

Lost after Transition:

The Development of a Conceptual Framework and Model for Patients with Colorectal Cancer and a Stoma who have completed Therapeutic Interventions.

Volume 1: Thesis

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“All significant diseases, especially those issuing from a malignancy of the abdomen, are heralded by a greater or lesser upheaval of personality.”

(Friedrich von Schiller, German Poet, Philosopher and Physician, 1759 – 1805)

The road to completion of this PhD thesis has been long with an enforced lacuna a year before the end so extending the time frame. The positivity and motivation to continue was made possible by my Director of Studies and Supervisor, Professor Joy Notter. Without her I would not be where I am now. It has been her unending patience, her kindness and caring and ensuring I took the required time off to make a full recovery to enable me to return to my studies.

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Abstract.

Colorectal cancer is the fourth most common cancer in the UK. The advances in cancer care are such that the longevity of this group has extended well beyond the five years through which the NHS follows them. The diagnosis of a colorectal cancer and a permanent colostomy for the patient causes challenges in terms of the diagnosis and treatment, and also in the need to adapt to the permanently changed bodily functions and body image they have to live with. Healthcare professionals are aware of the impact of cancer on patients and their relatives and carers, but research shows that there is little support guidance or help for them once discharged from follow up services. They report being told to 'go off and enjoy life ' but say they feel 'cast adrift ' with no recourse to further help and advice when they experience physical, psychological and psychosocial problems.

Aims of the study

- To Increase awareness, knowledge and understanding of the long term effects of colo-rectal cancer treatment on quality of life
- To develop a conceptual framework and education model that will contribute to the education and training of general and specialist nurses in this field
- To develop an information package for individuals who have undergone colostomy formation after a diagnosis of colo-rectal cancer

Methodology

To gather the rich, in-depth information needed for this study, a descriptive phenomenology approach was used to gather data from 19 participants from across England. Data was collected through a focus group, telephone interviews and a one to one interview. Interviews lasted from 45 minutes to one hour, and participants were offered access to an independent counsellor should they find the subjects discussed distressing.

Findings

The steps for analysis as described by Giorgi (2009) were used to analyse the data sets, with Epoché and reduction repeated several times, initially 5 themes emerged, and refining led to the identification of different coping lifestyles. The outcome from

all participants was that they had had no support mechanisms after final discharge. The coping styles gave clear indicators as to how they coped, and could be used to enable health professionals to identify the best way to help and support this vulnerable group of patients. The overall data sets were used in conjunction with government recommendations and professional expertise to develop a conceptual framework and model for a care for life plan that could be issued to all patients. If given while still attending for treatment it would then provide a portfolio that would support them for the rest of their lives.

Conclusion and recommendations

There is currently nothing in place nationally or locally for these patients after reaching the five year mark and discharge. Current Survivor Care Plans (SCPs) for use from diagnosis until end of treatment are available, but none of the participants had ever had one. The conceptual framework and model developed in this study, can be used to fill the current service gap, and meet the recommendations from the Cancer Task Force for NHS England (2016). It emphasises the importance of taking a whole person, whole pathway approach to improve quality of life for people living with and beyond cancer. The Care for Life Plan will enable the patient to know what to expect over the following years after treatment has finished and whom to contact if there are problems or queries. It also contains guidance to help professionals implement it and guide patients for the long term.

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Glossary of stoma terms.

Abdomen: area of the body between the chest and the hips in the front part of the body that contains the digestive organs.

Accessories: products (such as ostomy covers, skin barrier rings, paste, etc.) that are used to enhance the performance of the pouch

APER: Abdominoperineal resection

Anal cancer: cancer of the anal canal.

Anastomosis: surgical join of two pieces of bowel

Barrier opening: the pre-cut hole in the skin barrier/wafer

Body image: the mental picture the individual retains of their physical being.

Bowel: Part of the digestive tract. The small bowel is also called the small intestine, and is located between the stomach and large intestine. The large bowel is also called the large intestine or colon and is located between the small intestine and the rectum.

Colorectal cancer: cancer of the colon towards the rectum on the left side.

Closed-end pouch: a pouch that has no opening at the bottom and is removed and discarded after each use

Colostomy: a surgically created opening between the large intestine (colon) and the abdominal surface

Colonoscopy: camera examination of the colon for disease.

Diverticular Disease: non-malignant disease of the large intestine causing out pouchings in the colon. Typically seen in Westernised countries.

Drainable pouch: has an opening at the bottom, which allows stool or urine to be drained and re-closed with a tail clip, tap (for urostomy pouches)

FOBT: test to detect faecal occult blood

Filter: some pouches have an integral filter that helps release gas build-up from within the pouch

Flange: ring that is attached to skin barrier and pouch on some two-piece systems. Flanges are designed to snap **securely** together to join the barrier to the pouch.

Hemi-colectomy: surgical removal of half the colon.

Imperforate anus: lack of anal opening when a baby is born

Irritation: soreness, redness or inflammation of the skin

One-piece ostomy pouching system: the skin barrier/wafer and pouch are made as one unit

Opaque: a beige pouch film that helps conceal pouch content

Ostomy: a surgically created opening (called a stoma) in the gastrointestinal system to allow the passage of stool or in the urinary system to pass urine

Peristomal skin: the skin surrounding a stoma

Plastic: the materials used to manufacture the pouch.

Pouch: The bag portion of an ostomy appliance that collects and contains urine or stool.

Pre-cut: skin barriers/wafers that are available pre-sized.

Rectosigmoid: area of sigmoid colon on the left side as it joins the rectum

Skin barrier/wafer: the adhesive portion of an ostomy appliance that attaches to the skin. These are applied to the skin around the stoma (called peristomal skin). Helps protect the skin from stool or urine, which can be very irritating.

Stoma: a surgically-created opening on the abdomen surface, constructed of intestinal tissue. Also commonly called an ostomy. The stoma should be moist and red. Stool or urine leaves the body through this opening instead of the anus or urethra.

Temporary colostomy: involves the diverting of the colon to the abdominal wall to create a stoma. Unlike a permanent colostomy, the lower part of the colon and digestive track remains in place within the patient to allow for healing and repair.

TME: total mesorectal excision.

Transparent: clear pouch film; pouch content is visible

Two-piece ostomy pouching system: skin barrier/wafer and pouch are separate and attached together with a round, plastic ring (called a flange). Pouch can be easily removed without having to remove the skin barrier/wafer.

CHAPTER 1:

CONTEXT OF STUDY.

Lost after transition: development of a conceptual framework and model for patients with colorectal cancer and a stoma who have completed therapeutic interventions.

The overall purpose of the study was to create a conceptual framework and model which would improve quality of life for patients who have been discharged from care five years post diagnosis. My realisation of the need for this study evolved as a result of my years of experience of working as first a nurse specialist and then nurse consultant with this group of patients. As treatments have improved and survival time extended it became increasingly apparent that the NHS policy of discharge at five years with its accompanying sudden cessation of interventions, leaves patients reporting they felt 'let down' and/or 'abandoned'.

I have worked in this field of care for the last 30 years during which time I have successfully completed research projects utilising both focus groups and individual interviews. In addition part of my role as nurse consultant, I have played a lead role for the Department of Health in the development of colorectal cancer support groups.

Takacs (2003) hypothesises as to whether positionality causes bias to the epistemology, an important issue for this study because phenomenological research is epistemological not ontological. However, Takacs (2003) goes on to suggest that individuals live their lives in their heads although they are constantly re-confirming dialogue with themselves. Assumptions are made and based on each person's own individual positionality which may also bias how each individual perceives their world. Harding (1992) suggested that through recognizing and analysing the cultures in which the researcher is positioned it is then possible to take positive steps to become more aware and objective. Bourke (2014) takes this further arguing that the act of examining the research process within the context of positionality is reflexive.

The nature of qualitative research means that the researcher is also the data collection instrument, and thus it is not unreasonable to suggest that their beliefs will be important variables in the study as a whole. Accepting this, interpretation of the data consists of two related concepts. Firstly, the way the researcher accounts for the experiences related by the participants and secondly, the way in which the participants make meaning of their experience (Bourke, 2014). Therefore, the potency of the research process is positively or negatively affected by the researcher and participant.

A diagnosis of colorectal cancer and its subsequent treatment, often with a stoma, can adversely affect the patient's quality of life (Denlinger and Barsevick, 2009). Following treatment which may well have included neo-adjuvant and adjuvant chemo/radiotherapy as well as surgery, patients have a range of physical, emotional and psychosocial needs. To enhance the quality of life of colorectal cancer patients during their treatment phase and onward into the survival phase, there needs to be growing recognition of the negative sequelae that this group of patients present (Taylor et al, 2011). Therefore, the study looked at what the participants were saying about their care or lack of care, after their final discharge from hospital therapeutic interventions and are sent out to the community as 'cured' and to continue their life. Quality of Life (QoL) is being increasingly recognised as an important outcome measure in comparing different treatment modalities for the same disease. Therefore, future QoL measures may be one of the determinants in advising patients whether to undergo abdo-perineal resection (APR and a permanent stoma or risk poor functional results after a low resection without a stoma which will therefore compromise the patients QoL (Ortiz & Armendariz 1996, Wexner 1998, Langenhoff 2001, Anthony 2003). However, much of the QoL literature around APR or low resection shows that patients with colorectal cancer and a stoma did not have a poorer QoL (Grumann 2001, Harisi 2002, Allal 2005, Yoo 2005, Arndt 2006, de Campos-Lobato 2011, Varpe 2011,) but Jess 2002, Pucciarelli 2008 and Yau 2009 found that having a stoma did affect the patients QoL.

Assessing the patient's needs through the trajectory of colorectal cancer and a stoma, is not just important during the treatment phase but needs to continue through the patient's life. Traditionally patient outcome measures after colorectal cancer surgery have been for overall specific cancer survival such as complications, clinical health status, functional and biochemical indices. However, over the last three decades there has been increasing interest in the QoL which is now regarded as a key measurement. WHO (1999: 19-37) defines QoL as:

"An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment".

The transition from active care to post care treatment can be critical to the long term health plan that not only takes the patient through the first five years (accepted time

span that if there is no recurrence after primary care, the patient is considered “cured”) but for the rest of their life. In many places in the United Kingdom (UK) a Holistic Needs Assessment (HNA) takes place between the clinician /specialist nurse and patient which encompasses all aspects of a cancer patient’s life (Torjesen, 2009). However, these are only used during the treatment phase and post treatment phase and at five years the patient will be discharged. From the authors’ own experience with colorectal cancer patients with a stoma, it is after this time when further support is needed especially when there maybe existential, vocational or social concerns, the fear of recurrence of cancer and problems with the stoma as the patient ages.

