UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
School of Health Sciences

Living with locally advanced rectal cancer:

An exploration of the everydayness of living with rectal cancer.

By

Jane Winter

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ABSTRACT.

Advances in treatment and prolonged survival times mean that increasingly individuals are living with advanced cancer, yet services remain disease orientated. This thesis has documented the process of undertaking a longitudinal qualitative study to explore the everydayness of living with locally advanced rectal cancer. The study has identified how this can influence individual's day to day lives when the focus of care moves away from cure, but prior to the transition to 'end of life' care. The aim was to obtain data in which to situate local service development based on those aspects which were accorded primacy by the participants.

This interpretive study used a longitudinal qualitative approach which was informed by phenomenology. The philosophical works of Heidegger, Merleau Ponty and Van Manen were influential in this work which involved ten participants, with locally advanced rectal cancer. Successive interviews with ten individuals were undertaken over a two year period. The 38 interviews were analysed using a combination of frameworks offered by Miles and Huberman and Saldana.

Individuals during much of this time concentrated on maintaining normality in their everyday lives. The drive for stasis and focus on day to day living allowed the individual to remain in the present and distance a future which was associated with illness and annihilation. Crucial to this was the ability to self-manage. This allowed space to create a self-definition of health. Uncertainty during this time was life affirming. Avoiding those who may challenge this, was desirable for as long as possible. As illness progressed there was an inverse relationship between the 'boundness' of the body and the 'boundness' of the individual.

Insights from this study raise the need for further research and exploration of alternative models of supportive care whilst focusing on the wellness of individuals and self-management within their daily lives.

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DECLARATION OF AUTHORSHIP

I, Jane Winter

declare that the thesis entitled

'Living with locally advanced rectal cancer: An exploration of the everydayness of living with rectal cancer.'

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- This work was done wholly or mainly while in candidature for a research degree at this University;

- Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;

- Where I have consulted the published work of others, this is always clearly attributed;

- Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

- I have acknowledged all main sources of help;

- Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;

- None of this work has been published before submission

Signed: …………………………………………………………………..

Date:………………………………………………………………….

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Chapter 1. Introduction.

The study.

This study arose from my own interest in developing services that respond to the needs of colorectal cancer patients. The focus of this study is to reveal how living with locally advanced rectal cancer permeates the everyday lived world of an individual. The aim is to design services which accord primacy to those aspects which the individuals themselves identify as important.

Increasingly, the longevity of patients with advanced colorectal cancer is being extended (Bokemeyer et al, 2008), whilst service development in supportive care remains relatively static. Local services are currently disease and symptom orientated and concentrated around key times of diagnosis, active treatment, recurrence and end of life care. Whilst support at these times is vital there are protracted periods of time when individuals are not receiving treatment or end of life care. As a Clinical Nurse Specialist, my concern is that we are failing to meet the supportive care needs of these individuals because we have never explored the phase of their illness when they are living with advanced cancer but have not made the transition to palliative or end of life care services.

As the study has evolved the focus has concentrated more specifically on how the meaning of living with locally advanced rectal cancer permeates the everyday world. This 'everydayness' of the individual is key to understanding how the individual's perceptions of health and illness are shaped and how that subsequently influences their approach to managing their day to day lives with colorectal cancer.

To gain that understanding, a cross sectional study felt inadequate. I believed that only by studying individuals over a prolonged period of time would the nature of living with advanced colorectal cancer and the meaning involved, reveal itself. Through adopting a longitudinal approach to the data collection, the patients self-definition of health and illness and how that influences self –management over the course of the illness, could be explored in greater depth. Rectal cancer, in this context, has not previously been explored. Greater numbers of patients are being

treated and are living for longer periods of time than ever before. Expected survival is constantly improving.

Within the thesis experience will be discussed in terms of its existential meaning. To achieve this I refer to those aspects of the individuals life which relate to time, in the subjective sense, space, in terms of how we locate ourselves within our world, relationships and how these are experienced as an 'embodied' human being (Van Manen, 2006). The research question remained intentionally broad in an attempt to elicit those aspects which the participants themselves viewed as important.

The aim of the study can therefore be summarised as: to explore the meaning of living with locally advanced rectal cancer and how that meaning permeates the everyday lived - world of the individual.

The objectives of the study lie in:

- The exploration of meanings associated with living with locally advanced rectal cancer over the period of time when the focus moves from cure to palliation, but prior to the transition to end of life care.
- The exploration of how those meanings influence the individual's self-definition of health and illness as an embodied being.
- Highlighting the subsequent impact that self definition has on self-management strategies within individual's daily lives.
- The exploration of these phenomena over time to understand the dynamics of the experience.
- The evaluation of the implications of living with colorectal cancer for service development and future research.

The study question:

'How does the meaning of living with locally advanced rectal cancer affect the 'everydayness' of the individual through the course of their illness during the transition from curative treatment to end of life care?'

The context.

There are a number of key areas within the literature that relate to the individual experience of living with cancer. Previous research has been undertaken which relates to specific population groups such as breast or ovarian cancer and is often orientated at key times through the illness experience. Much of this work is cross sectional and a number of methods and methodologies are employed to appropriately answer the research questions. Substantial bodies of evidence exist which surround diagnosis, treatment, recurrence, adjusting and coping following treatment and end of life care for individuals and their families who are affected by cancer.

Reflecting the complexity of the nature and impact of being diagnosed with cancer, these studies offer valuable insights into aspects of a multidimensional subject. Much of the literature that describes 'living with' cancer relates to life after potentially curative treatment when entering a phase of survivorship. Little evidence exists which explores the day-to-day experience of living over an extended period of time with active cancer and the impact that has in the everyday world of the individual (see Chapter 2, Literature review).

In addition, little work has been undertaken with individuals who are diagnosed with colon or rectal cancer (see Chapter 2). There is a paucity of work that explores the impact of living with locally advanced rectal cancer over the months and more commonly, years, that individuals undergo treatment or the impact of this on their day-to-day life.

Increasingly individuals are living for a number of years following a diagnosis of 'inoperable' rectal cancer. As healthcare professionals, we need an understanding of how this is experienced by the individual, to offer appropriate supportive care. Currently management is very symptom and disease orientated and little work has been undertaken which explores how self definition of health affects the individual's day to day life or what services would be required to support understanding and self management in the future.

Importantly, the perspectives that guide the study and the theoretical assumptions within the study need to be outlined and clarified in order for the context of the study to be clear.

Background.

Colorectal Cancer.

In the UK, there are approximately 37,000 new cases of colorectal cancer each year and around 16,000 deaths (Cancer Research UK, 2009). This represents around 10% of cancer deaths in the UK (Cancer Research UK, 2009). 'Colorectal' refers to any part of the large bowel; the colon and rectum. Typically around 60% of cancers arise in the colon and 40% in the rectum. In the UK in 2005; 14,018 cases of rectal cancer were reported (Cancer Research UK, 2009) and in 2006 the number of deaths were reported as being 5,838 (Cancer Research UK, 2009).

Colorectal cancer is the second most common cause of cancer death after lung cancer and has an overall 5-year survival rate of around 50% (Cancer Research UK, 2009). Around 20% of patients have distant metastases at presentation and of the remaining 80% half will go on to die from their disease in the following 5 years. Mortality in males is far higher than in females, with 22 per 100,000 in men, compared to 14 per 100,000 in females (Cancer Research UK, 2009). Local figures suggest around 300 new colorectal cancers are diagnosed each year within the researcher's Trust.

Surgery remains the only curative intervention for the disease; however the range and availability of adjuvant and palliative treatments are increasing, resulting in a greatly improved lifespan. Palliative chemotherapy can now prolong the average survival from 9 to 20 months and advances in liver surgery, radio-frequency ablation and symptom management have dramatically improved symptom control and quality of life for those patients with metastatic disease (Bokemeyer et al, 2008).The five year survival rates for colorectal cancer have doubled over the last thirty years (Cancer Research UK, 2009) and between 1998 and 2007 the age-standardised mortality rate has fallen by 16% (Cancer Research UK, 2009).

Rectal cancer is treated quite differently to colon cancer due to its situation within the pelvis. The key to being able to remove rectal cancer and hence offer a potential cure, lies in the ability to remove the tumour with clear margins of 'disease free' tissue. Due to the confined nature of tissue within the pelvis this can be difficult and some patients will be 'inoperable' despite attempts to shrink the tumour with chemo and radiotherapy.

The thesis is directly focussed on the period of time between the transition from curative treatment, to end of life care. In order to clarify this delineation the definition of 'end of life care' within this study, will be in keeping with the definition published by the Dept of Health (2008) in the recent publication of the end of life Care Strategy:

> *End of life care, is care that; helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the **last phase of life and into bereavement**. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.*
>
> **Source:** National Council for Palliative Care (2006)

Within the context of this study the distinction has been made that the transition to end of life care would be taken at the point where the individual was referred to the palliative care services locally.

Rectal cancer anatomy.

Whilst the specific anatomy and physiology of rectal cancer may not be vital within the context of this study, the physical nature of locally advancing pelvic disease is peculiar to this group of individuals. Despite the disease being distinct from the illness experience per se, it is important to have a broad understanding of the structures involved to appreciate the unfolding story and the sequelae of advancing illness, within their experiences (Appendix i).

However, the nature of the progression of colorectal cancer often means a protracted disease process over a period of some months or years. This occurs without necessarily presenting with extensive or complex symptoms. Consequently many patients do not require the input of specialist palliative care services, so are cared for within their own homes by District Nurses and General Practitioners, with sporadic hospital outpatient appointments and imaging surveillance.

The political context.

At the inception of the study in 2002, the political agenda was focussed on improving the delivery of cancer services which had evolved since the 'Calman - Hine' Report (Expert Advisory Group, 1995) and The Cancer Plan (Dept of Health, 2000). At that time, 'Shifting the Balance of Power: the next steps' (Dept of Health, 2002) had outlined the need to identify service models which will resulted in high quality care and services for all people with cancer and their carers, yet research into that area was limited.

In 2004, The National Institute for Clinical Excellence (NICE) produced a paper aimed at improving supportive and palliative care for adults with cancer (Dept of Health, 2004) which acknowledged the need for high quality, well coordinated

services based on the needs identified by users. The paper clearly stated that patient needs often went unnoticed by health professionals and that there remained a paucity of research evidence related to many areas of supportive care. The paper highlighted the need to target research at these gaps and stated that "the nature of research in supportive and palliative care is somewhat different to that found in other areas of cancer care, particularly drugs and therapies" (Dept of Health, 2004, p133).

Within the NICE guidance, particular attention was paid to the hierarchy of evidence available. Whilst the usefulness of a randomised controlled trial was acknowledged, the guidance suggested that this takes account neither of the question or problem affecting patients and families, nor of the "healthcare context in which the service is operated" (Dept of Health, 2004, p135.). Recommendations of the paper included a focus on the investment in longitudinal studies of patient and carer experiences and expectations of both illness and health and social care with the aim being able to address the best ways of meeting needs at different points in time during the disease pathway.

More recently a number of strategic documents have been published by the Department of Health which clearly outline drivers for change. They appear to be changing the shape of service delivery and looking towards future services. The key documents in terms of the strategic direction for services are; The Cancer Reform Strategy (Dept of Health, 2007) and The End of life Care Strategy (Dept of Health 2008). A number of other key papers are also important to acknowledge:

- NHS operating framework 2009/10 (Dept of Health 2008),

- High Quality Care for all (Dept of Health 2008),

- Carers at the heart of 21st Century families and communities(Dept of Health 2008),

- Commissioning framework for health and well being (Dept of Health 2007),

- Our Health, Our Care, Our Say (Dept of Health 2006)

- Creating a patient led NHS (Dept of Health 2005).

The papers represent the breadth of services which are required over an expanding illness trajectory. Within the Cancer Reform strategy, the main focus for service provision lies with improving prevention strategies, improving diagnosis and treatment, reducing inequalities and improving the experience of individuals living with and beyond cancer. Through ensuring care is delivered in the most appropriate settings, rapid access to treatment can be improved (Dept of Health 2007).

Similarly the End of Life Care Strategy (Dept of Health, 2008) has aimed to eradicate the disparity of hospice care provision and the mismatch between patient's preference for place of death and actual place of death. The End of Life Care Strategy stretches beyond solely cancer care to include all conditions in all care settings. It offers a challenge to societal taboos around discussing death and dying and offers family and carer support through the last stages of life and into bereavement (Dept of Health, 2008). The proposal amounts to a co-ordinated approach to caring for the dying which acknowledges the centrality of patient choice in the process. This represents an important phase in care which the participants within this study will inevitably enter as a transition from their current illness experience.

However, there has been a significant gap in the exploration of the stage in the patient's pathway which occurs following treatment and prior to end of life care. Yet, patients living with active or advanced cancer present probably the widest spectrum of needs of all groups defined by the Cancer Reform Strategy (NHS Improvement Programme, 2009). Guidelines for commissioning services are explicit in their recommendations for identifying the needs of individuals living with and beyond cancer. This is a very broad spectrum of patients (those with and living beyond). Living 'with cancer and beyond' implies not only those with active disease

but those who have survived curative treatment and have entered a survivorship pathway (National Cancer Action Team, 2009).

There appears to have been some recent integration of the survivorship agenda and those individuals living with active disease who have not yet reached end of life care. Whilst potentially there are a number of similar difficulties for both of these groups of individuals, there are some very fundamental differences in their anticipated futures and they arguably need different approaches to rehabilitation and accommodation of change.

The National Cancer Survivorship Initiative (NHS Improvement Programme, 2009) have recognised this and have developed a work programme which consists of seven work streams to explore the services needed to support those living with and beyond cancer. The second work stream is aimed at managing active and advanced disease. This work is very specifically aimed at individuals who are living with cancer (and are not curable) but have not made the transition to end of life care: a group which have previously not been isolated as possibly having different needs from individuals in other phases of their illness.

When working in the day to day care of individuals in this situation, the challenge is to translate such initiatives into meaningful interventions and developments in practice. It was therefore important that the approach for the study was congruent with the aims of the study. It was important that the philosophical context of the research reflected the intention to explore meaning for those who participated.

The Philosophical Context.

This study was designed to develop an understanding of the meaning and of living with locally advanced cancer. Through an approach informed by phenomenology, (discussed later in Chapter 3) which was developed from the philosophical work of Heidegger, Merleau Ponty and the pragmatic approach of Van Manen.

Using phenomenological approaches for work which is both descriptive and exploratory is entirely appropriate where a phenomenon has not been explored extensively in previous research (Strauss and Corbin, 1990). The contextual importance of the study in relation to the experiences of those involved and the longitudinal nature of the collection of data provides a depth to the data that can be supported by this approach.

Phenomenological approaches support research questions which question the way the world is experienced, as it is experienced (Van Manen, 2006) and ask for the very nature of the phenomena by uncovering and describing the essential structures and internal meanings of the lived experience (Merleau Ponty, 1962). By concentrating on the dynamic aspects of the patient's pathway the experience can be described from the perspective of the patients, through time, to uncover a deeper understanding which allows the reader to be more informed and subsequently understand the full significance of its meaning (Van Manen, 2006)

Phenomenology as an approach to inform the study.

Phenomenology is a movement within philosophy, which is used to focus on human interests (Taylor, 1993). It originates from the work of Husserl (1859 - 1938) and subsequently, Heidegger (1889 - 1976). Following the work of Husserl, which was arguably rooted in the positivist paradigm, phenomenology evolved from outside the traditional, positivist, experimental, scientific, methodology (Jasper, 1994), to facilitate inductive, descriptive and/or interpretive research, which describes a particular phenomena (Omery, 1983).

Phenomenology allows for collection of descriptions whilst preserving the spontaneity of the experience (Morse and Field, 1995, Rose, Beeby and Parker, 1995, Jasper, 1994). Taylor (1993), suggests a close link between phenomenology and nursing through their shared approaches to viewing individuals as; "subjective beings who's experiences are meaningful in terms of the context in which they find themselves" (p175). The philosophical underpinnings of this approach lead to

uncovering what lies at the ontological core of the participants by discovering what it means to live their life (Heidegger, 1962).

The concept of capturing the essence within phenomenological approaches relates to the core meanings which are understood through a shared experience (Patton, 2002), with the focus in the individual situation. Phenomenology has been described as "the study of essences" (Van Manen, 1990, p10) with the research focused around making sense of the human experience and develop a deeper and better understanding (Silverman, 1984) and therefore plan sensitive and relevant interventions.

As a nurse, my interest lies in developing a deeper understanding of the existential meanings to inform clinically relevant service provision in the future. The research was intended to raise awareness of aspects of living with cancer which were previously unexplored or taken for granted to develop an understanding of the subjective experience of those involved to explore what might support their future well being (Van Manen, 2006). It is those shared meanings and understandings (Benner, 1994) among the participants which enabled greater insight into the experiences of living with rectal cancer.

Chapter Summary.

This study is aimed at exploring how the meaning of living with locally advanced rectal cancer affects the everydayness of the individual through the course of their illness, during the period when the focus of care moves away from cure, but prior to the transition to end of life care. Increasingly the longevity of this group of individuals is extending and the supportive care remains relatively unchanged. Locally, services are often aimed at diagnosis and curative treatment and palliative care services are frequently focussed on end of life care. There appears to be a gap in the support services available to these individuals. Before services are developed it is important to understand the experiences of these individuals and how those services may be designed by according primacy to those aspects which the

individuals themselves identify as important. National policy and guidelines are directing healthcare professionals to address these needs and yet there is not a substantial body of evidence to ascertain what this means to individuals and more specifically, those with advanced rectal cancer. Chapter 2 will explore the literature currently available to support the need for a study which focuses on meaning and experience to complement existing knowledge of living with locally advanced rectal cancer.

Chapter 2: Literature review.

Introduction.

There is a wealth of literature which relates to the concept of 'living with' cancer. However this presents itself as a very broad construct. The notion of 'living with' has been interpreted in many ways which include all aspects of the patients experience from living with a genetic predisposition to developing cancer, through until end of life care. The majority of the literature relates to having had a diagnosis of cancer which has been treated and for which the individual has potentially been cured. This surrounds the concept of survivorship.

 For the purposes of this review a search has been undertaken, which is related to both the aims of the thesis and the research question. There were two main goals within the review. Firstly to explore the existing qualitative literature in relation to living with advanced cancer and secondly, to critically appraise that literature as research in its own right.

The literature search was undertaken and scrutinised using a series of inclusion and exclusion criteria. In keeping with the philosophy of the study and the need to ascertain relevant qualitative literature the review concentrated on those papers which used qualitative approaches. The search was undertaken in conjunction with a joint reviewer.

There is little literature which explores the phase of illness which this study is concerned with and despite exploring citations and the 'grey' literature very few studies were uncovered. There is an extensive body of literature which focuses on survivorship and diagnosis and similarly end of life care. As a result of the search and selection strategy, nineteen papers were identified as relevant and are discussed within this chapter. All were qualitative papers and all were appraised using the Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Programme, 2002) framework for qualitative appraisal (Appendix ii)

Within the chapter, a metasynthesis of the literature is presented in conjunction with both discussion and appraisal. The qualitative metasynthesis revealed six main themes which are described as: relationships, control, practicalities, perspective,

mortality and self. There were other findings in individual studies, which did not relate to these themes and have been incorporated in a section entitled 'Exceptions'.

The findings are then discussed in relation to this study, both in their contribution and the gaps in the existing literature which they reveal.

The purpose of the review.

The primary aim of the thesis was to explore the experience of living with advanced rectal cancer. The literature search was therefore intended to explore the experience of living with advanced (incurable) cancer and more specifically rectal or colorectal cancer. The literature review was particularly directed at the period of the patients experience when the focus is no longer on cure but the individuals have not made the transition to end of life care, to reflect the participants within this study.

At the outset of the review it was important to undertake a thorough search of the available literature. The search strategy was formulated prior to the search and included a series of inclusion and exclusion criteria which informed the process. Following a rigorous search and appraisal using the CASP tool, 19 qualitative papers were included. Data extraction and synthesis culminated in a metasynthesis of the findings from these studies which will be presented within this chapter.

Critical Appraisal.

Appraising quantitative research is a well established process with clear and defining characteristics. These are incorporated in the framework published by The NHS Centre for Reviews and Dissemination, The Cochrane Collaboration. (CRD, 2001).

However, as a result of the methodological diversity and the philosophical underpinnings of qualitative research, there have been great difficulties in reaching consensus as to the defining characteristics of good quality, qualitative research.

There has been suggestion that not only is there disagreement in relation to defining characteristics, but also as to whether criteria for quality should exist at all (Dixon-Woods 2007). The justification for this assertion lies in the notion that the imposition of criteria may result in the creativity of the work being stifled (Dixon-Woods, 2007). However, despite the lack of consensus, there appears to be a common theme in that all approaches should be viewed as a method for the development of new knowledge, based on a systematic process of analysis of existing research findings (Thorn et al, 2004). Key to the success of this process is transparency, which adds to its credibility, transferability and theoretical potential (Pearson 2004).

The Cochrane Qualitative Research Methods Group has been established by a number of researchers who have an interest in developing and supporting methodological work on the inclusion in systematic reviews of findings from studies using qualitative methods. The Joanna Briggs Institute in Adelaide hosts the website where the contribution of qualitative work to systematic reviews is advocated (Joanna Briggs Quality and Assessment Review Instrument, 2004)

Whilst they concede that consensus has yet to be reached they do offer a number of key elements which should be included in a chosen check list for appraisal of qualitative studies:

- Research question - Relevance?
- Research Method – does it fit with the goal of the study?
- Selection of participants – adequate description, motivation, characteristics?
- Gathering of data – how, role of researcher, level of control of the participants.
- Theoretical framework – inductive / deductive perspective?
- Analysis – inter / intrarater agreement, extreme cases, reflection or interpretation?
- Results – answers the research question?
- Conclusions – supported by detailed evidence?

- Usefulness for body of research –consistent, new?
- General evaluation – quality, use?

Karin Hannes, 2008 (www.joannabriggs.edu.au/cqrmg)

Critical appraisal is an integrative part of any systematic review. Once the search strategy has been completed and the relevant papers have been identified an appraisal of those studies must be undertaken to assess the quality of the work. Historically, qualitative papers have been excluded from many systematic reviews as being weak (Estabooks et al, 1994) when being judged by quantitative criteria. However appraising qualitative studies will naturally require a different set of criteria. Establishing criteria for qualitative appraisal remains problematic and a number of renowned researchers continue to contribute to the discussion.

A united view appears to be the necessity to create a set of criteria which are distinct from those which are applied to quantitative research studies. Noyes and Popay (2007) accord primacy to subjectivity, flexibility and adequate description. Hammersley (2001) views assessment of qualitative research in terms of its capability to generate theory. Denzin and Lincoln (1994) highlight the need to focus on subjectivity; Pearson (2004) argues the importance of transparency as being central to credibility, transferability and theoretical potential. A key point is raised by Dixon – Woods et al (2004) who advocate the need to develop systems of appraisal that take into account the methodological approach being used for the study.

These facets can be integrated, to some extent, in an appraisal tool. A number of tools for quality appraisal appear to be available; however, the recommendations of the Cochrane Qualitative Research Methods Group are to use a tool such as the Critical Appraisal Skills Programme (Critical Skills Appraisal Programme, 2002) or JBI QARI (Joanna Briggs Quality and Assessment Review Instrument, 2004) which will provide a comprehensive review. A third tool also has been developed by the National Centre for Social Research which was based on a synthesis of 29 other

frameworks for appraisal (Dixon – Woods, 2007) and advocates four fundamental guiding principles. That the research should be:

1. Contributory – in advancing wider knowledge or understanding about policy, practice, theory or a particular substantive field.
2. Defensible in design – by providing a research strategy that can address the evaluative questions posed.
3. Rigorous in conduct – through the systematic and transparent collection, analysis and interpretation of qualitative data.
4. Credible in claim – through offering well-founded and plausible arguments about the significance of the evidence generated.

(Spencer et al, 2003)

For the purposes of this review the CASP appraisal system was used. It appeared to offer all of the aspects which were incorporated in the other tools and provided a pragmatic and structured framework for assessment. It is widely used and has been widely validated in respect to covering all of the procedural aspects of the study being appraised.

The 19 papers were individually appraised using the CASP tool prior to a Meta synthesis being undertaken. A numerical scoring system was developed for the purposes of this review which aided appraisal and provided some weighting to the value of each paper (Appendix ii).

Literature search.

Search strategy

A systematic search strategy of the following electronic databases was conducted (Table 1)

Table 1   Record of electronic databases searched.

Database	Years
Medline	1950 – 2008 (3/08)
Embase	1980 – 2008 (03/08)
CINAHL	1982 – 2008 (03/08)
Psychinfo	1985 – 2008 (03/08)
BNI	1994 – 2008 (03/08)
Web of Knowledge	All years
Pubmed	1966 – 2008 (03/08)

The search terms Cancer (or neoplasms or malignancy or carcinoma or tumour or tumor) were used and combined with: living, advanced, palliative, incurable, colon, rectal, colorectal, experience as described in Table 2. Initial searches uncovered 3388426 'hits' (including duplicates). When combined as described in the tables and duplicates removed a total of 152 papers were selected for review. A further 44 were sourced through citations (Total 196). Once again duplicates were removed.

The abstracts of those 196 papers were co-reviewed by both research supervisors and 72 papers were selected for in depth review. One of the research supervisors read those papers in greater detail. Following a meeting where the inclusion and exclusion criteria were applied once more and the content reviewed against these criteria, a total of 19 papers were chosen for the final review. All of the papers were read by the co-reviewer prior to inclusion in the review.

Inclusion Criteria

- English Language

- Published between 1980 and 2008

- Relating to advanced cancer

- Patients 18 years and older

Exclusion criteria

- Children's cancers

- End of life papers

- Patients who were potentially cured / survivorship

- Evaluation of specific interventions (eg:chemotherapy, analgesia, transplants)

- Evaluation of specific symptom control (eg breathlessness, nausea, vomiting, fatigue)

- Randomised controlled trials

- In-patient evaluations

- Drug Trials

- Policy statements / papers relating to policy development

- Related to carers

This resulted in 19 papers which were agreed to be suitable for inclusion (Table 4)

Table 2   Search Strategy – combinations of search terms.

SEARCH TERM	AND	AND	AND	AND
Cancer				
Living				
Advanced				
Experience				
Cancer	Living			
Cancer	Living	Advanced		
Cancer	Living	Advanced	Experience	
Palliative				
Cancer	Palliative			
Cancer	Living	Palliative		
Cancer	Living	Palliative	Experience	
Incurable				
Cancer	Incurable			
Cancer	Living	Incurable		
Cancer	Living	Incurable	Experience	
Colon				
Rectal				
Colorectal				
Colon	Cancer			
Colon	Cancer	Living		
Colon	Cancer	Living	Advanced	
Colon	Cancer	Living	Advanced	Experience
Rectal	Cancer			
Rectal	Cancer	Living		
Rectal	Cancer	Living	Advanced	
Rectum	Cancer	Living	Advanced	Experience
Colorectal	Cancer			
Colorectal	Cancer	Living		
Colorectal	Cancer	Living	Advanced	
Colorectal	Cancer	Living	Advanced	Experience
Colon	Cancer	Living	Palliative	
Colon	Cancer	Living	Palliative	Experience
Rectal	Cancer	Living	Palliative	

SEARCH TERM	AND	AND	AND	AND
Rectal	Cancer	Living	Palliative	Experience
Colorectal	Cancer	Living	Palliative	
Colorectal	Cancer	Living	Palliative	Experience
Colon	Cancer	Living	Incurable	
Colon	Cancer	Living	Incurable	Experience
Rectal	Cancer	Living	Incurable	
Rectal	Cancer	Living	Incurable	Experience
Colorectal	Cancer	Living	Incurable	
Colorectal	Cancer	Living	Incurable	Experience

The study was deliberately designed to explore the pathway from knowing that the focus of care had moved from cure, yet prior to the transition to end of life care, so the literature review excluded research which related to this latter part of the pathway.However, there are a number of qualitative researchers who have contributed greatly to the literature relating to end of life care over the preceeding years. It is important to acknowedge the seminal works by authors such as; McNamara (2001), Lawton (2000), Copp (1997), Kellehear (1993) Buckman (1993) and Glaser and Strauss (1965) which have contributed greatly to the body of literature which surrounds death and dying. Whilst these works have informed this study, they have been excluded from the review because the focus of this study is intended to lay with the period during the pathway which precceds this time.

The numerical values (Appendix ii) were added to the assessment tables within the review (Table 4). There were a wide range of scores with the highest being 26 (Allchin – Petardi, 1997) and the lowest 11 (Colyer 1996). The median score was 17. Much of the scoring was lowered due to poor focus on reflexivity and ethics. There was also limited methodological justification in many of the studies.

There were a number of difficulties that arose during the process of evaluating the selected studies using CASP criteria. Inclusion and exclusion criteria were clearly

applied before selection of papers for inclusion, with qualitative work being a pivotal feature. As a consequence the appraisal frameworks which were available were scrutinised and CASP appeared to offer the most comprehensive and pragmatic approach for use. However, having completed the process there appear to be a number of limitations which arose and warrant further discussion within the context of the review.

One of the most problematic areas as a reviewer was the application of a process which appeared to have little accommodation for the fundamental differences in philosophical approach which underpin the various methodological approaches of the studies.

Qualitative work by its very nature relies on its theoretical assumptions and presuppositions to shape the work and entirely context orientated. However, a broad appraisal framework can arguably never accommodate this diversity. There was a constant tension throughout the process in comparing different methodological approaches, which have diverse philosophical assumptions which seemed impossible to judge by one single set of criteria.

As a reviewer primacy was accorded to transparency, apparent integrity and credibility or reliability of the findings. Within the context of this study it was important to assess relevance and utility for informing the review of relevant literature which related specifically to the experience of living with advanced cancer. Sadly the lack of reflexivity hindered the degree of integrity which was afforded to the studies, although publication constraints may have had a prohibitive effect on their inclusion within the published paper.

TABLE 3 - APPRAISING THE PAPERS USING THE CASP FRAMEWORK

No	First Author	DESIGN / METHOD	SAMPLING	DATA COLLECTION	REFLEXIVITY.	ETHICS	DATA ANALYSIS	FINDINGS	CASP SCORE.
1.	Ekwall, E.	Phenomenological Appropriate for the aims of the study which is described as necessary to gain deeper understanding and illuminate the essence of the experience.	12 women with advanced Ovarian Cancer. Sample selection is explained as consecutive from the registry. 8 declined - no reason given in the text. Inclusion and exclusion criteria are described.	Justification for the method is given. Collected through interviews with prompting if required. Recorded at a preferred location for the participants – 10 at home and 2 in the hospital. Open interviews. No modifications were made during the study to the approach.	Not addressed within the text.	Ethical approval discussed and also the ethical principles guiding the study.	Clear description of the data analysis process. Examples of the process are given which clearly illustrate the steps in the thematic analysis. Explicit findings. Illustrated with data to support the findings. No critical examination of own role as researcher. Husserlian approach informed by the work of Giorgi.	Presented as explicit themes then discussed in light of the wider literature. Trustworthiness discussed thoroughly as well as the implications of the findings for practice.	25
2.	Groot,M.	Single case study Appropriate for the aims of the study – described as the start of developing a concept for further research to be based upon. Justification for the single case study is included.	One couple – a patient and her husband. She had been involved in a previous study of successive interviews for another study and was recruited when the focus of her care changed.	One semi structured interview – recorded by two researchers in the participant's home.	Not addressed. The researchers are described simply as experienced nurses.	Consent is discussed in both written and informed terms. Ethical approval is not discussed. Confidentiality is discussed.	Thematic content analysis. Validated by the participants. Undertaken by two researchers independently than compared and reached a consensus. Presented as a case study with extracts form the interviews interwoven to support the discussion.	Presented as a descriptive case study with 3 major themes. Described as a descriptive study in its own right which is not intended to be generalisable. Implications for practice and further research are discussed	17

| 3. | Coyle, N | Phenomenological Appropriate for the aims of the study. Justification for the choice of approach is given and the goals of phenomenology. | Patients attending an oncology centre who had expressed a desire for hastened death on at least one occasion. The context is outlined and inclusion and exclusion criteria. 8 participants were approached – one declined therefore 7 included. | Successive interviews (2 -6) over a 3 – 6 month period. Interviewed until saturation of the data was described as being achieved. Recorded at a preferred location for the participants. Recruitment is described as stopping when no new data was acquired. Interviews were transcribed prior to subsequent interviews for member checks. | Described in terms of the participants not being known to the researcher. | Not discussed | Thematic content analysis. Reviewed between interviews to inform the subsequent interviews. Cluster coding performed after each interview. The data is described as being transcribed as a whole at the completion of the set of interviews. There appears to be an inconsistency within the report regarding when the analysis was actually performed. Participant validation of the previous interview prior to the next is described. Data is included which supports the interpretive analysis. | Limited presentation of existing literature and limitations of the study are described. Transferability is addressed. | 16 |
| 4. | Houldin, A. | Grounded theory Appropriate for the aims of the study aims and justified as a methodology by the guiding principles. | 14 patients with advanced colorectal cancer – who were recruited as part of a larger study. Approached by one of the researchers. 4 further patients were approached and their refusal discussed. | Semi structured interviews either in the outpatient clinic (10) or in the patients home (4).no reason for the choice is offered. Interviews were tape recorded and transcribed. | Not discussed | Ethical approval was granted by the local committee. Written consent was gained. | In depth description of the analysis and process of coding and constant comparative analysis. Supported with quotes within the paper. | Findings are extensively discussed in relation to the literature and also the clinical implications from the study. Limitations are addressed. | 18 |

| 5. | Lindqvist, O | Phenomenological Appropriate for the aims of the study discussion around phenomenology and justification for the choice of methodology is given to enable the meaning to be illuminated. | 18 patients with locally advanced prostate cancer. Consecutive patients with locally advanced disease through 3 treatment centres. Approached by their physicians. One pt refused and 2 died between recruitment and the planned interview. | The findings are based on a subsequent (2nd) interview. The initial interview was centred on the functional assessment in prostate cancer tool. Semi structured interviews carried out In the participants homes All except one were tape recorded. One was hand written. 17 of the 18 were conducted in the participants own home. | Not discussed | Ethical approval is Described. As is the consent process. | A process of several structural analyses is described with supporting data from the interviews. Coding and thematic analysis were described using a hermeneutic approach inspired by Riceour. The three phases of naïve understanding, structural analysis and comprehensive understanding are clearly described and illustrated with excerpts from the data. Illustration of the steps in the analysis is given. A theoretical model of living with HRPC is described. | The findings are presented with extensive discussion of the literature in the third phase of the process – comprehensive understanding. The findings are discussed in terms of their credibility and trustworthiness in their own right. The discussion in relation to healthcare professionals are discussed. | 19 |
| 6. | Ryan, P | Phenomenological Appropriate for the aims of the study and described as being useful for uncovering or understanding a phenomena about which little is already known | 5 older patients with advanced cancer which was described as sufficient to reach saturation, Purposively selected. Recruited via their physician | Longitudinal data, 3 -6 interviews per participant over 1 – 6 months. Three of the participants died during the study. The number of interviews was regulated by death or saturation. Interview findings informed subsequent interviews and participant validation is described. Interviews were tape recorded in the participant's home. | Not discussed | The consent process is described. Also that the study was approved by the university board. Confidentiality is addressed. | Data analysis is described as following each interview and subjected to contextual processing. Ie within define aspects of the context of the individuals lived world. Narrative summations were then composed for each participant. The result is 5 individual narratives informed by Munhall's process of analysis. | The findings are presented in a way designed to reflect each participant's contribution then the discussion attempts to draw those together. This is reviewed in light of the original research question but not the relevant literature. Limitations are acknowledged. Practice & education implications for nursing are suggested. | 15 |

| 7. | Carter, H | Grounded Theory Appropriate for the aims of the study although rationale for this choice is not given. It is described as an extension to a previous study to focus on what matters most to patients. | 10 patients with advanced cancer – 3 more declined. 3 withdrew during the study – reasons are given. Convenience sample from a larger study looking at malignant and non malignant disease and what matters most when living with dying. Approached by the physical then contacted by the research team. A convenience sample was used. | Open interviews. Tape recorded and transcribed 4 in hospital setting and 6 at home. Inclusion and exclusion criteria are given. Participants were initially contacted by a third party. | Not discussed | Ethical approval was sought and given. The consent process is described in detail. | Data analysis is described although it is unclear at what stage and whether it was used to inform subsequent interviews. NU*DIST software was used following manual analysis to assist coding. Saturation is described as being achieved prior to analysis of the final interview. Illustrative quotes are included in the paper. | The findings are presented with excerpts from the data. Some illustration of how the findings were extracted from the data. The findings are discussed in light of the literature and the authors include a section which relates to what is already known and what this study adds. The limitations of the study are addressed. Also the implications of the findings. | 14 |
| 8. | Luoma,M. | Phenomenological Appropriate for the aims of the study which intended to explore meaning. Discussion around phenomenology and what it would add to the QOL tool currently being used for the study. | Sub group of a larger chemotherapy clinical trial group. 25 patients participated although 32 were approached. Consecutive patients with advanced breast cancer. Interviewing ceased at saturation – 18 patients. | Semi structured Interviews conducted in outpatient rooms. Interview structured around the format of a QOL tool. (QLQ C30). Audiotaped interviews. | Not discussed | Consent is discussed prior to the interviews taking place. Ethical approval was also gained. | ATLAS Ti 4.1. was used for analysis and the findings were structured in the format of the QLQ C 30 – which is not consistent with a phenomenological study. The process of analysis is clearly described and the findings are supported by data from the interviews. Husserlian approach informed by the work of Giorgi. | Results are discussed as themes arising from the data and illustrated with quotes from the original data. The findings are discussed in terms of what they appear to add to the existing QOL data and in relation to the existing literature. They highlight the need for longitudinal work. | 17 |

9.	Pilkington, F	Qualitative – descriptive methodology Appropriate for the aims of the study and discussed in relation to the principles of Parse's theory.	14 women with a gynaecological cancer being treated on one centre. Approached by one of the researchers and interviews conducted either in the outpatient setting of the hospital (12) or in the participants home (2).	Semi structured interviews – tape recorded.	Not discussed	Ethical approval was given by the organisation ethics committee approval is not discussed.	Thematic analysis using Parse' approach to thematic analysis. They were therefore interpreted and presented in a format guided by the central themes and concepts of Parse's human becoming theory.	The findings are discussed in light of the existing literature and the implications for both practice and future research are identified. The paper is strongly orientated to nursing. The limitations of the study are not addressed.	21
10.	Hedestig,O.	Phenomenological Appropriate for the aims of the study as designed to explore meaning.	7 men with untreated localised prostate cancer. Purposive sample. One declined of 8 approached.	Open interviews conducted in the participant's homes. Tape recorded.	Not discussed	Ethical approval is discussed and obtained.	Interpretation of the transcripts was made using Ricoeur's process of analysis. The three phases of naïve understanding, structural analysis and comprehensive understanding are clearly described and illustrated with excerpts from the data.	Clear description of the findings. Some discussion in relation to existing literature but not comprehensive. Discussed in relation to the original research question. Credibility of the findings mentioned but not discussed.	21
11.	Howell, D	Qualitative Appropriate for the aims of the study. No specific methodology is identified. The study is part of a larger qualitative study done in preparation for a survey study.	18 women with recurrent ovarian cancer. Recruited from 2 hospitals and a local support group. Approached by a third party.	Semi structured tape recorded telephone interviews.	Not discussed	Ethical approval from the organisation. Informed consent was obtained from the participants. Confidentiality also assured.	Thematic analysis undertaken but not clearly described as a process or illustrated. Findings are supported by extracts from the data.	Limitations are described in terms of the size and transferability of the study. The findings are discussed in relation to the literature and whilst confined to one province of the country the findings are valid in their own right.	14

12.	Howell, D	Qualitative Appropriate for the aims of the study and part of the previous study (11).	Part of the same study as 11. 18 women with recurrent ovarian cancer. Recruited from 2 hospitals and a local support group. Approached by a third party.	Semi structured tape recorded telephone interviews.	Not discussed	Ethical approval from the organisation. Informed consent was obtained from the participants. Confidentiality also assured.	Thematic analysis undertaken but not clearly described as a process. Findings are supported by extracts from the data. Although the findings differ from the above study the process is identical.	Limitations are mentioned but not described in depth. Implications for practice are discussed.	14
13.	Thome, B	Qualitative. Large sample size for a qualitative study but a qualitative approach is consistent with the aims which are to explore the experience.	41 older patients (mean age 83) with advanced cancer. Sub set of a larger study.	Tape recorded semi structured interviews, in the participant's homes. Conducted by members of the research team.	Not discussed	University ethics approval was sought. Informed consent is discussed.	Thematic analysis is described as step by step process, informed by Miles and Huberman. Consensus was reached across the research teams as to coding and categories. Saturation was reached after coding 35 interviews. Illustrations are included within the paper.	Limitations are not discussed. Some of the findings are discussed in light of previous literature. Limitations are not identified. No implications for further work are included.	15
14.	Arman, M	Phenomenological Presented as four individual case studies. (Multiple Case study) which appear to be informed by phenomenology. The philosophical underpinnings of phenomenology are discussed.	4 women with advanced breast cancer interviewed four times over a year, They were women who were included in a larger clinical trial exploring complementary medicine use alongside conventional care.	Longitudinal study 4 successive interviews with 4 women. Semi structured interviews. Tape recorded and transcribed by one researcher. Co validated by a second author.	Not discussed	Regional ethics approval was gained, informed consent is discussed and confidentiality maintained.	The process of analysis is unclear although the findings are supported by data from the interviews. Although separate interviews the findings are presented as an amalgamation of the studies. Development of themes is unclear.	The literature is discussed within the findings. The findings are reflected back to the original aims of the study to obtain a more profound understanding of the life perspective of women with breast cancer. The limitations of the study are not addressed.	20

15.	Davies, M.; Sque, M.	Rationale is given for the use of Grounded Theory which is appropriate for the aims of the study.	10 women with advanced breast cancer. Participants were approached by a third party. Inclusion and exclusion criteria are included.	Semi structured interviews. Conducted at a location chosen by the participants – usually their own home. Audio taped interviews. Modifications to the interview guide were made following a pilot study.	Not discussed	Ethical approval was gained	Interviews were transcribed immediately. The process of analysis is described in detail and the findings are supported with findings from the data. Illustration of the coding is not provided.	The literature is integrated within the findings. The limitations are broad and well described. Theory is generated from the study. Areas for further research are identified.	21
16.	Ohlen, J	Phenomenological Justification and philosophical context is discussed and supported.	16 participants with GI cancers. States some refused but not numbers or reasons.	Inconsistent data collection. Described as conversations. 2 face to face with 4 participants. 3 or more with 5 participants plus 50 telephone conversations but not clear with whom.	Not discussed	Ethical approval was obtained and informed consent throughout the study.	Thematic analysis is described through the use of Ricoeur's process of analysis. The three phases of naïve understanding, structural analysis and comprehensive understanding are described. Examples from the conversations are included in the data. No illustration of the process is included.	There is a small section related to previous studies but not discussed in light of the findings from the study. The comprehensive understanding does not include the literature. Implications are discussed for nursing care and palliative care as a whole. Limitations are not discussed.	21
17.	Allchin – Petardi, L	Justification and description of phenomenology as an appropriate methodology. Also description of Parse's theory	Eight women with ovarian cancer, No indication that anyone refused. There is no mention of the setting. Nor who approached the participants in the first instance.	Open interviews –audio-taped. No mention of location is made.	Not discussed	Ethics are not considered within thepaper.	Thematic analysis using Parse' approach to thematic analysis. They were therefore interpreted and presented in a format guided by the central themes and concepts of Parse's human becoming theory. Examples of the extraction – synthesis process are included.	No integration with the existing literature – purely descriptive. There is a literature section which precedes the findings but no reflection on the literature is made in light of the study. Recommendations are made from the study for future research and practice.	26

18.	Colyer, H	Feminist methodology. Justification given and appropriate for the approach from the researcher.	Three women participated, one declined to have her findings published so the data is presented from 2 of the 3 interviews. It is unclear how the participants were recruited	In depth semi structured interviews. No mention is made as to how or where the women were recruited or where they were interviewed.	Not discussed	Not described	The tape recorded interviews were transcribed and 'ghosted' into autobiographical stories of the two women.	There is no discussion of the findings in relation to the existing literature of the experience. The political context for service delivery is addressed through discussion of the patriarchal dominance within the NHS.	11
19.	Mathieson, C	Grounded Theory Justification for the methodology is given.	Purposive sample. 27 initial interviews with cancer patients. Then a second wave of successive interviews with 10 participants to ensure breadth of tumour sites.	Semi structured interviews were audiotaped and were transcribed prior to each subsequent interview. Participants were recruited through a third party and interviews conducted in the patients own homes. Laryngectomy patients had notes taken during the interviews,	Not discussed	Not discussed.	Thematic analysis through constant comparison described in depth and the findings clearly illustrated as a process from the interviews. Excerpts are also included in the findings.	The finding revisit the original aims of the study and the evidence base provided within the literature. Strengths and weaknesses of the approach and the limitations of the study are addressed comprehensively.	21

Undertaking the appraisal.

Nineteen papers were included in the review of which only two were undertaken in the UK. The remaining papers were undertaken in the Sweden (6), USA (4), Canada (4), Finland (1), The Netherlands (1), and New Zealand (1).

Country	Authors
U.K	Davis & Sque, (2002) Colyer, M, (1996)
SWEDEN	Ekwall,E. (2007) Lindqvist, O (2006) Hedestig,O. (2003) Thome, B (2003) Arman, M (2002) Ohlen, J (2002)
USA	Coyle, N (2006) Houldin, A. (2006) Ryan, P (2005) Allchin – Petardi, L (1998)
CANADA	Pilkington, F (2004) Howell, D (2003) Howell, D (2003) Mathieson, C (1995)
FINLAND	Luoma,M. (2004)
THE NETHERLANDS	Groot,M. (2007)
NEW ZEALAND	Carter, H (2004)

A variety of qualitative methodologies were used with the most common being phenomenology (9). Other studies used grounded theory (4) Feminist theory (1), case study (1) and 4 used a non specific 'qualitative' approach.

Methodology	Author.
Phenomenology.	Ekwall,E. (2007) Coyle, N (2006) Lindqvist, O (2006) Ryan, P (2005) Luoma,M. (2004) Hedestig,O. (2003) Arman, M (2002) Allchin – Petardi, L (1998) Ohlen, J (2002)
Grounded Theory	Houldin, A. (2006) Carter H (2004) Davis & Sque, (2002) Mathieson, C (1995)
Feminist	Colyer, M, (1996)
Case Study	Groot,M. (2007)
Qualitative approach	Pilkington, F (2004) Howell, D (2003) Howell, D (2003) Thome, B (2003)

All used samples of patients with advanced cancer but the site of the tumour, and hence the gender of the sample groups varied.

Tumour Site.	Number of papers.	Authors.
Gynaecological	6	Ekwall,E. (2007) Howell, D (2003) Howell, D (2003) Pilkington, F (2004) Colyer, M, (1996) Allchin – Petardi, L (1998)
Breast	3	Davis & Sque, (2002) Luoma,M. (2004) Arman, M (2002)
Colorectal	2	Groot,M. (2007) Houldin, A. (2006)
Prostate	2	Lindqvist, O (2006) Hedestig,O. (2003)
Mixed tumour sites	6	Coyle, N (2006) Lindqvist, O (2006) Ryan, P (2005) Carter H (2004) Ohlen, J (2002) Mathieson, C (1995)

Fifteen of the studies were cross sectional studies and four of the studies used longitudinal methods (Coyle, (2006), Ryan, (2005), Arman, (2002) & Ohlen (2002).

The research findings.

Appraisal of the research evidence.

So far within this chapter the process of searching the literature and arriving at the final nineteen papers for inclusion has been described. The nineteen papers have been reviewed in a process which reflected the qualitative nature of both the review and the study itself.

The critical appraisal of the research process as described within the papers including the quality as a piece of research has been addressed using the CASP framework. However the second aspect which is of equal importance within the study is an integrated account of the findings of those papers. Reviewing the papers and selecting them for inclusion is the initial phase of the review, followed by a critical appraisal of the research process which lead to the next phase.

This phase involved a qualitative metasynthesis of the literature which explored the experience of living with advanced cancer. The papers needed to be appraised in such a way that their value and utility are examined both within the context of this study and as a credible piece of work in their own right.

Whilst I would be the first to argue that as a novice researcher there may be an 'impudence' in undertaking this process and making a series of judgements about the work of far more experienced authors, I do feel the process of critical appraisal is an integral part of the study as a whole and my development as a researcher.

The purpose of this section is to expand on the table and not only review the individual papers in terms of their process but also their utility and value in contributing to my own study.

The literature.

The findings from the 19 papers are quite diverse. Interestingly ten of the nineteen studies were sub groups of larger studies. The study by Groot (2007) recruited participants for a study looking at terminal illness then chose to undertake a single case study on a participant when the focus of her care was seen as 'living on borrowed time' as she failed to deteriorate in her health. The study published by Coyle (2006) was part of a study which sought to explore the experience of living with advanced cancer and the participants were recruited from an American clinic which specialised in pain and palliative care. The participants were chosen from a larger study where the entry criteria were based on expressing a desire for hastened death. Hence some of their experiences would be quite specific to individuals with those desires.

One of the two papers which addressed the experiences of colorectal cancer patients was the study undertaken by Houldin (2006). The study was part of a larger study which explored the experiences of colorectal cancer patients and their carers. Cross sectional interviews were undertaken with the patients during their first cycle of chemotherapy. Whilst much of the data is relevant it is gathered at a time when treatment dominates in the experience and may not reflect the cancer experience as a whole. The study by Luoma (2004) was developed along a similar process. The interviews were with patients who were taking part in a chemotherapy trial for women with advanced breast cancer. Both papers describe the importance of quality of life and quality of life tools (QOL) in a manner which is consistent with a trial philosophy. The interviews were undertaken after the second or third cycle of chemotherapies as the intention was that the participants would be able to discuss the experience of their treatment. The study, whilst described as focussing on the experience is intrinsically related to the chemotherapy experience.

Similarly the study by Lindquist (2006) was part of a larger longitudinal study which was aimed at exploring the impact of living with advanced prostate cancer. The data was collected as part of the second phase of interviews. The first phase had focussed very much on a functional assessment of physical problems and this data

was as a result of subsequent interviews. As a consequence the findings are very physically orientated and functionally focussed, again with a feeling of having a foundation in quantitative work.

There are two studies which are both taken from the same larger study undertaken by Howell (2002). The study was designed to explore the experiences of women with advanced ovarian cancer and the two papers represent different aspects of that experience. The first is focussed predominantly on the experience of recurrent ovarian cancer and the second describes the impact the illness had in their lives. The study is also reported to have explored; diagnosis and treatment, therapy choice decisions, acquisition of information, involvement in decisions, changes in lifestyle and enlistment of supportive care. These aspects do not feature in the two studies which are included.

A study which focussed largely on disability was that of Carter (2002). Her research paper offered the findings from a sub group of patients who were involved in a study which was an extension of a study that focussed on 'what matters most' to people with a disability. The larger study included a sample of individuals who had experienced stroke, arthritis and chronic pain. The intention was to explore the aspects of 'living with dying' from the patient's perspective and offered the findings from a sub group with advanced cancer. Similarly the study undertaken by Thome (2003) was founded in a non cancer population. The focus of her study was to explore the health of elderly populations in Sweden and her paper reflects a sub group of participants who had cancer.

The selection of participants for the paper by Arman (2002) was influenced by the inclusion in a larger study of 120 women with advanced breast cancer. The paper reflects a subgroup of four women who were included in the arm of the study in which participants were also undertaking complementary therapy.

