

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

**QUALITATIVE DESCRIPTION OF THE ADULT PATIENT EXPERIENCE
OF CANCER-RELATED CACHEXIA (CRC): A PILOT STUDY**

A thesis presented in partial fulfilment of the requirements for the degree of

**Master of Philosophy
in
Nursing**

**MASSEY UNIVERSITY, PALMERSTON NORTH,
NEW ZEALAND**

**MARIKA JANE STUBBS
2008**

ABSTRACT

This thesis explores the experience of living with cancer-related cachexia (CRC) from the patient perspective. Critique of the literature indicates few examples where patients have had the opportunity to speak. Following a challenging recruitment process, six people living with the syndrome were interviewed to elicit their narrative. Their stories were examined and themes identified relating to their personal feelings and how these affected social interactions. Thematic analysis was applied to produce what is a rich qualitative description of the experience from this small sample.

Living with CRC requires development of strategies to survive. Emergent themes included the loss of sense of self and a changing relationship to the social world, social isolation and dissatisfaction with truth-telling by health professionals. Recommendations are made to mitigate the suffering of patients by empowering them through better information and acknowledgement of their condition. The balance between nutrition and wellbeing is re-examined, calling for a reorientation of perspective from a focus on intake towards a focus on quality of life.

This clearly falls within the nurse-as patient-advocate paradigm and the relevance and meaning of this research to the nursing profession is explored. Potential areas for further research in regards to both patient experience and nursing practice are extrapolated.

ACKNOWLEDGMENTS

The contribution of each participant was integral to the completion of this work. Their willingness to share thoughtful insights and wisdom contributed enormously to this thesis. Without their generosity, this thesis simply would not exist. I thank you all.

Thank you to my friends and family who have kept me company during this journey. I couldn't have wished for a merrier band of travellers. They provided encouragement and moral support, doled out freely and in generous portions when I needed spurring on. Their firm and consistent refusal to indulge my doubts along the way is deeply appreciated. I am especially grateful to my beautiful teenager, who refrained from playing her beloved drum kit whenever required and never complained when her mother was lost in thought. Special thanks to Neil, whose proof-reading skills were indispensable.

My enduring thanks go to my supervisor, Professor Jenny Carryer, who had enough faith in my ability and in the project to take on a true beginner. Her expectations of excellence were consistently communicated with kindness, honesty and patience. The example of academic rigour she provided is one which I will benefit from always. The time and space she trustingly granted me were artfully combined with unstinting support.

Finally, I want to express my gratitude to Dr. Vivien Lane, whose different and thoughtful way of questioning the world first inspired the researcher in me. This work has benefited from her wisdom.

CONTENTS

ABSTRACT	ii
-----------------------	----

ACKNOWLEDGEMENTS	iii
-------------------------------	-----

CHAPTER ONE: Introduction and overview

1.1 Introduction.....	1
1.2 Aims.....	1
1.3 Background to the study.....	1
1.3.1 Personal perspective informing this research.....	1
1.3.2 Relevance.....	2
1.3.3 Justification.....	3
1.4 Overview of the study.....	3
1.5 Overview of the thesis.....	4
1.6 Conclusion.....	5

CHAPTER TWO: Literature review

2.1 Introduction.....	6
2.2 Nomenclature.....	6
2.3 Incidence/impact.....	6
2.4 Aetiology.....	7
2.5 Diagnosis.....	8
2.6 Interventions.....	8
2.7 Conclusion.....	11

CHAPTER THREE: Qualitative descriptive methodology and research method

3.1 Introduction.....	13
3.2 Methodology.....	13
3.2.1 Interpretive description.....	13
3.2.2 Thematic analysis.....	14
3.3 Meaningfulness.....	15

3.4 Research method.....	16
3.4.1 Participant selection.....	16
3.4.2 Sampling and sampling technique.....	17
3.5 Ethical issues.....	17
3.5.1 Informed consent and patient right to choose.....	18
3.5.2 Confidentiality.....	18
3.5.3 Risk versus benefit.....	19
3.5.4 Exclusion criteria.....	21
3.6 Recruitment.....	22
3.7 Data collection.....	24
3.7.1 Interviews.....	24
3.7.2 Field notes.....	25
3.8 Data analysis.....	25
3.9 Conclusion.....	27

CHAPTER FOUR: The participants

4.1 Introduction.....	28
4.2 Arthur.....	28
4.3 Simon.....	28
4.4 Bill.....	29
4.5 Sally.....	29
4.6 Sherpa.....	30
4.7 Irina.....	30

CHAPTER FIVE: Embodiment and meaning

5.1 Introduction.....	31
5.2 Coming to know.....	31
5.3 Knowing in progress.....	34
5.4 Dissatisfaction with truth-telling.....	37
5.5 Conclusion.....	41

CHAPTER SIX: The social world

6.1 Introduction.....	43
6.2 Loss of sense of self.....	43

6.3 Changing relationship with food.....	47
6.4 Loss of adult status.....	52
6.5 Withdrawal from the social world.....	56
6.6 Conclusion.....	60

CHAPTER SEVEN: Discussion

7.1 Introduction.....	61
7.2 Summary of findings.....	61
7.3 Discussion.....	62
7.3.1 Adoption of the medical gaze.....	63
7.3.2 Lack of understanding about the experience.....	64
7.3.3 Conflict.....	64
7.3.4 Ethical principles.....	65
7.4 Limitations.....	67
7.5 Reflections.....	68
7.6 Recommendations.....	69
7.6.1 Research.....	69
7.6.2 Praxis.....	70
7.7 Concluding statement.....	70

REFERENCES.....	71
------------------------	-----------

APPENDICES

Appendix A: Participant information sheet.....	79
Appendix B: Consent form.....	82
Appendix C: Ethical approval	83

CHAPTER ONE: INTRODUCTION AND OVERVIEW

1.1 Introduction

Within this thesis I explore the experience of cancer-related cachexia (CRC) as recounted in interview by participants. CRC is an involuntary wasting syndrome experienced by many cancer patients. The patient experience of CRC is not well documented in the literature and therefore, nursing to date has been largely ineffective in devising interventions to ameliorate suffering. Although it will not be possible or appropriate to form generalizations from the data described within this document, this important research will inform nursing practice and therefore potentially improve quality of life for people with end-stage cancer who are physically wasting due to CRC.

1.2 Aims

The **primary aim** of this research is to produce a descriptive account of the experience of CRC from the perspective of the cachectic adult. This will allow the **secondary aims** to be met. These are, to provide direction for future nursing research into CRC and to begin producing recommendations for improved nursing practice related to CRC.

1.3 Background to the study

1.3.1 Personal perspective informing this research

As an interpretive researcher, I feel it is permissible and appropriate to write in the first person in order to explain the particular orientation I bring to this research project. During eight years as an oncology nurse specialist, I have had countless conversations with people who have CRC. Statements of helplessness and expressions of guilt for not being able to eat are not uncommon and can be compounded by the patient feeling misunderstood. Literature searches indicate that the patient voice is not clearly heard, which means that many of their needs may be unrecognized, and therefore unmet.

I have witnessed families endure frustration and conflict during the end stages of a loved ones life, in part because the patient experience of CRC is not understood. Those living with CRC appear less troubled than family about their own refusal to eat. Some cachectic people verbalize feeling pressured to eat, and guilt when they cannot. Patients have also stated that their quality of life would be improved if loved ones had a greater appreciation for the involuntary nature of CRC.

I am interested in the fact that health professionals who specialize in oncology and palliative care health do not discuss CRC with sufferers, thereby giving cachexia taboo status. When I have asked colleagues why this is, the dominant idea expressed is that to explicitly talk to the patient about the fact that they have CRC would cause undue distress because having the information would not alter the final outcome (impending death) because the only way proven to reverse the process is to successfully treat the cancer. My own experience is that when patients raised the issue of their profound, intractable weight loss, and we then talked about CRC, they often expressed relief at being heard and a desire for me as nurse-advocate to explain to family that they simply cannot help not eating normally. This has led me to question current practice. I wonder if we as nurses actually explained to patients and their families that their condition can be labeled (ie. it has a name), it is involuntary and therefore it is not their fault that this could ease guilt for the patient and ameliorate frustration and misunderstanding within the family unit.

1.3.2 Relevance

Cancer is the dominant cause of mortality in New Zealand. Since 1995, new registrations have increased by 17.3% and deaths by 7.4%. (Ministry of Health [MOH], 2008). Although these increases are significant, there is some evidence to suggest the trend is beginning to reverse. In the year 2004 to 2005, new registrations decreased by 3.2% and deaths by 2.1% (MOH, 2008), suggesting that screening programs and improved treatments may have potential to reverse this trend. Despite this, cancer remains the leading cause of death for both female and male New Zealanders and incidence over time continues to follow an upward trend. The tendency for malignancy to emerge later in life, combined with the ageing of the population ensures the consequences of cancer will continue to persist as a significant health issue.

In consideration of these facts, reducing the incidence and impact of cancer is now a government mandate throughout Australasia. The dearth of initiatives aimed at forging cohesion between historically disparate clinical policies, national agendas, highly specialized resource delivery and patient support services has been recognized. This has prompted the creation of targeted national strategies, aimed at decreasing fragmentation of service provision and improving coordination of care. The first such document, following closely behind a similar directive in Australia, is the New Zealand Cancer Control Strategy (Minister of Health, 2003). The contents describe six overarching goals which combined, are targeted towards reducing incidence, mortality and morbidity by improving service delivery across the continuum of the cancer journey, thereby improving quality of life. Another key area for action is to

address the need for increased New Zealand-based research which investigates the social, behavioral, environmental and psychological effects of cancer.

1.3.3 Justification

This project contributes to the current impetus towards mitigating the impact of cancer and will add value to the collective knowledge of health professionals. The importance of this research lies in its contribution towards achievement of the government mandates; specifically, “Goal 4: Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care” (Minister of Health, 2003, p.39).

Given that cachexia is present in up to 80% of people with advanced cancer, a considerable number of New Zealanders will experience the syndrome. Current lack of effective anti-cachexia treatment means some people may live in a cachectic state for months. Despite its prevalence, the literature has repeatedly failed to capture the patient experience of CRC (Poole & Froggatt, 2002). Studies have been undertaken to explore causes of quality-of-life deficits in cancer patients and cachexia has been implicated. Greater comprehension of the patient’s perspective may in future improve the way we educate patients and families about CRC. It is imperative we attempt to address the apparent knowledge deficit about the meaning that sufferers ascribe to CRC. It is impossible to identify unmet patient needs unless understanding of the experience is disseminated in the literature. There is a clear and present need for greater exploration.

1.4 Overview of the Study

The experience of living as a person who has cancer-related cachexia is explored and analysed using data obtained by conversational interviews with 6 participants in their narratives of daily morbidity. With direct reference to the currently available literature, it is demonstrated in chapter two that while the medical discourse has focussed on aetiology and treatment, nursing discourse has largely relied on family and caregivers to describe the experience. It is argued that sufferers are not adequately informed about CRC and this is due in part to the silence of nurses. Lack of information brings consequences for vulnerable patients as they are forced to surmount challenges for which they are unfairly unprepared. The changing appearance of the body and altered behaviour around food creates a constellation of repercussions which impact on quality of life. The challenge for nursing, if we are to practice in the holistic tradition which

we hold up as the ideal paradigm of care, is to facilitate greater discussion about CRC, both with patients and families, and within our collegial and academic discourse. .

1.5 Overview of the Thesis

This thesis is presented in 7 chapters:

Chapter One: This chapter describes the background underpinning this research with direct reference to my own personal perspective and motivations. The specific primary and secondary aims are outlined.

Chapter Two: A literature review is presented which explores both the medical and nursing discourse within which CRC currently resides. In this chapter, the gap in the literature which this research aims to partially fill is confirmed and clearly elucidated.

Chapter Three: Methodology and method are described in this chapter. I present here some arguments illustrating that qualitative description is applicable for this project and demonstrate understanding of my chosen analysis method. A full description of participant selection, the interview process and the challenges to recruitment is offered. Ethical matters particular to this project are also considered.

Chapter Four: Each of the participants is introduced. The purpose here is to acknowledge the enormous contribution each has made, despite experiencing difficult circumstances, to our collective knowledge through their generous participation.

Chapter Five: The thesis continues with the presentation of data from the interviews and field notes which are examined and deliberated upon using the framework of thematic analysis. This chapter describes the themes expressed by participants as they develop an awareness of CRC and the meaning which each then has ascribed to physical wasting.

Chapter Six: Building upon the previous chapter, presentation of data continues by illustrating the themes present in participants' expressions of the personal consequences of CRC within the social world. These are, a changing relationship with self, other people and with food.

Chapter Seven: This thesis is concluded with arguments detailing the meaning of the results and relating these to professional practice. The aims of this project are reviewed and findings are situated squarely within the nursing domain. Implications for future research are discussed and the limitations of this project are examined.

1.6 Conclusion

This chapter has briefly described the topic of this study and the genesis of the research topic. The relevance of this research and justification for undertaking this project has been provided with reference to the emerging national consciousness evidenced by recent government mandates for improving person-centred cancer care. An overview of the research has been presented and the content of the thesis chapters outlined. The following chapter gives examples of the current discourse surrounding CRC and further identifies gaps in the literature.

CHAPTER TWO: LITERATURE REVIEW

Cachexia (kə'kɛksɪə) from Greek *kakhexia*,
[*kakos* bad + *hexis* condition] (Collins Australian Dictionary, 2005).

2.1 Introduction

Amongst the complications suffered by people with cancer, cachexia is perhaps the most physically obvious, distressing and debilitating. CRC is a syndrome causing an irreversible state of starvation underpinned by gross derangement of normal metabolic processes (Wilson, 2000). This chapter reviews the current literature related to CRC and given the complex nature of the syndrome, has been organised into sections detailing particular aspects including incidence, aetiology, diagnosis, and interventions. Firstly, it is important that the nomenclature surrounding CRC be described.

2.2 Nomenclature

Cancer-related cachexia syndrome is not well understood, either in aetiology or treatment, explaining why there is no common nomenclature throughout the literature. It is referred to variously as cancer cachexia syndrome (CCS), cancer cachexia, cancer-associated cachexia (CAC), anorexia-cachexia syndrome, neoplastic cachexia, and cancer-related cachexia (Agteresch et al., 2002; August, 2003; May, Barber, D'Olympio, Hourihane, & Abumrad, 2002; Muscaritoli, Bossola, Aversa, Bellantone, & Fanelli, 2006; Pfitzenmaier et al., 2003; Vadell et al., 1998). Cachexia can also be associated with rheumatoid arthritis, chronic obstructive pulmonary disease, congestive cardiac failure and acquired immune deficiency, but whether the pathogenesis and systemic effects are identical is unclear (Morley, Thomas, & Wilson, 2006). In this thesis, the term 'cancer-related cachexia' is used with the abbreviation 'CRC'. This gives the clear indication that it is only cachexia as a direct result of cancer which is being investigated. It is recognised that an agreed definition would help standardise inclusion criterion for trials with cachectic participants (Dahele & Fearon, 2004).

2.3 Incidence/Impact

The syndrome is widely reported to be present in 80% of people with advanced cancer (Bruera et al., 2003; Laviano, Meguid, & Rossi-Fanelli, 2003; Vadell et al., 1998) and directly contributes to death (Khayat, 2000). Around 20% of cancer patients die from

cachexia rather than tumour burden (Argiles, Meising, Pallares-Trujillo, Guirao, & Lopez-Soriano, 2001). Despite its prevalence, sufferers and carers are rarely cognizant of the syndrome beyond the obvious symptoms (Poole & Froggatt, 2002).

The literature agrees that markers of cancer cachexia include anorexia, asthenia, fatigue, weight loss, muscle wasting, decrease in motor skills, metabolic disturbances and impaired immunocompetence (Brown, 2002; Khan et al., 2003). An important theme is that cancer cachexia is involuntary (August, 2003). The syndrome can occur across a range of malignancies, appearing commonly in solid tumours originating in the gastrointestinal tract (GIT), pancreas, lung and prostate (Argiles et al., 2001) and with less frequency in breast, lymphoma and haematologic cancers (Damsky Dell, 2002; Nitenberg & Raynard, 2000). Patients with head and neck cancer are at the greatest risk for cachexia-induced malnutrition (Lees, 1999). Although cachexia results in body wasting and gross malnutrition, it is viewed very differently in the literature from the 'self-induced' starvation of anorexia nervosa. This is borne out by the fact that it does not appear at all in the *International Journal of Eating Disorders*, nor is discussion of this phenomenon clearly evident in *Psycho-Oncology* publications.

2.4 Aetiology

Historically, dogma surrounding aetiology has been that the tumour exerts parasitic effects upon the 'host' (Bruera & Sweeney, 2000). Currently, aetiology is divided into three categories, which are not mutually exclusive. These are: suboptimal food intake; metabolic derangement; and cytokine production by tumour and patient tissue (August, 2003). Several cytokines, chiefly tumour necrosis factor (TNF), interleukin 1 (IL-1), IL-6 and IL-8 have long been implicated (Pfitzenmaier et al., 2003).

Controlled experimentation has recently shown, at least in prostate cancer, that serum levels of TNF α and IL-8 are much higher in those with cachexia than those without, and that neither chemotherapy nor radiotherapy causes increase in cytokine levels (Pfitzenmaier et al., 2003). Serum levels of TNF have also been shown in controlled experimentation to correlate with severity of weight loss in people with GIT cancer. This adds weight to the hypothesis that cytokines at least in part are to blame for the syndrome (Bossola et al., 2000).

An emerging theory is that anorexia and fatigue (both fundamental aspects of the CRC syndrome) could in part be caused by a chronic stress response indicated by elevated endogenous cortisol levels (Lundstrom & Furst, 2003). Resting energy expenditure (REE) has been found to be increased in the majority of cancer patients. The expected

response to this would be to increase dietary intake which does not happen in advanced cancer patients (Bosaeus, Daneryd, Svanberg, & Lundholm, 2001; Langstein & Norton, 1991)

2.5 Diagnosis

There are no specific universally accepted criteria for the diagnosis of CRC. Most clinicians simply rely on body weight and physical appearance (Kotler, 2000). Testing of prealbumin, albumin, ferritin and other trace elements has been noted as useful because they are reliable indicators of overall nutritional status (Whitman, 2000). The work of Pfitzenmaier et al., (2003) indicates there may one day be a definitive blood test for cytokine levels which can be used to definitively diagnose the syndrome. Using a 3-factor profile of weight loss, reduced food intake and systemic inflammation measurements is now thought to be useful (Fearon, Voss, & Hustead, 2006). Visual analogue scales have been used to detect appetite changes but the validity of such tools is doubtful when appetite changes are only small (Laviano et al., 2003)

2.6 Interventions

Although anorexia is a hallmark of the disorder, it is not the cause. If it was, aggressive renutrition would reverse the process and this is not the case. Studies assessing enteral and parenteral feeding have shown no survival benefit (Bruera & Neumann, 1998; Nitenberg & Raynard, 2000; Mirhosseini, Fainsinger, & Baracos, 2005).

The only pharmaceutical agent proven effective in clinical trials at causing weight gain is megestrol acetate (Vadell et al., 1998; Winkler, 2004). Some believe that although appetite improves with this treatment, there is no subsequent improvement in overall quality of life (Jatoi, Kumar, Jeff, & Nguyen, 2000). Others state quality of life improves, although this does not translate into improved functional status (Vadell et al., 1998). Treatment with appetite stimulants can ameliorate weight loss but this is due to fat gain rather than appreciable increase in functional muscle mass (Bruera & Neumann, 1998; Nitenberg & Raynard, 2000). Corticosteroids are often prescribed to increase appetite, energy levels or to reduce nausea. Whilst shown to have some clinical benefits, these are typically short-lived, lasting up to 4 weeks and the side effects can be prohibitive (Lundstrom & Furst, 2003). Since it is recognised that caloric supplementation has little or no impact on the trajectory of cancer cachexia (Pfitzenmaier et al., 2003) the rationale for increasing intake is not sound.

