

# Doing what I have to do: Experiences of colorectal cancer in rural NSW



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# ABBREVIATIONS

- General Practitioner - GP
- Hunter New England Local Health District - HNELHD
- Health Education & Training Institute - HETI

## **Aim**

It is known that colorectal cancer is a leading burden of disease in Australia and that rural people with cancer have poorer outcomes. Little is currently known about what it is like for rural people in NSW undergoing surgery for colorectal cancer. The study aimed to understand this experience, to inform and shape future practice.

## **Methods**

Interpretive description was used to guide the study. Semi-structured interviews were conducted with nine rural people in NSW. Thematic analysis was used to develop the themes arising from the data.

## **Results**

Control, interconnectedness, embodiment and transformation were major themes. The participants lost control over their normal lives at diagnosis. They placed their trust in the doctors and did as advised, feeling that this was the right thing to do. Trust could be diminished when recovery was different to expectations. Family support was important for the participants. The level of informational and emotional support required, varied. Some had recovered fully, but others were left with significant losses as a result of surgery. These included bowel disturbance, fatigue, pain and depression.

## **Conclusion and implications for practice**

Currently, only some of the people having surgery for colorectal cancer in rural NSW have their emotional, informational and physical needs met. To redress this inequity and provide the support needed for them to maintain control of their lives, it is essential to identify needs early and as they arise, and ensure an understanding of their expected recovery, changes that may occur and their plan of follow up care.

## **Keywords**

Colorectal cancer, rural, needs, trust, interpretive description

# EXECUTIVE SUMMARY

## Context

Colorectal cancer is a major burden of disease in Australia, and the second most commonly diagnosed cancer for men and women, with diagnoses rising each year. Over a fifth of the population live in rural areas within Australia, yet little is known about the experience of colorectal cancer in the rural setting. Historically, supportive management of people with colorectal cancer has not always been provided.

## Implications

This study has clear implications for practice, because to meet increasing demand for cancer services, new ways of providing effective, supportive care to a greater number of people with cancer must be considered, within budgetary and staffing constraints. The study has strongly demonstrated the need to develop a system to assess and support the needs of all people having colorectal surgery in this area, which works in partnership with them and is flexible, as individual needs vary and change over time.

## Approach

Interpretive description was used to guide the study. In depth, semi-structured interviews were conducted with nine people who had surgery for colorectal cancer and who lived in rural areas. Inductive, thematic analysis identified 96 initial codes which were eventually merged into four major themes. Ethics approval was received in December 2012. The research question was: What is the experience of people living in rural NSW who undergo surgery for colorectal cancer?

## Findings

Four themes were identified that together characterised the experience of the participants.

### Control

The theme control encompassed how the participants managed their cancer. Trust and confidence in the treating team, particularly the surgeon was important. The participants trust was diminished when treatment and recovery differed from their expectations. All participants did what they felt was right for them and their family. This mostly manifested as a need to do exactly what they were told by the doctor, but could mean declining treatment if that is what they felt that they had to do for their own wellbeing.

### Interconnectedness

Interconnectedness described the way the participants connected with their family and health team, and how they absorbed information about their cancer. Family support was important, but this also meant participants worried about the effect of their cancer diagnosis on their family. Participants were treated locally to minimise disruption to family and only travelled out of area with family support. Informational and emotional needs varied greatly. For some, a discussion with their surgeon was sufficient, whilst others

desired but did not receive, professional support. The health teams' behaviour impacted positively or negatively on their experience.

## Embodiment

Embodiment was about how participants' bodies manifested the cancer, cancer treatment and side effects. Life limiting bowel changes occurred for some if they had a permanent or temporary colostomy, resulting in embarrassment, shame and restriction of social life. Severe and poorly managed pain was sometimes experienced whilst in hospital.

## Transformation

The theme of transformation highlighted how having colorectal cancer changed the participants. They described active, independent lives before surgery. After, whilst some participants were largely unchanged, others had significant losses in their lives, including ongoing bowel issues, depression, fatigue and unemployment. Some had no idea of how they should be followed up, or how to access services to assist their recovery.

## Recommendations

To adopt a system locally, that will effectively assess, monitor and support the needs of the people and their families who have surgery for colorectal cancer, to assist during surgery and with the resolution of effects of surgery, to maximise recovery and independence. Through the use of a targeted approach, provide resources to people that need them, when they need them.

To explore how this can be achieved within the constraints of distance to services, existing budget and staffing, recommendations developed as a result of this research include:

1. The Cancer Services team working in partnership with people with colorectal cancer, their families and General Practitioner to ensure that they have clear information and understand their plan of follow up, expected recovery time, and changes that may occur as a result of their treatment.
2. Promoting the use of the CORE values (collaboration, openness, respect and empathy) of NSW Health, through the development by the Health Education & Training Institute (HETI) of an online education module, for all health employees, to engage with, and positively impact on the experience of people with colorectal cancer and their families.
3. Undertaking serial needs assessments on all people having surgery for colorectal cancer to identify their physical, psychosocial and spiritual needs. Undertake these prior to surgery, during treatment and after treatment has finished, because needs change over time.
4. Conduct further research to evaluate the current and future use of needs assessment tools, including when and where they are used, with the intention of adopting an effective tool. This study could form the first phase of a mixed method study.
5. Ensuring access to care coordination, according to need, to facilitate the provision of supportive care. This includes referral to specialists such as the social worker, psychologist or dietician.
6. Ensuring access to a stoma nurse, as required to facilitate optimal self-management.

# INTRODUCTION

This report is a summary of the research project undertaken by the researcher whilst a participant of the Rural Research Capacity Building Program sponsored by the Health Education & Training Institute (HETI) and Hunter New England Local Health District (HNELHD). It will be of relevance those parties involved in the care and management of people with colorectal cancer. A recent gap analysis of the current processes involved in the diagnosis and treatment of colorectal cancer patients at metropolitan hospitals within HNELHD, confirmed that less than optimal outcomes were not uncommon<sup>(1)</sup>. With the projected increase in colorectal and all cancers, demand for cancer services are likely to outstrip budgetary increases and staffing capabilities within existing models of care. Cancer services are following the trend within the broader health system of an increasing focus on patient centred care<sup>(2)</sup>. Hence it is important to use resources appropriately to provide the best possible service within budgetary constraints. Different models of service delivery are currently being explored. It is hoped that this study may assist that process, by providing rich, qualitative data about what it is like to undergo surgery for colorectal cancer in rural NSW, as scant information currently exists.

# BACKGROUND

Colorectal cancer is the second most commonly diagnosed cancer in the world<sup>(3)</sup> and in Australia<sup>(4)</sup>, and is the second largest cause of cancer death in Australia<sup>(5)</sup>. One in twelve people in Australia will develop colorectal cancer in their lifetime<sup>(6)</sup>. Over 20% of people with cancer live in non-metropolitan areas<sup>(7)</sup>. With the number of people diagnosed with cancer rising every year<sup>(2)</sup>, colorectal cancer impacts on the lives of many rural Australians. The Cancer Institute NSW Cancer Plan 2011-2015 proposed to focus on rural people in NSW. The plan aimed to improve quality of life through better identification of needs and a more responsive patient centred approach for patients and carers<sup>(2)</sup>. This aligns with UK guidelines for colorectal cancer management, which recommend that patient needs and preferences should be part of the plan of care. The patient and their family should be supported to make informed choices with their health team and given accessible, evidence-based information tailored to their individual needs<sup>(8)</sup>. The guidelines in Australia are currently out of date, and have been rescinded on the National Health and Medical Research Councils website. Psychological as well as physical care was recommended<sup>(9)</sup>. This all suggests that people with colorectal cancer and their families in rural NSW might expect a person centred approach tailored to meet their actual needs and is certainly the intention of these guidelines.

The literature was reviewed using the Clinical Information Access Portal search engine, focusing on literature relevant to the experience of the rural person with colorectal cancer. There was a large body of evidence, much of it quantitative, pertaining to cancer in general as well as specific aspects of the cancer journey. Existing research findings identified the need for further cancer research in the rural context. There were a few qualitative studies worldwide pertaining to colorectal cancer, but no studies looking at the overall experience of the rural person with colorectal cancer in Australia. As there was very little research on this experience, the literature review included studies pertaining to the cancer patient experience for other cancers as well as for colorectal cancer. Some aspects are shared and relevant, but other parts are unique to colorectal cancer.

## Colorectal cancer in the rural context

The Cancer Institute NSW acknowledged that the number of people surviving cancer is increasing each year, creating ever greater need for rehabilitation and treatment of longer term effects occurring as a result of cancer treatment and disease<sup>(2)</sup>. Although survival rates continue to improve globally, Australians in rural areas with colorectal cancer have poorer outcomes<sup>(3,10)</sup>. Baade et al<sup>(3)</sup> found this to be the case in their study in rural Queensland and believe it is about more than just distance from treating centres. The authors proposed possible explanations that included lifestyle factors associated with lower socioeconomic areas. Martin et al<sup>(7)</sup>, found rural and remote Australians had reduced access to supportive cancer care services and were also less likely to use them. The authors assert that future planning must include the needs of the rural population. Butow et al<sup>(11)</sup> undertook a systematic review to better determine the needs of urban, regional and rural people with cancer in Australia. The authors concluded that further research was needed to gain insight into the needs of rural people with cancer. They found that most of the research available focused on breast cancer. They acknowledged the importance of providing high quality, supportive care, including meeting informational, emotional, needs of daily living and physical functioning needs. However they found this may not have been provided to rural Australians. They felt rural people had different needs to their city counterparts that need to be explored further through research. A local needs analysis<sup>(1)</sup> within HNELHD, focusing on the management of colorectal cancer within metropolitan centres found evidence of poorer outcomes. Assignment of a coordinator is currently not routinely provided in the rural setting, usually being provided only to people referred to a medical or radiation oncologist. In essence, determined by histopathology and not need. A cancer care coordinator is a specialist nurse who assists with coordination, makes referrals to services such as social worker, psychologist or dietician, and provides informational and emotional support<sup>(12)</sup>. In contrast, rural people with breast cancer are supported through surgery and in the short term. They usually have access to breast care nurses, specialist cancer nurses who also provide coordination and support. This supportive care has been shown to reduce psychological morbidities through early identification and referral to specialists<sup>(13,14)</sup>.