Whilst the findings are all contributory in terms of the overall experience of living with advanced cancer they do reflect specific sub groups within those populations.

The goal within qualitative research is not one of generalisability, but transferability is rarely discussed and is important. The limitations must be appreciated within these sample groups.

The remaining nine papers are stand alone pieces of research which vary in their contribution to the overall literature.

Ekwall (2007) provides a robust justification for the use of phenomenology to explore the experiences of women with ovarian cancer. Although the translation into English from Swedish is at times not grammatically correct the study clearly outlines the need to elucidate these experiences to develop nursing support. The aim of the study is to know what it means in their everyday lives and so develop a structure of support. She does describe her approach as being Husserlian, although there is no obvious discussion around prior assumptions or evidence of bracketing in the paper. There is a good illustration of how the themes were developed from the data in several areas and the findings are supported with extracts from the transcripts. The study offers interpretation, as opposed to pure description. There is clear discussion around the need for transparency within the research process as an indicator of trustworthiness. She focuses on isolation as a key issue and the overarching theme from the study is living in limbo. The study is really useful in the way it draws on the transitions literature and issues around assuming responsibility for one's own health. However, it is a cross sectional study, with patients either having, or just completed, chemotherapy.

As well as the study by Thome (2003), the study by Ryan (2005) from the US, also drew on elderly participants. Although methodological justification was discussed the size of the study was justified by saturation of the data. This study included 5 participants and is described as phenomenological. However, the study is longitudinal, with each interview being informed by the previous interview and saturation being the endpoint. This is more in keeping with a grounded theory approach. There are inconsistent numbers of interviews as 3 of the 5 participants died during the study, hence the variation in the number of interviews. The findings

are presented as five narratives with no theory being developed from the findings. The discussion is given in relation to the implications for caring. The study is very descriptive in its nature.

Two of the remaining studies use Parse' theory (Pilkington, 2004, & Allchin-Petardi, 1997). Both studies outline the context for the study and situate the research within a nursing perspective. The theoretical assumptions which inform the studies are discussed and Parse' theory outlined. Both review their findings in relation to the existing literature and describe their contribution to that literature. They describe their work as rigorous and substantiate their findings with extracts from the literature. They both follow the same process of analysis which develops theory in relation to 'becoming human'.

Two papers also use a phenomenological approach which has been developed by Ricoeur (Hedestig, 2003, & Ohlen, 2002). Similarly these papers both follow the same methodology and analysis. Ricoeur suggests a series of steps and defines these as a dialectic process of interpretation between the text and the reader. They both offer a first interpretation, a 'naive reading', a 'structural analysis' and the final step of a 'comprehensive understanding'. Whilst both papers adhere to his model the generation of the themes is not obvious or supported with illustrations from the transcripts to show the development. Quotes are included to support the findings but the step from naïve reading to structural analysis is not transparent. The findings of Hedestig's paper describe the experience as being a specifically masculine experience, however, although the participants are all male, the aspects of being alone, uncertain, afraid and worried are not necessarily gender specific. Ohlen discusses the philosophical context, ontology and methodological justification at length in the paper, which provides a clear foundation for the study. However, the study is described as 'longitudinal', which is justified by a succession of 'conversations' but there is little clarity beyond that. There appear to have been 39 face to face encounters and 50 telephone conversations with 16 patients. There is no indication of over how long these took place or how these were analysed to produce

the structural analysis. There are inconsistencies amongst the numbers of interviews per participant and no discussion around why the endpoint of the study was reached.

The study undertaken by Davis and Sque (2002) is one of two papers from the UK. The paper clearly describes the process of analysis and synthesis although illustrations of this are not included. The findings are supported with extracts from the papers and the methodological considerations are discussed.

The final two papers by Colyer (1996) and Mathieson (1995) are quite distinctive papers. The former paper uses a feminist methodology and has powerful findings; however these are based on 3 cross sectional interviews done with women with 'cancer in a sexual organ'. Unfortunately one of the participants withdrew her permission so the findings are based on two interviews. However, they do raise many of the same experiences as those with greater number of participants. The methodological discussions and the theoretical assumptions are very clearly outlined within the study and the author's viewpoint is transparent.

Extensive theoretical assumptions are also present in the paper by Mathieson (1995); the focus of the study surrounds identity theory and uses a grounded theory approach. The methodological assumptions and contextual information support the study strongly and there is extensive discussion around the analysis and coding. It is a substantial paper which affords the opportunity for many extracts from the data and so enhances the transparency of the work.

Sadly, despite a fundamental tenet of interpretive research being reflexivity and transparency there is an absence of discussion in any of the papers in regard to either aspect. The authors do not address their role as researcher within the studies and how their own epistemological stance is important in shaping the study. Without this aspect it is difficult to champion research which embraces the philosophy of openness and transparency which is needed within any qualitative work. Similarly the discussion around ethical aspects of the studies is scant. Most of the papers

concede approval via a recognised committee but not any guiding principles or potential difficulties.

However, there are a number of papers which have value both in terms of research and in respect to their contribution to the foundations for this study. The studies highlight that there is a greater need for robust, transparent and contributory research which explores the experience of living with advanced cancer, during the period of the individual's illness when they are aware that they can no longer be cured, but prior to the transition to end of life care. The review also highlights the need for longitudinal work which will capture the experience which can be missed in cross sectional studies.

TABLE 4 – THE FINDINGS

ID No	First Author	Year and country	Title	Methodology	Method	Sample	Findings	Conclusions
1.	Ekwall, E.	2007 Sweden.	Recurrence of ovarian cancer - Living in limbo	Phenomenological	Open interviews - Thematic content analysis.	12 women with recurrent ovarian cancer	The women were trying to live in the present, feeling alienated with an increased threat of death. The paper describes coping with bodily changes and the impact of their illness on their relationships.	Meta theme of 'living in limbo'The author suggests that "Living in limbo" can be described as a phase of a health-illness transition characterised by loneliness.
2.	Groot,M.	2007 Holland	Living on borrowed time: Experiences in palliative care.	Single Case Study	Semi structured interviews. Thematic content analysis.	One patient with colon cancer & husband.	Three themes were identified: shifts in the interpretation of physical signs and symptoms, altered view of the future and altered choices and priorities	The findings increase understanding of the phenomena of living on borrowed time. Further study of the themes needs to be undertaken to help patients integrate into their 'new reality'
3,	Coyle, N	2006 USA	The hard work of living in the face of death	Phenomenological	Semi structured successive, interviews. Thematic content analysis.	7 patients with advanced cancer of varying sites.	The sub themes relating to hard work were; orientating themselves to the disease and maintaining control, searching for and creating a system of support and safety, and struggling to find meaning and create a legacy	Living in the face of death entails a succession of losses and changing of self Loss of control, power, identity, Place in the world and future all result in the formation of a new Identity.
4,	Houldin, A.	2006 USA	Salvaging their normal lives: A qualitative study of patients with recently diagnosed advanced colorectal cancer	Grounded theory	Semi structured interviews. Thematic analysis	14 patients with advanced colorectal cancer	Findings yielded six domains: feeling life is disrupted, experiencing physicians, feeling unprepared for everything, rethinking parenting, Wondering "why me?" and dealing with it.	The meta-theme that explained study participants' experiences with recently diagnosed advanced colorectal cancer was "salvaging their normal lives."
5.	Lindqvist, O	2006 Sweden	Reclaiming wellness - Living with bodily problems, as narrated by men with advanced prostate cancer	Phenomenological	Semi structured, successive, interviews. Thematic content analysis.	18 patients with prostate cancer	Findings show that meanings of living with bodily problems are to live in cyclical movements between experiencing wellness and experiencing illness.	Focus by healthcare professionals on symptoms can obstruct the ability to reclaim wellness.

6.	Ryan, P	2005 USA	Approaching death – A phenomenologic study of five older adults with advanced cancer	Phenomenological	Semi structured, successive, interviews. Thematic content analysis.	Five patients over 65 with advanced cancer of varying sites.	The study found that: genuine caring, compassionate honesty from trusted healthcare professionals, cautious hopefulness maintained by patients and their loved ones, unquestioned faith, an involvement in desired life activities, and positive interactions within the healthcare system and in personal relationships were meaningful.	The study concluded that individual experiences were valuable in their own right and that care should be individualised for each patient.
7.	Carter, H	2004 New Zealand	Living with a terminal illness - patients priorities	Grounded theory	Open interviews Thematic analysis	10 patients with advanced cancer of varying sites	Five themes: intrinsic/ personal factors, extrinsic / external factors, future issues, perceptions of normality, taking charge.	The study highlighted the importance for the patient in taking charge and suggests that understanding patients needs will help health care professionals develop appropriate management strategies and assessments.
8.	Luoma, M.	2004. Finland	The meaning of quality of life in patients being treated for advanced breast cancer.	Phenomenological	Semi structured interviews. Thematic analysis	18 patients with advanced breast cancer.	Reduced autonomy due to physical symptoms, changes in social functioning / relationships,	Cross sectional and raised the need for longitudinal studies. Three meta themes: Patients ability to control the illness experience, personal growth and hope.
9	Pilkington, F	2004 Canada	Quality of life for women living with a gynecological cancer	Qualitative.	Semi structured interviews. Thematic analysis	14 women with a gynaecological cancer	The study identified four main themes which describe the experience as :Quality of life is treasuring loving expressions while affirming personal worth, as consoling immersions amid torment emerge with expanding fortitude for enduring	The themes provide a unified Description of living with a gynaecological cancer. Care can be enhanced when patients feel listened to, cared about and understood.

10	Hedestig,O.	2003 Sweden	Living with untreated localised prostate cancer.	Phenomenological	Unstructured interviews. Thematic analysis	7 patients with advanced prostate cancer	Emerging themes of feeling alone, uncertain, afraid and worried. Deeply affected by sexual dysfunction. Participants describe a number of coping strategies employed	Living with untreated localised prostate cancer amounted to living under a dark shadow that was a threat to life.
11.	Howell, D	2003 Canada	The impact of ovarian cancer perceived by women.	Qualitative.	Semi structured telephone interviews. Thematic analysis.	18 women with ovarian cancer	The study describes alteration in role, function, relationships, fears for partners and children, lack of control, living with uncertainty, stigma and facing death. It also describes sources of support.	Women reported the impact on their day to day lives, sources of support and the study explored the implications for practice for cancer nurses arising from the understanding gained.
12.	Howell, D	2003 Canada	Womens experiences with recurrent ovarian cancer.	Qualitative.	Semi structured telephone interviews. Thematic analysis.	18 women with ovarian cancer	The study describes waiting for recurrence, tackling the diagnosis, managing treatment related concerns, attempting to regain control	Healthcare professionals need to understand the meanings associated with monitoring tumour markers. More research is needed into the impact of recurrence.
13.	Thome, B	2003 Sweden	The experiences of older people living with cancer	Qualitative	Semi structured interviews Thematic content analysis. Plus QOL questionnaire	41 patents over 75 with cancer	Four main categories were identified: 1) living with cancer means bodily, mental, social, and existential experiences; 2) being aware of the disease or not; 3) handling of daily life; 4) feeling affirmation or rejection from healthcare professionals.	The experience is compounded by Age, co-morbidities, Perception of current and previous life and the impact of their illnesson their daily living.
14	Arman, M	2002 Sweden	Living with breast cancer - a challenge to expansive and creative forces	Phenomenological	Semi structured successive Interviews. Thematic analysis.	4 women with advanced breast cancer	Individual presentations where women's descriptions outline the tensions between life and death, polarization of life perspective, increased authenticity of self.	There was an increased awareness of the relationship between life and death, which constituted a disclosure rather than an actual change in life perspective. The closeness to death is transformational and healthcare professionals need to bemore aware of the depth of suffering.

15	Davies, M.; Sque, M.	2002 UK	Living on the outside looking in: a theory of living with advanced breast cancer.	Grounded theory	Semi structured interviews. Thematic analysis,	10 women with advanced breast cancer	Five categories: reconciling a different me; time bomb; media effect; professional waning; rescuers. The category 'reconciling a different me' was the core theme.	The findings raise issues regarding appropriate support, increasing isolation, fear of recurrence being confirmed, limited psychological resources, lack of professional awareness of the effect on embodied knowledge.
16	Ohlen, J	2002 Sweden	Being in a lived retreat – embodied meaning of alleviated suffering	Phenomenological	Semi structured interviews. Thematic analysis,	16 patients with advanced cancer	Two themes – meanings of experience / alleviation of suffering, Movements in alleviation.	One meta theme – being in a lived retreat. Implications for healthcare professionals relate to flexibility of care, control of care and conceptualisations of the body.
17	Allchin – Petardi, L	1998 USA	Persevering through having ovarian cancer – 'weathering the storm'	Phenomenological (Using Parse' human becoming theory of nursing)	Semi structured interviews. Thematic analysis	8 women with ovarian cancer	Three core concepts surfaced: deliberately persisting, significant engagements, and shifting life patterns	The study substantiates the literature on the concept of deliberately persisting. It expands the theory of persevering through difficult times and presents it as a multi dimensional phenomena of the human – universe – health process.

| 18 | Colyer, H | 1996 UK | Womens experience of living with cancer | Feminist. | Semi structured interviews. Thematic analysis | 3 women with gynaecological cancer | The author describes the process of diagnosis and treatment and also as conveying a catastrophic nature of a diagnosis of cancer, which leads to a painful, existential crisis and feelings of bewilderment, powerlessness and isolation | The study reinforces the need for a shift to biopsychosocial models of health which empower women to be more involved in the decision making process. Existential crises and emotional Pain need to be recognised as A major problem for cancer Patients and those around them. |
| 19. | Mathieson, C | 1995 Canada | Renegotiating identity – cancer narratives | Grounded theory | Semi structured interviews. Thematic analysis | 37 patients with cancer of varying sites. | The study highlights three areas involved in identity and a diagnosis of cancer; threat to identity, biographical work and renegotiating identity. | The study discusses the implications for narrative analyses in the social sciences, to explore renegotiating identity. |

Synthesising findings from the studies.

Meta synthesis.

Sandelowski (2004) describes qualitative research synthesis as being distinct from other reviews of literature. She also suggests that this can take two distinct forms: i) a qualitative meta summary, which is a quantitatively orientated aggregation of the findings of qualitative research, which could include summaries or surveys of data but often represents a more quantitative logic. ii) a qualitative meta-synthesis, which represents an interpretive integration of qualitative findings which are themselves interpretive syntheses of data (Sandelowski, 2004). Meta-synthesis of data is aimed at providing an accurate interpretation of a phenomenon (Pearman, 2004).

A meta synthesis has also been described as both an interpretive product and the analytic process by which the findings of the studies are aggregated, integrated, summarised or otherwise amalgamated to create a larger interpretive composition of all the studies within a targeted domain (Barroso, 2003).

Having identified 19 papers which satisfied all of the inclusion and exclusion criteria a meta synthesis was undertaken. This involved exploring and listing all of the themes identified in the individual papers and collating them clusters of themes. Then patterns were identified between those findings and synthesised into a review of the findings across the papers. This was scrutinised by one of the research supervisors to ensure accurate representation of the findings from the papers. An example of this is offered in Fig 1.

These findings are represented by six main themes which can be interpreted as; relationships, control, practicalities, perspective, mortality and self. There were findings from individual papers which represented deviant data or exceptional findings which are discussed in a seventh category called exception.

NB. The ID numbers assigned in Table 4 (p50 -54) will be used within the metasynthesis as superscript to guide the reader to relevant papers.

Fig 1. Example of thematic analysis – Perspective.

Study no:	Theme.
1.	Not thinking about the future.
1.	Hoping to live longer.
1.	Uncertainty is reinforced by the inability to give a prognosis.
1.	Greater fear of death with no prognosis.
1.	Link with sense of survivorship prior to diagnosis of recurrence.
1.	Disappointment / alienation.
2.	Tentatively looking ahead.
2.	Interpretation of signs and symptoms.
2.	Withdrawing from social activities.
2.	Change in perspective.
3.	Making the threat less overwhelming when viewed as a Chronic illness such as diabetes.
4.	Feeling life is disrupted.
4.	Standing still with the future on hold.
4.	Dealing with it.
5.	Living one day at a time
6.	Reflecting on the ability to achieve a life plan.
6.	Relative to pre illness state (as a reference point for now).
8.	The impact of faith on perspective
8.	The value of ordinary everyday things.
9.	Difficult times / negative experiences the contrast with good times.
9.	Live each day and enjoy it.
9.	Appreciation for ordinary things.
9.	Drawing strength from the experience to carry on.
10.	Being alone with the experience.
10.	Fear and uncertainty – the constant threat.
11.	Anticipating recurrence – fear of waiting / inevitability
12.	Change in day to day living
12.	Living with uncertainty.
12.	Fear of the unknown.
14.	Makes you think about what you are going to do with what is left.
14.	Re-evaluation of life – 2 paradoxes Conformity v's non conformity, certainty v's uncertainty.
16.	The meaning in the social world
16.	The stigma of cancer and medical discourse.
18.	Influence of presence of death on perspective of life.
18.	Facing uncertainty.
18.	Living in the present.
18.	Becomes isolating / paralysing
18.	Cancer is synonymous with destruction.

Relationships.

Relationships are central to the experience of adjusting to living with advanced cancer. All except two of the papers explored the impact of the experience of living with advanced cancer on relationships in some form. A number of elements were highlighted across a diversity of inter-relationships with friends, family and healthcare professionals. The support from friends and family is described as important both in terms of coping and in shaping individual interpretation and meaning of the illness. Friends and family provide much of the context for the experience and offer a connection with a 'higher' acceptance and realisation of deeper views of life [14]. Relationships are described both in terms of positive impact and negative impact, particularly when exploring the impact on relationships with partners and children. There are a number of references within the literature which describe issues of 'burden' and the effect this can have within the dynamics of a relationship. Kinship is often raised as a positive aspect of relationships with fellow patients and also the interactions and experiences with healthcare professionals. The alterations in relationships are often linked with alterations in role and the subjective interpretation which transpires as a consequence of being aware of adjusting to a new or changed role in life.

Relationships with friends provide a vehicle for mediating social isolation [8, 9, 17, 12]. Good, strong friendships provide affirmation of worth and lessen the experience of loneliness. Relationships with friends and co-workers are described as providing the motivation to 'keep going' [17],

> "*Participants spoke about valuing in the choosing, prizing and acting of their choices to go on*" (Allchin – Petardi, 1997)

Which is especially important in respect to sustaining employment and the beneficial effect this has on a personal sense of self worth [8, 17]. The one to one response from support networks in general are described as having a greater impact on life functioning and well being, than societal or environmental factors [7,8,12].

The importance of those who are viewed as providing unconditional support cannot be underestimated [8, 16, 19].

> *"Taking a long view of the suffering was expressed by experiences of pleasure and joy when together with other people and sometimes when alone, giving strength and courage to face the suffering of daily life again" (Ohlen, 2002)*

In contrast to this, sometimes individuals experience a re-evaluation of friendships and an opportunity may also arise which allows the individual to remove people they feel are unwanted from their lives [8, 17]. A social 'cleansing' can be achieved and feels legitimised, or at least the consequences feel more justified. If the friendship no longer feels equal due to a perceived loss of social functioning, it can be challenged and removed from the individual's life [1,8,19]. This appears to be largely dependent on the extent of other support which is available and the inner strength of the individual concerned.

More often the 'cleansing' is described in terms of re-evaluating relationships and focussing on those which are true and supportive [4,8,9,12,14,15]. There is a natural withdrawal from those relationships which feel less genuine. There is often a sense of monitoring the reaction of former friends closely. The way the friends now treat the individual will set the scene for the future friendship [1,7,8,15,19].

> *"The women also related that people around them treated them differently now that they were ill" (Ekwall, 2007)*

Feeling a sense of awkwardness or fear from friends can often signal an end to the friendship [1,7,16].

One study in particular [10] defines this activity as being a solitariness which is self chosen. Withdrawal and social isolation within this study are described as creating a sense of self-preservation, partly as a desire to prevent feeling pitied, but also so as

to not feel a burden within a relationship. Once again, security was found in the kinship derived from fellow patients where a sense of pity would be absent. This is re-iterated in terms of increasing autonomy and preventing stigma in other studies [7, 8, 9,15,18,19,]

This sense of burden on both friends and family is highly prevalent within the literature and looking for signs of burden within those relationships is commonplace [1,4,7,9,18,].

> *"participants expressed that they did not know how to talk about the cancer without worrying their children" (Houldin, 2006)*

This sense of being a burden can increase the need for self-driven isolation as a protective strategy. Often individuals describe a deliberate distancing strategy from those around them as not only do they not want to exacerbate that sense of burden, but they equally don't want pity or condescension.

Strength can be derived from socialising with individuals in similar situations and relationships which are formed with other patients are important in the adjustment process and in reducing a sense of isolation [1, 10, 15.] This has been described as 'kinship' [15]

> *"This was noted in the search for kinship with others in a similar situation" (Davis and Sque, 2002)*

and appears to play an important role in mediating a social identity. This appears to be beneficial in two aspects, firstly these are relationships which are formed during illness and therefore have no previous point for reference or comparison with the new relationship and also in terms of the individual feeling they are not the only person who understands what they are experiencing and the relationship is formed on a common problem, There is a strong sense in much of the data that individuals

are treated differently following their diagnosis and therefore this is absent in these relationships.

Conversely, some studies report that the closer the previous relationship, the greater the sense of safety which is derived from support at this difficult time [1, 3, 12, 19].

> *"this is accomplished by addressing the meaning of the illness as it is negotiated in one's 'most important defining relationships" (Mathieson & Stam, 1995)*

The opposite of this can equally apply and many relationships experience great uncertainty during advanced illness[8, 10].

The need for practical care can dramatically alter the dynamics of relationships along with role adjustment. Yet when this is achieved successfully there is a strong sense of increased closeness and bonding within a family [3, 4, 9]. Feeling protected and safe with the family is a key aspect of coping with daily life. However the same vigilant observation for signs of becoming a burden are apparent and often with the concern that increased exhaustion within the family may lead to 'abandonment' [3].

> *"There was concern that increased demands might lead to increasing family exhaustion, even abandonment" (Coyle, 2006)*

This leads to a heightened awareness of how much pressure can be placed on even the closest and most caring of relationships.

The realisation that life has changed forever can be emotionally distressing for an individual regardless of the extent of support from friends and family[12.]Those with children feel this impact quite profoundly, the side effects of treatment and the physical manifestations which are visible to the friends of their children have an inhibitory impact on the social functioning of their children [1, 4, 7, 8, 12]. For example – not having their friends round because of nausea, vomiting or hair loss. Being able

to discuss their illness with their children is difficult without creating fear [4,8,12]. Also the changes which are bought about in their children's lives as a result of their illness [12] and future death.

This change in relationship is very profound in regards to intimate relationships. Lack of intimacy is frequently described as a part of withdrawal from close relationships. Dislocation from close relationships is frequently described, often as a result of a change in perspective[15] following a diagnosis, but also as a result of treatment and its effects. Changes in physical appearances are described as being a hindrance to being able to socialise[1, 9].

> *"The changes in their appearance were described as a great hindrance to socialising" (Ekwall, 2007)*

Altered body image and sense of sexuality has a powerful effect on intimate relationships and can compound the sense of disconnectedness which prevails in many close relationships. A fear of being rejected following treatment is often described [1, 2]. This change has been attributed not just to physical changes in the body of the individual but in the ability to conceive and have children and perhaps the purpose of their sexual relationship[12]. The need to feel connected remains however and the need to feel valued and loved is strong.

This is also apparent in the difficulties in role adjustment and renegotiation[19]. The shift from caregiver to receiver has a profound effect on the dynamics of a relationship, along with other alterations in role such as giving up work, needing more domestic help, rethinking parenting and concerns for the future [2, 8, 12, 19]. A reduced sense of autonomy can be felt as a consequence[2, 8].

 Worries for the future of one's children are frequently described[4, 7, 12, 19] and the need for planning and organisation is often mentioned. This is discussed further in the section on control, but is central to the sense of finiteness and togetherness which is needed during this phase of the illness. The social space has been redefined

as one of illness rather than health[19] and is navigated from a new perspective, which can often be one of isolation[10].

This disruption in identity and disruption in relationships requires adaptation and assimilating into the personal identity of the individual and as a consequence a readjustment of relationships with others. Changes in the role of those around them can increase stress[10], husbands who are attempting to maintain a household and their previous role can experience excessive tension[8.12] and reports arise of women's concerns for their husband's health[12.]

Relationships with healthcare professionals are often described in a variety of ways. During treatment these appear to be key, but as the illness progresses the interactions appear to diminish[15]. These relationships are important in terms of viewing self worth and a perceived change in attitude when the focus of care is no longer on cure can be quite a negative experience for those involved. Being treated as a patient and not a person was viewed as unhelpful [4, 9] and was seen to create unnecessary barriers.

Control

As with all of the other themes many of the aspects of the experience of living with advanced cancer are interrelated. Feeling in control is often synonymous with being, or appearing to be well. This involves the ability to take charge of one's life and distance oneself from situations which will challenge that sense of control. Seeking information and feeling involved in making decisions further enhances that sense of being in charge. A loss of control is always viewed with negativity and regaining control is vital. The inability to regain control signals a decline in health which necessitates adjustment. Attempting to normalise life is commonplace and is one of the aspects associated with a good quality of life. All of these facets are underpinned by the need to retain dignity and a sense of self worth.

Retaining a sense of control for those concerned is an important part of coping with their experiences. 'Taking charge' is a statement which is made frequently

throughout the data[1,4,5,7,] and has been strongly associated with the ability to define and actualise individual needs, choose courses of action and act on those choices.

Seeking self help activities and complementary therapies are frequently described activities, particularly in the papers which focus on breast and ovarian patients[1, 2, 3, 9, 10, 11;] Although there are a higher proportion of papers dedicated to breast or ovarian cancers that any other specific tumour site in this review.

There appears to be an inverse relationship between control and dependence, which is closely observed. Creating a sense of balance through that control can create a renewed view of life [3, 4, 7,] where material needs and extrinsic values become less important.

 Feeling central to the decision making processes during interactions are key to a sense of control within their care[3].

> *"The participants felt they had to manipulate and negotiate an unknown and unfamiliar healthcare system and try to remove themselves from the anonymity of being just a case, a disease or statistical probability" (Coyle, 2006)*

Interacting with healthcare professionals has the potential to create uncertainty and feeling in control is strongly linked with making informed decisions and feeling a sense of parity within the relationship. A negotiation process can ensue which results in concession to treatment and even the loss of body parts to regain a feeling of control over the body [15.]

> *"Hallowell, (2002) suggested that regaining control over a body with breast cancer could be facilitated by the 'elimination of dangerous body parts' The feelings associated with possible recurrent disease had led to the request byone participant for a prophylactic mastectomy, in an attempt to regain*

control over both the disease and the fear of the disease" (Davis and Sque, 2002)

A pivotal part of this is the ability to gather the necessary information to make those decisions which are vital to ongoing treatment [10,] Information gathering is mentioned frequently within the data and is seen as empowering. It serves to create a sense of parity in the dialogue with healthcare professionals, in terms of feeling equipped to have the necessary discussions [10] [11,] This is seen as vital in the quest for a second opinion or for pursuing complaints about care and leads to an enhance sense of control [11.], particularly in the circumstances of advancing disease.

Being able to refuse treatment is mentioned in some of the papers as being a difficult and challenging path which requires a high level of control and autonomy[8,] [10, 11;] Autonomy and control are inextricable in these circumstances where an enormous amount of effort is required to sustain that control. This has been linked with the desire to maintain the status quo, or keep things 'just as they always were'[3,8,] and feel able to retain that control for as long as possible.

'Keeping things as they were' is clearly described within the literature as a coping strategy, and a sense of control is a prerequisite to achieving this. Lifestyle changes are also often discussed and the ability to direct and maintain those changes creates an increased sense of autonomy.

There are times where this sense of control can be lost, especially within times of great uncertainty and increased awareness of symptoms or impact of symptoms on lifestyle force an acknowledgement of change and a process of readjustment. During this time the ability to create the appearance of wellness is important [4, 5, 8,]

"in other words, when reporting physical symptoms, participants used words which minimised the magnitude" (Houldin, 2002)

Often this is related to controlling symptoms such as pain[5,] which can be achieved with varying success.

> *"knowing what to do when bodily problems arise, such as taking a pain killer, when the pain comes, makes it possible to control the problem and provides space in which to experience being well"* (Lindquist, 2006)

The side effects of treatment, such as hair loss can lead to a feeling of loss of control [8,] and can cause frustration where it is important to the individual to retain control over the knowledge of the diagnosis and the hair loss is an external sign which is uncontrollable.

This appearance of wellness is crucial in terms of feeling in control and in terms of how much the public face of their illness can be managed, in terms that the physical manifestations of the illness create a sense of self betrayal as control becomes less easy. The body forces the recognition of not being able to do or achieve certain things and becomes out of the individual's control [5,8,12] and leads to significant distress. Active measures are employed to try and counter this loss of control and strive to regain wellness, or at least the illusion of wellness[4, 5,8,12]. Coping strategies can in part achieve some balance between the 'pacing' and the 'pushing' [7,]

However the inability to achieve this is met with great sadness and fear, which is immensely profound and is often difficult to share with friends and family[12.] This signifies a loss of independence which is challenging both physically and psychologically. Attempting and in part succeeding to regain some independence can make the individual feel in control once more[16,] though this is often to a lesser degree than previously,

This control is described as being synonymous with a greater quality of life. The sense of feeling autonomous and in control are described as leading to a sense of peace and relaxation which in turn has a positive effect on individual symptoms.

This feeling of autonomy and control are also described as an affirmation of self worth [9]. There is also felt to be a link with dignity in that the individual is in control of the symptoms and not vice-versa[7,9,16,] the ability to 'take charge' appears to transcend the sense of dignity at times [4,7,9], and is viewed as an intermediate step in achieving control.

The control in terms of when to delegate authority is also important, the sense of giving permission or requesting help is important as opposed to feeling it thrust upon them[9],

In one particular study[4,] the sense of control of one participant was taking to the extent of extreme dieting to exhibit control when reverting to a coping strategy which she had used in her life previously to feel in control.

Seeking out alternative therapies is commonplace[3, 9, 11, 12,] In some instances these were unproven alternative therapies[11], but the need to drive the direction of treatment is powerful and this can provide an avenue where taking charge and treatment appear to merge[9.]

Practicalities.

Closely linked with this control are the practical issues which arise. Not all of the papers describe the day to day practical aspects of the experience, but those which do are very symptom orientated. The link between control, symptom management and life function are clearly articulated and are viewed from a variety of perspectives. The impact of treatment and the illness itself on the ability to maintain a work role and independence within the home environment are a source of frustration and loss of dignity. Side effects of treatment are distinct from the effects of illness and are seen as a necessity in terms of prolonging life. This distinction creates a sense of increased tolerance where treatment related effects are experienced which is absent in the data relating to illness. The financial pressures increase with the inability to work, which in turn places an increased pressure on relationships with friends and family. Healthcare professionals are seen as providers

of information to manage the effects of treatment and can offer practical advice which can minimise the impact on the individual. The sense of the body being the vehicle for navigating everyday life is strong and is seen as the key to performing the practical, day to day tasks which sustain a normal life. Individuals will go to extraordinary lengths to minimise the disruption to daily life.

Pain is one of the most frequently mentioned concerns[3, 5, 6,8,13, 16,]

> *"The practical work the participants undertook in regard to control of pain began with internal work" (Coyle, 2006)*

and its influence in terms of restricting daily life. Fatigue is also a frequent concern and practical steps are undertaken to manage these on a daily basis[4, 5, and 6,7,13].

> *"Fatigue is described primarily as a hindrance, in the present tense and little can be done to reduce it. The past tense is used to describe how much less tired one was then or how ones stamina has declined" (Lindquist, 2006)*

Both of these symptoms cause distress through the limitations they place on everyday life and can lead to restrictions in social activities and leisure activities[2, 3, 5,6,7,13,16]. A reduction in these symptoms and the ability to control them are synonymous with a positive influence of the advancing disease, for example cure or remission[3, 5,7,13, 16]. Effective analgesia is employed to maximise the body's potential[16.]

> *"The ways the body can be endured are described as being through the use of drugs, personal support and care" (Ohlen 2002)*

There is a sense of evaluating the family's ability to provide practical help which is discussed in the data[3,] and an assessment of what external help may need to be sought in an attempt to cope with advancing symptoms on a practical level. A

transient 'phase' of dependence in physical functioning is accepted, but only if there is a sense that this will be a temporary problem [2,3,8,12.]

> *"this was the work of decision making and risk – benefit analysis" (Coyle, 2006)*

Those with concurrent co-morbidities express a high degree of distress with advancing symptoms which may exacerbate a pre-existing illness, condition or general age related concerns[6, 13.]

There becomes a point where all pain is synonymous with cancer and the ability to make a distinction between the two (cancer and general pain – such as back ache) is lost[5.] A further interesting distinction is made within this study[5] that metaphors which are used to describe fatigue are fewer and less dramatic than those associated with pain. That those linked with pain are far more closely associated with the cancer and those relating to fatigue are viewed in terms of the ability to live on a daily basis and sustain a normal life. This is described as a hindrance as opposed to a reflection of the illness. This creates a sense of a hierarchy of significance within the data.

This reliance on the body to sustain independence and achieve practical aspects of day to day living is crucial in appearing to lead a normal life [5, 12, 16]. The body in this case allows that to be sustained. Therefore when the body is unable to sustain the required level of activity distress occurs.

Whilst side effects of treatment are debilitating, they are often viewed as a means to or cost of, prolonging life and are subsequently tolerated and contended with[3, 4, 5, 7,8,12]. With treatment being perceived as a conflict between the enemy (in terms of its effects) and hope[8]. Side effects of treatment can be dramatic and prevent basis activities such as removing cold items from a fridge [4: even] if these are viewed as minor physical effects they inevitably undermine the independence of the individual and are seen as frustrating.

Undertaking a healthy diet, exercise and positive activities are described as practical activities which can create a sense of wellness [1] and assist in delaying the advancing disease.

Often changes in daily routines are instigated in an attempt to accommodate deterioration in health and 'pace' oneself throughout the day. Resisting limitations can been achieved by substituting activities which give rise to a sense of frustration, with lighter, less challenging activities[2,8,10,12,16,]

> *"New preferences and priorities were put in place and the borrowed time is filled differently" (Groot, 2007)*

A further way of achieving this is by redefining their standards and so achievement was more attainable and therefore a sense of achievement – particularly in relation to being able to help the family was greater [8.] In some cases there are descriptions of participants pretending to continue with a normal lifestyle in an attempt to control their experience.

Information relating to treatments and side effects are really important aspects of coping and facing the sequelae of each round of treatment[4]. Interactions with medical staff are closely linked with this and various amounts of information appear to be gained in relation to the quality of that relationship.

The impact of the illness on the ability to work is highly significant. Often the illness and the effects of treatment require medical retirement from work which is psychologically and financially challenging [4, 7, 10, 12]. Reduced physical functioning and the ability to cope with pain are also frequently mentioned. Those who are able to sustain employment describe a mediating effect on the illness and a buffering from the illness experience[8, 10, 12.] The effect of the treatment on the ability to concentrate can be frustrating, especially within the workplace[8].

The disruption in routine is seen as frustrating and is again linked to a loss of control. That awareness of the limitations of symptoms or the restrictions which result from them create a great sense of dislocation from their previous world, this has been described as being an 'outsider in the world of healthy people'[8.] It is a time when comparisons with their level of activity and functioning are made with their pre-diagnosis state[8.]

Perspective

All of the studies describe a change in perspective. The way life is viewed following a diagnosis of advanced cancer is changed in a number of ways. The themes which relate to perspective encompass those which describe an altered view of the world and the place of the individual within the future. This can lead to a prevailing sense of isolation and uncertainty within their life world and strategies are employed by which to manage this. Recurrent disease brings with it a fresh set of issues which compound the diagnosis even further at times. Signs and symptoms of the illness reinforce the need to view the world from a new perspective and engender a deep sense of fear. The social world of the individual has changed and the need for new social groups can emerge. Faith can play an important role in managing to view the world from a new perspective and can assist in achieving a more positive outlook.

There is a strong sense of making those involved rethink about what to do with the time they have left [2, 4,16,19] and leading to a re-evaluation of life and priorities [2,9,12,16].

> *"Mrs Johnson felt she had changed her priorities, other things were more important now "(Groot, 2007)*

There is a process which ensues whereby the individual reflects on the ability to achieve their own life plan[7] and these thoughts are all viewed in relation to their pre-illness state as a point of reference [3,19].

> *"Through telling their stories, contrasting life before cancer and life after cancer, they attempted to gain some sort of perspective to their life as a whole" (Coyle, 2006)*

The former meanings on which life was planned have changed dramatically[3,,12,16,19]. The need and drive to redefine the individual's perspective themselves is strong and again synonymous with control.

The search for meaning is powerful and will be discussed in the section relating to the self, but it does have a profound impact on the individual's perspective. Sometimes this entails a period of reflection and review on their lives[3, 4,] occasionally questioning their choices or the impact of their lifestyle on their health [3, 4].

Uncertainty can make this a complex process. Both the stress of the uncertainty and the efficacy of coping strategies will influence the perspective of the individual in relation to their experience and also their future[4.] The meaning of an individual symptom can be analysed and viewed in terms of its impact on the illness as a whole and the implications for the individual's survival[3.]

> *"The meaning of the illness became different. Changing from one of imminent danger to one of chronicity. With this change, the meaning became less overwhelming" (Coyle, 2006)*

However this is difficult without any real sense of how time and the future will unfold. The sense of 'living in limbo'[1] is powerful within the data and influences the polarisation on daily life[4,9.] Living each day and being determined to enjoy it appears in some of the studies[1,4,5,6,9] and is linked with a new perspective from which life is being re-evaluated. This is described as a feeling of disconnection and as though the future is on hold [4] as though the world is continuing around the individual, not with them. Focussing on the here and now necessitates a diversion from the future which in turn makes it easier to cope on a day to day basis[1,4,6,5,9,12,16]

There are times where this can be overwhelming and lead to despair – however occasionally hope that the illness can be restrained creeps into their thoughts which give rise to hopes for greater longevity[1, 5].

The presence of death within their everyday lives is a powerful influence on this perspective [1,10,12,18] and the ability to live in the present is used as a stabilising influence when facing a high level of uncertainty[1, 4,10,16,18]. This effort to stay in the present can also lead to a feeling of isolation and has been described as paralysing[4, 10, 18]. It has also been described as 'existential loneliness'[1] The very nature of cancer and its association with destruction and death irrevocably alter the perspective of those affected [2, 12, 18].

> *"but there was always the sword of Damocles hanging over their heads"*
> *(Groot, 2007)*

Although some of the studies highlight a greater sense of togetherness within relationships, this is borne more from a sense of the finiteness of the relationship[1.] In an attempt to manage this, some of the literature suggests that viewing cancer as a chronic illness, such as diabetes, can render its threat less overwhelming[3] and subsequently easier to address. Even viewing the illness as purely a chronic condition in itself can be helpful [3.]

The lack of prognosis can exacerbate the negativity and uncertainty[1, 2, 12] this in turn can lead to rising fears of death and difficulty in adjusting. If symptoms are more apparent then this process of acceptance can be smoother as they cannot be denied [1,3,19].

Recurrent disease can magnify this problem. Those who felt a strong sense of survivorship can experience more difficulty in adjusting and view the recurrence as more alienating and disappointing than those with a first diagnosis[1, 11,12, 19.] The presence of death is described very clearly by those with recurrent disease [1, 19.] Although this is described in relation to a previous potentially cured picture and

therefore those individuals with advanced disease at diagnosis have no comparative perspective. There is a strong feeling that the impact is greater when on a foundation of a perspective of having survived. The data with these women focussed strongly on the oscillation between hope and despair [1.] Feeling unprepared for the diagnosis and the experiences that followed make this more difficult to cope with [4.]

The perspective of the individual is often mediated by their awareness of their illness. Interpretation of signs and symptoms, of feeling well versus the evidence on scans is quite difficult to rationalise[1]. Those with fewer symptoms find this more difficult and are less tentative about looking to the future[2, 5.]

> *"as time went by, Mrs Johnson felt increasingly better; the couple slowly extended their plans and activities" (Groot, 2007)*

Symptoms are seen as representation of losses to some[4] which in turn can extend a sense of bitterness[1].

Fear is a key feature in many of the studies and this is clearly interwoven with uncertainty and death [1,2,4,9,12,18] There is a sense of living on the 'threshold of the unknown'[1] this refocuses the individual on the day to day and the mundane, and leads to a sense of valuing these things for their own sake and trying to enjoy each day [1,4,6,5,9,12,16]

The very real possibility of imminent death pervades the data. Phrases such as 'the spectre' of death appear regularly within the data. This brings a constant threat to life and the ever present diagonsis[4, 18]

> *"a diagnosis of cancer may not in itself be a death sentence, but it raises the spectre of death and thus brings life more sharply into focus, often prompting examination of who we are and what we are doing with our lives" (Colyer, 1996)*

Which creates a sense of fear that is bought into the foreground with each hospital visit. Feelings of uncertainty are high at this time[4] and are related to the potential for the consultation to reveal that the cancer is further advanced and out of control.

A change in perspective is also contemplated within the social world of the individual, the stigma and the change in social circumstances has an impact on the individual's perspective.[19,]

> *"selectively monitoring relationships was a common mode of active renegotiation. In this regard a few participants reported dramatic withdrawals in a physical and psychological sense from their friends."* *(Mathieson & Stam, 1995)*

The illness will have a different meaning to those around the individual and an important achievement is the ability to draw strength from the experience and carry on [14, 19]. A sense of liberation is clear within the data, along with the devastation, that the individual now is able to concentrate on themselves without feeling selfish [14,].

Reconciling the old self with the new self is quite an adjustment process which has been forced on the individual by their illness[7, 19.] Often symptoms are viewed as not merely symptoms but as a representation of losses[4] eg, loss of bodily control, weight, sexual function.

The amount of information available, particularly in relation to survival figures and public accounts of traumatic death from cancer can influence the perspective of the individual. Relationships with fellow patients and their experiences may also shape the view of the individual's future[7, 12.]

The influence of having a strong faith is mentioned as having an impact on this perspective[9, 16,] and the interpretation of meaning for the individual. The sense that

god is giving a purpose to their suffering appears to alleviate some of the distress and lessen the impact of declining health.

Priorities in general often change. Aspects of life which were important prior to diagnosis often change in their significance when the future of an individual is threatened[2, 7]. Often this is linked with the importance of relationships and values with less material significance and more focussed on a new system of values, which are deeper and more meaningful.

Mortality – life and death.

Much of the experience of any life limiting or threatening experience is inherently associated with the life / death continuum. Within the literature this frequently appears to be linked the altered perspective on life and the proximity to death. That polarisation of perspective which accompanies an acknowledgement of a life limiting illness creates new levels of awareness and potential wisdom[14]. As a consequence this can lead to a profound transformation in the sense of self. This is described as a complex struggle with no clearly defined stages, or endpoints as part of a dialectic[14]. The transformation of self and increased awareness of mortality can lead to a process of renegotiation and drive for greater authenticity. The increased awareness of death is interrelated with fear, loss and uncertainty but has also been described as a period of personal growth for some.

An awareness of death necessitates renegotiation. It encourages a reconsideration of the essentials in life and a demand for greater authenticity as an individual[14]. Those values in relation to materialistic needs and external features seem less significant[14] and in reality these transformations are quite difficult to achieve. Frustration can be seen where this transition is hard and it is an often arduous process[7]. Confronting ones own mortality is challenging and arduous and creating any sense of equilibrium is difficult. This is described as creating a balance between enjoying life and preparing for death which is hard to achieve[14]. As independence is lost the turmoil increases in terms of ceasing to be what they were in life and facing

impending death[3.] This is important within the literature related to self and creating meaning or legacy and feeling the pressure of time to achieve this[3.]

"The legacy was urgent and time sensitive" (Coyle, 2006)

Fear is again a strong component of this and the 'spectre of death' brings life into focus [4,8,10] Fear is present not only in terms of death but also in terms of pain[8.] Especially when speculating on what may lie ahead as the disease progresses. Death is often at the forefront of the individuals mind from the time the diagnosis is given[12.] Any sign of pain or sensation of pain is strongly linked with a painful death[5.]

There is a profound sense of loss[1, 15] not just in terms of losing the battle for survival, but in terms of losing or being denied a future.   Those with young children articulate this very powerfully and often describe the anguish at the thought of not being there for their children as they grow up[12.]

There is a prevailing fear of the unknown yet having no alternative other than to face it [9.] The inevitability of death is frequently discussed but often in relation to uncertainty[7]. Channelling the negative energy of fear into more 'useful energy for living creatively'[18] has been described as providing a coping strategy.

There is description of a sense of personal growth prevailing at this time[8], although more focus is placed on determining and realising philosophical positions about the meaning of life in the face of death[7.] A heightened ability to enjoy life more fully and appreciate the smaller pleasures created a positive aspect to the experience.

The need for support from individuals who understand this can be vital. Support groups can be seen to provide this component to the experience but can also dissipate death related anxiety through group cohesion[15.]

However the comparison with others is also suggested to have a negative side in relation to associating the future with the potential for severe pain and death[5]

Self.

Much of the literature relates to the self and the internalisation of the experience. Although there are distinct links to the various aspects of the individual: in the physical sense, the social sense, in terms of identity and relationships. There are powerful descriptions of the exploration of examining who one is as an individual, what they would like and how they would like to be[17]. This is interlinked with the drive for authenticity, being oneself and taking control[14]. The proximity to death enhances and polarises the individual's life. Renegotiation of identity and personal transformation are integral parts of the experience. Preparation for death and the drive to create a legacy are strong. Along with scrutinisation of the individual achievements and purpose in life.

The physical self has a strong impact on the experience of living with advanced cancer where bodily state, function and the individual's ability to perform daily activities are key to the individual's definition of self [7, 18.] This is reflected both in the ability to be involved in activities and the state of emotional well being[7, 18,]

Body image is an important component of the physical self and physical changes affect self image which in turn affects the individual's social and personal interaction[1, 12, 18.] Bodies can be altered by both the disease and the effects of the treatment[1, 7, 15, 18] either the surgical treatment or chemo and radiotherapy.

> *"The obvious physical changes, caused primarily by chemotherapy had a negative effect on the women's views of themselves" (Ekwall, 2007)*

The effects of treatment have a profound effect on both personal and social individuality[15, 18].

Sexual dysfunction is addressed in two of the studies[4, 10] specifically in men. The side effects of treatment for prostate cancer and pelvic radiotherapy can lead to impotence which is described as having 'their manhood restricted'[10,]

The impact of all of these aspects can result in alienation and isolation[1, 18]. The physical consequences can be viewed as a constant reminder of the illness and result in a stigmatisation of the individual who feels 'attacked' by the disease and its treatments[18, 19]. This has been described as 'the enemy within – the cancer and the enemy without – the stigma'[18,] or 'Living on the outside looking in'[15.] Feminist literature describes a double burden; being female and the stigma of the illness[18.]

There is much discussion in the literature around redefinition of self, in terms of acknowledging change in the self [12,15], experiencing disrupted feelings of 'fit' [19] feeing disembodied in terms of space/time and culture [18] trying to regain the former self and hence delay advancing disease[1], and admitting change and adjusting[5,15].

> *"when one discovers that one's body is stopping one from doing what one has always done in the past" (Lindquist, 2006)*

Establishing a sense of a pre-cancer identity is a conscious process and creates an ability to then adjust to how different both life and the individual has become[15.] There is a process of shifting back and forth between the old and the new before letting go of the old, forces a focus on individual mortality[15.] An acceptance is borne as a result of being unable to reconcile the old with the new and acceptance of this can shift the focus to living with their disease[1, 15.]

> *"being a strong survivor was integrated into the women's self –concept and strengthened their view of themselves" (Ekwall, 2007)*

This relies strongly on recognising they are no longer their old self and [1,19] subsequently create the space for the new self [19.]

> *"Faced with these options, the patient has no choice but to re-evaluate her identity within the horizon of her social radius"…"The concept of renegotiating was framed in our patient accounts in terms of a) the stigma of the cancer and b) the constraints of the discourse of medicine" (Mathiesen and Stam, 1995)*

Sometimes reflection on the old self can create a sense of having not made the most of life [4,] being stuck in a cycle of work and caring for a family without time for oneself is suddenly realised. This can create a desire to have a new kind of life based on new values[4.] A desire for authenticity is strong, to 'let the mask fall[4]' and value real and genuine aspects of life and relationships. Whilst being true to oneself or daring to be oneself[4.]

This also has an impact on the social identity of the individuals[12, 18]

> *"there is a need to admit the possibility of reconstructing the altered or broken woman image differently into a more valid representation which is comfortable for the women involved and accounts for the cancer experience" (Colyer, 1996)*

the feeling of loss of connectedness with the social network increases loneliness and isolation[16] there is a disruption in relationships, the social space they used to occupy has been reshaped and redefined[19] therefore interactions within their relationships are renegotiated from a revised position[9,]

Most individuals describe the change in self at some point within the literature[3, 4, 7, 12, 18]. Some describe anger and bitterness, which is coupled with a low mood, lack of tolerance and often depression[8, 18;] This can be closely linked to physical functioning and the ability to carry out daily activities[7, 8.] Often there is a process of conscious denial in order to counter the sense of losing the will to live which then can enable the individual to keep going[8.]

The search for meaning within this is profound. The sense of 'why me?' the how and why[3] and the blaming of self [3, 10]

> *"Struggling to find meaning in what was happening was deeply personal and internal work frequently involving emotional turmoil, questioning, blaming, loss, grief and mourning. The struggle to find meaning took forms of both trying to understand how this could be happening to them as individuals and trying to import meaning to the event itself" (Coyle, 2006)*

Feeling responsible and a failure[1, 10] can result in poor emotional functioning and low mood [4,8,12]. Struggling to find meaning in what is happening is deeply personal work, which requires questioning, blaming, turmoil, loss, grief and mourning [3.].

Admitting to symptoms and adjusting, recognising and accommodating them are all difficult processes to go through[5]. These are closely linked with the desire to apportion responsibility. Some of the physical deterioration is viewed as the responsibility of the treatment and some the individuals themselves[3.].

There is a deep, embodied meaning in the sense of enduring the illness through the body[12, 16].

> *"Endurable bodily experiences are expressed in narratives through getting help to hold back and dampen unpleasant symptoms to gain strength and courage" (Ohlen, 2002)*

This leads to a further renegotiation of identity[19] and a need to be treated as an individual and not a disease[9]. This is also closely associated with the role of being a patient and feeling they have a voice[4, 12, 19].

Creating a legacy is an important part of the sense of self, something to be remembered by in the sense of a desire for a continued existence[3, 6] feature in the data. The desire for inner development and growth can be strong but this needs to be

balanced with a capacity to achieve the individual's goals, or a sense of failure may prevail[4.] This can be difficult to achieve when there is competing pressure to live in the moment [3.]

Providing for children for the future and feeling their life has had a purpose, or they have made achievements are integral to succeeding to create a legacy[3.]

> *"the creation of a view of themselves for posterity incorporating evidence of their own value, of a certain significance to their existence and a justification for how they lived and what they did" (Coyle, 2006)*

The suggestion in the literature is that this is driven far less by a sense of generosity, than that desire for a continued existence[3.] This can be key to the adaptive process when facing a transition to terminal care and can offer a bridge between existence and non existence[3.] A diagnosis of cancer changes the formal identity and estranges it from normal reality[18,]

> *"A diagnosis of cancer threatens our carefully constructed conformal identity, estranging it from normal reality" (Colyer, 1996)*

The same paper suggests that as women live with their cancers they experience an existential crisis, loss of identity, fracturing of body image and a process of re-embodiment and renegotiation of self[18.]