Some treatments are aimed at inhibiting the action of the cytokines which are thought to be partly responsible for CRC. Medroxyprogesterone acetate (MPA), used in the palliative stages of cancer to treat cachexia, has been found to inhibit TNF, IL-1 and IL-6 (Lundstrom & Furst, 2003). Thalidomide also inhibits TNF production and has been shown to reverse loss of both weight and lean body mass (Khan et al., 2003). These results are not conclusive as the study sample was small and no control or blinding was employed. Some pre-clinical experimentation has been done using erythropoietin to ameliorate anaemia (which is often implicated in cachexia) and it has been found that this also decreases IL-6 levels (Kanzaki, Soda, Gin, Kai, Konishi, & Kawakami, 2005). Dronabinol, a marijuana derivative, has been shown to increase appetite and mood in cachectic AIDS patients (Beal et al., 1995) but has not shown efficacy in cancer patients (May et al., 2002).

The term 'nutriceuticals' began to appear in literature over the last seven years and refers to food nutrients which appear to have specific effect upon tumour and host tissues (August, 2003). The nutrients so far studied in this context are the amino acids glutamine and arginine, nucleic acids and essential fatty acids (Heys, Walker, Smith, & Eremin, 1999; May et al., 2002). Despite uncontrolled trials showing promising results (Barber, Ross, Voss, Tisdale, & Fearon, 1999), a randomised, double-blind, placebo-controlled trial has shown that daily supplementation of fish oil (eicosapentaenoic acid) did not positively influence appetite, nutritional status or quality of life in cachectic cancer patients. Additionally, the treatment is not well tolerated (Bruera et al., 2003). Fish oil continues to be investigated but to date does not show a significant anti-cachectic effect (Persson, Glimelius, Rönnelid, & Nygren, 2005). A randomised, controlled, stratified clinical trial has shown that infusion with adenosine 5-triphosphate (ATP) inhibits weight loss and helps maintain lean muscle mass in cachectic patients with non small cell lung cancer (NSCLC) (Agteresch et al., 2002).

It is worth noting here that many clinical trials for anti-cachexia drugs exclude patients who are receiving anti-neoplastic therapy as otherwise it is too problematic to attribute results (usually weight gain or improved functional status) specifically to the anti-cachexia treatment. This is of some import as those who are cachectic but not receiving cancer treatment may have already exhausted treatment options or be too unwell to weather a treatment regimen. The result is that CRC treatments tend to be investigated at a late stage in the natural history of the syndrome and participants often have high morbidity levels and reduced functional status. It would be of interest to discover whether some of the anti-cachexia treatments investigated to date showed a potentiated effect if used together with cancer treatment.

Researchers advocate counselling, nutritional education and practical advice such as eating small, frequent meals (to cope with early satiety) and using plastic utensils to ameliorate dysgeusia (taste alterations) – a side effect of some chemotherapeutic agents (August, 2003; Whitman, 2000). Progressive resistance training has been employed to help prevent loss of muscle tissues and has been studied in AIDS-related cachexia (Evans, Roubenoff, & Shevitz, 1998). Recent investigations indicate that progressive resistance training may attenuate the skeletal muscle wasting seen in CRC and positively affect quality of life although there are challenges to initiating this therapy with a cachectic cancer patient who has end-stage disease (Hemming & Maher, 2005; Al-Majid, 2008). The importance of early identification of nutritional shortfalls is important and the nurse as patient advocate is a recurring theme (Finley, 2000). Family and patient benefit from the knowledge that neither is to blame when a patient does not desire food (Finley, 2000).

Caregivers want more information about intake cessation before intake completely stops (Cope, 2002). Assisting carers to understand cachexia to be a natural, common and unavoidable progression of morbidity may alleviate conflict around food. Some patients eat only to please their loved ones (Sutton, Demark-Wahnefried, & Clipp, 2003). Caregivers have said that what they need most is understandable information in a timely fashion (Levine, 1999). Wilson (2000) sees the word cancer as an acronym to guide nutritional interventions: Conversation, nutritional Assessment, introduction of a Nutritional plan, recognition of Complications arising from nutritional support, Evaluation of a patient response, Reassurance for patients and carers (p.24).

In many cultures, patients are reported to become isolated from the normal social activities which occur around the act of eating. This may be compounded by depression and anxiety accompanying altered body image (Holder, 2003). The impact on family and social roles is complex. Patients and families of dying patients believe that a person's strength is under his or her own control and not eating enough can be interpreted as not trying hard enough to get well (Ferris, von Guten, & Emanuel, 2002).

Signs and symptoms which are associated with high levels of stress include poor physical functioning, reduced appetite, reduced functional status, fatigue, altered physical appearance and reduced social relationships (Higginson & Winget, 1996). These are all implicated in cachexia and therefore the psychological and social ramifications are potentially enormous.

By definition, end-of-life care takes place over a restricted period of time and therefore, patients and carers need a practical understanding of issues surrounding cachexia long

before they arise (Cimino, 2003). In their observational study on the psychosocial needs of cancer patients, McIllMurray et al., (2001), found 51% of respondents wanted more support in dealing with changes in body appearance and 39% of respondents felt they needed advice about food and diet.

Holden (1991) was one of the first to explore the experience of CRC from the patient perspective, finding some evidence to suggest that sufferers are less troubled than family members about lack of nutritional intake. However, Holden's (1991) results are not patient focused, and results describing family perceptions are incorporated in preference to the patient voice. In the introduction to a later PhD, McClement (2001) referenced Holden (1991) heavily, emphasising that the patient experience of the phenomenon had not been comprehensively described in the intervening 10 years. Using qualitative interviews with patient, family and caregivers, McClement (2001) developed theory to describe ways in which family members balanced patient needs while meeting their own needs, in relation to provision of nutritional care. The focus remained on describing the feelings of family, and care-givers, with the patient experience not distinctly described. Recognising that care givers have been used as proxies for patients in describing CRC-associated distress motivated Hopkinson, Wright, McDonald and Corner (2006) to qualitatively examine the prevalence of concern about weight loss in advanced cancer sufferers. Predictably, findings included that concerns around eating are commonly experienced and require further research.

A recent, small, exploratory study has begun to fill the space in current literature. Hinsley and Hughes (2007) have probed the CRC experience directly, by recruiting twelve participants who were living with the syndrome. Each took part in a face-to-face, minimally structured interview. It was reported that feelings of being 'different', with regards to appearance, culminated in social isolation. Despite attempting to adapt to living in the cachectic state, there came a time when participants could no longer continue readapting and expressed feelings of having become subsumed by emaciation. This study articulated the need for psychological support for people with CRC and identified that education strategies may be a key component of preventing relationship malfunction between the patient and family members. To date, exploration of the CRC experience from the first-person point of view is limited (Hinsley & Hughes, 2007) and further qualitative research is required.

2.7 Conclusion

This chapter has identified the information through which current understanding of CRC has been constructed. The syndrome is not fully understood from a bio-medical

perspective nor, more importantly for nurses, from the patient perspective. The main reason for this is that family and care givers have often been used as proxies for information, resulting in a paucity of the patient voice. The reason for this is unclear. My conjecture is that it may be due to the ethical considerations inherent in using palliative populations as informants. These considerations are challenging and the high morbidity states typically seen in people living with CRC necessitate a particularly thoughtful approach to the conduct of research. It is also difficult to transparently investigate the experience of this syndrome with patients unless they are first informed that they in fact do have CRC and reluctance to divulge this has obstructed research. The result for nursing is that we have only brief glimpses into some aspects of the CRC experience. This makes it impossible for nurses who are located within a holistic framework of care delivery to adequately meet the needs of sufferers. Literature describing nurse-led, patient-focussed initiatives to ameliorate suffering within the context of CRC is scant and this must in part be related to the fact that the literature does not comprehensively contain the patient narrative. Therefore, it must be accepted that myriad unanswered questions related to CRC continue to hamper the provision of adequate support.

CHAPTER THREE: QUALITATIVE DESCRIPTIVE METHODOLOGY AND RESEARCH METHOD

3.1 Introduction

In the previous chapter I discussed the literature as it currently relates to the existing description of cancer-related cachexia (CRC). Much of this is expressed from a bio-medical perspective and the ontology has developed within a traditional scientific construct. Whilst helpful, this approach has gone only a small way toward understanding the CRC experience from the patient point of view.

In this chapter I discuss the qualitative descriptive methodology which underpins this research. Thematic analysis, the method of data analysis for this project, is then described, including the way in which it has been utilised in this study. Principles inherent in ethical research and the way in which these relate to this project will be elucidated.

3.2 Methodology

A qualitative descriptive (interpretive description) design has been applied to this project. Owning a post-positivist perspective on research requires rejection of any single theoretical stance or “fixed and final discovery of truth” (Corner, 1996, p. 202). A qualitative paradigm is especially suited to nursing investigations which aim to deepen understanding of the way in which participants (informants) experience some aspect of health and illness and requires the researcher to approach the study with a commitment to the participants’ point of view (Gillis & Jackson, 2002). Exploration of these processes within a qualitative paradigm provides critical insights into and understanding of, the CRC experience and therefore will help identify the needs of participants. Such insights could not be gleaned from reliance on quantitative approaches (Gillis & Jackson, 2002). Investigation of the human experience of a complex phenomenon about which there is a paucity of literature dictates that this project is best approached from the qualitative paradigm.

3.2.1 Interpretive description

Qualitative description demands of the researcher no commitment to one particular philosophical standpoint. That is, the researcher chooses to present the facts describing

the phenomenon in everyday language whilst resisting the opportunity to put their own interpretive spin on what they hear but this is tempered by the notion that all description necessarily entails meaningful interpretation (Sandelowski, 2000). Therefore, given that there is currently no definitive description of the experience of CRC in literature, interpretive description is a justified methodological framework. While some call this a non-categorical approach (Thorne, Kirkham, & MacDonald-Eames, 1997), Sandelowski (2000) deems it a categorical approach in its own right. Interpretive description is founded in the smaller scale inquiry of an experience for the purpose of generating a description which has the ability to inform clinical understanding (Thorne, Kirkham & O’Flynn-Magee, 2004). Viewed from a professional nursing perspective, implicit within the notion of informing clinical understanding is using this new understanding to inform patient care, which is a secondary aim of this research. Qualitative description is not about generating new truth, but describing cogently and making sense of, the truth that already exists within the experience of CRC. It has been applied to several studies describing cancer experiences including receiving external beam radiotherapy (Hedestig, Sandman, Tomic, & Widmark, 2005a), living after radical prostatectomy (Hedestig, Sandman, Tomic, Radisa, & Anders, 2005b) and notably, an exploration of body image and cachexia (Hinsley & Hughes, 2007). This research is approached from an interpretive orientation, using thematic analysis to interpret participants’ raw, rich textual data.

2.2.2 Thematic analysis

Thematic analysis is seen as a method foundational to qualitative research which has relevance spanning a range of theoretical and epistemological approaches. Braun and Clarke (2006) argue that it is this very theoretical freedom which allows flexibility in its application and is a strength of the method. It is a form of pattern recognition within the data, where themes become categories for analysis (Fereday & Muir-Cochrane, 2006). Like any analysis process, the skills required must be learned. Boyatzis (1998) describes four stages required to develop thematic analysis skills. Initially, the researcher must be able to sense themes; that is, the ability to recognise a “codable moment” (p. 9). The second stage denotes being able to recognise codable moments consistently and therefore, reliably. Thirdly, the researcher must develop a code to analyse or “capture the essence of their observations” (p.11). The final stage is interpreting the themes and in doing so, contributing to knowledge. This implies that some knowledge relevant to the area of study is a crucial foundation to making sense of patterns to produce and interpret each theme. Boyatzis calls this “tacit knowledge” (p. 8).

Thorne, Kirkham and MacDonald-Eames (1997) recommend an inductive analysis strategy in preference to a deductive strategy when the aim is to produce a qualitative description. Thematic analysis can be applied in either of these ways, or by using a hybrid approach, combining both (Fereday & Muir-Cochrane, 2006). An inductive approach requires the researcher to categorise data “without trying to fit it into a pre-existing coding frame” (Braun & Clarke, 2006, p.83). This necessitates approaching data with an open mind and thereby supporting the emergence of any themes living within the participants’ statements. A phenomenologist would denote this as ‘bracketing’. In contrast, the deductive approach is more theoretical and is particularly useful when seeking to answer a specific research question (Braun & Clarke, 2006). This means approaching the data with preconceived ideas about what to look for. Given the dearth of literature describing the CRC experience (as noted in chapter two), participants’ data was analysed using an inductive thematic analysis approach informed by Burnard (1991). This seemed the most reasonable way of analysing text generated from unstructured interviews about an under-researched phenomenon. My approach is grounded in an interpretive orientation that acknowledges the individual nature of the illness experience, yet also allows for shared realities. The data, rather than my own theoretical position, generated the resultant themes.

Analysis began immediately after the first interview, using the iterative mode - necessitating returning repeatedly to the data as interviews progressed to discover emerging issues or gaps which could be further developed and filled (Grbich, 2004). Throughout this thesis I refer to themes as ‘emerging’. This is not meant to imply that the process was passive as themes did not simply organically emerge. Rather, I experienced the extraction and development of themes as an active and challenging intellectual process.

3.3 Meaningfulness

Meaningfulness (or validity) is fundamental to ethical research. This is difficult to define when using qualitative methods. Part of proving rigour in qualitative description involves ensuring transparency. That is, making “complexities visible throughout the analytical process” and articulating these complexities in a way which openly recognises “a certain tentativeness about the final research outcomes” (Thorne et al., 2004, p.170).

Given the expected morbidity level of participants, this research project is deliberately not longitudinal in design and therefore, offering participants the opportunity to verify transcripts was considered, and then discounted. Field notes were generated to help

counter over-reliance on textual data alone and review of the literature was ongoing prospectively throughout this study.

There are various research paradigms and none has a monopoly on quality (Peshkin, 1993). However, interpretive description presents challenges to the clear description of validity. Traditional ‘goodness’ in research was defined within an empiric epistemology which cannot consistently be applied to qualitative research. Herein lies the challenge for naturalistic inquirers. We must express reliability in a different way from the hegemonic empirical framework. For example, Beck (1993) talks about credibility, fittingness and auditability. Other forms of accountability are noted as the moral imperative, moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness and probable truth. Emden and Sandelowski (1998) call these things ‘the criteria of goodness’ (p. 206). These are all different ways of saying the same thing. That is, I (as the researcher) need to clearly elucidate what is being done and this must correspond with what is actually being done. Furthermore, what is being done must be morally and ethically defensible.

The validity of this research is demonstrated in several ways. In chapter one I made explicit the personal perspective from which this research is approached, thereby acknowledging the influence which my place in the world necessarily exerts upon the qualitative research process (Rose & Webb, 1998). Throughout this chapter, I offer an honest and open representation of the recruitment challenges, data collection and analysis process. The ‘goodness’ of this research lies in the perceived trustworthiness of the processes and the resulting thesis. Ultimately, the desired outcome is that meaningfulness will be apparent due to people familiar with this field recognising truth in the outcomes and perceiving this as a credible piece of work.

3.4 Research method

3.4.1 Participant selection

Eligible participants were adult cancer patients experiencing a state of cachexia related to malignant processes and who were accessing health services at any one of the three approved recruitment sites. For this research, ‘adult’ was defined as being aged 18 years or older. As described in chapter two, there are no universally accepted criteria for diagnosis of CRC. Clinicians traditionally rely on body weight and physical appearance as diagnostic tools (Kotler, 2000). People with CRC were those deemed to be cachectic in the clinical opinion of a member of their clinical treatment team.

Participants were required to provide written informed consent and have unimpaired vocal function.

As there were criteria for inclusion, so there were necessarily criteria for exclusion. These were people with a known cognitive impairment (eg, unstable brain metastases), non-English speakers or active participants in a clinical trial. The ethical implications of each exclusion criterion are addressed in section 3.5.4 of this thesis.

3.4.2 Sampling and sampling technique

The number of participants for qualitative research is dictated by data saturation and sample sizes typically include 5 – 50 people (Streubert Speziale, 2003). The original recruitment target was 6 – 9 participants. Six participants were purposively sampled, then interviewed by me. The achievement of data saturation, whereby sampling continues until no new information occurs, was considered unlikely for two reasons. Each participant chose one interview as opposed to several shorter exchanges, meaning that subsequent approaches for the purposes of further exploration or clarification of meaning were not attempted. Additionally, recruitment challenges (comprehensively described in section 3.6) led to only a small number of patients participating.

It is posited however, that in qualitative research, true data saturation is a myth and that if saturation does occur, this can only be relevant to a particular sample at a particular time (Morse, 1989). Participants were experiencing the phenomenon of interest (CRC) and volunteered to take part, indicating willingness to talk. These are what Morse (2007) terms “qualities of a good informant” (p.530). Ultimately, though small in number, participants were ‘good informants’.

Only people suffering cancer-related cachexia can provide first-hand accounts of the experience and the meanings attributed to it. However it must be noted that one limitation of a purposive sampling technique is that results may lack generalisability (Llewellyn, Sullivan, & Minichello, 2004). Given that it would be inappropriate to try to generalise findings from this small project anyway, this was not deemed to be a problem.

3.5 Ethical issues

Prior to commencing this project the research proposal and associated documentation was submitted to the Central Regional Ethics Committee and approved after minor changes which did not affect the research design. The ethics committee has been

furnished with the required annual progress report and a final report will also be provided. Formal locality approval was granted by Chief Executive Officers from each institution where participant recruitment occurred. As a matter of courtesy, the Regional Cancer Treatment Services Research and Protocol Committee were also informed and indicated full support for the project. As with all reputable research involving humans, the core principles governing conduct (World Medical Association, 1996) were adhered to and these are now identified and discussed.

3.5.1 Informed consent and patient right to choose.

Participants were given as much time as they needed to consider the written information at home. This varied from two days to two weeks. I followed up by telephone to answer any initial questions they had and interview times were then arranged. I explained at this time that I would arrive with a consent form which would require their signature before proceeding. In each case, the scheduled interview was the first time the participants and I actually met. I explained that the participant could ask for the interview to be terminated at any time and that this would not have any impact upon their medical or nursing treatment. The consent form was signed by the participant in front of me prior to turning on recording devices.

3.5.2 Confidentiality

Confidentiality was protected in several ways. At the end of each interview, each participant was invited to choose their own pseudonym to be used from that point forward during the transcription. This was done after the recording devices had been switched off, so that the pseudonym could not be linked to the recording. A confidentiality agreement had been prepared and approved by the Central Regional Ethics Committee to be used if professional transcription services were required. This was not utilised due to the fact that I undertook the transcriptions. Identifying features were removed from transcripts as they were developed. Tapes and transcripts were stored in a locked filing cabinet in a secure office during analysis. After completion and acceptance of this thesis, hard data (tapes, transcripts and signed consent forms) will be held in secure archives at Massey University for ten years, in accordance with the Central Regional Ethics Committee requirements. Electronic data including audio files of interviews were stored on a password-protected computer to which only I had access and after completion and acceptance of this thesis, these will be deleted.

3.5.3 Risk versus benefit

Ethical issues surrounding the legitimacy of interviewing the terminally ill require discussion. Many (although not all) CRC sufferers are in the palliative stage of their disease. The issue of whether or not it is ethical to conduct research within the palliative population has been debated. The absolutist view is that no research using palliative patients is morally justifiable (de Raeve, 1994) and could be considered “an affront to the dignity of those people...and an expression of profound disrespect for the emotional and physical state of such patients” (p. 301). I disagree, as implicit with this statement is the astonishing idea that these patients do not warrant ongoing commitment to the improvement of their care. Like Bruera (1994) and Raudonis (1992), my approach is that it is in fact scientifically inappropriate, ethically wrong and overly paternalistic to deny this population the opportunity to contribute to research. Corner refers to these arguments as “the degree of morality” (1996, p. 203). I argue that the nursing profession must be motivated to provide best quality care and so research in partnership with palliative-stage patients is a moral imperative. This is supported by Arraf, Cox and Oberle (2004) who argue that “research is essential to advance knowledge about this population” and “to improve care that individuals receive while potentially preparing for their own death” (p. 600).