## The need for trusting relationships with health professionals

People with colorectal cancer require surgery as all or part of their treatment<sup>(15)</sup>. International and Australian studies suggested that the general practitioner (GP), in both the metropolitan and rural setting, was the key factor in determining which surgeon was used and the location where people had their treatment<sup>(10,16,17)</sup>. Australians usually had a long standing and trusting relationship with the GP<sup>(18)</sup>. Pascoe et al<sup>(19)</sup>, in a study of Australian people with colorectal cancer believed that a poor relationship with the GP actually hindered the referral process. Studies in the USA and Australia have found that both GPs and patients wanted many of the same things from a surgeon, including good medical skills, timely appointment and good communication back from the specialist<sup>(19,20)</sup>. GPs believed that some patients did not recognise the seriousness of their symptoms and felt patients delayed presenting themselves. GPs felt the general practitioner had a key role to play in cancer management, from the recognition of symptoms, making referrals, pain management, psychosocial care, and follow up. Clear, effective channels of communication between the specialist and GP resulted in better supported patients<sup>(4,21)</sup>. Local and international studies showed that the surgeon was identified as the strongest influence and primary information source of women with breast cancer<sup>(16,22)</sup>. Trust in the surgeon was very important<sup>(22)</sup> and was often built from confidence in their expertise<sup>(23)</sup>. Urban Australians considered it important that they were treated by a specialist colorectal surgeon rather than a general surgeon, as is common in the rural area. This study also

found informational needs and decision making preferences varied, with the majority wishing to be actively involved in the decision making process but some happy to leave their treatment decisions to their surgeon. The authors found women preferred a shared decision making style and men preferred to be more passive. Overall, a consultative style that allowed for participation was favoured and was found to be most likely to foster trust<sup>(23)</sup>.

### **Informational needs of the colorectal cancer patient**

The body of literature suggests that there is still a need for better information to be given to patients, including those with colorectal cancer. They have unmet informational needs including information on pain, wound management, recovery, diet and bowel disturbances <sup>(24, 25)</sup>. Research findings varied on the amount of information required. Salkeld et al<sup>(23)</sup> looking at urban people with colorectal cancer found that getting as much information as possible was not important for everyone. However, several studies have suggested that women with breast cancer, including rural women, generally have high informational needs <sup>(22, 26)</sup>. A systematic review of information on the internet regarding colorectal cancer, identified that 80% of internet users had sought health information online. The authors assessed colorectal cancer information online and found that it was often poor quality and inaccurate, and rarely focused on issues post-surgery such as bowel changes and post-operative complications<sup>(27)</sup>.

### **After colorectal surgery**

A phenomenological study looking at the immediate postoperative period of people with colorectal cancer in Sweden, found the participants were worried about losing control of their health and of wound complications. Participants had feelings of insecurity surrounding their colorectal cancer diagnosis<sup>(28)</sup>. A qualitative study in the UK found respondents struggled with their “violated body” after colorectal surgery, with fear and hope identified as themes<sup>(29)</sup>. Another colorectal qualitative study, found that one year post surgery, people with colorectal cancer were living with the uncertainty of cancer recurrence<sup>(30)</sup>. Two studies looking at colorectal cancer found that post-operative pain was common, but generally considered to be well managed through use of pain relief, resulting in lower levels of pain than expected<sup>(28, 31)</sup>. There was a large body of literature around the stoma and bowel problems following surgery <sup>(25, 32-34)</sup>. Those with stomas had higher rates of depression and poorer quality of life<sup>(35)</sup>, with greater support needs<sup>(36)</sup>. Social interaction was curtailed due to fear of odour from the stoma, stoma accidents and difficulty finding toilets<sup>(37)</sup>. Despite this, most people have little recollection of any discussion about bowel changes, sexual dysfunction or impact on quality of life when consenting for colorectal surgery<sup>(38)</sup>. It was not uncommon to find reduced quality of life following colorectal surgery, as a result of depression, pain, impact on work and social life, uncertainty, changes to sense of identity and body image, fatigue, physical inactivity or distress <sup>(39-41)</sup>.

### **Colorectal cancer support**

There was a surprisingly small body of research regarding psychological support of people with colorectal cancer. McConigley et al<sup>(10)</sup> looking at rural Western Australia, found the best support that could be provided to people with cancer in general, was to provide ways of allowing them to be treated close to home. It was also identified in NSW that travelling distances for cancer treatment caused not only financial strain but impacted on quality of life<sup>(42)</sup>. A UK study looking specifically at colorectal cancer found that although the participants turned to their family for support, they had to provide a reciprocal supportive role due to family distress<sup>(43)</sup>. A mixed methods Australian study found that people with colorectal cancer were open to using telephone peer support services and that low usage was largely due to lack of awareness of their existence<sup>(44)</sup>. Another study in the USA, found little interest in attending a support group program<sup>(45)</sup>. McGowan et al<sup>(46)</sup> found that colorectal cancer survivors were open to the idea of, and benefited from a tailored programme of physical activity. Yates<sup>(12)</sup> believed there was a need for people with cancer to have

access to a cancer care coordinator. She defined these as nurses with specialist skills and knowledge that case managed, ensured there was a plan in place that was communicated to all concerned, and ensured required care was organised and delivered. They improved quality of life by actively promoting self-management, providing education and acting as patient advocate<sup>(47)</sup>. Whilst this management is well established for breast cancer it is still not the case for all people with colorectal cancer. This is reflected in the literature, with few studies on cancer care coordinators, but many about the role and benefits of a breast care nurse that coordinates the support and management of people with breast cancer. Use of formal needs assessment tools to assess the needs of the person with cancer are considered useful. They can identify and validate issues and assist with communicating to the health team what the person actually requires support with <sup>(48, 49)</sup>. Supportive behaviour shapes the patient experience for the person with colorectal cancer, as it is affected by the people providing that care. Several studies have determined that kindness, empathy, friendliness, courtesy, helpfulness and the ability to communicate well, all contribute to higher satisfaction. This is particularly important when making decisions about treatment <sup>(23, 28, 50)</sup>.

There was a clear gap in the literature overall and in particular qualitative studies, regarding people undergoing treatment for colorectal cancer in the rural setting in Australia. It confirmed the need for qualitative research in this area to better understand the experience.

## **The research question**

What is the experience of people living in rural NSW who undergo surgery for colorectal cancer?

# **METHOD**

## **Methodology**

The methodology used to shape the study was interpretive description. Interpretive description was designed for qualitative research projects that seek to understand a phenomena, through finding themes and patterns within the data and interpreting these for the purpose of informing clinical knowledge<sup>(51)</sup>. It allowed the researcher to work within a framework that was broader than some traditional methodologies but would remain structured enough for clinical health research<sup>(52)</sup>. It allowed for interpretation of data but remained grounded in a way that would be of use in the clinical setting<sup>(51)</sup>. Interpretative description was an appropriate approach for thematic analysis<sup>(53)</sup> in its acceptance that there are multiple truths<sup>(54)</sup> and that reality is subjective and derived by human interaction within their culture and society. Recognising that the social world is produced and reproduced by people, allowed the researcher to capture the richness of the participants complex and contradictory experiences<sup>(55)</sup>. Use of an interpretive position let the researcher view the experience from different angles and acknowledge that understanding must be in the context of the individual and their life experience<sup>(51)</sup>. Acknowledging the iterative rather than linear nature of this research, the results and discussion were combined and reported as findings<sup>(56)</sup>.

## **Ethics**

Ethics approval was obtained in December 2012 from the Hunter New England Human Research Ethics Committee. Pseudonyms have been used throughout and other identifying information such as the name of surgeon or place of work, have been removed to fully anonymise the participants.

## **Data Collection**

Potential participants were identified from medical records from Manning Hospital, John Hunter Hospital and Calvary Mater Hospital, of people living in postcodes 2312 and 2422-2430, which comprised the Manning, Great Lakes and Gloucester areas. Participants had to be over eighteen, be able to consent, have had surgery for colorectal cancer in 2012. They were excluded if they had a prior professional personal or relationship with the researcher. The medical record search was able to identify every admission in 2012 that had been coded as C18-21 (colon, rectal, recto-sigmoid junction and anus). Every admission identified was manually checked by the researcher to find people living in the postcodes and alive at discharge, creating a shortlist to check in further depth using the Clinical Access Portal, an electronic record. The researcher checked the surgical discharge summary, any recent medical admissions, referral to palliative care or admission to an aged care facility. Immediately prior to sending the letter of invitation, the information was rechecked, to minimise the risk of distressing the person or their family if their condition had deteriorated. If there was any doubt about the health of the person they were excluded.

