cancer, how it has affected you and how you have coped with it. These conversations will be completely private and will only involve you, your spouse/partner (if you want them to be involved) and one of the researchers. It is anticipated that each discussion should last one hour. If you agree to take part in the study, you are still not obliged to take part in all four discussions. The researcher will take the lead in the discussions and give guidance on what could be talked about, but it is up to you whether or not you want to talk about what is suggested. The researcher will meet you in a place that is convenient to you, for example in the clinic, in your home or at your place of work.

With your permission the discussions will be tape recorded, so the researcher does not miss anything important.

In addition, we would like to obtain some information from your hospital records. Only information in relation to your recent diagnosis of cancer will be looked at. This information will be maintained in the strictest of confidence.
What do I have to do?

There is no extra ‘treatment’ involved in this study. As stated earlier, you will simply be invited to take part in a discussion about your experience of having cancer on four separate occasions over the next 18 months.

What is the drug, device or procedure that is being tested?

No new treatment is being tested. This is simply a discussion on your experience of having cancer.

What are the possible benefits of taking part?

Taking part in this study will benefit future individuals with cancer, as we will know more about the experience and how best to provide information and support services to meet their needs. However, it is not expected that your participation will help your illness, but the discussions may help you deal with things that have been bothering you.

What happens when the research stops?

If you feel you need referred to a counsellor to discuss any concerns you may have that is possible. It is important to stress that these are additional discussions above your normal appointments with your consultant, and these will continue as normal.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.
Will my taking part in the study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

Contact details:

If you require any further information, please do not hesitate to contact one of the research team:

Name: Gillian Prue  
Telephone No: (028) 9036 8542  
Email: ge.prue@ulster.ac.uk

Name: Oonagh McSorley  
Telephone No: (028) 9036 6649  
Email: oc.mcsorley@ulster.ac.uk

Name: Eilis McCaughan  
Telephone No: (028) 7032 4091  
Email: em.mccaughan@ulster.ac.uk

This completes Part 1 of the Information Sheet.  
If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in Part 2 before making any decision.
Part 2

What will happen if I don’t want to carry on with the study?

You can withdraw from the study at any time. Before each of the discussions, the researcher will contact you to ensure that you are still happy to be involved. If you withdraw, we would like to still be able to use the information collected up to your withdrawal.

What if there is a problem?

If you have a concern about any aspect of the study, you should ask to speak with the researchers who will do their best to answer your questions (028 9036 8542). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

Will my taking part in the study be kept confidential?

All information that is collected about you during the course of the survey will be kept strictly confidential and protected under the provisions of the Data Protection Act. Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it and will be kept in a locked filing cabinet and on a password protected computer.

What will happen to the results of the research study?

It is planned that the results will be published, once the study is completed, in a research journal and presented at conferences. It is important for you to know that you will not be identified in any report. Once the study is finished, if you wish, we will write to you to give you a summary of the findings.
Who is organising and funding the research?

The survey is being organised primarily by researchers from the University of Ulster, in collaboration with the Belfast City Hospital. The study is being funded by the Ulster Cancer Foundation (UCF).

Who has reviewed the study?

In order to ensure that the survey is appropriate for individuals with cancer to take part in, the survey has been reviewed by experienced researchers in the University of Ulster. It was also given a favourable ethical opinion for conduct in the NHS by the Research Ethics Committee in Northern Ireland.

Thank you for taking the time to read this information sheet.
Please take some time to consider the study before agreeing to participate.
Appendix 4: Participant consent form

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Exploring the experience of men and women with colorectal cancer.

Name of Researcher: Gillian Prue

1. I confirm that I have read and understand the information sheet dated .................
   (version ............) for the above study. I have had the opportunity to consider the
   information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time,
   without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of any of my medical notes and data collected during
   the study, may be looked at by responsible individuals from the University of Ulster,
   from regulatory authorities or from the NHS Trust, where it is relevant to my taking
   part in this research. I give permission for these individuals to have access to my records.

4. I understand that the interview will be tape-recorded and there is a possibility
   of direct quotation being used.

5. I agree to take part in the above study.

Name of Individual                      Date                      Signature

Name of Person taking consent
(if different from researcher)          Date                      Signature

Researcher                             Date                      Signature

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes
Appendix 5: Interview schedule

Interview topic guides

The interview topic guides are suggestions about what might be discussed with participants. The areas to be explored initially are outlined below. As the study progresses, and certain themes emerge, the interview guide may change to permit exploration of these themes. It is anticipated that the data collected from initial interviews will inform subsequent interview guides.

a. Participants background to their illness, their cancer journey so far. In follow-up interviews the current situation should be established.

b. Discuss their current information and support needs and issues. Determine if these needs are changing over time.

c. Discuss the information and support they have received so far, what was useful, what was needed.

d. Explore the information and support provided by the health care system and support from lay sources.

e. Explore their individual coping styles; discuss whether or not they are actively seeking information and support (gender differences).

f. Explore whether or not their coping style has changed over time.

g. Discuss how they have developed the coping strategy they use – inbuilt, information gleaned from friends, relatives, peers, information obtained from the internet (gender differences).

h. Explore their prior experience of the healthcare service.