During each consenting process and interview, I occasionally felt uncomfortable with the fact that participants were contributing to research that is partly constructed in order for me to gain a masters degree. This has given me the sense that I am using participants for my own gain. Pure altruism motivated each interviewee to contribute their time and emotions whereas the same cannot reasonably be said of my involvement. Many times I have privately wondered if they thought about this. Although none of the participants gave me any hint of what they felt in this regard, one particular piece of research has helped me feel slightly less unnerved about this.

Barnett (2001) interviewed 109 advanced cancer patients in their own homes regarding experiences of medical care and subsequently sought feedback from subjects about the interview process. Interview duration varied from 30 – 83 minutes and the majority of subjects found the length of interview to be acceptable. Many stated that they valued the opportunity to express their feelings about the disease experience, with 66% glad to have taken part, while 34% had no strong feelings either way. None expressed regret at having participated. Thus, the interview was considered to be a “positive or neutral experience by all respondents” (p. 158). Interestingly, subjects perceived the clinical background of the interviewer as particularly relevant. Participants found it comforting to be interviewed by someone with a solid clinical understanding of advanced cancer.

This does have the potential to cause role conflict for the researcher as they navigate the path between impartial researcher and cancer clinician.

Members of this vulnerable population may feel obliged to consent if the researcher is involved in their care delivery. Thus, for this study, the roles of nurse researcher and clinician were separated completely. Although employed on a casual basis by one of the hospitals which was a recruitment site, I had no prior contact with or knowledge of any of the participants.

In-depth interviews can be emotionally draining and it was imperative that risk for participants was mitigated. Through each interaction, I maintained alertness to verbal and non-verbal cues which signalled tiredness, distress and increasing emotional fatigue. The skills I have developed through years of experience in talking with cancer patients about a whole constellation of topics (including prognosis, fear of mortality and body image) were conscientiously applied.

Regardless of whether distress was identified or not, participants were reminded several times during the interview that the process was voluntary and therefore, may cease at any time. Patients were assured that cessation of the interview would have no negative consequences for the quality of their ongoing care or damage their relationship with their therapeutic team. A statement of this fact also appeared in the Participant Information Form (PIF). de Raeve (1994) would agree with this strategy, as the caveat she offers for allowing interviews in the palliative population is when the decision is made to suspend research entirely when a participant is deemed too distressed to continue. No one asked for their interview to be ceased or postponed. Anecdotally, the participants in this study made positive statements at the end of our interviews. All stated that they valued the process, felt comfortable and each quite clearly indicated that they felt the subject was important to research. I was left in no doubt about the desire of each participant; that their contribution might in time, assist other people with cancer and CRC.

If a participant became emotionally upset, a referral to counselling or pastoral services was offered; none felt they needed to take advantage of these services. It must be remembered, however, that crying is a normal human response to feelings of grief and is entirely expected. Simple acknowledgement by the researcher of patient distress is, in itself, thought to be therapeutic (Barnett, 2001; Dean & McClement, 2002). One participant became visibly tearful during interview while she was discussing the subject of dying. When I offered to turn off the tape, she refused and stated that she wished to continue. She did not want to be referred to counselling services. It is also

recognized that while this population is unlikely to reap direct health benefits from research participation, some participants report that they appreciate and value the attention and opportunity to be heard (Dean & McClement, 2002).

It is possible that family members may at some point in the future request tapes, especially if the participant has since died and the grieving process leads to wanting to hear the participant's voice. During the approval process, the Central Regional Ethics Committee did identify the potential for this situation to arise and recommended that I give thought to how this might best be managed. I approached this in the following way. As each interview began, I explained the reason for two tape recorders – one for digital recording for use during transcription and one to produce a traditional tape for the participant if they requested it. At the conclusion of each interview, I offered the tape to each participant, none of whom wanted possession. Therefore, I have not received consent from any participant to enable me to release recordings. As all participants had talked about family members, I feel they declined access to their recordings out of the same concern that I have relating to the potential inability to control access to it as their physical condition deteriorates.

3.5.4 Exclusion criteria

The decision to exclude non-English speakers is another ethical problem. It could be reasonably argued that denying participation based on English-speaking ability is, in principle, inequitable and unethical. However, the provincial area in which this study was undertaken does not have a formal medical interpreter service. This results in bilingual family members often being used to navigate communication barriers on behalf of patients. To allow such a scenario to develop for the sake of gaining data for this project would have been fundamentally ethically wrong when considering participant safety and privacy. Accordingly, this exclusion is justified on the grounds of participant safety and feasibility. This project is small and in part, aims to provide future research direction. It is anticipated that further research resulting from this project will include larger sample sizes and allow for non-English speaking participants.

Over-burdening vulnerable patients is to be avoided. Patients already enrolled in a clinical trial and those with a known cognitive impairment were excluded from participation for this reason. In this way, the most vulnerable members of this population were deliberately excluded.

3.6 Recruitment

Recruitment for this study was originally envisaged as occurring over three months. Inability to meet recruitment targets is a potential risk for any researcher, and the recruitment time frame was extended by a further six months as challenges to recruitment became evident.

Initially, I visited two local hospitals providing oncology treatment services and presented my proposal to oncologists. Despite an encouraging response, no referrals were subsequently forthcoming. I also formally met with the oncology nurses and each nurse was provided with a folder containing an abstract, inclusion/exclusion criteria and several participant information forms (PIF). The response was positive, with all agreeing to identify potential participants and offer them a PIF on my behalf. Patients could then contact me if they had interest in participating. The first participant was recruited within one day of my visit. Three months passed with no more participants. I initiated regular telephone contact with the nurses I had identified as holding key positions of influence and with an oncology dietician to give them regular reminders about the study. It was paramount to keep the project in their consciousness as I was not present on site to identify potential participants or offer participant information forms myself. During almost every one of these conversations I heard statements to the effect of ‘I had someone who would have been ideal, but they are not very well so I didn’t give them the information’. It is unlikely that someone with cachexia could ever be considered well and being ‘well’ was not an entry criterion. Although the majority of these patients would be considered obviously *unwell* with CRC, most were seen in the outpatient setting and so were still ambulant, verbal and actively living. This type of exclusion was freely voiced by most of the nurses and the dietician. Worryingly, no one who admitted to this type of participant vetting appeared to understand or have insight into the ethical implications of denying a cognitively intact adult patient the opportunity to read the information and make an autonomous choice based on this. If a larger study of this type was to be conducted, this would pose a significant problem as bias would be introduced, compounded by the random exclusion which I have seen result when clinical workloads are heavy.

With the benefit of hindsight, which is often stunningly clear, the definition of CRC used for this study also impacted negatively on recruitment. As shown in chapter two, there is no consensus about diagnostic tools (or even an agreed definition) of CRC. For this reason, inclusion criterion simply stated that the participant had to have been diagnosed with CRC by their treating clinician. In practice, this means that someone needs to *appear* to be wasting based on clinical opinion. After some discussion with

clinicians and the oncology dietician about the lack of referrals, it became apparent that although the tradition in oncology is to decide someone is cachectic based on clinical presentation, when this method is applied to research, the key recruiters tended to back away and were reluctant to commit to the label. It is recognised that the lack of rules around diagnosis continues to impact on recruitment for studies with people who have CRC (Dahele & Fearon, 2004). If I had chosen to apply some of the suggested formal diagnostic techniques to the inclusion criteria (including serum TNF, skin fold measurement, systemic inflammatory markers, serum albumin, ferritin) this would have been well outside the bounds of normal intervention in most cases in this country. This would have directly resulted in sizeable problems in obtaining ethical approval and access to resources.

Initially, I had deliberately excluded NZ hospice as a recruitment site for the following reason; I was concerned that the issues of living with CRC could become confused with what it is like to be dying, and I suspected that these were two very different experiences. However, the problem of slow recruitment took over from these doubts and I formally approached two hospices to consider joining the project as recruitment sites. One local hospice did agree and eventually provided participants. The other hospice declined and two main reasons for this were given. Firstly, that the clinical work load did not allow for the PIF to be given to potential participants. Secondly, that the research proposal was written with the focus on cancer patients and that people accessing their service were palliative care patients. These arguments are intriguing. The largest group to access hospice services in this country consists of people who have cancer (although admissions related to other end-stage conditions is growing) and there was never any suggestion within this research project that patients without cancer would ever be approached to consider participation. I assume that this unfortunately pedantic use of semantics concealed another, more plausible explanation.

Recruitment was open for nine months, six months longer than anticipated. Clinicians identified fourteen potential participants during that time and they were referred to me. One person who was given the PIF died whilst considering participation. One person gave verbal consent over the telephone and requested a postponement immediately prior to the interview. Subsequently, they declined to take part. Four stated they were 'not feeling up to it'. One stated that research is 'not my cup of tea' and one did not identify themselves as having CRC. Ultimately, 6 participants provided written informed consent and were interviewed by me.

3.7 Data collection

3.7.1 Interviews

My interviewing technique was influenced by Bernard (2006) who believes there is nothing informal about unstructured interviewing and both parties - interviewer and interviewee - know what they are doing and there is no shared feeling that either is engaged in just pleasant chit chat. As the interviewer, I defined the focus, while the participants determined the content.

The interviews did resemble two-way discussions and I initiated each one with a statement like 'There are some things I really want to know so to get us started, could I ask you a couple of questions and we'll let the interview move along from there'. This approach was well received by all participants and I believe it reduced the pressure on them during the initial stages of interview. It is recognized that allowing patients to discuss things completely unrelated to the purpose of the interview may have therapeutic value for the participant (Minichello, Madison, Hays, & Parmenter, 2004). Although, this was by no means the primary aim of this project, I did remain sensitive to other topics. McClement (2001) speaks of abandoning the interview guide to allow patients to explore and express thoughts as needed and then returning to the guided interview questions. Dean & McClement (2002) agree, stating that the researcher does need to accept that to postpone adherence to the research agenda in favour of responding with sensitivity and compassion to emotional distress is appropriate practice. All participants remained quite focused and when we deviated from the research topic during our conversations, the detours were short and there was no difficulty in spontaneously returning to the main topic.

It is known that cachexia causes conflict between family members and patients (Ferris, von Gluten, & Emmanuel, 2002; Hughes & Neal, 2000) and I perceived family presence at interview as a potential risk to the validity of data. The immediate presence of relatives or carers may serve to temper what the participant is willing to say. I also wanted to avoid having relatives answer on behalf of subjects. For these reasons, relatives' presence was not preferable, but deference to participants' wishes in this regard took precedence. Interviewing in the home may help allay relatives' concerns for patient safety because they may remain close by if required, but not present in the room. Each participant chose the time and place for interview. Four participants were interviewed in their own homes, with at least one family member nearby. One interview took place in a quiet room near my office and one was conducted in a coffee shop at the participant's specific request.

Data was collected using two recorders. A digital recorder was used to aid later transcription in addition to a traditional tape recorder. This was used so that tapes could be put aside in the event that a participant requested to have a copy. I honestly hoped that participants would not request their tapes, as I had reservations about whether or not they might be able to autonomously and effectively control access to them as their disease progressed. None of the participants requested access to or possession of their tape at any time.

I was cognizant of the fact that I held assumptions about the patient experience of CRC and did look for confirmation of these during interview. While these assumptions did at times guide the interviews, I was extremely conscious of being open to new information that was not consistent with my previous anecdotal experience of talking to CRC sufferers.

Attrition is a natural consequence of engaging in research work with palliative stage patients (Dean & McClement, 2002). In end stage disease, symptoms including cachexia can accelerate rapidly. Participants were all offered the opportunity to have one interview of about one hour, or several shorter exchanges. All chose to be interviewed only once, and therefore natural attrition did not become a problem. Also related to the morbidity level of participants, I chose not to offer transcripts to them for validation purposes. My concerns were that I did not want to burden someone whose condition might have progressed rapidly, nor, as previously stated, did I want the situation to arise where a participant had possession of data which they no longer had the ability to independently control access to.

3.7.2 Field notes

Immediately after each interview, I created field notes to supplement the raw interview data. These are textual translations of my feelings and impressions about each interview, each participant and the interview process we experienced together. The field notes include a description of the setting and interactions which were not recorded where these were felt to be potentially relevant to the research topic.

3.8 Data analysis

Each interview was transcribed verbatim by me. I listened to each recording immediately after interview. The initial transcription for each one was quite rough as I skipped over words which were not clear. I would then repeat this process whilst listening and reading the transcript concurrently, filling in the gaps. This meant each

transcript was the result of multiple drafts. During this time, the question of detail arose. Each transcript could have loose or tight coherence with the recording. There is much debate regarding transcription methods (Rapley, 2007; Silverman, 1998). I felt tight coherence was important out of respect for the informants and that my moral obligation to them dictated that I take every care in transcribing their words. I investigated the Jeffersonian transcribing conventions which require the insertion of symbols to denote pauses of different lengths, voice inflections and syllabic emphasis (Jefferson, 2004). Transcripts began to appear extremely technical and data became, for me, less accessible. This seemed to negate the previous argument. Whilst this method might be important to apply in phenomenological research, I moved away from it and settled upon a flexible version of Poland's (2002) method which suited interpretive description and thematic analysis well. This enabled me to continue transcribing verbatim but with less interactional detail evident. This was a justifiable compromise as I now felt reconnected to their words and my use of field notes alleviated my concerns about over-reliance on interview data alone.

The next process was heavily influenced by Burnard (1991) and proceeded as follows:

1. Field notes were made after each interview
2. Immersion in data by making notes on general themes within each transcript.
3. Re-reading of transcripts whilst noting the headings required to incorporate almost all data (open coding).
4. Categories grouped together under broader headings
5. List of categories and sub-headings reviewed and revised
6. Transcripts re-read and compared to the list of categories and sub-headings.

Stages nine to ten of Burnard's (1991) process include cutting out sections of transcript and grouping these together. He also describes grouping these 'meaning units' using a word processing technique designed for analysing minimally structured interview data (Burnard, 1994). I found it easier as a neophyte researcher to have a tactile relationship with the data and did not pursue the word processing method however, there are sound reasons for using computer-assisted qualitative data software (CAQDAS). It may provide for a more objective and thorough searching for occurrences of codes – especially for large data sets. CAQDAS is designed to increase repetitions and therefore, generalisability of findings. Since I transcribed interviews myself and generalisability of the findings is not feasible or appropriate for this masters level research, CAQDAS was not seriously considered. Although the total number of transcribed words in this study totalled 47,000, this is a small amount of interview data. Given that I undertook

the transcriptions, I felt comfortable and familiar enough with the data to a degree where manual analysis was possible. For this project, I felt strongly that engagement with data within its original context was important and felt my lack of experience with CAQDAS could confuse the analytic process by alienating me from participants' data. Computer assisted coding can lead to fragmentation of informants statements (Webb, 1999) and therefore, may have in fact endangered, as opposed to strengthened, validity. In her study of researchers' experiences of analysis, Webb (1999) found manual manipulation of data to be preferable for beginning qualitative researchers. This was due to the learning processes inherent in this experience providing a strong base from which to use electronic coding later, in a meaningful way.

Gradually, themes emerged as I experienced each 'codable moment' and transcripts were colour coded to display these. Transcripts were then cut up according to theme and each theme placed in a designated folder. Each thematic folder was then analysed and reflected upon to ensure that the information within was in fact relevant to that theme. Interviews were analysed for both common and divergent themes.

During this time I began to feel frustration at the compartmentalisation which is necessary in analysis. I experienced increasing difficulty linking the themes together as a whole. This prompted creation of a large wall-map of categories and thoughts which allowed me to visualise the analysis in its entirety as it began to emerge. Much of my frustration at the separateness of themes was attenuated as I now began to link themes and so be able to see a global view. The wall-map had the appearance of a web, with no depiction of a natural hierarchy of themes. Much later, I discovered this is a documented analysis strategy. Attride-Sterling (2001) describes the thematic network technique which necessitates creating "web-like illustrations that summarize the main themes constituting a piece of text" (p.385). She argues this process is a reliable and sensitive tool for conducting thematic analysis.

3.9 Conclusion

This chapter has discussed the theoretical framework embodied in the chosen methodology of qualitative description. Thematic analysis has been shown to be applicable to this research and complements qualitative descriptive methodology. The methods have been described and ethical issues relevant to this study have been identified and discussed. The next chapter introduces the participants who require acknowledgement for their significant contribution to this work.

CHAPTER FOUR: THE PARTICIPANTS

4.1 INTRODUCTION

This chapter introduces the participants. I feel it is important to frankly acknowledge their presence within this thesis. Each permitted a stranger into their homes and lives during a difficult and personal time in order to contribute to this research. Each exists as whole person within this work, rather than a collection of data quotes. It was always considered likely that some participants would die during analysis or while this thesis was being written. Bill and Simon have both died.

4.2 ARTHUR

Arthur has multiple myeloma and has received two stem cell transplants for this. He is a tall man who volunteered that he currently weighs 58kilograms (kg). He has retired early from his professional practice due to the physical limitations of his disease. It is Daffodil Day and he tells me he has come to our interview straight from his daughter's school where he has been giving a talk to the students about cancer. He wears his daffodil on his chest proudly, under multiple layers of clothing visible above the collar of his woollen jumper and I cannot make out his body shape under the layers. It is as if only the visible extremities exist and there is no body under his clothes. His specific request was to be interviewed in his favourite coffee shop. He promptly orders a coffee and muffin which he takes over an hour to eat entirely. Arthur is married and has children, all of whom live at home. He talks volubly and plainly about the effect of weight loss for him and his family. We talk for over an hour and I actively end the interview as I'm becoming concerned that he is getting tired and am conscious he had arrived after already being out for some time. He sees himself as a cancer survivor and uses this term several times.

4.3 SIMON

Simon received his original diagnosis of bowel cancer almost three years ago and at that time, was treated with surgery and adjuvant chemotherapy. He was diagnosed with metastatic disease nine months ago. Despite a loss of 20kg, he has the appearance of someone who is healthy. He puts this down to having been 'tubby' before his recent weight loss and volunteers his current weight to be 75kg. Despite his appearance, he reports classic symptoms of CRC such as early satiety and anorexia. He retired from his work six months ago, which was a little earlier than he had planned, due to

increasing feelings of tiredness and asthenia because his job required long hours of standing. Simon lives with his wife and feels that she is more concerned than he about his weight loss. He is currently receiving chemotherapy for his metastatic disease and wears a hat because the thing which bothers him most about his appearance at present is his chemotherapy-induced hair loss. He views death as a natural progression of his disease but with the caveat that he equally “might get hit by a big red bus”.

4.4 BILL

Like Simon, Bill has bowel cancer. At the time of diagnosis (five months ago) his disease was already metastatic. He states that during his surgery, he was ‘opened up and they had a look and they couldn’t really do much’. He is receiving chemotherapy and our interview takes place during his ‘beautiful week off’ this regimen. His cachexia is beginning to reverse. At his lowest, he weighed 50kg but states he is now up to 60kg. He looks thinner than this to me. Bill lives with his wife, who is nearby in the next room. His adult children have left home. He has photographs to show me. One is of him at his lowest weight. The other is pre-diagnosis because he wants me to see what he looked like before “all of this terrible thing”.

4.5 SALLY

Sally has breast cancer and has recently been diagnosed with multiple metastases to her lung, liver and bone after a clinically free period of 16 years. We spoke in the living room of her flat. Sally doesn’t know how much she weighs, preferring not to take too much notice of numbers. She knows she is losing weight based on the fit of her clothes. She volunteers that she used to be a size 16 and always felt healthy about her weight. She does not know what size her clothes are now but has had to buy smaller ones over the past couple of months. Sally is tall, appears emaciated and I observe her to be to a small size 8. She is taking nutritional supplements and is now having regular admissions to hospice. She is not receiving antineoplastic treatment at present. She tells me most of the pressure to eat comes from within herself and she mostly does try to eat. Sally expects that she will die because of her cancer and feels this will likely happen within months. She lives with her adult son, who is present in the room during some parts of our interview. Sally strongly expressed her opinion that while the gain for her is negligible, her motivation for participating in this project was to contribute to helping future cancer sufferers

4.6 SHERPA

Sherpa has mesothelioma, diagnosed approximately three months ago. He relates his disease to having worked for many years around asbestos. He says nobody cared in those days about wearing personal protective equipment and in any case, it simply was not available. He volunteers his current weight to be 64kg, believing he has lost approximately 12kg. At present, he is experiencing profound asthenia and has had to move out of his bedroom, into a room on the ground floor because he often feels that he does not have the physical strength to navigate the stairs. He experiences rich family support from his wife and adult children.