A final eligible group of 35 people was reached, comprising 24 men and 11 women. Systematic sampling was used to recruit from the group by ordering them into chronological order by the date of surgery, and sending a letter of invitation to every third person<sup>(57)</sup>. The letter was posted to their home address and it introduced the researcher, outlined the rationale for the study and their part in it (see Appendix 1). The participants' knowledge of the research study and its aims was gained from this letter and through discussion with the researcher prior to consenting to the study. Invitation was by this single letter only and no contact was made with people that chose not to respond. Invitations were sent initially to the first 15 people on the ordered list, as this was logistically an easier number to manage if they all wished to be interviewed. Seven men and one woman responded, three men and four women did not. Purposive sampling was used to recruit the final participants, with invitations being sent only to the remaining women in the eligible group<sup>(57)</sup>, in order to try and redress the gender imbalance. This resulted in one further woman being interviewed. In total, ten men and eleven women were invited to participate in the study. From these people invited, seven men and two women chose to participate. Saturation was not used to determine sample size because all interviews were carried out prior to commencement of data analysis. The researcher and mentor concurred with Thorne that the notion of saturation is flawed, with infinite variations in experiences being possible<sup>(51)</sup> and believed that enough rich data would be generated from the nine interviews to achieve a meaningful analysis.

The participants' ages ranged from 50 to 85 at the time of interview, with a mean age of 66. All or part of their investigations and treatment occurred locally. All had surgery for colorectal cancer, with two people also having chemotherapy and one person having concurrent chemotherapy and radiotherapy. Four required a permanent or temporary stoma. Seven in-depth interviews took place in their local Community Health Centre and two in the participants' homes, according to their preference. Participants were able to bring a support person with them. Two chose to do this and brought their spouses. Anything said by the spouse was not included in the data analysis as ethics consent was not sought for this. The participants consent was obtained in writing prior to commencing the interviews. The interviews, all conducted by the researcher alone, had a mean length of 41 minutes, and were recorded using two audio devices. Interviews were conducted by asking semi-structured questions from a pre-prepared list (see Appendix 3), that explored their thoughts and recollections from the time of commencing investigations for colorectal cancer, through diagnosis and until surgery. The participants were free to reveal anything they wished. The questions sought to ascertain why they made their surgical choices and identify influencing factors. The researcher ensured the pre-prepared questions were asked to each participant, seeking clarification only when necessary. The participants were offered a copy of their transcript but none chose to do so. Initially the research question sought to explore the period from diagnosis until surgery, but it was clear from all the interviews that whilst it may be easy to compartmentalise an experience into parts in theory, in practice

the experience occurred as a whole to all of the participants. The participants outlined their whole cancer experience and included what was of importance to them.

## Data Analysis

In order to heighten understanding of the meaning of the experience, a field journal was kept by the researcher with accompanying notes about the interview, setting, background, time and dates and was completed immediately before and after the interviews, and used to enhance the analysis of the transcripts. Thematic analysis involved identifying patterns within the data, then organising and interpreting them<sup>(53)</sup>. All interviews were transcribed verbatim by the researcher, with notes made contemporaneously of comments or issues that were important or required further exploration. This assisted the researcher in gaining a deeper understanding of the data<sup>(53)</sup>. Data analysis was all done manually and without the use of a computerised software program. Initial coding was performed by the researcher using a line by line approach, cutting up the transcripts so that all data was coded, to ensure that nothing that may have emerged as important was missed<sup>(53)</sup>. This approach allowed the researcher to compare, contrast and evaluate the data and begin collating into codes<sup>(55)</sup>. Ninety six initial codes were identified. Using an inductive process, codes were grouped to become themes. Descriptive themes were identified first and evaluated further to identify interpretive themes. Codes were discussed with the mentor and tested by the researcher to ensure the codes fitted into the themes and a coding and theme table capturing the essence of the experience was completed<sup>(53)</sup>. The themes were inductive, being completely grounded in the data<sup>(51, 53)</sup>. Saturation of themes was achieved with all the themes well populated and very little loss of coded data.

## Reflexivity

Reflexivity is the process involved in developing an awareness of self, personal beliefs and opinions and how these impact on the conduct of the research and data analysis<sup>(58)</sup>. The researcher works as a Nurse Practitioner in medical oncology and was formerly an oncology clinical nurse specialist and breast care nurse at the time of the interviews. The researcher was aware of the impact her views might have on the research. To this end a reflexive journal was kept<sup>(59)</sup> and reflective discussion occurred throughout the project with her academic mentor and the Rural Research Capacity Building Program team. The researcher had worked extensively with people with breast cancer and was used to clients often having high informational needs and levels of distress. The researcher believed in the benefits of care coordination to improve patient outcomes. The researcher was a novice researcher, with some experience in clinical trials for cancer, and had completed post graduate study, including a Masters degree.

# FINDINGS

Four major themes emerged from the data which interacted and overlapped with each other but overall captured the unique and diverse experiences of the participants. These were control, interconnection, embodiment and transformation. Whilst the themes were universal and shared in various permutations, the spectrum was wide. Throughout the experience, from before diagnosis to after completion of treatment, the participants outlined what were described as being relatively straightforward colorectal cancer experiences and more intense and complicated experiences. After treatment, there were those that had fully recovered mentally and physically and life was much the same as it always was, and those that had not fully recovered and for whom life was different.

## **Control: “I don’t know him from a bar of soap and in two weeks he’s going to cut me open”**

The theme control, broadly concerned the way the participants managed their cancer and their trust in themselves, the system, the doctors and treating team of health professions. The participants felt loss of control and took measures to reclaim it. They were pragmatic about what was able to be controlled, surrendering and asserting control at times.

### **Trust**

Having trust was fundamental to the participants cancer experience. Initially the participants trusted implicitly in the system and the people in it. However, over time and with negative experiences, the participants trust was weakened, along with their sense of control. Trust in the surgeon was vital. It allowed the participants to hand over control of their body to the surgeon to operate on; a doctor that they may only just have met and did not know. The participants had confidence in the expertise of their surgeons and that the surgeon would do the right thing by them. The participants had a fundamental belief in the integrity of their doctor. They expected that the doctors were honest and trustworthy. Trust could either be implicit and unreserved, being afforded to the surgeon because of the job title or be more conditional, being given only after the consultation, as expressed by Kim:

*Once you meet this bloke he just instils confidence...I can honestly say if he said I've got to open you up again, I'd do it tomorrow.*

Daryl, like all the participants, was willing to place her trust and her body into the hands of the surgeon to operate on her despite not knowing him:

*I don't know him from a bar of soap and in two weeks he's going to cut me open.*

Trust allowed some to take a passive role, surrendering themselves with confidence. It stemmed from the belief in the expertise of the treating team and particularly the surgeon. The participants deferred to that knowledge. Overall, the literature recognised that trust in their surgeon is important <sup>(16, 22, 23)</sup>, as is supported in this study, but the participants illustrate exactly what that means to them. Rather than a being just a generic word, trust, to the participants, meant placing their life in the surgeons' hands and this is not spelt out in the literature.

The participants sense of control was in part determined by their expectations. Total trust in the doctor remained throughout the whole experience for some participants, but for others the trust was challenged and doubt surfaced when things did not go as expected. Les was originally expecting to have radiotherapy but was later told surgery only was required. He illustrated what it felt like to live with a decision that he was unsure was right but trustingly accepted. Doubt crept in when he lay awake at night. If he had his time again he would have questioned the doctor until he felt comfortable that the treatment offered was best for him:

*Was it unnecessary surgery or not? ...I took his [surgeon] word that it had to be cut out...I thought well they're the specialists. They know what they are doing so I never asked them. But sometimes in the night I just lay there and think well why didn't they just try that in the first place and then do the surgery.*

The participants were shocked and disappointed when things were different to their expectations, including their recovery. It illustrated that their needs are different before and after surgery:

*I didn't think it was going to be as horrendous as it was. I still thought at that stage it was going to be open me up like appendicitis and pull it out and sew it back up again. - Kim*

*It's not as quick a recovery as I thought. I expected to be back at work in a month. - Shane*

Scheer et al<sup>(38)</sup> found that most people had little recollection of their discussion with the surgeon when consenting to surgery for colorectal cancer, so expectations are likely to differ as was the reality for many of the participants and highlighting the importance of this consultation. Where explanation was either given or recalled it worked better, as illustrated by Glen who was made aware of her expected recovery:

*They said it would take six months to get over it and be very careful because it was major.*

In determining choice of surgeon, the participants were referred by their GP. The participants accepted this without concern and was not of great significance to them. This is reflected in the literature<sup>(10, 16, 17)</sup>. They were happy to trust the judgment of their GP. Where a particular surgeon had been requested, it was because the participant had positive previous experience of them. Unlike their urban counterparts in Salkeld et al's<sup>(23)</sup> study, the participants placed no importance on their surgeon being a colorectal specialist. The participants' responses differed from the literature, because they largely made no mention of the surgeons' expertise as a reason for referral by the GP, but were similar regarding timely appointment and locality:

*He [GP] recommended Dr [surgeon] and that was it. He [GP] gave me a referral and said it was just around the corner - Lindsay*

Unlike Gillies analysis<sup>(1)</sup>, time from referral by the GP to specialist for colonoscopy, and then surgery was largely considered timely and in the main not an issue for the participants. Typically time from colonoscopy to surgery was under a month.