In a review of the literature on information needs of the cancer patient and their carers cited that the most frequently unmet needs were practical in dealing with treatment led information and coping information (Adams et al, 2009). Although information was available during the treatment trajectory from specialist nurses, the need for information after cessation of therapeutic intervention increased the patients need to seek information by comparison with fellow patients they had made contact with, by personal communication or through support groups. Festinger (1954) referred to this comparison with others with the same disease as “social comparison” and that human beings seek to view outside images to evaluate their own standing and pathway in their disease. This comparison of people who are doing well in their disease trajectory is seen as ‘upward comparison’ and those who compare with others whose condition is worse is seen as ‘downward comparison’. When patients compare themselves favourably with others it can be associated with a positive adjustment to their disease and outcome (downward comparison), and those who make an ‘upward comparison’ can help enable people to cope with their current stressors and inspire hope for their own future.

There is a large amount of unsolicited and unrecorded, anecdotal information around the areas of searching for final answers, fear of recurrence, coping with a stoma through different ages and insufficient on going information. The Department of Health (DoH, 2007), suggest that there are eight areas of survivorship improvement:

Table 1. Eight Areas of Survivorship Improvement.

<ul style="list-style-type: none">• Information, communication, decision making and choice.
<ul style="list-style-type: none">• Co-ordination and continuity of care.
<ul style="list-style-type: none">• Psychological support.
<ul style="list-style-type: none">• Supportive and palliative care.
<ul style="list-style-type: none">• Appropriate training for healthcare professionals.
<ul style="list-style-type: none">• Helping patients to meet the cost of cancer.
<ul style="list-style-type: none">• Measuring patients' experience as a mechanism for improving the quality of services.
<ul style="list-style-type: none">• The critical importance of clinical nurse specialists.

(DH, 2007).

Yet these areas only cover the time from diagnosis to the five year survival mark. It is after this that cancer sufferers are known to experience psychological worries over the fear of recurrence (Lee-Jones et al, 1997), discharge from therapeutic intervention (Thomas et al, 1997), clinical depression (Massie, 2004), uncertainty about the future (Holland and Reznik, 2005) and social implications such as return to work and social and community integration (Schag 1994,Short et al, 2005).

Barriers to cancer survivorship care, long term, are seen as the term 'survivor' being applied to those with a diagnosis and under current treatment and do not take into account those with a cancer history. Once released from active treatment, post treatment and surveillance, cancer 'survivors' are uncertain about their interface with the health care system (Odle, 2008). The psychological and psychosocial problems related to colostomy pouch disposal also suggest that a percentage of patients associate change and disposal confidence with more negative thinking about life with a stoma, diminished confidence in self-stoma care and the inability to socially integrate (White, 2002).

In April 2016, NHS England produced an important guidance document – Implementing the Cancer Taskforce Recommendations: Commissioning Person Centred Care for People affected by Cancer. The short document starts by reiterating the 2015-2020 Strategy for England: Achieving World-class Cancer Outcomes, and emphasises the importance of taking a whole person, whole pathway

approach to the commissioning and provision of cancer services. Importantly it highlights the need to improve quality of life for people living with and beyond cancer as a key component. The Secretary of State, in September 2015, in his statement of support for this new strategy, committed to ensuring that every cancer patient receives the interventions known as the 'Recovery Package' (Chapter 6). The guidance is intended to support commissioners and strategic clinical networks to ensure every person affected by cancer will have access to the Recovery Package and stratified follow-up care pathways by 2020, specifically breast, colorectal and prostate as set out in the cancer strategy. It describes the actions that will be needed to deliver this including checklists for developing service specifications. When developing and implementing these interventions, commissioners will have to take into account the duties placed on them under the Equality Act (2010) and reducing health inequalities, besides their statutory duties under the Health and Social Care Act (2012). Service design and communications should be appropriate and accessible to meet the needs of diverse communities.

The Recovery Package is described as a set of essential interventions designed to deliver a person centered approach to care for people affected by cancer. This includes a holistic needs assessment (HNA), a treatment summary (TS), a cancer care review (CCR) and information about health and wellbeing events. Everyone with cancer should be offered an HNA and care plan. Effective assessment and care planning can lead to early interventions, diagnosis of consequences of treatment, improved communication and better equity of care. The HNA and care plan ensure that people's physical, emotional and social needs are met in a timely and appropriate way and that resources are targeted to those who need them most. It should take place around diagnosis, at end of treatment, whenever the patient's needs change or at any other time at the patient's request.

The Treatment Summary (TS) is developed to support improved communication between cancer services and primary care. The TS is produced at the end of first treatment or treatments given and sent to the patient's GP and other primary care professionals to inform them of any actions they need to take. The patient also receives a copy to help improve understanding of their condition and to provide a summary to share with other professionals. Treatment Summaries may also be used at other points, for example, following treatment for recurrence or referral from secondary care to palliative care. It is used to inform the GP cancer care review,

which is also part of the Recovery Package. A copy of the TS in the case notes is also useful for medical staff if the patient is admitted in an emergency after primary treatment is complete.

The Cancer Care Review is populated from the TS and completed by a GP or practice nurse in order to discuss the person's needs. It is carried out within six months of a cancer diagnosis and covers post-treatment support, financial impact of cancer, patient awareness of prescription exemptions, possible late effects of cancer and cancer treatment and information needs to enable self-management.

Health and wellbeing events provide an opportunity to inform and educate patients about the clinical and holistic aspects and ongoing management of their health. They also serve to impart information about local facilities, supportive care and opportunities that are available to individuals and their families. Every individual with cancer should be offered the opportunity to attend a health and wellbeing event at the end of treatment, to support them to self-manage their condition.

Currently, within the National Health Service of the United Kingdom (NHS UK), at five years, if there has been no recurrence or metastatic spread and scans show no progression or unexplained changes, the individual is considered to be 'cured'. Invariably patients are told at their last clinic appointment "to go away and enjoy life". However, having been a colorectal clinical nurse specialist for 20 years and a nurse consultant in colorectal disease for more than a decade, my experience is that for many of the patients there are long lasting repercussions from the surgery and adjuvant therapy, which lead to physical and psychosocial changes and challenges. All these individuals need to seek help from wherever they can find it as there is no accepted way they can refer themselves back to hospital and a specialist team, and often GPs cannot answer their queries.

There is a degree of elation on completion of treatment for colorectal cancer and a colostomy, but this is often coupled with the anxiety of losing contact with the medical team and specialist nurses or conversely never wanting to see them again which suggests an association between somatic anxiety and psychological distress. As increasing numbers of people are being treated for cancer successfully today, it therefore follows that more will survive to pass the five year mark (CRUK,2012). In coping and passing the five year mark (the world wide accepted time scale that the cancer has been 'cured') these individual's lives need to be catered for and valued.

If, as Rodgers and Knafl (2000) describe, concepts are the building blocks of theory therefore concepts can be viewed within a socio-cultural and emic context.

Survivorship Care Plans (SCPs)(NCSI,2013) are frequently referred to as key mechanisms for support, but these only cover the time from diagnosis and during the time until discharge. They do not offer long term or lifetime strategies for support. They are made up of two elements, a written summary of the cancer and a recipe of instructions regarding whom to see for routine follow up. Chrischilles et al (2015) in their research found that only one in four individuals reported that they had received a SCP with both elements and were certain about the doctor who was caring for them. The seven-year survey of older individuals post-surgery reported that they had not received a SCP at all. The authors concluded that many cancer patients lack adequate help and support to successfully move from “being a patient to a survivor”, let alone to develop the strategies for self-management in the longer term.

It has been known for some years that individuals need more than a SCP that is only active in the early stages of diagnosis and treatment. Arora et al (2011) found that over 60% of post treatment ‘survivors’ in their study lacked the help and support they needed once their treatment ended. Each individual’s cancer trajectory is unique, and Carr (2004) suggests that the problem is that the lived experience of cancer is beyond the experience of those not afflicted. Therefore, Little (2000) argues, many of the individuals find that, describing what they are going through is “beyond the scope of language” (Little 2000) and thus they are unable to enable healthcare professionals to see into their world. Consequently, clinicians do not understand how the treatment affects patient’s quality of life (Arora, 2011). The individual’s cancer trajectory is unique to that individual and Carr (2004) suggests that the lived experience of cancer is poorly understood by those not afflicted.

Historically and metaphorically, survival has been associated with war or laws of nature and in cancer it is metaphorically aligned with war, fighting battles and survival (Chapter 8). One of the first people, Mullan (1985), described his personal experience of cancer and how this might affect an individual holistically and evolve over time. From then the concept of ‘survival’ after treatment for cancer started to take hold in the literature, yet no definition was given. Aziz and Rowland (2003) suggest that cancer is now classed as a chronic disease with physical and psychosocial outcomes and ‘survivorship’ can be defined as a process starting at diagnosis, involving uncertainty, a life changing experience and has a plurality of

negative and positive aspects along a continuum. There is a lack of general agreement in the literature as to when an individual begins to think of themselves in the terms of 'survivor' (Little et al 2000, Leigh 2001, Vachon 2001, Ganz 2005).

However, other writers suggest that to be termed a 'survivor' the individual must live for at least five years after the diagnosis of cancer (Carter 1989,). For many individuals the experience of a colorectal cancer diagnosis and permanent stoma, is without doubt, a memory that remains vivid in the individuals head combined with the sudden realisation of vulnerability and mortality. Mullan (1985) compares 'survivorship' with nature and of having three seasons - acute, extended and permanent. Carr (2004) suggests 'survivorship' is waiting and wondering all the time. These criteria were adopted by the National Coalition for Cancer Survivorship in the United States of America as their criteria of membership as 'anyone with a history of cancer from diagnosis and for the remainder of their life' and from whence the 'survivorship' idea in the UK originated. (Leigh & Logan, 1991). In defining how 'survivorship' is described, medically it means after treatment has finished, but if looking to establish a timeframe this could be any time from 2,5 or even 10 years after diagnosis or when a cure is achieved. Many support groups disregard this time frame and a 'survivor' is any one after a diagnosis of cancer regardless of recurrence or persistent disease. To find a linguistic term for life after a cancer diagnosis that is harmonious with all concerned – patients, healthcare professionals, voluntary support organisations, it appears strange that what has been accepted is an oxymoron – surviving cancer.