Exceptions

Whilst the meta synthesis offers the opportunity to review the current literature and synthesise it in a way which provides a comprehensive review of the qualitative literature which relates to 'living with advanced cancer' it is important to acknowledge those findings within the literature which appear in individual studies and are not common across the literature.

Whilst the main themes related to relationships, control, practicalities, perspective , the self and mortality there were exceptions which occurred as isolated findings in particular papers. Often these relate to the specific research question, or reflect the philosophical assumptions, or may be as a result of the sample population or community where the study was based Which may be relevant within that particular study, but may not be relevant within other studies.

The study undertaken by Ekwall (2007)[1] reflected not only on the experience of living with advanced ovarian cancer, but also on aspects which related to recurrence. They highlight the significance of monitoring tumour markers within this group and the weight which is placed on the watchful waiting for those results. The raised tumour markers were often the first sign of any recurrence and therefore play a significant part in the experience. The need for information is noted within this study, as with other studies; however this is discussed in relation to the need to know information at the time of the primary diagnosis and so introduces a comparative component to the literature. They also strongly advocate the impact of maintaining a positive attitude in coping with the effects of both the cancer and the treatment, but also in influencing the outcomes.

In contrast with this, the study by Groot (2007)[2] discusses the impact of denial on the ability to cope. The study, however was a single case study and therefore relates solely to the individual and her partner and their ability to view declining health in general terms rather than related to specific signs and symptoms of her disease. The author acknowledges the potential lack of ability to generalise the findings as they represent an individual case.

Information is also mentioned in the study by Coyle (2006)[3] though in a different context. They sought information to achieve a greater sense of parity in discussions with healthcare professionals which related to their illness or treatment. Alternative sources of information are described. The participants use the internet, libraries and friends and family to gather evidence to attend consultations. In feeling a sense of achieving the feeling of being 'just a patient diminished'. Within this paper there is

a powerful overtone related to faith. Descriptions of belief in an after life or that some 'greater good' will be achieved from their death, helped to cope with the fear associated with dying. The need to follow a role model was also mentioned, famous individuals who have coped with great adversity such as Christopher Reeve are cited as inspirational to this group of participants. This is an aspect which is not discussed in other papers.

Interaction with healthcare professionals is also mentioned by Houldin (2006)[4] and Lindquist (2006)[5]   In the former study there is a criticism of healthcare professionals in relation to the feeling of lack of preparation for any aspects of the experience. They describe interaction with doctors in a negative light and at times as 'distressing'. They describe physicians as depersonalising their experience and being uncompassionate. Although an element of hope was also described within discussions around the efficacy of future treatments.

In contrast to many other studies the work of Lindquist (2006) is very orientated to the meaning of pain and how that is representative of the disease. Being in contact with medical staff and developing understanding is seen as beneficial in terms of controlling symptoms and as a consequence reclaiming wellness.

One of the aspects which is peculiar to the findings within the paper written by Ryan (2005)[6] is the aspect of travel. The paper describes interviews with an elderly group of patients in the US which are written as a succession of stories. Within these narratives each story unfolds ands any of the experiences are similar to those described in other studies. However, travel to and from the hospital from the rural community is described as difficult. Within this study, their relationships with healthcare professionals are also described and the importance of trust within that is highlighted as being crucial to its success.

The study by Luoma (2004)[8,] raises the importance of response to treatment. Interestingly the study was produced in conjunction with the data collected from a

clinical trial so although purely qualitative, is very orientated to quality of life aspects which are consistent within a trial.

Dignity is not an aspect which is overtly referred to within much of the data, however much discussion is formed within the study by Pilkington (2004) [9]. Although some of the participants linked this with the ability to sustain control, the study also relates a sense of dignity to affirmation of personal worth and not being pitied.

Interestingly, the relationship with the physician is once more raised in the paper written by Hedestig, Sandman and Widmark (2003)[10] where they refer to the doctor as a companion. Due to the static nature of prostate cancer there is a sense of the longevity of their relationship and as a consequence a greater familiarity and confidence.

One of the two papers included which were written by Howell (2003)[11] is specifically orientated to the experience of recurrence in ovarian cancer. In a similar way to the work of Ekwall (2007)[1] the waiting and watching is dominant in the dialogue. Although not directly related to the experience of living with advanced disease, the impact of anticipating a recurrence has a profound affect when it occurs which cannot be distinguished from the rest of the data. Once more, within this group of similar women the search for information is powerful and highly significant in terms of decision making with treatment options.

The second paper (Howell et al 2003)[12] very much relates to the impact of advanced ovarian cancer and the results are very much in keeping with the main body of the literature. They do however address information seeking from the partner's perspective and describe information seeking activities by the husbands of the participants.

As with the paper by Ryan (2006)[6] the study undertaken by Thomé (2003)[13] used a sample of elderly participants living with cancer. The dynamics in these individuals

were slightly different in that they report death as offering a release. At times this has been described as an escape from 'a miserable and unwanted life situation' or in relation to extreme loneliness in old age.

The effect of the media is described in the data produced by Davis and Sque (2002) [15.] This is not alluded to in other work but appears as a powerful influence within this study of women with breast cancer. This is described in terms of both a positive and a negative effect. The ability to portray inspirational stories and provide effective health promotion is lauded; however, some of the participants reported distress at the stories, especially those not associated with survival

The cultural and social influences are raised as pivotal within the feminist perspective offered by Colyer (1996)[18]. Written over ten years ago and so arguably may no longer be relevant; the paternalism within healthcare is discussed at length along with the guilt which may be experienced by the participants she describes within her study.

In the oldest study in the review, by Mathieson and Stam, (1995)[19,] ; identity is the core concept within the research. They raise the potential for the individual to be defined by their disease which can lead to objectification and stigma.

Chapter Summary.

A basic indicator of quality in qualitative research is said to lie in its transparency and reflexivity (Pearson, 2004), which was sadly not evident in most of these studies. This may be a reflection of the qualitative component being in addition to the larger quantitative work, or may be due to publishing constraints. However, as an integral part of the process this is obviously important. Similarly ethical considerations are poorly addressed, not in relation to obtaining ethical approval or consent for the study, but in terms of the researcher / participant relationship and the impact on the individual of being involved.

These studies do offer insight into some problems which arise as a consequence of having advanced cancer but are often being explored as a sub group of a larger study and therefore the impetus for undertaking the study has a different focus.

As a body of literature, the existing qualitative work attempts to uncover the experiences of individuals living with advanced cancer. However, despite the breadth of methodological approaches described the justification for their use is weak. Often a short acknowledgement of the potential for qualitative work is offered, but this remains unsubstantiated by any depth of theoretical assumption guiding the work and as a consequence methodological justification is not robust. Qualitative methodologies have the potential to explore the everyday worlds of patients and their priorities and hence generate relevant and meaningful advances in practice as a consequence.

Historically, nursing has adopted a problem centred approach to care and research as a consequence often reveals a succession of problems for which to find solutions. However, most individuals however severe their illness have fluctuations in their lives which are hard to reflect in cross sectional, problem orientated or disease

focussed studies. Little evidence exists which truly explores their experiences, rather than exploring their difficulties.

Only two of the papers were from the UK and whilst this may not influence the experience of individuals per se, healthcare systems and cultural norms do vary which may not only influence the context of the data, but also access for recruitment of participants. Both papers were based on female participants (Davis and Sque, 2002) and Colyer (1996). Only two papers were focussed on colorectal subjects, one of which was a single case study in The Netherlands and one which was based around a larger quality of life study in the USA.

The main findings from the literature review and meta-synthesis suggest a focus on individual relationships, control, perspectives, mortality, self and the practical aspects of living with advanced cancer as well as some aspects which are peculiar to individual studies. However, it appears there are a number of gaps in the literature which suggest areas for further exploration.

The everyday world of the individual and the impact the illness has on day to day life is poorly described. Specific knowledge which relates to colon or rectal cancer is minimal and whilst some aspects of the experiences will be transferable across all tumour sites, there are also experiences which are peculiar to rectal cancer. Many of the studies are treatment orientated and cross sectional.

Longitudinal work can truly capture the experience over time as opposed to cross sectional work. There is a lack of evidence which relates specifically to advanced colorectal cancer and a lack of conceptually sound published work which clearly articulates theoretical assumptions and methodological justifications which guide the studies.

Much has been written regarding development of truly patient centred services and services which reflect the needs of the patients yet little evidence appears to exist which scratches the surface of the day to day nature and impact of living with advanced cancer, prior to the transition to end of life care. Many studies are informed by models of service delivery as opposed to being grounded in patient experience.

This study will explore the experience of living with locally advanced rectal cancer, over the course of the illness when the focus is no longer on cure, but prior to the transition to end of life care.

Chapter 3: Method

Introduction

Within the thesis it is important to describe both the perspectives guiding the study and the methods adopted to explore the meaning of living with locally advanced rectal cancer. This chapter will explore the theoretical assumptions and perspectives that informed the research and expand on the discussion around phenomenology and the philosophical underpinnings which were introduced in Chapter 1.

As a paradigm, interpretive research is outlined and the rationale for adopting this approach will be offered. Although the study does not profess to be phenomenological in the true sense, the influence this has had and the contributions of Husserl, Heiddeger and Merleau Ponty require acknowledgement. In particular the pragmatism of Van Manen is considered as he offers a pragmatic approach to undertaking a phenomenologically informed research study which privileges the role of informing practice. Although an educationalist, his guiding principles are readily transferable into the nursing arena.

A pivotal feature of this study is the longitudinal approach to data collection. Although not a new concept, it is important to outline the nature of longitudinal research and particularly its place in the qualitative arena. The concepts of time and change within longitudinal work will be explored both within their own right and within the context of the study. The contribution of a longitudinal approach will be considered and how that enhanced the research.

The chapter will also describe the methods used for the study and how the data collection and analysis unfolded. Key ethical principles will be clarified and their implementation outlined.

The contribution of the frameworks described by Miles and Huberman (1994) and Saldana (2003) are central to the data analysis process. The partnership of the two provided not only a comprehensive approach for the analysis but enabled the data to be explored in terms of the fluctuations in intensity of the themes, emerging new themes and epiphanies between successive interviews.

For the authenticity (Guba and Lincoln, 1989) of the study to be judged, clear explanation of the perspectives guiding the study and the method are required. Transparency (Guba and Lincoln, 1989) in the process of enquiry and analysis are key to achieving this. Placing the study in context and clear explanation for the decisions made during the study enhances this.

Interpretive research.

Research methods can be viewed on a number of different levels, as ways of examining the world. Perhaps the most fundamental of these is the philosophical background which informs the approach and is based on a broader view of what actually constitutes valuable knowledge and truth. It is this conceptualisation of truth that lies at the core of philosophical doctrines that have studied the nature of knowing and emerge as epistemologies through which research approaches have been aligned. Where there has been consensus within a scientific community these beliefs have been described as 'paradigms' (Kuhn, 1962).

Within healthcare, Cartesian dualism has dominated scientific enquiry and methods which arise in this paradigm remain the 'gold standard' to this day. Truth within the positivist paradigm relies on the replication and verification of observable findings. Almost exclusively medical researchers have employed methodologies which seek truth through the objectification and quantification of research subjects and which yield empirical data without recognition of the context and the meaning of what happens to those involved in the experience.

The nature of illness has traditionally been viewed in terms of theoretical, scientific constructs. The 'randomised controlled trial' is championed within the accepted hierarchy of research and is still viewed as the highest quality of evidence available (Dept of Health, 2004).

As a consequence the current foundations for the development of patient care have evolved from a paradigm which demands the disassociation from reality which

accords primacy to the patients understanding (Lawton, 2003). The biomedical construction of cancer care has been strongly focused on discussion of prognosis, treatment, side effects and disease free survival (Corner, 1997) and the conceptualisation of illness as a result is described in terms of a disease which is distinct from the individual experiencing it (Corner, 1997).

In contrast, the perspectives guiding this study are aligned to those of Merleau Ponty who asserts that; - a subject who is essentially 'in the world' is necessarily embodied (Matthews, 2002) and as a consequence the two (the disease and the individual) remain inseparable. The philosophy developed by Merleau Ponty asserts that 'the world is not what I think but what I live through' (1962) and this is perceived as a meaningful whole within an individual's relational and cultural context.

A philosophy for practice.

Biomedical approaches to research do not always resonate with the interests of nursing where focus is on the mediation and construction of experience (Beck, 1994). Exploring the nature of the patients understanding or experience of their illness requires a philosophical approach where making sense of the world through interpretation and description could complement work which has a stronger focus on the relationship between hypothesized variables. Equally it offers the opportunity to answer questions which through the use of more traditional positivist approaches, have remained unanswered. Through the development of a better understanding of the interaction between the experience of ill health and the individual (Lawton, 2003) it may ultimately increase the development of practice, which is embedded in the 'life world' of patients.

The search for a philosophical approach to answer the question of experience requires a method which can offer an experiential dimension, where the participants reveal what is meaningful to them. The 'open ended-ness' of an approach which facilitates understanding from a first person perspective can therefore offer a dimension which could otherwise be missed.

Phenomenology as an approach to inform the study.

There are a number of theoretical perspectives that may orientate a study. With the goal of Phenomenology being to describe human experience as it is lived (Merleau Ponty, 1964) it offers an alternative to more traditional approaches or understandings of illness, because the focus of the research lies in the 'life worlds' of individuals. This feature of phenomenology arises from its philosophical lens (Thomas and Pollio, 2002)

The influence of Husserl, Heidegger and Merleau Ponty.

The work of both Husserl and Heidegger are widely acknowledged to be at the forefront of phenomenological development (Paley, 1997) and whilst both have their roots firmly within the phenomenological arena there are definite distinctions between the philosophical underpinnings they represent (Koch, 1995). Merleau Ponty's work is an extension of some of their philosophy but offers a basis of phenomenological enquiry which privileges the role of the body in the experience, an aspect missing in previous work. He also focuses on the primacy of perception within experience, again a key principle guiding this study.

Husserl and Heidegger.

As the founder of phenomenology, Husserl's doctrine involved returning to the lived world of experience to study phenomena as they appeared through consciousness. A central tenet of his work was the recognition of the validity of this experience and meaning, in developing knowledge through description. One of the major difficulties with his approach lies in the necessitation to 'suspend belief' on the part of the researcher in search of objectivity. This, he suggests, can be achieved through the use of 'bracketing' (Husserl, 1928). His belief was that this ensured a traditional scientific approach, which he purported to be the only way of ensuring trustworthiness within the data (Fleming, Gaidys, & Robb, 2003).

However, this does not resonate with more contemporary existential approaches that view his doctrine as too rigorous and systematic (Paley, 1997). Through Husserl's life his philosophical stance evolved from his initial focus on the importance of rigorous science, to being centred around the 'Lebenswelt' or 'life world' through a process of radical reflection (Mathews, 2002).

In contrast to this, the work of Heidegger focuses on the ontological question of' being' (Heidegger, 1962). This includes the notion of context as an inherent part of the approach to knowledge a belief that was counter to the development of knowledge in Husserlian terms. Heidegger also rejected the notion that we can ever be free from our prior understanding or experiences and challenged the use of bracketing. As a philosopher, Heidegger reacted against the Cartesian traditions which were inherent in the Husserlian approach (Koch, 1995) and claimed to be more concerned with the notion of 'being' in which existence can only be known in relation to others and other objects. He challenged the Husserlian interest in the theory of knowledge which required the ability to suspend belief.

Hiedeggerian phenomenology approaches knowledge development as a transcendental condition (Pietersma, 2000) in other words, a condition, in the absence of which, knowledge would not be possible. He also developed the role of interpretation within phenomenological work by taking his work beyond the very descriptive doctrines which were espoused by Husserl.

Merleau Ponty.

Heidegger's view is shared by the philosophy of Merleau Ponty, who, although largely influenced by Husserl, shares a similar critique of his work with Heidegger.

One of the key elements of Merleau Ponty's philosophy is perception (Merleau Ponty, 1964). He asserts that all knowledge takes place within horizons opened up by perception and all meaning occurs through perception (Thomas and Pollio, 2002). As an approach to exploring the experience of an individual it allows the freedom for the participant to discuss what is meaningful in their relational and

cultural context through his belief that 'what I am aware of is meaningful to me' (Merleau Ponty, 1962). In contrast to Heidegger's writings, which are clearly focused around philosophy, much of Merleau Ponty's work is situated in psychological discourse that makes his doctrine of knowledge more difficult to isolate. However, what he shares with Heidegger is a criticism of Husserl. He felt strongly that perception held validity in its own right and challenged Husserl's notion of the need to appeal to transcendental reflection to answer epistemological questions.

Another of the key influences Merleau Ponty has on this study is his focus on embodiment. His approach embraces the conceptualization of embodiment and although this was not a word he used within his work, he founded his philosophical approach in the theory that existence was known through the body. The world becomes a perceived world of meanings, which include our own bodies and other embodied beings and is shaped by past experience. He suggests:

> "For us the body is much more than an instrument or a means; it is our expression in the world, the visible form of our intentions. Even our most secret affective moments, those most deeply tied to the humoral infrastructure, help to shape our perception of things" (Merleau Ponty. 1962. p5).

His critique of Husserl was that Husserlian phenomenology assumes the conception of knowledge that was asserted in the writings of Descartes and as a consequence adopts the notion of Cartesian duality. However, it would be impossible to undertake a narrative study without a degree of reflection/reduction when analysing the data. This contributes to the notion that this study is unable to conform slavishly to phenomenology, as there will inevitably be a degree of reduction to practically manage the data.

The pragmatism of Van Manen.

Van Manen offers a refreshing and pragmatic approach to undertaking research that is informed by phenomenology. His work complements the work of Husserl, Heidegger and Merleau Ponty whilst translating very theoretical philosophical doctrines into an understanding of praxis. As an educationalist, his interest lies in pedagogy, but the principles of this work are readily translatable into a healthcare arena.

He clearly articulates the dynamics of phenomenological reflection in order to attempt to grasp the essential meaning of something. In an attempt to clarify and make explicit the structure of meaning within a lived experience, he asserts that ultimately the goal of phenomenological reflection is 'to affect a more direct contact with the experience as lived' (Van Manen, 2006, p78). Although meaning will inevitably be both multi layered and multi dimensional, in a practical sense, conducting thematic analysis enables the text to be approached and analysed in terms of objects of meaning, structures of meaning or themes. As a result, reflecting on lived experience then becomes a process of reflexively analysing the structural or thematic aspects of that experience (Van Manen, 2006, p78).

In a similar philosophical stance to his predecessors he described lived research as 'human science', through the study of 'persons' who have 'consciousness' and act purposefully within the world by creating objects of 'meaning' (Van Manen, 2006, p4). What is important within this study is the impact the illness has on those units of meaning over time.

Van Manen (2006) pragmatically describes the life world of the individual as having four core existential facets. He attributes this work to the development of the work of Merleau Ponty (table 5).

Table 5.	**Four core existentials.**

Lived Space (spatiality). Lived space is not the setting in a physical sense, but felt space. As a concept it relates not only to the physical world but it goes beyond geography to explore how we are located in our individual life worlds.

Lived Body (corporeality). The body subject or embodied being itself, which is seen in relation to space, time and relationship.

Lived Time (temporality) Lived time relates to subjective time as opposed to hours, days or weeks. This also relates to the future and the past and how this shapes an individuals life.

Lived Other (relationality). This relates to interpersonal relationships, roles and the greater communities an individual belongs to.

Taken from Van Manen (2006) pp 101 - 106

Whilst this study does not present itself in any way as an exemplar of phenomenological research, it is important to re-iterate the principles of phenomenology and its philosophical traditions which have influenced the assumptions which guide the study and the process of analysis. However the work of Van Manen draws together the founding philosophical principles into a refreshingly uncomplicated way of knowing the world. He defines phenomenology as asking 'what is this experience like? without abstracting it' (Van Manen, 2001). As a result the research will develop insight and consequently bring the research into contact with the participant's world. For the purposes of this study I have drawn together the founding principles of Van Manen's work to outline the phenomenological influence they have on the research presented in this thesis.

His work is guided by founding beliefs that:

1. Phenomenological research begins in the life world.
2. It is a human science that studies 'persons', the personal and the individual, which is pursued against a background of a broader context.

3. The research should not loose sight of the praxis.

4. The real understanding of phenomenology can only be accomplished by 'actually doing it'

5. If done well it will become compelling and insightful.

6. It is the explication of phenomena as they reveal themselves to the consciousness of the individual, therefore the significant world of the human being.

7. Phenomenological reflection is retrospective and always recollective. Reflection relates to experience that has been lived through and so by definition must be past.

8. The study of phenomena is that which makes it what it is. Without which it could not be.

9. It is the systematic attempt to uncover and describe the internal meaning and structures of a lived experience.

10. Phenomenology attempts to describe and interpret lived or existential meanings to a certain degree of depth or richness.

11. It is explicit and self-critical.

12. At its most basic level; it is fundamentally a search for what it is to be human.

Adapted from Van Manen (2006)

As a novice researcher this was attractive as it presented a means to achieve the aims of the study, in a practical way, which is informed by phenomenology.

Longitudinal research.

Longitudinal approaches to research have been well established in many fields. They are not peculiar to interpretive work and are associated with a range of methodological approaches. A pivotal feature of this study is the exploration of experience over time. It was vital therefore to find an approach to capture this data that would acknowledge the pivotal role of time and change.

A wide range of longitudinal studies exist, some of which are still in progress, with the majority focussing on quantitative work (Henwood and Lang, 2003). Although quantitative and qualitative studies exist they differ greatly in their objectives. Quantitative studies tend to focus on measurement of change, the extent of that change and its nature, within population groups (Molloy et al, 2002). Areas such as population trends and causal relationships are frequently studied using methods that build a data set over an extended period of time. This time frame can be variable and reflects the purpose of the study. Ruspini (2002) describes the three most commonly used longitudinal designs as:

1) Repeated cross sectional studies, carried out regularly but using a different sample group from the last
2) Prospective longitudinal studies (panel) repeatedly interviewing the same sample group
3) Retrospective longitudinal studies in which participants recall and reconstruct events of their own lives.   (Ruspini, 2002, p3).

Qualitative longitudinal studies, in contrast, are used to achieve a depth of understanding in terms of 'how' and 'why' changes occur.

Although 'longitudinal' appears to be a very broad concept, there are some basic key features, which will usually be present in all studies. Elliott et al (2007) suggest longitudinal work can be broadly understood in terms of understanding what has happened to a set of research cases over a series of time points. This is in contrast to cross sectional studies, which focus on collecting data at one particular point in time.

Ruspini (1999) in earlier work explored the characteristics of longitudinal research and suggested three key characteristics which should be present:

1. Data are collected at two or more distinct points.
2. The subjects or cases are either the same or broadly comparable.

3. The analysis involves some comparison of data between or among periods.

Menard (1991) describes longitudinal data that has been collected in Quebec for over 300 years. Within Europe, many studies have been established over the past century and a number of large national studies are well documented within the UK. Many of these are 'panel studies' whereby cohorts of individuals are recruited who will provide information about themselves or their circumstances and are subsequently re-visited on multiple occasions (Featherman, 1980; Scott and Alwin, 1998; Taris, 2000, Hollan et al, 2006).

A cohort has been defined as a 'sample of individuals who experience the same life event within the same time interval and are followed over time' (Ruspini, 2002, p34). Examples of these include; The National Child Development Study (NCDS) and The British Household Panel Study. These large studies explore change at both an individual level (Hakim, 1987) and offer a wider view of the dynamics of social phenomenon (Ruspini, 2002). These studies aim to add a cultural or social context to the data and study particular aspects of change and behaviour (Bynner and Fogelman 1993).

Alternatively, cross sectional studies serve to provide a different type of data set. These offer information relating to trends, such as political opinion polls and do not follow the same group of participants for each data set. One off retrospective data collection techniques can also be used and offer an efficient and cost effective way of collecting data. Any retrospective data collection however will have a number of inherent difficulties, which are largely attributable to selective recall, and accuracy of memory. This is often referred to as quasi – longitudinal work (Molloy et al, 2002) as data is not gathered over a period of time and at successive points.

Longitudinal Qualitative research.

Longitudinal qualitative approaches to research are able to complement quantitative work by asking the 'why' and 'how' questions (Holland et al, 2004). As individual

perspectives are naturally subject to change, for many reasons, qualitative research can explore this on different level of understanding. The nature of longitudinal qualitative study can offer insight into experience and how that changes through time.

Any analysis will reflect both the theoretical approach to the study and the unit of analysis. The major challenge lies in capturing the temporal elements of the data.

Holland et al (2004) argue that anthropological studies and community studies are the major social sciences disciplines involved in long term fieldwork, which can be described as qualitative longitudinal work. Within this field Epstein (2002) suggests three formats of study; continuous research with the same small population group, periodic restudies at regular / irregular intervals, and /or returning after a lengthy interval of time since the original study (p64).

Variations in suitable time periods are offered to clarify what would constitute longitudinal work not least of which is Saldana's assertion that fieldwork becomes longitudinal when it progresses over a 'lonnnnnnnng time' (2003, p3). In spite of its initial flippancy, this does highlight one of the key issues when exploring the essential characteristics of this approach. There is no consensus in the literature which suggests ranges from one year (Young, Savola and Phelps, 2001) to a life course (Ruspini, 1999). Saldana (2003) suggests that if he were forced to specify a minimum length in his field (of education) he would say nine months (p4). He also is emphatic that the vital feature of qualitative longitudinal work is that each study is context specific and, as with other approaches, is driven by its particular goals, research questions, conceptual framework and methodology (Saldana, 2003).

Along with the length of the study, the other essential features of longitudinal qualitative work are time and change (Saldana 2003). Whilst the research question, methodology and conceptual framework shape the study the emphasis within the study is focussed around the individual's understanding of their lives and experiences and how these may change through time (Thomson, and Holland,

2003). Saldana also suggests that a longitudinal approach may be adopted for two purposes:

1. To capture, through long-term immersion, the depth and breadth of a participant's life experiences.
2. To capture participant change through long-term comparative observation of their perceptions and actions.

He bases this in the notion that if our movement through time is how we live our lives (Levine, 1997) and if time cannot be separated from change (Sztompka, 1993) then these two purposes will naturally emerge. A challenge to this philosophy may be that time and change are not completely indistinct entities and that whilst change may well occur over a given time, time does not necessarily result in change.

Time – the pivotal feature of longitudinal work.

The notion of time is the critical feature of longitudinal work and the importance of time, the temporal dimension of life, is particularly significant within this study. The very nature of longitudinal work privileges the importance of time. The interplay of temporal and cultural dimensions of life have been raised within the literature around qualitative longitudinal work in general (Neale and Flowerdew, 2003) mainly in relation to grasping the nature of social change or the impact of structural change within communities or social trends. Although this study is not exploring social trends or large social change, the importance of culture is very relevant. The need to recognise the dynamic nature of individual lives appears to have provided the impetus for qualitative longitudinal work and it is this exact feature that underpins this study.

Studies that have employed longitudinal methods have acknowledged the need to redefine the concept of a life cycle with using that of a life course and thereby

recognise that life is not necessarily a series of defined stages within a linear chronology (Harris, 1987). Once again this resonates with the aim of the research in looking beyond the fixed, arbitrary sequencing of life courses which views time in distinct predetermined units to the perceptual nature of viewing time within the context of a life limiting illness which has its own turning points and pivotal moments. Not 'a progress through a predetermined structure but negotiation of a passage through an unpredictably changing environment' (Harris, 1987 p27). Hawking (1988) defines this aspect clearly when suggesting each individual has his own personal measure of time that depends on where he is and how he is moving.

Neale and Flowerdew (2003) discuss not only time, but texture in social life. They discuss texture as relating to subjective meanings, relationships, cultural practices and identities (p192) and suggest that it is the interplay between texture and time, which provides longitudinal qualitative research with its distinctive qualities. It is this relational component, associated with how individuals structure time, which can be studied in greater depth within a longitudinal study in contrast with the tensions that can arise between situational, historical and spatial time (Morgan, 1996). If time can be viewed as both an individual and subjective construct, then any analysis will require some process of identification of 'then' and 'now' within the structure of the study.

Change.

Saldana (2003) suggests that although no universal definitions of change exist there are a number of existing attempts to conceptualise change with in the literature. These range from focussing on 'a succession of differences in time' (Nisbet, 1976, p97), to 'a process not an event of individual and shared meaning' (Fullan 2001, p52) and include 'a continuous unending stream of events, because life is nothing else but movement, motion and change' (Sztompka, 1993 p9).

Saldana does however conclude that an 'all purpose response, which will satisfy every academic discipline is impossible and impracticable to construct' (Saldana, 2003 p9). He qualifies this by explaining that if time and circumstance are contextual then by definition change must be contextual. This is echoed by both Fullan (1999) and Pettigrew (1995) who advise individual researchers to explore change in relation to their own studies at the outset of analysis, to explore if change has occurred within the study. Within this study change is explored in relation to the initial data, ie; what remains the same, what are different, what are missing and what new aspects have emerged in subsequent interviews.

Approaches to Qualitative Longitudinal Research.

Although there are a relatively small number of qualitative longitudinal research studies in the cancer literature, within education, many longitudinal studies appear to have been undertaken. They explore aspects of development across differing time frames. Pollard and Filer (2002) undertook a study using ethnographic methods, which explored the educational careers of 17 children between the ages of 4 and 16. Holland et al (2004) offer this as an exemplar, which held insights not just for the complexity of the learning process but how and why changes occurred to children at pivotal moments during this time.

Many other ethnographic studies within education have highlighted aspects that would not have been obvious from using quantitative approaches and provide evidence across the spectrum of school-aged children. Studies exploring transitions from school into adulthood (Gordon and Lahelma, 2003), from the age of 12 – 18 (Yates et al, 2002) and in primary schools (Galton et al, 1999).

Within psychology, studies have followed transitions in life and key area such as developing identity (Krauss, 2000), becoming a parent (Henwood and Proctor, 2003) and ageing (Small, Dixon and Hulsch, 1999).

Within healthcare little longitudinal qualitative work has been undertaken. As an example, when undertaking a short literature search of Zetoc (British Library's electronic table of contents) and OVID (covering CINHAL , MEDLINE, OVID, BNI and Psych-info) entering the search term 'qualitative' revealed 27,365 and 124,311 'hits'. When combined with 'longitudinal' these reduced to 119 and 52 respectively, across all disciplines.

Many of the papers describe work based in chronic disease management such as diabetes (Lowe et al, 2005), heart disease (Barnes et al, 2006), mental illness (Ochocka et al, 2006) and health promotion (Stewart-Knox et al, 2005). Within cancer, Woodgate and Degner (2003) describe a qualitative longitudinal study that explored the perspectives of children and their families in Canada. Using constant comparative analysis they developed illness narratives for the children, who described their experiences of suffering over a period of time and how their beliefs and expectations changed over that time. This was part of a wider study (Woodgate, 2001), which described the symptom course of children with cancer through the disease trajectory.

What did a longitudinal approach add to this study?

One of the benefits of undertaking longitudinal work lies in the flexibility of approach, which can be developed as the study progresses (Elliott et al, 2007). Thomson has described longitudinal studies as being likened to wine, deepening in flavour and character over time (Thomson, 2007). Importantly, the structure of longitudinal qualitative work facilitates both an iterative and reflexive approach where theory can be developed and explored in subsequent interviews to either refine or expand a theoretical framework.

Along with the concept of exploring change over time, Yates (2003) suggests that qualitative longitudinal work can explore how experience is shaped within a

particular individual biography and offers the possibility of insights, which will contribute to a greater picture.

The repeated collection of data can take many forms, as with any research, but will be in keeping with the methodology and the research goals. The results are therefore intended to provide a dynamic picture – 'a movie, rather than a snapshot' (Neale and Flowerdew 2003. p192). This is not intended to offer a superior approach to cross sectional work but an alternative way of viewing a period of experience without such heavy reliance on retrospective recollection and the inherent difficulties within it.

Undertaking successive interviews requires both analytic and interpretive questions, to integrate with the descriptive questions and develop the qualitative trajectory (Saldana, 2003). The iterative, processual nature of qualitative research and consequent re-formulation and refinement of research questions over time are supported by this approach and help to situate the data within its context. Revisiting participants allowed for clarification of concepts and development of ideas. The fluidity of their experiences, the fluctuations, the changes in perception and definition of health and the impact this has on the individuals over time are all uncovered within the data. Using a longitudinal approach to this provided a different view from a single cross sectional interview approach.

Within this study it was hoped that the use of successive interviews would develop a deeper understanding of the experience of the individuals involved and how that changes across time, with the intention to illustrate the dynamics of individual lives of the participants as opposed to moving towards a 'saturation' of the data. The approach was supported through the use the work of Miles and Huberman (1994) and Saldana (2003) who in combination offer a robust framework for data analysis

Study design.

Sample.

The sample was selected to serve the aims of the study (Coyne, 1997). As the study was aimed at exploring the experiences of individuals with locally advanced rectal cancer, the appropriateness and adequacy (Morse and Field, 1995) of the sample needed to be ensured. Whilst the potential for any study is constrained by certain practical limits, the sample size needed to be large enough to generate meaningful data. Using a purposive sample (Patton, 2002) of patients who have been diagnosed with inoperable rectal cancer either as a result of primary or recurrent disease maximised the potential for relevant and meaningful data to be gained

The participants needed to be appropriate due to the small size of the sample group and based on the theoretical needs of the study (Morse and Field, 1995). To ensure information rich data therefore, cases from which an optimum amount of information could be obtained concerning issues that were central to the purpose of the research were used (Patton, 2002, Coyne, 1997, Holloway 1991).

The sample were successive patients who were discussed at the local colorectal cancer MDT meeting and identified as being 'inoperable', due to locally advanced rectal cancer.

Eligibility

Eligibility criteria were outlined at the outset of the study when ethical approval was obtained. Those criteria were:

Inclusion criteria
- Diagnosis of inoperable rectal cancer.
- Being able to undertake informed consent.

- Not involved in any other study at the time of recruitment, with the exception of chemotherapy drug trials.
- Over 18 years old.
- Willing and able to participate.

Exclusion criteria
- Prognosis of less than three months.
- Learning disabilities.
- Known psychiatric illness.

The participants.

The participants all lived locally. Six men and four women participated in the study and the age range was 45 – 75. Nine of the participants completed the study by undertaking four interviews, which were spaced between three and four months apart. The tenth participant (Frank) unfortunately died unexpectedly, before the third interview could be planned.

Ethics

A number of ethical implications needed consideration both in planning and executing the research. It was important to acknowledge the potential difficulties in research with groups of patients who may be considered vulnerable and plan at the outset to minimize any distress that could potentially be caused. Rigorous scrutiny during the application process to the Local Research Ethics Committee was required, as was the Research and Development process within my own Trust. It was also important to explore the aspects which could cause potential conflict and were perhaps less obvious at the outset. The nurse researcher role has the potential to cause conflict and transparency from the outset was vital to acknowledge these factors. Also, the potential for the interviewing process to have a therapeutic role

needed to be explored and the need to consider the impact of finishing the study on the individuals.

Whilst naturally it was the intention that the study cause no distress to the participants, for the duration of the study support was available from Wessex Cancer Trust from a qualified, independent counsellor, whose details were given to all of those involved.

Participant information sheets (appendix iii) were given at least two weeks before commencing participation and as part of the ongoing consent process. Prior to each interview this was discussed again. Written consent was obtained from participants prior to commencement of the study and prior to each subsequent interview. Confidentiality and anonymity were assured throughout the study; psuedonyms were allocated to each of the participants and used throughout. Consent was obtained at the outset and prior to each subsequent interview (Appendix iv).

Ethical approval.

Approval for this research has been received from both the Local Research Ethics Committee and the Research and Development department at **** NHS Trust.

Recruitment.

The participants were identified through presentation at the colorectal cancer multidisciplinary meeting at a local NHS Trust. Following the decision that the cancer was inoperable, discussion was initiated with the consultant responsible for the patients care. Both the consultant and a clinical trials practitioner approached the patients during the outpatient consultation, at which point the information sheet was given outlining the study. Attached to the sheet was a reply slip indicating interest. Following receipt of the reply slip, I contacted the participants by phone to discuss the study and answer any further questions. It was vital from the outset that the objectives for the study were transparent to

those participating and that they felt they could share their experiences in a situation where they felt comfortable and not vulnerable.

Data collection methods

Data collection.

Data collection was based around successive interviews with patients who agreed to participate in the study. A series of interviews were conducted at 3 -4 month intervals on four occasions with the participants understanding that they were free to withdraw at any point. Transcribed data was stored in accordance with the 1998, Data Protection Act and the University of Southampton policy.

The data was collected using semi-structured interviews and guided by an interview schedule (appendix v). Three approaches were considered for the interviews; unstructured, semi-structured and structured (Holloway, 1991). Semi structured interviews are widely acknowledged as being appropriate for exploring complex and sensitive issues (Barriball & While, 1994). In this case semi structured technique allowed the participants to have the freedom to explain the experience in their own words, with the freedom to identify those experiences which were most salient to them as individuals.

The timing of the interviews required a degree of flexibility to allow for the sensitivity of the subject (Hutchinson and Wilson, 1992) and the opportunity for full description. It appeared that the relationships I was able to build with the participants became crucial to a genuine understanding (Carr, 1994) and the depth of information gained could have been as a result of this closeness (Clarke, 1998). There are two important dimensions to the study which needed to be highlighted at the outset which were:

i) The potential nurse / researcher conflict
ii) The therapeutic nature of interviewing.

Both of these aspects will be discussed in further in relation to enhancing the transparency of the study.

The interviews took place where the participant chose. Nine out of the ten participants chose for this to be in their own home. One series of interviews was undertaken in a counselling room in the hospital.

Interviews.

The purpose of phenomenological interviewing has been described as primarily to uncover knowledge, which relates the specific phenomena being studied within the research study (Sorrell & Redmond, 1995). However, it could be argued that rather than purely uncover that knowledge a degree of creativity is involved (Kvale, 1996) which takes the process to a dynamic, interactive level which requires a high level of preparation and skill to execute. A number of considerations contributed to the success of the interview and in preparation these needed careful consideration.

The location of the interview was crucial for the participants to feel comfortable. If the prevailing principle in the relationship is equity (Seidman, 1998) then the choice of location to a great extent should remain with the interviewee, which it did.

Using an unstructured or semi structured approach is usual within phenomenological studies where the openness of the questions will allow the participant to highlight those aspects of their illness which are important to them and how their lives are affected by those aspects. It is the skill of the researcher, which leads to the proper balance of structure and flexibility (Sorrell & Redmond, 1995).

Using a tape recorder during the interview allowed for accurate representation of the dialogue (Seidman, 1998) and the opportunity to return to the original interview for clarification on as many occasions as I desired. For accurate analysis it was important that as a researcher my interview should not shape the data but merely guide the interview within the research question. Crotty (1996) suggests this is best achieved through the use of one opening question through which the rest of the

interview develops. The questions, which may then arise, have been generated by the dialogue, not by a pre set agenda. In this process the interview structure is cumulative as the interview progresses. The questions may then be used to clarify experiences or generate greater depth.

A number of skills are crucial to the success of the interview and the extent to which they are effectively applied will ultimately influence the quality of the dialogue and the study as a whole. Effective, facilitative communication skills and interpersonal sensitivity (Gordon, 1997) are at the core of good interviewing techniques. This aspect of the research approach has been suggested as being attractive to nurses who use these skills perhaps to a lesser degree, in their everyday practice (Gordon, 1997). It was important that I was able to use these skills which I have developed within my clinical practice, to maximise the acquisition of relevant data.

The integrity, which is required to provide accurate representation of the participants meaning and experience, has been paramount. The relationship of trust between the participants and me as the researcher was key to its success and the veracity of the research is an extension of this relationship.

The therapeutic nature of interviews.

It was important to acknowledge at the outset of the study that the interviews themselves had the potential to be therapeutic or harmful for the participants. As a researcher I saw no conflict, provided this potential was recognised. As a practitioner I offered the participants the opportunity to continue with regular meetings following the study if they felt cessation of the interviews would have a negative impact. I left that decision solely with the participants as I had the capacity within my clinical role to continue if a therapeutic benefit would be gained. Only one of the participants requested this. There was the potential therefore for the interviews themselves to shape the experience and that needed to be acknowledged during data collection. Work has been undertaken which explores the therapeutic nature of being able to tell ones 'story' (Banks- Wallace, 1998, Taylor, 1997,

Remen, 1996, Mayers, 1995, Heiney, 1993, Krietemeyer & Heiney, 1992), and it has been thought to provide a number of benefits including; finding meaning in their cancer experience, distraction from physical and mental pain and instilling hope (Heiney, 1993).

The Nurse / Researcher relationship.

In the past tension has been felt with nurses undertaking research in a field where they have worked as a clinician (Williams, 1995, Merrell and Williams, 1995). Often difficulties arise when undertaking participant observation or focus groups due to professional boundaries and familiarity with the research setting (Hanson, 1994, Bellman, 2004). It has equally been acknowledged that the understanding of the context of the research can increase its effectiveness due to enhanced empathy and trust within the setting (Seymour and Ingleton, 1999). The importance of transparency is paramount within the ethical framework of the study. The opportunity for participants to be approached by a clinical trials practitioner, rather than the researcher, minimised any sense of obligation to participate which may have been be felt on behalf of those approached. The dynamic approach to the consent process allowed for renegotiation of informed consent.

The opportunity to secure a research fellowship meant I was able to work outside the clinical field where the research participants were being nursed and they were able to be supported by another team member. Equally undertaking the research in such a responsible manner required the ability to undertake critical self examination and reflection which could then be refined within the supervisory relationship with more senior academics. Where change and praxis motivate the research agenda it is important to explore issues of power within the research / researched relationship (Williams, 1995).

Rigour.

Arguably, validity in qualitative research may simply be judged by the extent to which an account accurately represents the phenomenon to which it refers

(Hammersley, 1990). However, much debate has surrounded the concept of rigour within qualitative work over the last 20 years which has resulted in some consensus as to the prime indicators of quality. Koch (1994) (Table 6) adapted the work of Guba and Lincoln (1989) to formulate a framework for establishing trustworthiness in qualitative research where she describes trustworthiness as being synonymous with rigour.

Table 6. Koch's Framework

	Scientific paradigm criteria	Qualitative paradigm criteria
Truth values	Internal validity	Credibility
Applicability	External validity	Transferability
Consistency	Reliability	Dependability

Koch, T (1994)

In essence these facets allow for discussion around; whether the work addresses the fit between the respondents' views and the researchers' representation of them, whether the results are transferable to other settings, whether the research process is illustrated as logical, traceable and clearly described and that the data are truly interpretive of the narrative. Therefore dependability and credibility are both ways which can illustrate the rigour of the process and be used to judge the trustworthiness of the findings.

Guba and Lincoln (1989) were very explicit in their assertion that the steps taken in the research process must be clearly described, as they are integral to illustrating truth in a study, including clear documentation of the decisions made at different stages of the analysis.

Transparency in the analysis and illustration by the extracts from the data help in ensuring this. Returning to the respondents for participant validation is a well established method for supporting the accurate reflections of the participants. This is echoed in the work of Spencer et al, (2003) when they describe the importance of

rigorousness in conduct – through systematic and transparent collection, analysis and interpretation of qualitative data. Also in that the work must be 'credible in claim' – through offering plausible arguments about the significance of the evidence generated.

Pearson and Lockwood (2007) provide a concise and clear framework for assessing credibility within qualitative systematic reviews in health and social science and their descriptions encompass all of the necessary elements in their section on rigour. These were useful to be aware of when applying the CASP model for evaluation, both to appraise the research evidence within the literature review and to critically appraise this study during the discussion.The key components of Pearson and Lockwood's framework are:

Rigour.

1. There is congruity between the stated philosophical perspective and the research methodology.

2. There is congruity between the research methodology and the research question or objectives.

3. There is congruity between the research methodology and the methods used to create the data.

Rigour in methods and data.

1. Congruity between the research methodology and the representation and analysis of data

2. Congruity between the research methodology and the interpretation of results.

3. There is a statement locating the researcher culturally or theoretically.

4. The influence of the researcher on the research and vice versa is addressed.

5. Participants and their voices are adequately represented.

Rigour in methods and conclusion

1. The research is ethical and has evidence of ethical approval.

2. Conclusions drawn in the research report do appear to flow from the analysis, or interpretation of the data.

Data analysis.

Exploring the options for an appropriate analytical framework entailed a number of considerations. Primarily the process of analysis needed to be congruent with the approach, which was adopted to undertake the research. Undertaking a study of this size would inevitably yield vast quantities of data, which required both a pragmatic and systematic approach to building a robust database. The data analysis within this study was provided by a partnership between the frameworks of Miles and Huberman (1994) and Saldana (2003). While Miles and Huberman offer a practical design covering all aspects of the process of analysis, Saldana's work complements this with a longitudinal framework. The processural nature of Miles and Huberman offered techniques for data reduction, display and conclusion drawing, whilst Saldana offered questions to inform the analysis. The questions support exploration of the data, contextual aspects and privilege the constructs of time and change which are so pivotal within this study.

Within a longitudinal study the analysis is often an iterative process, with the initial insights potentially informing further data collection and revisiting any developing theoretical propositions as the study progresses (Cowley 2000), whilst at the same time the analysis follows a 'horizontal logic' (Kohn, 1997), which focuses on embedded units and cases before comparisons are undertaken across data sets. Saldana's framework provides the tools to take the analysis along a longitudinal path and offers a visual framework to record the findings. One of the most appealing aspects of this framework was the apparent opportunity to record fluctuations in intensity of the themes as they flow through the datasets.

Miles and Huberman.

Miles and Huberman (1994) assert that phenomena exist in an objective world as well as the mind and that stable relationships can be uncovered among them. Using qualitative analysis, complex events and processes can be explored which exist beyond mere association. This process of analysis can be defined as consisting of three concurrent flows of activity (Fig 2. Miles and Huberman, 1994):

1. Data reduction (selecting, focusing, simplifying, abstracting, and transforming the data from transcriptions, documents and field notes)
2. Data display (an organised assembly of information which permits conclusion drawing).
3. Conclusion drawing and verification (drawing conclusions from the data).

Fig 2.
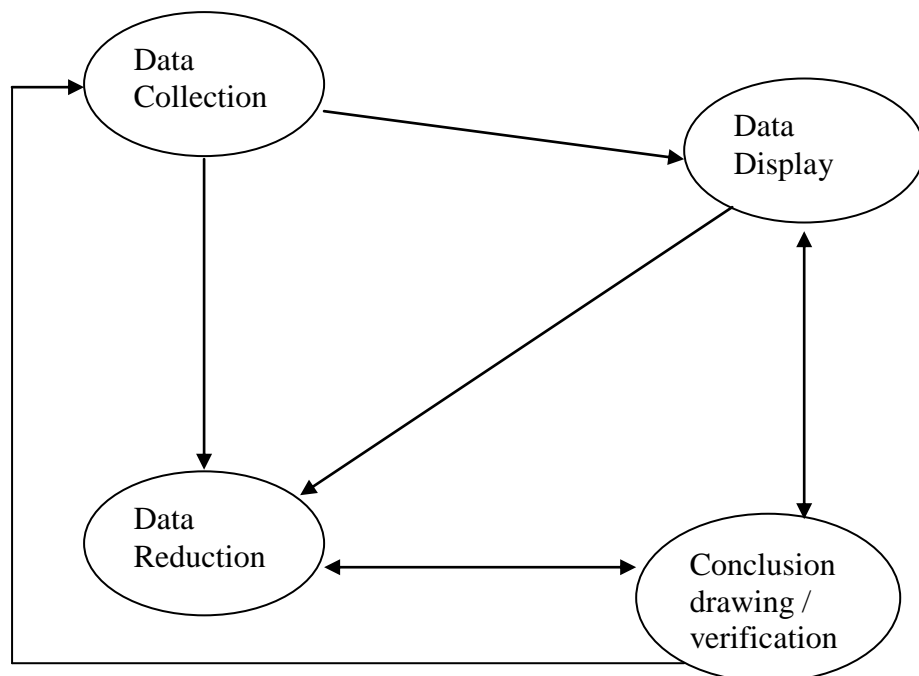
Components of data analysis: Interactive model (Miles and Huberman 1994 p.12)

For this study, the appeal of this framework lies both in its pragmatism and its compatibility with the framework of Saldana, who refers to Miles and Huberman within his own work.

The cyclical nature of data analysis is illustrated in Fig 2. This figurative representation offers a visual display of the continuous, iterative nature of the analysis. The process needs to be clearly documented, along with a clear definition of the unit of analysis, which in this study is the individual participant. Further explanations of these stages in the analysis are offered in appendix vi.

Adhering to these tactics ensured the basic quality of the data. The tactics were designed to draw meaning from the display through exploring patterns, contrasts and relationships, to build the individual cases.

In an exploratory study such as this, where little is already known about the phenomenon a number of individual experiences can be explored. Baseline datasets adapted from the frameworks of Miles and Huberman and Saldana provided a comparative data set for successive interviews.

The initial interviews were transcribed verbatim and a thematic analysis of those ten interviews was undertaken. This provided a baseline for subsequent analysis. Three of the interviews were selected at random by one of the research supervisors and the thematic analysis scrutinised and reviewed to ensure accurate representation. The initial thematic analysis generated 27 clusters of codes which were derived from first level coding (illustrated in Appendix vii). These in turn were reviewed in relation to the patterns they generated. Four major patterns emerged from the data; continuity versus change, certainty versus uncertainty, adjusting versus resisting the illness experience and cancer as an embodied experience.

The subsequent analysis was undertaken by repeating the process of thematic analysis of each interview and contrasting the clusters of codes with those previously uncovered in the initial interviews. A data display was created from the

clusters of codes to facilitate comparison with subsequent interviews. This was in turn explored using the matrix offered by Saldana (2003) (Figure 6) to highlight change over the interviews. Cross sectional analysis was not undertaken between participant's subsequent interviews, the analysis process was linear through the successive interviews of each participant and their experiences compared to the previous data set. Interviews were grouped by epiphanies in their experience which signified a fundamental change in the meaning of their illness. Once again this was checked by one of the research supervisors. Illustration of how the interviews fell into each phase is illustrated in Table 6.

Saldana.

Saldana's work describes his experience of developing longitudinal qualitative research as Professor of Theatre. His core text; 'Longitudinal qualitative research, Analysing change through time' (Saldana, 2003) is a culmination of twenty years of research and personal experience through which he has developed his own approach to analysing data which has been collected through long-term studies. He focuses on the concepts of 'time' and 'change' as being prime within his approach and spends considerable time discussing definitions of both and drawing on previous work from other researchers. Through bringing these concepts together he offers guidance on data analysis.

Saldana's book discusses his own journey, the challenges and successes he has faced and how that has strengthened his framework as a consequence. He draws heavily on Wolcott's (1994) three levels of research; description, analysis and interpretation of qualitative data and uses a framework of sixteen questions through which to guide the analytical process. Although his own experiences lie within the field of theatre and his approach is rooted in ethnography, through which he derived data from long-term observation of participants in social settings, he readily admits he prefers to be viewed as having developed an approach, which relies on a 'shamelessly eclectic' (p13) combination of methods. An appealing admission as this work is also somewhat eclectic.

As a researcher the framework offered a pragmatic framework, which although not used within healthcare appeared to be highly appropriate and readily transferable for use within this study. One of the key attractions for this work lay in the opportunity to not only explore time and change, but particularly in the opportunity to explore aspects which: increase, decrease, are idiosyncratic, are missing or highlight individual epiphanies (Saldana, 2003). It is also the fluctuation in intensity that is so appealing and unique to longitudinal work.