### **Control over their lives**

The participants described loss of control over their normal lives. This was documented in Jonsson et al's<sup>(28)</sup> phenomenological study. Typically the participants were fit and healthy people who visited their GP infrequently, but as they were being diagnosed, they described normal life being suddenly gone:

*I never had to go near a doctor and all of a sudden I was being bombarded with them. Tests and blood tests and other things. - Shane*

The participants believed in acting promptly on a positive screening test or presentation of symptoms and most chose to see their GP promptly. The participants believed that it was the right thing for their health, recognising that early detection and treatment of cancer gave a higher chance of cure. Pats response was typical:

*If you get it [the cancer] today you've got more chance [than] even if you leave it for another month.*

There were several factors that caused delay. As recognised by Hanks et al<sup>(4)</sup>, not realising the significance of symptoms was the most commonly expressed factor:

*The GP asked me if I had been bleeding and stuff and I said yeah. Must have been for a while but I sorta ignored it. Silly thing to do but....I put a lot of it down to stress. - Shane*

Family responsibilities or family problems were also cited, illustrating the complexity of cancer diagnosis within a family. It does not happen in isolation to life, but as a part of it, and other issues took precedence over managing their own health for a period of time. Kim was alone in having presented to his general practice over a period of years, with symptoms that with hindsight he believed were from his colorectal cancer. As Pascoe et al<sup>(19)</sup> identified, a poor relationship could hinder diagnosis:

*Four years. They gave me an x-ray. They [GP] sent me for an x-ray and the x-ray came back and they couldn't really see anything because there was too much wind in there...They [GP] told me to go home and have a gaviscon or something. - Kim*

Doing what the participants felt was the right thing for themselves and their family was central to their cancer experience. The rationale was ultimately about doing what they felt they needed to do to stay safe and recover rather than die from the cancer. Dallas and Daryl represented either end of the spectrum:

*Do everything you're told. Do what the doctor says. Don't shy away from it. I think that's what helped me a lot. He [surgeon] said do this and I done it... Much as I hated it I had to do it. Yep... But it was scary. I thought I was going to die there for a while if I didn't do as I was told. - Dallas*

Dallas was not just doing what he was told. He genuinely believed that what he was doing was vital for his survival. When Daryl elected to discontinue treatment, she too genuinely believed what she was doing was vital for her survival, by avoiding the emotional and physical void she felt would result if she continued:

*If I'd have fallen into the hole of "you have this intravenous [treatment] every week or twice a week", I don't know [pause], I would rebel and I would pull the plug, pull everything out [and say] I'm not having nothing. No more, I'll die. Forget about it. That's what I'd do, but I wouldn't let myself get into that hole in the first place.*

The notion of the participants doing what was right for them was a significant finding, as it was not readily found in the literature, providing an understanding behind their reasoning around treatment choices. It might appear on the surface as compliance or non-compliance with recommendations from the doctor. Underlying is the rationale that choices are made from a genuine belief that the participants are doing the right thing for the wellbeing of themselves and their families.

An unexpected aspect of losing control was when they woke from surgery. Many participants experienced panic, anxiety hallucinations, shortness of breath or believed they had died. These were unpleasant sensations and often frightening. Kerry described his experience:

*When I woke up after surgery I thought I was gone, because all the lights were so bright and I was groggy and didn't know where I was. And I was looking at the lights and couldn't breathe.*

This was not an expected finding but is documented in the perioperative literature about surgery. Consensus accepts this is not uncommon following surgery, particularly on waking from anaesthetic. Although recommendations are for clear education beforehand and providing a calm reassuring environment <sup>(60)</sup>, none of the participants described receiving this.

To regain control, a range of coping strategies were employed after diagnosis and particularly in the lead up until surgery. Not worrying or thinking about it or thinking too hard was typical, as was getting on with normal life. Lindsay described his attitude:

*I just put it out of my mind until it was time to do it [have surgery]. I didn't do anything special. I still went and played golf, did the things around the place.*

These attitudes were rarely recognised in the literature where it is much more common to find descriptions of emotional turmoil <sup>(26, 28)</sup> as experienced by Shane. He described his feelings as "a rollercoaster of emotions". He was unable to ignore or get on with normal life as well as he wanted. For him, his conscious experience of living had been occupied by the knowledge of having cancer and sleep was the only respite:

*I used to wake up some mornings and forget I had it. So for a few seconds then yeah that's right then it dawns on you. That's right you've got cancer.*

Having a sense of what would happen to them after surgery helped participants feel they were in control and helped them plan their life. Some of the participants had already had follow up colonoscopies and knew the time their next one was due. A clear plan including expectations of recovery, timing of specialist appointments and colonoscopies, and even when a point in time had been reached that meant the participant could be considered cured, gave a sense of control and certainty. Despite this, and coupled the fact that the Cancer Institute NSW and other guidelines recommend the use of a clear plan <sup>(2,8,9)</sup>, not all the participants had one, resulting in confusion and distress:

*I don't know if I'm supposed to be having blood tests every month or whatever. I don't know. - Shane*

Overall the participants were pragmatic and accepting of their diagnosis of cancer; it was happening and they had better accept it. They would need to have surgery to resolve it. The literature focused heavily on people with breast cancer <sup>(16, 22, 26)</sup> but contained some studies on colorectal cancer <sup>(29, 30)</sup>, and the participants generally demonstrated less distress and more equanimity than this literature. Lindsay described a typical view:

*There not much you can do about it. I mean it's there.*

The degree to which participants were able to trust, was directly connected to the nature of their relationships with health professionals.

## **Interconnectedness: “I’m not going to let you do it on your own. We’ll do it together”**

Interconnectedness broadly encompassed the human interactions of the participants with family, friends, and health professionals, for support and information and their use of sources such as the internet and other written literature. It illustrated how these shaped the experience. Family affected their choices of treatments, of feeling supported and of feeling alone. Participants described how qualities and behaviours of their health professionals impacted both positively and negatively on their wellbeing.

### **Supportive needs and preferences**

Family support was important for all participants and demonstrated in different ways. Family were who the participants turned to for support after diagnosis and this is supported in the literature<sup>(43)</sup>. It was important for many to have family physically present during treatment and at appointments and the participants gained strength from this. Some participants were alone during their treatment and in the months after for various reasons, including choosing to not burden their family or disrupt their adult childrens work. The participants with spouses spoke about the beneficial emotional and physical support they received. They went to appointments and treatments together. Children and siblings were other sources of support:

*She [spouse] never missed one day...The family backs me up all the way. It's been a great help. - Dallas*

The participants who were parents expressed sentiments that demonstrated a desire to protect or shield their loved ones and were concerned about upsetting them. The participants, carried the responsibility of being parents and someone who cares about and for others. They illustrate the reciprocal nature of relationships:

*I tried to stay positive and that ...for the kids. - Shane*

*I didn't want to upset them [grandchildren] about anything like that [having cancer] you know. - Pat*  
Daryl delayed initiating treatment largely because of higher priorities at the time and this illustrates the participants desire to ensure the wellbeing of their families, in her case above her own needs:

*I put that off because [spouse] was ill and I was looking after him.*

Whilst the general view was of feeling either well supported or as supported as you needed or wanted to be, Shane described a sense of loneliness that was not expressed by the others. Ultimately the cancer is yours alone to bear:

*Even if there is other people, it comes down to you. You are alone with it [the cancer] emotionally...It's just you and it in the end.*

The participants detailed their information sources and informational needs which varied. The primary information source for the participants was the surgeon. This comprised of a verbal consultation, sometimes with the aid of a diagram or model to illustrate. They also had a preadmission consultation at the hospital. This was often considered an adequate amount or even too much information:

*I don't think I'd look for any more. - Lindsay*

*Plenty of information right along the way - Pat.*

Some participants wanted professional support and peer support but were not offered these services and did not know how to access them. Time of need was before surgery, during the immediate recovery period and longer term. The participants recognised that they did not always know at the time of surgery what they wanted but only with the benefit of hindsight. They asked for the services of a cancer specialist or counsellor to provide details on what surgery was really like and detailed information on recovery:

*The doctors need to advise the patient if they want to see a counsellor or something like that, instead of saying come back in three weeks and we'll chop you up...A counsellor or someone to go and see and say do you want to talk, do you have any concerns before the operation. That you need to talk about... There's things you should be told...Someone professional to come and see them or to ask if they wanted to see someone who knows a lot about it. - Les*

*I probably wish I'd had someone to talk to that had been through it. That would have helped a lot... Before hand as well as after. - Shane*

*I wanted to talk to somebody that had been through it...Cos I was in the unknown...I rang [national helpline]. He was nice and helpful and whatever but I didn't get to talk to anybody. - Daryl*

Where participants had a choice of where to have treatment, the family influenced choice. This was largely a decision made by the participant independent of family, but about the family. Family welfare was central to that choice. Unlike choice of surgeon, where the participants were happy to be directed by their GP, location is influenced by family primarily. Where participants had surgery in a city it was always with the support of, or encouragement of their family who were physically with them whilst they away from home. Shane was clear on his rationale:

*He [Endoscopist] wanted me to go to Sydney to have surgery down there. I just said no. I said my children are up here.*

The internet as a source of information was used minimally and this differed from the literature, being of little significance for the participants. It was more important for their adult children who offered their parent information that they had learnt. Kim summed up the general consensus:

*I mean you can't self diagnose yourself on a computer can you?*

What the surgeon had to say had much more importance for this group and highlights the importance of the consultation with the surgeon. It raises questions on the way education at this point is provided, considering Scheer et al<sup>(38)</sup> found that people had little recollection of the content of their discussion when consenting for colorectal surgery.