4.7 IRINA

Irina has bowel cancer which has metastasised to her liver. At the time of her diagnosis four years ago, she describes undergoing 'massive' surgery, radiotherapy and adjuvant chemotherapy. A short time later during the same year, she underwent further surgery to remove a liver deposit and believed at that time that 'they'd got rid of it'. Irina has not worked for many months now as she is not physically able. She volunteers that last time she weighed herself she was 55kg, but appears to be thinner than this right now. She is frail and shifts about in her padded armchair frequently as her bones stick out and she has difficulty keeping comfortable. She feels her family has more difficulty than her in accepting her situation. Her husband is present for most of the interview. Irina is the only one of the participants to become tearful and when I offer her some tissues, and remind her that the tape can be turned off anytime, she says that we should keep going.

CHAPTER FIVE: EMBODIMENT AND MEANING

Man is not destroyed by suffering; he is destroyed by suffering
without meaning (Victor Frankl 1905 – 1987)

5.1 Introduction

The previous chapter introduced each participant's story, providing a background against which the journey of CRC has been experienced for each. This chapter and the next present the themes from the analysed data, describing the experience of CRC from the participants' point of view. Each theme is introduced and illustrated with direct participant quotes or field notes and finally, linked to the literature with narrative. In striving for validity, I freely accept and admit that my own subjectivity must have necessarily influenced and become embedded within the following analysis.

The experience of living with CRC is an arduous journey which has phases along a continuum. This chapter begins by discussing how each participant experienced **coming to know** they have cachexia. What they did not know and what they came to know, prompts a tendency to reframe themselves in light of what they now understand. This is called **knowing in progress**. During this time, body weight alters in meaning from something related to fitness and nutrition and becomes a physical manifestation, or proof, of cancer. Once knowledge of cachexia is granted to participants, (I say granted because it is almost always withheld) they become aware that part of the truth about their state has been denied them. This leads to **dissatisfaction with truth-telling**.

5.2 Coming to know

This theme discusses how each participant 'came to know' they have the CRC syndrome. During the interviews, each participant was asked if anyone had ever told them or their families that they have CRC and what that is. None of the participants had ever heard the word cachexia prior to reading the participant information sheet (PIF), except Bill, who had read the word cachexia in a cancer book shortly before our interview. I had anticipated that exposure to the PIF would most likely be the first time potential participants became explicitly aware that their weight loss is the result of a cancer-related syndrome. As described in chapter two, it is already known that beyond the obvious symptoms, sufferers are rarely cognizant of the syndrome (Pool

& Froggatt, 2002). From this knowledge stemmed one of the challenges regarding the PIF. I knew that I would be introducing people to a syndrome that they may not know they had but I felt it was important to be open about cachexia. Much consideration was given to the wording of this within the PIF.

There is no research into what sufferers feel upon learning the term and given that, I wondered what it is like to be told. My firmly held preconception going in to this research was that participants would express relief at having this new knowledge as I felt instinctively it might ease their burden. However, none expressed surprise, relief or any strong feelings about learning the term CRC. In describing his feelings about the word cachexia, Arthur said

Doesn't worry me...either way (p. 29)

Simon also, seemed untroubled, saying,

There's always a label for everything these days....they make them up (p. 14)

Bill felt,

It doesn't make much difference (p. 18)

Sherpa described his feelings about learning the word cachexia slightly differently,

S: I felt a bit sort of.....maybe, offended. I mean, I didn't know. I didn't recognise the word, no idea what it related to specifically. You know, I was an academic and it didn't, you know, strike a chord with me at all. Um, well that's basically what I thought about it.

M: So you don't think, am I right that for you it's not helpful?

S: It's a non event. (p.15)

Later, we returned to this topic,

S: Well, the word itself...it's like saying 'this is what you've got' and....it doesn't sound good. //they should try and make it more user friendly // it doesn't *sound* nice. It doesn't....appeal. (p. 27).

In talking with Irina, she describes her feelings slightly differently,

M: So, for you, has it been helpful knowing that term [cachexia]....or not helpful....?

I: Um....it's ah well, just an acceptance to think that well, obviously it is recognised.
(p.35)

This excerpt subtly indicates that for Irina, learning the word facilitated reconciliation for her, between her physical state and a known medical syndrome.

As my interview with Bill progressed, he returned to the topic of finding out about his CRC,

....no-one was quite understanding of *why* I didn't want to eat. We just knew it was perhaps a um, typical cancer thing. But, nothing more. So, to have a reason why, might have been comforting. (p. 26).

On the whole, these expressions appear largely ambivalent. In the sub-text of these statements, it was as if each participant inherently knew and did not feel the need for a label to validate their experience. This is confounding when situated with the context of my previously stated clinical experience which informs me that many people who have CRC are interested in learning the label. Very often, people express feelings of comfort in the normalising nature of identification. In common with Bill, who made direct reference to this, Irina was the only other participant who alluded to this in her statement above. While all participants seemed to have an *implicit* understanding that their wasting was cancer-related, none had received *explicit* confirmation of this. Therefore, for these participants, not knowing the name for CRC did not preclude having an awareness of it. While there is some research about what it is like to be informed of a cancer diagnosis, this is the first time that feelings of learning about CRC have been described. A similar study has been conducted with eleven participants, who were interviewed for about one hour in their own homes (Hinsley & Hughes, 2007) The study used an in-depth, conversational style of interview designed to encourage participants to tell their stories but did not report any aspect of what informants felt upon learning about cachexia. This supports further investigation of the issue and is discussed in chapter seven.

The reason for these surprising expressions of disinterest about the label are not clear from this research. It may be that cancer diagnosis overrides concerns about other things or that CRC becomes strongly linked to cancer in the person's experience and so does not become perceived as a separate issue. In talking with participants, there

was for me, the unspoken sense that it is not understanding the syndrome which was unimportant, merely that the name for it did not add value. While the actual word or label ‘cachexia’ did not evoke strong feelings in the participants, emerging awareness of the syndrome itself was central to their experience and this is called ‘knowing in progress’.

5.3 Knowing in progress

For these participants, what they did not know and what they came to know influenced the meanings ascribed to, and connected with, their changing bodies. As we talked, it became evident that participants had begun reframing some of their experiences within the context of living with CRC and this is called **knowing in progress**.

Weight loss preceded cancer diagnosis for all participants. This is known to be typical in malignancy as weight loss is often the presenting symptom. Although unexplained, informants applied many other reasons for their changing bodies, except cancer. Irina describes simply losing her appetite; Arthur felt he was losing weight because he was stressed at the time and Sherpa ascribed the initial loss of a few kilos to his ongoing exercise regimen. All participants describe anorexia and sometimes the initial weight loss this facilitated could be dramatic. Even when weight loss was profound, the tendency was for participants to not link it to cancer. Bill illustrated this in his description of losing almost 20kg in the space of four weeks,

M: When you lost that weight, before you had the scan and were diagnosed, what did *you* put it down to?

B: Well, I didn’t know. It came on so dramatically and I thought I must have had something like irritable bowel syndrome or something like that because I’d gone off food and I suppose for about ...oh...July, August I’d wake up in the night with quite severe pains in the stomach and that, I put down to the food digestion was at that particular stage, and that’s where it was hurting (p. 3)

Prior to his diagnosis of bowel cancer, Simon experienced rectal bleeding and mild weight loss combined, which he ascribed initially to simple haemorrhoids.

As long as the weight loss remained unexplained, it was considered abnormal by participants and was the main impetus for seeking medical investigations. All the participants sought medical advice related to their weight loss and, in each case, it was investigations for that issue which ultimately led to cancer diagnosis. *After*

cancer diagnosis however, knowledge that malignancy is present, began to prompt a reinterpretation of the meaning of weight loss from something unexplained and therefore abnormal, to something accepted and normalised as part of the disease for all participants. Bill gives a typical expression of this,

Now, I realize that losing weight is a sign of cancer and I understood that I was probably fairly normal, what was happening (p. 18)

All the participants in this study expressed the opinion that they now view weight loss as an expected part of the disease. Only Sally, who had been diagnosed with breast cancer 16 years before, immediately related her weight loss to cancer. She describes a period of weight loss steadily for a year prior to learning she had bone metastases and despite being incorrectly diagnosed with allergies and a gastric ulcer during that time she said,

.... and I *did* think it was cancer returning (p. 3)

Given that Sally had been clinically free of breast cancer for well over a decade by this time, this statement would tend to indicate that after weight loss is first connected to cancer, the connection does not persist for only a finite time, but becomes an ongoing narrative in the sub-text of a person's life. With the emerging knowledge of malignancy, comes the expectation that weight loss will follow.

Each participant, except for Sally who expressed her weight in clothing size, volunteered their current weight in kilograms. Like committed dieters, participants were able to recite their weight loss history, and this revolved around both kilos lost and kilos gained. Each kilo gained, providing a source of pleasure and achievement and each kilogram lost, representing failure. Sherpa was the only participant who had routinely weighed himself prior to his illness. For the others, this ability to recount weight loss history only developed after diagnosis of cancer.

All participants were asked 'If you gained weight now, what that would mean to you?' In each case, this question elicited responses indicating that this would denote a lessening of tumour burden somehow and therefore weight gain is anticipated with pleasure. Sherpa illustrated this best,

I'd be pleased. I'd be thinking that's good//Yeah, well you'd think something was getting better anyway//it must be good if you're putting on weight//I'd be very happy (p. 20).

Conversely, I asked each participant how they would feel if they lost weight now. In each case, participants believed that more weight loss would indicate cancer progression. Irina felt that if she lost weight she would think

Okay, at the root of all this is the cancer (p. 24)

She tempered this by noting that during her cancer journey, there were medical interventions which also caused weight loss and for her, it was a mixture of disease and treatment. This is indeed true in so far as treatment-induced anorexia, mucositis and constipation have some impact on intake but as the genesis of CRC is not intake-dependent, this type of weight loss is different but largely impossible to clearly separate out from CRC. Simon was very clear in attributing his ongoing weight loss directly to disease process. When asked what he saw as the reason for his weight loss he said,

...it's probably the progression of...the cancer to other parts of the body (p. 4).

Therefore, though tending not to relate weight to cancer initially, after diagnosis, once the link between cancer and weight loss had been made, all participants then reframed the context of their weight loss, now seeing it as something negative. Sherpa described a strict fitness routine and careful monitoring of his diet prior to cancer. During this time, he felt happy if he was not gaining weight and took pride in his careful guarding against weight gain. This was because slimness to him, at that time, meant health. Now, he wants to gain weight and I asked if this was because body weight now had a different meaning for him. He replied,

Yeah, it hasn't got the same feature, you know, same aspect (p.21).

The dominant idea expressed by participants is that the meaning ascribed to body weight is dependent upon context. One consequence of this is that being able to increase weight has now become desirable and something to aim for, because gaining weight is now equated with gaining health. Not surprisingly, wanting to return to a healthy state is a recurring theme. This has led to increased vigilance for all participants. All participants except Sally weigh themselves more frequently now. Bill felt that he probably would do this for the rest of his life despite the fact that prior to his illness, it had never entered his mind to weigh himself. All participants gave the sense that they are more watchful of their bodies now. It appears to be evident that increased vigilance around body weight is carried out much like watchful waiting. Though Sally does not weigh herself, she often now has to buy clothes in ever decreasing sizes and in this way is conscious of monitoring her body, but in a less direct way. It would seem that

whilst not linking unexplained weight loss to cancer pre-diagnosis, the link is made retrospectively after diagnosis and once made, this link becomes continuous. Thus, the changing body is experienced by participants as a physical manifestation of cancer and becomes a proxy in place of formal monitoring as an ongoing barometer of disease. This would seem a heavy burden indeed to carry for life. Whether or not weight loss is then perceived as impending death, has never been empirically studied and is not clear from this research, although Sally noted that,

if you've got the slightest bit of intelligence, you know that not eating is one of the signs of being near death (p. 17)

At the time of interview, Simon alone saw his weight loss as a positive thing in his life because he felt his smaller frame had improved his golf swing. This was intriguing because later on, Simon told me he was taking Fortisips (a brand of nutritional supplement) and wishes he'd had them sooner. So, whilst for Simon there has been a positive effect from weight loss, fear about continuing along his current weight-loss trajectory is also apparent and something which he is trying to actively avoid. The other five participants were also currently taking nutritional supplements in the form of pre-prepared fortified drinks, displaying a desire to minimise ongoing weight loss. The notion of 'knowing in progress' which has been described here is similar to the process of 'rethinking' as identified by Hinsley and Hughes (2007), which refers to feelings of uncertainty which develop for the person experiencing CRC whenever they look at their bodies during times of weight loss. Within this theme, there is expressed a fluidity in the meaning ascribed to body weight. Altered physicality presents circumstances in which emerging consciousness of an altered self causes reflection and this is part of a process whereby participants no longer take a competent body for granted. This is discussed in more detail in chapter six however, as participants progress through 'coming to know' and 'knowing in progress' there is an emerging sense that information-giving in preparation for this reflection has been withheld. This is expressed as dissatisfaction with the degree to which clinicians had told the truth about cachexia and this is now discussed.

5.4 Dissatisfaction with Truth-telling

As described earlier, participants expressed no strong feelings about not having heard the term 'cachexia' or 'CRC' before and appeared to find the label easy to accept. While not particularly caring about the *label* 'CRC', all participants considered having information about the *syndrome* important. Information about CRC was felt to have been inadequate and, in some cases completely absent. This is expressed as

dissatisfaction with truth-telling and was harder for participants to accept than the new label itself. All informants felt it would be to their benefit if their families were more fully informed about CRC, specifically with regards to the involuntary nature of the syndrome.

One problem related to truth-telling was the perceived mismatch between the participants' needs for dietary discussion and the medical approach towards this. Arthur, Bill, Sherpa and Irina talked about the decision they felt their oncologists had made not to engage in discussion about food. Bill expressed his feelings as follows,

It would have been very helpful for the family to understand. We're constantly amazed at the lack of understanding by the medical profession about diet and they tend to have their own special skills and anything outside that is foreign. We've got some very good doctors but when we talk about diet, the quick response was 'Oh, that won't do you any good' (p.19)

So it's quite surprising how compartmentalized I suppose, the medical profession tends to be//he [oncologist] wasn't interested in diet either or any alternative things (p. 20)

The perception here was that there is a demarcation line for specialist oncology clinicians between CRC and cancer treatment. Participants felt that their specialists did not see nutritional needs as part of their brief. The expressed notion here is that nutritional aspects of cachexia are viewed by medicine as separate and not the oncologists' concern.

Arthur thought nurses displayed more of an interest than doctors and Sherpa felt nurses are ideally placed to engage in partnership with sufferers and families about CRC,

S: We need more informed information...about it. [cachexia] That would help.

M: Before it started or...as it was beginning?

S: Before! I mean, you've got to go down to the nursing level. They can do an awful lot at that level, if they're interested, if they're informed.....I'm talking about the nurses. (p. 29)

The use of the phrase 'you've got to go down to the nursing level' can be interpreted differently depending upon context. Sherpa meant no disrespect to the profession. Rather, by using the phrase 'down to the nursing level' Sherpa recognised that nurses

occupy a place closer to the patient than oncologists in terms of time and space and therefore are potentially powerfully situated to engage in patient advocacy with regards to CRC. Nurses will generally have more frequent, sustained contact with a patient and their family. Even during outpatient cancer treatments, nurse-patient and nurse-family interactions are very often prolonged, occurring over several months and for several hours each time. Within the statements above, Sherpa also implies that like oncologists, nurses are not always either interested in or adequately informed about CRC and as a result, are not as effective as would be ideal in the advocate role. Of note here is that, of the participants who had seen a dietician to receive supportive consultation regarding diet, all had been referred by a nurse. This was felt to be due to the perception that nurses are more willing to engage with dietary support and discussion than oncologists. Although nurses had referred patients to a dietician, in each case, this had been done *without* making mention of CRC. This is interesting and possible reasons for nurses' reluctance to disclose is discussed in chapter seven.

Every participant was specifically asked how they felt nurses could help better with communication and information provision about CRC and the way this might best be approached. Irina advised,

When people talk to families and so on....to sort of explain that this [cachexia] is quite a common feature and I would emphasise that it's not just the cancer but can be the treatment as well. They won't always feel like eating and they won't probably want to eat as much. And the foods they've always liked in the past, they suddenly won't want to eat. And suddenly they'll ask you for something out of the blue that well, might be asking for the impossible....//they might be asking for dead possum or something out of season or whatever. It's a bit like that. //at some stage they need to be warned that this is not uncommon (p. 41)

In common with the other participants, Sherpa had not received information about nutrition or CRC and felt that he, and particularly his family, would have benefited from information,

Some sort of general information for the care givers, you know. You're in hospital, they're all over you, you're out of hospital and at home and you think 'Where's all these things?'//and sometimes it's not there and you've got to try to ask//they don't understand. They *may* not understand so I think//some advice for the care givers. (p.19).

Within this expression, Sherpa gives the impression that there is for him, a feeling of having been let down. Now knowing about CRC, he reflects that in leaving the hospital

environment and returning home without enough information, there surfaced for him the dawning realisation that he was now adrift and trying to ask for help from his family, who were not equipped to give it, because they had not been provided with the necessary education to allow it.

Sherpa had experienced medical treatment for a cardiac condition in the past. He compared the lack of information about his general condition (in particular, CRC) negatively, as opposed to the excellent information he felt he had received from the cardiac team. He voiced disappointment that the hospital providing him with treatment and support is the designated cancer centre for the region and felt the information he had received was inadequate in light of this,

S: Well, I think generally, in terms of this particular problem [CRC] um....a bit more understanding. A bit more, perhaps.....nobody mentioned it to me. I mean, it just happens. There's nothing to say you're going to get it or you may get it or, it may make you feel.....

M: And that it's quite normal?

S: ...yeah! We need more informed information. (pp. 28-29)

The recurring theme here is that participants wanted transparent information, sooner and wanted their families to be told about CRC clearly. Arthur was alone amongst the participants in feeling that this might best be done away from the patient,

A: Nurses really need to involve family and talk to them about approach//and I would say in my experience, out of earshot of the patient.

M: Why, would you say that?

A: So that the patient doesn't feel like they're being categorised or being looked at as 'Oh that's right, you're the poor bugger who can't (eat). (p. 42)

The importance to Arthur that his family be able to receive knowledge, even when he is not present in the discussion, is paramount. For these participants, inadequate truth-telling is experienced as universal with regards to CRC and this facilitates unrealistic expectations and misconceptions around food and its relationship to CRC. One consequence of this is the resulting focus on food consumption as an indicator of disease status, explored in chapter six.

The truth-telling component of nurse, doctor and patient communication has been investigated within the oncology setting, usually with regards to voicing diagnosis, history taking or breaking other bad news such as disease recurrence (Moore & Butow, 2004). There has been less success in investigating why information with regards to CRC is routinely withheld or not discussed early enough with sufferers and their families. The reason for incomplete truth-telling specifically regarding CRC has, to the best of my knowledge, never been formally investigated. To some extent, truth-telling in health care is a cultural artefact, whereby the extent of truth each patient requires or is comfortable with, is dependent upon the way in which they have enculturated their own health values. Unless we ask people about their needs with reference to shades of truth, we will invariably only meet some peoples' information needs, some of the time.

A significant repercussion of incomplete truth-telling is noted as widespread private and public dissatisfaction with clinician-patient communication, specifically with regard to cancer. Moore and Butow (2004) call this the "communication crisis in oncology" (p. 26). This issue is known to be prevalent in nurses' attitudes to open discussion of cancer with geriatric patients, when this is perceived to be terminal. Research of truth-telling practices has revealed a staggering 60% of respondents said they would withhold a diagnosis of metastatic lung cancer from an 80 year old, female patient. 56% of respondents said they would withhold other information if instructed to by a family member of a patient (Maestri-Banks & Gosney, 1997).