The process.

An initial set of five 'framing questions' are aimed at providing the contextual aspects of the study and consequently locate the work within that context. Seven subsequent 'descriptive questions' are aimed at helping to answer the framing questions and inform the four more complex 'analytic and interpretive questions', which conclude the framework. Further explanation of these questions is given in Appendix vi.

The three fundamental elements of longitudinal qualitative research are the length of the study, time and change (Saldana, 2003). Although no consensus exists regarding the optimum length for a study Saldana suggests a minimum of nine months is reasonable and the endpoint should be defined by the requirements of the individual study. What appears to be key, is the systematic assembly of data in order of collection, which will inevitably be a chronological sequence. What Saldana appears keen to avoid is the notion of time as a purely linear construct. He suggests time is both a 'cultural' and 'physically contextual' construct (Saldana, 2003 p6), which is both an individually and subjectively interpreted construct (Levine, 1997). This resonates with the theoretical assumptions of this study, which view time, 'not as a progress through a predetermined structure but the negotiation of a passage through an unpredictably changing environment' (Harris, 1987 p27).

Within this framework time is also viewed as data in itself. As the exploration of change in any sense has 'then' and 'now' as a prerequisite, Saldana is keen though to locate his framework, not in a construct of moving from 'then' until 'now', but

moving 'through' which allows for a 'processual immersion' (p8) as opposed to a jump from one defined time point to the next.

Saldana examines many definitions of change and asserts that, as with time, it is contextual and an integral part of the study which has an influence on the outcome of the research. He suggests that 'we should be flexible and allow a definition of change to emerge as the study proceeds and its data are analysed, ironically, allowing the meaning of change to change as a study progresses' (p10). This allows for the individual to search for meanings of change within individual studies.

Although he concludes that describing what changes occurred over a period of time is the basic outcome for a longitudinal study, the process of analysis and interpretation will provide additional findings that rise above a purely descriptive data set.

No standardised methods exist for longitudinal qualitative work and the approach to the research will largely be determined by the goals of the study. Saldana suggests; 'the challenge for qualitative researchers is to rigorously analyse and interpret primary language based data records, to describe credibly, vividly and persuasively through appropriate narrative, the processes of participant change through time' (p46).

He advocates Miles and Huberman's (1994) approach to data analysis as offering practical solutions to locate phenomena, such as critical incidents, patterns, themes and trends through a process of comparison and contrast across the data sets. He builds on this framework with his approach to analysis by offering a series of framing questions, descriptive questions and analytic and interpretive questions to guide the researcher.

Using Wolcott (1994) as a conceptual framework of description, analysis and interpretation he suggests a researcher will be able to not only chronicle when, but what types of changes occur (as description). After identifying the essential features

and the interrelationships among them (p12), the nature and meaning of those changes will emerge which will lead to theoretical development (as interpretation).

Framing questions.

The framing questions are aimed to explore the context of the study and consequently locate the work in that context (Fig 3).

Fig 3.

Framing Questions.
1. What is different from one pond or pool of data through the next?
2. When do changes occur through time?
3. What contextual and intervening conditions appear to influence and affect participant changes through time?
4. What are the dynamics of participant changes through time?
5. What preliminary assertions (propositions, findings, results, conclusions, interpretation theories) about particular changes can be made as the data analysis progresses?

(Saldana, 2003, p67)

Descriptive Questions.

The roles of descriptive questions (Fig 4) are both to help answer the framing questions and inform the more complex analytic and interpretive questions which follow. The questions are to an extent self explanatory, but clarifying their relevance within the research process remains important.

Fig 4.

Descriptive questions.

1. What increases or emerges through time?

2. What is cumulative through time?

3. What kinds of surges or epiphanies occur through time?

4. What decreases or ceases through time?

5. What remains constant or consistent through time?

6. What is idiosyncratic through time?

7. What is missing through time?

(Saldana, 2003 p99)

Analytic and interpretive questions.

Four key questions are offered within the text that takes the data from the descriptive level to the interpretive level (Fig 5).

Fig 5.

Analytic and Interpretive questions.

1. What changes interrelate through time?

2. What changes through time oppose or harmonise with natural human development or constructed social processes?

3. What are participant of conceptual rhythms (phases, stages, cycles and so on) through time?

4. What is the through line of the study?

Saldana, 2003. P127

Whilst Saldana describes his sixteen questions which provide the longitudinal framework he stresses these are flexible in their application. He also strongly recommends not asking the question unless willing to provide an answer. The

questions however provide a comprehensive approach to the longitudinal analysis that complements the work of Miles and Huberman (1994) and supports the longitudinal approach to the study. The framework offered the tools to take the analysis along a longitudinal path and provided a visual framework to record the findings. The framework gave the opportunity to explore those aspects identified in the initial analysis over time and explore both the fluid nature of the experience and the undulating patterns that emerged through time.

 In accordance with Saldana's theatrical background, he uses the analogy of interviews as scenes from a play, or chapters in a book. He often refers to research in general as a metaphoric 'ocean' throughout the book, whereby thematic categories within interviews are 'ponds', which form greater 'pools', as part of a wider 'ocean' (p68).

In his chapters that introduce longitudinal qualitative studies he suggests water is a more appropriate metaphor than that of landscape, which is often used (p5), as it holds fluidity, a vastness and a depth, which have ever- present motion. Similarly he alludes to the possibility of exploring deeper and within layers which conform to the idea of the three dimensional nature of an ocean. He extends this metaphor to the researcher as a diver, deciding whether to remain in shallow water and explore from the surface the variety of marine life, which can be done by returning to the land and itemising his or her observations, or diving deeply into the sea and through the immersion into the depths, develop a greater understanding of different contours to the experience. Equally choosing which aspects to concentrate on and which areas are important are decisions which the researcher makes when planning the study, or diving trip.

Figure 6   Longitudinal Qualitative Data Summary Matrix

DATA TIME POOL/POND: FROM ___/___/_____ THROUGH ___/___/_____

STUDY:_____ RESEARCHER(S):_____

(when possible or if relevant, note specific days, dates, times, periods, etc. below; use appropriate DYNAMIC descriptors)

INCREASE/ EMERGE	CUMULATIVE	SURGE/EPIPH/ TURN POINT	DECREASE/ CEASE	CONSTANT/ CONSISTENT	IDIOSYN- CRATIC	MISSING

DIFFERENCES ABOVE FROM PREVIOUS DATA SUMMARIES

CONTEXTUAL/INTERVENING CONDITIONS INFLUENCING/AFFECTING CHANGES ABOVE

INTERRELATIONSHIPS	CHANGES THAT OPPOSE/HARMONIZE WITH HUMAN DEV/SOCIAL PROCESSES	PARTIC/CONCEPT RHYTHMS (phases, stages, cycles, etc. in progress)

PRELIMINARY ASSERTIONS AS DATA ANALYSIS PROGRESSES
(refer to previous matrices)

THROUGH LINE

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Table 7– Interviews.

ContinuityVersus Change

	NIGEL	EDDIE	PETER	JOAN	HARRY	MARGARET	KEITH	WENDY	MARIA	FRANK
Continuity Versus Change	Interview 1	Interview 1	Interview 1 Interview 2	Interview 1 Interview 2	Interview 1 Interview 2	Interview 1	Interview 1	Interview 1	Interview 1	Interview 1 Interview 2
It's on the Move.	Interview 2	Interview 2 Interview 3		Interview 3 Interview 4	Interview 3 Interview 4	Interview 2 Interview 3	Interview 2	Interview 2 Interview 3	Interview 2 Interview 3	
You can't really hide from it anymore.	Interview 3 Interview 4	Interview 4	Interview 3 Interview 4			Interview 4	Interview 3 Interview 4	Interview 4	Interview 4	

Certainty versus Uncertainty

Certainty Versus	NIGEL	EDDIE	PETER	JOAN	HARRY	MARGARET	KEITH	WENDY	MARIA	FRANK
Certainty Versus Uncertainty	Interview 1	Interview 1	Interview 1 Interview 2	Interview 1 Interview 2	Interview 1 Interview 2	Interview 1	Interview 1	Interview 1	Interview 1	Interview 1 Interview 2
But it's growing	Interview 2	Interview 2 Interview 3		Interview 3 Interview 4	Interview 3 Interview 4	Interview 2 Interview 3	Interview 2	Interview 2 Interview 3	Interview 2 Interview 3	
It's in charge now	Interview 3 Interview 4	Interview 4	Interview 3 Interview 4			Interview 4	Interview 3 Interview 4	Interview 4	Interview 4	

Adjsuting versus resisting the experience

	NIGEL	EDDIE	PETER	JOAN	HARRY	MARGARET	KEITH	WENDY	MARIA	FRANK
Adjusting Versus Resisting the illness	Interview 1	Interview 1	Interview 1 Interview 2	Interview 1 Interview 2	Interview 1 Interview 2	Interview 1	Interview 1	Interview 1	Interview 1	Interview 1 Interview 2
Maintaining the resistance	Interview 2	Interview 2 Interview 3		Interview 3 Interview 4	Interview 3 Interview 4	Interview 2 Interview 3	Interview 2	Interview 2 Interview 3	Interview 2 Interview 3	
I am struggling	Interview 3 Interview 4	Interview 4	Interview 3 Interview 4			Interview 4	Interview 3 Interview 4	Interview 4	Interview 4	

Cancer as an embodied experience

	NIGEL	EDDIE	PETER	JOAN	HARRY	MARGARET	KEITH	WENDY	MARIA	FRANK
Cancer as an embodied experience	Interview 1	Interview 1	Interview 1 Interview 2	Interview 1 Interview 2	Interview 1 Interview 2	Interview 1	Interview 1	Interview 1	Interview 1	Interview 1 Interview 2
I know its there.	Interview 2 Interview 3	Interview 2 Interview 3	Interview 3	Interview 3 Interview 4	Interview 3 Interview 4	Interview 2 Interview 3	Interview 2	Interview 2 Interview 3	Interview 2 Interview 3	
Which bit of my body will disintegrate.	Interview 4	Interview 4	Interview 4			Interview 4	Interview 3 Interview 4	Interview 4	Interview 4	

Chapter summary.

This chapter has outlined the perspectives guiding the study and the methods employed to collect and analyse the data. The influence of phenomenology has been outlined along with the contributions of Husserl, Heidegger, Merleau Ponty and Van Manen. The process and contribution of longitudinal qualitative research has been considered along with the frameworks offered by Miles and Huberman and Saldana. Particular attention has been focussed on the interview process as the primary tool for data collection. Ethical aspects have also been considered. Illustration of how the combination of methodological approaches and considerations were translated into the process of data analysis and interpretation have been described , which have lead to illuminating the meaning and impact of living with advanced cancer on the everydayness of the individual.

Chapter 4: The findings.

Introduction.

The interviews were conducted over 3 - 4 month intervals for four successive interviews. Initially ten participants were recruited and interviewed (6 male and 4 female) unfortunately very shortly after the second interview with Frank he died suddenly. The content of the subsequent following data sets are based on interviews with the nine remaining participants. A summary description of each of the participants is offered (Table 7) to give context to their experiences.

Using the framework offered by Saldana it was possible to explore the data through the identification of a number of changes from the original thematic analysis generated from the initial interviews. Through highlighting what was different from the previous datasets, these changes naturally emerged. In addition to the changes it was important to note intervening contextual conditions which frequently preceded the change.

Through the analysis process the themes were re-explored and viewed in relation to the perception of health which was expressed by those interviewed. The themes which had emerged from the initial analysis were continuity versus change, certainty versus uncertainty; adjusting versus resisting the illness experience and the illness as an embodied experience. It is important to re-iterate that these interviews were conducted over a protracted period of time where in between these difficulties a sense of stasis was able to prevail and normality created a manageable and contained world to live within.

Table 8. Summary descriptions of participants.

Summary descriptions of participants.

Name	Age at start of study	Date of original diagnosis and pathway.	Contextual information.	Date of death	Time to death from last interview
Nigel	47	Diagnosed June 2005 Downstaging chemo / radiotherapy APER Nov 2005 (Palliative)	Single. Both parents alive and well, although not living locally. Father is a vicar. Nigel had no strong religious beliefs. Worked as a postman until his diagnosis and never returned to work. Had a wide circle of supportive friends and a range of interests. Had his own house where he lived alone.	Nov 2007	13 months
Eddie	52	Original diagnosis Feb 2002. Right hemicolectomy followed by chemotherapy. Pelvic recurrence July 2004. Downstaging chemo / radiotherapy Hartmanns Jan 2005 (Palliative)	Married to Christine. Two grown up daughters, one living locally. Worked in an electronics factory until his recurrence – never returned to work. Few friends. Spent most of his time alone and walking the dog. Owned his own house which he shared with his wife. Also had a tear in his bladder as second operation which never healed so had a permanent catheter.	Dec 2008	22 months
Peter	45	Diagnosed April 2005 Following emergency Hartmanns procedure (Palliative) Post operative chemo / radiotherapy.	Married to Laura One son Sam aged 6 at the start of the study Owned their own business which they were unable to continue with when he began his treatment. They initially moved to a smaller house, they then moved in with Peters parents. His father died during this study. He and his family were practising Catholics.	August 2006	5 months

Joan	58	APER Jan 2003 Pelvic recurrence Jan 2005 Inoperable.	Married to Brian. Has three grown up sons who all live locally. Worked as a shop assistant until her diagnosis – never returned to work. Good support from friends locally. Lives in a second floor flat which they own.	Alive 04/09 No palliative care involvement (not required)	N/A Last interview 02/06
Harry	75	Diagnosed Jan 2005 following emergency Palliative Hartmanns procedure Post operative chemo / radiotherapy.	Married to Angela. No children. Lives in their own bungalow. Retired at the start of the study, but had previously been a factory manager Good network of supportive friends. Active interests in golf and maintaining an allotment.	Alive 04/09 Receiving palliative care.	N/A Last interview 04/06
Margaret	62	Diagnosed Dec 2004 following emergency Palliative Hartmanns procedure	Married to Michael. Had three grown up children. Two living locally. Lived in own house with Michael. Supportive friends nearby. Worked as a PA prior to her diagnosis – never returned to work.	July 2006	6 Months
Keith	72	July 2004 Anterior resection (Palliative) Post operative chemo	Married to Kay. Had three grown up sons and one daughter. One son living locally. Lived in own house with Kay Was retired at the start of the study. Previously worked as a mechanic A keen gardener.	March 2006	10 months

Wendy	56	Diagnosed December 2003. Downstaging chemo / radiotherapy. APER July 2003. Pelvic recurrence Oct 2004 Inoperable.	Married to Gordon. Had one grown up daughter living locally. Some friends but very insular relationship with her husband. Both parents alive and living locally. Ran a business with her friend until she began treatment – then ceased. Didn't work again. Spent most of her time with her cats.	March 2006	4 months
Maria	52	Diagnosed with rectal cancer July 2002. Anterior resection August 2002. Followed by adjuvant chemotherapy. Sept 2004 pelvic recurrence – inoperable October 2004 Chemo / radiotherapy	Single parent with one grown up daughter, Sarah, from her first marriage (aged 24 at the outset of the study) One daughter, Millie, from a different relationship (aged 10) and no contact with Millie's father. Lived with Millie in rented accommodation. Full time mother to Millie and hadn't worked since her birth.A few friends locally. The rest of her family(sisters) live away. Ended the relationship she was in, when she was diagnosed with recurrent disease.	Feb 2008	20 months
Frank	68	Diagnosed Sept 2004 Downstaging chemo / radiotherapy. Palliative APER April 2005	Lived with his wife Ruth in their own home. Two sons both living in Australia. Retired when the study started. Had previously been a construction foreman Avid football fan and keen gardener. Supportive friends living locally.	Sept 2005	2 weeks after interview 2.

APER – Abdomino-perineal excision of rectum – Excision of the rectum and anus formation of end colostomy
Hartmanns procedure – Excision of upper rectum / sigmoid with end colostomy and remaining rectum left in situ
Anterior resection. – Excision of part of rectum +/- some of sigmoid colon with primary anastamosis.
Right Hemicolectomy – Excision of ascending colon.

*Procedures are classified as palliative if the excision margins are involved at operation and tumour remains.

Continuity versus change.

The participants during the course of this study did not proceed through a succession of steps within their pathway, in the sense of a classic journey often described in advanced disease. This created many of the difficulties in the data analysis which have been described in Chapter 3. However, there were key epiphanies which created defining moments within those pathways and marked turning points within the data which strongly affected the direction of the dialogue. Vascillating between certainty and uncertainty and continuity and change were crucially affected by the awareness of both progressing disease and subsequently distant metastases. Within the context of the theme of 'continuity versus change' these epiphanies are described in terms of 'It's on the move' and 'You can't hide from it anymore', respectively. Similarly, in the second theme of 'certainty versus uncertainty' these epiphanies are described in terms of 'But it's growing' and It's in charge now'. These were terms used by the participants during their interviews to describe these turning points, which occurred at varying times across their individual pathways..

Through the course of the interviews it became increasingly obvious that the complexities of living from day to day with a life limiting illness result in a number of tensions for the individual concerned. What became evident from the data was the multi-layered, multi-facetted nature of the way the illness permeates the everyday world of the individual and is often hard to capture in words and is dynamic in nature.

Although not always overtly articulated these layers are clearly present within the dialogue. At times there appear to be subtle changes and at others, harsh life altering moments which reverberate through all aspects of life and change the life-world of that individual from there forward.

There is strong sense from all of those interviewed that maintaining the status quo becomes life affirming, in the sense that change will inevitably be a negative consequence of the illness at some juncture. Whilst life can continue as it is and as

normally as possible, death and dying will be kept at a distance. Positive efforts are made on a daily basis, to ensure that life remains unchanged.

All of the participants made reference in their first interviews to keeping life 'normal'.

> *'I have quite an ordinary life really. I have a routine like anyone else. I get up, have breakfast with Brian, he goes to work. I do the housework, shopping – all the normal things. I go for a walk if I can, go and get the paper, that sort of thing, all the things I've always done really' (Joan, Interview 2).*

To some extent, although varying in intensity, the participants acknowledged their lives had fundamentally changed. Yet, as a prospect for these individuals, change holds negative connotations. The very nature of knowing that life will be prematurely ended results in a focus on any slight deviation from the norm as potentially signifying some sort of decline.

> *'Physically I am back to the strength I was before, I am getting on well at the moment, I feel I am getting stronger, you know, but the minute I have a problem it's all related to the cancer – nothing normal like a cold anymore' (Nigel. Interview 1)*

For some there are times when suppressing this feeling can be difficult and thoughts emerge which can be overwhelming. Feeling like '*suffocation*' as though there were no way out. Seeing a path through this is often very hard and focusing on the mundane helps to create a sense of security.

> *'Sometimes I think about what is really happening. I can't get my head round it though. The more I think about it, the more I panic. My heart races – like a panic attack, then I panic more and I think I'm going to suffocate. During the day I try to distract myself and do something I can concentrate*

on. Even if that's making a cup of coffee. The worst time is at night, when I am on my own. I wake up at about 2 or 3 in the morning and think about what is going to happen. That's when I can't calm down, my mind races ahead and I am terrified. I begin to sweat with fear. I really frighten myself but I can't stop it' (Maria. Interview 1)

Focusing only on the present further promotes a feeling of security. By not looking forward or back comparison is avoided, therefore any judgment is suspended in relation to declining health and consequently any recognition of change. By focusing on the here and now the individual is able to cope on a daily basis whilst avoiding the prospect of an uncertain future.

'I take one day at a time really, it makes it more manageable' (Joan. Interview 1)

The importance of creating stasis throughout the data cannot be over emphasised. There is a tangible comfort derived from that stasis. A feeling that life could stay this way every day and the quiescence that stasis creates, appears to evoke a feeling of security. All of the participants strive to maintain normality, stasis and continuity of the ordinary in order to achieve this.

'I try to take the dog for a walk each morning. We do the same circuit we always have done. Down to the park, over the bridge, then we walk right round the park and back again. Then I come back here and sit for a while in this chair, read the paper- that sort of thing. It keeps me busy, passes the time and keeps the dog happy'(Eddie. Interview 1)

Taking control and actively self-managing can further promote consistency and continuity. As a way to ensure stasis and maintain a sense of normality, most participants want to hold the sense of responsibility for managing their day-to-day lives.

'I'm quite happy sorting myself out, I don't need Mike's help. I can do everything I always did before the operation. The children try to do things because they think they are helping, like cutting the grass. They're not though, I insist on doing it myself – I always have done it I'm no different now' (Margaret. Interview 1)

During treatment an element of control is relinquished to health professionals but only on a temporary basis and only in relation to the treatment itself. There is a tension with the disruption which treatment brings and the intrusion by healthcare professionals into their everyday world. This compromise is allowed because of the potential benefit that treatment can offer and the additional longevity, which can potentially be achieved as a result. This belief is the motivation for tolerating the effects of treatment and is seen as a trading for buying extra time.

'The side effects are not too bad really. My hair hasn't come out and I don't get the sickness that others at the hospital get. They said it would give me 20 months instead of 6 without it – so I will finish the course – I have to' (Joan Interview 2)

Outside of the treatment arena, greater distance from the hospital offers the opportunity for greater control. Visits are fewer when no treatment is being given and this allows for the individual to take more responsibility for their own health.

'Apart from the outpatient appointments I have every 3 months and the scan every 6. I don't have any contact with the hospital. I prefer that. When I go it reminds me more of the cancer. I try to forget about it in between. (Harry Interview 2)

Recognizing and acknowledging change is a double-edged sword. Whilst it is necessary, in order to counter the effects this may have on everyday life, acknowledging change, in the sense of deteriorating health, brings with it a sense of defeat. The recognition of change as a result of this is minimized.

'I go to my allotment whenever I can, I don't go every day now like I used to. I tend to drive down there as its cold at the moment. That way I can stay awake then in the evenings too' (Frank Interview 2)

Change is accommodated, challenged and tested. Adjustment is made with a huge effort to diminish the effect on daily life. Often changes are so subtle on a daily basis that these do not become apparent until an activity is undertaken which happens less frequently than others and a comparison can be drawn. The stark realization that this can bring with it, the lack of achievement and hence evidence of a decline in health, can often result in further similar activities being avoided.

'I used to cycle everywhere, but I do that less now. My backside was uncomfortable after the operation so I got out of practice. I'm not so used to it now so I find it harder. I still go out for walks though. There's a lovely path along by the sea so I tend to do that instead now. (Keith Interview 1)

All of the participants discuss a wish to maintain normality and within that discussion those who have been forced to give up work as a consequence of their illness frequently address work. There are no exceptions to this within the study – all of the participants had given up their jobs, who were working at the time of their diagnosis. However, there is a sense of awareness that they would be unable to perform as effectively as before and hence would not attempt to return to a situation, which would highlight that change.

'We ran a nursery before this happened. There's no way we could manage now though with all of the treatment etc. We have sold up and bought a smaller house which is easier to run (Peter Interview 2)

Even the most simple of tasks, such as walking the dog, become hugely significant in terms of how far can be walked, at what speed and for how long. Minor adjustments in routine are then made to minimize this realisation. A new route, so

less obviously shorter and less opportunity to meet old friends who may remark on change is often instituted and therefore a sense of continuity prevails.

> *'I used to play a lot of golf; I still do, but tend to take a buggy most days or just play nine holes. I go on my own more, it means I can nip off to the loo if I need to sort out my bag, or if I want to stop I just do. I tend not to hang around after now. My friends ask where I have been, or what treatment I am having if they do see me, but that's not very often. (Harry Interview 2)*

Short terms goals are instituted to replace long-term goals. More achievable goals and the subsequent feeling of achievement they bring enable the individual to feel more functional.

> *' I feel I am getting stronger, I can cycle up to the hospital now' (Nigel Interview 1)*

These goals replace previous activities and subtly become the new benchmark for monitoring any decline in health.

> *'I have started swimming now I'm not at work and try to go at least twice a week. I try to do twenty lengths at least twice a week, which I manage, so I am really pleased. I stopped whilst I was having the radiotherapy, but I've started again. I still get a bit tired, but that's probably the radiotherapy still – I just go at my own pace really. (Maria Interview 1)*

The opportunity to achieve small goals is actively pursued and lack of this opportunity or activity creates increased uncertainty. Setting individual goals within the individual's own life world creates a sense of control and supports self-management. The participants, who immerse themselves in daily routines where those goals remain unchallenged, appear to welcome this.

Occasionally the realisation of this process becomes apparent, often when confronted with a previous goal, which was once achievable. This cannot only cause unease, but in some will raise extreme feelings of desperation and despair. The sense of losing control gives a feeling of being overwhelmed by the illness and a stifling sense of helplessness which needs to be controlled, in order to continue life as normally as possible. The threatening nature of the lack of achievement of goals can result in increasing isolation and further withdrawal from the individual's day-to-day activities. This results in a balance of trying to avoid the unachievable within an everyday world to maintain continuity and minimize change.

> *'I ran a cattery with my friend before all this. Only a small one, but we were very busy. I've pulled out of that now because I don't know when I'll need more treatment. I found that difficult. I planned my day around my work, but I don't want to carry on incase I can't do it anymore. Not that I feel any different now, but you don't know what's going to happen really. You don't know what's around the corner; I have plenty to keep me busy at home though' (Wendy Interview 1).*

This becomes a very difficult balance to achieve, particularly in relation to role. Existing roles are challenged during illness, treatment and the consequences of treatment. The core of an individual's 'situatedness' within their life world is challenged. This is particularly obvious in relation to the dimension of 'lived human relation' (Van Manen, 2006). The role of parent, provider, carer, grandparent, partner, friend and colleague all change. Relationships are altered and the complex dynamics of an individual's life world become displaced. Maintaining normality during this adaptation and redefinition of role serves to protect from the overwhelming realization of how the illness affects the very 'being' of the individual. Maria describes this with incredible clarity

> *'my mother died in her 40's from breast cancer. She was dying really from when I was ten, until I was fourteen. It dragged on and on. When I look back at that time all I think about is her dying. She was always dying, I don't want*

Millie to look back and remember me in that way. I'm determined her life won't be affected by my illness. I will keep life as normal as possible for as long as I can. I don't want to take away her childhood. We always thought in terms of how this or that would affect mum – I'm not going to let that happen to her'(Maria Interview 1)

The fundamental impact on the self is so profound that even extended periods of adjustment do not allow for adaptation. The uncertain nature of the illness and the lack of any tangible sense of what is to come, create a background of anxiety, which is often managed by immersion in the mundane and the achievable.

'I have never had any trouble filling my time. I spend quite a bit of time doing art and music. I mess around on my computer and read I used to be into cycling. I am walking as well and can cycle a short way now and am hoping to build it up. (Nigel Interview 1).

He then goes on to say:

Its weird, if I was told, you know, you've got six months to live, you'd think – right take my money out of the bank and have a good time because you don't know how long you've got, but I don't know. I might wake up tomorrow and start to feel ill, which is a strange way to live. I have asked what will happen, but no-one will tell me. ' (Nigel Interview 1).

Some uncertainty can be accounted for; the effects of treatment on the physical self, the fatigue and the side effects of chemotherapy or radiotherapy can be rationalized and can often provide a focus, which allows for distraction from the underlying uncertainty.

' I get tired, very tired. But that's normal with chemotherapy. I have spoken to friends who say everyone gets that. They said at the hospital it would

happen – it's a side effect. Nothing to do with the cancer. The treatment
causes more trouble than the cancer. It'll stop when the treatment stops'
(Peter Interview 2).

'Visit friends and family, now that's all been taken away. Because of how I
feel, when I have all of this (points 2 chemo) I feel really grotty and don't
want to go out. You know I've got a stoma bag, well, when I'm having that
(chemo) I get a lot of diarrhoea, sick feeling, I feel really tired and lethargic
and I don't feel like I want to go out and socialise. (Joan Interview 1)

New relationships appear to be formed with individuals in treatment settings, who
have no prior knowledge of the individual and therefore have no sense of individual
change. Often those individuals have a shared situation and common ground, which
creates a new sense of belonging and a different role. Relationships with healthcare
professionals develop and the hospital environment becomes part of the life world
of the individual. In a similar nature to achieving short term goals, the routine which
is afforded by a treatment regimen creates an alternative structure and with it a sense
of continuity in itself – albeit in the short term.

'The nurses when I go for chemo are very good, it's a very friendly family
*atmosphere, they call me Joan, not Mrs ***, it's a good service. (Joan*
Interview 1)

On a Monday and Tuesday I come to clinic for my chemo, the nurses are
brilliant and the doctors, then Thursday I have the district nurse who takes
the pump off. (Joan Interview 1)

Substituting new roles and adapting old roles can signify change, which at times is
difficult. Wendy described this as '*screaming on the inside where nobody can hear'*.
This sense of internal desperation and drive for external calm was present in many
of the interviews. It permeates the closest of relationships, as there is a deep sense of
existing in a parallel world. All of the participants describe, in varying degrees, a

sense of life continuing around them and at times feeling suspended from their normal world.

Margaret very clearly describes her sense of standing on a cliff edge, with her friends and family watching to see if she falls. The enormity of the consequence of '*going there*' to her is too much. The distance she feels from her friends and family is clear yet she deliberately tries to adjust to the change in the family dynamics because the alternative is the equivalent to '*stepping off the cliff*'.

The change in the dynamics of their life is affected by the attitude of those around them. The 'dance' of friends and family around the individual is continuous. Judgments are being so obviously made and the situation being weighed up in terms of the impact on their relationship.

> '*so much goes unsaid, especially with my children. They want to help, they try to do practical things which just make me feel like an invalid but they don't ever talk about what's really happening. There's a big, big difference between doing the shopping, which I am perfectly capable of doing, and talking about your mum dying. I wonder if we will ever have those conversations. We skirt around them, but never do. (Margaret Interview 1)*

There is a heavy burden on the individual to retain the appearance of wellness in order to promote that continuity. Retreating into the world of the ill person is acceptable during treatment and not only provides support from fellow patients but offers 'time out' from their own life world. The pressure the individual places on maintaining normality, especially for those closest to them is great. As a parent or partner there is a protective element for the individual they are trying to shield from the reality, which in itself is enormously difficult. There is a burden placed on the individuals by themselves to remain well and protect those around them, especially those who have relatives living with them still;

' I drop Sam at school, do all the normal things, the come home and sit, some days I don't move till I have to go and get him, but at least I save my energy for when he comes in' (Peter Interview 2)

Maintaining continuity when the individual's life world has so fundamentally changed creates a dynamic throughout every facet of their complex and complicated lives. Although the individual strives to retain normality and a sense of ordinariness, priorities inevitably change. Withdrawal into their own world can be marked by some changes in attitudes that create their own challenges. Ignoring the minutia of some day-to-day frustrations can cause tension within close relationships as can the change in interest in bigger issues such as world affairs or long-term consequences of actions. Their perspective feels different from those who also inhabit that world.

' I find myself less and less interested in the news and what's going on in politics and stuff. Problems with climate change or whatever, they are just such big problems I find them depressing. The smaller, day to day problems – I just don't care about anymore' (Nigel Interview 1)

'It's on the move'

Whilst no evidence to the contrary exists, the participants keep this world reasonably constant, allowing for occasional periods of reflection – frequently to affirm their perception of health as being static. The longitudinal nature of the data illustrates that stasis can be attained for protracted periods of time and the sense of normality can remain unchallenged. However there is a pivotal point at which the data changes dramatically. This relates to becoming aware that the cancer is locally progressing. Within the data this is crucial in terms of renegotiation, reflection and realignment within the individual life world. A number of aspects of the previous data remain present in subsequent interviews but what frequently changes is the intensity of that experience.

The tensions which were discussed in the first stages of the analysis continue. The data continues in its complexity in terms of being both multi-layered and multi-facetted.

Having worked extensively to maintain the status quo and the resulting affirmation of life, assimilating the knowledge that the cancer is progressing is devastating. Having attended for routine surveillance they were told that their scans had shown an increase in size of their primary tumour and as a consequence they would need to undergo further treatment with chemotherapy.

> *"It's on the move again, not that I would have known, I don't feel any different. The cancer is growing and he said I needed more chemotherapy to keep it in check" (Harry Interview 3).*

Within the data this is clearly epiphanic for the participants. Whilst being able to maintain continuity and stasis the potential for this to occur has been both minimized and avoided. Having been given this information life will once more, never be the same again. Many of the same feelings emerge, yet with greater intensity and uncertainty, than at the initial diagnosis. The cumulative nature of these emotions can at times, be overwhelming and raise a tangible sense of desperation which needs to be controlled.

> *"I was shocked, I couldn't believe it. I wanted to tell him to shut up. Once he started to speak I knew what he was going to say, I could tell by the look on his face. I should have known when he checked Mike was coming in. He bent down towards me and I thought – no – don't say it, don't say it – please. I wanted to shout at him to stop and run out of the room. But I didn't – I just sat there and smiled at him when he smiled at me. Why would he smile when he just said that to me?" (Margaret Interview 2)*

Whilst the inevitability of this event was acknowledged in the previous data, as a consequence of the extensive effort which has been invested in maintaining

continuity, this has been very effectively quashed. The wave of negativity which accompanies this event is monumental. The news has shaken the core of the individual's ability to keep life 'normal' and focus on the ordinary.

> *"It's not just the bad news; it's what follows, the treatment, the chemo. Six more months coming here every couple of weeks" (Joan) Interview 3*

The sudden awareness of the cancer progressing is frequently described as being far worse than the original diagnosis. Those feelings and emotions which accompanied the original diagnosis re-emerge with a greater intensity, sense of fear, foreboding and dread.

> *"It's worse than the first time, much worse. First time I didn't know what would happen. They make you feel you will be ok with the chemotherapy, like it's a breeze. This time I know what's coming. What if it isn't working – then what?" (Keith Interview 2)*

Managing that feeling is complex and feels unattainable at first. The awareness of that change becomes stifling once more and can signify 'the beginning of the end' for many of those involved. The prospect of more treatment and the effect that will have on the individual's lives is devastating. Prior experience increases this anxiety; the knowledge that the protective defences which have been so carefully developed will be once more destroyed and control once more lies within the healthcare arena is disappointing.

> *"I don't want to go to the bloody hospital all the time, I hate it there. I know everyone there is nice, friendly. But I don't care. They have to be it's their job. They go home every night to their normal life. When I leave there I don't leave the cancer there – it comes with me – it's always bloody with me. I will never be able to leave it anywhere. Those nurses are going to invade my life again, I know they are helping but I don't want them in my life – what choice do I have?" (Maria Interview 2)*

The re-emergence of the healthcare professional's role within their life world is only accepted very specifically in relation to the treatment and the associated side effects. There are no mentions of district nurses as new treatments do not necessarily involve visits to maintain treatment devices and the frequency of treatment means this can be undertaken at the hospital.

> *"At least I don't need the district nurse again this time. That's one less day I have to stay in" (Harry Interview 3)*

This change allows for focus of the treatment solely within the hospital setting and a sense of 'compartmentalising' healthcare professional involvement and disassociation from life outside the hospital.

The ability to recognize and acknowledge change is suddenly thrust into the individual's world, without warning. Yet on reflection the signs were often there.

> *"My right leg has been swollen for a while now. I went to my own doctor who said it was where I had had the radiotherapy – it was stopping the drainage. I guess deep down I was worried it was something else stopping the drainage. But it seemed reasonable to me" (Nigel Interview 2)*

The sense of negativity is more profound, far more tangible that the original interviews. In the first interviews there was anticipation that adjusting and living with a life limiting illness felt somehow containable. That feeling of control, which was developed so skilfully, is lost. There are at times a glimpse of an expectation whereby it could be regained, this could be a temporary setback.

> *"The chemo worked last time, kept it at bay for this long – why shouldn't it do it again" (Harry Interview 3)*

But at the outset this seems like an impossible task. The sense of feeling stifled is once more very intense and difficult to contain or more importantly – control.

"I am just about to start it – next week. I don't want it; I don't want anything to do with it. I don't care if its doing me good. I hated it last time. I just want to go – to walk, and walk, and walk – as far away as I can and not come back" (Wendy Interview 2)

There is a dread associated with restarting treatment which affects the very core of the individual life world, the negativity of the change is increased to such an extent that at times it feels inexpressible.

"I want my freedom; this will take away my freedom again" (Margaret Interview 2)

The way the individual is situated within their life world is once more dramatically altered. Relationships, roles and the ability to sustain that continuity and stasis have gone.
Those close appear to begin to talk or behave differently and a tangible tension emerges.

"My friends have changed. It's a bit like it was first time. They walk on eggshells around me. I keep telling people to treat me the same. No matter how much they try the change gets through" (Nigel Interview 2)

That drive to be treated the same and keep life normal becomes stronger, yet somehow less attainable. Those around become '*wary*' (Margaret) and conscious of their interactions.

"Why do people go on and on about it. It's not the only thing I do – have chemo. People seem scared to talk about anything else – and it's the one thing I really don't want to talk about"(Maria Interview 3)

Assimilating the enormity of the implication of the cancer progressing is complex. It is a process which is viewed from a position of increasing isolation and solitude.

The withdrawal into the individual world and the distance which arises from that withdrawal is intensified. The loneliness feels greater. The attempts of those around to show compassion and understanding are a constant reminder that life has irrevocably changed once more.

> *"People keep sending me flowers – I have had loads. It's nice to know I have friends but I don't want flowers. My house looks like a funeral parlour"*
> *(Margaret Interview 3)*

Intense renegotiation and reflection are employed. Taking stock of life and the fear surrounding death, which has been kept at bay some time, have now emerged.

> *"it is sobering, very sobering. It forces you to think about your life again"*
> *(Keith Interview 2)*

Once more the social group which surrounds treatment re-emerges into the data. Old contacts are re-established and new friendships are formed within the hospital setting. There is a curiosity surrounding the exploration of what has happened to those who were acquaintances during previous treatment also a compulsion to make comparisons by most of the participants.

> *" I have been trying to find out from the nurse if they know what has happened to Angela – they say they cant remember her" (Joan Interview 3)*

Some of the participants have remained close friends with those individuals who they met during initial treatment and describe the negative experiences which they have witnessed through supporting their friends. The sense that they will follow the same pathway is concrete. Many opportunities to identify with those individuals are sought and the sense of inevitability that they will experience the same sequence of events, symptoms and process of dying is irrefutable. Margaret illustrates this really clearly when describing a group of women who met during treatment.

"when we all started our first treatment there were four of us. We met having radiotherapy and stayed friends. Julie and I both had the same cancer, the others had it in their head and face. Two of them have died. Julie died last month. She had a horrible, horrible death. It went to her lungs, her bones – she had two broken ribs and broke her hip. She was in so much pain. It was horrible, horrible" (Margaret Interview 3)

Those who have not kept in touch with individuals from their previous treatments appear to have less anticipation of how devastating the effects of what is to follow could be.

"I will take it as it comes. I don't know how I will feel this time" (Eddie Interview 2)

However much or little they are able to draw comparisons, the sense of closeness to their death is stronger. The ability to focus on small pleasures is honed in on, yet with far less consistent success than previously. Fear is a more prominent feature of their daily lives and often their worst fears and reinforced by their experiences within the treatment clinics.

"He seemed fine last time, didn't look ill at all. It was a big blood clot apparently. Could happen at any time. Don't think it was something he probably had thought about really" (Nigel Interview 2)

The burden on the individual to remain well and appear that life is normal has become even more important. Protecting friends and family becomes a priority and the ability to conceal many of the difficulties is developed further.

"I have become an expert in looking like I am ok. If people ask me I say I am well. I don't want to have a conversation about being ill. Why would I? I don't think people do really want to know. My sister is always so pleased when I say I am fine. She can skirt over it then" (Maria Interview 3)

Wendy describes this as having a

> *'split personality – the real me which no-one can see, in my bubble, and the façade which I put on for everyone else" (Wendy Interview 3)*

Attempts to show compassion can be at times viewed as intensely irritating and further acknowledgement of the new situation for the individual which can be met with hostility.

> *"Why would I need Bob to cut my grass? I can do it myself I am not an invalid" (Eddie Interview 3)*

There is a re reflection on what this signifies in relation to loss for the individual. The loss of hope is huge, any hope which had been carefully built is destroyed.

> *"if it is back again so quickly then what next. I have hardly had anytime since my chemotherapy – which they said had shrunk it down – now this. What next." (Nigel Interview 2)*

> *"I have just had the rug pulled from under me really" (Maria Interview 2)*

A period of reflection of what this may mean in terms of loss of what may have been and loss of a future is viewed with frustration, injustice and resentment. This is often a relative reaction in terms of how long the period from the original diagnosis had been. Those who had a shorter space of time expressed a greater element of inevitability and degree of resignation. Those who had perceived themselves as being well for longer found this more difficult.

> *"it has been quite a long time since my first treatment, there is a part of you which thinks – maybe I could be ok. You allow yourself that little indulgence every now and again – quietly mind, just to yourself" (Harry Interview 3)*

There did not appear to be any sense that the longer this period of time had elapsed the more inevitable this event could have been. The adept self management strategies over a period of time have allowed a distance and a sense of normality to prevail.

However, distancing from old social networks continues. Any opportunity which might expose the change is avoided effectively.

> " I never see anyone from work now. They ring and leave messages. I don't suppose we would have anything in common anymore, best left well alone" (Harry Interview 4)

Once more, the loneliness and isolation which has appeared through disengaging with those around is strongly present. The feeling that no-one else knows how this feels was expressed frequently and the participants felt that those closest could never really understand.

> "He tries, he really does. He says – I know what you are going through. How could he, really how could he. I'm in this one alone. I have always known that. It is destroying him, but in a different way. He thinks of life without me. I don't have that luxury. When I go, I go. There is no life for me then. That's what no-one really grasps. Its not death per say. It's not having any life – does that make sense. That's it the end, there is no way out for me" (Wendy Interview 3))

This appears to give greater impetus to the notion that the isolation can only be managed alone and the distance between even the closest relationships unfolds. The vacillation between attempting to re-control the individuals life and self manage during treatment creates a sense of defeat. It forces the recognition of change and an acknowledgement of ill health.

"I have to have my treatment at the same time on the same day – when they tell me to. I have no choice. They have the power and I am their prisoner in the day unit. I wait until they are ready for me. They have infiltrated my life again – I'm at their beck and call again" (Maria Interview 2)

Once more short term goals are bought into play. Often the inability to achieve the same goals is attributed to the effects of the chemotherapy.

"I do try to do things as normal – well in the week I feel ok. During the treatment I feel lousy and for the week after. I have about a week when I feel ok though. Not as good as usual though. I am really tired if I try to ride my bike now. Still, when I finish I should be back on it" (Nigel Interview 2)

Similarly the inability to keep life 'normal' is attributed to the treatment.

"it just upsets the routine really. Have to plan things around it and not too far ahead cos I don't know how I will feel" (Eddie Interview 2)

Attempts to sustain continuity can falter and lead to a sense of failing. This sense reinforces the fear which is underpinning the new place in the world and the dread becomes more tangible

I can't contemplate what will happen if this doesn't work – I just can't" (Wendy Interview 3)

The ability to feel able to self manage decreases, the competing impacts of both the illness and the effects of treatment sabotage these attempts and a spiral of resignation and acceptance begins

"I do usually walk the dog each morning, get the paper and come back and read it. I don't always feel up to it now though. Christine has arranged to have the paper delivered. It means I can walk the dog later if I need to. If I

can't she will do it. I try – even if it's just up the road. Gets me out then."
(Eddie Interview 3)

The awareness of those issues which were previously discussed in relation to the wider world issues, politics, events, are missing within the dialogue. The participants become increasingly introspective. There is a tangible polarisation of their life world, which appears to shield them from comparison with their previous life world and allows less reflection of how they appear situated within that world.

"I just think about today really. That's all" (Keith Interview 2)

The quiescence and stasis which was so strongly being cultivated within the initial interviews, is less present. Life feels more chaotic and threatened. Following the awareness of progressing illness is a turmoil which feels difficult to contain and adjust to. Encounters which accentuate this are avoided but are not as effectively managed as previously. Fewer references are made which relate to maximizing opportunities.

'You can't really hide from it anymore'.

Within the second phase of analysis aspects within continuity and change were explored in light of the participants becoming aware that they had progressive disease. This awareness was raised following routine Surveillance CT scans which are performed at either 3 or 6 monthly intervals. Usually 6 monthly scanning is undertaken but this can be modified depending on whether the individual is included in a drug trial which demands 3 monthly imaging or if any symptoms or blood tests raise suspicion of further disease. An epiphanic change within the data occurred with the discovery of secondary cancer.

The dynamic between continuity and change continue throughout the data. The tension which the individuals experience as a result of trying to resist or acknowledge the change and the negative impact which that has on their individual perception of health reaches a further peak when they become aware that they have

cancer which has spread to other organs. A distinction is clearly made between the previous experience of a sense of containment and the perception that they now have no control.

> *"That's it now. There is no stopping it. It's just a matter of time now"*
> *(Nigel Interview 3)*

The ability to maintain the status quo and consequent life affirming perception of health which felt less distinct in the previous analysis has almost completely disappeared. Individuals do reiterate – *'where there is life there is hope (Keith)'*, but the sense of conviction which has previously accompanied that is far weaker now.

Some of the participants described the consultation where they were told of their secondaries as being very similar and equally devastating.

> *"I could tell when I went in something was wrong. I could sense it. He took a deep breath in and said, I'm afraid the CT scan is not good news. It has shown spread of the cancer to your liver… I was rooted to the chair. I couldn't move, or come to that breathe. I couldn't look at Gordon, I knew he would be crying and then I would cry. I wasn't going to, I just wasn't going to. It felt like a battle of wills. It was deathly silent. He was just looking at me – like I should have been doing something – what for heavens sake. What could I do, what would anyone do, what do other people do. It's like your worst nightmare?" (Wendy Interview 4)*

The same participants also recalled how the conversation continued and once again all described a similar consultation.

> *"I don't know why I asked. I suppose it's a natural question, but I was not ready for the answer – 6 months without treatment – 18 months with – 18 months, 18 months. How many of those months having treatment? That would mean Millie would be barely 12. I wasn't ready for that…. You can*

never take that back though. I can hear it as clearly now. 18 months. I woke
up the next morning… not that I had slept much, and thought 17 months and
29 days to go" (Maria Interview 4)

The more adept the participants appeared to have become at maintaining continuity, normality and focusing on the value of ordinariness, the more difficult this appeared to be. The way they now viewed themselves within their life world has once more been irrevocably challenged.

"for a while you feel suspended, it is too grim to think about. Then a cold
creeping fear comes in which is worse" (Margaret Interview 4)

The reactions and attitudes of those around them lead once more to a sense of defeat, submission and many experience pity which they find frustrating.

"you get so many platitudes from people, I know they mean well, but why do
it. The worst thing you can say to anyone is – you must be positive. I have
started to say now – about what exactly? My friend Jackie who I have known
for years, we ran or business together, said it – I could have slapped her"
(Wendy Interview 4)

Sustaining their role within the family and their relationships is tiring. The ability to present a façade is well developed but can be threatened by the slightest action which brings to the fore the recognition of change.

"I have a routine now at bedtime. I tell Mike I will bath and go to bed and
then it starts. It takes about an hour to prepare the bed, change my bag, and
feel that I can't smell the blood and pus. Then the air freshening begins. In
case he pops in to say goodnight. I open all the windows for ten minutes
because the smell is so heavy – it clings to everything. How can we go to our
sons for Christmas? Mike has no idea what I go through, so how could he

possibly understand. Jo has an en-suite bathroom so the colostomy excuse
wears pretty thin now' (Margaret Interview 4)

This illustrates also how changes in relationships continue to cause tension and a process of disengagement appears to begin. For some, partners are less and less included in what becomes an essentially private life world.

"I had the makings of a relationship when this all began. I ended it though.
It was only going to get worse. I knew how it would all unfold, I went
through it with my mother. The fewer people who are involved the better"
(Maria Interview 4)

Despite the knowledge that their illness could potentially continue for sometime – as it has previously, death and dying are far more commonplace in the dialogue. The increase in anxiety is tangible and a dread of what can only accompany more change pervades their day to day lives.

" I don't want anything to change. Well, if it could all go away that would be
different I suppose. Every time something new happens it's another disaster"
(Nigel Interview 3)

Individuals continue to make great effort to maximize the opportunity to achieve small goals and adjust their behaviour to avoid the realization that they may not be able to achieve them once more. Again, treatment is often cited as the rationale for this and focus shifts away from the cancer.

" we don't look after the grandchildren at the moment. They are often full of
cold I need to avoid when I am having chemo. I don't think I'd have the
energy to look after them. We go to visit them instead. When this is finished
we can start again" (Keith Interview 3)

The appearance of being able to actively self manage continues to be synonymous with remaining well and being in control. As a consequence the sense of deterioration can be minimized. This is however especially obvious for those with younger children, where shielding them from the truth is paramount. Those participants with younger children continue to make concerted efforts to maintain normality, often remaining completely inactive during times when the children are absent – to allow time of activity when they are at home.

> *" Millie walks to school with her friend now. It's only round the corner. First thing in the morning it's as much as I can do to sort breakfast and a packed lunch. If I stand for any longer the pain is unbearable. It feels like I have a huge heavy weight here (points to pelvis) and if I stand for too long I will turn inside out. If I lie down before it gets too bad I can manage. I can't really take any pain killers, well I can, but then my bag grinds to a halt, which is painful too. Either that or I am sick. I have it off to a fine art now. Once she has gone I lie down on the settee. If I need anything I crawl to get it. I have a water bottle beside me and sometimes I stay there all day. I crawl to the downstairs loo if I need it. Then I can keep going long enough to make tea. I lie down when she goes to do her homework and then we lounge on the settee in the evening – I don't think she knows. I know it can't go on much longer like this" (Maria Interview 4)*

Often information is not communicated in full to the family, especially children – regardless of age. Which increases the sense of being able to continue to offer protection.

> *" I tell them as much as I think they need to know. I will tell them if I am getting sicker" (Keith Interview 3)*

Often there is a recognition of the need to 'take stock' of life. Tentatively think about the future and anticipate what may lie ahead. Developing metastatic disease is closely associated with death, in a much stronger way than previously. Each time

the situation becomes viewed as worse, the preceding dilemmas become less significant. The individual perception of their 'situatedness' within the world has completely changed. The association with cancer and death is in the forefront of much of the dialogue and the interviews can provide the opportunity for voicing those deepest fears which often remained unspoken.

> " I don't really talk about it. What can I say. It terrifies me. I lie awake at night and shake I am so scared. I have my own room so Laura doesn't know. She goes up to bed once she thinks I am asleep. I sleep downstairs now. My legs are too painful to get up there. I used to run up there with Sam, chase him up to bed and he would scream and laugh………. I used to love doing that when he went to bed. He used to dive under the duvet and hide, giggling, waiting for me to jump on the bed. Now all they (the stairs) do is remind me of what I can't do anymore"(Peter Interview 4)

One more the sense of living in a parallel world prevails yet with far greater intensity. Dialogue often shifts to preparation for death and how that may affect their family and those closest. The presence of physical symptoms, although mainly related to the primary tumour, increases awareness of the failing reliance of the body, which cannot be distanced.

> " I look at myself sometimes and wonder what Gordon sees. I wonder if he sees the person I was – or how I am now. There is nothing about me which is me. I am fat, bald, not pretty anymore, not feminine anymore. With this monstrosity (stoma). Sometimes I think its someone else in the mirror – then realise its me. Sometimes I wonder if he'll be relieved when I go" (Wendy Interview 4)

The life world has shifted to one which is far more illness and treatment orientated and the sense of wanting to keep some feeling of control becomes heightened. The drive to achieve a degree of self management remains strong although can only be achieved in relation to small goals and the achievement of smaller tasks.