### **The impact of professional relationships**

Relationships with health professionals were an important aspect of the participants' experience. Although this is well reported in the literature <sup>(18, 20, 23)</sup>, the findings of this study illustrate the nature of this unique relationship. The relationship enabled the participants to facilitate action that would not be appropriate where they did not know each other well enough:

*My local GP made the appointment for me and said that's the date you are going.* - Daryl

*I was there with the wife and he [GP] looks at me and says I haven't seen you in a while you'd better go and have a blood test.* - Lindsay

As documented in the literature, a poor relationship impacted negatively <sup>(19)</sup>. Kim changed GP to get a diagnosis and others like Shane did not get the advice needed. Shane expected to be told what tests and investigations he should have after surgery and this lack of information hindered his recovery and he worried that a cancer recurrence might be missed or preventable:

*I don't know what I'm supposed to be doing or anything. The GP hasn't said much to me.*

Evidence from the literature highlighted the importance of keeping the GP informed about the plan of care for better patient support <sup>(4, 21)</sup>. This did not happen for Shane. The participants found that the qualities and behaviours of health professionals had a positive or negative effect on their experience. This was reflected exactly in the body of literature regarding what patients liked and found supportive <sup>(23, 28, 50)</sup>. The participants interpreted facial expressions and body language to determine that bad news was about to be given to them. Trust and confidence in the team could be impacted when the participants described incidences or remarks where a member of the health team spoke negatively about another team member's character, behaviour or actions. These comments were made directly to the participants, witnessed by, or overheard by them. Characteristically, supportive behaviours included good communication, kindness, directness, approachability, compassion, knowledge, humour and helpfulness. The following comments illustrate a range of experiences good and bad made about members of the health team:

*He's a gentleman... I like that he talks straight... no beating around the bush.* - Kerry

*Nothing is too much trouble for her...no matter what I wanted or wanted to know she was there.* - Dallas

*I got upset with him...he said there's nothing wrong with your hand and I said you tell that to my bloody hand when it goes numb and I drop something.* - Les

*Some doctors are very compassionate. Not only are they good surgeons but they can communicate. And some don't mean to be aloof. They don't mean to be but they are. No warmth.* - Kim

*He went real crook about that ...he wasn't real happy.* - Dallas

Supportive behaviour was particularly important to the participants given the personal and embodied nature of their concerns.

## Embodiment: “I can take pain, but that was just excruciating”

Embodiment was about how the cancer and the effects of its treatment were manifested within the person as a result of their colorectal cancer. It was about the nature of occupying, or being caught in a body that was altered, wounded, unfamiliar, and one that could not necessarily be relied on as before. It included physical and mental pain as well as changes to bowel habits. The participants found different aspects of their treatments harder to tolerate and confronting to experience. This included psychological difficulty, chemotherapy side effects or surgical recovery.

Some of the participants were symptomatic at diagnosis, with others being diagnosed following a positive Bowelscan result. Symptoms most commonly included rectal bleeding but some also had weight loss, anaemia or fatigue. The majority were surprised to be diagnosed with colorectal cancer. Typically they expected it to be a benign condition like haemorrhoids or polyps:

*Oh I just thought polyps...I walked in with thoughts of oh yeah bit of bleeding they'll fix that...I got that big a shock ...I couldn't comprehend it for a long time. I didn't think it was that bad. - Dallas*

### The impact of pain

A minority of participants experienced post-operative infections, which were painful and slow to heal, requiring readmission and surgical intervention. The infections occurred shortly after discharge and were frightening. Although some participants experienced no pain, many of the participants did. Poorly managed pain was an unexpected factor for them. It happened acutely and in the longer term, with some participants continuing to experience pain. Several studies on colorectal cancer described pain being well managed <sup>(28, 31)</sup>, so this differed, with instances of pain described whilst in hospital, that were so severe that death was considered a viable escape:

*I can take pain, but that was just excruciating. - Kim*

*I didn't think I'd be in that much pain. Murder it was...It got to the stage when I didn't care. After the operation I didn't care. I said to the wife I don't care if I die now. - Dallas*

### The impact of the stoma

Some of the participants had a temporary or permanent colostomy which caused them all psychosocial and physical problems. The issues outlined were reflected in a large body of literature <sup>(32-35)</sup>. The stoma had a massive impact on their life and they often described it with hatred. Logistically they found it difficult to clean themselves and change the stoma bag independently. The shape of the stoma could make it difficult for them to apply the stoma bag. Bowel movements could be erratic and frequent. Mentally it was difficult to accept and the reality of life with a new stoma made the participants feel very depressed:

*Some nights in bed it would leak and burst open and that's not a good thing. At 2 o'clock in the morning you've gotta get up and change things. Go and have a shower and get it all done again. And I used to lose it quite a bit. Get quite depressed actually. - Kim*

*If you're out and have a blowout or something happens you know, very embarrassing. So I don't go out much anymore. I stay at home a lot ...Yeah the bag's my biggest downfall. A couple of times I've said to [spouse], I think I'll go out the back and shoot myself. It's very hard. - Dallas*

The participants, as reports from the literature have identified <sup>(34, 35, 37)</sup>, described practical issues such as needing to find appropriate toilets where they could change the bag and restrictions on foods they liked, that now caused diarrhoea. Accidents when out were a reality, causing huge embarrassment and making it easier to stay at home. The participants felt shame and embarrassment about loss of control over their bodily functions, that they felt they should have command of as adults:

*You've got no control over it. It just does its own thing when it wants to... So I was sitting in his office talking to him [specialist doctor] and I could feel it go, and I said look, I've got to go, the bag's activated. And he said toilets are just there and I said I've got to use the toilet near the car. I had spare bags in the car. By the time I got there and back to the toilet, the bag's busted over the base plate...and it was coming out and was all over my shirt....I just washed my shirt down and yeah I left. Didn't even go back to the office. It was embarrassing. - Les*

The bowel changes could persist even after the reversal of the stoma for some time, continuing to cause restrictions on their life. Kerry explained how he has had to adapt to this change:

*To keep an appointment I won't have breakfast. I'll wait until I get home. Sometimes if I have breakfast my bowels will work five times before I leave the house.*

The participants reflecting what was found in previous research, appreciated the services of the stoma nurse<sup>(33, 36)</sup>. They required these services until they had learnt to manage their stoma themselves or had a routine that worked for them, which took time. Finding the right stoma appliance that did not leak was important. When the participants were comfortable they no longer needed the service, they often felt a sense of achievement. Dallas, summed up his experience and demonstrated the resilience typically shown:

*I do everything myself now. Before it was pretty hard. Now I've got it down to pat.*

The ongoing nature of some of the issues arising as a result of the surgery for colorectal cancer resulted in changes to the participants lives.

## **Transformation: “I’m not the same person I was”**

Transformation concerned the changes that occurred as a result of colorectal cancer to the participant. The person they were at the time of diagnosis, was the sum of their life experience to that point. It was influenced by their previous lifestyle, work, social life, support network, family and personal knowledge, experience and fear or otherwise, of cancer and death. The participants experiences ranged from those left largely unchanged by the experience to those that had been left with a diminished life as a result of physical and mental changes.

### **The impact of having colorectal cancer: Life before and after**

The way the participants felt when they received their diagnosis was influenced by their previous experience of cancer. Those that had family members affected by cancer were usually more concerned and had a greater awareness of what it is to die from cancer. For Kerry there was a known genetic component that had cast a frightening shadow over the life of his extended family. Others like Pat had been told “*it wasn't hereditary*”. The majority had some experience, most commonly from parent or spouse's parent with cancer and this impacted in a variety of ways, from feeling that they had an understanding of the disease to feeling that you could die. There was a clear impact on their spouses and children too. Kerry described his wife's thoughts after being told her husband had colorectal cancer:

*Oh God I'm like the rest and gonna end up a widow.*

Participants described their life before diagnosis of cancer. They described being physically fit prior to cancer, with those of working age in paid employment and all with independent lives. They were physically active, for example Glen maintaining her rural property, Kerry cycling many kilometres, Lindsay golfing and

Shane lifting weights. Others were active in local clubs. Some lived alone but the majority were married or in de-facto relationships. Having cancer, to varying degrees, left the participants with changed lives, and some with significant losses. For the participants left debilitated in any way, the colorectal cancer resulted in greater change to their previous lives. They described no longer being able to work in either a paid or voluntary capacity, reduced ability to carry out household responsibilities, reduced fitness, loss of independence, loss of energy, loss of social life, difficulty of living with a stoma, bowel changes and dietary changes and this was reflective of the literature <sup>(39-41)</sup>. Les described the impact on him:

*I worked [with food] so I can't go back to work because it's too unhealthy...I still get depressed because what am I going to do? What kind of work can I do?*

This was not a universal view as others' lives were either normalising or were back to normal. For some of the participants, they felt that the whole process was relatively straightforward and were less impacted by the experience. Pat captured this viewpoint:

*I didn't let it bother me. I was never sick.... I suppose mine was pretty straightforward.*

Pat said he was lucky to have come through so well from his colorectal cancer. This was a common response, particularly when they described their life being largely unchanged or felt they were recovering well. Several also felt lucky not to have lung cancer, being former smokers:

*I got off fairly lightly in fact cos I smoked for a lot of years...I consider I'm way in front. - Lindsay*

Following surgery, many participants felt physically weaker and fatigued for a long period of time and this impacted on their life and responsibilities:

*Just wish I could get some energy back. It's my only wish, energy. The week before all this nonsense started I was mowing the lawns - Glen*

The participants demonstrated and described resilience, tenacity and determination in their words and actions. None gave up, even after changes to expectations and setbacks to recovery. Loss of hope was only ever transient for the participants. Kim illustrated:

*There's still a bit of fight left. Let's see how he [surgeon] goes when he chops it [the tumour] out.*

The participants employed recovery strategies to try and help themselves back to health. Recovery had been self-motivated with varying degrees of success. They felt that attitude was important, with many citing that positivity had been helpful. Pat explained:

*It's the attitude. You've got to go in positive.*

Staying engaged with the world seemed to have a protective effect on mood, for example by being involved with a club. One participant got a dog to ensure he went out walking each morning. Depression, acknowledged or described in other terms was experienced by the participants. There was a degree of low mood in the participants that had been left with physical issues that was not present in the participants that had recovered fully, or felt on track to recovery.