Life changing and uncertainty are two terms associated with the diagnosis of cancer and 'survivorship'. For many individuals, after the shock of diagnosis and treatment plan, the individual will review and assess their life and their priorities. Even with today's advancements in the treatment of colorectal cancer, individuals and their families still consider it a 'death sentence' as opposed to surviving and having a relatively normal life after treatment has finished. For some it's a transformational period and evidence that individuals make positive life changes after such a diagnosis is seen in the literature (Mullan 1985, Carr 2004, DeMarco et al 2004,). Social connectivity, family relationships, intimate relationships and everything that makes up the individuals' life are all affected by a diagnosis of cancer, which is an extreme experience involving body image change as well as the possibility of a shortened life and disruption of the individuals sense of identity.

In the older individual given the diagnosis of colorectal cancer and its subsequent outcome, the effects of treatment and adjuvant therapy can leave them with psychological and physical issues such as depression, anxiety about recurrence, fatigue, pain, cognitive impairment and finding it harder to overcome these issues in combination with exacerbation of other co-morbidities. With the diagnosis of colorectal cancer and a permanent colostomy come the positive effects and negative effects of a cancer diagnosis. The positive is the chance that death will be defeated at least for the noticeable future and there may be the chance of a normal life span. The negative is that the alternative to survival is death. For the ageing population the diagnosis combined with co-morbidities can create complex problems for the surgery and for the rehabilitation and for some this is just another hurdle that may not be overcome.

As the five year longevity rate begins to rise researchers need to understand the connection between the somatic disturbance and the physical upheaval that a colorectal cancer diagnosis brings. Figure 30 (page189) shows the concept of an event that is colorectal cancer and a colostomy and how an individual starts to understand how to cope with the diagnosis. It was thought that human beings were goal directed and there was no explanation of how these goals were pursued due to the lack of attention to the strategies that human beings use. From the researchers' own group of participants came the diagram that the individuals use to cope after a cancer diagnosis. Cancer related distress has been negatively associated with positive health behaviours yet it is seen that repetitive or frequent thoughts about cancer are not necessarily distressing to the individual. Harper et al (2007) suggest that a cancer diagnosis and treatment may offer a 'teachable moment' to be captured by the specialist nurse to help the individual to evaluate their priorities and begin to think about behaviour change. Discussing and talking about change at this time in an individual's life is a prerequisite for behaviour change and a time for the individual with cancer to reflect upon what is important in their life.

A main aim of the study was to develop a conceptual framework for patient centred care after the transition from "patient to person." In order to do this a method had to be identified that would facilitate gaining insight into, and increased understanding of the patient's journey. The choice was made to use descriptive phenomenology to explore how individuals feel after they have reached the five year mark and beyond following a diagnosis of colorectal cancer and a permanent colostomy. It appears from the research and the researcher's many years of experience of working with this

group of individuals that they feel “let down” or “abandoned” when they are finally discharged from therapeutic intervention.

CHAPTER SYNOPSIS.

Using a phenomenological approach, quotes from participants provide key illustrations firstly of the developing analysis, and then of the implications in practice. To indicate that these are from the data collected in this study, these quotes have been annotated in red. In addition the compilation of life experiences which form a cornerstone of the analysis have been annotated in blue as while they are from this study, they are in depth descriptions of participants’ lived experiences.

However, this study built upon previous research and experiences of myself as lead researcher. In these previous studies I had also gathered qualitative data sets. As with this study, all previous research had included ethical approval, informed consent and agreement for extracts to be used in the study at the time and in later work. Quotes from previous work have been annotated in burnt orange.

CHAPTER 2. COLORECTAL CANCER.

This chapter includes the clinical information about colorectal cancer. The start is the historical context of the rise of surgery from the early mention in the bible until today with gut sparing surgery to where possible a stoma may not be done. Epidemiology and aetiology is described looking at the incidence of bowel cancer. The development of screening as health promotion is described and how more defined screening is being piloted. The government’s Five Year Forward View (FYFV) by the Cancer Task Force is discussed looking at the metrics needed for Clinical Commissioning to understand what is needed to help longevity of cancer patients. Body image and a colostomy with its negative effect, is discussed and how for many this may cause problems with social connectivity, personal relationships, family interactions and financial implications.

CHAPTER 3. METHODOLOGY.

This chapter describes the overall aims of the study:

Aims.

- To explore the experiences and quality of life of people living life long with the outcomes of treatment for colorectal cancer and colostomy formation.
- To increase healthcare professionals awareness, knowledge and understanding of the long term effects of colo-rectal cancer treatment on quality of life
- To develop a conceptual framework and model for a Care for Life Plan for patients after transition from therapeutic interventions for colorectal cancer and stoma formation.

The study design followed the guidelines for descriptive phenomenology given by Giorgi (2009), and a full description of the approach used is given and the positionality of the researcher is also discussed.

CHAPTER 4. FINDINGS AND FIVE THEMES.

A description of how the study was set up is given and the way the interviews were carried out with the participants enabling the researcher to understand the participants' lived experience description (LED). The purpose was to understand how individuals feel after they have reached the five year point and they are told they are 'cured' and to go away and enjoy life. What do these patients need in their years of longevity after treatment especially as many are living more than 20 years and are trying to cope with cancer related problems and co-morbidities.

CHAPTER 5. COPING STYLES.

The initial epoché revealed 30 consistent descriptors/ feelings from the participants so therefore a second analysis and epoché was conducted and produced the 5 themes that the participants were all describing. This is complemented by each of the five themes being divided into three sub themes with participant descriptions. The five themes are then shown with participant's vignettes. Using Van Mannen (2014) it can be considered that the individuals in the researcher's sample are out of step with the body after surgery and that health care professionals can help to recover a "liveable relation with their psycho-physical wellbeing". Using Van Mannen's (2014) research, it could be argued that the interview data from the participants would illustrate the elements of the five identifiable phenomenological aspects of body experience that life threatening illness impacts upon.

CHAPTER 6. LIVING BEYOND COLORECTAL CANCER: LINKING THE FINDINGS TO POLICY AND PRACTICE AND THE NEED FOR CHANGE.

For many individuals the elation of completing treatment and arriving at the five year mark is coupled with the anxiety of not seeing any of the clinical team again. Adaption to life after a diagnosis of colorectal cancer and a colostomy will depend on the length of time it will take the individual to work through the grieving process and what factors make it hard to adapt. In the PROMS (2012) report involving patients living beyond cancer, it was evident that there was a wide range of on-going problems for those living beyond the end of treatment.

The Five Year Forward View (FYFV) 2015-2020 suggests a package called the 'Recovery Package' which is a set of essential interventions designed to give a person centred care programme. The Care for Life Plan is a CIPS based (Co-ordination, Intervention, Prevention, Surveillance) care plan and is a patient centred care approach including responsiveness to the patients' needs at the time of appointment.

CHAPTER 7. THE WAY FORWARD: THE DEVELOPMENT OF A CONCEPTUAL FRAMEWORK TO PROVIDE CARE FOR LIFE.

In this study it was evident that while the themes that emerged covered the key issues they did not illustrate that the interviewees had told a chronological story and that for each individual, revealing that each had a differing amount of time to achieve transition from 'patient' to 'person'. Current so called Survivorship Care Plans (SCPs) only cover the time from diagnosis up to and including the five-year discharge point. For this group the results of cancer care and treatment is increasingly being cited as a chronic condition. For most chronic conditions and illnesses, care provision includes long term follow up and clinical review, yet in contrast, this group with what are acknowledged to be major physical, social and psychological issues, are left to fend for themselves. To develop a conceptual framework that is efficient and effective, consideration needs to be given to how it can be slotted into existing services at the same time as identifying the constituent elements needed to deliver care for life. The plan needs to be accessible, acceptable and appropriate for all colorectal cancer patients who have reached the five-year discharge point.

CHAPTER 8. THE LEXICON OF CANCER. THE ROAD TO EMPOWERMENT: INVOLVING THE PATIENT AT THE CENTRE OF THEIR HEALTHCARE.

Metaphors can help illustrate complex issues and can illuminate a description of cancer to the lay public. Metaphors can add clarity and depth of meaning to a situation in the patient / doctor relationship. The metaphor offers both the patient and physician a common language and shared understanding offering both simplification and connection.

There have been repeated calls to engage the patient and public and involve patients to be at the centre of their healthcare. Self - management after discharge has received growing attention as an effective approach for long-term condition management. For the colorectal patient with a colostomy during their treatment and follow up phase (the first five years) there is continued involvement with the healthcare team. However, once the five-year mark is reached there is little for the patient in the way of “organised” support with many patients reporting the feeling of being “cast adrift”.

CHAPTER 9. REFLEXION AND REFLEXIVITY.