There is evidence that clinical truth-telling practices are continuing to shift over time towards more open and truthful disclosure and the benefit of this for the patient continues to be debated (Tuckett, 2004). It could be seen that withholding truth about CRC is of benefit, and has evolved within nursing from a desire to avoid placing the patient in a situation where hope is overcome by demoralisation. Conversely, the reasons may not be patient-focussed, stemming instead from reluctance to engage in challenging communication scenarios. Whatever the explanation, the result is that CRC was not openly discussed with these participants. Reasons for this intriguing approach to truth-telling are considered in chapter seven.

5.6 Conclusion

This chapter identifies the themes which have helped describe the way participants experienced coming to know that they have CRC. Participants describe not being aware that their weight loss is evidence of a known syndrome, although this did not preclude having an awareness that something was physically wrong. It was the diagnosis of cancer

which provided an explanation for weight loss which each participant then interpreted as 'reasonable' within the context of cancer and this then allowed normalisation of it. The strength of the connection made between cancer and weight loss is profound enough to prompt altered behaviour around body monitoring. This takes the form of increased surveillance, as weight becomes a barometer of disease whereby weight loss and gain are interpreted respectively as disease progression or disease regression. None of these participants expressed strong feelings about learning the word cachexia, however, these feelings of ambivalence were not applied to gaining knowledge of the CRC syndrome. Rather, each expressed dissatisfaction with truth-telling and felt earlier information would have benefited them, and particularly, might have assisted their families to acknowledge and accept the fact that the participant cannot exert control over the condition.

I now move to discuss the implications of cachexia on a person's identity and way of relating to the social world.

CHAPTER SIX: THE SOCIAL WORLD

Well you get used to anything. Your abnormal slowly becomes normal, it's a bit like that (Sally, p. 38)

6.1 Introduction

As the participants moved through 'knowing in progress', and the meaning of body weight becomes a barometer of disease, participants began to reframe their identity within the notion of wasting. This is experienced as a **loss of sense of self**. This is expressed in terms of changes in the way they present physically, how they feel about themselves, their relationship with other people and with food. The **changing relationship with food** which then develops leads for some participants to **loss of adult status** as food becomes the conduit through which family relate to them. This prompts **withdrawal from the social world** as each participant attempts to minimise the consequences of these changes. The way in which each participant embodies and expresses these experiences is now discussed.

6.2 Loss of sense of self

Though CRC is a different physiological process than simple starvation, in the later stages of each, the physical appearance is very often similar and therefore imbued with strong meaning across many cultures. Participants who appeared obviously cachectic, used words to describe themselves within their new bodies.

Sally described herself as,

A stick figure (p. 33)

Bill described himself as follows,

I was very very thin. I looked a little bit like a Belsen victim [Bergen-Belsen was a Nazi concentration camp]// before I started losing weight and when I was a whole person, I never worried much about salads or cucumber.... (p.7)

Bill is not unique in describing his appearance as that of a concentration camp internee during the holocaust of the second world war as others who are cachectic have described

themselves this way (Hinsley & Hughes, 2007). Right at the start of the interview, Bill told me he had always felt very proud of his physical strength, which has now waned to the point where it is no longer possible to walk any distance. I spoke to Bill's wife on the telephone whilst arranging an interview time. She began to tell me that she felt for Bill, that the cachexia had been worse than the cancer and not being physically strong anymore had profoundly affected his self esteem and identity as a man. I explained that this was exactly the type of data I was hoping to record on tape and that while I was pleased that she was willing to share these things, I would prefer to wait until the interview. During the interview when we talked about this issue, Bill did not voice the same degree of concern in as straight forward a manner. However, the statement 'when I was a whole person' is imbued with sadness, loss and the implication that an identity change from one who is healthy (complete) to one who is diseased (incomplete) has occurred.

Irina echoed Bill's expression of incompleteness in describing herself as 'scrawny'. While talking about what she thought her family felt about her weight loss she said,

I think it is concerning to the family...um...they don't like seeing their mother (or) father, sister, brother, husband and wife....fade away (p. 29)

The expression of fading away implies becoming smaller, and less than before. The implied notion of disappearing altogether is also present here. Irina told me her doctor had written in her notes 'anorexic' which she understood as meaning someone skeletal suffering from anorexia nervosa. She was offended by this as she (quite rightly) does not see herself as suffering from that eating disorder. Within the cachectic body, there is profound loss of lean muscle mass which is a hallmark of the disorder. With this comes asthenia and loss of strength and each participant described these symptoms. For each, this led to general weakness. Sally, Arthur and Sherpa described this as having feelings of being an 'invalid'. Compounding physical weakness, for Irina and Bill, being much thinner (and smaller) caused physical pain, in addition to the feelings of becoming less physically present.

Irina said,

I don't like being scrawny. It's harder when you want to soak in a big hot bath. I've got a rubber thing that I sit on now because it's hard on your backside... there's no flesh there. (p. 27)

Similarly, Bill describes physical pain as a result of wasting. He told me that he grew a

beard when he was 50kg because the bones sticking out on his face at that time made it too painful for him to tolerate shaving. Both Irina and Bill had previously enjoyed the ritual tasks of bathing and shaving respectively, as part of a normal day and felt regretful that these familiar and comforting activities were no longer achievable in the same way that they had been before. So, while thinness is a visual trigger for changing identity, physical pain due to diminishing body size can also rob a person of a sense of normality. Of interest here, is that Irina and Bill (the participants who most clearly expressed feelings of incompleteness) were also the participants who were experiencing the most physical pain from emaciation. This indicates the possibility that the combination of pain and reducing size might be correlated with the degree to which someone finds themselves feeling less complete.

For all participants, the body has become a focal point of cancer and a constant physical reminder of disease. Nettleton and Watson (1998) discuss taken-for-grantedness whereby, in our day to day lives during times of wellness, the body is taken for granted or absent. This default position of absence becomes replaced by consciousness of the body only when pain, suffering or disease causes some degree of physical dysfunction. The excerpts above indicate enhanced daily awareness of physicality as a result of CRC. This was also alluded to in the discussion of increased vigilance towards the monitoring of weight in the previous chapter. Williams (1996) draws on research findings from investigation into the experience of chronic illness to explain that original embodiment (taken-for-grantedness) becomes a memory as patients waver between disembodiment and reembodiment. This movement necessitates that the sufferer undertake 'biographical work' to redefine their physicality and therefore their identity and world. As the body changes and becomes smaller, the participants in this study began to ascribe themselves a different status and used the various terms already described to express the way they view themselves within their new bodies. This would tend to indicate a degree of acceptance and ownership of their changing identities. The process of developing a new sense of self described above may be an example of 'biographical work' carried out within the context of CRC.

Simon alone did not use any words relating to weight or appearance to describe himself now and does not have any pain which he relates directly to weight loss. He felt that this in part relates to the fact that he still appears to be of normal weight, despite a loss of 20kg because prior to CRC, he described himself as having been 'quite tubby'. It is possible that it is only once their appearance becomes viewed as abnormal to society, that CRC sufferers label themselves as being physically diminished and in doing so, take on the identity of one who is wasting.

With the emergence of a new identity, comes regret for loss of the old. Sally and Bill were interviewed in their own homes and wanted me to see pictures of them before their weight loss.

Bill has a photograph of himself ready on the table when I arrive at his house to show me. It depicts an excruciatingly thin man which is recognizably him. He tells me he weighed 52 kilograms on that day and says he looked 'pretty gaunt'. At the end of the interview when that tape had been stopped, he led me into his living room to show me framed photos on the wall of a family trip several years ago. He expressed loss and regret that he no longer looks like the strong, well muscled man in the picture and I would not have recognized him as the same man if he hadn't told me. I asked him if he identified himself with the picture. He said he did, he felt it was like looking at a different person, although he could recognize the essence of himself in it. (Field notes)

Irina too, provided me with photographic evidence that she is not the same as she was, handing me three photos of herself before she had her recurrence.

She looks vital and strong and is wearing shorts, displaying her body. I can't help noting that now she is wearing clothes that completely cover her despite the unusually hot weather. I didn't ask but wondered if this is because she feels less comfortable with people seeing her body now. (Field notes)

We discussed her feelings about these pictures

M: How do you feel when you look at these? Does it feel like you're looking at you?

S: Yeah. Well, //..I mean it's a different person but you still see the essential you (p. 47)

Like Bill, whilst acknowledging the change, she recognizes herself, but as a changed person. She likened the feeling to seeing a photograph of oneself as a child. That is, you can see it is you, but you have greatly altered since then. Here is evidence that the chronological story of the biographical work undertaken within the context of CRC includes a shifting consciousness around appearance. This has an impact upon body image and identity. The relationship with self is assessed, adjusted and rearranged as participants attempt to make sense of the physical changes they observe. The loss of sense of self embedded within this experience influences the relationship each participant has with food.

6.3 Changing relationship with food

Readjustments which result in the changes in self perception which have been discussed, lead to participants experiencing alterations in the meaning ascribed to food. As a new sense of self emerges, so too, does a new relationship with food; the meaning of nutrition has altered for participants. Food has taken on much greater meaning and importance than it had for participants before cachexia. This is expressed as an increasingly conscious connection between nourishment and survival. Sally gives an example of this,

I have never been a comfort eater. I've never been a snacker//I've never had a problem with food. I've never had to worry about being overweight. So, I don't eat for comfort, there's no emotion for me bound up in food (p.14).

In the above excerpt, Sally is talking about the way in which she approached food and eating prior to her cancer-related weight loss. Interestingly, like many people who have never experienced being overweight, she voices the often unspoken myth that all people who are of larger than 'normal' size eat for comfort and have an overly emotional relationship with food.

A short time later she said,

It's very difficult to explain but you actually *feel* so bad when you don't eat. As soon as you can get some food in again you feel a sense of wellbeing (p. 18).

Irina echoes this,

I don't find food very comforting [anymore] (p. 39).

Within these statements is acknowledgement that food no longer possesses the same quality of solace which was present for these participants prior to having cachexia and for Irina, this has produced feelings of discomfort. The meaning of food has also changed dramatically for Bill. Talking about his relationship with food prior to his CRC he says,

I've never been a fanatic about food. Its fuel and I like it, but it hasn't been the be all and end all of my life. (p. 21)

Now, Bill is deeply interested in food. Gaining weight did in fact become the be all

and end all of his life as he was initially refused chemotherapy on the basis that he was emaciated beyond the point where it was considered likely that he could survive a chemotherapeutic regimen. For each participant, being able to eat is interpreted as being healthy. Being able to eat is experienced as comforting and nourishing. All the participants spontaneously voiced their acceptance that they would most likely die from their disease but regarded their constant battling with food as linking them with life. All stated that they wished that they *wanted* to eat as they did before, but simply cannot. Sally expressed this clearly,

I do *try* to eat because any sensible person knows that you've got to eat and especially if you think you're very very ill it's just survival instinct to try (p. 13)

For Sally, it appears that trying to eat, even when this is impossible, has become a symbolic expression of trying to live. Conversely, not being able to eat normally creates feelings of disconnection from the world,

S: ...you *are* sort of detached from life and you don't feel that you've got quite the energy to enter the world (p. 34)

S: It is a horrible horrible thing to go through. I think in some ways it's (weight loss) is more distressing than the pain because you just//....You know how you get depleted and you want your meal if you've been working hard or something?

M: Mmmm

S: And if you couldn't eat it, you wouldn't feel well. You wouldn't feel good. You don't get that sense of wellbeing. In the winter, you're colder because you haven't eaten//You know that feeling of having a nice hot bowl of soup in the winter? It's gone. And, all those feelings of wellbeing.....so it's really quite unpleasant. (p. 39).

The notion of physical pain being preferred to inability to consume normal amounts of food is interesting and I asked for clarification about this

M: So you think, you think that you'd almost rather have pain than lose that part of you? [being able to eat]

S: Well, with degrees//we're not talking about screaming pain//I'm talking about pain kept under control, not being on a rack or anything but....you know, you get a little bit even when you're on stuff (analgesics), but not eating is actually quite distressing and distressing for people around you I think. (p. 40).

As the meaning of food becomes literally more vital, participants tended to actively become more literate with regards to nutrition, as part of fighting the disease. This is expressed by seeking food knowledge, often from books not written by health experts or from the internet. Bill gives a typical example of this knowledge seeking behaviour around food which has developed for him since his cancer diagnosis,

All the cancer books we've got say that meat is very acidic and...if you really want to fight it (cancer) it's not a good thing (p.19)

Arthur, Irina and Simon also described investigating food as therapy. Foods which are designated as 'good' for cancer or 'bad' for cancer are then encouraged or avoided accordingly.

It appears that for some, even though they are not eating much, what they eat becomes more meaningful and important for its health-giving benefits. This strategy of knowledge seeking is adopted as the significance of food grows within daily life. Alongside the perception that food joins us to life, participants expressed the notion that food is to be valued and respected. Arthur illustrated this as follows:

I physically think about it [not being able to eat] when I go out to a restaurant and I know I'm going to have a beautiful meal here and I'm not going to do it justice (p. 7)

Sally, Irina, and Bill also talked about not being able to eat food which had been prepared for them and each also used the phrase 'not going to do it justice'. Thereby, food is ascribed a certain value and preciousness which is to be respected.

Sally, Arthur and Irina all still regularly cook for their families when they feel physically able to do so. I asked them if they have trouble psychologically handling food that they know they are not going to enjoy. I had wondered, when approaching this research, whether or not this situation contributes to suffering. The consensus was that this did not cause psychological distress. The only problem each faced whilst preparing food, was the physical tiredness and asthenia which made this difficult. So, whilst fearing the eating of food, preparing and handling it does not appear to be troublesome for participants, beyond the required physical work.

Participants often spoke of feelings of fear related to food. The sight or smell of food when not hungry or a large plate of food has become 'terrifying' and anxiety provoking. Having to eat, or forcing oneself to eat when one does not want to, is experienced as work and managing some mouthfuls provides a sense of accomplishment. This has

developed into a combative situation between each participant and their food. Sally expressed her struggle with this,

.....well, it's quite horrible really. It's horrible not being able to eat. It's a chore and you do get a bit anxious about it.(p. 8)

Something on a plate tends to *horrify* you.....because it's huge. You know when you're ill, if you've got to do something or you're tired, it looks like a *mountain* when it's a molehill – it's like that “ (p.12) and later “I'd rather dig a ditch honestly, (than eat) it'd be less hard work. (Sally p. 16)

As described in chapter two, small portions are known to be helpful yet this information was left for patients and families to discover on their own, despite the fact it has been in literature for years. This is one negative effect of denying patients knowledge about the CRC syndrome.

Bill said,

..I could smell them cooking in the kitchen...and I was put off long before it came so I *tried* to eat but as I say, it either hurt, or I didn't like the taste of it or if I did, I was sick afterwards. Not always, but often enough to be very, very wary (p.7)

Here Bill is also expressing a recurring theme for all the participants that the fear related to eating is not simply around the sheer effort it takes for people with CRC. It is also generated from experiencing the physical consequences of eating. Each participant described classic symptoms associated with CRC including dysgeusia (altered sense of taste), and early satiety. When fighting against these and managing to eat, consequences included pain, nausea, vomiting, diarrhoea and constipation. The body's ability to tolerate food having now been severely compromised, added to anxiety for Sally,

Well I got to the stage where I did (enjoy food) but before that I really was more bothered about whether I was going to keep it down or [see it in] my next bowel movement (p. 39).

Bill said,

I remember full well saying one night, 'Well you know what? I'd really love a poached egg on toast, that's exactly what I want'. I had the poached egg on toast and had to go away and sick it all up again so, that wasn't very encouraging for anybody (p. 15).

Irina, Arthur, Sherpa and Bill all gave examples of particular foods they have become frightened of and avoid because of the physical sequelae they now relate to them. Like Sally, Irina said she felt frightened to see her food appear almost immediately in a bowel motion looking the same as it had on the plate. These are typical experiences for people with CRC, and for these participants, food is often associated with physical pain. Arthur stated this succinctly,

I know that it (eating) is going to hurt. So I don't even attempt it (p.31)

When talking about a recent period of CRC- induced weight loss Bill said,

Well, I *wanted* to [eat]. During that awful period when I did eat things I often had to go and vomit because it upset my stomach//there were very few things I could eat without problem. I didn't *want* anything to eat. And when I did, it caused problems like vomiting or pain.//and the easiest way was to not, not worry about it I suppose (p. 6)

He is describing here that period of time where he was anxious to gain weight because his access to chemotherapy had been deemed to be dependent upon the ability to do this. In addition to the expression of fear about eating, his description suggests that psychologically desiring food is a separate experience from physically desiring food and these conflicting desires can be experienced concurrently by someone who has CRC.

Arthur also feared eating. In describing a family member giving him food, he said

Her (wife's) sister said 'You've got to build him up again' and threw a big meal like that! [indicates large size meal with hands] on my plate and said 'Get that inside you'//and I was sitting there going [grimaces] at the thought of it. If you know it's going to be uncomfortable doing it, you tend not to force it. (p. 9)

Discomfort caused by ingestion, the fear that this generates, and the effort required in attempting to overcome these obstacles leads to participants seeking only food that is 'easy' to eat. All the participants used this word to describe their preferred meals and these differed. Bill began eating ice cream and drinking milkshakes because they were bland and he did not think they would physically hurt to consume. In contrast, Sherpa now finds cold things and sweet things unpalatable. Many of the available liquid nutritional supplements are notoriously sweet and all the participants gave this as the reason for not enjoying their taste.

The commonality of expressions in this theme lies in the contradictory nature of two opposing perceptions which are experienced concurrently. Food is recognised by participants as a source of nourishment providing connection to life and as an enemy to be approached with caution because the physical consequences of eating are feared. In essence, food and eating have become hardships to be faced and endured rather than a source of physical and social pleasure. Being frightened of certain foods and struggling to eat for survival against a backdrop of constant battling against food and one's own disobedient body has consequences for the relationships between participants and their families and one of these is loss of adult status.

6.4 Loss of adult status

The daily experience of feeling fear around food and not being able to eat, whilst *wanting* to and *trying* to, has consequences for the relationships between participants and their families. In the previous chapter I discussed evidence that participants now spend more time monitoring their bodies and do this by using body weight as a barometer of disease. This increased surveillance around health state is also carried out by family members but the expression takes a different form. That is, participants feel that their families vigilantly monitor their food intake and have begun to relate to the person with CRC through food, as one might do with a small child. This is experienced by participants as being infantilised and losing adult status.

Within the context of identity, there are comparisons to being childlike. When talking about having people checking up on her to see how much she has eaten, Sally says,

I'd hate it. Because, I'm still a grown adult and if I only want eat to half an egg I'll only bloody well eat half....because you can't lose too much of that self determination or you're going to lose the bit that you need for your own good (p.15)

Sherpa said,

...I mean, like, mothers have *always* been...that's been one of the things is to tempt kids to eat, you know. 'It's good for you'. Um, and all of sudden I'm looking at that you know, and listening to the things they're saying to me and it's like that, you know, going back [to childhood]. (p. 18)

When asked about what it is like to have to attempt eating, Irina too talked about losing adult status. In common with Sally and Sherpa, she likened her eating behaviour to that

of a child. She stated that she sometimes feels frustrated to be eating like a ‘picky kid’ in relation to food and expressed it thus,

...that is *hard*. I mean, it’s a bit like eating, you know, the frustration with picky kids. You know? I see my daughter angsty [sic] over her little girl’s meal and the little darling will eat a certain amount and then she wants to leave it. And [daughter] has spent *so long* preparing that food for her//and I thought ‘the little monkey!...and that’s the way I feel (that people) will look at me (p.13).

Later, Irina likened the way she sometimes feels now when she is chided and censured for not eating, to how she felt when she was a child,

And you know, if you weren’t careful, it’d be pulled out of the cupboard and put on the table for you at tea time if you hadn’t eaten your lunch, or breakfast or whatever. You know? That is *hard*. (p. 14).