## **Death and uncertainty**

Fear of death was underlying in the experiences and for some was the driver for treatment and they typically spoke with humour and understatement:

*I'm happy to go with that [recommended treatment]. It's better than a pine box. - Kerry*

*I didn't think I was gonna die anyway. [Laughs] - Pat*

Fear of death from anaesthetic, rather than the cancer was a real concern to some, as described by Les:

*I was frightened that I would die on the table.*

Younger or older age was significant, being considered reasonable to die at an older age but unfair when young. Glen, the oldest participant said:

*At my age it's no big deal. You look at all the young ones sick...You've got to die of something.*

Shane, the youngest participant, was the most concerned. He went for staging investigations before surgery with the thought of death from cancer in the forefront of his mind:

*I thought when I was going to go and have the scans it was going to be everywhere and that would be the end of you.*

Living with the uncertainty of the risk of cancer recurrence was found in phenomenological studies such as Ohlsson-Nevo et al<sup>(30)</sup>. The participants were living with uncertainty to a greater or lesser extent. Many of the participants were accepting of their situation. Some participants had been given stronger assurances that their cancer would not recur:

*I know some people go and see the doctor and he tells them you've only got two months left in you, but that was never ever mentioned. Nothing like that...All the way long he said don't worry about that we'll fix this you know. - Pat*

Living with uncertainty a reality, but was easier for some than others. For example Kim said:

*Well you can't guarantee it won't come back. You know you live with that, what can you do? I suppose I've got a year and a half more that I should have got.*

Some of the participants were trapped by their experience. Shane illustrated how he was unable to move forward with his life, being traumatised by his experience. He struggled with uncertainty and remained haunted by the threat that it would return. He illustrated the enormity of the impact colorectal cancer can have on life. He remained in his anguish, with no psychological supports in place to assist his recovery:

*You sort of relive it every day. It's something you can't forget about...I'm not the same person I was... physically, mentally, both.*

Overall the four themes illustrate the difficult and challenging aspects of the participants experience. The experience was straightforward for some and complex for others so whilst some made a full recovery, others were left with significant losses in their lives.

## STRENGTHS AND LIMITATIONS

**Study strengths:** This study provides much needed qualitative research on the experience of rural people who had surgery for colorectal cancer in NSW as little existed.

**Study limitations:** The majority of participants were men and it is unknown if different information may have been obtained if there were more women interviewed. It is also unknown why less women responded to the invitation. The study was limited to public patients that had at least part of their treatment within the hospitals used in the medical record search. It does not capture people that had all their treatment in the private sector or outside of area. Further qualitative research is recommended on these aspects to gain a broader view of the rural colorectal cancer experience.

## CONCLUSIONS

The study sought to find out what is the experience of people living in rural NSW who undergo surgery for colorectal cancer. It has identified four major themes which were: control, interconnection, embodiment and transformation and provided insight specifically into that phenomena. In doing so it has added to the body of qualitative literature on colorectal cancer and has implications for practice, policy and future research.

The study reflects the literature, identifying that trust in the health team is important, but highlights what that looks like; participants being prepared to place their lives in the hands of the surgeon. Although limited specialist services are a feature of rural areas, a specialist colorectal surgeon was not considered important for the participants that had surgery locally, as the literature had shown it was for their metropolitan counterparts.

The participants did what they felt they needed to do regarding treatments, for their safety and wellbeing, largely manifesting as doing what the doctor recommended, but not always. This provides an understanding on why people make their choices.

Unlike treatment choice, place of treatment was often determined with the families wellbeing in mind. The result of this was that local treatment was often chosen to minimise impact on the family. This has important ramifications for practice, supporting the findings in McConigleys et als research<sup>(10)</sup> and highlighting the need for providing high quality local services in the rural setting, but also ensuring adequate support is available to assist the person and their family to have treatment out of area if needed or desired.

For the participants, the internet and other written information was of little importance and they placed more importance on spoken conversation with their doctors. As research has suggested that not much is remembered about the consultation when consenting for surgery, this raises issues about how information is delivered to this group. Their adult children, the next generation preferred their information delivered differently, again suggesting the need for flexibility.

For many of the participants things were different to their expectations, even from before surgery and some had no idea about their follow up. Many participants, reflecting what is found in the literature, were left with unresolved physical and psychosocial issues and had little idea of how to access services. This highlights the necessity for serial assessment of needs to identify requirements. Despite the fact that it would have been able to determine issues requiring assistance, needs assessment was not mentioned by any of the participants. The study also has implications for communication between people with colorectal cancer their family and health team in both the acute and primary setting and for coordination of care. Again, in line with reports in the literature, participants were affected by behaviours of health staff, stressing the importance of good communication.

The participants' cancer experience was multifactorial, in part determined by the sum of their life experience at diagnosis and must to be taken into consideration, but is currently not routinely assessed. The study has shown that overall it can be very different for each person to undergo surgery for colorectal cancer in rural NSW. Individual needs vary according to their situation. Some people have a relatively straightforward surgery and recovery and their needs are adequately met, yet this is clearly not the case for others.

## RECOMMENDATIONS

The priorities as a result of this study are to focus on three key areas, to ensure best practice, patient centred outcomes for patients who undergo surgery for colorectal cancer and live in rural areas. These are improving communicative practices, providing needs assessment and the provision of services. They should be delivered within strengthened partnerships between patients and families and their acute and primary health care providers. To explore how these can be achieved within the constraints of distance to services, existing budget and staffing, recommendations developed as a result of this research include:

**Communicative practices:** The Cancer Services team to work in partnership with people with colorectal cancer and their families to ensure that they have clear information and understand their plan of follow up, expected recovery time, and changes that may occur as a result of their treatment. How this is delivered should be according to the patients' needs and preferences. Promoting the use of the CORE Values (collaboration, openness, respect and empathy) of NSW Health, through the development of an online education module by HETI, for use by all health employees, to engage with, and positively impact on the experience of people with colorectal cancer and their families,

**Needs assessment:** Undertake serial needs assessment on all people having surgery for colorectal cancer to identify their physical, psychosocial and spiritual needs. Commencing these prior to surgery as this has been identified as a key time of need, through treatments and after treatment has finished, because needs change over time. Conduct further research to evaluate the current and future use of assessment tools, including where and when they are used, with the intention of adopting an effective tool for assessment of needs in future. This study could form the first phase of a mixed method study.

**Provision of services:** Ensure access to care coordination, according to need, to facilitate the provision of supportive care. This includes referral to specialists such as the social worker, psychologist or dietician. Ensure access to a stoma nurse, as required to facilitate optimal self-management.

Adoption of these priorities locally will effectively assess, monitor and support the needs of the people who have surgery for colorectal cancer and their families. By using a targeted approach, resources can be provided to those people that need them, when they need them. Any models of future care need to be flexible enough to accommodate the needs and preferences of rural people which is characterised by limited local resources and distance from specialist services. Consideration should be given to qualitative studies such as this, which highlight the meaning and impact on people when they are undergoing surgery for colorectal cancer and live in rural areas.