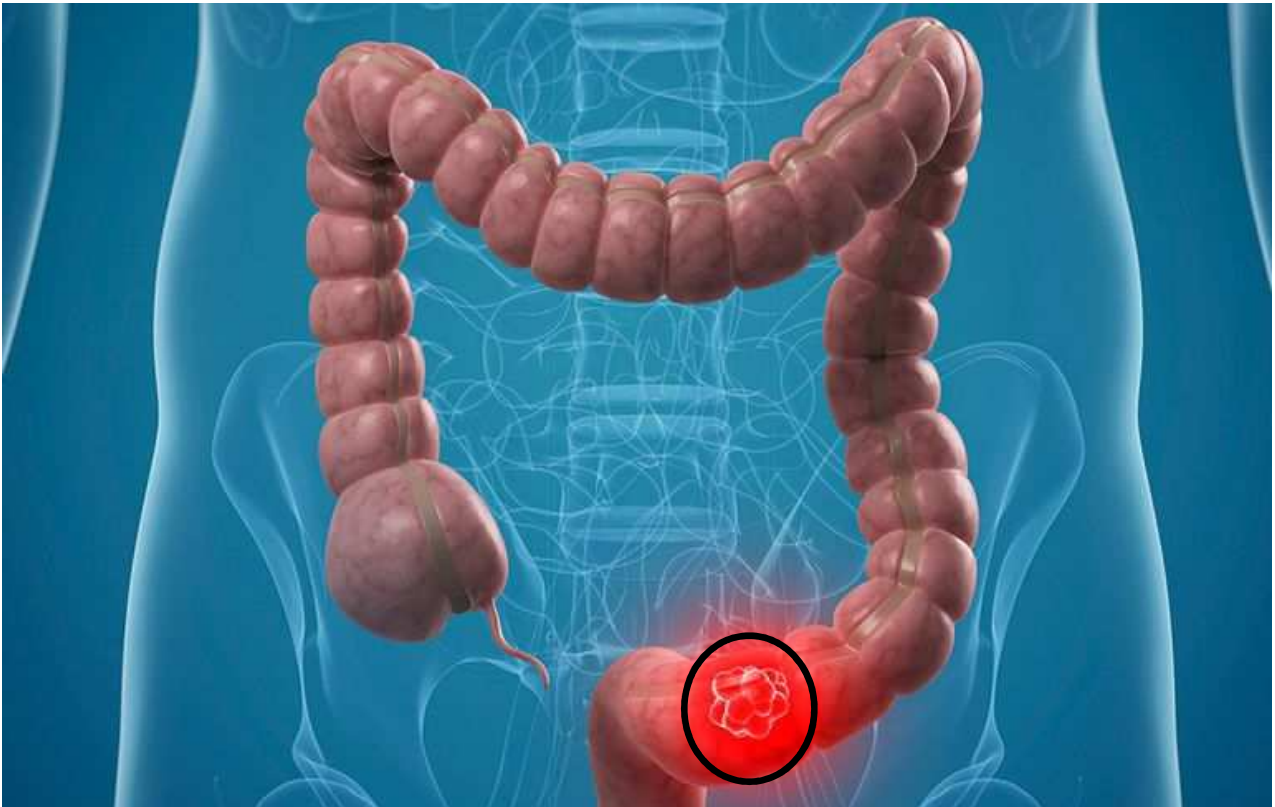
Examination of the researcher's awareness and openness about the research process and why a phenomenological method was used. There was a need to understand what the participant was saying and the world from which they come. The researcher's goal was to understand the nature of human experience after colorectal surgery when the five year mark was reached.

CHAPTER 10. CONCLUSION AND RECOMMENDATIONS.

There appears to be a current gap in existing literature and government policies and reports about what this group of patients needs are and will be during their longevity. Advances in cancer prevention, diagnosis and treatment mean more people are surviving cancer and this number is rising by 3% per annum. While increasing longevity rates are to be celebrated, the experiences and needs of those who have completed their primary cancer treatment are relatively neglected.

CHAPTER 2:

COLORECTAL CANCER.



(Black, 2012)

Modified from Getty Images <https://www.gettyimages.co.uk/license/535643931>.

Accessed 02/07/2018

Historical context.

For clarity, extracts are given of the historical context below.

The evolution of the stoma can be traced far back through history with the pre Christian Israelites being aware of the problem of abdominal injuries and the consequences of the spillage of 'dirt'. In the Bible (Judges 3, v 21-23) Eglon, the king of Moab, is stabbed by Ehud:



"He took the dagger and thrust it into his belly and the shaft went in after the blade so that he could not draw the dagger out of his belly and the dirt came out".

(Black, 2000).

Celsus (55BC-AD7) quoted by Dinnick (1934) noted that if the small bowel had been penetrated nothing could be done. However, he felt that if the large bowel could be sutured to the abdomen all would not be lost (Black 2000). Impediment of the artificial anus or stoma was considered by Lord Chesterfield (Black, 2000) to be defined as 'dirt' and as such, was matter out of place. Douglas (1966) describes 'dirt' as implying two conditions, a set of ordered relations and a contravention of that order (Black, 1992, Black, 2000).

The earliest recorded milestone in stoma surgery is the perfection by Heister, in

Flanders in 1707 (Black, 2000), of enterostomy operations on battle casualties. Heister attempted to fix injured gut to the abdominal wall to exteriorise it so that it could not slip back into the peritoneal cavity. He noted that when the wounded intestine had healed, faeces would no longer be voided by the anus but by the abdominal stoma. As to wearing a tin or cloths over the stoma to soak up the excrements he observed that this was troublesome but “it is better to part with one of the conveniences of life than to part with life itself” (Black 2000:34). Littre (1732) after dissecting the body of a neonate observed the imperforate anus and recognized that the rectum was divided into two parts both of which were closed and connected by a few strands of tissue (Black,2000).The upper portion was filled with meconium and the lower half empty. Littre (1732) presumed that it would be possible to bring the upper portion of the bowel to the abdominal surface as a stoma where it performs the function of an anus (Black, 2000).

Surgeon William Cheselden (1756) was noted to be one of the first surgeons to help perform a colostomy. He had noted that patients with congenital malformations or strangulated hernias developed preternatural exits for the intestinal contents, yet continued to live for many years. His patient Margaret White had developed an umbilical hernia 23 years previously and at the age of 73 her abdominal wall broke down, allowing the bowel to prolapse from the hernia orifice (Black, 2000). Cheselden (1756) removed the dead bowel and left the part that was still viable so that a transverse colostomy was raised. Margaret White lived for many years after this procedure excreting via the colostomy (Black, 2000).



(Black, 2000)

Surgeons working on the Napoleonic battlefields came to realise that if bowel injuries occurred, the dead bowel should be removed and the open bowel pulled through and sutured to the lower end of the wound. This would enable faeces to pass out of the abdomen in the hope that peritonitis could be avoided. A French surgeon, Dominic Larrey (Black, 2000), organised a surgical service for the assault on Cairo. He expounded that injured bowel should be exteriorized and in the theatre of war anastomosis of the bowel should not be undertaken. This was re-iterated by Ogilvie in 1944 when undertaking surgery in the Western Desert during the Second World War. Although there were occasional successes in raising stomas, the mortality rate was high as a result of peritonitis caused by faecal contamination. It was not until the second half of the 19th and early 20th centuries that some of today's procedures were developed (Black, 2000).

In 1887, Allingham performed a loop colostomy by bringing a loop of bowel onto the abdomen and passing a rod under the loop to prevent it slipping back into the abdominal cavity. A distal and proximal hole was made in the loop of bowel on either side of the rod. This procedure was used as a diverting procedure and is still in use today (Black, 2000).

From the middle of the 19th century until the present day, the basic concept of colostomy construction has remained unchanged, although many technical improvements have taken place. One improvement by Hartmann in 1923 was the elective resection of the recto-sigmoid cancer with a left iliac fossa colostomy. Patey and Butler followed in 1951 with abdominoperineal resection using colicutaneous suturing to remove cancerous growth that had extended into and past the anal sphincters (Black, 2000). Colicutaneous suturing and extraperitoneal colostomy helped to avoid the problems resulting from stenosis or prolapse of the bowel that had caused so many problems with earlier surgery (Black, 2000).

Epidemiology and aetiology.

Colorectal cancer (CRC) incidence is defined using the International Classification of Disease (ICD-10), tenth revision codes C00-C97 (WHO, 2016). Although examination of the data from the last 20 years reveals that there are marked divisions between the younger and older population with the incidence halving in

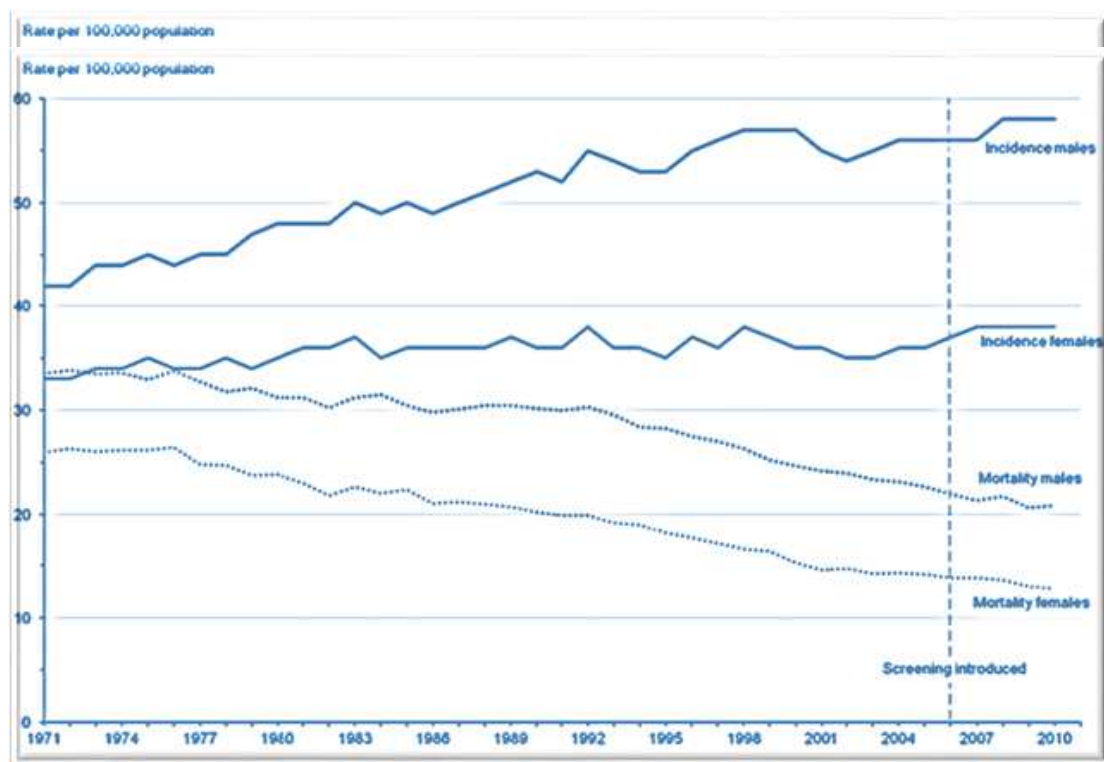
younger population, yet have risen exponentially in the older population. It is clear that an understanding of the molecular events that initiate and promote colorectal cancer development is important to allow the recognition and identification of the “at risk” individuals in diagnoses when histological methods are not sufficient. However, CRC was the third most common cancer in both males and females and the age standardisation incidence rate for CRC has remained fairly constant over the last 10 years (ONS, 2015). It is a common disease throughout developed communities across the world. It is increasingly being accepted that a degree of risk is environmental, with increase of disease risk found in people who are obese, inactive, smoke, drink alcohol, consume animal protein and fat intake, although reduced risk is seen in people who consume greater quantities of fruit and vegetables. Consequently CRC and the rising incidence of Diverticular Disease and colonic cancer in the Western world is seen to be generally higher in industrialised countries with a Western life style where there is an association with low dietary fibre intake and high intakes of processed fast food and obesity. Recent epidemiological studies into CRC and the role of folate may show that there is some influence in the way folate works in the silencing of DNA uptake and cell change (Giovannucci et al 1995, Kearney et al 1995, Chyou 1996) and the higher intake of fruit and vegetables have an association with protection from CRC and colonic polyps which are often precursors to CRC (Taylor et al, 2002).