" the chemo I had before was not as aggressive as this. This is awful. The diarrhoea is like nothing I could have imagined – I can't keep up with changing my bag sometimes. I try to plan a routine to give me sometime to paint, but I can't manage that most days –well not outside anyway. I used to go to friends houses a lot for supper too. I tend to invite them here now it's easier. I have bought a dishwasher which has made a big difference" (Nigel Interview 3)

The need to feel functional in some way remains important and much effort is invested in this to promote a sense of continuity. An absolute resignation of not being able to work again is articulated, which increases the sense of not functioning.

"they have signed me off for good now from work, that's it" (Eddie Interview 4)

There is an increase in activity within the family in assimilating some of the roles which have been previously undertaken by the participants and undertaking tasks – which once more contributes to a sense of being able to contribute less.

" I know they are right, it is easier sometimes for them to do things. They just don't realize how hard that is for me to accept – I am not old. I used to do things to help my dad when he was older, shopping and stuff. I am nowhere near his age" (Keith Interview 4)

Maria has gone to extraordinary lengths to achieve this, but does recognize the need for planning for her daughter's future.

"one of the hardest things I have had to do is plan for Millies future. There is no dad to take over, Sarah, my eldest daughter is going to have her. She will look after her, but she is only 25 herself. I have decided to send her to boarding school. We have been franticly reading old Enid Blyton books so

she will see it as an adventure. I know she needs consistency in her life and much as I want to see as much of her as possible I don't want her to watch me die. That is how she will remember me, I know. I want her to enjoy her childhood, spend times with her friends. If she is here she won't do that when I am sick. She is so sweet – I know she will want to look after me. I can't put her through that. I have spoken to *** (school). Sarah has visited and they understand what is happening. That will give her some normality. She will go to Sarah during the holidays…….. I just can't imagine not being there for her. It feels physically painful to think about it. I try not to – but I can't help it, it is overwhelming sometimes" (Maria Interview 4)

Renegotiation and reflection increase and the finite nature of their lives is tangible – throughout the dialogue. Extreme feelings of fear and at times terror are present, the sense of screaming on the inside remains strong for most of the participants and managing this fear is highly problematic.

"sometimes I shout. I don't mean to and it's not cos I am angry. It just sort of escapes. I have frightened Mike before. I think its pressure building inside. Like a pressure cooker – then I burst" (Margaret Interview 4)

Increasingly their life world becomes more introspective and focused around their immediate environment. Their world feels completely distinct from those around them.

Withdrawal and increasing isolation are obvious and the sense that many experiences may be for the last time are often voiced. Social distance becomes the norm, although it perpetuates the sense of internal isolation it becomes protective to the individual and also avoids any potential stigma.

" Christine still tries to get me to go out, come to bingo she says, as if I can forget what happened last time. She worries I am depressed because I don't go anywhere. I just sit. I don't think I am depressed. I am just comfortable

here. When we argue she says I am just sitting here rotting, waiting to die. I can smell that smell more now, you know the cancer smell. So she could be right. It suits me though"(Eddie Interview 4)

The feeling of continuity has been relinquished in the most part in acknowledgement of change. The illness has become their world.

"cancer, cancer – its everywhere, in the papers on the telly, always sad stories about people dying. That's me – I am cancer, first and foremost I am cancer" (Margaret Interview 4)

Even if they try to avoid acknowledging that change at times they can't avoid it

" I used to see people up the hospital and think poor sod. No hair, skinny, sick, really sick – now that's me. When I go for my appointment people look at me like that and I can tell they are thinking what I used to think – at least I'm not that bad. They look at me in a wheel chair, then they look at Laura (pause) and I know what they are thinking, I just know" (Peter Interview 4)

The dread which is associated with looking at the future is massive. The future feels only negative – the intensity of this feeling is far greater now than ever before. There can be a realisation and acknowledgement that life can now get no better.

" I often think is this the best it gets now? Can it only get worse .Christine says no of course not .. and then it does… it gets worse" (Eddie Interview 4)

Being unable to achieve all but the smallest of goals for most of the time is symbolic for the participants. It signifies the presence of a shorter life or a closer death. The changes are too great to counter. The sense of facing a '*dead end'* can lead to an overwhelming sense of helplessness and vulnerability.

"it never really goes away, that feeling of death. Mum says its gods calling. It is always there like it's a part of me I can't shake off. It's more like god is waiting – hovering- but I don't know when – you know – I don't want to know really. The further away the better. I guess this is what they mean by a dead end, (laughs)" (Peter Interview 4)

The sense of quiescence and stasis is no longer tangible. The cumulative nature of emotions has resulted in a sense of turmoil for most of the participants. Where little respite is found.

"you can't really hide from it anymore – its there. You can pretend to everyone else that everything is fine, life carries on – but inside – no way – no way at all. Its chaos."(Nigel Interview 4)

The ability to retain a sense of hope and positivity has also greatly diminished. The treatments are viewed as buying time, but often at a cost which is difficult to reconcile. Having that finiteness has quashed most positive expectations. The sense that anything positive can now be achieved in life is missing. It makes the participants distinct from those people around them who are well and that perpetuates the barrier which can't seem to be bridged. The sense of uncertainty providing affirmation of life is barely there.

Acknowledgment of this change becomes difficult on many levels within the life world. The difficulties experienced in the conflict between certainty and uncertainty, adjusting and resisting the illness experience as an embodied individual and closely linked.

Certainty versus Uncertainty.

Although as a theme within the data, uncertainty and certainty were neither broad nor representative of a substantial volume of the data, they were woven throughout the interviews and presented a significant challenge to the participant's day to day lives. It presented a theme which wove itself throughout the data. Almost in parallel with continuity and change, the vacillations which arose in the participants lives were often as a consequence of the relationship between the two opposing forces which create a sense of flux at a time when achieving a sense of consistency and stasis is important.

The fear of change within a life limiting illness appears to be fundamentally associated with uncertainty for all of those interviewed. One of the only certainties at present is a premature death from cancer and the knowledge that a dying process will precede it in some form. Focusing on the present creates a distance from this, allows protection and offers the opportunity for dissociation from the inevitable. Being able to dissociate is crucial in terms of coping for those interviewed. Paradoxically the continuity and normality that focusing on day-to-day functioning affords, becomes life affirming. Coping on a daily basis with daily life gives a sense of achievement.

> ' I focus on one day at a time really. I set myself a list of jobs to do at home for the day so I know what I have managed to do before Gordon comes in from work. If I didn't do that I would just sit here and think – and that would be disastrous.' (Wendy Interview 1)

Managing during the day seems easier than the night-time for some of those interviewed. Sleep was frequently disturbed The concerted effort that is employed during the day is less effective during the night.

> 'it's the getting back to sleep after that initial waking up thing which is hard. Sometimes I just get up and read. Then I'm always tired' (Nigel Interview 1)

Margaret and Wendy both report many sleepless nights lying thinking about what will happen in the future and what time they may have. The individual's perception of time has so fundamentally changed. The future used to be planned and anticipated positively; it was looked forward to with the potential for new experiences. Talk around plans for retirement, travel, children growing up, marrying, grandchildren and growing old together no longer have any basis in reality. There is an accompanying sense of profound loss..

> '*we used to sit and watch the Sam playing. We talked about his life, him growing up, what he might do when he's older. We'd discuss the challenges he'd face, the teenage heartache he might have with girls and what we would do when he left home. Now all that is empty, I can't even protect him when he's older. Thinking about those things is really hard. I can't bear the thought of not being there for him' (Peter Interview 1)*

The loss of hopes, the loss of dreams and the loss of what might have been is present. For most of those interviewed when they contemplate their future it is viewed with dread. The future appears to hold little in the way of positive features and is therefore no longer contemplated if possible.

Time is measured differently. Living from day to day becomes the norm. This is difficult for those around to adjust to and can create further tension. For most, no long-term plans are made and no long-term dreams or aspirations are vocalized and therefore there is less potential for disappointment.

> ' *I don't want to raise Ruth's hopes. I'd like to plan to see our children in Australia next year, but I don't know how I'll feel. I may need more chemo. I don't want to plan anything in case we have to cancel it and she'd be so disappointed. I keep telling her to go with her sister, but she won't' (Frank Interview 1)*

Occasional goals can be extended for special occasions – a wedding or a birthday, but this is only approached with trepidation. All of the participants articulated a reluctance to make any definite plans beyond their next check up, blood test or scan.

> *' I have changed the way I think and plan stuff. I would think vaguely ahead, sort of nothing major. I mean I have been on holiday once. Someone said when is your next one and I said I want to see the results first. That's three weeks, so depending on that I'll decide what to do next' (Nigel Interview 1)*

The motivation for agreeing to have surveillance investigations appears to be to seek affirmation of this self-definition and affirmation of continuing life. The potential for this to be challenged creates tension and further focuses the individual on the present until that moment arrives.

> *"I have a scan coming up, that's usually ok. I get the results about 2 weeks afterwards. It should be fine, I feel fine" (Joan Interview 1)*

> *'they don't want to see me at the hospital – so they must think I'm doing ok' (Harry Interview 2)*

Within the new 'timeframe' anything beyond that time can be uncertain and therefore planning is not really undertaken The individual perception of time is no longer measured in terms of years or months but in terms of achieving short-term goals. The lack of any forward planning creates a sense of certainty and stability where valuing that ordinariness maintains the status quo and once again affirms life – in the here and now, which can stay unchallenged.

> *'It becomes normal, the situation at the moment. I don't seem to be getting any sort of answers. I don't think the doctors are prepared to commit themselves' (Eddie Interview 2)*

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Contemplating anymore than that, can once again lead to feeling overwhelmed by helplessness.

> *'When I think about how things could be this time next year, if there is a this time next year, who knows. I know there are no guarantees. When I saw the daffodils coming up in the garden I thought – is this the last time I will see them come up – I think that a lot- which triggers me off again' (Wendy Interview 1)*

The lack of knowing creates an uncertainty which allows the individual the space to believe they remain well. No evidence to the contrary can help to perpetuate the status quo. In all of the interviews the importance of evidence was significant. The lack of any evidence of progression in the cancer on a CT scan becomes life affirming.

> *'The last scan was clear, so I just wait for the next one now. I'm sure I would know about it if the cancer was growing – wouldn't I? (Keith Interview 1)*

Keeping control and self-managing appears to be synonymous with good health. The sense of being able to self-manage, not require any input from healthcare professionals or help from friends and family is an important part of appearing well. The lack of any evidence to the contrary and the positive self definition of health create the opportunity to feel in control.

Input by healthcare professionals who are not directly related to the cancer is acceptable; as they are viewed as being a short-term necessity and not associated with any increase in dependency or loss of ability to self manage. For example the stoma nurse, to check supplies, or the district nurse, to have the line flushed during chemotherapy.

'I do see a district nurse, but only when I have to have the chemo pump removed. There's no need for her to come in otherwise. When the chemo finishes I won't see her any more' (Eddie Interview 1)

There is a definite distinction between the need for support as a consequence of the treatment and the prospect of needing support for a decline in health overall which is associated with dying or signifying advancing cancer.

This distancing appears to minimize the impact on the individual's self-definition of health. The individual has created a perception of their health, which allows them to function in their life world on a day-to-day basis.

' if I am in the shops and I bump into someone I know they usually say how well I look. That gives me a real boost' (Margaret Interview 1)

Avoiding contact with healthcare professionals allows this to remain unchallenged. Often, a patient having a limited knowledge may be seen as a failure on the part of healthcare professionals, however within this group of individuals the lack of knowledge further allows for the creation of a definition of health which goes unchallenged and can potentially remain positive. There is no suggestion that they require more knowledge than they have. For Nigel, he uses the Internet to access any knowledge he wants and that is sufficient. For the other participants, there is no obvious effort to pursue any greater understanding of their illness.

'But it's growing'.

This gap in understanding and knowledge continues until new knowledge is acquired which challenges that self definition of health. Concrete evidence from the CT scans which clearly show that the cancer is growing, creates an epiphany within the data. It forces an acknowledgement of the presence of the illness and the necessity for further treatment which generates a marked change within the data. The feeling of fear is once again strongly present and the sense of having to

relinquish some control over managing their lives creates an air of frustration and resentment.

> *"shocked I suppose, more than anything, yes , of course, if I think back then yes, it was always going to happen, but you let yourself hope that it might not, hope that nothing will change" (Joan Interview 3)*

> *"Angry, scared…….. and dread, yes (pause), that's it, dread – here we go again – but worse – that sinking feeling – the thought of having to put up with more treatment, more hospital, more everything about cancer I have been avoiding so well" (Maria Interview 2)*

Being able to focus on the present has developed a sense of constancy in their lives. The sense of an uncertain future becomes part of the everyday world to the point that it is not always in the consciousness. The uncertainty, along with its paradoxical sense of being life affirming has been undermined by the new knowledge.

> *"It goes round and round in my head, I cant take it out of my head now – its there, its part of me and has changed the way I think, again. I look at Gordon sometimes and think – is he thinking about it too – you know – watching telly in the evenings and he's sitting in the chair – I look at him and think – is he thinking about it or just watching telly. Its like being in the whole bubble thing again and looking out – looking at him and wondering what he is thinking – I can't ask him though." (Wendy Interview 3)*

There are many times in which the future and its inherent uncertainty have been contemplated but the uncertainty has ironically become a comforting aspect of the illness experience.

> *"I didn't want to know, its weird, when you go for the scan, you just trot along as you did last time. I hate having them, I know what could happen, but you still go, you still don't think to say no, it isn't a choice, you go. The*

when you get the results you think – I didn't want to know that – I was
happier not knowing – well, maybe not happier as such, but it was easier.
Now I know and I can't un-know it" (Margaret Interview 2)

Where there is uncertainty there has always been hope.

"no news is always good news in this game" (Harry Interview 3)

The acquired knowledge that the illness is progressing has marked impact on that
sense of hope. The knowledge that the cancer is once again growing is associated
with greater fear and instability, where any certainty regarding the illness appears to
be leading to annihilation.

"knocked the stuffing out of me really. Intense deflation and disappointment
– so quickly too. Its bad news, bad news, makes you think about what might
happen next" (Nigel Interview 2)

Prior to having that knowledge the individuals were able to fill that gap with their
own definition of their health, which often does not reflect reality.
That lack of awareness allows creativity and whereas uncertainty is frequently in
life, a challenge, it has become a constant which serves to be reassuring.

"I know I am in a routine, Christine gets really angry with me, but I'm not
bothered. I don't know what will happen, I have enough to deal with as it is,
what with this (Catheter) and this (stoma) and working stuff around that – I
don't need anything else on top of that to think about" (Eddie Interview 2)

In an attempt to sustain this, focusing on the present continues. The focus on the
ordinary everyday tasks supports the status quo. To achieve manageable short term
goals and diverts the focus from the future.

"I quite like going the same thing everyday – I like walking the dog, getting the paper. The time passes easy enough" (Eddie Interview 2)

Whilst an adaptation to uncertainty has evolved as the illness remained relatively stable, this is thrown into turmoil when the definition of health is radically challenged by new knowledge. The new knowledge forces the focus into the realization that annihilation becomes closer and the life world once again will never be the same.

"I am still reeling really, there are so many aspects of what is happening which make me angry, upset, disappointed and worried – I don't know where to start. I don't think I could actually say what the worst bit about it all is – its all so horrible…….
Then I think of Millie. I feel so cheated. Cheated out of our future and I know, I just know, what it will be like for her – I went through it with my mother – I am going to change her life for ever and she has no choice. I can't change that, people say you can do things to make it easier –that's just relative – it can't ever be easy. One of the nurses in the chemo clinic suggested I make a box of memories to give to her, what's that all about? She said you put things in a box as memories. She might be able to sum up her life in a box.(pause) I do write her letters though, I think it's important as she grows up to know as much as she can about me and how much I love her. I feel so guilty when I think what this will all mean to her" (Maria Interview 3)

More effort is employed to focus on the present in an attempt to cope which is increasingly frustrated and sabotaged by reality.

" I think having to have the chemo means you have to face what's happening – you can't hide from it – it becomes a reality every time you go into that building"(Nigel Interview 2)

There is an accumulation of the sense that the prospect of death has become more certain and the foreboding is once more tangible.

> *"Gloomy prospect really – I try to put it to the back of my mind – try not to dwell on it – miserable really" (Harry Interview 3)*

Having progressive disease brings the certainty of more treatment, more hospital visits and the accompanying loss of control which is associated with this in relation to self managing on a daily basis.

> *"I dread going in there, its not just the chemo –its how it makes me feel for the week after and I am washed out – when I am really tired I find it harder to cope with what is happening – I need my strength to fight it" (Wendy Interview 3)*

There is no certainty in relation to how this will unfold, what effects it may have and the impact this will have on their lives is.

> *"it's a strange thing to try to understand – everyone knows what you mean when you say it has spread, but just that its growing and hasn't spread is different – I try to tell friends it hasn't spread – but its growing – I don't think they really understand. When you can't see it its more difficult to explain" (Nigel Interview 2)*

The need to understand and have more knowledge isn't powerful within the data, perhaps this is once again linked with the potential to challenge the individuals self definition of their health.

> *" I didn't ask – I asked the first time and really I don't think they know how you will react. They have a list of side effects and say you might get this or that – or none of them. You see people in the clinic who are really sick and*

wonder if it will effect you like that – they don't know though – so I don't ask – take it as it comes" (Joan Interview 3)

The sense of not forward planning remains constant, the desire to not plan results in a lack of disappointment if those plans cannot be realized. Similarly achievements can be limited to small, short term goals which in turn enables avoidance of not achieving larger more complex tasks.

"Christine keeps saying – why don't we go on holiday – just go down to Weymouth, there is caravan park there we always used to go to- its not far. I might – when all of this has finished. I don't want to plan anything at the moment – see how I am. (Eddie Interview 3)

Long term expectations are few and therefore long term goals are few.

" I don't want to think about it, I get up and do each day one at a time – just today – I will think about tomorrow tomorrow" (Nigel Interview2)

Fear seems associated with the long term and therefore the short term becomes a safer place on which to focus. The inevitability of death has become more real and hence more certain. The future is once again focused on with negativity, dread and insecurity.

"some times it's the small things which make you think, when you get a letter or a leaflet which advertises something – we have an arts centre in town and I had a leaflet through the door advertising whats on – it went through to the pantomime in December – and I just sat down and thought – god, will I be here? It catches you unawares. (Margaret Interview 3)

There is a parallel unpredictability in terms of how the future will unfold in regard to the process of the illness, the ability to manage, remain 'bound' and as a consequence sustain the appearance of wellness. The ability to achieve a sense of

containment can be challenged and added efforts to sustain the stasis are then employed.

> *" I manage at the moment, I have my routine as I said, which I keep to. The chemo gave me diarrhoea last time though – I am worried it'll be worse with this new one, and that means I'll have to do that wretched bag all the time"* (Wendy Interview 2)

'It's in charge now'.

Whilst the knowledge of advancing disease created a change in direction of the data there still remained a degree of uncertainty which appeared reassuring and offered containment. The lack of knowing, the lack of perspective on how the illness may unfold created a degree of uncertainty which the participants were able to fill with their own perception of their health and their future. However, the evidence that the cancer as spread to distant parts of the body is devastating. There appears to be a certainty of death which accompanies a diagnosis of secondary cancer , which locally advancing cancer didn't hold.

> *"that's it now, that's it really"* (Nigel Interview 3)

Being aware of metastatic disease is devastating to the sense of control and containment which has been regained to some degree.

> *"it's spread – it's in my liver now. Who knows what next?"(Margaret Interview 4)*

The burden of certainty becomes much more challenging once the knowledge that the illness advancing has been realised.

> *"you cant avoid what this means now, its spread, it could be everywhere soon – then that'll be it. Laura understands completely – it's my mum – she doesn't get it. We will have to tell Sam soon – the school are good – we will*

go in and talk to them – then try to talk to him. What can you say? If he asks
me loads of questions I doubt I will be able to answer them – because I don't
know" (Peter Interview 3)

The recognition of metastatic disease is somehow more concrete in terms of its
significance than locally progressing disease. It symbolizes loss of containment and
control which is largely insurmountable.

"the chemotherapy is to try to control it really – I don't know if it will, but
they will try, I won't know for 3 months if it is doing anything – I have to
wait 3 months before I have a scan. It seems like a hell of a long time at the
moment" (Keith Interview 3)

The certainty is of approaching death and uncertainty has been reduced to a point
that it holds little significance in terms of the implications for the future.

"no one can tell me how long I have got – I ask what will happen and they
don't know – so when Gordon asks me – I don't know, no-one knows. I don't
want to know – what if its not long – I don't want to know that – do I?"
(Wendy Interview 4)

Certainty becomes annihilating and extreme strategies are employed to limit that
impact on the individual and their families.

"its strange, sitting here talking about it, I try not to really. I talk about it as
little as possible normally, I think about it, most of the time, In one way or
another, but just to myself. I try not to dwell on it. When the children ask I
tell them I am fine – I don't need to worry them" (Keith Interview 3)

" If Mike knew the palaver I went through every night he would be staggered
– he has no idea. I couldn't go to stay with anyone else – they would expect
us to stay in the same room – he would too, I would think, it wouldn't occur

to him what I go through. I am glad. He doesn't need to know. (Margaret Interview 4)

The gap in the individual's perception of their health which they were able to fill with their own definition of health has largely been filled by the reality of their illness. The balance has now been tipped away from their favour and there is a resignation that this will be irretrievable.

" I can't change it, its in charge now – its out of my control. I just stay like this for as long as I can" (Nigel Interview 3)

This brings with it an overwhelming sense of helplessness and panic which is hard to contain.

"I have spent most of my life feeling in control – which I don't now. I have always really been on my own, looked after the children on my own – been independent – been in charge, good or bad –(laughs) more the latter. I have no control over this – that is what I find suffocating. The not knowing, the not being able to change what is going to happen" (Maria 4)

Great efforts are employed to try to stifle that sense which at times can be all consuming. Determination to focus on the here and now can allow for some sense of control and clarity.

"When Gordon has gone to work , I go and sit in the summerhouse with the cats – I talk to them, play with them feed them, brush them – you know – just have time with them. Its odd to imagine what Gordon will do with them – it wont be the same – they are spoilt now I am here all the time" (Wendy 4)

The uncertainty which had previously become life affirming has taken on a different meaning. There has been a shift from uncertainty as means of avoiding thoughts of impending death, to a certainty of premature death without the knowledge of how

that will unfold. The ability to maintain ordinariness and as a consequence, stability, is slipping away and having to contemplate its significance is at times unbearable.

> *" When I was first ill and didn't feel too bad, I used to take Sam to school and pick him up every day. Now my legs hurt too much to do both in one day. If Laura pushes me in the chair (points to wheelchair) I could - but then his friends would stare at me. I don't mind, but they are bound to ask 'what's the matter with your Dad?' and you know where that conversation will go"*
> *(Peter Interview 4)*

The days are still more focused but the panic and fear can take hold during the night. That can be far more intense. The sense of isolation is more prevalent during the night. The realisation that death approaches is far stronger during this time and the night-time is the most difficult to contain that fear.

> *"I am terrified. I begin to sweat with fear. I really frighten myself, but I can't stop it" (Maria Interview 4)*

> *"Because it takes me so long to get settled in bed – if I have to get up to pee, or sort out the bag – it takes me ages to get comfy again – then I start to think. It seems worse when its so quiet and I know Gordon is in the next room – all calm and peaceful – that makes me worse" (Wendy Interview 4)*

Forward planning remains a problem the occasional glimpse into hoping with trepidation that time may be longer than has been contemplated appears in the dialogue.

> *" they don't know – maybe when this is all finished, the treatment and stuff – we could have a trip away somewhere – its hard work for her too. Maybe think about a bigger trip if things are stable" (Keith Interview 3)*

Those who feel this has happened more rapidly than they had anticipated find this

harder and an urgency can creep into the discussion.

> *"I haven't had time to stop and think really – its happened so quickly – I don't think if you had asked me at the beginning of all this – how it would unfold – I would have thought it would be like this. Maybe it will be calm for a while – Laura needs that – we both do – before its too late (Peter Interview 3)*

Healthcare professionals are still seen to undermine that control. They are still viewed as a necessity to access life prolonging treatment and are very much valued in terms of treatment related aspects of their care.

> *"the nurses are really kind and caring. They are stretched but they try to get us all through as quickly as possible. We just have to be patient. We don't have any choice about time – but you feel lucky if you are out of there by teatime – it's a long long day" (Nigel Interview 3)*

There is a sense that the knowledge those professionals have could jeopardise the self definition of their health which they are trying to hold on to – so avoiding those discussions can be overt at times.

> *"Its just like being in the hairdressers really, I know most of the nurses, I know about their families and their lives – we just chat really – nothing heavy – just pass the time – like the hairdressers" (Wendy Interview 4)*

This in turn allows perception of time to be self defined and to a large extent unchallenged.

> *" I like to think I will be able to make this time next year – no one has said otherwise, not that I have asked directly" (Keith) Interview 4)*

There is a real notion of finiteness in the dialogue but there is a dissonance with the sense of mortality which they are trying to sustain. This results in a disconnectedness from people and situations which might challenge that and create tension.

> *" If they don't know then any of us can hazard a guess. People say I look sicker – but that doesn't necessarily mean anything concrete. I see people in clinic who are fine and look fine – then they are dead the next week. There is no point in talking about it – its all conjecture" (Nigel Interview 4)*

Once more the drive for knowledge, understanding and insight has diminished. There is a sense that any newly acquired knowledge would be negative in its nature and therefore unwelcome, destructive and annihilating.

> *" I think about what will happen next. Mum had breast cancer – so it was different. She had agonising pain in her bones, real agony. She had so much morphine she slept most of the time. I couldn't stand that" (Maria Interview 4)*

There is little discussion around expectations any more, there is a silent recognition that many expectations may be false hopes and that polarization in the present can allow for avoiding those types of discussion with friends and family.

> *"just take one day at a time, that's what I say to Christine – one at a time" (Eddie Interview 4)*

Increased efforts are employed to protect those around them from the sense of change. A façade of positivity is often employed and those darkest fears are often not verbalized.

> *" I say to Gordon – don't worry – its not that bad – I don't think he believes me for a moment" (Wendy Interview 4)*

That paradox which has allowed uncertainty to be life affirming is ebbing away and the harsh certainty of what lies ahead is prevalent in the dialogue. The individuals' experiences challenge their own self definition of health and distancing from others to avoid further challenge is commonplace.

Adjusting to versus resisting the illness experience.

Being given a diagnosis of a life limiting illness appears to heighten self- awareness. Those aspects of life that have been taken for granted and have never really been scrutinised are suddenly raised into consciousness. All of those interviewed described themselves as being fundamentally changed as an individual at some point during the dialogue.

> *"it shocks you right to your boots, I can't explain it, I have nothing similar to compare it to. I am still shocked" (Keith Interview 1)*

There is a sense that life cannot and will not ever be the same. Striving for life to remain the same becomes of a focus of daily life and resisting the need to acknowledge that change becomes important. Active, conscious steps, are taken to counter the effect on the existential self – which has suddenly been brought into the foreground.

> *"I keep telling myself – its ok, its not that bad, its ok. If I keep telling myself it might sink in" (Wendy Interview 1)*

Many aspects of everyday life, which were previously undertaken without much conscious thought, or depth of contemplation, now have a presence.

> *"I hadn't really stopped and thought about it really. You just get on with your lives, go from year to year. It never occurs to you that it won't carry on like that, why shouldn't it? Now, I have to plan everything, nothing is spontaneous, I always have to think about the bag," (Margaret Interview 1)*

The vacillation between adjustment and resistance starts at the point that that information is given. The sense that life will never be the same, whilst everyone else around you continues feels difficult to reconcile.

A 'double existence' can begin to prevail, the image of the old self, hiding the new self for as long as that can be possible.

> *'My friends and family have changed towards me. I have four sisters, one is coming down next Monday and she's going to spend three days with me, which is nice she keeps in contact with me quite a lot, she's very good, she's a nurse herself, then my other sisters… Gladys says the more I talk to you about your illness the more you worry so I wont talk to you, I think that's fear. Susan…, she lives down the road, I haven't seen her for 3 months, she's kept away, the other one I haven't seen her, she's kept away, I've only got one sister now who's really close, is it because she's a nurse, she understands. Its not frightening, I think the other three are frightened' (Joan Interview 1)*

Reflecting on this becomes an everyday event that permeates the individual's everyday activities and leads to a process of renegotiation.

There is a feeling of seeing life from a new perspective that is increasingly a lonely one. The shared world has been fractured and the 'lens' through which life is viewed becomes distorted and feels incompatible with anyone else in the individual's world. This process of renegotiation and of raising awareness enhances the feeling of isolation and loneliness.

> *'in the cold light of day its hard. When it comes down to it, its only me, my body, my cancer and my life. Of course it affects everyone around me, but in a different way. They are frightened of me dying and not being here. I'm just frightened of what's coming and when. It's only me who will feel it, whatever 'It' is' (Wendy Interview 1)*

All of the participants expressed a desire to be needed and feel included, yet this existential isolation was untouchable and impervious to their efforts. It remained at a

level that could not really be touched or reached. The awareness of ones individual mortality can be so intense that it remains distinct from anyone else's awareness.

> *'I get days when I don't feel good, I feel really, really bad and negative about everything. I feel that I have just been dragging my friends down and you know, there is no point, it would be easier to jump off a cliff, not to worry anyone'(Nigel Interview 1)*

All of those interviewed describe a distancing and disengagement to some extent. Trying to hold on to a sense of the old self is comforting, change is viewed as negative in these circumstances, where the old self was a living self and the new self, becomes a dying self.

> *"sometimes I just long to be able to turn back the clock. Just a year, that's all. We were so blissfully unaware of what was coming. We have always been so happy. We still are happy sometimes. We still have each other. But it wont ever be the same" (Wendy Interview 1)*

Although there is an increasing sense of isolation and at times desolation there is also a need to push others away which can lead to further isolation. Changing activities to avoid those who knew you as the old self can avoid the acknowledgement of that change. Also, the dynamics of existing relationships and friendships begins to change. A level of superficiality emerges. It is not clear whether both parties, as a result of not wanting to acknowledge the change, cultivate this. Keeping a sense of control seems pivotal in this. If it is through individual choice that the disengagement takes place then the decision has remained with the individual – it is under their control.

> *" Its up to me at the end of the day. I could still see them, but I don't want to really. We don't have the same things in common anymore. They seem awkward, don't know what to say I suppose. Its easier not to" (Eddie Interview 1)*

One of the most difficult adjustments relates to the ability to 'make sense' of what has and is happening.

> *' I don't really understand what is happening in there (points to pelvis) I can't feel it or see it, but I know its going to kill me sooner rather than later' (Frank Interview 1)*

The stark realization of one's life being finite and the lack of control which that brings feels very lonely, isolating and frightening. To acknowledge life as being finite and accept death is required. Although it has always been a prospect, it has been in the dim and distant future after a full and long life.

> *' of course everyone is going to die, we all know that. But its not something I'd reckoned on thinking about yet. I never relished the thought of growing old or retiring, now I'd love to have that opportunity' (Margaret Interview 1)*

That awareness of one's own mortality, that is, suddenly being very conscious of it, is harsh and difficult to adjust to. For those around them, the acceptance of a finite life for the participants could lead to an acknowledgement of all life as finite. The desire to avoid this realisation perpetuates the tactics to normalise life and thereby avoid facing all of their inevitable deaths.

> *'if I try to talk to Ruth about it she says don't think about it dear. Listen to your body if you were ill, you would know' (Frank Interview 1)*

The fundamental difficulty with this appears to be that the world of the individual is not really a shared world any more. The individual has been dislocated from their old life world, in many ways, but most strikingly in the recognition of their lives being shortened. The tension between inhabiting a shared world and the movement in and out of a shared world into the world of one who is dying is incredibly difficult to manage.

> *' sometimes I feel like I am in a bubble, bouncing along, in my own world.*
> *Every now and again I bump into them (family). But I can't touch them –*
> *there's a distance there now. They will never come inside my bubble, I know*
> *that sounds daft, but there's only room in here for me. I go through their*
> *lives beside them but not with them in the same way. I think it's my safety*
> *bubble. I'm safe in here, no-one can reach me. I know it could burst*
> *anytime.' (Wendy Interview 1)*

Striving to make some meaning from the illness experience is really helpful in the adjustment process for some of those interviewed. Inclusion in clinical trials, raising money for charities, helping others in similar circumstances are all ways which can create a feeling of positivity from what could otherwise be consistently negative. Trying to make sense of a limited life can never be positive for these individuals, therefore searching for meaning within the experience is really important.

> *'my parents are deeply religious and I have always been a practicing*
> *catholic. I do wonder why this is gods plan for me – it doesn't make sense to*
> *take me from my family. Nicky has lost her faith completely. Yet the church*
> *and the school are really helpful and caring. My mum finds that*
> *comforting…….., my dad just cries' (Peter Interview 1)*

All of the participants refer to change and renegotiation of life. The drive for life to remain normal and focus on the day-to-day, achievable aspects of living can lead to a sense of creating a façade. Being in control and appearing well, even at some of the most difficult times can enhance the feeling of remaining well.

> *'I'm fighting it. I may feel grotty on the inside but I am trying not to show it.*
> *Its not taking over my life (Joan Interview 1)*

This sense of bargaining to achieve greater longevity, of holding out – '*in case something new comes along (Harry)*, drives even the most fundamental sense of

existing. Frequently the participants discuss '*where there is life there is hope (Keith)'*.

There are many times when they test those around them. Often to see if they 'buy in' to the self-definition of their health. Harry describes a game he plays to see what his wife really believes of his future, by discussing plans months ahead, which he acknowledges to himself may never happen.

> '*we used to drive down to Spain every year, through France. I often say 'lets go next year' – I can tell she knows we won't but she always says – yes, we should' (Harry Interview 2)*

This creates an element of deception, which is quite tangible in a number of the participant's interviews. This is not deception in a dishonest sense, but in the sense of genuinely creating an expectation that may not have any basis in reality because the reality is too distressing to contemplate. There is a sense of buying into a future, which may not be a reality. Eddie often tells his wife they can't use their savings as he is keeping them for when he retires and his wife never challenges him.

This is marked in those who have young children. The drive to protect the child for as long as possible from the notion that their parent may be dying is profound. The sense of when to approach this, is not defined, only the importance of the child's life not being dominated by their parent's illness. Two of the participants have very young children and the determination this provides to create as 'normal' a world as possible is vast. The burden of appearing well is especially strong in these two participants, more so than the others. It feels unsustainable and must inevitably come to an end. However, at present this allows space for not having to acknowledge the reality of not seeing their children grow up and the existential distress, which accompanies those thoughts. This is also evident in those participants with adult children too. It manifests itself differently and tends to result in more distance, or avoiding conversations, which may lead to discussing the future.

'The boys ring every week still, where ever they are. They just say hi, what have you been doing, can I speak to mum and I just say yes' (Keith Interview 1)

or as Joan describes:

I'm close to the oldest one, they are all close to me but the oldest one is more concerned than the other two, Derek will just ring up and say how did you get on with chemo and that, how do u feel?, oh I'll pop in Saturday with Luke – my grandson to see how you are, but he doesn't talk a lot, I think he's frightened. So I don't talk about it. The oldest one is the only one who mentions it, the other two brush it away, brush it away, mums not ill really, we'll brush it away (gestures) (Joan Interview 2)

When that reality becomes too much, there is a process of disengagement, of regrouping and readjusting to face the world through a slightly different 'lens' (Geertz, 1993) Acknowledging some change in health becomes inevitable and sometimes acknowledgement of the small changes can deflect the focus from any major change. The re-engagement can be on the participant's terms. This relies on an acceptance of their new self-definition of health. Once again there can be a process of testing to ensure compliance, which can create disharmony in the dynamics of their relationship.

'I have supported *** football club all of my life. When I was younger I never missed a game. I went to all the home games up until I was ill. I still have a season ticket. I don't go to all the home games now, the new ground is further to go and it wears me out. I often suggest we go into town instead, that way Ruth can shop and I wait on a bench outside. We have a blue badge too now so I can park nearby. I don't have to walk so far then. Ruth doesn't notice there's anything wrong then cos I don't get puffed out' (Frank Interview 2)

This re-engagement follows a period of renegotiation and repositioning. This can often be seen through comparison with others.

> *' I look at all the people who come into the clinic each time we go. You can see some of them going downhill really quickly – of course you don't know what cancer they've got, they treat all sorts on the same day. My friend has it in her pancreas – that's bad isn't it? I do look and think will that be me? (Joan Interview 1)*

The world is viewed as distinct from the world of 'healthy people' and that creates a divide that appears to be insurmountable. This creates a sense of being irrevocably separated from their previous life world as a result. It is a part of being unable to inhabit a shared world, even with those closest and results in a barrier within many relationships. For some of the participants this manifests itself in anger and frustration with individuals who do not appear to appreciate their health.

> *'I look at people who don't have illnesses and feel jealous. I look at my mum and dad sometimes and think – why are you still alive? What do you do with your lives? – nothing. Just sit rotting – why can't I have their time? (Wendy Interview 1)*

Once again the anger is welling inside, when people close to them focus on aspects of life deemed to be trivial or inconsequential. Not all of the participants discussed this, but those who did, did so with great passion. Similarly, complaints about instances the participants view as minor and insignificant can create a great sense of anger and injustice.

> *' it does make you wonder sometimes, when people are moaning about the weather, or the price of petrol. If that was all I had to worry about (Harry Interview 2)*

The body being raised into the consciousness is difficult and will be discussed in more depth later, but is pivotal in that realignment and re-engagement process. Positive thinking is frequently referred to as being key in maintaining an ordinary existence that often verges on life affirming denial. Seeking selective information supports this process as information that is not selective may challenge the individual's definition of their health.

> *'they said I would loose more blood during the chemo, they give me drugs to thin my blood whilst the line is there. That makes the tumour bleed. It will stop when I finish chemo' (Peter Interview 1)*

In contrast to information needs at the time of diagnosis there is a real sense of silence in terms of the need to develop further understanding.

The tension between adjusting and resisting the illness experience frequently results in a sense of being in 'limbo'. This is often discussed and although mentioned as a potentially negative aspect of living with a life limiting illness appears to be life affirming and therefore serves a positive purpose. Of course the perception of time is once again an important feature of this and the sense of being in limbo is not seen as one, which will continue forever. However the alternatives are far less attractive so limbo is not an undesirable place to be, in fact it is relatively positive. It is an interesting contrast within the dynamic of time, as the nature of feeling in limbo is synonymous with suspension of time. In this sense it feels positive in the delaying of the inevitable and appears closely linked with resisting thoughts about death.

> *' I keep my life the same really, I just potter on as normal really. Nothing has changed really. My day to day life is the same, I manage ok. I don't need any help. I don't feel ill. So I tell myself I am ok.' (Keith Interview 1)*

Maintaining the resistance.

The drive to maintain normality, focus on the ordinary and achieve a status quo – to delay any inevitable decline persists within the data. Life continues this way for as

long as possible and any potential challenges to the self definition of health are quite successfully suppressed until there is tangible evidence that the cancer is growing once more. Once again this raises issues around certainty and uncertainty, and continuity and change. Cancer has a very powerful association with death.

> *"Your worst nightmare"(Wendy Interview 2), "disastrous" (Wendy Interview 2), "There is nothing worse you could be told" (Maria Interview 2), "a death sentence" (Harry Interview 3),*

Those aspects of life that have been taken for granted and have never really been scrutinised are suddenly once more raised into consciousness.

> *" you are never going to be the same once you are told that. It changes your life forever" (Keith Interview 2)*

This is powerful at the time of the original diagnosis and once again at the point that they are given the information that the cancer is no longer contained and is growing.

When the there is a significant change in the self definition of their illness there is an accompanying dread of having to discuss the changes with those around them.

> *' I don't go out very much anymore, I don't want to really. People just ask about my illness and they look at me, as though, as though they are searching to see signs of the cancer'(Wendy Interview 3)*

> *"I really don't want to go over and over it. Friends look at me with pity – I don't need their pity, or their flowers – I just want them to treat me as though I was the same person I was before this happened. They tiptoe around me. I can see it in everyone at one time or another" (Margaret Interview 3)*

Often this results in avoiding those groups of people.

> *" everyone asks how you are – its not so bad when its ok, but now I don't want to answer – even the people I play golf with, who I have known for years, I avoid. I just want to play golf – I go there to get away from this not talk about it. I have a couple of new mates who I can play with who don't know yet – I am making the most of it – soon they will" (Harry Interview 3)*

This in turn results in isolation from friends and family. Often it is easier to avoid the discussion than confront it.

> *"They ask and they ask and they ask, why they can't stop going on and on. They were never really interested in me or Gordon before this – so why now. I prefer being on our own, no questions – they want to know for their sakes not mine. I really resent that. (Wendy Interview 3)*

> *"I used to really enjoy big, family Christmas' now all I think of is – I hope its at Joyce's then I only have to go for the day, then I think, oh no, they will be looking at me to see if I look any different, then they wont let me help and make me sit down, you know, the list is endless" (Joan Interview 3)*

The ongoing vacillation between adjusting and resisting leads to difficulty in sustaining the status quo. The desire to keep life normal is so powerful that is places great pressure on their daily lives.

> *" I want to still do the same things I normally do, I want to walk the dog down to the common, it just seems further away now" (Eddie Interview 3)*

The lack of any constancy is closely linked with the desire to make sense of a situation which is inherently irrational. Attempting to focus on the mundane and the ordinary can achieve a sense of control.

" I want to take Millie to her piano lessons, it seems silly, but its really
important that I carry on doing those things which make me a normal mum"
(Maria Interview 2)

There is a difficulty with being able to conceptualise something which is not visible such as the growth of a tumour. It is hard to really know what is happening other than something is growing and this can lead to pain and discomfort when in a confined space within the body.

" it could be scarring. They said I would feel discomfort after the
radiotherapy and of course the surgery I had in the beginning. There is a lot
of scarring and this can affect the nerves – they said I could have side effects
from the radiotherapy at any time" (Maria Interview 2)

The knowledge that cancer is growing results in the need to re-examine the finiteness of life and readdress that sense of one's own mortality. Again, the sense of isolation and fear is magnified by this new knowledge and a further need to re-examine one's self definition of health prevails.

"they don't really know how fast it will grow, it has been quite slow until
now. It could carry on like that, who knows. Plus the chemo will slow it
down and shrink it so I don't expect it will be a problem for a little while
longer. (Harry Interview 3)

The skilful self definition of health has previously allowed a distancing from the reality and enabled greater resistance in adjusting to the prospect of living with a life limiting illness. However, the concrete evidence from the CT scan and the accompanying raise in the levels of tumour markers in the blood are unavoidable evidence that the illness will be a problem sooner rather than later.

"you can see it clearly on the scan. He showed me the scan from 3 months
ago and the scan now – he showed me where it is and I could see the dark

patches he said were the cancer. My blood level is now 43 – I don't know what that means but its high apparently" (Keith Interview 2)

The ability to 'normalise' and focus on the ordinariness of daily life falters dramatically and the individual is confronted with their own mortality once again.

"I never really thought anything about it, until I couldn't manage it anymore, I still walk, but cycling – not now – I am knackered if I try. When I think how much I used to cycle when I did my round" (Nigel Interview 2)

Instinctively the urge to withdraw, once more, is strong.

"I try not to speak to them – I find that easier" (Margaret Interview 3)

The need to dislocate from an already fractured life world prevails and that sense of being disconnected from those closest is prevalent in the data.

" I don't think he really understands. He talks about his Dad having cancer and me having Cancer as though it is the same. I have been to the hospital with his dad. They said prostate cancer can go on for years and years. He will just have an injection every couple of months. It's not the same. It's easier for him to think it is. (Joan Interview 4)

As in the previous interviews that sense of movement in and out of a shared world is strong and has now attained a greater level of complexity.

"I am on my own most of the day, doing my own thing really. The days go really quickly – its lunchtime before you realise. Well I put off doing that bag as long as I can so that's half the day gone. Once I have sorted the cats and thought about tea Gordon is home. He has been really busy at work all day and what have I done – come to think of it he never asks really (pauses). I haven't done anything" (Wendy Interview 3)

Being able to continue with the façade is pivotal in being able to distance the future.

> *" No-one round here knows – I don't want them to know. As long as I can cope I don't have to think about making plans for Millie. (Maria Interview 2)*

Vacillating between a new and an old self is a dynamic which appears to be always fluid, never really static. This fluidity makes adjusting at any stage problematic. The need to compare with others in powerful. Both in relation to people being well.

> *" they don't know what it feels like. I look at my friends, all of whom are well intentioned, but they are healthy. That makes them fundamentally different from me. It makes me see people in a different light" (Nigel Interview 2)*

and people being ill

> *"she looked awful, really yellow, I have never seen anyone that colour before. The nurses said it was because she had the cancer in her liver" (Keith Interview 2)*

An integral part of this self definition are the comparisons with those who are viewed to be in similar situations. The interest in those friendships in the chemotherapy clinics are used to develop a sense of perspective on their own situation. In this instance it is useful as there are no real comparisons and no real answers can be given in terms of how the individual illness may unfold.

> *" he had chemo for 6 months and then they operated on his liver. They said they could cure it. If it has spread now they can operate, sometimes" (Maria Interview 2)*

The sense of individuals being unable to truly understand creates a distance, a barrier and forces further dislocation from their previous life worlds and supports self management.

> *"They don't phone often now. When they do I just say I am fine. You can sense the relief on the other end of the phone. Like they hold their breath in case you say you are worse. Even if I am I don't say now. They don't know what to say". (Joan Interview 3)*

Seeking selective information can be used to create a sense of security and stability.

> *" I have asked for a second opinion. I am going to *** they said they may be able to operate and remove the cancer. Different surgeons have different skills – there's no harm in trying. They said whatever happens I will need to have the scan 3 months into the chemo then maybe operate after that. It's important that I try other places, before its too late (Nigel Interview 2)*

The inevitability of further treatment leads to suspending the urge to resist what is happening in order to be compliant and re-establish some sense of control

> *" you can't say no, well you wouldn't. If it will triple my life expectancy then I have to, its not really a choice? (Wendy Interview 2)*

There are opposing forces in terms of the urge to resist and challenge, which are at odds with the need for compliance with treatment and '*falling into line' (Harry).* For many that sense of '*screaming on the inside' (Wendy*), remains stronger than ever. Loss of control fuels the need to regain the control which has taken so much effort to acquire.

There is a sense of a greater internal struggle than in the previous data. Which is in parallel with the sense of isolation which is prevailing.

The ability to make meaning from the situation is lessened for some – in an attempt to take stock before confronting what was happening. The discussion around undertaking trials, fundraising or charitable work for 'the greater good' is far less obvious in the data as a sense of self preservation emerges.

> *"I have to do what is right for me, everyone has an opinion – yet none of them is me. I know I have to go through with the treatment – but having a prospect of perhaps being able to have further surgery makes it less arduous" (Nigel Interview 2)*

The presence of death which has been stifled, has resurfaced and appears to be more in the foreground. It has become far more pronounced from the perpetual shadow which was noted in the first interviews and pervades much of the dialogue.

> *"you are more aware of it really (death), on the TV in the papers on the news – its always about death. You pick up a magazine and its always about cancer, you go to the supermarket and its breast cancer awareness. You can't get away from it – there's always pink stuff everywhere in Asda. Seems petty really, but I get quite angry about it. I can't get away from it. Awareness – huh. (Wendy Interview 3)*

The need to create a new self definition of health is required in order to adjust. This redefinition is formed in relation to the previous definition and in light of the newly acquired knowledge. The need to feel functional and feel able to make a valuable contribution to their life world is a vital part of the adjustment process.

> *" that's it as far as work is concerned – don't suppose I can ever go back now" (Nigel Interview 2)*

A balance between fear, regret and acceptance is sort in a world where their place in that world still feels 'in limbo'. A part of that resistance is a determination to distance these aspects which are negative. Adjustments in their perception of their

health, their role, their relationships, their bodies and their longevity cannot be underestimated. The enormity of the adjustments which are potentially ahead are difficult to contemplate. A process of adjustment requires daily renegotiation and assimilation which supports the sense of focusing on the here and now.

> *"its strange watching the rest of my family. My youngest has always been impractical, never been able to make a cup of coffee without spilling it everywhere – yet he has really come up trumps with helping in the garden – I have always provided the veg for the family and he has really taken that on. (Keith Interview 2)*

The individual perception of time is not in keeping with that of those who surround them and this can create tension.

> *"I don't want to put it off until next week or the week after – who knows what could happen between now and then – I don't see why we have to wait – he often says calm down, there's no hurry – not for him maybe" (Wendy Interview 3)*

The adjustment of those around, which is also inevitably difficult, can continue in parallel. This creates an impact that is not always in harmony. Disengaging from this process and withdrawing can act as a protective mechanism which is difficult to break away from.

> *"I give up sometimes, its too much effort to argue. We would be falling out all the time" (Margaret Interview 3)*

Retaining a sense of the old self is comforting and reassuring – yet the comparison with the present self can be hard. Trying to maintain the illusion of that old self for as long as possible is important. The lengths which some of the participants have gone to in order to achieve this is extraordinary. There is a feeling that sustaining that old self, continuing to manage and not acknowledging that change is

protective. Avoiding situations where this is apparent can be really hard and can increase isolation and withdrawal.

> " I don't see them really, we used to go out when we worked together, I don't want to see them now. We had such a laugh when we worked together, but it reminds me of how different things are now – I used to think – when I go back to work I would start going out with them again – that's not going to happen now I guess" (Margaret Interview 3)

The adjustment/resistance process unfolds along a number of avenues, none of which result in any real stasis, which is why it becomes a perpetual process. The abnormal gradually appears to become normal, particularly in relation to bodily changes. Adaptation occurs in terms of self-managing the gradual changes and those changes which become too great to assimilate or require a dramatic adjustment incur a degree of rationalisation.

> 'it is important to me that I don't change. I think I have adjusted to this (points to stoma) with no problem. I try to do the same things I have always done…… I don't go down the pub anymore as the beer upsets this (points again) and I don't really like to go out at night anymore, so I miss seeing those friends. And of course not working anymore means I don't see the mates I used to work with anymore……(silence). (Eddie Interview 3)

This becomes overwhelming at times and focusing once more on the ordinary becomes a distraction.

> ' I keep decorating the house. I don't want Brian to have to think about it when I'm not here. He's not very practical. I think about it when I'm cleaning sometimes – it catches you unawares. I just suddenly think – he won't do this – this is going to get dusty' (Joan Interview 4)

There are times when it becomes important to contemplate and plan for a life without them. The practicalities of families, homes and the future can often be addressed with military precision. The sense of control, which that creates, is also important. The ability to plan and execute ideas enhances the sense of the importance their place in the world holds. The meaning and significance that their absence will create is important in acknowledging the value of their current existence.

> '*I don't know how he'll cope without me. We are so close. We are one person really, we do everything together. Even more so now I'm at home. I worry he won't be able to carry on without me. (Wendy Interview 3)*

This further ascribes meaning to their life and whilst often contemplated in solitude and with fear, is vital in justifying their need to continue to exist. The importance of providing for others is an affirmation of the utility of their existing role and enhances the sense of being 'functional'.

> '*being a mother is who I am. Especially as I am on my own, there's no one to take over. My eldest daughter would, I know, but she's only 24 and has her own life. This is my call. I am affecting all of their lives enough as it is. I can't imagine anyone else reading to her, making her sandwiches or taking her to gym' (Maria Interview 3)*

'I am struggling'.

There is a really strong turning point in the data when the resistance can no longer be sustained. An overwhelming sense of defeat prevails and an accompanying loss of control enters the dialogue. This is strongest at the point when metastatic cancer has been diagnosed and intensifies as the body becomes less bound and 'present to hand' (Heidegger, 1962).