# REFERENCES

1. Gillies D. Colorectal Patient Surgical Project. Newcastle, Australia: Hunter New England Local Health District, 2013.
2. Cancer Institute NSW. NSW Cancer Plan 2011-2015. Sydney: Cancer Institute NSW; 2010.
3. Baade PD, Dasgupta P, Aitken JF, Turrell G. Geographic remoteness, area-level socioeconomic disadvantage and inequalities in colorectal cancer survival in Queensland: a multilevel analysis. *BMC cancer*. 2013;13(1):493-.
4. Hanks H, Veitch C, Harris M. Colorectal cancer management - the role of the GP. *Australian family physician*. 2008;37(4):259-61.
5. Cancer Council Australia Colonoscopy Surveillance Working Party. Clinical Practice guidelines for Surveillance Colonoscopy - in adenoma follow-up; following curative resection of colorectal cancer; and for cancer surveillance in inflammatory bowel disease. Sydney: Cancer Council Australia; 2011.
6. Courtney RJ, Paul CL, Sanson-Fisher RW, Macrae FA, Carey ML, Attia JR, et al. Colorectal cancer screening in Australia: a community-level perspective. *The Medical journal of Australia*. 2012;196(8):516.
7. Martin JH, Coory M, Baade P. Challenges of an ageing and dispersed population for delivering cancer services in Australia: more than just doctors needed. *Internal medicine journal*. 2012;42(4):349-51.
8. National Institute for Health and Clinical Excellence. Colorectal Cancer: The diagnosis and management of colorectal cancer. London, UK: National Institute for Health and Clinical Excellence, 2011.
9. Australian Cancer Network Colorectal Cancer Guidelines Revision Committee. Guidelines for the prevention, early detection and management of colorectal cancer. Sydney, Australia: The Cancer Council Australia and Australian Cancer Network; 2005.
10. McConigley R, Platt V, Holloway K, Smith J. Developing a sustainable model of rural cancer care: The Western Australian Cancer Network project. *Australian Journal of Rural Health*. 2011;19(6):324-8.
11. Butow PN, Phillips F, Schweder J, White K, Underhill C, Goldstein D, et al. Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. *Supportive Care in Cancer*. 2012;20(1):1-22.
12. Yates P. Cancer care coordinators: realising the potential for improving the patient journey. *Cancer Forum*. 2004;28(3):128-32.
13. Eley R, Rogers-Clark C. Consumer perceptions of the effectiveness of a breast care nurse in providing coordinated care to women with breast cancer in Queensland, Australia. *Australian Journal of Advanced Nursing, The*. 2012;29(3):56-61.
14. Voigt B, Grimm A, Lossack M, Klose P, Schneider A, Richter-Ehrenstein C. The breast care nurse: the care specialist in breast centres. *International nursing review*. 2011;58(4):450-3.
15. Koh CE, Solomon MJ. Surgery for colorectal cancer. *Cancer Forum*. 2014;38(1):53-8.
16. Ristevski E, Regan M, Birks D, Steers N, Byrne A, McGrail M. Communicating about breast cancer: Rural women's experience of interacting with their surgeon. *Australian Journal of Rural Health*. 2012;20(1):22-8.
17. Conner-Spady B, Marshall D, Bohm E, Dunbar M, Loucks L, Hennigar A, et al. Patient Factors in Referral Choice for Total Joint Replacement Surgery. *Medical Care*. 2014;52(4):1.
18. Piterman L, Koritsas S. Part I. General practitioner-specialist relationship. *Internal medicine journal*. 2005;35(7):430-4.
19. Pascoe SW, Veitch C, Crossland LJ, Beilby JJ, Spigelman A, Stubbs J, et al. Patients' experiences of referral for colorectal cancer. *BMC family practice*. 2013;14(1):124-.
20. Kinchen KS, Cooper LA, Levine D, Wang NY, Powe NR. Referral of patients to specialists: factors affecting choice of specialist by primary care physicians. *Annals of family medicine*. 2004;2(3):245-52.
21. Davies E, Van Der Molen B, Cranston A. Using clinical audit, qualitative data from patients and feedback from general practitioners to decrease delay in the referral of suspected colorectal cancer. *Journal of Evaluation in Clinical Practice*. 2007;13(2):310-7.
22. Bettencourt B, Schlegel RJ, Talley AE, Molix LA. The breast cancer experience of rural women: A literature review. *Psycho-Oncology*. 2007;16(10):875-87.
23. Salkeld G, Solomon M, Short L, Butow PN. A matter of trust--patient's views on decision-making in colorectal cancer. *Health expectations : an international journal of public participation in health care and health policy*. 2004;7(2):104-14.
24. Lithner M, Johansson J, Andersson E, Jakobsson U, Palmquist I, Klefsgard R, et al. Perceived information after surgery for colorectal cancer--an explorative study. *Colorectal disease : the official journal of the Association of Coloproctology of Great Britain and Ireland*. 2012;14(11):1340-50.
25. Nikoletti S, Young J, Levitt M, King M, Chidlow C, Hollingsworth S. Bowel Problems, Self-care Practices, and Information Needs of Colorectal Cancer Survivors at 6 to 24 Months After Sphincter-Saving Surgery. *Cancer Nursing*. 2008;31(5):389-98.
26. Drageset S, Lindstrøm TC, Giske T, Underlid K. Being in suspense: women's experiences awaiting breast cancer surgery. *Journal of Advanced Nursing*. 2011;67(9):1941-51.
27. Wasserman M, Baxter NN, Rosen B, Burnstein M, Halverson AL. Systematic review of internet patient information on colorectal cancer surgery. *Diseases of the colon and rectum*. 2014;57(1):64-9.
28. Jonsson CA, Stenberg A, Frisman GH, Kirurgi- och o, Omvårdnad, Institutionen för medicin och h, et al. The lived experience of the early postoperative period after colorectal cancer surgery. *European journal of cancer care*. 2011;20(2):248-56.

29. Ramfelt E, Severinsson E, Lützn K. Attempting to Find Meaning in Illness to Achieve Emotional Coherence: The Experiences of Patients With Colorectal Cancer. *Cancer Nursing*. 2002;25(2):141-9.
30. Ohlsson-Nevo E, Andershed B, Nilsson U, Anderzén-Carlsson A, Institutionen för hälsovetenskap och m, Örebro u. Life is back to normal and yet not - partners' and patient's experiences of life of the first year after colorectal cancer surgery. *Journal of clinical nursing*. 2012;21(3-4):555-63.
31. Brown C, Constance K, Bédard D, Purden M. Colorectal surgery patients' pain status, activities, satisfaction, and beliefs about pain and pain management. *Pain management nursing : official journal of the American Society of Pain Management Nurses*. 2013;14(4):184.
32. Danielsen AK, Burcharth J, Rosenberg J. Patient education has a positive effect in patients with a stoma: a systematic review. *Colorectal Disease*. 2013;15(6):e276-e83.
33. Boyles A. Patient outcomes and quality of life following stoma-forming surgery. *Gastrointestinal Nursing*. 2010;8(8):30-5.
34. Brant J, Walton A. Chronic Diarrhea in Post-treatment Colorectal Cancer Survivors. *Oncology*. 2010;24(7):45.
35. Ross L, Abild-Nielsen AG, Thomsen BL, Karlsen RV, Boesen EH, Johansen C. Quality of life of Danish colorectal cancer patients with and without a stoma. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. 2007;15(5):505-13.
36. Foskett K. The role of the colorectal and stoma clinical nurse specialist. *Journal of Community Nursing*. 2012;26(6):11.
37. McCaughan E, Parahoo K, Prue G. Comparing cancer experiences among people with colorectal cancer: a qualitative study. *Journal of advanced nursing*. 2011;67(12):2686-95.
38. Scheer A, Chan B, Moloo H, Poulin E, Mamazza J, Auer R. The Myth of Informed Consent in Rectal Cancer Surgery: What Do Patients Retain? *Diseases of the Colon & Rectum*. 2012;55(9):970-5.
39. Gray NM, Weller D, Campbell NC, Hall SJ, Browne S, Macleod U, et al. Modifiable and fixed factors predicting quality of life in people with colorectal cancer. *British journal of cancer*. 2011;104(11):1697-703.
40. Phipps E, Braitman LE, Stites S, Leighton JC. Quality of life and symptom attribution in long-term colon cancer survivors. *Journal of evaluation in clinical practice*. 2008;14(2):254-8.
41. Lavdaniti M, Barbas G, Fratzana A, Zyga S. Evaluation of depression in colon cancer patients. *Health Science Journal*. 2012;6(4):681.
42. Zucca A, Boyes A, Newling G, Hall A, Girgis A. Travelling all over the countryside: travel-related burden and financial difficulties reported by cancer patients in New South Wales and Victoria. *The Australian journal of rural health*. 2011;19(6):298-305.
43. Hall S, Gray N, Browne S, Ziebland S, Campbell NC. A qualitative exploration of the role of primary care in supporting colorectal cancer patients. *Supportive care in cancer : official journal of the Multinational Association of Supportive Care in Cancer*. 2012;20(12):3071-8.
44. Ieropoli SC, White VM, Jefford M, Akkerman D. What models of peer support do people with colorectal cancer prefer? *European Journal of Cancer Care*. 2011;20(4):455-65.
45. Bui LL, Last L, Bradley H, Law CHL, Maier B-A, Smith AJ. Interest and participation in support group programs among patients with colorectal cancer. *Cancer nursing*. 2002;25(2):150-7.
46. McGowan EL, Speed-Andrews AE, Blanchard CM, Rhodes RE, Friedenreich CM, Culos-Reed SN, et al. Physical activity preferences among a population-based sample of colorectal cancer survivors. *Oncology nursing forum*. 2013;40(1):44.
47. Regan M, Mills J, Ristevski E. Cancer care coordinators' relationships with the multidisciplinary team and patients: Everything to everyone. *Australian Journal of Cancer Nursing, The*. 2012;13(1):12-9.
48. Shim E-J, Lee k-S, Park J-H, Park J-H. Comprehensive needs assessment tool in cancer (CNAT): the development and validation. *Supportive Care in Cancer*. 2011;19(12):1957-68.
49. Richardson A, Medina J, Brown V, Sitzia J. Patients' needs assessment in cancer care: a review of assessment tools. *Supportive Care in Cancer*. 2007;15(10):1125-44.
50. Schoenfeider T. Get a good rate: nurses' kindness was found to be one of the key determinants of patient satisfaction by researchers in Germany. *Nursing Standard*. 2012;26(38):61.
51. Thorne S. *Interpretive Description*. USA: Left Coast Press Inc.; 2008. 271 p.
52. Thorne S, Kirkham S, O'Flynn-Magee K. The analytic challenge in interpretive description. *International Journal of Qualitative Methods*. 2004;3(1):1-11.
53. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3:77-101.
54. Sandelowski M. In response to: de Witt L. & Ploeg J. (2006) Critical appraisal of rigor in interpretive phenomenological nursing research. *Journal of Advanced Nursing* 55(2), 215-229. *Journal of advanced nursing*. 2006;55(5):643-5.
55. Green J, Thorogood N. *Qualitative Methods for Health research*. Second, ed. London: Sage Publications Ltd; 2009.
56. Blignault I, Richie J. Revealing the wood and the trees: reporting qualitative research. *Health Promotion Journal of Australia*. 2009;20(1):40-5.
57. Polit D, Beck C. *Nursing research: Generating and assessing evidence for nursing practice*. 8th ed. Philadelphia: Lippincott Williams & Wilkins;; 2008.
58. Clancy M. Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse Researcher*. 2013;20(6):12-6.
59. Houghton K. Linking aims, paradigm and method in nursing research. *Nurse researcher*. 2011;20(2):34-9.
60. Chassidy D-E. Alleviating Anxiety and Preventing Panic Attacks in the Surgical Patient. *Association of Operating Room Nurses AORN Journal*. 2013;97(3):354.