Colorectal cancer (CRC) incidence rates in the United Kingdom (UK) are among the highest in the world (Cunningham et al, 2002) and updated figures from the Office of National Statistics for England (ONS, 2012) and Cancer Research UK show there were around 41,100 new cases of bowel cancer in the UK in 2013, equating to 110 cases diagnosed every day (CRUK, 2012). Bowel cancer is the fourth most common cancer in the UK (CRUK, 2013) and accounts for 12% of all new cases in the UK (CRUK, 2013). However, in males in the UK, bowel cancer is the third most common cancer, with around 23,000 cases diagnosed in 2013. In females in the UK, bowel cancer is the third most common cancer, with around 18,200 cases diagnosed in 2013. Almost 6 in 10 (58%) of these bowel cancer cases in the UK each year are diagnosed in people aged 70 and over (CRUK, 2011-2013) with most of the cancers occurring in the rectum.

Cancer of the anal canal or of the skin at the anal verge (anal margin carcinoma) is rare occurring in approximately 1-2% of all large bowel carcinomas and is less well documented historically. Today there is a much improved outlook and for this group

and there is much less likelihood of stoma formation in these groups of patients. This type of carcinoma is known as a tumour of squamous epithelial origin. Regional lymphatic spread will be to the inguinal lymph nodes and the para-rectal nodes. Here surgery would take the form of total rectal excision and permanent colostomy, but is often complicated by delayed perianal healing (Black, 2000). In the 21st millennium there has been a notable change in the way care of the patient with anal margin carcinoma is treated. Radiotherapy has various ways of helping the clinician treat the patient and has the ability to assist in the overall prognosis by promoting a curative response. However, for some patients with anal margin carcinoma it has been found that just having radiotherapy to the area can result in a curative outcome doing away with the need for surgery and a permanent colostomy (CRUK, 2014).

Table 2. Bowel cancer incidence and mortality rates, by sex, England, 1971–2000.

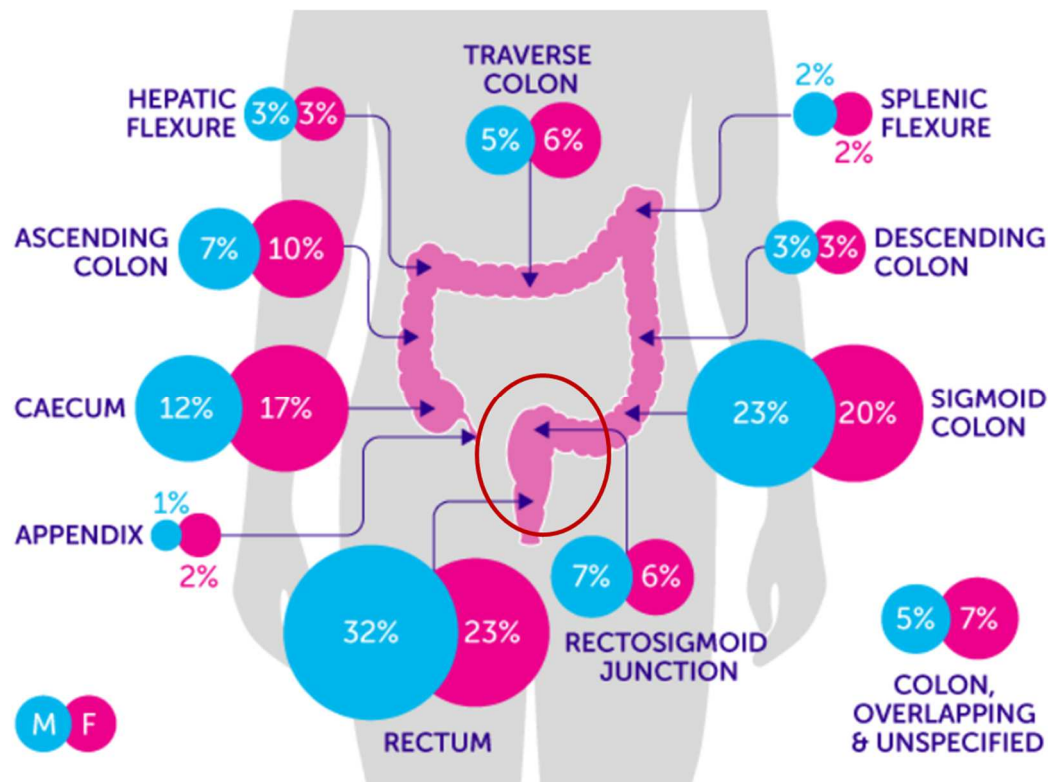


(Office for National Statistics 2016).

Since the late 1970s, bowel cancer incidence rates have increased by 14% in the UK. The increase is greater in males where rates have increased by around 19% rather than in females where rates have increased by less than 3%. However, over the last ten years bowel cancer increased by 5% in the UK. The increase is larger in females where rates have increased by 6%, than in males where rates have

increased by 3%. Bowel cancer in England is more common in males living in the most deprived areas but there appears to be no similar association for females (CRUK, 2012). The UK incidence rate is 20th highest in Europe for males and 17th highest for females. 1 in 14 men and 1 in 19 women will be diagnosed with bowel cancer during their lifetime.

Figure 1. Colorectal Cancer Site Incidence in %.



Modified from Cancer Research UK,
http://www.cancerresearchuk.org/sites/default/files/cstream-node/inc_anatomicalsite_bowel.pdf, Accessed May 2018. (Red circle denotes where 54% of colorectal cancers occur).

In a society where preventive medicine is increasing research suggests that there may be value in chemoprevention using non-steroidal anti-inflammatory drugs (NSAIDs) in reducing risk and/or prevention of CRC. Support for the direct effect of NSAIDs has shown evidence that it reduces the cyclo-oxygenase (COX) type 2 increases cellular components in colonic tumours and also that NSAIDs provide some protection in experimental colonic carcinogenesis and induce cell death or

inhibit colon cancer growth (Peleg et al 1994, Giovannucci et al 1995, Langman et al 2000).

Women who are prescribed oestrogen either after hysterectomy and bilateral oophorectomy or are menopausal, are shown to be at reduced risk of CRC. It is considered that reduction rates are as high as one third making hormone replacement therapy (HRT) equal to NSAIDs in the possible up-regulation of cells in CRC. However, many of the epidemiological studies that suggest that HRT is associated with protection against colonic cancers, there is not an overall agreement on this as the use of the oral contraceptive does not show the same outcome as using oestrogen only HRT and research is currently on-going in this area (Hoffmeister et al, 2007). This becomes a conflict for women taking HRT and also becomes a dilemma for Health Care Professionals (HCPs) as they need to weigh up the care/benefit ratio and therefore there is a great need for women to have an advanced health assessment post treatment.

Two decades ago the NHS Executive, (1997) formally raised awareness of CRC, which over the years had not enjoyed the same public, political and professional profile that breast cancer has. A professional concern has always been that there is less understanding, even in 2016, from the public about symptoms of CRC, facilitating early diagnosis of the disease. Their report built upon the Calman / Hine (1995) report on cancer policy for the commoner cancers and focussed on the role of the health care professional and managers regarding improving services for CRC (NHS Executive, 1997). Within the NHS at the time of publication of the report, there were no national screening programmes for CRC and little pressure to develop services. However, the NHS Executive (1997) report proved to be a pivotal time for change in CRC policy. Their plan outlined radical reform of the UK's cancer services with the aim of improving outcomes and reducing inequalities in National Health Service (NHS) cancer care. Its main recommendation was to concentrate care into the hands of site-specialist, multi-disciplinary teams. At the time research had shown that there was sufficient scientific basis for screening the population for CRC and the clinical guidelines for CRC were published by the Royal College of Surgeons of England and the Association of Coloproctology of Great Britain and Ireland (ACPGBI, 2007).

The Development of Screening in the UK.

One of the main themes in the guidance document (NHS Executive, 1997) was the quality of diagnostic services, noting that imaging and histopathology are of importance but the most crucial element would be the endoscopic service and adequacy of this service would become vital as the utilisation of good endoscopy facilities would be needed for bowel screening. In 2003 the government committed to providing a colorectal cancer screening programme aiming to treat and diagnose patients at the earliest stage, with enhanced endoscopy services supported by Faecal Occult Blood Tests (FOBT) undertaken in the person's own home. It has been shown that 50-58% of people invited to take up bowel screening do so within six months of the invitation (CRUK, 2016). In England where the initial faecal occult blood test (FOBT) result is not seen as definitive, a conclusive result is sought through two repeat FOBTs. The FOBT is to detect early stage CRC and is based on the assumption that small quantities of blood lost from the tumour can be detected in the stool sample. The recommendation of sample collection by the person undertaking the screening is to take a smear from 3 consecutive stool samples and place on the card that is supplied and send it back to the screening hub.

For FOBT to be effective there needs to be compliance of the population and it is important that return rates are higher in the older generation as CRC is age related and CRC incidence exponentially increases with age. In areas with low socioeconomic status, compliance has been found to be lower than the middle classes and this is seen in all health interventions in this group of the population (Hart, 1998, Cunningham et al, 2002). Of those screened around 8 in 10 (79-83%) people who have an abnormal bowel cancer screening result in England are referred for colonoscopy. The remainder do not have a colonoscopy either because a specialist screening practitioner decides colonoscopy is not necessary/appropriate, or the screened person fails to book or attend a colonoscopy (Logan et al 2012). 2%-3% of people who have bowel cancer screening in the UK have a definitive positive (abnormal) result, in any given screening round. Positivity rates are slightly higher in first screening than in subsequent screening. There appears to be more time for tumours to develop before the first screening than before the subsequent screening which, is to be expected.