The above quote also illustrates that without proper insight, family members assume, despite what the person with CRC says, that being able to eat normally is somehow still under their own control. The amount eaten and the desire for food can be so minuscule as to be almost unbelievable to someone who is well. So, claims of early satiety (a common manifestation), or just not being hungry are sometimes simply not believed. This begins to discredit their own truthfulness. Not being believed with respect to oral intake is deeply distressing to cancer patients who are cachectic (McClement, 2001). It implies that not eating enough is tantamount to not wanting to get well. This can be felt as extreme pressure by the person with CRC, as they struggle to hold their ground as a cogent adult.

It is recognised that some families who are concerned with renutrition for their family member with CRC do develop strategies to increase intake. Arthur termed this ‘fattening up’. McClement (2001) describes this desire to feed a person with CRC as the sub-process of “fighting back” (p.77). She identified vigilant surveillance, coaxing, begging, bargaining, threatening and force-feeding as methods used by family members.

Participants in this study spoke of coaxing and happily, no one described being force-fed. Arthur in particular had experienced bargaining as a strategy for increasing food intake. This was related to family pressure and he gave the following example of his son bargaining with him at the dinner table,

[Son] will sit back next to me and say ‘If I eat that pumpkin, you’ve got to eat those beans, that pumpkin and that bit of cranberry stuff you’ve got there’ (p.

27-28) // I'll eat my pumpkin if you eat three more beans (p. 36).

Arthur later talked about having a 'child-sized portion', overtly labelling his eating behaviour as having regressed. Sally put this slightly differently and talked about needing 'invalid' food, like a mother might make for a sick child. She expressed the desire for her family to acknowledge her need for a more flexible approach around meal times,

Set meal times are probably not right for you when you're not able to eat// because that centres your anxiety on a certain time (p.9)

The perceived waning of adult status for Arthur, has created unpleasant feelings of being in conflict with his family,

If somebody says 'eat it, you've got to eat it'....a little wall comes up, you know? I don't *got* to do anything ///I feel a bit angry (pp.23-24)

In acknowledging the loss of dignity that infantilisation around nutrition causes him, Arthur expressed a desire for food surveillance by others to cease,

Sometimes it's just nice to *be* ...the way my wife or [middle son] treats me, that's just normal....and it is with dignity. Okay, sometimes they say 'Well you should be eating more blah blah blah' But when we go out, she doesn't make a big issue of it//but if you can do....behave the same way as normal.....you just wouldn't feel that pressure of 'something's going on here' (p. 43).

In essence, all the participants wanted their food intake to be regarded as normal. Sally also appreciated it when her disordered eating was not monitored by others,

But they're very good at the hospice, the way they put food down in front of you, (then) they take it away without comment. That's good. (p. 40).

Sherpa also described feeling pressured to eat,

Well I'll say that it creates a bit of guilt ah, in *both* parties. One for the person who's not eating and the other for the party that is preparing the food and *trying*, you know.... (p. 18)

Within this expression, Sherpa subtly indicates recognition that cajoling a loved one to eat is done with the best of intentions and that it indicates trying to help. However,

it is still experienced by participants as unwanted pressure and these excerpts illustrate that this can be experienced as a contributory factor to suffering. McClement (2001) found that being cajoled by family members to eat despite feeling anorexic did anger patients and only one participant in her sample reported positive feelings about being encouraged to eat. In contrast, all the informants in this study were mostly positive about the increased vigilance. I asked Bill about this,

M: Did you ever wish that people would leave you alone, with regards to food?

B: No. I was grateful for their help. I didn't always like what they did but I was very grateful because I knew that they were working on my behalf.//don't push it [don't push help away]. No, I could understand that though, I could. If someone was really pushing and said 'You must eat this up' and got grumpy, it would be very stressful. (p.22).

Irina said,

I know one particular friend and we could have meals as often as we liked there// she's quite, you know, *careful* about food and she'll want to please me and she'll want to put food in front of me that I would enjoy and eat. And then if I just said 'Look, sorry but I can't eat any more of this'//um, it would be, it would be tricky [laughs]//I would just feel bad about it. Irina (p. 17)

When asked about feeling pressured to eat, Sally said something similar,

..you feel a little bit of it (pressure) when someone prepares you any food because I mean, it's all in your background and upbringing if someone prepares you food, you eat it. (p. 10)

Irina added to this,

Well there is always an element of that when somebody's gone to the trouble of preparing you a meal and you're obviously not enjoying it....that is *hard*.//...I would *like* to be able to say I enjoyed it but it's *hard*. "...it is the pressure that you do feel and of course there's always this element of being brought up in homes where you jolly well ate what was put in front of you and um...you know....you didn't waste your food (p. 14)

Bill described similar feelings when I asked him how he felt when he put food in his mouth that he did not want to eat,

Well, it didn't feel good at all and I'd only eat a little bit of some things.....i just had a spoon of it and I couldn't have any more so I felt guilty because I'd disappointed the people who had made it and they were worried because they thought what on earth can they do? (p. 17).

In the above statements, there is recognition of reciprocity which develops as each tries to please the other. The person trying to eat aims to please the person who is trying to help them to eat. This is a normal expression of love and regard as preparation of food by family for the person with CRC is underscored with notions of nutritional sustenance necessitating health (Holden, 1991). All participants in fact felt that their family members wanted them to increase intake for beneficent reasons and largely deeply appreciated their concern. However, this was tempered with a desire that family didn't keep pressuring them. It would appear that being related to via a conduit of food has potential to be experienced as a feeding relationship similar to that between a parent and child. Thereby, having to accept the ebbing of adult status is tolerated by participants with CRC out of a desire not to cause their families any more distress than that which they naturally feel about their loved one having end stage cancer. So, there are increasing demands made of the patient at what is already an immeasurably difficult time in their lives. This is likely to be, in part, because permission not to eat is difficult for family members to give. It is known that greater awareness of the inability of sufferers to control intake may mitigate relationship breakdown (Hinsley & Hughes, 2007) and ease anxiety which profound anorexia creates within the family (Poole & Froggatt, 2002) but these participants did not benefit from this information because they simply did not receive it. This clearly reiterates the need for more complete truth-telling.

A changing body image, dysfunctional relationship with food and the loss of adult status within the family that these create for participants, prompts adoption of yet another coping strategy to weather the cumulative effects of all that has gone before. That is, the decision to withdraw from the social world in an effort to mitigate their own suffering. The experience of this is now described.

6.5 Withdrawal from the social world

A changing physical appearance and an altered relationship with food has resulted in the social consequence of isolation for some participants. All the participants felt as though people looked at them differently now. For some, this has fostered feelings of isolation which set the precedent for seeking to withdraw from social interaction outside the home. Sally, Sherpa and Arthur all spoke about not going out in public

because of their wasting appearance. Bill also gave an example of this,

B: The first time I was seen by people after the operation was when the band came to see me as you can see, I'm very frail and probably only about 53 kilograms

M: Were you nervous about people seeing you?

B: Yes I was. Yes I was. I was in two minds. People rang me up to come and see me and I was almost in two minds to say either yes or no.

M: Why?

B: Partly because I didn't want to see my old friends when I was looking so, looking gaunt

M: What did you think they would think?

B: I don't know. I just thought oh, you look terrible (p.30).

Sally had also been affected by this,

M: How about the way you look at the moment, given that it's different from how you did [look before]. Has that had any effect on you? Do you think people look at you or has it stopped you going out?

S: Oh, that's horrible. Uh, because I lost a lot of weight quite rapidly people did look at me like that and no, I don't like that.// and ah, you do tend to become reclusive.(p.10)

Sally felt that physical tiredness was the main cause of her isolation but says this about looking different now,

Sometimes I almost feel [like] going past someone in the street or driving past with [son] in the car and stopping and apologising 'Yes, I'm alive' Because they've all written me off. Like I'm a ghost, you know? (p. 38)

Sherpa too, spoke about his experience of entering the social world within an altered body. He is not going out in public now as much as he used to and I asked him if that was related to his changed appearance. He said,

..there is an element of that because if you go out...um, I mean clubs, organisations that I belong to they will recognise (that I have cancer) right away. Now, whether they say anything about depends on the individual, you know. And that would be a sort of a bar. Um, it would discourage you *from* going out, if I did. (p 13)

There can sometimes be pressure from family which further impacts on social isolation. For Arthur, it is sometimes his family who encourage him to withdraw,

A: When I was first crook, I'd go to the supermarket. It's only a block away from where we live. My [wife] is saying 'Don't go there'. Why not? She said 'You'll run into people you know. I said 'Darling, I walk past them every day. They don't recognise me. Some of them would come up and say "I'm really sorry'. I said 'why? (They said) 'I've spent months looking at you thinking 'poor bugger'.

M: And why do you think that she didn't want you to bump into those people (was it) because she felt you would have hurt feelings?

A: (wife was) scared. Small town// You can actually see them thinking 'poor bastard' (p. 18)

This is an example of 'shielding' sufferers from the potentially discomforting reactions of others in response to the altered outward body image. It is recognised as a protective strategy which family members sometimes enact in defence of a loved one who has CRC (McClement, 2001). Arthur has a high profile in his community and his diagnosis of multiple myeloma was reported in the local paper. He talked about his wife being horrified about this, but he wanted people to know because he felt that people might perceive his physical wasting as being related to AIDS.

In contrast, Simon wasn't troubled for the same reasons when going out in public perhaps in part because at the time of interview, he still appeared to be of normal body weight. He was quite definite that he did not avoid going out due to weight loss. He felt, that if anything, he was more bothered by his treatment-related hair loss.

The common subtext within these expressions is that the altered body is experienced as one which publicly denotes each person's 'cancer victim' status. Thereby, one of the most fundamentally private states (ill health) becomes a matter for public perusal and commentary and this is completely beyond control by the sufferer. Feelings of being 'different' with regards to appearance have been implicated in contributing to social isolation amongst people who have CRC (Hinsley & Hughes, 2007). Van Manen (1990) discusses this phenomenon as a loss of taken-for-grantedness and this

has been described earlier within the theme ‘loss of sense of self’. In describing the experience of seeing one’s own body as others see it, Charmaz and Rosenfeld (2006) coined the phrase “the looking glass self” (p. 37) which is both social and subjective and is dependent upon social interaction. Perhaps Sartre (1956) gives the most cogent description of this idea by stating “I cannot be embarrassed by my own body as I exist it. It is my body as it is for the Other which may embarrass me” (p. 353). In essence, for these participants, the aspect of their lives that is CRC becomes an open book to the wider world because the body is read as text. The discomfort this creates results in reluctance to enter the wider social world. This is compounded by challenges met within the social world of food.

Food is an important aspect of any culture and is used to create and maintain relationships (Ikeda, 1999). In this way, eating is a social activity and not being able to eat socially acceptable amounts also contributes to social isolation for the participants, as they withdraw from the social world of eating. Irina and others expressed a desire to hide the fact that they were not eating or hide the amount, because it would be seen as unusually small. Here, Irina talks about attending a birthday party where the food was served as a buffet,

Where you can *hide* it, it’s ok.//and I was able to get way with that simply because it was a big afternoon tea and you could eat as much or as little as you liked..... and it wouldn’t be noticed, you know? (p. 16).

The expressions here illustrate the fear of societal judgement and watching. Like a naughty child, the consequences of not being able to ‘eat up’ are actively avoided by attempts to disguise intake which might be perceived by others as disordered. This echoes the waning adult status as intake, like the body, becomes something which is publicly surveilled.

You’d like to be able to eat up and...please them. I just don’t...I always avoid sort of, accepting dinner invitations from...or going anywhere I’m expected to eat with other people or whatever....I turn down party invitations and things like that (p. 15).

It was a fortieth birthday party and it was going to be in style at a restaurant over in [city]. And I really didn’t feel as though I had the strength to cope with that.... but then I thought you know, they’ve paid for an expensive meal for us and I sort of pick (at the food). You know, don’t do it justice. I don’t think that’s on really. (pp.15-16).

Arthur, Sally, Bill and Sherpa also felt discomfort around food intake when in public. This indicates reluctance to eat outside the domestic world of the family, as following the normal societal rules around eating becomes another burden to endure. There is also continuity and stability embedded with eating patterns and behaviours (Beardsworth & Keil, 1997) and destabilisation of this compounds isolation from the social world of food. Insulation from normal routines can also be brought about by the loss of appetite which is almost universal in CRC. Each day has a rhythm revolving around food and not being able to consume in a normal way can distance someone from the social world they have come to know.

Irina expresses losing her sense of order and structure as the normal eating routine has become eroded

You live within this sort of regime don't you, of um, breakfast at a certain time, lunch, dinner. They're a framework around which you build your day and if you send that out the window (p. 39).

6.6 Conclusion

Building upon themes described in chapter five including coming to know, knowing in progress and dissatisfaction with truth-telling, this chapter continues the description of meanings attributed to the CRC experience by participants. The emergence of a new sense of self and identifying as one who presents as wasting, sets the scene for social consequences, as challenges begin to accumulate. Inability to continue eating normally creates an environment both inside and outside the home which is experienced as irrevocably different than it was before CRC. As the orientation towards food alters from one of normality to one of combativeness, a shift in familial relationships occurs. This revolves around a loss of adult status, as family members take on the monitoring of food in a way which is experienced by participants as evocative of childhood. As participants vacillate between attempting to please family, and recoiling against waning adult status whilst fighting to meet their own needs, their quality of life is affected.

This process is undertaken against a backdrop of increasing social isolation and accelerating feelings of difference. In order to minimise the potential for negative effects of social interaction, withdrawal from the social world is chosen as a necessary strategy, as participants attempt to avoid subjection to increased private and public surveillance around their physical appearance and nutritional intake.

CHAPTER SEVEN: DISCUSSION

7.1 Introduction

The previous two chapters have presented the analysis of data. This thesis is now concluded with a discussion of the findings, positioning these with relevance to nursing. The primary aim of this research is to produce an account of the CRC experience from the perspective of the sufferer. First, a summary of the findings is described in relation to the primary aim. This allows the secondary aims to be addressed. These are, to provide direction for future nursing research into CRC, and to begin producing recommendations for improved nursing practice. Synthesis of findings is discussed in relation to these secondary aims. Perceived limitations of this research project are described and reflections on the research process are considered. Finally, the concluding statement is made.

7.2 Summary of Findings

Just as the aetiology of CRC is poorly understood, complex and multi-factorial, so is the experience of living with it. In order to move through this journey intact, participants are required to participate actively with a changing body. This human endeavour is undertaken not in private, but within the social world and the challenges this produces are significant.

It does not appear to be usual that people are informed of the syndrome that they are experiencing. This is manifested in the expressed need for more information about CRC, before it became physically evident and symptoms progressed. A commonly held perception was that eating meant getting well. Body weight subsequently became a disease barometer by proxy, as did the amount of oral intake. Body weight and oral intake, having now been ascribed great importance as objective measuring tools of disease state, become vital indicators of health. This reinterpretation of weight and nutritional intake led to acceleration of the monitoring frequency of these barometers, in an ongoing effort by participants and their families to assess health. As weight gain and increased appetite became desirable proof of an improving disease state, pressure was exerted, by family on participants, to eat more. Participants and their families developed complex coping strategies during this time. Strategies developed by families to assist disordered eating included bargaining, cajoling, tempting, and censuring intake when it was perceived to be too small. Strategies were developed by participants to help themselves. These included avoiding food perceived to create

painful consequences, seeking only food that they considered ‘easy’ to eat, searching for food knowledge and rediscovering foods from childhood.

Participants experienced the physical effects of cachexia, including weakness, anorexia and asthenia. One consequence of this was an altered ability to function physically (competently) within the world. In an effort to make sense of their experience, participants reconstructed their sense of self. A loss of sense of self was endured as each participant experienced diminishing sense of control over their previously obedient and competent body. Being ‘less competent’ with regards to bodily control and nutritional intake, coupled with the need of family to increase surveillance of weight and intake, was expressed as a loss of adult status. This loss of adult status was compounded by a lack of truth-telling born of paternalism. Valuable knowledge which might have been used by the participants and their families to better approach issues around eating was denied, further robbing these adults of the potential for their altered eating behaviours to be properly acknowledged and understood.

The effects of CRC on the body and on eating behaviour cannot effectively be hidden and are open to interpretation or misinterpretation by others within the social world. This compounded the already significant repercussions of CRC for these participants. As participants became thinner, heightening visibility of disease, loss of taken-for-grantedness increased and was reinforced by the reactions of others. Similarly, disordered eating became subject to public perusal as evidence of disease. This increasing vulnerability to being assessed by others culminated for participants in withdrawal from the social world of people and the social world of food, as they sought to self-limit interaction to avoid being watched and therefore judged.

The complex adaptive strategies described above, allowed obstacles to be navigated. They are the biographical work necessarily undertaken by these participants to ‘survive’ the experience of CRC.

7.3 Discussion

The journey described above is undertaken by each participant without reference to a map. For each participant, and their families, the coping strategies described above were self-initiated and self-taught. The main reason for this is that not enough information had been given to indicate for participants and families what to expect such as, how to approach eating and the likely physical symptoms and signs experienced as CRC develops. A particularly significant problem arises from this. Because not enough information had been given, family and patients had no awareness that CRC

is not dependent upon intake and this firmly held misconception is in fact, hopelessly wrong. Other people with CRC have expressed the view that if they eat, they will get better (Hinsley & Hughes, 2007). By not discussing CRC properly, the potential effect for participants is to have increased pressure placed upon them to eat. People around them can be inclined to think that eating more will help the person with CRC gain weight. Because calorie intake does not influence weight loss or gain in CRC (Winkler, 2004), any pressure to eat is misplaced and unfair. As described, the inability to consume 'normally' can cause the person with CRC to be perceived as being less than competent to monitor their own intake, and so a child- parent relationship towards feeding develops. The paradox here is that children "have an innate ability to self-regulate energy intake" (Ikeda, 1999, p.157), yet this is denied the adult with CRC.

There is an apparent tendency for participants to tolerate increasing pressure and infantilisation. This evolved out of desire to assist coping by their families, but was experienced as stressful. Participants expressed dissatisfaction with the lack of truth-telling by nurses and doctors and felt they and their families might have benefited from more complete disclosure. It is considered likely that lying by omission increases the existential suffering within the context of CRC and is grossly unfair.

Nursing traditionally regards the artful combination of words, touch, education and treatment to be the most potent of therapeutic interventions. This tends to be driven by the tenet deemed central by nurses to nursing practice - holism. Fulfilling this principle requires engaging with patients as complete beings and not the sum of their signs, symptoms and body parts. Pride is taken by the profession in having the insight and willingness to engage holistically, particularly in areas which are perceived in nursing as having been overlooked by medicine. Why then, has the very form of engagement most strongly espoused from within our own profession, been overlooked within the context of CRC? Possible reasons for this are now discussed.

7.3.1 Adoption of the medical gaze

CRC is most often recognised by the classic clinical appearance of someone who is obviously wasting or has experienced weight loss which is deemed to be significant. In my clinical experience, cachexia is not acknowledged as being a problem which warrants attention, until this type of presentation is in evidence. The dominant CRC discourse in medicine is focussed on investigation of drugs or serum markers to develop diagnostic tools. Medicine is eerily silent with regards to the human experience of CRC. Only when cachexia becomes severe enough to prompt visual recognition of it, are supportive measures considered. Even then, there is a lack of open discussion with

the patient. Ultimately, it seems that visual prompting (by presenting as wasting) is necessary before the syndrome is addressed in an indirect and opaque way. Although it is beginning to be recognised that CRC happens very early along the cancer trajectory, this is not the traditional or dominant way that understanding of CRC has been expressed. Participants in this study described the perception that nutritional and body weight issues are perceived as separate to the medical brief and that medicine did not attempt to engage in discussion about these. Except Simon, all the participants in this study did appear clinically cachectic and although Simon did not, he had lost a significant amount of weight (20kg). Even for these obviously cachectic participants (thereby giving the required visual clues), CRC had not been openly addressed by doctors. It may be that nursing practices have been modelled to some degree on the dominant explicit discourse. It may be that nursing has adopted the medical gaze towards CRC and silence has been modelled upon this. Therefore, the hegemonic power of medicine to influence the clinical milieu to the extent that nurses disengage with their own philosophical approach to practice is considered a potential reason for silence.