## 1. Participant information sheet



### Invitation to participate in cancer research project

**Research Project: The experience of rural people in NSW with colorectal cancer requiring surgery following their investigations for cancer, through diagnosis and until surgery**

#### Invitation

You are invited to participate in this research project investigating your experiences from when you were diagnosed and until you had surgery for bowel cancer. This research is being conducted by Ms Rachel Pitt, a clinical nurse specialist in Oncology at Manning Hospital, Taree

#### Why is this research being done?

The purpose of the research is to gain a better understanding of what it is like for people who have had bowel cancer, in the time period just before they are diagnosed with cancer and may be having investigations, after they are diagnosed and until the point when they have surgery and what their thoughts were at this time. This will include how they reached their decision to have what surgical procedure at which hospital.

Learning about these experiences may contribute to health professional's knowledge of the needs of people with bowel cancer and help ensure we are providing optimal care for people with cancer in rural NSW in the future. The research is supported by the Health and Education Training Institute and Hunter New England Local Health District.

#### Why are you being invited?

You are being invited because you have had surgery for bowel cancer in 2012 or 2013 and live in the Manning, Great Lakes or Gloucester areas.

#### What would you have to do to take part?

Participating in the research will involve having an interview and discussing your experiences just before diagnosis to when you had surgery. This will usually take about an hour. You will be asked some questions about the time of your diagnosis until your surgery. The questions are open ended: For example: Can I take you back to the time you started investigations for bowel cancer? Can you tell me what that was like? What were the next few days like? Were you alone or was anyone with you at the time you were diagnosed? Tell me about your choice of surgery? There are no right or wrong answers. The interview can be in your home or in the Community Health Centre so that it is wherever you feel most at ease. The entire interview will be recorded. Before you start you will need to sign a consent form to record that you are happy to take part.

You are very welcome to have a family member or friend present during the interview.

You will receive a follow up phone call within one week by Rachel Pitt to check if you have any questions or would like referral to any support services and this will be the end of your participation.

#### Do I have to take part?

Your participation in the research is entirely voluntary. You will continue to receive the same care from your health team whether you decide to participate or not. You can choose to withdraw from the study at any time.

**Will I get paid for this?**

There is no reimbursement for participation in this study or for travel costs.

**Are there any risks or benefits from taking part?**

You will be asked a few open questions to allow you to talk about what it was like for you in the time following your diagnosis of cancer and until you had your surgery. It is possible that you may feel upset from having a discussion relating to this time. You do not have to talk about anything that you do not wish to. You may stop the interview at any time either for a break or permanently. You do not have to give any reason for not answering or discontinuing the interview. There is no benefit to you as an individual from participating in this research.

**Will my information be kept safely?**

Your information will be coded so that it cannot be personally identified. Any other persons you discuss will be identified only to describe the relationship to you for example husband, wife, partner, son, friend, carer etc. Your information will be kept within a locked file and I will be the only the researcher will have access to this. When the research is written, you will be given another name, a pseudonym. Details that may be identifiable will also be changed such as your exact age, sex, ages and number of children should these arise in discussion in the interview. The recording of your interview will be destroyed on completion of the research project. You are welcome to have a copy of your transcript after it is typed and a summary of the research on completion.

**How will the research be used?**

The research is due for completion in 2014. The final report will be submitted to Health and Education Training Institute, Hunter New England Local Health District and Hunter New England Area Cancer Services. It will also be submitted for publication in rural or cancer related journals and presentation at rural or cancer related conference.

**Does this research have permission?**

This research has been approved by the Hunter New England Local Health District's Human Research Ethics Committee. Reference number 12/12/12/5.16

**How do I make a complaint if I want to?**

If you wish to make any complaint about any aspect of the project or your participation, you can contact Dr Nicole Gerrand, Manager, and quote Reference number 12/12/12/5.16  
Research Ethics and Governance Unit, Hunter New England Local Health District  
Locked Bag 1, New Lambton NSW 2305.  
Phone: 4921 4950

**What do I do if I want to take part or I have questions about the research?**

If you think you might like to participate or have any questions you wish to ask then please contact, Rachel Pitt in the way that suits you best:

Phone: 6592 9724 or mobile 0438 229 231  
Both the numbers have a messagebank  
Email: [Rachel.pitt@hnehealth.nsw.gov.au](mailto:Rachel.pitt@hnehealth.nsw.gov.au)

Post: Post the reply slip on the bottom of this sheet using the postpaid envelope supplied back to;  
Rachel Pitt  
Oncology, Manning hospital, PB Box 35, Taree, NSW

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### **Return Slip**

I am interested in taking part in the research titled: The experience of rural people in NSW with colorectal cancer requiring surgery following their investigations for cancer, through diagnosis and until surgery and am happy to be contacted by Rachel Pitt

Name:

Phone number:

Signature:

Preferred contact time/date if any:

## 2. Consent



### **The experience of rural people in NSW with colorectal cancer requiring surgery following their investigations for cancer, through diagnosis and until surgery**

I \_\_\_\_\_ (insert participant name) agree to participate in this research project.

I have read and understood the Participant Information Statement and any questions that I have about the project have been answered.

Participation will involve one face to face interview to talk about my experience following a diagnosis of cancer. This interview will be audio recorded and that I can stop the interview and/or audio recording at any time for a break or permanently.

I understand that I do not have to take part in this research project my participation is voluntary and I can withdraw from the project at any time. I understand that not taking part or withdrawing from the project will not affect my relationship with the researcher or any care that I may receive now and in the future at any hospital.

I understand that my information and interview responses will be coded so that I cannot be identified and stored securely in accordance with ethical research standards.

I understand that the data and findings from this research project may be published or used in future studies and that my information will be coded so that I cannot be identified.

Name of Participant: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date:

### 3. Semi-structured interview questions used for all participants



**Health**  
Hunter New England  
Local Health Network



**HETI**  
HEALTH EDUCATION &  
TRAINING INSTITUTE

#### Semi-structured interview questions

Thank you for consenting to talk to me today. Consent signature confirmed

I will be taping this interview with these recorders. Remember you can stop at any time you like for a break or to finish. This is absolutely fine.

There are no right answers I am just interested in what your thoughts are and you do not have to reveal any information that you do not feel comfortable in doing so.

I am interested in your story, particularly focussing on the time starting with investigations for cancer, between diagnosis and until surgery and what that was like for you.

Can I take you back to the time you started investigations for bowel cancer? Can you tell me a bit about what that was like?

Depending on what is ascertained from this question secondary prompts may be but not limited to the following:

What were the next few days like?

Were you alone or was anyone with you at the time?

When where you diagnosed?

What where the next few days like?

Who was the first person you told about your diagnosis?

Did you seek advice or support from family or friends?

What about any services (professional or volunteer).

Tell me about your choice of surgery?

Tell me about the hospital you chose?

Can you tell me what you mean by that?

Had you thought of this before you knew you had cancer?

If someone you knew called you today to say they had the same diagnosis that you did, what do you think you would tell them? Would you give them any advice based on your own experience?

Is there anything else that you would like to add before we finish? Anything missed or not covered?

## 4. Sample of coding table

Theme	Code	Definition of code	Example
Control	Accepting of fate/fatalistic	Accept that you have got cancer and that is the reality	If that's what's gonna happen that's what's gonna happen
Control Transformation	Age	Cancer is ok if you are old and unfair if you are young	I was the youngest person in there. They'd all been in there and had the same thing that day. I was the only one that got the bit of news you know.  At my age it's no big deal
Control	Cancer is common	Caner is common and a lot of people get cancer  Fatalistic?	You listen to the funeral announcements on the radio in the morning every second person's cancer.  There's that many cancer patients going to be hitting this ward there will be no room for anyone
Control	Cancer spreading	Leaving cancer untreated leads to a poorer prognosis	Get into hospital as quick as you can cos it spreads. You don't have to be a doctor to know that. If you get it today you've got more chance than even if you leave it for another month
Control	Choice of location	Why you chose where you could have treatment	He wanted me to go to Sydney. Have surgery down there. I just said no. I said my children are up here.
Control	Choice of surgeon	Whether you were given a choice of surgeon or just sent to one by the GP	He <u>sent</u> me to a surgeon  He recommended Dr x and that was it. He gave me a referral to and said it was just round the corner
Control	Coping style- not thinking about it	I cope with my cancer diagnosis by not thinking about it and getting on with my life	I didn't mope around I didn't worry me that much. I thought ok that's done now get on with the operation.
Control	Determination	Determination to recover from cancer treatment or effects as a result of cancer treatment	I'll get there. I'm determined to get there
Control	Diagnosis delay	The reasons that caused a delay in treating or diagnosing the cancer	I just put that down to stress. Just stress.  I was looking after x