The ability to conceal reality is being lost and is accompanied by a resignation that the illness is advancing beyond the point that it can be hidden from those around the participants.

> *"I really don't think I can go on like this anymore" (Margaret Interview 4)*

The dialogue becomes bleaker. Death becomes more present. Thoughts around death permeate even the most mundane of activities. Eddie sums this up when he says;

> *'I do spend a lot of time thinking about it really. It's like, background stress; it's there all the time and sort of becomes normal' (Interview 4)*

Imagining the world continuing exactly as it is but without the participants being present is a very regular, often daily event. Every birthday, Christmas or special event is viewed as potentially being their last and they will often imagine what the following years will be like without them being there.

> *'how can I ever contemplate not being in her life, I cherish every day with her and I think she thinks I'm odd sometimes when cry when she does little things, like pass a piano exam. But I'm thinking about those things I will never get to see and wondering how that will feel for her on her own. No-one should ever have to think of these things' (Maria Interview 4)*

Making sense of life as being finite is difficult. Being so aware of ones own mortality colours even the smallest of tasks.

> *" I am struggling to walk the dog to the paper shop now" (Eddie Interview 4)*

Despite attempts at continuing to maintain the appearance of a normal life, the loss of reliance on the body sabotages these efforts.

"Do you know, some days its all i can do to get washed and dressed, then its time to get ready for bed again, makes me wonder why I bother" (Wendy Interview 4)

The body has become unreliable and makes many of the attempts at performing the usual tasks much more difficult. Summoning the energy to sustain this becomes virtually impossible.

"All I want to do is be able to play a game with him, just a short one – I can't even do that now. We used to charge around the common, then we strolled, now I can't get there. Its odd really, I don't think about the big stuff , you know, don't think I should have climbed a mountain or run a marathon. Things people say they regret never doing. I'd be quite happy if I could just play football in the garden " (Peter Interview 3)

Despite changing routines and goals the sense of failing is present.

"What's the point, I won't be able to finish it – so I won't start" (Margaret Interview 4)

Being able to conceal this from those closest is no longer possible and the resistance becomes futile.

"She sees how hard it is now. I don't want pity, but I see it in her face. She would never say it. Perhaps that's unfair, its sadness more than just pity. I will never be the man I was and she sees that. She won't say it and won't talk to my mum about it, so she just hides it. I wish she would see her friends more. She doesn't go out hardly at all now, even though mum is here. I think she would actually feel guilty if she had a good time. I don't want that though" (Peter Interview 3)

This lack of resistance allows a self definition of health which is more realistic on the inside but results in desperate attempts at times to present a facade to those around them.

> *"He doesn't know what I do when he isn't here. At the weekends I just say I am shattered from how busy I have been in the week. Busy doing nothing! (Wendy Interview 4)*

The sense of being able to 'fool' those around is disappearing from the data. There are still some desperate attempts for containment, but the restriction in activity cannot go unnoticed. An accompanying need to accept help is often begrudgingly acknowledged.

> *"She will see me soon, I can't crawl around here in the holidays when she is at home. It is making me think i need to sort it out, I will, soon" (Maria Interview 4)*

Bargaining is now more difficult and the trade off for treatment and buying extra time is now no longer present. Despite treatment the illness pushes on and is destroying attempts to resist its progress.

> *"I do wonder if it was all worth it. I won't ever know though. You can never know if it has given you extra time or not" (Nigel Interview 3)*

The nature of being an embodied individual forces acceptance of the progressing illness.

> *"do you know some days I am exhausted, it takes all my energy to get up, but if i don't, I might not tomorrow and then the next day etc etc (Nigel Interview 3)*

The close monitoring of those fellow patients has stopped, and the focus is now felt on themselves as others observe their decline.

> *"I hate it when people stare, I find it hard not to be rude. Its like I am on display. It makes me dread going there. I suppose i used to do it – I hope I wasn't that obvious" (Peter Interview 4)*

The introspection continues. For some this continues to a greater degree than others and is generally mediated by the presence at hand of the body. The rituals associated with masking the reality becomes more complex as attempts to resist the change continue.

> *"I am going to get ready earlier and earlier now, It takes so long" (Margaret Interview 4)*

> *"Christine keeps saying, what an earth are you doing in there all that time? (Eddie Interview 4)*

The disengagement is more powerful, the withdrawal and self isolation is marked and deliberate. The illness continues to change the individual's presence within their world.

> *"I choose to stay here, that's what I want. I don't want to go on any trips or see my family, I am ok here" (Eddie Interview 4)*

The sense of living in a world which is distinct from those healthy individuals around them remains in the dialogue and there can be a sense that individuals who are healthy do not appreciate their good health whilst they have it.

> *"I do often look at my parents and resent them being so bloody old and not really have any problems. They don't do anything either – what a waste!" (Wendy Interview 4)*

Attempts to counter the sense of defeat are met with greater challenges. Not just in relation to the presence of death, but the unknown quantity of what is going to unfold. A panic and helplessness is at times evident within some of the dialogue, which unfolds with the perspicuity of what lies ahead.

> *"I suppose that's it really, I can't fight it now. What will happen, will happen. But I wish I knew what that was. No one will tell me, whenever I ask I get gloomy looks and people just shrug. They must have some idea. I guess they don't want to warn me. I am sure it would be easier to prepare myself and my friends if I knew. My Dad tells me it will be gods will.... not really very helpful though. Being a vicar he can reconcile what will happen. I'm not sure I can. I am scared, very scared the unknown is worse I think. Perhaps it won't be that bad after all – who knows?(Nigel Interview 4)*

Being able to achieve small goals continues to be satisfying and can occasionally provide a sense of still being able to distance what lies ahead. Resisting what lies ahead is really no longer possible.

> *"If I can just finish the jobs around the house that will be ok. Its amazing how many things I have never finished. Sometimes I wonder why I started one job without finishing the last. Christine says she doesn't want me to finish them, she likes there always being another little job for me to do."*
> *(Eddie Interview 4).*

Cancer as an embodied experience.

By its very nature, rectal cancer is in a physically difficult place. The pelvis, particularly in males, is narrow and unaccommodating of any excess growth. The lumen of the bowel will become more and more narrow as a tumour within the bowel grows and will eventually block off completely. A number of options are available for managing this and the participants have undergone various interventions to minimize the impact of this, or reduce the possibility of this happening (see individual case descriptions). All of those interviewed have tumour present, within either the rectum or within the pelvis (having had the rectum removed). They have all had attempted surgery for removal of the tumour. There appear to be two distinct, but interlinked facets of the embodied nature of their illness. There are those visible, touchable, concrete, physical manifestations of the cancer but there is also an effect on the individual sense of inhabiting the world as an embodied being, which goes far deeper than just a notion of altering the physical aspects of the individual's life.

During the initial interviews the participants had already experienced varying degrees of intensity of the impact of their illness. Eight of the participants had already had colostomies formed during surgical treatment and this in itself had changed their physical being in a number of ways. Two of the participants felt they had adapted with relative ease to having a stoma, which, as Harry describes was a necessity that he feels he has put into perspective.

> *'I know this colostomy is there to stop my bowel blocking. If it wasn't there it would block and then burst. So I have to come to terms with it' (Harry Interview 1)*

However, the degree of impact on the body varied among the participants and as a consequence the impact on the daily life varied. Whilst adjustments in lifestyle are inevitable there are trade offs for maintaining the appearance of good health, which are negotiated by the individual. Often this entails limiting activities to a familiar area where they are manageable.

"I have changed the things that I grow in the allotment this year. I haven't dug in any potatoes or planted onions. I've stuck with salad crops and I may put some beans in – things that are easy to grow and don't need much upkeep" (Harry Interview 2)

Having a colostomy was described in many instances as a reason for becoming increasingly socially isolated and inhibiting arrangements to visit friends and family.

'I don't go to my daughter's house anymore at all. The dog sniffs my bag and I'm really embarrassed. I squirt perfume all over me – I'm surprised the dog doesn't choke (laughs), but he still does it. It's awful. Everyone says it doesn't smell – but the dog obviously smells it. (Margaret Interview 1)

The unpredictable nature and lack of any ability to control bowel function with a stoma creates a focus for planning activities. The experience of having had times where stoma bags have burst, creates a lack of confidence in the reliability of the body and as a consequence can dictate the extent of people's social interactions.

'I went to bingo one night with Christine to keep her company – she thought I needed to get out, she'll never ask me again. I had half a lager and my bag burst. I didn't even make it to the toilet, it was everywhere…….... She goes to a different club now, (Eddie Interview 1)

Individuals will go to great lengths to avoid situations where this unreliability may be exposed. Even a simple shopping trip is timed around the predicted pattern of their bowel function, or the availability of facilities to change a stoma bag. Often despite the best planning this can go wrong – with disastrous consequences for the individual and reinforcing the anticipated stigma of being unable to retain control over bowel function.

'I have had a couple of nasty accidents. That sort of thing you are aware might happen any time' (Nigel Interview 1)

This is very evident in the dialogue, even in those individuals who feel they have assimilated having a stoma into their lives.

> *'Having a stoma wasn't too difficult to get used to, its just going to visit people, its awkward when people are there, and I think where shall I put it. I am happy with it now. I didn't feel it really changed who I am as much as the cancer, its strange not having a bottom (you know –points) anymore, but I've coped with it. I cope with the stoma, I cope with not having a bottom any more, I've brushed away what happened and that's it (draws line in the air)'. (Joan Interview 1)*

This increased presence at hand of the body creates a cycle of knowing and recognizing limits and subsequently not testing them. Avoiding that challenge can avoid a sense failure and lessen the need to acknowledge a loss of reliability.

Travel was mentioned many times during the interviews. Many of the participants chose not to travel due to the unpredictability of their bowel function, the potential for lack of adequate facilities for changing stoma bags or the potential for soiling sheets in another's house or in a hotel.

> *'I wanted to go to my daughters for Christmas, but she only has one bathroom and if the children want it and I am in there I don't know what I'd do' (Keith Interview 1)*

Travelling any great distance can become inconceivable so many opportunities are lost through lack of confidence in the reliability of the body. Two of the participants had planned to bring forward a 'trip of a lifetime' but felt unable to risk flying or staying in a hotel. The issues around insurance are vast and often prohibitive which also creates a stronger sense of injustice, frustration and helplessness. But simultaneously legitimizes the decision not to travel. Travelling to visit children and grandchildren at such an important time is rendered almost impossible.

The expectation that family and friends should then travel to the participant creates a further burden of placing demands on family at a time when it is important to remain well and maintain an appearance of wellness and normality.

> *"I don't want to trouble them. They have their own lives. Its not like I'm about to pop off. If I was ill I'm sure they'd come. I keep telling them I am ok when they talk about visiting" (Frank Interview 2)-Frank died two weeks after this.*

Hiding these changes to perpetuate the sense of wellness becomes part of everyday life. Creating an illusion of normality in attempt to ignore bodily changes becomes a driving force and when unable to maintain that illusion the individual can disengage and renegotiate to achieve a redefinition of health and a strategy for maintaining normality.

> *'my daughter is in Liverpool, even if I could get there, what would I do with my bags, where would I throw them away. I don't want to have that discussion.' (Eddie Interview 1)*

However, this does represent a much deeper effect on the embodied self. The ability to take their body for granted is challenged during illness. The illness increasingly breaks down any neutrality and creates a transparency which as a consequence exposes its vulnerability. The illness results in the body not functioning as it should, which ultimately, will lead to death. The sense of being let down by the body and being unable to rely on the body is strong, even during the initial interviews.

Having a stoma can serve as a constant reminder of the cancer and one that is consciously present in their lives. Whilst an attempt is made to rationalize the practical management of the bag its symbolism reaches far deeper.

> *'I hate it, I detest it, I really hate it. Everything that has changed in my life is there, (points) in that bag. It'll never go away. I can never go back to being*

me again. It will be there for the rest of my life………. Every day, I have to look at it, see it, reminding me of being ill. If it wasn't there I'm sure I could forget for a while – but I can't. I just wait for it to make a noise, or work and then I have to change it. Some days I don't get dressed til lunchtime, that way I don't have to look at it in the shower, or think about what clothes I have to wear to hide it. (Wendy Interview 1)

Wendy is adamant she will never accept it and focuses very clearly on the impact it has had on her life, her relationship with her husband and the very core of her being. For her it represents her illness and she clearly describes the association with the cancer.

Those individuals who did not have a stoma experience their own problems. They have great difficulties with control of bowel movements and diarrhoea.

'I can't go out for the day anymore in case I need the toilet and there isn't one there. I can't hold on anymore. I have to know exactly where the toilets are where I am going. When I have to go I have to go' (Keith Interview 1)

The lack of reliability increases social isolation and disengagement by the individual. Even within the closest of relationships there is frank evidence of disengagement.

Coping with the changes has usually resulted in a withdrawal from most forms of intimacy. Only two of the participants had let their partners see their stomas.

' my wife had a mastectomy twenty years ago and she wears a false breast. We both know why we have these attachments and what they mean, but then that has become part of who we are (Harry Interview 2)

Those who hadn't shown their partner describe this as a real barrier. Wendy offers a vivid description of how this has affected their life;

> ' I can't bear Gordon to touch me – in case he feels the bag. I can't bear
> him near me anymore. I'm not feminine now so why would he want to. I
> can't where nice clothes anymore, I never wore any clothes in bed until I
> had this thing' (Interview 1)

Although much of this is related to the actual stoma there is a deeper more profound
problem, which is readily focused around the stoma.

> 'We are still close, but sex – forget it. When I first had my surgery I had my
> son living with me and he said "no we can't do it when he's here wait till
> he's gone, moved". He's now moved, he's gone, so I said I think it's about
> time we got together and he said, "Joan, I'm happy as I am". I think he's
> frightened, cos I've had surgery down there, I said to him you know the
> surgery made me smaller down below (smiles) and they've sewn up my
> backside and I've got this (points to stoma), that don't help .He wont look at
> it, when I wash and I've cleaned it around I say to him do you want to have a
> look? And he says no – he's frightened. (Joan Interview 1)

The side effects of the radiotherapy and surgery often include impotence in men and
two of the participants' discuss this openly in terms of

> 'the treatment has taken away my manhood' (Nigel Interview 1)

and

> 'yeh, like I could anyway! I've got this bag stuck on my belly, this tube
> coming out of my bladder and crap pouring out of my backside – nice.
> (Eddie Interview 1)

This distancing was present in all of the interviews. Of those participants with partners all except Joan (she only has one bedroom) had moved into separate bedrooms and justified this by explaining they felt more comfortable if they needed to manage their stoma during the night.

> *"it saves me waking Angela up if I need to empty my bag" (Harry Interview 1)*

> *"a couple of times when I first came home the bag leaked in the bed, it was horrendous. I was so embarrassed. I could never risk that happening again" (Eddie Interview 1)*

A tangible physical barrier appears to have been established very early on in the illness.

The distance however, enables the individual to once again create their own definition of health and present an appearance of being well.

Ongoing treatment creates further problems. Chemotherapy treatments have a variety of side effects, which the participants experience in varying degrees.

> *"diarrhoea, diarrhoea and more bloody diarrhoea – as if I didn't have enough to start with. I am worn out. I have my treatment over three weeks, an injection on the first day, then 2 weeks of tablets that wipe me out really. I am so tired. I have a week off in between when I feel vaguely normal. Then I dread it, back again for more poison. I can't say no, it's buying me time, that's all I keep thinking – time – at any cost" (Maria Interview 1)*

> *"It's made the ends of my fingers completely numb, I can't feel anything. Which is a pain cos I have to ask Laura to help me with my bag. She says she doesn't mind, she likes to help – but I do. It's embarrassing. I feel like an old*

man – I don't want her to help. They say I might get some feeling back

sometime, they can't say when though" (Peter Interview 2)

Almost exclusively physical symptoms can be attributed to the treatment and disassociated from the cancer itself.

"Once the treatment finishes I will be able to do more. I will be able to walk

further and get back to how I was. I want to start playing tennis again, Millie

is really interested in playing now" (Maria Interview 1)

There are some aspects, which are experienced which are not common to all of the participants. Eddie describes a smell, which he says is the cancer itself

'I can smell it, Christine can smell it. The first time I had the cancer she told

me to go to the doctor cos she could smell it, smell cancer. She said I smelt

like her mum when she had it. That's how we knew it was back, I was sitting

in the chair and she looked at me, I knew what she was going to say before

she said it. I can smell it – she said………you can't describe the smell – if I

tried to describe it to you I couldn't, its thick and heavy, sort of sweet, you

can't describe I, its horrible – but we can both smell it. It doesn't matter

what I do – it won't go away and I can't hide it – its with me all the time'

(Eddie Interview 1)

Although Eddie clearly describes this in relation to a smell, he highlights an issue that many of the participants mention in relation to the inescapable nature of their illness. When Wendy discusses her stoma she describes the same problem, the sense that they will never be able to escape from their situation and they have physical reminders of their illness.

The focus on evidence of growth of the cancer is central to the individual's definition of their health. The results of CT scans and blood tests are seen as the

only evidence that the cancer is being contained. The pivotal feature of the scan is the fact that no secondary cancer has developed.

> *'It hasn't spread anywhere, that's the main thing. The chemo has kept it under control. (Nigel Interview 1)*

Not judging time beyond the next CT scan has become part of life. It is integral to the individual's self-definition of health and is used as life affirming when no sign of developing disease is present.

I know it's there'.

As the illness progresses, far greater efforts to self manage its impact are exerted. Focusing on day-to-day life, remaining as ordinary and normal as possible requires immense effort by most of the participants. This effort in itself is exhausting, but seen as a vital component in maintaining that façade and creating an illusion of normality. As symptoms emerge new strategies are implemented to manage their effects on day-to-day life. Remaining bound is increasingly difficult and requires further isolation and disengagement to sustain.

All of the participants assert that they manage during this period, with increasing demands placed on their ability to self manage, stay in control and often keep the reality of their illness secret from those around them.

> *"I am fine, I can mange perfectly well by myself. I don't need help from anyone"*(Maria Interview 2)

Often attempts to help by family and friends are seen as negative. They threaten to expose an increasing vulnerability which has been so actively disguised. Scratching the surface of the assertions that physically the individuals are coping reveals a myriad of complex and interlinked experiences.

Attempting to take control helps with this process. Coping with bodily changes can become a highly secretive activity. Divisive ways of managing to hide the results of a body, which can no longer be relied o to remain bound, are sometimes employed, which creates an element of deception and further distancing within a relationship.

> *'I lose mucous all of the time from my backside, and the tumour bleeds so I have to wear pads, Mike has no idea. I throw the pads out with my stoma bags – he doesn't need to know' (Margaret Interview 2)*

The finality of the change at times is overwhelming. Desperation and a sense of being out of control can take over. Trying to take control, even if this results in further withdrawal and disengagement feels less threatening, than acknowledging the context for the change.

There has always been an understanding that the cancer will never be cured and will ultimately shorten life. The lack of any evidence of metastatic disease is highly significant and is a point, which is fixed upon heavily within the dialogue.

> *'as long as it stays put that's good. If it starts to move, that's when I'll worry' (Harry Interview 3)*

The self-definition of health has appeared to allow for the presence of the cancer but has no room for change. Any significant change in the individual's general health challenges this notion and becomes threatening.

> *'I've just had a bad chest infection, I felt awful. It frightened me to death, I kept thinking it was the cancer, and I wouldn't get any better. Everyone kept saying – no its not- but I didn't believe them. I guess they were right – I feel ok now. (Joan Interview 3)*

It becomes difficult to distinguish between general health concerns and those that are attributable to the cancer. Once more, avoiding situations where change may

become obvious becomes included in the self-management strategy. Even a Sunday walk with the family, which used to provide the opportunity for exploring and sharing time with the family, suddenly creates a sense of desperation, dread and lack of control from the realisation it may no longer be feasible and the body may not be dependable.

> ' we used to meet up with the children for Sunday lunch quite often. There are so many great pubs in the Forest and we enjoyed seeing them and treating them. I avoid any restaurants now; it's really embarrassing when I eat because my stoma makes really loud noises. The kids think its funny – but I can't cope with I at all, (Margaret Interview 2)

The inability to rely on the body and the need to wear pads for most of the time, also contributes to physical withdrawal. By avoiding a situation where the body may be exposed as vulnerable or radically altered, creates less of a requirement to openly acknowledge that change.

Being unable to control body fluids is frightening and once more associated with the cancer. Those participants who have a tumour still in the rectum have more of an awareness of this.

> 'I often have a feeling down there (points) but I'm not sure if that's the cancer. I get a lot of discharge and mucous, bloody stuff – so I guess it is. It's very, very strange. Suddenly becoming aware of a sort of full feeling inside. It's not there all the time. Just now and again – sometimes it feels like its moving and then all this stuff comes out' (Margaret Interview 3)

> "Sometimes I just sit on the toilet and it pours out. Its weird. I pee into this bag and crap in this bag, then I have this jelly pouring out of my backside. Sometimes, when this isn't working properly (points to catheter) I pee out of my backside – Its like I am leaking everywhere"(Eddie Interview 2)

Those individuals who still had a rectum all referred to an increasing need to wear pads at night. As the interviews progressed they became unable to rely on their bowel during the night. They all purchase their own pads; most use sanitary towels, as they are readily available from the supermarkets.

> *"I just pop pads into the shopping and Mike wouldn't notice. He wouldn't think about looking at the shopping when I unpack it. So its not an issue" (Margaret Interview 3)*

None of them mentioned any intention of involving the district nurse of GP.

Pain began to become a problem for some of the participants. Deep pelvic pain creates a background problem which individuals become increasingly aware of.

> *"at first I thought it was just trapped wind and it would come and go. As time went on though it became more obvious. It's like having period pain but it spasms occasionally. Sometimes it feels unbearable. Like I've got a bowling ball in there (points) which is trying to come out. I can't stand up at times. I have to lie down. I try to take paracetamol when I feel it starting to stop it getting too bad. Sometimes I am too late and then its agony"(Maria Interview 2)*

> *"I know its there. They say it's not that big on the scan, but it is, I can feel it. I get   this pain in my groin, like someone is twisting a knife in there. Right there (points) through to my backside" (Wendy Interview 2)*

Some of the participants have more subtle symptoms, which they relate to treatment. Breathlessness features in both Eddie and Peter's interviews yet they do not associate it with the cancer.

> *"I have been anaemic whilst I have been having chemo. That's why I am so washed out. I feel knackered just taking Sam to school. I come back and I*

sleep for an hour or so. I was like this with the first lot of chemo. So when it finishes it'll be better. I don't want Laura to take him, I don't mind going together, and then we can walk the dog and kill two birds with one stone. I can't hold the lead at the moment – I can't feel it properly"(Peter Interview 3)

"I tend to sit down more when I do go for a walk. Makes the walk take longer then, get some fresh air" (Eddie Interview 3)

Eddie gets really severe urinary infections that mean he has to be admitted to hospital for intravenous antibiotics and he is always wary of the symptoms that precipitate them.

I've felt so rough though. I 've had six bad infections in 5 months when I've had to go into hospital and it just takes it out of me. My lips go black and my hand and arms go white and I can't stop shaking. They say that's because of the temperature. I sweat so much and it smells horrible. My whole body smells horrible when I'm like that it's an odour. The healthcare doctor came, but didn't know what to do. He wanted to give me tablets – but I'm on tablets. I just went to casualty and they admitted me (Eddie Interview 3).

He also struggles with severe pain in his penis. He has a suprapubic catheter but still has intense pain, which he associates, with having had a urethral catheter. He is sure that if he has the existing catheter removed the pain will go away.

"the worst bit is the penis, that is what really is sore, it is not so bad now when I am sitting here but sometimes I go to the toilet and I go and I empty my leg bag and I get this pain there, the only way I can deal with it is to sit down and sometimes even though everything should go down into the leg bag I am getting urine through the penis still, don't know why that happens, nobody seems to know, sometimes I look at it and I thought oh it looks all kind of bruised and well bruised really"(Eddie Interview 3)

However, he has been told that removing the catheter will never be an option as the hole he has in the back of his bladder, which is connected to his rectum, will never heal.

The increasing inability to remain bound becomes difficult to accept. The lack of control which is associated with the body is a constant reminder that the future can only be worse. Being absorbed in the present is once again very powerful and there is a definite sense of a public and private persona emerging more strongly than before. The sense of who the individual is has changed and is being hidden. The reality of which is far more complex than the exterior veneer.

Two of the participants described minimal disruption in their lives; Harry and Joan describe some physical aspects of their illness, such as a stoma but state that they manage with few problems. Despite this, throughout the interviews they describe changes in their daily lives which affect their embodiment. Joan describes feeling saddened by being unable to work, and how that has changed a large part of her life. Her family has withdrawn from her in an attempt to avoid discussion around her illness. All physical contact with her husband has ceased. All of these aspects of her life have a major impact, which remain largely unacknowledged by her. There is poor recognition as to the extent of the change for many of the participants, who often clearly describe changing activities; giving up golf (Harry), giving up going to the pub (Eddie), not going to watch football (Frank), not seeing family (Margaret). These are all activities which were important parts of their lives.

There is a sense that to acknowledge this change would be acknowledging the extent of their illness, which they have been at great lengths to avoid. There are times when the future is briefly contemplated

> *'I don't know what will happen. I don't really know what symptoms I should be looking for. I don't know what to expect and nobody will tell me. I ask the doctors and they don't know. The only answer I have had is from one of the*

hospital doctors who said – you will get weaker and weaker, but we can help
with any pain' (Nigel Interview 3)

As with other aspects of day-to-day life, not knowing how the illness will unfold makes the appearance of self-managing their lives is hard to sustain.

'Which bit of my body will disintegrate next'.

Maintaining the appearance of wellness was sustained for a considerable length of time. The skill in appearing bound was remarkable and expertly executed. The individuals develop an exterior that is presented to the outside world that masked the internal reality that they experienced in varying degrees.

There was a pivotal realization that this could no longer remain so secret. There is often an accompanying awareness that symptoms are directly related to the illness and not the consequences of treatment and that that reality can no longer be hidden from those within the individual's life world.

There is a sobering realization of the implications of this change despite attempts to maintain the illusion of stasis for as long as possible. The neutrality has now gone and the effect the illness is having becomes transparent. There is a sense that only as much as is necessary will be shared and some aspects will remain hidden. The attempts to keep the appearance of a bounded body continue, despite the underlying reality.

There is still a strong focus on living day-to-day and keeping today as similar to the preceding day as possible. There is an open acknowledgement that the future could be far worse.

> *"I am scared, I am so scared of what is happening to me. There is only one*
> *way out of this and it can only get worse. Each time I think, I can't imagine*
> *what else will happen, which bit of my body will disintegrate next? Its gross.*
> *really gross." (Wendy Interview 4)*

The sense of fear is powerful as the illness unfolds. It appears to be the failing body which forces the reality of the situation. The denial which has perpetuated other facets of the experience becomes physically unmanageable and unavoidable.

There is great resistance to this acknowledgement. It is accompanied by a strong sense of defeat. Failure to keep the illness at a distance and failure to keep going in the face of such adverse conditions are devastating.

> *"how can I face them, what can I say? Actually this might be it now. This might be as good as it gets. I don't want them to think I am giving up. I haven't given up. I just can't see a way out anymore" (Keith Interview 4)*

Having any further chemotherapy makes it harder. The chemotherapy drugs are more aggressive, the side effects are more extreme and the individual reserve to meet the demands of the treatments is lower than before.

> *"I think the drugs will kill me before the cancer does. I have never felt so sick in my life. I don't feel like I have enough strength to get through this. The sickness and the diarrhoea are exhausting" (Margaret Interview 4)*

The chemotherapy is still seen as a '*lifeline*' (Eddie) but the cost is far greater than before.

> *" I hate who I have become. I have photos of Gordon and I when we were younger. I was really pretty as a girl, long dark hair. I was always slim – I was always on a diet (laughs). Now I don't want to eat, I have no appetite at all and I look like this. If I look in the mirror I just cry. That's all that's left of me. But it's not me. The girl in the picture is me. I'm just a horrible bald cancer. That's all I am, a cancer, that is Wendy (points to picture) this is cancer (points to herself)" (Wendy Interview 4)*

There is an interesting dynamic between the need to have the additional time which is offered through treatment and the side effects of the treatment.

> *"If you had asked me before all this started if I could live like this I would have said no, definitely no. I would keep my dignity and bow out gracefully. Now it's a completely different story. Life and time at any cost. Another day I can see Millie is worth all of this. You can keep pumping this poison into me till I gasp my last if I thought it would give me another gasp!" (Maria Interview 4)*

There has been a great deal of reflection and the acceptance of the chemotherapy as a last option is frequently mentioned.

> *"if this doesn't work that's it. There is nothing else. I can't say no – its not a choice"(Nigel Interview 4)*

The awareness of how vulnerable and unreliable the body has become is more powerful than ever. Yet the lengths those individuals will go to, to avoid asking for help is staggering.

> *" I spend most of my days on all fours now. It's the most comfortable place to be for me. As long as I am on my own what does it matter. When ever Millie is out I crawl everywhere. It relieves that pressure in here (points to pelvis). Sometimes I can't move at all. I was stuck on the bathroom floor all morning once. I couldn't get out of the bath properly and slipped as I swung my leg over. I landed with full force on the side of the bath. It was like a white light moment, I don't know how long I was out for – then I couldn't move, just in agony. I put the towel over me and curled up on the bath mat. It was three or four hours before I could crawl into the bedroom" (Maria Interview 4)*

This is not uncommon among the participants. Margaret too crawls when she is alone in the house.

> " I know it sounds strange, but it is more comfortable, much more comfortable. I don't feel that dragging pain that I have when I stand up"(Margaret Interview 4)

Mobility becomes increasingly difficult for seven of those interviewed. Five of the participants have developed lymphoedema in varying degrees. This not only slows their movement but also makes it very difficult to get comfortable at night. Peter calls it his 'lead legs'

> "It's the oddest thing. These lead legs mean I have to be pushed around all day in a chair if I want to go anywhere. Laura has to take me. I can't do the stairs anymore, so I have dad's old room downstairs. But I get off to sleep and wake up with jumpy lead legs, I keep having to move them, they have a mind of their own, they fidget and have like a crampy pain – really tense"(Peter Interview 4)

Being able to sleep becomes problematic for a number of reasons. Maria wakes during the night terrified that she has died

> " I dream I am dead, then I wake up. Initially I think thank god for that I am alive. Then I start to shake and shake and shake – that's when I think. I can't get back to sleep, I keep thinking – what if I don't wake up, what if Millie comes in and I am dead, I can't let that happen. I need to get her away to school now………………(long pause) Well, soon, Do you know, I can't let go of her, I can't. I just can't - not yet". (Maria Interview 4)

There is also a combination of the practicalities in sleeping and the fear which seems to be more present at night. Being in a different room from a partner seems to

make this more difficult; yet there are no signs that going back in together would be an option.

> *"do you know, it takes me so long to get to bed, then to get comfy with all of this. Having gone through the whole routine with this (stoma), then dragged this on to the bed (left leg) I have to position a pillow under my knee, or I get a dead leg. I can't lie on that side because if I squash my bag it will leak during the night. I have to lie in such a way that my pad catches the grit and grot which comes out of my tail end too in the night and god help me if I need to wee" (Margaret Interview 4)*

This can be compounded if more interventions are needed,

> *"it was bad enough with that (stoma) and this (the tumour has now eroded out through the groin skin and there is an open wound) but apparently my kidneys aren't working properly. They keep checking my blood tests with the chemo and they are getting worse. The cancer is pushing into the tube that goes from my kidneys to my bladder and blocking it. I have to go and have a tube fitted to drain the kidney…… I'll have to sleep standing up" (Wendy Interview 4).*

All of these difficulties increase the sense of frustration and vulnerability. Needing more help from healthcare professionals, more interaction with chemotherapy staff and more frequent admissions to hospital as a result of the side effects of treatment compound this. There is a feeling that self-management is being sabotaged and the healthcare teams are taking over. There is great resistance to this and the only acceptance is agreed as sequelae of treatment and not as an indicator of advancing disease. If the need for increased professional help can be reconciled as being iatrogenic, then this is somehow acceptable.

Being unable to hide the physical symptoms makes the illusion of wellness less attainable. The external façade which has been so carefully constructed is being

dismantled. This appears to instigate further disengagement and more isolation to avoid exposure wherever possible.

There is an immense sense of isolation, which is present in the seven interviews where individuals acknowledged this feeling of defeat and that as an individual they have become defined by their illness.

> *"I think they just look at me as an invalid now " (Keith Interview 4)*
> *" I know they are thinking about cancer all the time they are talking to me" (Nigel Interview 4)*
> *"I don't want her to think of me as dying"(Maria Interview 4)*

There are more and more aspects of the illness that are permeating every facet of these individual lives. The interpretation of these is wholly negative and a sense of control is lost.

> *" I now have a fistula from my intestine to my vagina. It means the contents of my bowel just pours through my vagina and I have no control over it. The only thing they can do is give me another stoma and try to divert the flow higher up – I will probably do that, I just don't want to go into hospital any more. I can't go on like this though, I am so sore. I can't keep clean. I spend most of my days in the shower but never feel clean. My skin inside is red raw, it burns" (Margaret Interview 4)*

The perception of health, becomes wholly negative. The unbound body (Lawton, 2000) is hard to accommodate and withdrawal and isolation appear to be the only solution. The finality of these changes is immense and there appears to be no way out for those individuals. The fundamental change as an embodied individual is great. Daily living is met with a succession of activities that can be viewed in terms of independently being able to achieve them or requiring help. The individual's embodiment has changed so dramatically and the finality of that change is huge. The individual's life world becomes a world of an 'ill person', which remains

distinct from others who inhabit that world. Death becomes a presence which is increasingly difficult to ignore in the light of such change and the frailty which that change exposes reinforces this sense.

Chapter Summary.

In summary, the data illustrates the complexity of meanings which impact on the everyday lives of individuals living with locally advanced rectal cancer. Over a period of time a number of tensions exist in the everyday world of the individual as they live with their advancing illness.

The tensions between continuity and change, adjusting and resisting the illness experience and certainty and uncertainty create a dynamic which the individuals live with through the creation of stasis and normalisation. The embodied nature of the experience of the illness gradually undermines the ability of the individual to sustain the façade of appearing well and as the body becomes increasingly unbound the individual attempts to accommodate progressing illness.

The key findings within the study relate to the process of keeping life as 'normal' as possible for as long as possible. This is achieved through a series of self management strategies which support a self definition of health. This self definition is created by the individual who strives for this to remain unchallenged for as long as possible. There is an accompanying alteration in the perspective of time within the individual's life world which creates a dissonance with those individuals who also inhabit that world.

Paradoxically, uncertainty has a role in affirming life during this time. Shifting goals and frames of reference enables a sense of achievement for the individual. Information needs ebb during this phase of the illness and healthcare professionals are often actively distanced to minimise any challenge to this self definition of health.

Renegotiation of both self and social identity is commonplace. This is frequently accompanied by self driven withdrawal and isolation to perpetuate a sense of containment for the individual. The emerging change in the embodied experience of the illness and the problems which arise as a consequence of locally progressing rectal cancer can result in a loss of containment of a carefully constructed world. Eventually the façade cannot be sustained and the impact on the embodied individual is profound. Despite extensive efforts to achieve stasis an acknowledgment of advancing illness occurs and as the body becomes increasingly unbound, the embodied individual becomes more isolated and withdrawn.

Chapter 5:   Discussion and Conclusion.

Introduction.

The findings from this study demonstrate that for people living with advanced rectal cancer the 'everydayness' of the individual's life world is permeated by a number of tensions: certainty and uncertainty, continuity and change, adjusting to and resisting the illness experience and the effect of the body becoming unbound. These tensions are all central to the embodied individual's drive to sustain a 'normal' life. Whilst some of the findings from the data reflect the existing literature (Chapter 2) there are a number of new findings which both challenge and add to, the existing body of knowledge.

The data suggests that maintaining normality can be crucial to this group of individuals during the period of their illness which spans from the time they became aware they had a life-limiting illness to the transition to palliative or end of life care. Being able to create a self definition of health can allow normality to remain unchallenged and is a pivotal feature of creating a sense of stasis in day to day life. Self management strategies are central in achieving and sustaining the everydayness and distance from healthcare professionals or indeed any person or situation with the capacity to challenge this self definition of health.

This chapter presents a discussion around the findings which in turn translate into potential innovations in practice. The discussion will draw together the findings and examine the contribution this study makes to the existing literature. At the outset of the discussion, it is important to reiterate the fundamental principles which have guided this study from its inception. They are drawn from the Heideggerian philosophy (discussed in Chapter 3) which asserts that 'being' is the fundamental nature of what we are, which forms a cyclical relationship with time. Heidegger asserted that 'being' is what it means to possess a self. Therefore within this study, the assumption is made that the centre of our understanding is how that self relates to those things around us. This is supported by the underlying philosophy that "the world is not what I think, but what I live through" (Merleau Ponty, 1964, p xvii).

The notion that the individual does not 'have' or 'possess' a body, but 'is' their body is prime within the study

The key theme which runs through the findings is the drive for normalisation and stasis within the lived world of the individual. The focus on the everydayness of the individual is marked by the extreme efforts which are employed to sustain normality. The sense of stasis which can prevail as a consequence serves to delay or create a diversion from, an inevitable annihilation.

Stasis also helps reduce and manage uncertainty, although uncertainty cannot be seen as a negative phenomenon. Uncertainty within this study, allows for a construction of a self definition of health which remains unchallenged. The only prevailing certainty, advancing disease, will have a negative effect. This is not apparent in the literature. Much of the literature relating to living with cancer describes uncertainty as a negative feature, a barrier to adjusting, coping and adaptation, which is exacerbated by a lack of prognosis (Ekwall, 2007, Houldin, 2006, Ohlen 2002).

In an attempt to sustain normality, self management strategies are employed. The ability to manage alone appears to be synonymous with control. By avoiding interaction with healthcare professionals the individual's ability to achieve this and 'take charge' can be exploited and any challenge to the self definition of health is avoided. Taking charge of life is clearly described in the literature (Lindquist, 2006, Carter, 2004), where the appearance of wellness is important in the way an individual presents themselves within their social networks.

Healthcare professionals are at times associated in the literature with taking away control (Lindquist, 2006, Carter, 2004, Pilkington 2004). Certainly within this study, the presence of any healthcare professional that is associated with their cancer is unwelcome during a period where distancing from the illness is so important. Hospital based healthcare professionals appear to be synonymous with cancer and only those professionals who the participants don't associate with cancer or

challenge their carefully constructed self definition, are tolerated, for example, stoma care nurses and district nurses to flush chemotherapy lines.

The shifting of social networks furthers this ability to sustain an unchallenged self definition of health and any prospective challenge often results in a process of withdrawal and isolation. The individual often constructs a façade around their world to mask the reality of their situation and frequently, extreme physical difficulties are managed in secret and alone. An inverse relationship between the 'boundness' of the body and the 'boundness' of the individuals unfolds. The effect on the embodiment of the individual is profound. Despite the lengths the individuals may go to accommodate change, there is an increasing difficulty with the unreliability of the body which poses a challenge to self management strategies. The individual enters an increasingly polarised world which attempts to avoid the finiteness of their lives and create distance from their disease. A process of renegotiation occurs in an attempt to reduce fear of the future.

Discussing the key findings:

In order to discuss the findings of the study it is important to explore them in relation to both the existing literature, as examined in the literature review (Chapter 2) and the broader literature which exists beyond the cancer arena. The key findings relate to the role of self management, uncertainty and embodiment and how these contribute to the drive for normalisation.

Self managing as a vehicle for maintaining normality in the everyday world.

Whilst self management is currently a popular topic of discussion within the literature, it has a particular function within this group of individuals which appears to be distinct from the current debate. The literature focuses strongly on exploring self management as a means to support the NHS within the current economic climate and with an aging population (Newman et al, 2009). Targeting an evolving structure of healthcare delivery allows an individual with a chronic condition, such

as diabetes, asthma and arthritis to be more actively involved in their healthcare management, which is often seen as a vehicle for containing escalating costs (Greenhalgh, 2009). This has been described as the foundation for a pyramid of care, with lay led intervention at its base and increasingly specialised care at the top (Greenhalgh, 2009).

This is not to say that the other aspects of self management have been ignored within the literature. There are studies which explore concepts of empowerment (Miewald, 1997), the notion of 'living with' illness, through active involvement (Hopkinson & Corner, 2006) and the impact on self identity (Millen & Walker, 2002). However, there is a predominance of biomedical literature with a strong focus in primary care and healthcare economics (Expert Patients Programme Community Interest Company, 2007, Lorig et al, 2006, Department of Health, 2001). The absence of self management has also been described as a significant predictor of hospitalisation (Kendall et al, 2008). However, in the UK the evidence of success from initiatives such as the expert patient programme is weak (Reeves et al, 2008). Those who benefited most are those with reduced self efficacy and health related quality of life (Reeves et al, 2008). Success appears to be related to providing support for problems which cannot be addressed alone and are condition specific (Greenalgh, 2009). However the translation of these ideas into the field of cancer care could pose a new set of difficulties.

 Self management programmes are often aimed at offering a collaborative model of care with health care professionals (Kennedy et al, 2007, Expert Patients Programme Community Interest Company, 2007, Lorig et al, 2006, Embery, 2006, Foster et al, 2005) and place a heavy reliance on both concordance and the acquisition of knowledge. However, the fundamental nature of cancer is distinct from other illnesses, in both its trajectory and its treatment (Walker, 2003). Trajectories also vary significantly within different types of cancer, the broad range of treatment and their effects.

Self management support within cancer frequently focuses on empowering individuals following cessation of treatment, to remain healthy (Carlowe, 2009), where initiatives such as, the 'Living with cancer programme' have proved successful in supporting individuals to manage their conditions in partnership with healthcare providers (Carlowe, 2009).

However, the role of self management for the individuals within this study raises a different perspective. The motivation from the individual's perspective appears strongly linked with the drive to create distance: distance from individuals who have the potential to sabotage a carefully constructed world. The appeal of self management within this group of individuals could lie particularly in the ability to continue, unchallenged, with life, for as long as possible, at a time when healthcare professionals are seen as having the capacity to sabotage the new 'normality' and routine (Robinson, 1993). This self management would keep healthcare professionals at bay and perpetuate a self definition of health, based on their own perception, within their own relational worlds

An interesting dynamic presents itself in the data, in that, the 'intrusion' of healthcare professionals is tolerated in relation to some treatments when it is expected to cease with that particular treatment, allowing the individual to once more regain control. Healthcare professionals who are not associated with their cancer are admitted into the life world, for example; stoma nurses or district nurses as they are perceived as not challenging to the redefinition of health and not synonymous with death or dying. The participants within the study all focussed on maintaining the status quo and avoiding challenge, as an approach to managing their day to day lives in the face of advancing rectal cancer. The greater the sense of normality and continuity of life they are able to achieve, the greater distance from death or advancing disease they were afforded.

Bursztajen et al (1981) alludes to this in their work on chaos theory. This is also closely linked to the role of uncertainty within this study (which will be discussed later). He suggests that adopting a probabilistic view, where uncertainty is accepted,

can open the door to multiple possibilities. This framework of chaos theory suggests four barriers to this may exist, one being the healthcare professionals search for predictability and certainty. Within this data a judgement appears to be being made regarding the potential for those 'allowed in' to deconstruct the carefully built self definition of health and undermine the current uncertainty which is offering a form of protection. The exclusion of healthcare professionals in this manner further supports the success of creating normality in a day to day world, which is pivotal in creating a distance from what may lie ahead.

Knafl and Deatrick (1986) play a significant role in the body of literature surrounding normalisation. However, they frequently described normalisation in terms of a process of acceptance and integration (Knafl & Deatrick, 1986). This is also reflected other studies where 'Getting back to normal' is a familiar thread (Dorsett 1992, Wood – Dauphinee & Williams, 1987, Knafl & Deatrick, 1986). This includes activities such as ; viewing family life as essentially normal, defining the social consequences of illness as minimal and engaging in behaviour which demonstrates normalcy within the family (Dorsett 1992, Wood – Dauphinee & Williams, 1987, Knafl & Deatrick, 1986). These facets appear to be viewed in terms of improving the quality of life of both the individual and their families. Whilst on the surface appear to be similar to the intentions of the participants within this study, there are underlying differences which are not consistent with this data.

The writings of both Robinson (1993) and Knafl & Deatrick (1986) extensively explore the process of normalisation in relation to families with disabled children. They describe normalisation as acknowledging the chronic condition whilst minimising its personal and social significance, in essence making the child appear 'normal'. There is a sense of reintegration and acceptance as being prime within the literature, which is not present within the data in this study. Perhaps 're' –integrating is the key element in some studies, particularly in relation to an attempt to normalise after a single event. Within this study, an alternative view of normalisation appears to be unfolding. The need to normalise emerges far more in relation to the present and distancing the future, as opposed to reconstructing the past. There is little drive

to re-integrate, often withdrawal and self isolation are more prevalent within the dialogue. Whilst much of the literature suggests that achieving normality is somehow managed through reconstructing life, this study's data is arguably more focussed on delaying the future and sustaining the present.

This effort to actively be normal is difficult to sustain, as maintaining the ordinary has never before required conscious effort. Whilst on the surface, a superficial representation of this process is arguably unfolding, the reality is quite different. The sense for the participants within this study is one of continuing in a parallel world to those around them and is present from the outset of the data collection. The feeling of limbo or suspension from reality is mentioned often, along with a feeling of distance from those closest to them.

At times, distancing is desirable and actively pursued, particularly within relationships with friends and previous work colleagues. It is well documented that distancing from previous social groups allows bonding with in new social groups where the sense of belonging and feeling 'normal' is able to prevail (Little and Sayer, 2004). However the intention behind this can be variable. Within this study it appears to reduce opportunity for comparison with the past and allows acceptance within a new social group. Forming new friendships, particularly with other patients, can create a new sense of belonging with common ground which can be found in others in a similar situation. Within the literature this is described as 'kinship', which is useful in mediating identity and can offer a replacement for social networks (Ekwall, 2007, Carter, 2004, Luoma, 2004, Hedestig, 2003, Ohlen, 2002).

Keeping life normal allows the containment and self management process to continue and can relieve the feeling of placing a burden on the family. Reflecting on life in relation to becoming a burden on close family members has been well described (Ekwall, 2007, Houldin, 2006,Carter, 2004, Pilkington, 2004, Colyer, 1996) also the impact of the illness on children, especially younger children (Ekwall, 2007, Houldin, 2006, Carter, 2004, Luoma, 2004, Howell, 2003) which is

evident within the data where those with younger children go to great lengths to protect them from the realities of the unfolding illness.

Within this study one of the most important aspects of the research is the longitudinal nature of the data collection. As opposed to cross sectional studies, the longitudinal nature of the data collection allows the narrative to unfold as the lives of the individuals change through the course of their illness. As the narrative unfolds, the life world of the individual is reconstructed and the boundaries of normality become more fluid. Tishelman and Sachs (1998) suggest that individuals deal with disruptive situations by attempting to construct order and processes through which situations are transformed, thereby allowing the situation to become meaningful, understandable and manageable. Within the context of this study, this could be seen as adapting a concept of normality which is relative to the rest of the individual's life world. The more polarised and introspective this becomes, the fewer opportunities for challenge exist. Continuing with this process by creating an increasingly polarised and isolated world, supports the ability to perpetuate self management.

However, the normality and stasis is challenged by the new knowledge that their illness is progressing and creates a time of intense reflection, renegotiation and realignment. Within this study this presents itself as an epiphany. This is evident in the broader literature which explores the importance of being able to control knowledge, particularly within relationships with healthcare professionals (Ekwall, 2007, Houldin, 2006, Lindquist, 2006, Carter, 2004, Howell, 2003)

This readjustment creates a new set of challenges to be overcome and an altered view of the future once again unfolds. The individuals sense of what is 'normal' shifts once more. Changing the individuals frame of reference for 'normality' gives room for 'cognitive schemas' (Salander et al, 1996) to be constructed, which represent a new normality and therefore become potentially attainable and stasis can once more prevail. More short term goals appear within the data and greater introspection signifies a greater challenge to normalisation, the resulting impact is a

focus on living from day to day, which is prevalent within some of the existing literature (Ekwall, 2007, Houldin, 2006,Lindquist, 2006, Ryan, 2005, Pilkington, 2004, Howell, 2003, Ohlen, 2002).

This cycle appears to be repeated during the illness pathway at times where there is conflict between the evidence from imaging (CT Scans) and the individuals self definition of their health. This resonates with the literature which explores the presence of death and the role that the individual's awareness plays in mediating that effect (Ekwall, 2007, Hedestig, 2003, Howell, 2003, Colyer, 1996).

The data suggests that, maintaining normality can be crucial to this group of individuals during the period of their illness which spans from the time they became aware they had a life-limiting illness to the transition to palliative or end of life care. Being able to create a self definition of health can allow this to remain unchallenged and is a pivotal feature of creating a sense of stasis in day to day life. As the embodied individual becomes less bound the ability to self manage is severely challenged. As the body becomes increasingly present at hand the self management strategies become more complex and are often aimed at containment and control. The stasis becomes more difficult to sustain and as a consequence control is more difficult. The effect on the embodied self is significant and creating a sense of normality becomes far more challenging and potentially unattainable.

The role of uncertainty in living with advanced rectal cancer.

A broad range of literature regarding uncertainty has been written within the cancer arena, much of which has focussed on survivorship (Shaha & Cox, 2003, Clark, et al, 2001, Mishel et al, 2002, Mullan, 1985, Schmale et al, 1983, Shanfield, 1980). Uncertainty following treatment is often viewed as a challenge to overcoming the impact of having experienced cancer. Much of the literature links uncertainty with fear (Ekwall, 2007, Groot, 2007, Houldin, 2006, Luoma, 2004, Pilkington, 2004, Hedestig, 2003, Howell, 2003, Colyer, 1996) and focuses on fear of the cancer returning having been potentially cured. Living with advancing cancer is discussed

scarcely in the literature before the transition to specialist palliative or end of life care. However, within this study the role of uncertainty appears to offer some positive aspects which support the drive for normality and stasis.

Central to the large body of literature on uncertainty is the work of Mishel (1988, 1990) who offered an initial conceptualisation of uncertainty (Mischel, 1988) and subsequent reconceptualisation of uncertainty (1990). Within this latter framework uncertainty is described as; "the inability to determine the meaning of events and occurs when the decision maker is unable to assign definite values to objects / events and /or is unable to accurately predict outcomes" (Mischel, 1998). The reconceptualisation occurred following the realisation that perhaps the problem may not be resolved, but may become a part of the individual's reality (Bailey et al, 2007). This still places a heavy reliance on the notion of uncertainty as being a negative concept, or at least one which demands resolution. The potential for there to be a positive role for uncertainty is overlooked within much of the literature.

However, the findings from this study suggest that there is a period within the illness experience where uncertainty affirms life. Within the original framework, Mischel refers to the evaluation of uncertainty as an opportunity if it is seen as positive; however the work still infers the need for resolution. She links uncertainty to behavioural and societal norms which are sustained in a controlled and predictable way and as a result uncertainty is seen as disruptive (Mishel et al, 1984). Its endurance is seen as symbolising instability. Antonovsky (1987) echoes this in his writings which suggest that for life to be coherent it needs to be structured, predictable and ordered and uncertainty represents a loss of coherence. Mischel (1990) suggests that uncertainty in illness is a transitional (linear) process from one perspective in life toward a new, higher order, more complex orientation towards life.