7.3.2 Lack of understanding about the experience.

It is possible that nurses do not have a comprehensive understanding of the syndrome and therefore perceive themselves as ill-equipped to provide reliable information in a timely fashion to people with CRC and their families. Given the dearth of literature describing the patient experience of CRC, and the current climate of minimal disclosure, this could be seen as a reasonable explanation. It is however, unacceptable given that the nature of the problem and its attendant consequences fall so clearly in the domain of needing nursing care and management. When viewed from the perspective of an experienced clinician, this possible reason begins to appear less plausible. In chapter three, I discussed qualitative description and the reasons why this methodology complemented investigation into the CRC experience. Within this explanation is the expressed notion that qualitative description is not about generating new truth, but describing cogently, the truth that already exists within the experience of CRC. Additionally, meaningfulness of this project will in part be judged as valid if nurses familiar with CRC recognise truth in the outcomes and perceive this to be a credible piece of work. The implication here is that many experienced oncology nurses do already have the required knowledge to engage effectively in communication with patients and their families about CRC, what that is, and why it has occurred.

7.3.3 Conflict

Nurses sometimes practice deception based on the held perception that it is ‘not up

to a nurse' to disclose a diagnosis to a patient. There is some evidence to suggest that nurses tend not to give information which they know has not been first disclosed to the patient by a doctor, thereby, actively maintaining institutional hierarchy. This is a significant issue as it has been reported that 87% of nurses experience conflict with physicians about truth-telling (Sullivan, Menapace & White, 2001). Displays of mandated obedience to (male) physicians by (female) nurses has been the historically desirable relationship dynamic. Overt disobedience is undesirable to doctors and sometimes censured, leading to frustration at powerlessness for nurses (Farrell, 2001). It is argued that this frustration culminates in the enactment of horizontal violence and that the tendency is for nurses to adopt the dominant values of the oppressors, in conflict with their own philosophical standpoint (Daiski, 2004). Membership in the dominant group becomes coveted, leading to imitation of the admired oppressors. It is this imitation of the admired dominant behaviours which may have lead to adoption of the medical gaze discussed in section 7.3.2. This has lead to nursing relationship patterns being described as "oppressed group behaviours" (Daiski, 2004, p. 44). The result is that acting in conflict with the example of the dominant group is interpreted as subversion and may have undesirable consequences for the truth-teller.

On occasion, I have observed this in practice. I have heard nurses express the perception that engaging in truth-telling that is 'not allowed because the doctor hasn't told them yet' will result in 'getting into trouble'. Following this notion to its natural conclusion would indicate that patients are never likely to be told about CRC by a nurse because it is not discussed explicitly by medicine with patients and therefore, permission for disclosure by the nurse will not have been directly nor indirectly given. Such practice can in no way be condoned and breaches the prime responsibility of the nurse as a duty of care towards the patient, regardless of personal discomfort.

7.3.4 Ethical principles

Despite the fact that the use of deception is described as rare in quantitative investigation of nurses' truth-telling practices (Teasdale & Kent, 1995) this is not in evidence with regard to CRC. The principle of beneficence could be applied to argue both for and against truth-telling. Anecdotal evidence describing nurses' attitudes to information-giving about CRC described in chapter one, indicates there may be a tendency for nurses to use beneficence as a defence for withholding knowledge. Perhaps in nursing, some of the evident reluctance to disclose the truth when the truth is perceived as unpalatable has also arisen from the uncertainty principle. The uncertainty principle suggests that there is always an element of uncertainty about diagnosis and prognosis. Therefore, it is argued that complete truth-telling can never be achieved and to allow

patients to believe they are in possession of the complete truth is wrong (Tuckett, 2004).

In essence, the reasons for incomplete truth-telling about CRC by nurses are not clear. Possible explanations have been discussed and it may be that the explanation is likely multifaceted. Whatever the reason for it, this research indicates that nurses' silence has powerful potential to affect the experience of people with CRC. I have the sense that there is a degree of unconsciousness in this ongoing silence. Investigation into the experience of CRC from the sufferers' point of view is a recent phenomenon, producing a meagre handful of small qualitative explorations to date. This may have contributed to an environment which facilitates permission to overlook some forms of engagement with the patient (such as truth-telling). If we do not know what the truth is, how can we speak the truth? I have argued in section 7.3.2 that there are obstacles to the perceived validity of this idea but there may be some truth in it. But even if there exists a lack of knowledge about the *experience* of CRC amongst oncology nurses, it is inconceivable that there is also a lack of knowledge about the *existence* of the *actual syndrome*. Therefore, there is still no reasonable explanation for silence.

There is an issue related to CRC diagnosis which has become apparent whilst conducting this research. It is interesting and important that this issue be noted because the consequences have significance for nursing. In the very final stages of this thesis, I discovered literature emerging from a medical viewpoint acknowledging that cachexia is in fact phenotypically present often even at the time of initial cancer diagnosis, before weight loss is in evidence (Muscaritoli, Bossola, Aversa, Bellantone, Fanelli, 2006). This is a new way for CRC to be described and confounds the traditionally expressed view. The significance is that CRC may one day soon be recognised as an early beacon for cancer, and not a late, ineluctable consequence of progressive disease. If CRC is likely to be recognised in the future as a common and early cancer-related syndrome, and tools are developed to reliably diagnose CRC before it is clinically evident, this may create an environment whereby open discussion is mandated. It will no longer be considered conscionable to withhold knowledge about CRC from patients. The appreciable effect for nursing may be a subsequent shift towards earlier disclosure. This will require that CRC becomes reframed by the profession as something no longer hidden and easy to dismiss. Goals in relation to CRC must focus on early intervention and this is the area which nursing appears to overlook most consistently.

This thesis provides a clear mandate for nursing to reflect on current practice with regards to CRC. While I advocate for more complete truth-telling, this is with the caveat that serious thought and meaningful reflection is necessary in order for this to

be done in the best way *and* for the best reasons. I do not suggest that all people who have CRC would prefer to have more information. Rather, I suggest that practitioners should rely on effective therapeutic communication to first elicit patients' preferences for degrees of truth-telling.

7.4 Limitations

This research is considered to be an exploratory study. This is a small-scale investigation which was undertaken in part, to decide whether to launch a larger scale inquiry and how this would best be achieved. The small and exploratory nature of this thesis was dictated by three things. Firstly, that the perceived paucity of literature describing the CRC experience from the patients' point of view required a tentative approach towards building upon a small amount of literature to provide a firmer base for research direction than that which currently exists. Secondly, this research is the first of its kind in New Zealand to approach end-stage cancer sufferers with the explicit purpose of collecting qualitative data generated by open discussion about CRC. This was best achieved on a small scale. Thirdly, in relation to the masters degree, prescribed time limitations necessitated a concise approach. The result is that data generated in partnership with the participants is not generalisable.

It would be disingenuous to state that data saturation occurred. Data saturation simply was not possible when conducting one-off, minimally structured interviews about the human experience of a complex phenomenon, with 6 participants. Nevertheless, this does not negatively impact on the veracity of analysis in chapters five and six. This is because the fundamental characteristic of qualitative research is one of eschewing the notion of universal truth, in favour of accepting multiple realities. What has been created within this thesis is an authentic description of some aspects of the CRC experience. I call this the 'polytruth' of CRC.

Clearly, this research is not longitudinal. All participants had advanced cancer and except for Simon, presented as obviously wasting. It might be that collecting data at an earlier stage in the CRC trajectory produces different descriptions of the way CRC is experienced. Expressed needs may be very different in early stages of the syndrome, compared to those expressed in later stages. If so, this could be applied to both the psychological and physical polytruths of the experience and warrants consideration.

The behaviours and meanings of health and illness, nutrition, and body- image are culturally diverse across ethnicities, cultures and socio-economic status (Ikeda, 1999).

Although no one was excluded from participation based on ethnicity, all informants who contributed to this research were Caucasian New Zealanders of European descent, who did not identify themselves as being affiliated with Maori iwi. Therefore, it must be accepted that the resulting data reflects the experience of a mono-cultural group. Given that the cultural context of eating, food and body image are known to affect the way in which people identify and embody these things, research in partnership with members from the wider cultural group within New Zealand would enhance knowledge from which recommendations might be made. Similarly, body image is gendered within most societies. Of these participants, four were male and two were female and all participants were heterosexual. Notwithstanding the small number of participants, it is possible that bias related to gender-sensitive or sexual orientation-sensitive issues have been introduced. Whilst not clear from this research, men and women may experience some consequences of CRC in markedly different ways and these experiences could also be influenced by sexual orientation. It is considered likely that further investigation of these ideas would be helpful.

7.5 Reflections

Through this research I have gleaned that the experience of CRC is a larger world than that which I had imagined, despite my clinical experience. Sometimes we do not 'hear' people, or do not fully comprehend their meaning until much later, when a situation emerges prompting re-evaluation of something previously seen or heard. During recent months, I found cause for reflection on long past conversations with sufferers of CRC and, like the participants in this study, I began to reframe my own ideas as these began to shift from something known to something unknown and sometimes, back again. I find it difficult to adequately express the extent of my own learning about the research process and CRC during this time. Rather, I am left with the sense that it is only the undertaking of future research which will allow me to realise some of the lessons to be learned within this project.

I have particularly reflected on the issue of truth-telling about CRC and how this relates to the research process. One truth-telling issue within this project is that of having to first inform patients that they have CRC in order to recruit participants. This was undertaken with the knowledge that it is the research itself which most likely is the only reason that patients were told about CRC at all. Therefore, it becomes a moral issue. This led me to experience a period of careful consideration during the time that I spent writing the Participant Information Form (PIF). I wondered how it might be possible to responsibly and purposively sample for CRC sufferers without first telling them explicitly that they have CRC. Other studies of this type use euphemisms in

these cases and the word ‘cachexia’ is kept secret. I felt it was morally important, in considering the principles of informed consent, that full engagement with the word cachexia was required. I now perceive that discussing CRC is a requirement to open up opportunity for sufferers to engage with research. This was not experienced as detrimental to the participants in this study.

Reflecting on recruitment difficulties, there are things I would approach differently if I were to commence this project again. Principally, I would seek to avoid the ‘outsider’ status, which I believe greatly hampered recruitment. By seeking to recruit participants from institutions where I was not part of the clinical team, I ceded control over who might be approached and offered the PIF and who might not. Others became the gatekeepers. The feeling which emerged for me was that clinicians working with end stage cancer patients assumed that people at this stage of illness would prefer not be ‘bothered’ by participating in the project. This is in direct contrast to evidence that people with end-stage cancer value the opportunity to participate in minimally structured research interviews about their experiences (Barnett, 2001). I fully appreciate that this type of participant vetting no doubt stemmed from real respect and regard for the patient, but I argue strongly that this attitude is misplaced. As stated in chapter three, a total of fourteen people were given the PIF and referred to me. Seven of these subsequently declined to participate. This would tend to indicate that people experiencing a high degree of morbidity are eminently capable of making up their own minds. Thus, the paternalism inherent within this type of gatekeeping is situated in opposition to ethical practice.

7.6 Recommendations

This research has generated recommendations for nursing research and nursing practice.

7.6.1 Research

The silence nurses keep about cachexia indicates tacit unwillingness to deliver nursing care in accordance with the holistic paradigm. The reasons behind the genesis of this are not known. Investigation of nursing beliefs about, and behaviours towards, cachexia is recommended. Knowledge about something informs the attitude towards it. Therefore, in order to better understand nurses’ attitudes towards CRC, it might be useful to first assess knowledge. This might contribute towards understanding the context in which the profession has developed an apparent preference for silence. In

addition, understanding how well prepared nurses are to engage in CRC discussion has the potential to successively influence improvements in CRC education for nurses and patients.

Continuing research aimed at explaining the patient experience is also recommended. A substantial amount of research is needed in this area before a comprehensive description can be disseminated in literature. More careful investigation has the potential to inform practice to the extent that it will ultimately effect meaningful change in the majority of people living with CRC.

7.6.2 Praxis

This discussion highlights the requirement for practitioners working in this field to develop more fully the role of patient advocate with regards to CRC. It is apparent that nurses' silence contributes to the burden of having to self-initiate and self-learn coping strategies. Intense consideration by the profession of ways to ameliorate suffering is recommended. Earlier disclosure of CRC might be experienced by patients as beneficial. Education for patient and families, particularly about the loss of voluntary control around eating is also strongly recommended.

In place of the focus being on intake and weight, perhaps the benefit to the patient lies more with a focus on quality of life. Assisting patients and families to reorientate focus away from the perceived 'barometers of disease' and towards practices that enhance quality of life, has potential to mitigate the perceived erosion of family relationships.

7.7 Concluding statement

This thesis is a specific inquiry into the way in which CRC is embodied by 6 participants who have end-stage cancer. It emerged that knowledge of CRC was learned as a direct result of participation in this study. Participants identified that how they and others viewed their bodies altered over time. This led to a shifting and fluidity around body image, the way they saw themselves and the way others saw them. It emerged that a perceived lack of information about CRC contributed to existential suffering. Rather than preventing demoralisation felt by patients, the silence of our profession contributed to it. One tenet of exemplary nursing practice is holism and this is not clearly evidenced in the current nursing approach to CRC. Cachexia is part of our brief and the management of the patient experience of it, would appear to warrant that nurses pay it greater attention.

REFERENCES

- Agteresch, H. J., Rietveld, T., Kerkhofs, L. G. M., van den Berg, W. O., Wilson, J. H. P., & Dagnelie, P. C. (2002). Beneficial effects of adenosine triphosphate on nutritional status in advanced lung cancer patients: A randomized clinical trial. *Journal of Clinical Oncology*, *20*(2), 371-378.
- Al-Majid, S. (2008). The biological mechanisms of cancer-related skeletal muscle wasting: The role of progressive resistance exercise. *Biological Research*, *10*(7), 7-20. Retrieved December 4, 2008, from <http://brn.sagepub.com/cgi/content/abstract/10/1/7>.
- Argiles, J. M., Meising, S. H., Pallares-Trujillo, J., Guirao, X., & Lopez-Soriano, F. J. (2001). Cancer cachexia: A therapeutic approach. *Medical Research Review*, *21*(1), 83-101.
- Arraf, K., Cox, G., & Oberle, K. (2004). Using the Canadian Code of Ethics for registered nurses to explore ethics in palliative care research. *Nursing Ethics*, *11*(6), 600-609.
- Attride-Stirling, J. (2001). Thematic networks: An analytic tool for qualitative research. *Qualitative Research*, *1*(3), 385-405.
- August, D. A. (2003). Nutrition and cancer: Where are we going? *Topics in Clinical Nutrition*, *18*(4), 268-279.
- Barber, M. D., Ross, J. A., Voss, A. C., Tisdale, M. J., & Fearon, K. C. H. (1999). The effect of an oral nutritional supplement enriched with fish oil on weight-loss in patients with pancreatic cancer. *British Journal of Cancer*, *81*(1), 80-86.
- Barnett, M. (2001). Interviewing terminally ill people: Is it fair to take their time? *Palliative Medicine*, *15*, 157-158
- Beal, J. E., Olson, R., Laubenstein, L., Morales, J. O., Bellman, P., Yangco, B., et al. (1995). Dronabinol as a treatment for anorexia associated with weight loss in patients with AIDS. *Journal of Pain and Symptom Management*, *10*(2), 89-97.
- Beardsworth, A. & Keil, T. (1997). *Sociology on the menu: An invitation to the study of food and society*. London: Routledge.
- Beck, C. (1993). Qualitative research: The evaluation of its credibility, fittingness, and auditability. *Western Journal of Nursing Research*, *15*, 263-266.
- Bernard, H. R. (2006). *Research methods in anthropology: Qualitative and quantitative approaches*. (4th ed.). New York: Altamira Press.

- Bosaeus, I., Daneryd, P., Svanberg, E., & Lundholm, K. (2001). Dietary intake and resting energy expenditure in relation to weight loss in unselected cancer patients. *International Journal of Cancer*, 93(3), 380-383.
- Bossola, M., Muscaritoli, M., Bellantone, R., Pacelli, F., Cascino, A., Sgadari, A., et al. (2000). Serum tumour necrosis factor- α levels in cancer patients are discontinuous and correlate with weight loss. *European Journal of Clinical Investigation*, 30,(12), 1107-1112.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Brown, J. K. (2002). A systematic review of the evidence on symptom management of cancer-related anorexia and cachexia. *Oncology Nursing Forum*, 29(3), 517-530.
- Bruera, E. (1994). Ethical issues in palliative care research. *Journal of Palliative Care*, 10(3), 7-9.
- Bruera, E., & Neumann, C. M. (1998). Management of specific symptom complexes in patients receiving palliative care. *Canadian Medical Association Journal*, 158(13), 1717-1726.
- Bruera, E., Strasser, F., Palmer, J. L., Willey, J., Calder, K., Amyotte, G., et al. (2003). Effect of fish oil on appetite and other symptoms in patients with advanced cancer and anorexia/cachexia: A double-blind, placebo-controlled study. *Journal of Clinical Oncology*, 21(1), 129-134.
- Bruera, E., & Sweeney, C. (2000). Cachexia and asthenia in cancer patients. *The Lancet, Oncology*, 1, 138-147.
- Burnard, P. (1991). A method of analysing interview transcripts in qualitative research. *Nurse Education Today*, 11,(6), 461-466
- Burnard, P. (1994). Searching for meaning. *Nurse Education Today*, 14,111-117.
- Charmaz, K., & Rosenfeld, D. (2006). Reflections of the body, images of self: Visibility in chronic illness and disability. In D. Waskul & P. Vannini (Eds.). *Body/embodiment: Symbolic interaction and the sociology of the body* (pp.35-49). Burlington, VT: Ashgate.
- Cimino, J. E. (2003). The role of nutrition in hospice and palliative care of the cancer patient. *Topics in Clinical Nutrition*, 18(3), 154-161.
- Collins Australian Dictionary* (7th ed.). (2005). Sydney: HarperCollins.

- Cope, D. (2002). Management of anorexia, cachexia and weight loss in patients with advanced cancer. *Clinical Journal of Oncology Nursing*, 6(4), 241-242.
- Corner, J. (1996). Is there a research paradigm for palliative care?. *Palliative Medicine*, 10(3), 201-208.
- Crotty, M. (1996). *Phenomenology and nursing research*. Melbourne: Churchill Livingstone.
- Dahele, M. & Fearon, K. C. H. (2004). Research methodology: Cancer cachexia syndrome. *Palliative Medicine*, 18(5), 409-417.
- Daiski, I. (2004). Changing nurses' dis-empowering relationship patterns. *Journal of Advanced Nursing*, 48(1), 4-50.
- Damsky Dell, D. (2002). Cachexia in patients with advanced cancer. *Clinical Journal of Oncology Nursing*, 6(4), 1-5.
- Dean, R. A., & McClement, S.E. (2002) Palliative care research: Methodological and ethical challenges. *International Journal of Palliative Nursing*, 8(8), 376-380.
- de Raeve, L. (1994). Ethical issues in palliative care research. *Palliative Medecine*, 8(4), 298-305
- Emden, C., & Sandelowski, M. (1999). The good, the bad and the relative, part one: Conceptions of goodness in qualitative research. *International Journal of Nursing Practice*, 4, 206-212.
- Evans, W. J., Roubenoff, R., & Shevitz, A. (1998). Exercise and the treatment of wasting: Aging and human immunodeficiency virus infection. *Seminars in Oncology*, 25(SUPPLEMENT 6), 112-122.
- Farrell, G. A. (2001) From tall poppies to squashed weeds: Why don't nurses pull together more? *Journal of Advanced Nursing*, 35(1), 26-33.
- Fearon, K. C., Voss, A. C. & Hustead, D. S. (2006). Definition of cancer cachexia: Effect of weight loss, reduced food intake, and systemic inflammation on functional status and prognosis. *American Journal of Clinical Nutrition*, 83(6), 1345-1350.
- Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative methods*, 5(1), Article 4. Retrieved November 21, 2008, from http://www.ualberta.ca/~iiqm/backissues/5_1/pdf/fereday.pdf
- Ferris, F. D., von Guten, C. F., & Emanuel, L. L. (2002). Ensuring competency in end-of-life care: Controlling symptoms. *BMC Palliative Care*, 1(5).