Bowel cancer is found in 12-15% of men and 8% of women who have colonoscopy or other investigation following an abnormal bowel cancer screening result in

England. Bowel adenomas (polyps in the colon that differ microscopically from normal polyps) are found in 48% of men and 35% of women following colonoscopy in England, and of these 59% in women and 66% in men are intermediate-risk or high-risk. No abnormality is found in around 24% of men and 38% of women following colonoscopy in England.

At the time of writing, a policy has been agreed that in the next 2-5 years action will be taken after a single stool sample, which will prove to be more beneficial, as many patients will not collect 3 samples. The need for improvements to the bowel screening programme was set out in the new cancer strategy for England (ICT, 2015). At present just 58% of people who are sent the test return their samples for testing – and in some parts of England this figure is much lower. Therefore, the Five Year Forward View (FYFV) is that the screening uptake will increase with an ambition of 75% for FIT (single sample) test in the bowel screening programme by 2020, as take up is still less than hoped for (ICT, 2014). The new procedure will be offered to all men and women aged 60 to 74 every two years in a bid to spot the early signs of bowel cancer, and it is hoped that the single sample will encourage more people to undertake the screening process. The new kit relies on a method called the Faecal Immunochemical Test (FIT), which looks for hidden blood in stool samples. It is also far easier in terms of analysis to use than the current method that requires two samples from each of three separate stool samples, as by contrast the FIT test only needs one sample.

It is hoped that the new test will increase screening uptake by around 10% - meaning an additional 200,000 people could be tested each year. It could potentially transform the effectiveness of bowel cancer screening and early diagnosis of the disease. This bowel screening programme is crucial for the reduction bowel cancer, and research shows that this change will make the test even more effective.

The Five Year Forward View.

The Five Year Forward View (FYFV), this key statement, by the Independent Cancer Task Force, (ICT, 2014) focuses on the outcomes that matter most to patients and society and the need to ensure that there is a reduction in the incidence of cancer therefore improving the patients' experience and quality of life. In changing CRC screening several things need to be taken into account and the terms efficacy, effectiveness and efficiency were first defined by World Health Organisation expert

group in 1970 (White, 2000):

- Efficacy is described as the benefit or utility to the person of the service, treatment regimen, drug or preventive or control measure advocated or applied.
- Effectiveness of the activity and the end results, outcomes or benefits for the population achieved in relation to the stated objectives.
- Efficiency is described as the effects or end results achieved in relation to the effort expended in terms of money resources and time.

The outcome of the efficacy of CRC screening is the measure of reduction in incidence or mortality of those persons who access the service. Effectiveness is a measure of the CRC screening of the reduction of incidence or mortality in the whole community who are offered the test. Efficiency of CRC screening is dependent on the test not being carried out in isolation but being done at regular intervals and will depend on the proportion of the community who access the procedure

Performance Metrics suggest that in the FYFV (2015-2020) much could be done to slow the rise in the numbers of patients being diagnosed with cancer each year. The increasing incidence places a considerable burden on the NHS and upon patients and their families, as they undergo intensive and sometimes debilitating treatment. Therefore the FYFV recommends that attention is placed on two key ambitions, these are:

1. A discernible fall in age-standardised incidence of cancer and a reduction in the number of cases linked to low socio-economic groups. Although overall incidence has been rising, and there has also been an increase (5%) in age- standardised incidence rates over the last ten years. Prevention efforts such as screening, especially CRC screening, take time to feed through into incidence, beyond a five-year timeframe, but setting an ambition that is measured and reported on will keep the focus on these efforts. It will be in the longer term that benefits will be seen.
2. By 2020, adult smoking rates will have fallen much further. Smoking remains by far the largest modifiable risk factor for cancer, responsible for around 60,000 new cases per year in England. This strategy sets a specific ambition that adult smoking rates should fall to 13% by 2020.

Longevity.

For improvements in longevity, it will require a combination of earlier detection and diagnosis, better treatment and access to treatment, improved access to data and intelligence and reductions in variability around the country. There are three areas for focus:

1. Increase in one-year survival, with a reduction in Clinical Commissioning Groups (CCGs) variation. Living one year after diagnosis is clearly a pre-requisite for long-term life expectancy and data is available much sooner, which enables commissioners and providers to track progress. Having one-year expectancy trends beside the staging data, will specifically enable progress to be assessed on earlier diagnosis. It is suggested that one-year life expectancy should reach 75% by 2020 for all cancers combined, compared with 69% now. Reducing variability will be a key driver of overall improvement at the population community level. Variability cannot be eliminated entirely but raising cancer life expectancy across CCGs towards the highest levels should be possible
2. Increase in 5 and 10-year longevity after therapeutic intervention has ceased. It is far more meaningful for patients to have a ten year life expectancy than one or five years. Many experts believe it should be possible that, by 2034, that 3 in 4 patients in England diagnosed with cancer will have a life expectancy of at least 10 years following their diagnosis, compared with 50% now. This will therefore benefit around 150,000 patients per year. By 2020, 57% of patients should be surviving ten years or more after cancer treatment.
3. Reduction in life expectancy for older people has shown that recent international comparison data suggests that the deficit in life expectancy is even greater for older people than it is for younger age groups for some types of cancer. If the gap with other countries is to be narrowed, there is a need to do so with older patients.

The FYFV perspective of patient experience of quality of life.

The report (ICT, 2014) argues that the NHS will need to move to become a more patient-centered service in line with a change in the relationship between patients and professionals. In addition they comment on the need to transform the approach towards supporting people to live well outside hospital and to return to their lives as far as possible after treatment has ended. This can only be achieved with a significant focus on measuring and improving people's quality of life. For some areas,

there are no reliable measures, so these will need to be developed over the coming years and with continuous improvement in patient experience. In the latest Cancer Patient Experience Survey (CPES, 2014), 89% of patients said overall their care was excellent or very good. The report accepts, as the Picker Institute (2009) suggests, that patient expectations will continue to increase in coming years, so that maintaining or improving on this level of satisfaction will require considerable effort. Some areas of the country currently score poorly on patient satisfaction measures and it is expected that these areas will have to deliver significant improvement in the coming years. CPES (2014) should continue to evolve and will have to be repeated every year, with patient satisfaction measured for every hospital and CCG.

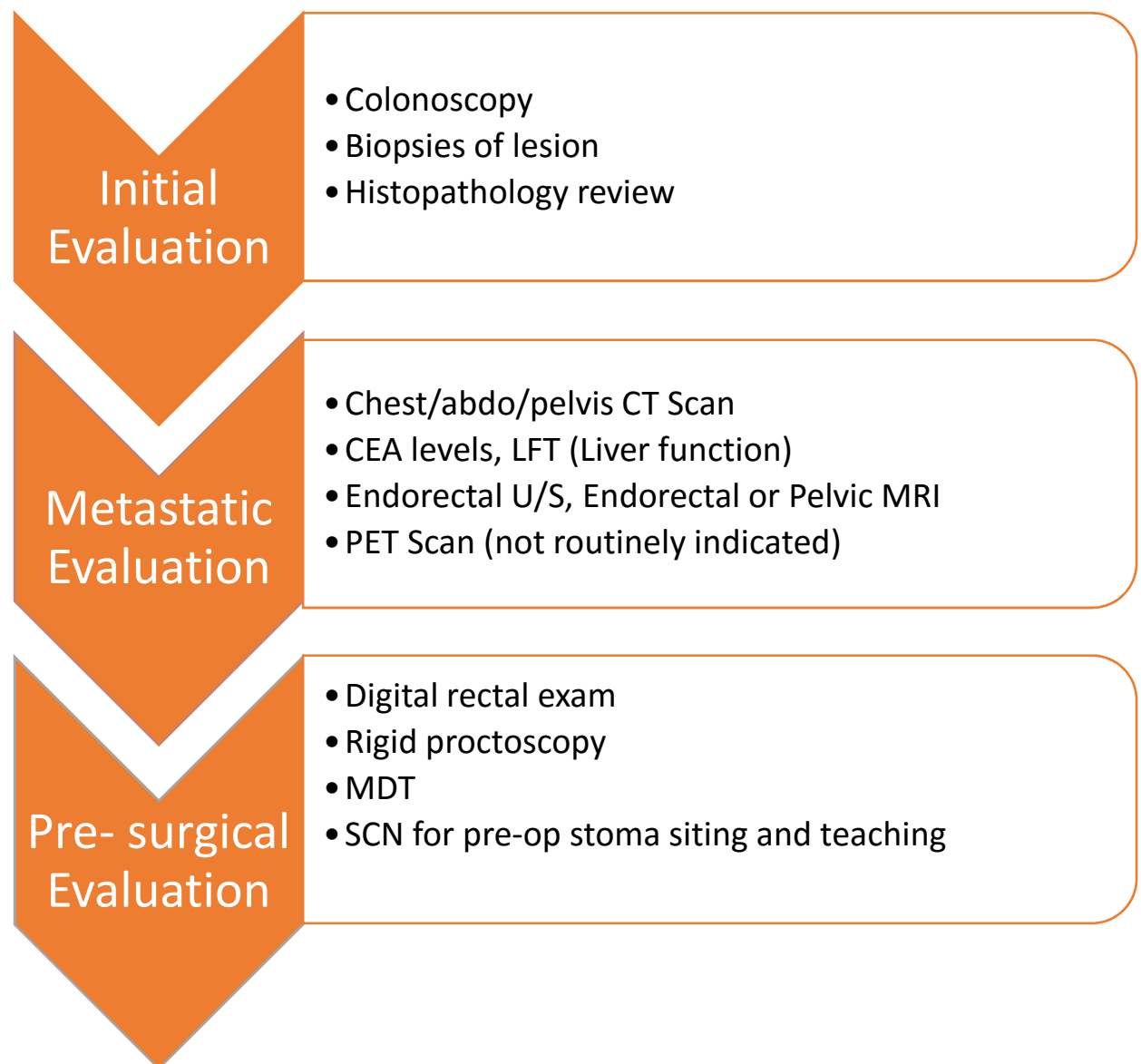
There also need to be strategies to enhance continuous improvement in long-term quality of life enabling people with cancer to lead healthy, fulfilled and productive lives as far as is possible. This should be regardless of whether they have completed treatment or are living with an advanced and incurable form of the disease. These should be supported by a national metric of quality of life, underpinned by a robust approach to measurement, which will incentivise the provision of better aftercare interventions, as well as more informed choice at the point of diagnosis.