Within this study, transition to a new understanding is viewed with caution, negativity and resistance. There appears to be an inverse relationship between complexity within the illness and the need for stasis; ie; the greater the complexity

which emerges within the life world of the participants, the greater the drive for simplicity, normality and stasis. This often involves reducing life to simple achievable tasks, as opposed to the long term adjustment which is an important facet of survivorship. The lack of long term planning reduces the potential for disappointment or renegotiation. In this study uncertainty is often viewed as a positive construct. Not as an opportunity per se, but as an alternative to the certainty of annihilation which is ahead. As a result, the uncertainty serves to reduce the sense of inevitable death.

Long term planning often only exists as far as the next CT scan or blood test which have the potential to undermine the individuals self definition of health. Motivation for continuing surveillance on the part of the patient appears to be to reinforce the self defined plateau which the illness has reached. On the contrary, the healthcare professional's motivation is to discover signs of advancing disease. Certainty in this context will almost always be negative, as the greater certainty is the inevitability of advancing disease.

 Being aware of locally advancing disease brings with it greater fear. It challenges the self definition of health and creates a greater certainty of annihilation. The literature suggests this may represent an increase in the presence of death or the spectre of death (Ekwall, 2007, Hedestig, 2003, Howell, 2003, Colyer, 1996). Knowing the truth destroys the carefully built façade and polarises the need to focus on the ordinary, mundane, day to day life world which is containable and possibly sustainable.

This lack of desire for information is counter to much of the literature around cancer. However, much of the literature relates to diagnosis, treatment and end of life care, which appear to raise their own informational needs, which are not required during the current stasis. There is a sense that knowledge will add to the fear of the future and undermine their own construction of life at hand. Containment is important and being able to sustain this relies on some uncertainty which won't contradict the façade. Information appears counter to maintaining that containment

and an element which may be peculiar to these patients, or may represent other patients at this point in their illness. It is however not described in the literature and as such remains unexplored.

With the awareness of advancing disease, the ability to achieve a sense of containment seems lost. The bigger picture for the future becomes more certain and an inverse relationship between certainty and self management prevails. Certainty becomes a burden which is bought about by the concrete evidence of spread of their cancer. Certainty of annihilation is very present in the data and presents itself as insurmountable. The previous uncertainty which created a knowledge gap the individual could fill with their own definition of health, has been removed. A greater sense of loosing control prevails which produces a further increase in the drive to focus on the here and now, with less success.

A potential explanation for these findings could lie in the work of Antonovsky (1979, 1987, 1993) which was discussed earlier. His work may offer support to the notion of focussing on health as opposed to disease or illness. His conceptualisation of salutogenesis offers a health orientated paradigm; a model of wellness. His work as a medical sociologist in the field of stress surrounded the exploration of why individuals react differently to stressors and in the face of adversity some individuals thrive. He explores the continuum between 'health-ease' and 'dis-ease' with a focus on the breakdown of resistance between the two. This salutogenic perpective shifts attention so the focus lies in the personal health resources of the individual and explore the strengths as opposed to the weaknesses (Malterud & Hollnagel, 1998).

Antonovsky (1993) suggests that as resistance becomes increasingly depleted one becomes more vulnerable to stressors. It is the individual's response which will determine the outcome. The stressor creates an individual tension, which can result in either a negative, neutral or salutary effect. Only when the demand exceeds the capacity to respond does the individual move towards a breakdown in health. The central concept within his theory is the sense of coherence (Antonovsky,1993).

As discussed earlier, the element of this model which places importance on events being structured, predictable and explicable are open to debate in this group of individuals, however, once coherence is viewed as distinct from control, it becomes more appropriate. Unlike locus of control or empowerment, coherence is not solely dependant on the controllability of events, but on two key factors; that events are comprehensible and that they are under some kind of control, though not necessarily ones own (Antonovsky, 1987) .

Coherence can therefore be present in the absence of control as it relies more closely on the clarity of events than their outcome. Within this study, the self definition of health offers the individual perceived lucidity, for the present. The focus on the individual achievement of current goals,(despite the shift away from previous goals) allows the individual a sense of achievement which can distance the external reality of the change in their health. The stasis which focuses on the day to day aspects of the experience enables those stressors to be controlled as the demand is adjusted to the capacity for achievement and attainment. As the illness progresses the individual becomes more vulnerable to a point where demand exceeds capacity and events are no longer controllable.

The work Echteld (2005) describes as 'response shift' is highly relevant within this. Whilst a change in the meaning of ones self evaluation occurs, this can be enhanced by identifying individual strengths, not solely in relation to health (Echteld,2005). Whilst he describes a process of adaptation ,which includes reducing functioning within certain areas of life, this does not necessarily need to be the norm. Corner (2008) clearly describes personal goals being achieved in a circular feedback process with disengagement occurring when these are viewed as unattainable. However a new approach to care may offer previously unrecognised and achievable goals and as a consequence improve the quality of life for that individual through a reduction in disengagement. The adaptive value of goal change is also described by stress – coping theory (Folkman, 1997) which is founded in the individuals perception of the stressor. Individual perception of the stressor appears central to

the impact of the illness experience on the everydayness of the individual and therefore needs to be viewed from within that world.

Within this study, uncertainty raises the potential to have a positive influence over this stage of the illness. The uncertainty which individuals experience whilst living with advanced rectal cancer creates an opportunity which affirms life. Focus on those goals which are achievable, even if this necessitates the formation of new goals, creates coherence and stasis. Uncertainty allows distance from the certainty of annihilation which the future will inevitably bring and allows normality to prevail at this time.

The nature of the inverse relationship between the unbound body and the unbound, embodied individual.

The theoretical assumptions within this study have included the notion that the self cannot be a disembodied consciousness, but is an individual, in a particular social and cultural setting, in a particular time. Embodiment has been described as an alternative way to thinking about and knowing human beings (Wilde, 1999) and how we live in and experience our bodies. There are certain features which are essential to the fundamental concept of embodiment and how the body orientates an individual to the surrounding world (Merleau Ponty, 1962), not all of which are conscious as, many remain forgotten during everyday activities (Sartre, 1956). As Heidegger, (1962) suggests, as long as the body is functioning it is 'ready to hand' and not at the forefront of consciousness so is often overlooked. However, during illness it becomes 'present to hand' and awareness or consciousness is raised of its presence, function and compliance with the demands placed upon it. This is often the case and a number of studies exploring disability (Toombs, 1993, Toombs, 2001) have clearly identified the importance of the reliability of the body and the consequences of this failing.

The findings from this study support the notion that the body becoming increasingly 'present to hand' over time, has a profound influence on the day to day experience

of living with advancing illness. The embodied self is naturally influenced by all of the aspects within the data but the extreme lengths individuals will go to in order to self mange their bodies are missing in much of the existing literature.

Bodies and their diseases have always been deeply metaphorical (Turner, 1992) and none more so than the powerful metaphors associated with cancer, which have been made clear in many well known texts (Corner, 1997, Martin, 1994, Haraway, 1991, & Sontag, 1989). The notion that cancer is a disease of cellular malfunction, with the accompanying failure of the system to cope which results in the body being invaded by itself (Haraway, 1991) is frequently reinforced by discussions with healthcare professionals. As a consequence, when a disease is disembodied, the patient remains distinct in medical discourse (Foucault, 1991). Cancer is often viewed as a disease which is 'mapped' onto an organism (Stacey, 1997) and is measured in terms of response to chemo and radiotherapies, disease free survival or progression and side effects from treatments (Corner, 1997). These issues are often reinforced by healthcare professionals and may further support the drive of these individuals to maintain a distance. Gadow (1980) asserts that the body a patient experiences and the body the practitioner experiences are rarely the same.

There appears to be an inverse relationship between the boundness of the physical body and the boundness of the individual. As the body becomes more unbound, so the individual retreats into a more polarised and contained world where primacy is accorded to the ability to manage independently of any help. The ability to continue unaided is important within this study and hides the reality of the disease from others.

Lawton (2000) wrote extensively around the sequestration of the unbounded body and 'dirty dying'. She suggests in her work in palliative care settings that individuals are marginalised as a result of the intolerance in western society of disintegrating and/or decaying bodies. She describes a loss of self hood, social identity and disengagement or withdrawal from society, in contrast to a background trend of more community care for the dying (Lawton, 2000). The data from this

study suggests an element of 'self driven' disengagement, quite early on in the experience, which precedes the experiences of those individuals within Lawton's work. It almost represents a metaphorical representation of the sequestration she describes within the physical environment of the hospice. Whilst the concrete nature of the building does not exist, the boundaries and constraints are emerging in a 'virtual' sense for the participants within the study.

Within the study interview dialogue, no District Nurses or GPs are involved. There are reports of extreme symptoms of breathlessness, pain and discharge which are contained within a private arena. There becomes a public and private persona as the facade becomes more complex. By not acknowledging change or suppressing change, the stasis – or illusion of stasis continues.

Whilst much of the data is orientated towards achieving stasis, as the illness progresses extreme circumstances unfold. Participants attempt to self manage and are determined that this continue for as long as possible; leaking bowel contents, fistulating tumours, ureteric obstruction, lymphoedema, urinary incontinence, mucous discharge are all contained or hidden. They are all coped with in private and with no help and no intention of seeking help. A number of explanations for this may exist and fear of stigmatisation could be an overriding issue. Fear of being judged by others because of becoming unbound or being viewed differently by those closest are all possibilities.

Perhaps there is a need to acknowledge the profound influence of the way individuals are socialised from a very early age. Their ability to contain body fluids in the public domain is carefully instilled. The fear of stigmatisation may be underlying this withdrawal. Stigma was described at length during the 1960's by Goffman, as a result of discrediting of an individual by not conforming to social norms, spoiling identity and resulting in imposed isolation (Goffman, 1968). This is as a consequence of rejection by society, which was particularly prevalent in the literature around HIV and AIDS (Alonzo and Reynolds, 1995). HIV carried a heavy burden of stigma as it was associated for a long time with a 'spoilt identity' (Mort,

1987). Containment of body fluid is an important facet of acceptance in social situations and the ability to no longer sustain that containment is potentially unacceptable and therefore the individual appears to retreat under their own volition before they are forced to do so.

Williams (1996) argues that there is a trajectory of chronic illness which involves a shift from embodiment, where the body is taken for granted in the normal course of everyday life, to an oscillation between states of dys-embodiment (ie, embodiment in a dysfunctional state) and attempts at re-embodiment. Within this data there appears to be a point where re-embodiment is no longer possible. This fundamentally is founded on all individuals existing as embodied human beings but is attempting to account for the realignment of body, self and society through the course of the illness. It may be reasonable to suggest that this crisis occurs where realignment is not possible and the society, self and body can no longer be aligned in an 'acceptable' way. Within this group of individuals, being unable to control body fluids represent an inability to rely on what is seen as, one of the most basic aspects of functional control.

The failing reliance on their bodies and the increasing 'presence at hand', creates a sense of defeat. Focussing on the day in hand prevents thoughts around the future and the increasing finiteness with which they view their life worlds. Self management can be synonymous with good health and even if this is tantamount to an illusion (Taylor, 1983) it appears to be a pre-requisite for being able to distance the emerging reality.

There is a marked distancing within physical relationships. Only one of the participants remained in the same bedroom as their partner and she only had a one bed roomed flat. Body dysfunction can have differing levels of impact but none are as significant as loss of bladder and bowel function in threatening dignity and self esteem (Toombs, 2001).The distancing and exclusion of partners allows for containment of the physical impact of the illness and hiding of some of the difficulties which arise and highlight the inescapable nature of the illness.

The progressive withdrawal and increasing isolation challenge the core ways of being in the world and the authenticity of the individual. This is not dissimilar to the writings of Heidegger, Sartre and Kierkegaard, when discussing authenticity. They suggest the notion of authenticity lies in the conscious self and its relational world with external pressures. Being authentic refers to being oneself as opposed to conforming to societal expectations (Heidegger, 1962). This relates to the vacillation in the study between multiple realities within the individual's life world and illustrates the tension between the presentations of an authentic or inauthentic self to those around the individual. As part of this mobilisation of resources, the participants in this study focus heavily on the normalisation process. Kelleher (1988) describes this as part of a 'bracketing off' process to lessen or minimise the impact on the individual's identity or facilitate its incorporation into the 'public self'. In the data this is referred to as a façade, but could arguably be representative of an inauthentic self, a public self.

This is also reflected in the work of Little and Sayers (2004), who explore the correlation between theories of terror management and the diagnosis of cancer. They suggest two facets to social identity. The first is a deep identity, which becomes challenged during extreme events and well up to the point that suppression becomes a struggle. The second is a conscious identity, which is constructed and reconstructed in light of events which are context dependent, conscious and appraised in accordance with cognitive, aesthetic and moral standards. The maintenance of a 'social self' is important at this time, and as the literature suggests – this forms a protective role in helping to conceal the reality (Houldin, 2006, Carter, 2004, Howell, 2003, Davies and Sque, 2002, Mathieson, 1995). This is clearly evident within this study.

There are times when this feels impossible and a process of disengagement, renegotiation and redefinition of health prevails and then re-engagement is possible. Corbin and Strauss (1987) discuss at length a series of three steps in navigating identity. The first lies in defining and redefining the self, the second in re-focussing

of direction and the third in integration. There is a resulting new conception of self which is derived from the past, present and future and arises out of what remains. This cyclical process of biographical disruption (Williams, 1996) and renegotiation appears at each epiphanic stage of the study. The process of contextualising (incorporating into the biography), coming to terms (arriving at some degree of understanding), identity reconstruction (re-integration into new self concept) and biographical recasting (giving new direction) which are described by Corbin and Strauss (1987) and do hold relevance within this study.

There is also a well developed literature on how individuals respond to illness and Bury (1982) is much quoted as illness creating a 'defining moment' and rupture in the individuals personal biography. Zinn (2005) asserts that whilst this in part is accurate it does not allow for contextual interpretation and individual coping strategies. However Fischer - Rosenthal (2000) advocate a concept of biographical structuring, where illness is not viewed in terms of rupturing, but as a task.

Arguably, much of the work around biographical disruption rests in a background of stability, in that biography is part of a stable identity (Williams, 2000). Williams also suggests that Bury does include context, which cannot be easily separated from meaning. He suggests there are two distinct aspects of meaning – the symbolic significance and the practical consequences. Whereas Bury's work (1982), outlined a framework which supported the notion of crises, such as illness, forcing an individual to take stock of everyday life and those aspects which were previously taken for granted.

Whilst all of these works relating to biography are relevant in parts, the participants experience a greater, encompassing experience of being an embodied individual who illness unfolds through an accompanying sense of being 'dys- embodied' (Williams, 1996). Whilst extreme attempts are made to appear well and keep life normal, the unbound body prevents this from being sustained. The increasing presence at hand of the body sabotages a carefully constructed façade, despite the lengths these individuals will stretch to conceal the reality, even to those closest to them.

In summary.

The inability to sustain the appearance of wellness and normality is directly related to the increasing presence at hand of the body. Throughout the data the participants have described the importance of keeping life normal and being able to self - manage independently of healthcare professionals. Paradoxically, the uncertainty they experience during this phase of their illness has the function of being life affirming as the only certainty ahead is of decline and failing health. Living in a context from those who also inhabit their life worlds can cause tension and conflict. Shifting the individual's frame of reference for goals creates a sense of achievement as distance from the reality of declining health. Information needs are lessened and the carefully constructed world of the individual becomes threatened by the realities which are permeating it on a daily basis. In an attempt to manage this world, withdrawal and isolation can provide a protective role. There is a redefinition of self and public façade is cultivated. The individual becomes unbound and no longer able to sustain the appearance of being well. The subsequent impact on the embodiment of the individual is marked. The key elements of this are summarised in Figure 7.

Figure 7 illustrates the balance of the elements of uncertainty, self management and embodiment in relation to their impact on the everydayness of the individual and the need for healthcare involvement. The fine balance which is present is represented by the base of the figure which highlights the vacillation as these factors change through time.

Figure 7: Diagrammatic representation of the everydayness of living with locally advanced rectal cancer.
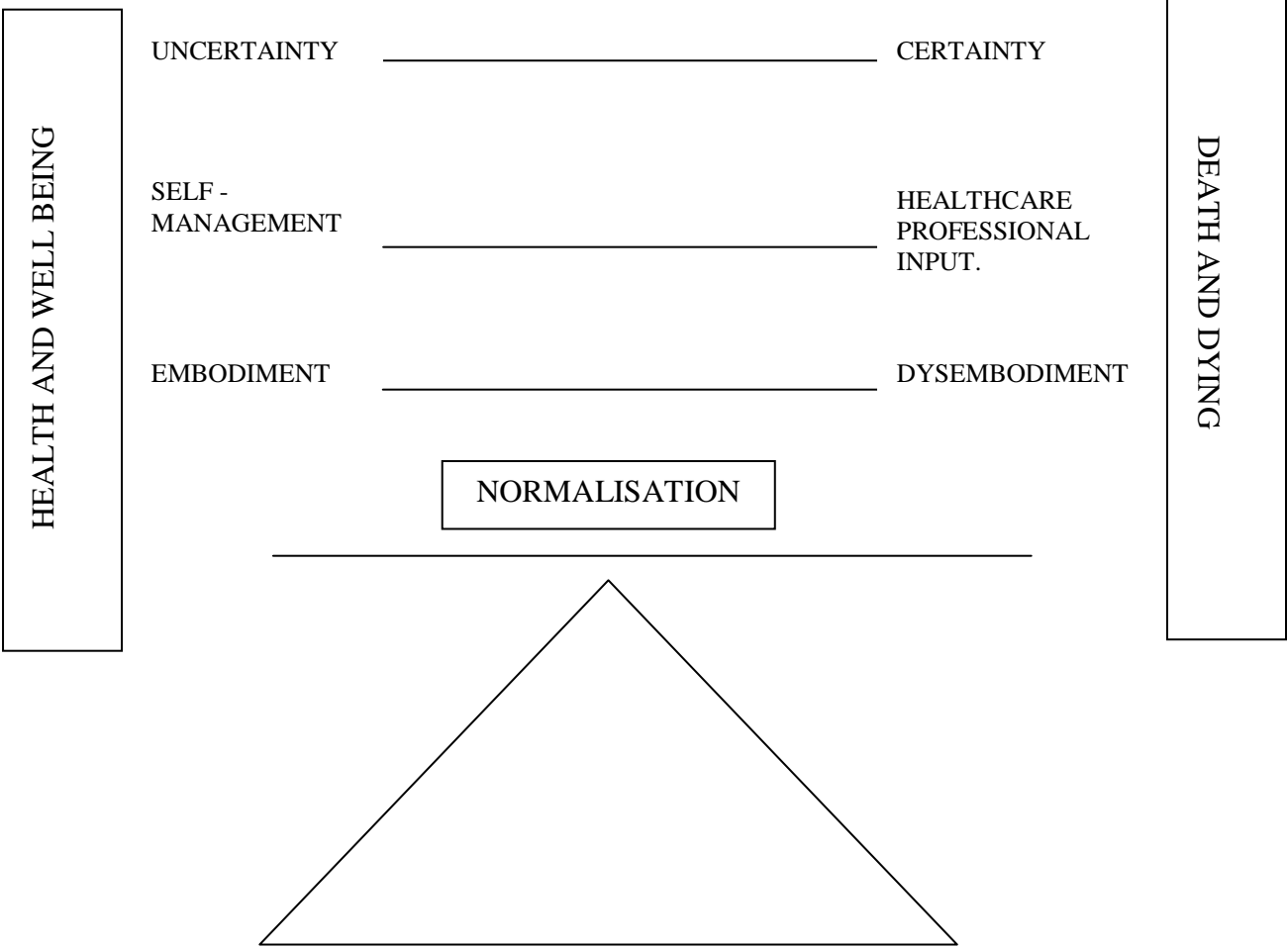
Critical review of the work.

Strengths and weaknesses

As a thesis the work represents a process of both the development of knowledge, which will contribute to the broader literature and the development of research capability within an individual. Some of the strengths and weaknesses of the study have evolved as a result of the two parallel processes and the learning curve which followed during those years. Any study will have its weaknesses and to be able to critically analyse ones own work, must be a crucial part of developing as a researcher.

The study, whilst being the product of a novice researcher, is also the product of the life worlds the participants have so willingly described and deserves recognition as such within the thesis. The study would have no utility if those individuals had not given their time and their interest in sharing very deeply personal accounts of their illness and its effect on their everyday lives.

As a study which was undertaken by a researcher who also had a role as a healthcare professional, there was an inherent dissonance between the nature of clinical practice, ie; the existing medicalised, disease orientated model of care and my own interest in uncovering the 'lived world' of the participants. My own preconceived ideas surrounding the topic were gathered at the outset of the study when the intention to undertake a study to develop and extend supportive care to this group of patients was undertaken. However, my preconceptions were rapidly shelved when the role of the healthcare professional was clearly insignificant within the life world of this group of individuals.

Choosing an approach for this work involved the exploration of a number of methods. Within medicine, the randomised controlled trial dominates the research agenda and the strong bond between medicine and science has ensured that this approach influences much of the healthcare agenda. Within a scientific quantitative approach, it is accepted that people become subjects within a controlled experiment

and a universal truth may then be secured via empirical measurement. This was however, not the approach which resonated with the goals of the research.

The process of selecting the appropriate approach required exploration of the philosophical underpinnings of research methodologies to ensure the theoretical assumptions of the study resonated with the methodological approach. The study had the potential during its evolution to become too heavily focussed in philosophy and a balance was sought between my own epistemological stance, the relative importance of the philosophical underpinnings of the study and the practicalities of undertaking the study. The challenge lay in reconciling the goals of the research with the theoretical assumptions of the study in a pragmatic methodological process which truly reflected the epistemological stance of the work. Heidegger suggests very early on in his work that there are richer and more diverse ways of being than existing as a 'thing' and that to explore what lies within a sphere of existence you do not have to leave it. (Heidegger, 1962). He suggests that "the horizon which is closest to us and which must be made ready for the analytic of 'Dasein' (being in the world) lies in its average everydayness" (Heidegger, 1962, p490). I would suggest this gives the backbone to the research.

The resulting pragmatism meant that the study does not adhere to the methodological process which would represent an exemplar of phenomenology. The pragmatic approach offered by Van Manen (2006) however, supported this notion and helped to validate the final approach. The study is informed by the philosophical writings of Heidegger and Merleau Ponty but is arguably weakened by not adhering to a phenomenological framework for data collection and analysis.

Van Manen also draws on the philosophy of Husserl, Heidegger and Merleau Ponty in his own work. His research focuses on pedagogy, which he defines as, the activity of teaching, parenting, education or general living with children (Van Manen, 2006). Although he suggests his methods are equally is applicable to disciplines such as nursing and asserts that when choosing a method for research, it should harmonise

with the interest which makes one choose ones profession in the first place (Van Manen, 2006).

This research closely adheres to the philosophy he applies to his research. He advocates that doing research is always to ask for the meaning and significance of experience in the life world and that the aim of phenomenological work is to transform lived experience into a textual exploration of its essences (Van Manen, 2006). Through using his approach it is possible to apply some of the principles of phenomenology to a piece of work which is unable to stick rigidly to the methods which are borne out of the various schools of phenomenology. Crotty (1996) describes this as new phenomenology, which has been adopted by nurses and transformed into a research method.

Traditional approaches to phenomenology are aimed at capturing essences in a pre-reflective form (Caelli, 2000). This I find difficult to reconcile as I would argue that during an interview process the participants are reflecting even during the dialogue. The longitudinal nature of the work means the participants have thought about the interview prior to subsequent data sets, so could never be held as examples of pre-reflective dialogue.

The work of Van Manen is consistent with an interpretive approach, which once more is founded on the Heidegerian principle that 'the meaning of phenomenology lies in interpretation' (Heidegger, 1962, p37).Complete phenomenological reduction is both impossible and unattainable in Van Manen's eyes and as a novice researcher I would agree. A structural analysis of a large data set was made possible by the ability to study the data, determine the meanings embodied in them (Van Manen, 2006) and then undertake a structural thematic analysis. He suggests there is no compelling reason to structure a phenomenological study in any one particular way, but the researcher needs to have the creativity and reflexivity to distinguish between incidental and essential themes (Van Manen, 2006). However, as a departure from the methods discussed in his work a longitudinal approach was also adopted for this study. One of the major strengths of the study lies in the longitudinal nature of the

work. Longitudinal qualitative research is complex and generated many challenges to working with the data. The added dimension of successive data sets to the cross sectional work posed further challenges to devising a rigorous approach to its management. Uncovering the work of Saldana offered a viable solution.

Although much of Saldana's work is ethnographic (based in the theatre) and the longitudinal nature of his work lies in single case studies, the framework for analysis he offered supported a credible and transparent approach to managing the data. The founding principles of Miles and Huberman and Wolcott were employed to analyse the individual data sets which were then mapped onto the framework offered by Saldana. During the analysis of the data, the intention was to suspend the notion of systematic progression through the interviews and be guided by key changes (epiphanies) in the temporal pathway for the participants. These epiphanies occurred very distinctly with two key factors. The first epiphany surrounded the knowledge that the tumour was no longer contained and was growing (clinically, progressive disease). The second occurred with the knowledge of distant metastases (typically in the liver or lungs). Whilst writing up the findings these key points were always how the data within the themes of continuity versus change and certainty versus uncertainty were going to be presented. However, as the chapter unfolded, these descriptive headings (progressive disease and metastatic disease) felt very clinical and constraining. This was not in keeping with the philosophy of the study which was to present the world view of the particpants. Therefore these stages in the pathway were named with quotes directly from the data to represent these changes.The key to the success of this was to suspend the notion of mapping the data sets in a chronological order onto the framework. It was only once the data was viewed in terms of the epiphanies which occurred that the analysis fell into shape.

The strength then lay in being able to explore the individual trajectories of the nine longitudinal studies and explore the epiphanies within each data set. The shared meanings between data sets allowed for the suspension of time as being criteria for analysis and accorded primacy to the events which were significant for the participants. This strengthened the data in terms of being truly embedded in the

narrative of the participants and as a consequence the findings were not shaped by a prescriptive process but by the natural dialogue which unfolded in the data.Those insights would not have been gained through purely cross sectional work.

Reflecting through the process of the study was important and the opportunity to have examples of the data analysed independently by one of my supervisors ensured the robustness of the analysis process. Whilst the findings are corroborated by co analysis there will always be the critique that there could, of course, be many alternative interpretations of the data.

To strengthen the credibility of the data a crucial element is one of transparency (Koch, 1995). If the process of analysis is transparent and the assumptions which underpin the study are transparent then the findings will be viewed as a result of the contextual elements which shaped them. Again this is a further argument for not being able to offer a pure study of phenomenology as any interpretation could arguably no longer represent the raw meaning that the individual experiences.

Alternative methods were contemplated. Midway through the study the possibility of grounded theory became more attractive. However, on reflection, this was embedded in the breadth of data and the overwhelming size of the data and the potential for managing the data more effectively using grounded theory was appealing. However, with hindsight this was definitely a reaction to a sense of panic and a drive for greater reduction and containment. Being able to adhere to the openness of the data enabled the experience to remain broad and include the everyday aspects which could have been lost through reduction.

Within approaches to phenomenology the openness of the questioning is crucial. As Gadamer (1976) suggested 'the essence of the question is the opening up and keeping open of possibilities' (p266). Also one of the strengths of this work lies in the exploration of stasis and the absence of problems, which could not have been achieved in a process of honing in. This is not a criticism of grounded theory but an

acknowledgement that it would not have provided the opportunities to explore the context which was offered by the approach this study employed.

One of the challenges within this study has been the illumination of what is absent from the data. Studies relating to illness and disease inherently become problem orientated and this is no exception. As a healthcare profession it is very easy to view the data in terms of a succession of challenges and problems which require help, support, intervention and strategic management from a healthcare perspective to overcome. However, I would argue that what this data represents is a succession of challenges which the individuals self define and self manage, within their life world until a point where this is no longer possible. The data creates a picture of how everydayness is influenced by these events and the extreme challenges individuals will address and overcome in order to retain that self-management and control. Not out of necessity, because the support is unavailable, but out of choice because healthcare professionals are often associated with the disease which they are striving so hard to distance themselves from.

Strength of this data must lie in raising the notion that hospital based healthcare professionals may not be the ideal individuals to provide support, as their approaches to care are inherently associated with the cancer and problematisation of the illness.

Similarly, one of the criticisms of a piece of work which uses only one data source is the lack of any triangulation of the data. However, with the intention of the work laying in the individual experience in their own life world the inclusion of multiple data sources would have introduced alternative perceptions when the focus of the study was to concentrate on the experiences of the individuals themselves. As a researcher the opportunity for multiple case studies was explored in great depth at the outset, however the depth of data which was achieved could not have been achieved due to the necessary breadth of multiple sources, which would have been required. Also the utility of other sources of data, with the exception perhaps of carers, would not have contributed to the aims of the study. One of the key

opportunities which the study was aimed at exploring was the potential for practice development. Arguably by including data from sources already involved in clinical practice the findings would have detracted from the intention to situate the findings firmly within the lived world of the participants.

With hindsight this was a large undertaking for a doctoral thesis. The breadth of the data gathered was difficult to manage and challenging for an inexperienced researcher. My own clinical background had the potential to hugely shape the data and influence my interpretation. The minimal references to the specialist nurses was initially concerning but in turn strangely liberating as a researcher. The potential conflict and tension which could have arisen as a result of the dual role quickly dissipated with the realisation that as a group of healthcare professionals we were not an integral part of their life world nor had any great impact on the everydayness of their lives. This is not at all to challenge the role and necessity of healthcare professionals within the illness experience of individuals with cancer, but an acknowledgement of those facets of life which are significant to this group of individuals in this phase of their illness.

This is distinct from much of the literature which explores the supportive care needs of patients at diagnosis, during treatment, survivorship, recurrence and end of life care, where there is a strong evidence base that the healthcare professionals play an important role. It is also not to say that the healthcare professionals involved during these elements of the illness experience would have any role in supporting the well being of the participants within this study. The reality of the data however, suggests that healthcare professionals are not associated with, nor perhaps perceived to be necessary to, this experience for the individuals involved.

This may be a result of the sampling strategy. However, these were successive patients, who were deemed to be inoperable by a Colorectal Cancer MDT meeting and must therefore be viewed as such. Only one of eleven patients approached declined participation. He also declined any treatment by the hospital. This naturally

raises the possibility of coincidence but otherwise could arguably be wholly representative of this group of patients who have a protracted pathway.

Raising the need for further exploration or a larger study is certainly indicated. It also raises a potential lack for differences across tumour groups. A tumour group with an inherently different pattern of manifestation and impact may offer different challenges and may include rapid progression through their illness trajectory. All of these issues raise valuable insights from the study and evidence for areas of future work.

A methodological weakness within the study could be the issue of validation by those who were interviewed. It is arguably an important part of the process of qualitative research and adds a further validity check against the representation of the data. However, in these circumstances a decisive point came during the second round of interviews. It had been my intention to return for subsequent interviews with a transcript from the preceding interview for two reasons. Firstly to validate what I had written, but secondly to ensure continuity between datasets and allow for discussion around events which had occurred since the previous interview. However, when I returned to Frank for his second interview he had deteriorated so dramatically that I made a decision at that time not to revisit the previous dataset as this in my mind had the potential to do harm. The discussions which ensued with Frank were difficult as he obviously was unaware of this marked deterioration and I felt at that time that to revisit his experiences from 3 months previously would create a situation which was not in his best interests and the consequences lay far beyond the remit of the research. It seemed harmful to raise to the consciousness such a marked difference from how he was three months previously to his current situation.

This created a clear delineation between the role of nurse and researcher and whilst it was important to ensure that he had an urgent medical review, which I was able to ask my colleague to arrange, I had no further role as a researcher with him. I made a decision at that time that due to the longitudinal research process and the potential

nature of the illness trajectory, participant validation through reading the previous transcripts would not be included in this study. A weakness from a research perspective, but on balance, an ethically necessary one.

One of the greatest challenges has been to present the data in a meaningful way which illustrates the stasis in between the illness events. There is a difficulty in describing an absence of challenge or problem which as a consequence can create the weakness that the data is viewed as a succession of extreme challenges which the individual faces in rapid succession. The reality is that these challenges are largely overcome and assimilated into the everyday world and are integrated with day to day living which is managed effectively by the individuals. The data is a culmination of the experiences over eighteen months which by the nature of the thesis has had to be reduced to manageable size.

Critical appraisal.

As a framework for appraising the literature which was used in this study it seemed appropriate to apply the same process to my own work. The CASP framework (Milton Keynes PCT, 2002) (Appendix ix).

Key contributions to the existing literature.

Before discussing the key contributions to the literature it is important to reflect on those seminal pieces of work which, whilst informing the study, were excluded from the literature review at the outset.

It is important to identify that the group of individuals within this study represent an emerging group of patients who are 'living with cancer' and are growing in numbers as treatments advance and longevity increases. As a group they are mainly unresearched and have previously been poorly recognised in the literature. However, there are elements within those key pieces of exisiting work focussed on

end of life care, which with hindsight are relevent within this group.There is a relationship with this work, albeit at an earlier stage in their pathway than perhaps has previously been recognised.

Glaser and Strauss (1965) described awareness theory within dying. They suggested a four stage model of awareness which progressed from closed awareness through; suspicion awareness, mutual pretence awareness to open awareness. This was developed further in their work in 1968, entitled 'Time for Dying'. This resonates with this work in relation to the latter of the two aspects they describe as being involved; certain death at a known time and certain death at an unknown time. However, within this study, it has been used with a positive approach by the participants. The introduction of the notions of shape and time they describe are also important (Glaser and Strauss, 1965), as within this study, time per se, has been suspended as the focus is firmly on the shape of the trajectory, which varies among the individuals involved. Buckman (1993) developed the work of Glaser and Strauss further when describing his three stage model of dying; an initial stage, a chronic stage and a final stage. Once again, he suggests a linear progression through a dying trajectory which is not described by the participants as such, but has relevance in terms of living with their illness, in the chronic sense. Kellehear (1993) describes this in terms of preparation for death, as does Copp (1999) in her work which explores facing impending death. She describes a process of redefining the self, which is similar to the participants within this study although, once again within a framework of dying. Her work also differed with the inclusion of nurses' views to shape her theory.

Whislt these seminal works relate more particularly to adapting and adjusting to death and dying, their relevence within this study should be acknowledged before continuing to explore the key contributions of this study to the existing literature.

The study has revealed an area of the individual's advanced rectal cancer pathway, which is relatively unexplored in the literature. Through the collection of longitudinal data, the nature and impact of the illness in the everyday life world of

the participants has unfolded over time. The crucial role of maintaining normality and focussing on day to day life creates a sense of stasis. The stasis serves to keep the future at a distance, where a future will inevitably signify decline and eventual death. The ability to self manage and create a self-definition of health during this time avoids any challenge to this. Uncertainty at this time also has a positive effect and becomes life affirming. Distancing from individuals who have the capacity to challenge this are avoided wherever possible, particularly healthcare professionals who are associated with their illness. Similarly information needs are minimal and the focus is on sustaining the appearance of being well for as long as possible. Individuals go to great lengths to manage on their own. As the body becomes less bound, the individual becomes more bound. Withdrawing into a more polarised and introspective world provides a sense of containment, which prevails for as long as the ability to self manage continues.

Implications for practice and further research.

The final aim of the study related to the implications of the findings for future service development and research.

There is a significant gap in the pathway which occurs following treatment and prior to end of life care. The participants in this study represent that group and have clearly articulated a desire to disengage from systems of care delivery. The drive for normalisation to delay an inevitable decline in health is supported by self-management and using uncertainty to a positive effect.

Strategic documentation relating to living with and beyond cancer, signposts the reader directly to the NICE Supportive and Palliative Care guidelines (NICE, 2004). The recommendations include the offer of physical, emotional, spiritual and social support; help for individuals to self manage the effects of their treatment and access to services for individuals with advanced cancer (Dept of Health 2007).

On paper it would be easy to assume that all aspects are covered, catered for and have been highlighted. However locally, much of the operationalisation of the guidelines has focused on palliative care services.

Interestingly the findings from this study appear to have highlighted a group of individuals who are determined to stay beyond cancer services for as much time as they can. This raises the question of the need for a model of support which is not borne out of the illness trajectory but could be used to maximise the wellness of the individual during this time.

Cost implications of services are always important and it may be possible that some services are being funded where the money could be channelled into alternative services. Corner (2008) is clear, that developing an understanding of what it is like to live beyond primary cancer treatment and how the health system should respond, is an important agenda. She quotes Frank's (1997) conceptualisation that self management programmes work best when integrated into clinical care and patient learning is reinforced by healthcare professionals. I have no doubt that this is fundamentally important when discussing the treatment and effects of disease and symptom control in individuals with cancer who have healthcare needs. My concern is that there is a need which is situated outside the healthcare arena, where self management is focussed in living 'in spite' of having cancer and is clearly disengaged from acute professional input.

This is of course, not to deny the necessity of the vast range of supportive care initiatives which have been developed over the past few years, but perhaps to acknowledge that at some junctures in the illness experience, distance from the healthcare arena is beneficial and important in maintaining a sense of normality. Inevitably these individuals will need easy access into the healthcare arena but perhaps need an approach to maximising their health which allows them to live well despite having cancer.

One of the key difficulties in addressing this aspect of care is the fundamental nature of nursing and healthcare. Nursing literature persistently denigrates disease orientated models of care and refers to holistic assessment at all parts of the patient journey, however the assessments fundamentally are problem focussed and as a consequence nurses can perpetuate the culture of problematising illness. This is not offered as a criticism of nursing, in fact, I would argue very strongly that nursing has a prime role in the identification of problems, assessment of impact on the individual and their families and formulation of planning to overcome those challenges across a holistic framework, which empowers the individual to make informed choices and decisions. Even within the self management arena I would concur that problems are addressed in conjunction with healthcare professionals, as Corner (2008) suggests to maximise the effectiveness of interventions. The issue here I would suggest is one of maximising wellness.

Kleinmann (1978) made a distinction 30 years ago between disease and illness. The idea that illness is culturally constructed and mediated by individual systems of meaning is not a new one. Nor that individual perception influences that meaning. Yet solutions and models of care appear to continue to be situated from within models of disease. It is tempting to think along the lines of a model of care such as health promotion, however, my instinct lies in a suggestion that a model of support for these individuals lies beyond the sphere of acute healthcare professionals. Not in terms of competency, but appropriateness. Whilst I believe there truly are nurses and a range of healthcare professionals, myself included, who believe ideologically and philosophically that they are committed to promoting health, in practice this is constrained by a broader focus on problematisation and priority in the utilisation of resources, which is necessary in the current financial climate.

The question remains however, who is best placed to provide a model of support which maximises wellness, and supports patients to live in spite of their cancer? My initial reaction is one of uncertainty, however I would suggest this should lie in primary care. Using the concepts outlined by Antonovsky (1979, 1987, 1993), it is useful to then view these individuals as having achieved a sense of coherence and

who remain salutary. As the narrative unfolds resistance and the opposing forces of health and health breakdown result in movement along the continuum. The balance eventually tips towards health breakdown and an increasing need for increased input in collaboration with specialist cancer multi-disciplinary teams (MDT's).

The identification of this process is pivotal in ensuring rapid access to specialist healthcare professionals and needs to be factored into a model of care for these individuals. However, this is easily achievable through the MDT's and via the cancer clinical nurse specialists, who will have been known to the patients previously but have not been a part of their support structure during this time.

A potential solution could lie in a model of support which would sit with general medical practice and provide general cancer nursing, rehabilitation and support. A model which focusses on maximising well care for individuals with access to specialist teams as necessary. Direct access to medical and healthcare offers a background of safety but in the forefront are those day to day activities which enable life to retain some normality.

 Many of these individuals want to work, want to lead active lives within their communities but withdraw to secure the stasis they describe. I would suggest there is a model of support which can identify the aspects of their life which are well and support them to live more active lives despite their illnesses, without jeopardising that normalisation and stasis. In fact, maximising the ability to achieve more 'normal' activities will have the potential to enhance that important part of their everyday lives

These individuals clearly have difficulties which they are determined to self manage which could be lessened with some degree of general nursing input. The issue arguably lays in personal choice and the associations which the existing services have with their disease. Services offered from outside the perceived cancer sphere may well be accepted, in the same way the stoma care and district nurses are accepted during chemotherapy treatment and those accessible ' in roads' to the

multi-professional cancer team will ensure a collaborative approach to maximising health potential and reducing illness.

As a piece of small scale research this will have potentially little impact on the wider healthcare arena, however, there appears to be a section of the patients experience which is not congruent with the existing healthcare agenda and may warrant further research and development.

Main recommendations.

- The development of a model of support which sits beyond the acute, specialist healthcare services.

- The development of a model of support which focuses on maximising the wellness of the individual living with incurable cancer.

- The development of a model of support which integrates self management but has rapidly accessible routes into specialist healthcare as problems arise.

- Recognition that distancing from acute healthcare is vital in achieving the degree of normalisation which individuals requires.

- The development of a research programme which explores this phase in the illness experience within different cancer groups and contributes to the understanding of normalisation.

Conclusion.

This thesis has documented the process of undertaking a longitudinal qualitative study to explore the everydayness of living with locally advanced rectal cancer. It was undertaken in order to uncover the meanings associated with living with locally advanced rectal cancer over the period of time when the focus moves from cure to palliation, but prior to the transition to end of life care. The study aimed to identify

how those meanings influence the individual's day to day lives over time, to understand the dynamics of the experience. The aim was to obtain data in which to situate local service development based on those aspects which were accorded primacy by the participants.

The study has provided detailed exploration of a period of time within the participants' pathway which has previously been poorly documented. The longitudinal approach has provided insight into a complex and dynamic period of time when individuals strive to maintain normality and stasis as a vehicle for delaying the future. The tensions which permeate the day to lives are:

- Continuity versus change
- Certainty versus uncertainty
- Adjusting versus resisting the illness experience
- Cancer as an embodied experience.

These tensions result in a number of challenges which the participants actively attempt to counter to maintain stasis and represent the key findings:

- Normality is pivotal in maintaining the 'everydayness'.
- Self management is crucial in achieving this.
- Uncertainty during this time becomes life affirming.
- Creating a self definition of health (in the absence of certainty) supports this and perpetuates the stasis.
- Avoiding healthcare professionals or individuals who may have the capacity to challenge this is desirable for as long as possible.
- There is an inverse relationship between the 'boundness' of the body and the 'boundness' of the individual.
- There is dissonance between the goals of the healthcare professionals and the goals of the individuals. When these two collide an epiphany occurs which requires intense renegotiation and readjustment.

As a healthcare professional involved in the care of individuals with colorectal cancer, a number of findings emerged which were unexpected and represent both the strength of using a longitudinal approach to the data collection and focussing on what matters most to those involved. The interviews were deliberately open to facilitate this breadth of data, which could arguably have been lost in more focussed approaches. However, the insights gained as a consequence provide information which is absent from much of the existing literature.

The role of uncertainty within this period of time affords the individual space and becomes life affirming. The certainty which lies ahead is one of advancing illness and distance from this is actively pursued. Goals and targets are adjusted to become achievable and as a consequence the life world becomes more polarised to accommodate this. There is resistance to developing any new understanding and consequently informational needs are minimal. The potential for any challenge to this is actively avoided which includes contact with individuals the participants associate with their disease. Containment is crucial and the focus lies in wellness and mobilising personal resources to mange this.

The insight into the role of self management is revealing. Being able to manage independently is not viewed in the biomedical sense, as much of the literature suggests. Rather as a vehicle for sustaining normality and distancing further challenge to the carefully constructed self definition of health. This in turn supports the sense of normality. When this is undermined, polarisation takes place once more and this can then continue until the next challenge.

As the body becomes increasingly 'present at hand' the embodied individual becomes more withdrawn and self isolating. Distancing is commonplace and maintaining a facade of wellness, which has been so actively constructed eventually becomes difficult to sustain. Maintaining normality becomes more and more complex, despite reducing life to simpler, achievable goals and the recognition of the inability to self manage creates a sense of defeat.

Appendices.

Appendix i.

Rectal anatomy.

The large bowel consists of the colon and the rectum. The rectum itself is between 12 and 15cms in length (Gray et al, 1995) and is usually divided anatomically into thirds – the upper, middle and lower, with the junction of the anal canal and rectum occurring at the pelvic floor, at the level of the levator sling. Radical resection of the diseased part of the bowel is performed and currently the gold standard regarding surgery for rectal cancer is a total mesorectal excision. This procedure focuses on the dissection between the visceral and the parietal fascia within the mesorectum and pelvis (Simunovic et al, 2003). In rectal cancer the type of surgery undertaken is determined by the height of the tumour within the rectum, for low rectal cancers where tumours lie within 5cms of the anal verge or less than 1cm from the anorectal junction an abdominoperineal excision of rectum or low anterior resection (depending on the degree of potential sphincteral damage) is performed. For higher tumours, where sphincter preservation is possible a high anterior resection is performed. Following resection, histopathological reporting is crucial to assess the depth of the excision margins, the number of nodes involved and whether or not the apical node (the most distal) is clear. Colorectal cancers are traditionally staged using the Dukes classification (Dukes,1932).The pathological staging of the tumour carries clear implications for recurrent disease.

Dukes staging	% of colorectal cancers	5 year survival
A	8.7	93.2%
B	24.2	77%
C	23.6	47.7%
D	9.2	6.6%
UNKNOWN	34.3	35.4%

% OF COLORECTAL CANCERS AND 5 YEAR SURVIVAL BY DUKES STAGE 1996 - 2002 (Cancer research UK, 2009)

Around 5% of primary rectal cancers are inoperable in the first instance, and loco regional recurrence after a preceding low anterior resection or abdominoperineal

resection remains common. The reported incidence varies within the literature from between 65% (Gundersen and Sosin, 1974) and 10% (Macfarlane et al,1993) and this huge discrepancy could possibly be attributable to recent changes in surgical technique, increasing specialisation of surgeons and advances in neo adjuvant treatments. Naturally, the site and stage of the primary tumour will have implications for recurrence. Around 20% of patients will have concomitant distant metastases at the time of presentation (Phillips et al, 1984, Pilipshen et al, 1984, McDermott et al, 1985, Michelassi et al, 1990, Amato, 1991, Mohiuddin and Marks 1993).

Pelvic anatomy.
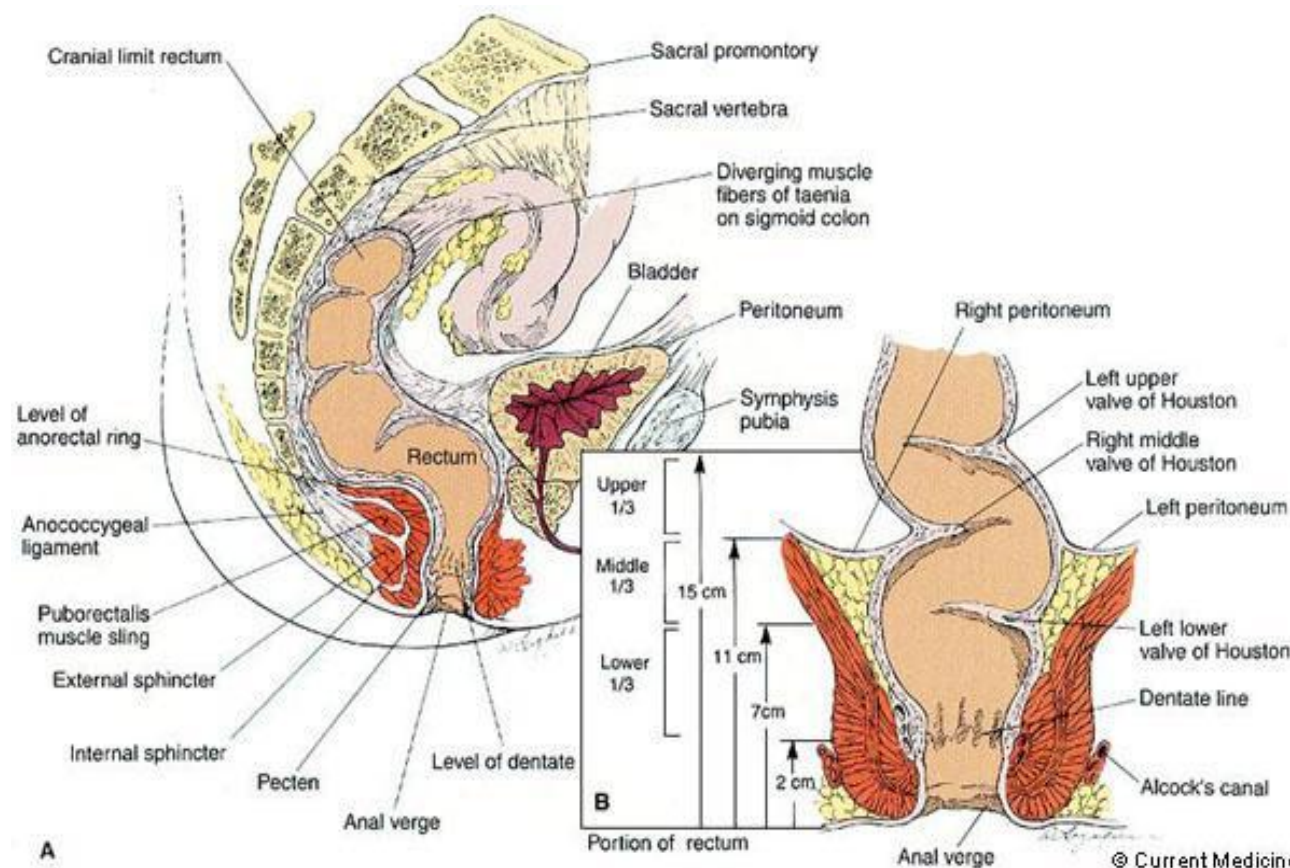
Local symptoms arise from involvement of sacral nerve invasion, ureteric invasion, bone involvement and residual rectal tissue destruction. Adequate control of the effects of this is the primary aim of treatment and options for treatment will be

largely influenced by treatment modalities that have been previously employed. Without treatment prognosis is poor, median survival ranges form 3.5 to 13 months and 5 year survival from 0 to 5% (McDermott, 1985). Often, due to the recurrent pelvic infiltration of the lateral or posterior pelvic wall sciatic pain is a problem. Radiotherapy and chemotherapy can offer short-term relief from symptoms and many patients will undergo some form of surgical intervention either to determine resectability or to treat complications like obstruction or perforation with formation of a stoma.

At some stage in their disease pathway most patients with inoperable disease will undergo radiotherapy, either in a neo-adjuvant capacity with or without concurrent chemotherapy, usually a 5-Flurouricil based regimen. This is undertaken post operatively if resection margins are involved or as a palliative intervention for symptom control.

The use of pelvic radiotherapy has a number of side effects resulting in functional problems, due to a number of pathological disturbances within the pelvis, which are associated with three main areas:

1. Reduction in anal resting pressure (due to internal anal sphincter injury)
2. Disappearance of the recto-anal inhibitory reflex
3. Reduction in rectal capacity and compliance.

(-Pedersen et al , 1986, Horgen et al, 1989, Mollroy et al 1992, O'Riordain et al 1992)

Functional outcomes in patients following radiotherapy include: increased frequency, urgency, partial emptying, tenesmus, incontinence (flatus, faeces or both), nocturnal leakage, perineal leakage/infection, loss of sensory function, erectile dysfunction and vaginal dryness. (Dahlberg et al 1998).

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Sent: 21 May 2009 13:51
To: Winter J.D.
Cc: Steward, Laura (ELS-OXF)
Subject: RE: Obtain Permission

[cid:807155112@21052009-26D5]

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Laura Gould
Rights Assistant
<http://www.surveymonkey.com/s.aspx?sm=3wZGSNtcvNv4Wn9WWBiGRg_3d_3d>

Appendix ii

The CASP Appraisal Framework.