- Finley, J. P. (2000). Management of cancer cachexia. *Advanced Practice in Acute and Critical Care*, 11(4), 590-603.
- Gillis, A., & Jackson, W. (2002). *Research for Nurses: Methods and Interpretation*. Philadelphia: F.A. Davis Company.
- Grbich, C. (2004). Qualitative research design. In V. Minichello, G.Sullivan, K. Greenwood, & R. Axford. (Eds.), *Handbook of Research Methods for Nursing and Health Science* (2nd edition ed., pp. 151-175). Frenchs Forest: Prentice.
- Hedestig, O., Sandman, P.-O., Tomic, R., & Widmark, A. (2005a). Living after external beam radiotherapy of localised prostate cancer: A qualitative analysis of patient narratives. *Cancer Nursing*, 28(4), 310-317.
- Hedestig, O., Sandman, P.-O., Tomic, R & Widmark, A. (2005b). Living after radical prostatectomy for localized prostate cancer: A qualitative analysis for patient narratives. *Acta Oncologica*, 44,(7), 679-686.
- Hemming, L., & Maher, D. (2005). Understanding cachexia and excessive weight loss in cancer. *British Journal of Community Nursing*, 10(11), 492-495.
- Heys, S. D., Walker, L. G., Smith, I., & Eremin, O. (1999). Enteral nutritional supplementation with key nutrients in patients with critical illness and cancer: a meta-analysis of randomized controlled clinical trials. *Annals of Surgery*, 229(4), 467-477.
- Higginson, I., & Winget, C. (1996). Psychological impact of cancer cachexia on the patient and family. In E. Bruera & I. Higginson (Eds.). *Cachexia-anorexia in cancer patients*. Oxford: Oxford University Press.
- Hinsley, R., & Hughes, R. (2007). The reflections you get: An Exploration of body image and cachexia. *International Journal of Palliative Nursing*, 13(2), 84-89.
- Holden, C. M. (1991). Anorexia in the terminally ill: The emotional impact on the patient and the family. *The Hospice Journal*, 7(3), 73-84.
- Holder, H. (2003). Nursing management of nutrition in cancer and palliative care. *British Journal of Nursing*, 12(11), 667-674.
- Hopkinson, J. B., Wright, D. N. M., McDonald, J. W. & Corner, J. (2006). the prevalence of concern about weight loss and change in eating habits in people with advanced cancer. *Journal of Pain and Symptom Management*, 32(4), 322-331.
- Hughes, N., & Neal, R. (2000). Adults with terminal illness: A literature review of their needs and wishes for food. *Journal of Advanced Nursing*, 32(5), 1101-1107.

- Ikedo, J., P. (1999). Culture, food, and nutrition in increasingly culturally diverse societies. In J. Germov & L. Williams (Eds.), *A sociology of food and nutrition: The social appetite* (pp. 149-184). Melbourne: Oxford University Press.
- Jatoi, A., Kumar, S., Jeff, A., & Nguyen, P. L. (2000). On appetite and its loss. *Journal of Clinical Oncology*, 18(15), 2930-2932.
- Jefferson, G. (2004). Glossary of transcript symbols with an introduction. In C. H. Lerner (Ed.), *Conversation analysis: Studies from the first generation* (pp. 13-23). Philadelphia: John Benjamins.
- Kanzaki, M, Soda, K., Gin, P. T., Kai, T., Konishi, F., & Kawakami, M. (2005). Erythropoietin attenuates cachectic events and decreases production of interleukin-6, a cachexia-inducing cytokine. *Cytokine*, 32, 234-239.
- Khan, Z. H., Simpson, E. J., Cole, A. T., Holt, M., MacDonald, I., Pye, D., et al. (2003). Oesophageal cancer and cachexia: The effect of short-term treatment with thalidomide on weight loss and lean body mass. *Alimentary Pharmacology & Therapeutics*, 17,(5), 677-682.
- Khayat, D. (2000). The many causes of quality of life deficits in cancer patients. *International Journal of Pharmaceutical Medicines*, 14(2), 70-73.
- Kotler, D. P. (2000). Cachexia. *Annals of Internal Medicine*, 133(8), 622-634.
- Langstein, H. N., & Norton, J. (1991). Mechanisms of cancer cachexia. *Hematology/Oncology Clinics of North America*, 5(1), 103-121.
- Laviano, A., Meguid, M. M., & Rossi-Fanelli, F. (2003). Cancer anorexia: Clinical implications, pathogenesis, and therapeutic strategies. *The Lancet Oncology*, 4,(11), 686-694.
- Lees, J. (1999). Incidence of weight loss in head and neck cancer patients on commencing radiotherapy treatment at a regional oncology centre. *European Journal of Cancer Care*, 8,(3), 133-136.
- Levine, C. (1999). The trouble with families: Toward an ethic of accommodation. *Annals of Internal Medicine*, 130(2), 148-152.
- Llewellyn, G., Sullivan, G., & Minichello, V. (2004). Sampling in qualitative research. In V. Minichello, G. Sullivan, K. Greenwood, & R. Axford (Eds.), *Handbook of research methods for nursing and health science* (2nd ed., pp. 210-241). Sydney: Pearson Education Australia.
- Lundstrom, S., & Furst, C. J. (2003). Symptoms in advanced cancer: Relationship to cortisol levels. *Palliative Medicine*, 17, (6), 503-508.

- Maestri-Banks, A., & Gosney, M. (1997). Nurses' responses to terminal illness in the geriatric unit. *International Journal of Palliative Care*, 3(2), 345-350.
- May, P. E., Barber, A., D'Olympio, J. T., Hourihane, A. N. P., & Abumrad, N. N. (2002). Reversal of cancer-related wasting using oral supplementation with a combination of [beta]-hydroxy-[beta]-methylbutyrate, arginine, and glutamine. *The American Journal of Surgery*, 183(4), 471-479.
- McClement, S. E. (2001). *Nutritional care in advanced cancer: The experiences of patients, families and health care providers*. Unpublished Interdisciplinary Doctorate of Philosophy, University of Manitoba, Manitoba.
- McIllMurray, M. B., Thomas, C., Francis, B., Morris, S., Soothill, K., & Al-Hamad, A. (2001). The psychosocial needs of cancer patients: Findings from an observational study. *European Journal of Cancer Care*, 10,(4), 261-269.
- Minichello, V., Madison, J., Hays, T. & Parmenter, G. (2004). Doing qualitative interviews. In V. Minichello, G. Sullivan, K. Greenwood & R. Axford (Eds.). *Research methods for nursing and allied health science* (2nd ed., pp. 411-446).
- Minister of Health. (2003). *The New Zealand cancer control strategy*. Wellington: Ministry of Health and the New Zealand Cancer Control Trust.
- Ministry of Health (2008). *Cancer: New registrations and deaths 2005*. Wellington: Author
- Mirhosseini, N., Fainsinger, R. L., & Baracos, V. (2005). Parenteral nutrition in advanced cancer: Indications and clinical practice guidelines. *Journal of Palliative Medicine*, 8(5), 914-918.
- Moore, R. J., & Butow, P. (2004). Culture and oncology: Impact of context effects. In R. J. Moore & D. Spiegel (Eds.), *Cancer, culture and communication* (pp. 15-54). New York: Kluwer Academic/Plenum Publishers.
- Morley, J. E., Thomas, D. R., & Wilson, M. G. (2006). Cachexia: Pathophysiology and clinical relevance. *The American Journal of Clinical Nutrition*, 83, 735-743.
- Morse, J. M. (1989). Strategies for sampling. In J. M. Morse (Ed.). *Qualitative nursing research: A contemporary dialogue* (pp. 117-131). Rockville, MD: Aspen.
- Morse, J. M. (2007). Strategies of intraproject sampling. In P. L. Munhall (Ed.). *Nursing research: A qualitative perspective* (pp. 529-539).
- Muscaritoli, M., Bossola, M., Aversa, Z., Bellantone, R., & Fanelli, F. R. (2006). Prevention and treatment of cancer cachexia: New insights into an old problem. *European journal of Cancer Care*, 42,(1), 31-41

- Nettleton, S. & Watson, J. (1998). The body in everyday life: An introduction. In S. Nettleton & J. Watson (Eds.), *The body in everyday life* (pp. 1-23). London: Routledge.
- Nitenberg, G., & Raynard, B. (2000). Nutritional support of the cancer patient: Issues and dilemmas. *Critical Reviews in Oncology/Hematology*, 34,(3), 137-168.
- Persson, C., Glimelius, B., Rönnelid, J., & Nygren, P. (2005). Impact of fish oil and melatonin on cachexia in patients with advanced gastrointestinal cancer: A randomized pilot study. *Nutrition*, 21, 170-178.
- Peshkin, A. (1993). The goodness of qualitative research. *Educational Researcher*, 22,(2), 23-29.
- Pfitzenmaier, J., Vessella, R., Higano, C. S., Noteboom, B. S., Wallace, J., & Corey, E. (2003). Elevation of cytokine levels in cachectic patients with prostate carcinoma. *Cancer*, 97(5), 1211-1216.
- Poland, B. D. (2002). Transcription quality. In J. Gubrium, & J. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 629-650). Thousand Oaks CA: Sage.
- Poole, K., & Froggatt, K. (2002). Loss of weight and loss of appetite in advanced cancer: A problem for the patient, the carer, or the health professional. *Palliative Medicine*, 16(6), 499-506.
- Rapley, T. (2007). *Doing conversation, discourse and document analysis*. London: Sage.
- Raudonis, B. (1992). Ethical considerations in qualitative research with hospice patients. *Qualitative Health Research*, 2 (2), 238-249.
- Rose, K., & Webb, C. (1998). Analyzing data: Maintaining rigor in a qualitative study. *Qualitative Health Research*, 8(4), 1998.
- Sandelowski, M. (2000). Focus on research methods. Whatever happened to qualitative description? *Research in Nursing and Health* 23(4), 334-340
- Sartre, J. P. (1956). *Being and nothingness*. New York: Philosophical Library.
- Silverman, D. (1998). *Harvey Sacks social science and conversation analysis*. Cambridge: Polity press.
- Streubert Speziale, H. J. (2003). A practical guide for sharing qualitative research results. In H. J. Streubert Speziale & D. R. Carpenter (Eds.), *Qualitative research in nursing: Advancing the human perspective* (3rd ed., pp. 323-336). Philadelphia: Lippincott Williams & Wilkins.

- Sullivan, R., Menapace, L., & White, R. (2001). Truth-telling and patient diagnosis. *Journal of Medical Ethics, 11*(1), 192-197.
- Sutton, L. M., Demark-Wahnefried, W., & Clipp, E. C. (2003). The Management of terminal cancer in elderly patients. *The Lancet Oncology, 4*, 149-157.
- Teasdale, K., & Kent, G. (1995). The use of deception in nursing. *Journal of Medical Ethics, 21*, 77-81.
- Thorne, S., Kirkham, S.R., & O'Flynn-Magee (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods, 3*(1). Article 1. Retrieved August 24, 2005, from http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf
- Thorne, S., Kirkham, S.R., & MacDonald-Eames, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing and Health, 20*(2), 169-177.
- Tuckett, A. G. (2004). Truth-telling in clinical practice and the arguments for and against: A review of the literature. *Nursing Ethics, 11*(5), 500-513.
- Vadell, C., Segui, M. A., Gimenez-Arnau, J. M., Serafin, M., Cirera, L., Bestit, I., et al. (1998). Anticachectic efficacy of megestrol acetate at different doses and versus placebo in patients with neoplastic cachexia. *American Journal of Clinical Oncology, 21*(4), 347-351.
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. New York: State University of New York Press.
- Webb, C. (1999). Analysing qualitative data: computerized and other approaches. *Journal of Advanced Nursing, 29*(2), 323-330.
- Whitman, M. M. (2000). The starving patient: Supportive care for people with cancer. *Clinical Journal of Oncology Nursing, 4*(3), 121-125.
- Williams, S. (1996). The vicissitudes of embodiment across the chronic illness trajectory. *Body and Society, 2*(2), 23-47.
- Wilson, R. L. (2000). Optimizing nutrition for patients with cancer. *Clinical Journal of Oncology Nursing, 4*(1), 23-28.
- Winkler, M., F. (2004). Body compositional changes in cancer cachexia. Are they reversible?. *Topics in Clinical Nutrition, 19*(2), 85-94.
- World Medical Association. (1996). *Declaration of Helsinki*. Retrieved July, 2005, from <w:\clinical\standard forms & procedures-gsk\gsk forms\ethics & regulatory\declaration of Helsinki-oct96.doc>

Appendix A



Massey University

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

Te Kura Pūkenga Tangata

Research title: Qualitative description of the adult oncology patient's experience of cancer-related cachexia

Short title: CRC project

Information sheet for participants

Introduction

You are being invited to take part in a small study because your oncologist has noticed you have lost weight due to cancer and may also be feeling unusually tired, feel full after eating only a little or have lost your appetite. The medical word for this is 'cachexia' (ka-kex-ia). We know that cachexia is quite common and up to 80% of people with advanced cancer may have cachexia at some time.

Please take as long as you need to read this information sheet and take time to consider any questions you have. It is your choice not to take part if you do not want to and you don't need to give any reason for this. If you decide not to take part, you will receive all usual treatment and your care will not be affected in any way.

About the study

We do not know yet exactly how cachexia starts but it is thought it happens because of a combination of reduced eating, changes in the way your body uses food (metabolism) and the body's stress response to cancer and/or its treatment. The only way we can reverse cachexia at the moment is by treating the cancer. Because cachexia is common, it is important that nurses have a good understanding of what it is like for people. We know that some people with cachexia feel isolated from their normal social roles and activities but this information has come from family members and health professionals. The purpose of this study is to ask patients themselves what it is like to have cachexia so that we can start to develop ways that nurses can help sufferers. This may also help to give direction for future research into cachexia.

If you decide to take part, you will be interviewed about your experience. The interview will be taped using a tape recorder. You will choose a made-up name that only you and the researcher will know and the tape will be transcribed using this name. No one except the researcher will be able to tell from reading the transcript that it is you. You may choose the time and place where you would like to be interviewed and bring a support person with you if you wish.

Interviews will last as long as you feel up to it, but are not expected to take more than 1 hour. You may prefer to have 2 or 3 shorter interviews or one longer one. This is completely your choice and you need not decide this until the interview process is underway, or, change your mind about this at any time depending on how you feel on the day.

Number of participants

6 - 9 people will take part in this study. While transcripts are being analysed, some points might emerge that require more investigation. If this happens, it is possible that some more people may be invited to take part.

Benefits, risks and safety

It is not expected that you will receive any direct medical benefit from taking part. It is hoped that your participation will benefit people with cancer-related cachexia in the future. The risk of participating in this study is that during the interview you might talk about some things which make you feel upset. If this happens, you will be referred to counselling or pastoral services if you feel as if you need this.

Participation

Your participation is entirely voluntary (your own choice). You do not have to take part. If you do consent to take part, you may decide at any time during the interview to have the tape recorder stopped. You do not have to answer any questions which you don't want to. You may withdraw at any time before analysis has commenced. However, once analysis has commenced, your data cannot be withdrawn.

General questions

Will my GP be told I am in the study? If you would like your GP to know, they will be informed with your permission.

What sort of questions will I be asked? There are no set questions for the interview. It will be more like a discussion about how you are feeling and the ways in which having cachexia is affecting you in your life. The reason for this is that we want to get a true picture of what it is like for you right now and to let you talk openly about your experience. Most of the questions will be prompted by something you have already said. For example, you might be asked "Tell me a bit more about that", "You mentioned you find meal times stressful, how does this affect you?" or "What do you make of that?"

If I agree to take part, do I have to answer all the questions? You do not have to answer all the questions and you may ask to stop the interview at any time.

Can I have someone with me during the interview? Sometimes it may be harder to discuss what you feel when friend or whanau are present but you are welcome to have any support you wish to be with you or near during the interview.

What if I have any concerns or complaints?

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate.

In the lower North Island, this service is called Advocacy Services Network Trust (ADNET) telephone: 0800 423 638 Or (06) 348 0074

Free fax (NZ wide): 0800 2787 7678 (0800 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

Confidentiality

No material which could personally identify you will be used in any report on this study. Tapes will be transcribed using a pseudonym. If professional transcription services are used, the transcriber will sign a confidentiality agreement before having access to tapes. Tapes, signed consent forms and transcripts will be kept in a locked filing cabinet in the locked office of the supervisor of this research for five (5) years after the study is finished. Electronic data will be stored on the hard drive of password protected computer. All data will be kept for 10 years. After this time, electronic data will be deleted and paper documents will be shredded.

Results

A summary report of the findings will be sent to you after data analysis.

This research project has been approved by the Central Regional Ethics Committee.

For further information please do not hesitate to contact the researcher or the academic supervisor of this research.

Researcher

Marika Stubbs RN, BN, PG Dip Oncological nursing

Nursing Lecturer

Universal College of Learning (UCOL)

Wanganui

Email: m.stubbs@ucol.ac.nz

Phone: (06) 965 3801 x60727

Mobile: 021 208 4549

Academic Supervisor

Professor Jenny Carryer RN, PgDipOnc, PhD, FCNA(NZ), MNZM

Clinical Chair Nursing

Massey University

Email: J.B.Carryer@massey.ac.nz

Phone: (06) 356 9099 x7719

Version 2, 2.4.07

Appendix B



Massey University

COLLEGE OF HUMANITIES AND SOCIAL SCIENCES

Te Kura Pūkenga Tangata

Qualitative description of the adult oncology patient's experience of cancer-related cachexia

PARTICIPANT CONSENT FORM

This consent form will be held for a period of five (5) years

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being audio taped.

I wish/do not wish my GP to be informed about this study

I wish to be interviewed alone/I wish to have support person with me

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:

Date:

Full Name - printed

Appendix C



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone (04) 496 2405
Fax (04) 496 2191

16 May 2007

Ms Marika Stubbs
14 Fromont Street
Wanganui East
Wanganui

Dear Marika

CEN/07/03/012 - Qualitative description of the adult oncology patient's experience of cancer-related cachexia (CRC): A pilot study
Ms Marika Stubbs
Whanganui District Health Board, MidCentral DHB

The above study has been given ethical approval by the **Central Regional Ethics Committee**. A list of members of this committee is attached.

Approved Documents

Information sheet and consent form version 2, dated 2 April 2007

Certification

The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports

The study is approved until **March 2009**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **May 2008**. The report form is available on <http://www.newhealth.govt.nz/ethicscommittees>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Final Report (for studies less than 1 year)

The study is approved until . A final report is required at the end of the study. The report form is available on <http://www.newhealth.govt.nz/ethicscommittees> and should be forwarded along with a summary of the results. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Requirements for SAE Reporting

The Principal Investigator will inform the Committee as soon as possible of the following:

- Any related study in another country that has stopped due to serious or unexpected adverse events
- withdrawal from the market for any reason
- all serious adverse events occurring during the study in New Zealand which result in the investigator or sponsor breaking the blinding code at the time of the SAE or which result in hospitalisation or death.
- all serious adverse events occurring during the study worldwide which are considered related to the study medicine. Where there is a data safety monitoring board in place, serious adverse events occurring outside New Zealand may be reported quarterly.

All SAE reports must be signed by the Principal Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event. If the adverse event is local and does not have the sponsor's report attached, an opinion on whether the event is thought to be related to the study should be given along with any other pertinent information. It is assumed by signing the report, the Principal Investigator has undertaken to ensure that all New Zealand investigators are made aware of the event.

Amendments

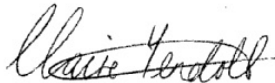
All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely



Claire Yendoll
Central Ethics Committee Administrator

Email: claire_yendoll@moh.govt.nz