Today, many of the metrics proposed in the FYFV are only available after a considerable time lag due to data collection and publication. It is important that commissioners and providers have access to more rapid feedback on the impact of interventions and more timely intelligence on the likely trajectory against the ambitions set out in the performance metrics. These metrics should be a key focus for Cancer Alliances, as the main vehicle for local service improvement.

A key recommendation is that NHS England, working with the other Arm's Length Bodies, should develop a cancer dashboard of metrics at the CCG and provider level, to be reported and reviewed on a regular basis by Cancer Alliances.

The dashboard will be generated by the National Cancer Intelligence Network (2015) in conjunction with NHS England. For people dying from cancer, there is a need for strategies within the system to ensure these patients and families experience a "good" death, with their preferences taken in to account. Much of end of life care is provided outside the NHS and suitable metrics have been proposed by these organisations. (Appendix 1).

Figure 2. Today's Pre-operative Stratified Care Pathway.



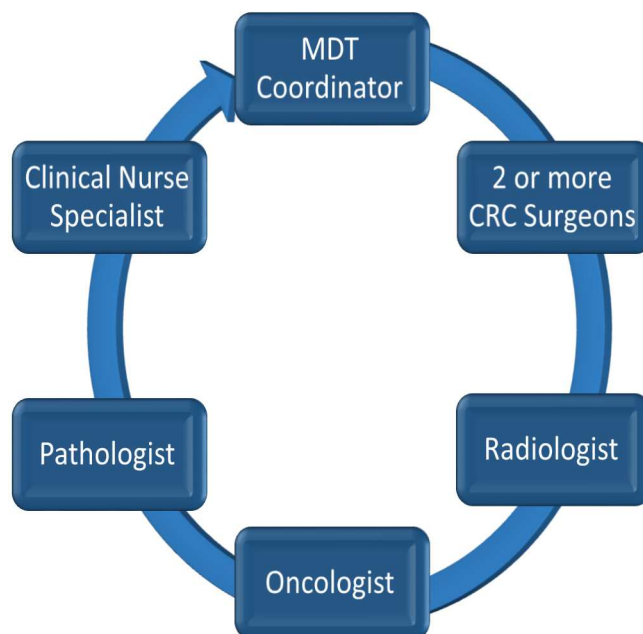
(Black, 2017)

The diagnosis of CRC is devastating for most individuals, with patients and families having to adapt to long term changes in the individual's health status and possibly a reduction in income if working, and in some instances a poor prognosis. The fear of cancer remaining is always uppermost for many people. When colorectal cancer is diagnosed it is important that assessment and discussion with a plan of care are undertaken as quickly as possible with a date given for the surgery to take place in the following thirty-one days. These "gold standard" guidelines are based on the recommendations of the Calman-Hine Report (1995) and the NHS Executive Report (1997a, 1997b). Giving a diagnosis such as CRC in clinic means the individual is

then bombarded with treatment options, percentages of disease recurrence, research trials and possible on going treatment after surgery. It is no wonder that many report that they find this stressful and worrying and cannot remember what they were told. Often faced with this scenario, individuals say afterwards that their mind turned to jelly and that they could not remember what the consultant had just told them, let alone come to an educated or informed decision.

The initial consultation of diagnosis and staging is always with a colorectal consultant and in clinic abdominal examination, rigid sigmoidoscopy followed by blood tests will be done. They are likely to be given appointments for a virtual colonoscopy, computerized tomography scan (CT scan) and if rectal cancer is suspected a magnetic resonance image scan (MRI scan) of the chest, abdomen and pelvis to ascertain if there is metastatic spread. After all tests are completed the consultant takes the patient's results to the colorectal multidisciplinary team meeting (MDT).

Figure 3. The Multidisciplinary Meeting (MDT).



(Black, 2017)

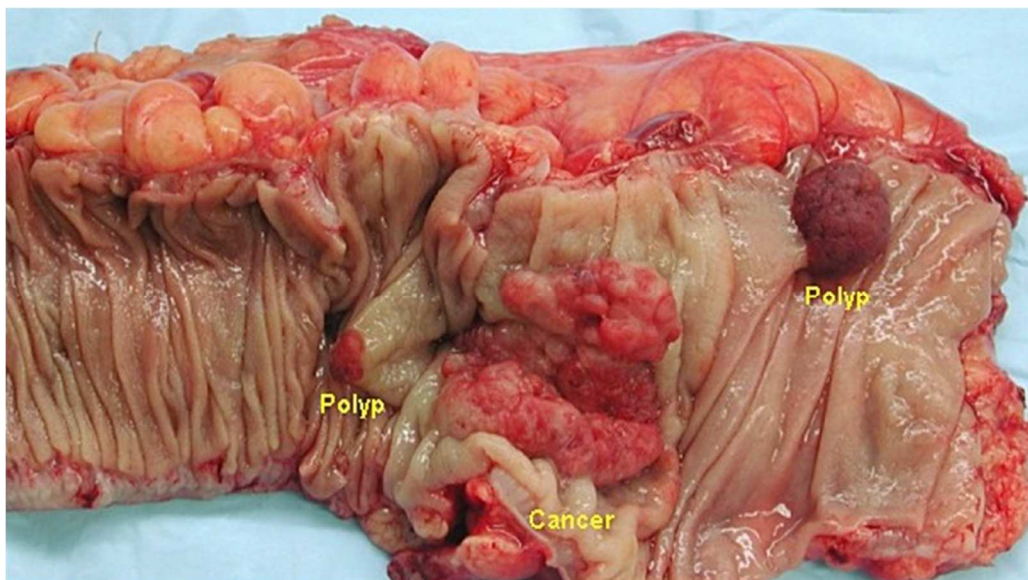
The MDT consists of core members with recognized specialist expertise in colorectal cancer including specialist nurses. This organization of care through a multidisciplinary approach with support teams specializing in specific aspects of the cancer journey is seen as a necessary starting point for optimal care and improved outcome, based on nationally agreed protocols (NICE, 2004 ACPGBI, 2007). At the MDT meeting the decision is made as to whether the patient should go for neo-

adjuvant therapy first or primary surgery and a colostomy possibly followed by adjuvant therapy. The decision regarding adjuvant therapy can only be made when the post-operative histological results are available.

Colorectal surgery.

Cancer of the left colon, low colonic cancer, rectal and anal cancer will invariably need a permanent colostomy as curative excision involves complete excision of the primary tumour and disturbance or removal of the anal sphincter. The aim is to ensure that the margins around the tumour are free, up to 2-5 centimetres from the tumour to prevent local recurrence.

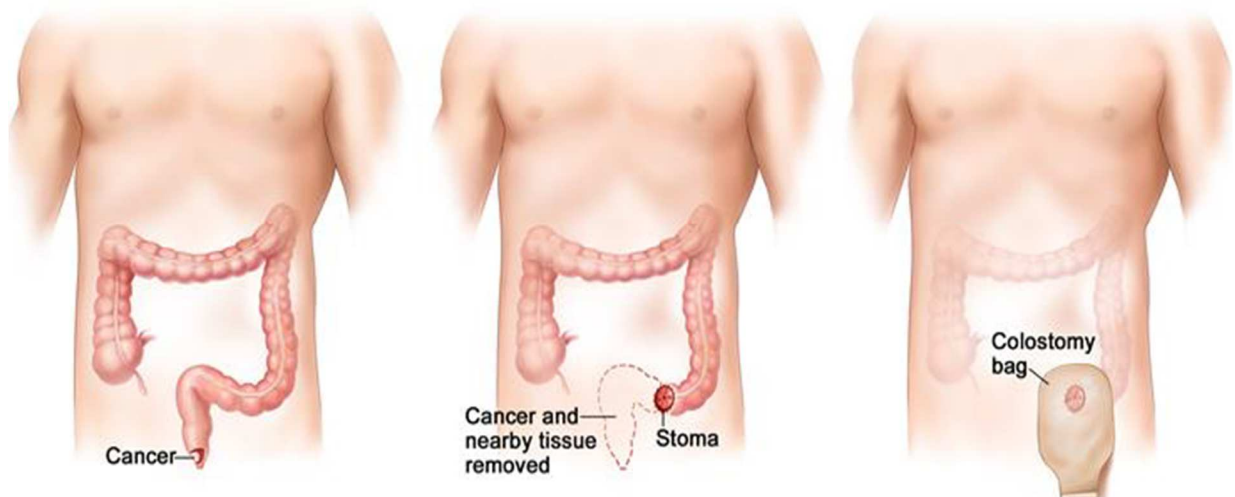
Figure 4. Dissected segment of diseased colon.



(Black, 2013. The Hillingdon Hospital NHS Trust).

This dissected segment of the lower colon shows 2 polyps, one small and a second larger polyp. Polyps are pre-cursors to colorectal cancer. The tumour between the two polyps is shown inside the dissected colon. The tumour does not appear to have exteriorised itself through the bowel wall making the grading as a possible Dukes A/B or T1/T2, N0.

Resection of the Colon with Colostomy



National Cancer Institute, <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/abdominoperineal-resection> Accessed May 2018

A left hemi colectomy is performed for all tumours of the descending colon down to the sigmoid colon. The peritoneal reflection on the lateral aspect of the colon is divided and the blood supply includes the left branch of the middle colic artery, the left colic artery and the superior haemorrhoidal artery along with lymph nodes from the area. Depending on the surgeon's expertise and technique a colostomy may be raised. A colonic cancer in the sigmoid area of the bowel can be removed by a less extensive procedure than the left hemi-colectomy. The sigmoid vessels are divided from the inferior mesenteric artery as this procedure ensures that there is still a good blood supply to the left side of the colon.

Cancer to the rectum is treatable and surgery is the primary treatment with it being curative in approximately 50% of all patients. The surgical treatment of rectal cancer is more complex than that of colonic cancer and a decision has to be made whether the anal sphincters can be saved. Any degree of damage to the anal sphincters will cause the patient to be permanently incontinent of faeces.

Figure 5. Colostomy.