The CASP appraisal framework was developed in 2002 (Milton Keynes PCT) with a view to addressing the constituent parts of qualitative research. There were three main areas within the research which the tool is designed to address:

- Rigour: has a thorough and appropriate approach been applied to key research methods in the study?
- Credibility: are the findings well presented and meaningful?
- Relevance: how useful are the findings to you and your organisation?

The framework addresses ten key questions, which have been adapted for use within this review to ensure consistency across the appraisal process. Each has been attributed a numerical weighting to evaluate each study which could potentially reflect its value in comparison with the other studies under review.

CLEAR STATEMENT OF THE AIMS OF THE RESEARCH

Quality	Criteria for assessment	Numerical value
Absent	No Statement of the aims or objectives	0
Poor	Aims stated but not situated within context	1
Reasonable	Aims stated but context not examined in depth	2
Good	Goals stated with importance and relevance	3

CHOICE OF APPROPRIATE METHODOLOGY

Quality	Criteria for assessment	Numerical value
Absent	Choice of methodology not discussed.	0
Poor	Methodology named but not described in the context of the aims of the study. No theoretical/ philosophical discussion.	1
Reasonable	Methodology described in relation to the study. Weak theoretical/ philosophical discussion.	2
Good	Research clearly aims to illuminate / interpret experience. Methodology situated within the theoretical assumptions guiding the study. Philosophical discussion.	3

RESEARCH DESIGN APPROPRIATE FOR THE AIMS OF THE STUDY

Quality	Criteria for assessment	Numerical value
Absent	No discussion	0
Poor	Weak justification for the design	1
Reasonable	Some justification in relation to the study.	2
Good	Full justification for research design as appropriate for the aims of the study.	3

RECRUITMENT STRATEGY APPROPRIATE FOR THE AIMS OF THE RESEARCH.

Quality	Criteria for assessment	Numerical value
Absent	No discussion.	0
Poor	Some discussion but appropriateness not discussed.	1
Reasonable	Description of recruitment strategy but no justification.	2
Good	Participant selection outlined. Discussion around recruitment and sampling strategy clear.	3

DATA COLLECTED IN A WAY WHICH ADDRESSED THE RESEARCH ISSUE.

Quality	Criteria for assessment	Numerical value
Absent	No discussion.	0
Poor	Scant discussion with little description of setting, approach or tools used.	1
Reasonable	Setting and approach outlined. Use of tools described. Some justification for cessation	2
Good	Setting described clearly. Clear description and justification to approach to data collection. Any modifications described. Tools used described clearly (eg topic guide). Discussion around cessation of collection.	3

ADEQUATE CONSIDERATION OF THE RESEARCHER / PARTICIPANT RELATIONSHIP

Quality	Criteria for assessment	Numerical value
Absent	No Discussion	0
Poor	Weak discussion. No evidence of reflexivity.	1
Reasonable	Reasonable discussion of role as a researcher and some reflexivity.	2
Good	Critical evaluation of own role as researcher. Evidence of reflexivity. Discussion of potential bias or influence on the study.	3

HAVE ETHICAL ISSUES BEEN CONSIDERED.

Quality	Criteria for assessment	Numerical value
Absent	No Discussion	0
Poor	Ethical approval mentioned but no further ethical considerations.	1
Reasonable	Consent discussed and some ethical considerations.	2
Good	Strong evidence of ethical consideration. Potential for harm and long term consequences of involvement addressed. Consent discussed. Principles considered.	3

IS THE DATA ANALYSIS SUFFICIENTLY RIGOROUS.

Quality	Criteria for assessment	Numerical value
Absent	No discussion of analysis.	0
Poor	Weak discussion with no illustration of development of themes. Limited inclusion of original data.	1
Reasonable	Some description and inclusion of original data to support the findings. Purely descriptive with little interpretation. Limited discussion of own role as researcher.	2
Good	In depth description of analysis. Illustration of generation of themes in thematic analysis. Sufficient data presented to support the findings. Critical examination of own role as a researcher. Discussion of exceptions / contradictory data.	3

IS THERE A CLEAR STATEMENT OF THE FINDINGS.

Quality	Criteria for assessment	Numerical value
Absent	Statement of findings absent.	0
Poor	Statement of findings but not discussed in relation to original research question. Credibility not addressed.	1
Reasonable	Some discussion of findings. Credibility and transparency mentioned. Weak / no arguments presented.	2
Good	Explicit discussion of findings, with evidence for and against the arguments. Findings discussed in relation to original research question. Credibility addressed.	3

HOW VALUABLE IS THE RESEARCH.

Quality	Criteria for assessment	Numerical value
Absent	Not valuable.	0
Poor	Limited value or contribution to existing body of knowledge	1
Reasonable	Contributory but the implications not discussed. Limited discussion of new areas for research.	2
Good	Contribution to existing body of knowledge is discussed. Consideration of the implications of the research for the future is discussed. New areas for research identified as a consequence.	3

Appendix iii.

Participant letter and
Information sheet

<div align="right">**Address.**</div>

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and discuss it with others if you wish. If there is anything that is not clear or if you would like more information please do not hesitate to contact me at the above address or telephone number.

Please take time to decide whether or not you wish to take part.

Thank you for reading this letter.

STUDY TITLE: LIVING WITH RECTAL CANCER.

I am currently undertaking a study to explore the experiences of people, like yourself who have been diagnosed with rectal cancer.

WHY?

I am particularly interested in discussing your experiences of your illness to gain greater understanding of the information and support you receive. Also to develop a greater understanding of your experiences so that we can ensure services are targeted at the needs identified by people who are using the services. The study will take place over the next 12 - 18 months and involve an interview every three to four months over that time, with a maximum of four interviews.

WHAT DOES IT ENTAIL?

If you agree to take part in the study it will involve participating in an interview every three months for up to eighteen months (no more than 4 interviews). I anticipate the interviews will be between an hour and an hour and half in length. The interviews will be audiotaped and will remain in my possession for transcription. Access will only be given to my course supervisor but your anonymity will be preserved at all times. The tapes will remain anonymous and will be kept at the university for 15

years before being destroyed. The interview may be conducted either at your home or in the hospital – whichever is convenient to you and at a time of your choice.

FURTHER INFORMATION.

There is no obligation to enter the study and you will be free to withdraw at any point, without affecting any future care you may need.

I hope that the interviews will not give rise to any uncomfortable effects, but understand that there are times when talking about your illness may be distressing. I have made arrangements that you may freely contact an independent person in strictest confidence should you feel any issues have arisen from the interviews which you wish to discuss further. There is a trained counsellor who may be contacted at **** Cancer Trust on the following telephone number: ****or at: ******

She is aware that the study is taking place and would be very pleased to provide any additional support you feel you might need. I will not be forwarding any names to her, but she is happy for me to pass her details to you for further reference.

I will of course be happy to discuss any issues myself, but would like to be able to offer you the reassurance of a confidential and anonymous service for your continued support. I can also contact your G.P. and inform them that interview has taken place if you wish.

Jane Winter.

If you have any questions or would like to discuss the study further, please do not hesitate in contacting me.

If you would be interested, please complete the slip attached and return it to me in the enclosed stamped addressed envelope, so I may contact you to discuss the study in more detail.

If I do not hear from you within 2 weeks I shall assume you do not wish to consider participating.

I would like to thank you for taking the time to read this letter.

REPLY SLIP.

Dear Jane
I have read the information sheet and would like to talk to you about becoming a participant in the study.
I give my permission for you to contact me.
My telephone number is:

Name:

Appendix iv.

CONSENT FORM

Title of Project: **LIVING WITH RECTAL CANCER.**

Name of Researcher: **JANE WINTER**

Please initial box

1. I confirm that I have read and understand the information sheet
Dated march 2005 for the above study and
have had the opportunity to ask questions.

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

3. I understand that sections of any of my medical notes may be looked at
by responsible individuals from Southampton university hospitals NHS Trust
or from regulatory authorities where it is relevant to my taking part in research.
I give permission for these individuals to have access to my records.

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

5. I *would/ *would not like my G.P. to be informed that I am participating in
this study.

_____   _____
Name of Patient   Date   Signature

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

_____   _____
Researcher   Date   Signature

   1 for patient, 1 for researcher, 1 to be kept with hospital notes

*please delete.

Appendix v.

Interview schedule.

'Living with rectal cancer'.

Open ended questions will be used to open the discussion.

1. Can you tell me about your illness?
2. Can you describe the effect this has had on your daily life?
3. How do you cope with the effects of your illness?

It is envisaged that these questions will only be used as a guide as the initial question should provide the lead into the discussion.

Appendix vi.

Miles and Huberman and Saldana – Expanding the data analysis process.

Miles and Huberman (1994) – Three concurrent flows of data analysis.

Data Reduction.

Arguably data reduction started at the outset of the study, when decisions regarding sampling, inclusion and exclusion criteria and interview guides were made. Data reduction made the data more manageable and analytic choices enabled selection and summary those pieces of text, which were relevant to the research question.

One of the strengths in the framework offered by Miles and Huberman is in the detail they offer to guide the analysis and the process for generating meaning. The key feature of analysis is the way the data itself is reduced through a process of coding. Miles and Huberman state that coding is analysis (p55), which assigns units of meaning to descriptive or inferential pieces of the transcript.

Codes are assigned to portions of the data that encapsulate their meaning. They are not the words themselves but a representation of their meaning that can then be organised into a system where they may be easily retrieved. These are organised into clusters of codes with similar properties.

Initially coding was undertaken by reading the transcripts and reviewing their content sentence by sentence. Labels were assigned to portions of the data. As the reading progressed, the list of codes expanded and gained conceptual and structural order (Miles and Huberman, 1994). Coding can be purely descriptive or developed into interpretive codes or pattern codes that offer inferential and explanatory labels.

During this process, knowledge was being generated on three levels:

1. Refining parts of the conceptual structure they bought to the study.

2. Acknowledging the contextual factors, which become more meaningful the more time was spent in the field.

3. Highlighting new concepts which may not have been present in the original conceptual structure.

(Miles and Huberman, 1994).

There is a distinction made between first and second level coding. First level coding involves attaching a label to groups of words, which is often a single term that is semantically close to the terms they represent and which summarises the segment of data. Pattern coding then leads to grouping these into smaller numbers of themes or constructs. There are four important features of pattern coding:

1. Reducing data into smaller, manageable analytic units.

2. As analysis is parallel with the data collection the fieldwork becomes more focussed.

3. The researcher is able to develop a 'cognitive map' which will evolve as understanding develops.

4. The groundwork is laid for cross sectional analysis as with multiple case studies by raising common themes and processes.

(Miles and Huberman, 1994).

Illustration of this process within this study is contained in Appendix vii. The example illustrates generating pattern codes, first level and clusters of codes and pattern generation across the interviews.

Generating pattern codes.

Within an inductive study, pattern codes are threads that run through the fieldwork and tie together pieces of data. These may be recurring phrases and common threads, or internal differences which lead to greater understanding and develop categorisation.

Pattern codes are used in analysis in three ways:

1. As a preliminary list of codes which can be can be applied to the next transcript to see if they fit.
2. The most promising codes are written up as a memo which expands the significance of the code.
3. Pattern codes are cross-checked in the next phase of data collection for qualification.

Data display

Data display provided an organised and concise assembly of the data which had been organised into matrices that are easily accessible. The decisions surrounding where to locate data were analytical choices which were interlinked with the reduction process. Developing these displays facilitated conclusion drawing and underpinned the next stage of analysis. This provided a visual display which avoided the use of lengthy and extended pieces of text. Within this study, the longitudinal framework offered by Saldana (2003) was used which offers a similar visual display but facilitates the longitudinal element of the analysis. Displays of data can either take the form of matrices (defined rows and columns) or networks (a series of 'nodes' with links between them (Miles and Huberman, 1994). The crucial point throughout this process was maintaining the balance between developing the display without losing the meaning and understanding from the data.

The framework provided by Saldana was vital in achieving this (appendix vii) . He offered a process which was similar to the concept of a time-ordered display (Miles and Huberman, 1994). This was appropriate in a study where the aim was to illicit those elements which were important to the participants as opposed to conforming to a pre-determined structure. These themes were used to explore subsequent data sets.

As one of the underlying principles of the study was the perception of health by the individual and the dynamic nature of that experience it was vital that the longitudinal nature of the study is addressed in an appropriate way.

Conclusion drawing and verification.

From the outset of the analysis the conclusion drawing process was being developed. Meaning was being developed as patterns emerged from the data. This is only a part of the third phase as verification is an integral part of the analysis. Verification is vital when testing the plausibility and validity of the findings.

Miles and Huberman (1994) offer thirteen specific tactics for drawing meaning from the data:

1. Noting patterns / themes – noting recurring patterns and themes within the data.
2. Seeing plausibility – exploring whether the trends , patterns and conclusions make sense.
3. Clustering – grouping events together if they have similar patterns or characteristics.
4. Making metaphors – Non data reducing and pattern making devices which help to connect the data with theory.
5. Counting – exploring frequency or occurrence of events.
6. Making contrasts / comparisons – establishing similarities and differences between data sets.
7. Partitioning variables – splitting variables, may help in finding more coherent descriptions and explanations.
8. Subsuming particulars into the general – linking specific data to general concepts and categories.
9. Factoring – Attempting to discover the factors underlying the process under investigation.
10. Noting relations between variables – Using displays to study interrelationships between different parts of the data.

11. Finding intervening variables – trying to find the presence and effects of variables intervening between observed variables.

12. Building a logical chain of evidence – trying to understand trends and patterns through developing logical relationships

13. Making conceptual / theoretical coherence – moving from data to constructs to theories through analysis and categorisation

Robson (2002) Adapted from Miles and Huberman (1994).

Saldana's Framework for analysis.

Framing Questions.

1. What is different from one pond or pool of data through the next?

Having identified the essential features of interview, using Miles and Huberman's framework (1994) and completed an initial thematic analysis (thereby creating a 'pool') Saldana suggests the initial framing question to explore what is different from one pool of data to the next. He emphasises the importance of focussing on differences as opposed to purely missing data. Adopting this approach was designed to create a greater awareness of contrasts and variability, which was more dynamic than a focus on searching for merely what was absent from the data. Any new or emerging data were then included in the framework as the study progressed.

2. When do changes occur through time?

Any contextual and intervening conditions surrounding those changes were be documented as they could interrelate with social, political and cultural changes or historical events. Chronicling these as the study progresses enabled identification of whether those changes were 'part of developmental trends in humans which are documented in the literature' (p78) or whether these relate to contextual conditions within the participants life. An example of this within this study would be the development of metastatic disease. This can help in developing conceptual phases or cycles within the study or serve as 'transitional markers' (p79).

3. What contextual and intervening conditions appear to influence and affect participant changes through time?

The key feature of qualitative work is that it is contextually embedded. The participants 'life world' are crucial to their own perception of their circumstances. Within longitudinal studies it is vital that how and why questions are also asked. Not just how, but how much and in what ways an individual's circumstance is involved with change. Contextual elements are 'givens' (Saldana, 2003, p161) within the participant's everyday world and provide location and stimulus for change. These provide the background to a 'life world', which can be affected by intervening conditions.

Saldana (2003) describes intervening conditions as; ' a contextual condition perceived as purposeful, unanticipated or significant action, structure or process that influences or affects participant change through time' (p162). The notion of participant perception is key to whether a condition is viewed as intervening or not. Becoming an intervening condition raises its position from the background context into the foreground for the individual. This can give rise to a cyclical process of structures, processes and actions having an influence or affecting change through time which in turn influences further change.

4. What are the dynamics of participant change through time?

The dimensions and variability of the data are dynamics within qualitative data. Dynamics enhance the subtlety of contextual conditions to provide perspective or contrast in relation to other dynamics (Saldana, 2003). The dynamics are represented by words, verbs adjectives and adverbs within field notes, which are carefully selected by the researcher to represent a particular characteristic of time and change. These words can be taken directly from the data (as in vivo codes) or be constructed by the researcher. Participant's thoughts, emotions, attitudes, values and beliefs are all examples Saldana suggests to be dynamic through time (p91).

5. What preliminary assertions (propositions, findings, results, conclusions, interpretation theories) about particular changes can be made as the data analysis progresses?

Two aspects of preliminary assertions are described within the framework, analysis in progress and analysis from the future shaping the past. Analysis in progress assertions, are those thoughts, emergent statements, and findings of particular themes or trends in the data that emerge as the analysis progresses (Saldana, 2003). These can be formed in time ordered matrices (Miles and Huberman, 1994) that are documented as the analysis progresses. The analysis however is a cyclical process in which subsequent data can inform the previous data set.

Descriptive questions.

1. What increases or emerges through time?

Categories and subcategories have been inductively generated through thematic analysis to provide the initial data set within the individual case. A proportionate increase or new emerging theme suggests a change within the narrative that requires careful documentation. Within this study the increase may be viewed in terms of intensity within subsequent data sets and will be recorded as such within the data Emerging themes may be subtle and not constitute a surge or an epiphany but are able to be recorded with in this framework. It is possible to view these in relation to contextual or intervening changes that may give the important background information underpinning the change.

2. What is cumulative through time?

Saldana talks about cumulative effects as arising through growth and development. Whilst he acknowledges that developmental variables are more suited to qualitative research as are difficult to quantify, he describes them with particular connotations, using concepts of knowledge, worldview and values as examples. Whilst these are synonymous with growth and development, it could be argued that development is not necessarily a constructive process. Implicit in his examples are the acquisition of a greater volume of the theme being studied. Within this study, development may

not necessarily be a positive facet and the cumulative effect, although the result of successive experience, may not result in growth.

3. What kinds of surges or epiphanies occur through time?

The concepts of surges and epiphanies are pivotal in defining the journey through an individual's narrative. A surge is described as the 'escalation of a variable or growth spurt' (p108) within the data. Saldana acknowledges that the rate a surge happens can produce a negative consequence, as the recipient is unable to assimilate this into their life and may as a consequence lead to a negative impact in physical or mental health. An epiphany has greater magnitude. It is described as 'a significant event that takes participant change to a different level, direction or quality' (p108). As an illustration he describes a piece of his own fieldwork with a young teacher who taught in an Hispanic community. She describes gunshots being fired near to the school and the lack of any reaction from the children, in contrast to her own fear and panic. For her this became a turning point in her career that redefined her perception of her role in their lives and what influence she would have over their future.

Although epiphanies need not be as obvious, to the participant they may be life changing and it is crucial that it is the participant's perception of the event's significance that counts. The key purpose of using a qualitative approach to this study is to illuminate those elements that are important to the participant. Within this study there were clear epiphanies within the data, for example, when the self definition of health was challenged by new knowledge uncovered through surveillance.

4. What decreases or ceases through time?

As the study progressed, some themes decreased or ceased completely. This could be in relation to increases in other themes or were omitted because they are not viewed as significant anymore. It was important to be aware of this as it is possible

that elements which were previously significant may be subsumed into the background as being 'normal', through a process of familiarisation.

5. What remains constant or consistent through time?

It was important that data that remains unchanged be acknowledged. Whilst it may be that the constant presence of a particular theme reveals nothing out of the ordinary, it is possible that it is highly significant. Being able to differentiate between background context and foreground relevance for analysis is a skill that needs to be developed as a researcher. Lack of change may represent positive stability but could also represent a negative, stagnant 'pond' (Saldana, 2003). The stasis within this study is a really important part of the data, which needed to be acknowledged as actively pursued by the participants as opposed to an absence of data per se.

6. What is idiosyncratic through time?

Idiosyncratic data refer to those phenomena that are ever shifting, inconsistent, and multidirectional (Saldana, 2003). Whilst some phenomena do not lend themselves to order or consistent development (Strauss and Corbin, 1990. p156) and are consequently difficult to include in an analytic framework, they could not be ignored. They can reflect intervening conditions or contextual conditions that interact with each other. It may indicate recoding may be required to explore new patterns in the data, or it may reflect an insufficiency in the dataset. Questioning the idiosyncratic before dismissing it was vital.

7. What is missing through time?

Strauss and Corbin describe this as 'Notably absent' data. If viewed in terms of what is present and what is missing? The notion that, if something is missing or absent from life this affects the perception of what is present (Saldana, 2003) is particularly relevant within this study. It may be if something is missing, another phenomena has replaced it, however this needs further exploration. What is missing may reflect an extension of a decrease in a previous data set, hence the importance of the iterative

nature of the analysis. The analysis however will not be complete if the possibilities of what might have been, should have been or could have been present in the study were not explored (Saldana, 2003).

Analytic and interpretive questions.

1.What changes interrelate through time?

When each interview was completed there was a data set which could be explored chronologically, by category, by theme and across subsequent data sets. Any overlapping pools of data could suggest an interrelationship which needed to be explored. Whether those interrelationships were perceived by the participants or highlighted through analysis they represented the interaction of phenomena (Saldana, 2003).

2. What changes through time oppose or harmonise with natural human development or constructed social processes?

There are natural human developments or constructed social processes. Saldana discusses Huberman's professional life cycle of teachers (1989), theoretical models of the 'coming out' process for gay and lesbian participants (Blumenfeld, 1998) stages of ethnic identity development (Benjamin, 1998), processes leading to enhanced social consciousness (Adams, 1997) and Kubler-Ross' stages of death and dying (1969) as being examples of these. Whilst challenging these as social processes or natural development could be undertaken, it is arguably not relevant at this time.

Saldana discusses both developmental and processual change as single elements but also raises the possibility of both being combined within one study. He refers to natural child development to describe and example of developmental change. He then refers to the schoolteacher he recalled earlier to discuss processual change. She radically changed her teaching philosophy, planned curriculum and lesson planning to meet the needs and culture of those individual students in the Hispanic community. Within this study there is an anticipated life trajectory which has been

dramatically altered and as a consequence opposes the perceived natural development. Arguable death is inevitable, but the timing is crucial to these individuals.

3. What are participant of conceptual rhythms (phases, stages, cycles and so on) through time?

Saldana suggests that there are natural life rhythms and cycles (p141) however during analysis he focuses on a series of phases, stages and cycles that may be present within the research. There stages of treatment, intervals between treatments and surveillance scans and blood tests which form patterns within the data.

A phase, he suggests has a short-term aspect, which characteristically has a beginning middle and an end. These may be discrete but are usually present within the data. This is in contrast with a stage that suggests a longer period of time for example childhood or adolescence. Adams (1997) defines a stage as a metaphor for growth or change, where sequential stages exhibit greater ' complexity' or 'differentiation' (p40). Stages within research could relate to transitional processes (Petrocelli, 2002), or cyclical processes (Winkelman, 1994) which are distinct from straightforward cycles.

4. What is the through line of the study?

The through line of the study 'describes, connects and summarises the researcher's primary observation of participant change' (Saldana, 2003. p151). Whilst he describes this in wholly ethnographic terms it appears to be a concept that can be sought within any longitudinal qualitative study. It refers to the prominent thread that weaves through the case study. This is similar to 'the central category' (Strauss and Corbin, 1998) or the 'central phenomenon' (Miles and Huberman, 1994). This can range from a single word to a paragraph that captures the qualitative trajectory.

Saldana suggests this can also be used to interpret meaning, of change and can be represented by an interpretive construction of the longitudinal phenomena.   It can be generated directly from the data (in vivo) or be constructed by the researcher. It

is not intended to provide the ultimate in reduction of data and is by no means the ultimate goal of the analysis, but it is an illustration of the 'conceptual essence' (Saldana, 2003.p155) of the study.

Appendix vii

Transcribed interview and example of analysis.

Interview 1. March 2005.

Int. Can you tell me about your illness?
Go back to the beginning if you like and
tell me what's happened.

Joan I know this all started 2 years ago but I have
forgotten a lot of it, I'm now, more really
concentrating on now, myself. I do that because
I've got my head round what happened, I had the
operation and had check ups and scans and blood
tests which were all clear, then by chance I had a
scan just before Christmas and that's when I found
out its come back. And really I have brushed away
whats happened in the past 2 years and I'm really
concentrating on now, my illness now. That's the
easiest way to cope with it.

> Concentrating on the here
> and now.

Int. Can you describe the effect it has had on aspects
of your life?

Joan I've changed from the person I was 2 years ago, I
do say to myself why me? why me?
Umm, but then everybody else with the same as
me is in the same boat.
Umm (sighs)

> Recognising change
> Comparing self with others
> with cancer.

Int. What support do you get?

Joan. I don't get a lot of support with my husband
because as you know he's deaf and dumb. I talk to
him and then I think, do he really want to listen as
he don't give me any answers, you know? He
doesn't say anything, he just brushes it away a little bit.

> Lack of understanding
> Buying in to the normality.

I've now started talking to his father, my father in
law, because he's got cancer as well, prostate
cancer. But they are not going to do nothing about it,
I talk to him a lot, father in law, he's got
cancer…… can't talk to mother in law cos she
don't take nothing in, but I do talk to him, and my
sister in law heather, she's very good.

> Finding common ground
> for support.
> Identifying with others
> with cancer.
> Enhanced relationship
> through common
> understanding.

Pauses.

Int. How do you cope with the effects of your illness?

Joan. I can forget about it, I can say to myself its not really happening, it's not there. It's strange, its strange I've got a funny way of thinking.
Pause
It's frustrating,
Thinks

Shall I tell you about my treatment?

Int. If you feel that's an important part of what's happening

Joan On a Monday and Tuesday I come to clinic for my chemo, the nurses are brilliant and the doctors, then Thursday I have the district nurse who takes the pump off.

The chemo is only Monday and Tuesday but the nurse cant come till Thursday to take the pump off – I don't know why, she only disconnects it

Pauses.

I do get very, very frustrated with my self, I feel as though I'm tied down, cos I'm one of these people who likes to keep going, go out, have a social life with my husband.

Visit friends and family, now that's all been taken away. Because of how I feel, when I have all of this (points to pump) I feel really grotty and don't want to go out. You know I've got a stoma bag, well, when I'm having that (chemo) I get a lot of diarrhoea, sick feeling, I feel really tired and lethargic and I don't feel like I want to go out and socialize.

Last saturday was the first time I'd been out since I started treatment, it was really nice, I had to make that effort for Brian, it was his bosses birthday, we went out, had a meal, a couple of glasses of wine, it was really nice. I feel I'm letting him down a lot.

| Pretending it's not there Avoiding reality |

| Routine around treatments. Acceptance of treatment related consequences. |

| Acceptance of District Nurses in relation to treatment. |

| Focus on well being of family Impact of treatment on lifestyle. |

| Social withdrawal, change in social activities. Impact of treatment on lifestyle. Focus / blaming treatment |

| Adjusting lifestyle. Loss of social orientation. |

I do feel he expects things

Int. things?

Well like last night, I'd been here all day, I felt really rough, he came in at 6 and I hadn't cooked the meal, sometimes he expects me to do things and I really would like him to help me,

In the end I went up the end of the road and got a take away, cos I couldn't be bothered to cook. Brian knew this, I would have thought he'd say sit down I'll do it, trouble is when I do feel grotty, I don't show it. That's deliberate, I try to keep going. That's my fault really.

I'm fighting it, I'm not giving in to it. I'm grotty inside but trying not to show it. Its not taking over my life, you know what I mean, with all this (points to chemo pump and stoma bag) don't you.

Pauses

Do you know, I can be so stroppy, I used to be so happy go lucky, laughing and joking all the time, especially at work, laughing and joking, I enjoyed it, I loved it, but since having all this I get so stroppy, I've got no patience. Is it cos I'm annoyed with myself? Or angry cos its happening to me.

Most of the time I feel so well, when I go into chemo they all say oh ….. you look so well., its good, it gives me moral support. If I feel well, I feel further away from dying.

Pauses

I have lots of scans, every 6 weeks,
I had a scan last week, the cancer has
shrunk down from 69, I don't know if they mean centimeters or millimeters to 43 and then this scan its gone down to 36, so its shrinking down. But I wasn't sure where it was, he said its right at the back, in the pelvic lymph glands, am I saying that right?

Expectations of others.

Impact of treatment on lifestyle.
Need for help

Hiding reality and keeping going

Trying to keep life 'normal'

Change of self

Distancing death.
Looking / appearing well.

Importance of surveillance versus lack of understanding

Pauses, takes a drink.

(Smiles) I don't know it's there, I've never had
no symptoms, the only thing I was a bit
constipated so had a bit of bleeding from the
backside, I didn't know I had a cancer. No-one in
my family has had it – only my cousin, its on my
dads side, my dad's sisters daughter, I don't know
if there's a connection.

Pauses – reflects.

Int. Who else supports you?

Joan. I have three boys.

I'm close to the oldest one, they are all close to me
but the oldest one is more concerned than the
other two, Rodney will just ring up and say how
did you get on with chemo and that, how do you feel?,
 oh I'll pop in Saturday with liam – my
grandson to see how you are, but he doesn't talk a lot,
I think he's frightened. So I don't talk about it.
The oldest one is the only one who mentions it,
the other two brush it away, brush it away,
mums not ill really, we'll brush it away (gestures)
but if I go over there and see them, fine we all sit down
and talk, that's getting better, if they are all there they
can, with all of them.

I can talk if they let me.

Having a stoma wasn't too difficult to get used to,
 its just going to visit people, its awkward when
people are there, and I think where shall I put it.
I am happy with it now.

I didn't feel it really changed who I am as much as
 the cancer, its strange not having a bottom anymore,
 but I've coped with it. I cope with the stoma, I cope
with not having a bottom any more, I've brushed away
(gestures) what happened and (draws line in the air)

Feeling well.
Lack of symptoms

Changing relationships.
Superficiality of
conversations to
maintain normality.

No opportunity for
discussion.

Reflecting on
embodiment.

I'm focusing on what's happening now, today and the future. I think about the future a lot, about dying, dying. And what will Brian do, how will he cope. The boys will be fine, they have their wives and children, they'll be fine……. How is Brian going to cope? I think its more difficult because of how he is – deaf and dumb. We've been married 29 years but he's not the boys father. They call him dad but they aren't his.

Its hard. This can take a long time to affect me. I like it when people like you talk about next year, it's really important to me that you think I'll be here next year. Every Christmas and birthday I think – is this my last?

Its like when I questioned about the benefit forms and she said ignore the six months, don't look at that, that wont be you, I thought oh good, I've got more than 6 months. Then I said how long can I have it for and she said forever and I thought well that's good, she must think I'll have forever!

I saw the registrar the other day, I've never asked them how long, I don't want to know.

Is it to do with the colon?
Has it jumped out?

He's pleased (the registrar) its shrinking down. This is my 7th one (chemotherapy) and I've 5 to go so it should b the end of May. Then they just keep scanning me and doing my blood to see how I go. Cos its unoperable, But I'm happy with that.

(Smiles) They can cut me off at the waist.

I do talk to my husband about that, about the treatment and the scans, but he wont talk back. I don't know how he feels.

Pauses

Int. Are there any other effects on your life and your Relationships?

Joan. Brian and I are still close, but sex – forget it. When I first had my surgery I had my son living with me

Trying to focus on the here and now. Intrusive thought about death. Planning for death. Imagining her world without her	
Uncertainty	
Perspective on the future	
Here and now	
Lack of understanding of disease.	
Keeping it in control	
Isolation within the closest of relationships	

and he said "no we can't do it when he's here wait till he's
 gone, moved".
 He's now moved, he's gone, so I said I think its about
time we got together and he said "Joan, I'm happy
as I am". I think he's frightened, cos I've had surgery
down there, I said to him you know the surgery made
 me smaller down below (neo vagina) (smiles) and
they've sewn up my backside and I've got this
(points to stoma), that don't help.he wont look at
 it, when I wash and I've cleaned it around I say to
him do you want to have a look? And he says no –
he's frightened.

I think he's frightened of the future as well you know.
Sometimes he'll ask, how's the cancer? And I tell
him and he says oh and he'll go on to something else.

Till his dad he hasn't known anyone else with it,
 but with him he just said- oh shame and that's all.
He doesn't talk about him either. When I told him,
you know, dads got cancer he just said shame, well
 he is eighty. He's getting on, that's ok, it's alright you
 know like he's had his life.

Pauses, thinks.

Its not just about dying its about doing everything
you wants to do. I have a neighbour who's really
 ill but carries on with chemo even though it makes
her so sick.

 I've said to Brian, get this over, finish this then we'll
 have a nice holiday, a nice break, I'd like to go abroad
 really, but not with this, I can't get on a plane with a bag,
maybe I'll go on a boat, perhaps to France. Then
 I'll have all my own facilities and plus the insurance is
very expensive especially as a cancer patient and with a
bag, someone said it was about a thousand pounds.

But I've got to go for something, haven't I? occupy
my mind. I would have loved to have carried on working,
I did enjoy my job, it was for me, but Brian didn't want
me 2 go back. I worked full time, perhaps I should do
 voluntary work. Perhaps here on the wards.
Its changed my life having cancer, its taken over.

Its funny, at home at the moment I'm thinking, I

| Isolation and Loss of sexual contact |
| Effect of disease on physical body and orientation within relationship. |
| Fear |
| Distancing |

Avoiding discussion

Minimising discussion

Perspective

Uncertainty.
Short term goals

Loss of work role.
Impact of cancer on role
Cancer 'taken over'

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must get this front room painted, must do this,
must do that, doing things that I think , Brian might
not be able to do it if I'm not here.
I think you must sort your clothes out Brian, ….
I'm trying to sort out dying, I'm trying to sort out Brian
for the future. I think on the other hand, I cant go out
and socialize, I want to not think about dying, I'm so
worried about my home at the moment. Its strange, I
have changed, were as before I came home did my
housework cooked the meal and that was that, didn't
think about the house, thought more about my work,
now I worry about the house.

Int. What about other support?

Joan. The nurses when I go for chemo are very good,
it's a very friendly family atmosphere, they call
me Joan, not Mrs ***, it's a good service.

Its awful to see the other patients and you look
and think will that be me. Other cancers are very
different like my father in law.

Patients there are so friendly, they are very forward
in telling you, where the cancer is, how long they
have got, some people know how long they've got. I
must have that sort of face, they all
talk to me, I do go home and worry for a while. I spoke
to a woman today with pancreas its come back
everywhere, they only give her months, she looked so well.

I think she needed someone to talk to, they haven't
got time in he clinic. She needs a specialist nurse,
talking is so important, you can ask them questions,
they are running around though they haven't got time
to sit down and really talk. You do need it.

Int. How has your life changed?

Joan. My friends and family have changed towards me.
I have 4 sisters, one is coming down next Monday and
she's going to spend three days with me, which is nice
she keeps in contact with me quite a lot, she's very good,
shes a nurse herself, then my other sisters, Gladys
says the more I talk to you about your illness the more
you worry so I wont talk to you, I think that's fear.
Susan, she lives down the road, I haven't seen her
for 3 months, she's kept away, the other one I haven't

Planning for death. Shift in priorities

Accepting role of HCP for treatment

Comparison with other patients, negotiating life expectancy

Belonging to a new social group. Talking with others in a similar situation.

Clinic staff busy Need to talk

Changing relationships with close family. Distance / isolation from family.

seen her, she's kept away, I've only got one sister now who's really close, is it because she's a nurse, she understands. Its not frightening, I think the other 3 are frightened, cos…

.. oh I lost my mother to… she had cancer, yes, she had cancer, they didn't know, she came in cos she broke her hip and her stomach swelled up, I don't know, it was only right at the end I knew she had cancer. It'll be on her death certificate- I'll have to look. But far as we know she just died.

Not reflecting on connection with mothers death

I was very close to my sisters before, very, ..very. but since I've been ill they've been withdrawn, they've backed back, is it cos they are frightened to see me, or frightened of the future, don't keep pressuring me, leave me alone and I'll get well, I'll be alright. They have changed.

Distance / isolation from family.

Pauses

Friends. I don't really have a lot of friends. Not my friends, no, socially, mainly, we just see one set of friends, they are Brians friends, deaf friends, we chat- waving our hands around, I love it. There were a couple of do's at Brians work I should have gone to, I felt awful I didn't go, I let him down. He loves his job, they all like him (smiles), he gets on well with the men.

Loss of social network with job. Isolation.

It's a new job, we just had all the hassle of him not being paid for 12 weeks so we lived on my sick benefit. It was all left to me to sort out, cos Brian didn't know how to go about it. A lot of forms and phoning up. Tribunal that sort of thing, but all that's sorted now, which is a relief, he got half the money he was owed, - brushed away.

Normal life carries on

Mainly I've only got one or two friends, all his friends. Sisters, they are like my 2 youngest boys, brush it away, like Brian. Ignore it. Brians mum and dad and sister are fine we meet and talk, she'll come and see me. She'll come with me.

Distance / isolation

I do start conversations deliberately, I say look, I show people my line, say I've had chemo. And they say forget it … we don't want to know. When I stop chemo

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people can avoid talking about it at all cos I wont have
a line. People ask when they see my line are you having
cancer treatment? And I say yes and they say, you look
so well are you really having it done and I say yes look at
my line.

I try not to worry,

What was the question again?

Int. How has your life changed?

Joan I know its there, but I do sometimes brush that back
and think- I haven't got it really. I don't go to bed
worrying about it and I don't get up in the morning
worrying about it. I do sleep well. I take one day at a time really.
It makes it more manageable.

I get up in the night cos I'm worried about my bag filling up,
but go back to sleep. I pretend I haven't got all this sometimes.
I wont let it get into my life all the time. I must stop worrying
about indoors all the time keeping it decorated and tidy.

I am trying to plan the future really but not for myself,
for other people.

Joan. That's it really.

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| Frustration with avoidance. |

| Living day to day Pretending its not there. |

| Focus on others. Living day to day |

Groups of Themes from interview 1 with Joan.

First level codes	Clusters of codes
Concentrating on the here and now.	
Trying to focus on the here and now.	Living in the here and now
Buying into the here and now.	
Appearing well	
Keeping life normal	
Maintaining normality	Keeping life normal
Pretending its not there	
Avoiding reality	
Superficiality of conversation to maintain normality	
Normal life carries on	
Minimizing discussion	
Feeling well – no symptoms	
Negotiating place in anticipated life expectancy.	
Renegotiating life expectancy.	Perspective on life
Imagining a world without her	
Perspective on future	
Intrusive thoughts about death.	
Planning for death.	Perspective on death
Planning for the future.	
Shifting priorities.	
Importance of surveillance	
Lack of understanding of disease.	Need for knowledge
Response to treatment	
Keeping it in control	
Not reflecting on mothers death	
Change of self	
Alterations in embodiment	Embodiment
Impact of cancer transcends physical change.	
Distancing from physical contact	
Reflecting on embodiment	
Fear	
Uncertainty	Managing anxiety
Short term plans / goals	
District nurse involvement.	

First level codes	**Clusters of codes**
Impact of treatment on lifestyle	Impact of treatment
Impact of disease on lifestyle.	
'Taken over' – blaming treatment	
Finding support from other patients.	
Finding common ground supportive.	
Comparing self with other with cancer	
Using comparisons to negotiate life expectancy.	Belonging
Reciprocal nature of support in relationships	
with other patients.	
New social group	
Identifying with others / belonging	
Common understanding	
Clinic staff busy	
Accepting treatment orientated health care professionals	Healthcare professionals
Accept D/N for treatment.	
Focus on well being of rest of the family	
Focus on others	
Expectations of others	
Change in role within family	
Impact of illness on children and relationships with them.	
Change in social orientation.	Realigning role
Loss of work role	
Distancing of relationship with sisters.	
Loss of social network	
Renegotiation of role within family	
Isolation within the closest relationships	
Isolation and distancing	
Acknowledging the need for help	Recognising limits
Lack of understanding from partner.	
Need for acceptance by partner.	
Loss of sexual relationship/ isolation.	Intimacy and acceptance
Effect of disease on physical body	
Effect of illness on orientation within relationship.	
Lack of opportunity for discussion	
Lack of opportunity to talk openly/ frankly	Need to talk
Frustration with avoidance.	
Practicalities.	Practicalities

Clusters of codes across all ten interviews.   **Pattern**
generation

Living in the here and now	
Keeping life normal	
Accommodating change	Continuity v's change
Control	
Need to talk	
Loss	
The future	
Uncertainty	Certainty v's uncertainty
Managing anxiety	
Fear	
Impact of treatment	
Embodiment	
Practicalities	The experience as
Physical signs and symptoms	an embodied being.
Side effects of treatment	
Bodily functions	
Belonging	
Healthcare professionals	
Realigning role	
Recognising limits	
Intimacy and acceptance	Adjusting v's resisting
Parallel world	
Children	
Managing alone	
Perspective on life	
Perspective on death	
Need for knowledge	

Saldana's framework. Joan – Interview 2.

	First level codes	Clusters of Codes	Differences from previous summaries	Contextual / intervening conditions
INCREASE / EMERGE	A sense of effects of treatment being the cost of staying alive. Using different strategies with different groups of individuals.	Bargaining Belonging	A stronger sense of bargaining and the 'trade off' with the treatment and the consequences as a vehicle for survival.	Very little has changed. She has been reflecting on her life and evaluating the impact of what has been happening on both herself and her life. She tentatively thinks about the future at times, but tries to remain in the present. The present is a positive place to be.
	A sense of becoming a 'different' person. Restructuring her sense of who she is and her future.	Embodiment Embodiment	A more powerful sense of an embodied experience and renalignment of who she is in her life world.	
	Fear for the future. Feeling rejected when asking for support from close family.	Managing anxiety Worried about potential burden	Worry about the potential impact of her illness on her family	
	Financial worries.	Practicalities	Impact of not working on their finances.	
	Sense of being in Limbo.	Limbo	Limbo is a positive place	

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CUMULATIVE	Greater sense of death lying ahead.	Perspective on death	More powerful feeling of death lying ahead and discussion of life for her family after her death.	Foreboding about the future is stronger as a result of her thinking about her circumstances. She still is not well informed about the nature of her illness and what may be happening in her body.
	Greater understanding of the unpredictable nature of her illness, but a lack of insight into nature of the disease and the effect of treatment.	Knowledge	More reflective around the potential for the illness to develop. But still not well informed about her disease	
	Efforts to maintain normality,	Keeping life normal	More intense efforts to create normality and stasis. More conscious achievement of goals.	She continues to be isolated and that has a cumulative influence on her introspection. She only really socialises with other patients and doesn't have the opportunities she would like to talk about her situation or experiences.
	Importance of achieving goals.			
	Feeling that her whole life has changed	Realigning role	More profound sense of being a different person and her position in her life world having changed.	
	Focus of friendships with other patients	Belonging	More focus on the need to belong to a group with things in common.	
	Need to talk – but cannot talk with family	Need to talk	Lack of opportunity to talk, increasingly isolated.	

SURGE / TURNING POINT	None		No epiphanic change, but subtle evolution of the experience and meaning	
DECREASE /CEASE	Uncertainty about her mortality	Perspective on life	More reflection around the finality of her life and less uncertain about her future.	Cessation of treatment.
	No treatment	Side effects of treatment	Not having any treatment at present.	
	No HCP's	Relationship with HCP's	No real contact with any healthcare professionals	
CONSTANT / CONSISTENT	Focus on the here and now Stasis of illness Keeping relationships with family unchanged Lack of intimacy / physical contact with partner focus of blame on stoma Superficial relationships with those closest	Here and now Stasis Intimacy and acceptance.	Little difference. Living in the here and now. Comfort derived from stasis and uncertainty. Distance in relationships	Little change Stasis is important to her. No evidence to the contrary exists, that her illness is also static
	No symptoms from illness	Stasis	No physical signs or symptoms of the disease.	

IDIOSYNCRATIC	Measuring time in 'blocks' between appointments.	Perspective on time	Discussing plans in light of forthcoming appointments and not making long term plans	A 'watch and wait' approach to her hospital care means she waits for the next appointment before making any real plans.
MISSING	Comradeship in treatment clinic District nurse input Recognising limits	Treatment related data Recognising limits	Cessation of treatment.	No longer visiting the hospital on a regular basis.

INTERRELATIONSHIPS	There is a clear link between the ability to maintain the stasis and normality and the lack of any evidence that her illness is progressing. The cessation of treatment has reinforced the notion that her illness has reached a plateau.
CHANGES THAT OPPOSE/HARMONISE WITH HUMAN DEV/SOCIAL PROCESSES	She is actively resisting any change or transition by focussing in the here and now.
PARTIC/CONCEPT RHYTHMS(phases, stages, cycles, etc. in progress)	She has completed a phase of chemotherapy treatment and is now in a stage where her experience is static and she lives from day to day.
PRELIMINARY ASSERTIONS AS DATA ANALYSIS PROGRESSES (refer to previous matrices)	She is focussed on the day to day and keeping life the same. Her routine is important and her isolation from others allows that to be perpetuated. She is becoming increasingly isolated from others who are in her life world. This allows her to perpetuate the stasis.
THROUGH LINE (IN PROGRESS)	Her everyday world is very focussed in the here and now. Long term plans are absent. Self management is crucial to this and allows her self definition of her health to be sustained. Uncertainty is a positive feature as it allows her to construct her own thoughts. Stasis is also positive.

Longitudinal Qualitative Data Summary Matrix -- Joan – Interview 2.

INCREASE/ EMERGE	CUMULATIVE	SURGE/EPIPH/ TURN POINT	DECREASE/ CEASE	CONSTANT/ CONSISTENT	IDIOSYN-CRATIC	MISSING
Bargaining Realigning lifeworld Being different Financial concerns Limbo is a positive Distance from family	Perspective on death Knowledge Isolation Normality Belonging Stasis	none	Treatment Uncertainty Contact with HCP's	Focus on here and now Stasis Intimacy and acceptance	Time	Treatment Limits

DIFFERENCES ABOVE FROM PREVIOUS DATA SUMMARIES

More intense feelings of trade off and consequences. More intense sense of realignment. More intense efforts to achieve stasis. More reflective. More intense need to belong to a new social group. Cessation of treatment so fewer encounters with HCP's No talk of long term planning

CONTEXTUAL/INTERVENING CONDITIONS INFLUENCING/AFFECTING CHANGES ABOVE

Subtle changes, no major change. Evidence of reflection / reevaluation. Cessation of treatment. No longer visiting hospital on a regular basis.

INTERRELATIONSHIPS	CHANGES THAT OPPOSE/HARMONIZE WITH HUMAN DEV/SOCIAL PROCESSES	PARTIC/CONCEPT RHYTHMS (phases, stages, cycles, etc. in progress)
Link between her ability to create stasis and lack of evidence of cancer activity. Cessation of treatment has reinforced her Belief she is on a plateau.	Resisting change. Focusing on the here and now	Living day to day. Finished treatment.

PRELIMINARY ASSERTIONS AS DATA ANALYSIS PROGRESSES

She is focused on the day to day and keeping life the same. Her routine is important and her isolation from others allows that to be perpetuated. She is becoming increasingly isolated from others who are in her life world. Which allows her to perpetuate the stasis.

THROUGH-LINE

Her everyday world is very focused in the here and now. Long term plans are absent. Self management is crucial to this and allows her self definition of her health to be sustained. Uncertainty is a positive feature as it allows her to construct her own thoughts. Stasis is also possible.

Appendix viii.

Application of CASP to this study.

The CASP appraisal framework was developed in 2002 (Milton Keynes PCT) with a view to evaluating the constituent parts of qualitative research. There were three main areas within the research which the tool is designed to address:

- Rigour: has a thorough and appropriate approach been applied to key research methods in the study?
- Credibility: are the findings well presented and meaningful?
- Relevance: how useful are the findings to you and your organisation?

The appraisal of the thesis will naturally differ from the appraisal of the literature in terms of having the entire study to hand, as opposed to having a paper which may have been constrained by the publication process. However the principals are useful to apply as a structured critique of the work.

Aims of the research.

The goals of the research are clearly stated and situated within the context of the study. The importance and relevance of the study are identified and located within the broader political context.

The aim of the study can be summarised as to explore the meaning of living with locally advanced rectal cancer and how that meaning permeates the everyday world of the individual.

The objectives of the study lie in:

- The exploration of meanings associated with living with locally advanced rectal cancer.
- The exploration of how that influences self-definition of health and illness.
- Highlighting the subsequent impact that (self definition) has on self-management strategies.

- The exploration of these phenomena over time to understand the dynamics of the experience.
- The exploration of the implications of these for service development and future research.

The findings from the study are discussed in light of contemporary policy and strategy for cancer services delivery.

Choice of appropriate methodology.

The theoretical assumptions are outlined at the outset of the study and the methodology is situated within those assumptions. The perspectives guiding this study arise strongly from both my work as a cancer nurse in clinical practice and my existing theoretical knowledge. This view has led to the desire to understand the individual experience from their perspective, in their 'life world'. The philosophical underpinnings are explored in depth with the research clearly aiming to interpret the participants experience. Central to this is the notion of 'being'. In the Heideggerian sense that 'being' is the fundamental nature of what we are and that this forms a cyclical relationship with time and the development of understanding (Mulhall, 1997).

Research Design appropriate for the aims of the study.

The research design is justified in terms of its appropriateness for the aims of the study. The study used a longitudinal, qualitative approach, with data being gathered in four successive interviews over a period of 18 months. The rationale for using a longitudinal approach is explored and the added depth which this accords to the data is outlined. The guiding principles of phenomenology are discussed and explored in relation to the appropriateness for the study. The analysis is informed by the work of Miles and Huberman and Saldana.

Recruitment strategy appropriate for the aims of the research.

The sampling strategy is outlined and the inclusion and exclusion criteria discussed. Successive patients who were deemed 'inoperable' were identified through the colorectal cancer MDT meetings. The patients were approached by an NCRI trials practitioner who introduced the study and gave the participants information. They then returned a reply slip indicating interest and contact was established and the study outlined further.

Data collected in a way which addressed the research issue.

Tape recorded, semi-structured interviews were undertaken with the use of a topic guide. Participants were able to stop at any point and consent was obtained prior to each interview. Discussion around cessation of data collection is addressed within the context of the individual participants. The interviews lasted between 45 and 90 minutes. The purpose of phenomenological interviewing is described in depth as well as the therapeutic nature of interviews for participants.

Adequate consideration of the researcher/ participant relationship.

The thesis explores the nurse / researcher relationship. The role of researcher is discussed reflexively and assumptions were documented at the outset of the study to review in relation to potential bias. Reflection on the study as a whole is incorporated into the discussion.

Have ethical issues been considered.

Ethical approval was granted from the local research ethics committee. The nature of ethics, the approval process and ethical considerations are all described. Unexpected ethical considerations are addressed as they arose and the study includes an in depth exploration of the ethical principles which guide research studies.

Is the data analysis sufficiently rigorous.

There is in depth description of the analysis, how the data was managed, reduced to a manageable size, interpreted, how the themes emerged from the data and meanings were assigned to sections of the transcripts. Baseline datasets for each participant were formed and subsequent data sets analysed in light of these. This way any increase, decrease, idiosyncratic data, missing data or individual epiphanies emerged (Saldana, 2003). The process is illustrated with examples of the translation from the transcript to the final themes. This was validated by co analysis of parts of the data by a supervisor.

Is there a clear statement of the findings.

The findings are discussed in light of the existing literature from the review and the broader literature. The findings are also revisited in light of the original research question. The process is transparent and the findings are firmly embedded in the data.
One difficulty was the problem of participant validation which was addressed as ethically as seemed appropriate at the time and raised issues around the appropriateness of participant validation in the exploration of declining health. New findings are discussed and explanations suggested.

How valuable is the research

The contribution to the existing body of knowledge is discussed. The strengths and weaknesses of the study are addressed and the implications for research and future practice are explored. New research questions are generated and new findings highlighted.

Returning to the original concept of rigour which was described by Pearson and Lockwood (2007) the issues surrounding congruence appear to have been addressed and conclusions which are drawn from the data are supported with evidence from the interviews

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