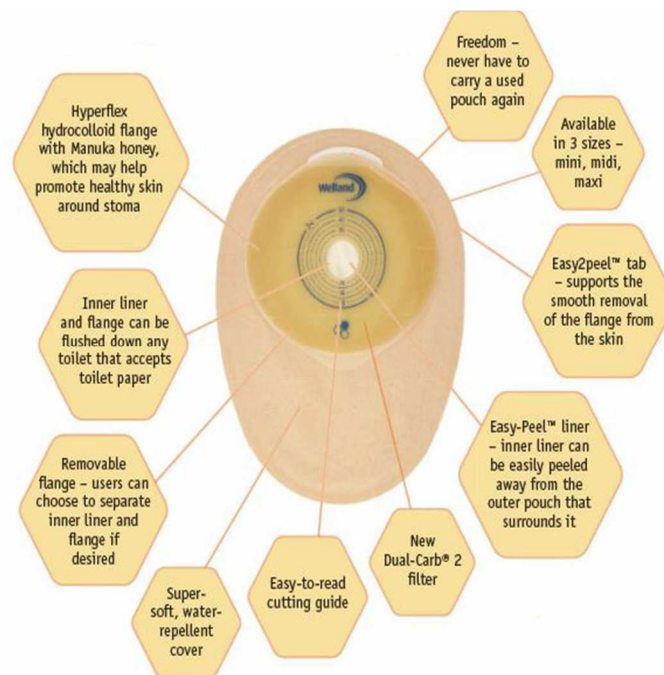
(Black, 2013, The Hillingdon Hospital NHS Trust).

Figure 6. Patient with colostomy appliance in situ.



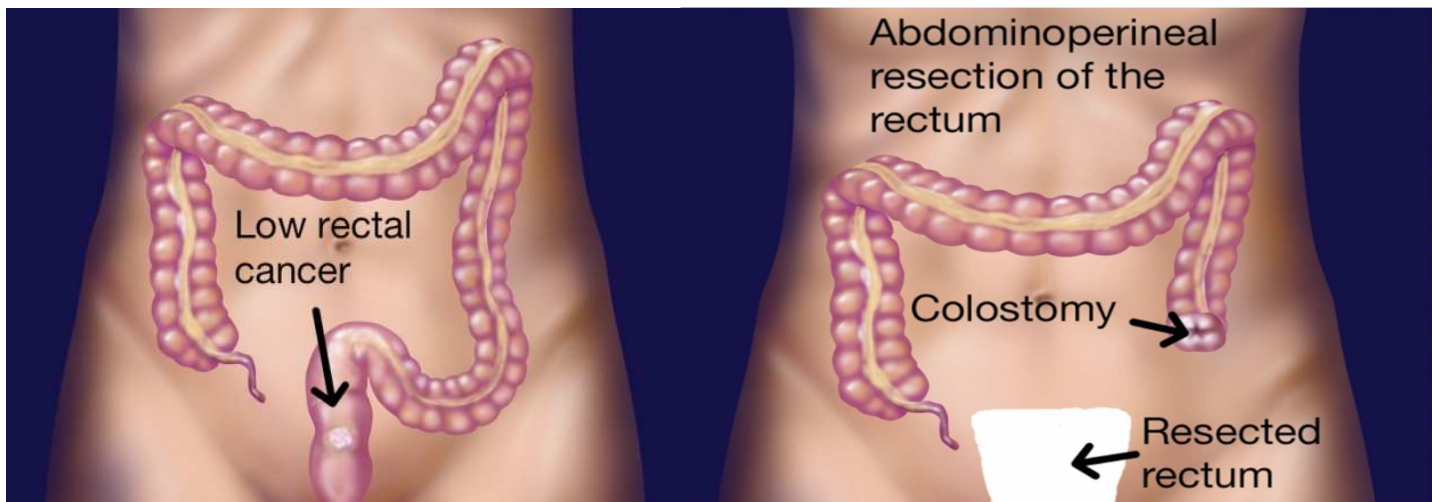
(Black, 2013, The Hillingdon Hospital NHS Trust).

Figure 7. The essential components of a one piece colostomy appliance.



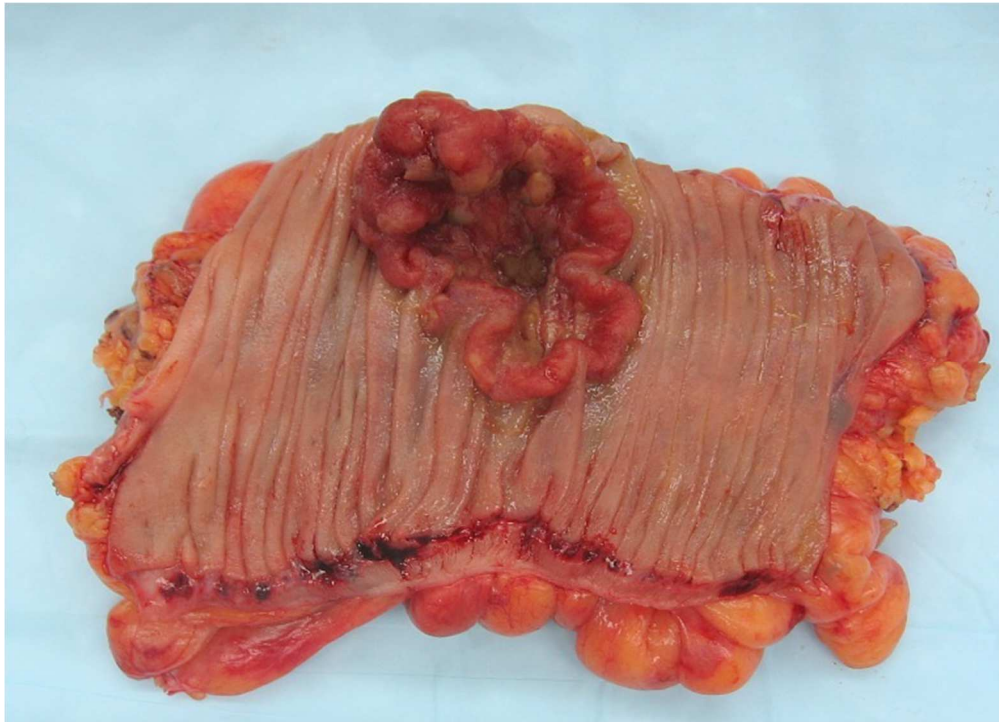
(Welland Medical,2015).

Figure 8. Abdominoperineal Resection of the Rectum (APER).



(Black, 2000)

Figure 9. Anal Cancer.



(Black, 2013. The Hillingdon Hospital NHS Trust).

This dissected section with anal cancer insitu includes removal of the anal sphincter as clear margins cannot be obtained. It would leave the patient incontinent, and therefore a permanent colostomy is needed.

Abdominoperineal excision of the rectum (APER) is the gold standard (Keighley and Williams, 1999) procedure for cancer of the rectum and removal of the anal sphincters equates with a permanent colostomy. With this operation there is significant risk of sexual impairment and/or urinary dysfunction in both male and female patients undergoing this operation. This operation has been the operation of choice for patients with rectal cancer and was first described by Patey and Butler 1951 (Black, 2000). The overall five-year relative survival of colorectal cancer patients in England is 50.7%. There is, however, variation by the stage of disease at diagnosis. 93.2% of patients diagnosed as Dukes A survived five-years from diagnosis compared to only 6.6% of those with advanced disease which has spread to other parts of the body at diagnosis (Dukes D). Currently only around 13% of colorectal patients are diagnosed with a Dukes A cancer but this proportion should increase as a result of the national bowel cancer screening programme.

Table 3. Comparisons of Dukes staging and the American TNM staging system.

Stage at diagnosis	Number of cases	Percentage of cases (%)	5-year relative survival (%)
Dukes A	26,727	8.7	93.2
Dukes B	74,784	24.2	77.0
Dukes C	72,806	23.6	47.7
Dukes D	28,377	9.2	6.6
Unknown	106,040	34.3	35.4
Total	308,734	100.0	50.7

Dukes Grading. Number of cases between 1996-2006 (England) of 5 year relative survival of colorectal cancer patients by stage at diagnosis. (NCIN, 2010).

Table 4. The American TNM staging system.

Tumour	
T1	Tumour only in the inner layer of the bowel
T2	Tumour has grown into the muscle layer of the bowel
T3	Tumour has grown into the outer lining of the bowel wall
T4	Tumour has grown through the outer lining of bowel wall (into another part of the bowel or another organ)
Node	
N0	No lymph cells containing cancer cells
N1	1-3 lymph nodes close to the bowel contain cancer cells
N2	4 or more nearby lymph cells contain cancer cells
Metastasis	
M0	Cancer has not spread to other organs
M1	Cancer has spread to other organs

(Cancer Research UK, 2010).

Today it is common for most MDT's in England to classify bowel tumours with the newer American TNM staging.

The Way Forward.

Over the years, due to the perceived stigma of having a permanent colostomy, surgeons have researched ways of operating on low and ultra-low CRC without the need for a permanent colostomy. However, for all the patients in this research, their colorectal surgery was done more than five years ago with many of them having had surgery in the previous 3 decades, therefore having a curative operation but left with a permanent colostomy. For many, but not all patients today, where there is access to a highly experienced colorectal surgeon, the prospect of colorectal surgery leading to a permanent colostomy may be avoided. This is because of the introduction of more advanced surgery for colorectal cancer known as total mesorectal excision (TME). This has become a standard surgical procedure and the base for improved clinical outcomes. TME is a system of colorectal cancer surgery management that defines the block of tissue to be excised and how this is to be achieved. It is now readily comprehended by non- surgeons such as the other members of the MDT, because of the development of specialised MRI radiologists and the superior images that are resultant of this technique. These images demonstrate the contours of the mesorectum and the distribution of the cancer within it.

Figure 10. Radiological image prior to TME.



(Black, 2013, The Hillingdon Hospital NHS Trust).

These images will therefore allow a rational basis for selecting cases for neo-adjuvant radiotherapy (DXRT) and / or chemo-radiotherapy (ChemoDXRT) where the mesorectal margin is liable to be damaged during surgery. This improvement in colorectal surgery in the 21st millennium shows that it is clear that local recurrence surgery has a substantial effect on overall survival due to the fact that many local recurrences are due to regrowth of local mesorectal residues (Heald, 1995). The Lehander-Martling et al (2000) reported the most significant evidence coming from

two groups, the Stockholm Colorectal Cancer Group and the Basingstoke Bowel Cancer Research Project, which showed a major impact of the surgical teaching programmes in an entire population using the TME approach (Lehander-Martling et al, 2000). Both permanent colostomy and the rate of local recurrence had been more than halved for the entire population of Stockholm County (Lehander-Martling et al, 2000). Until the use of TME there was an arbitrary 5 centimetre distal margin at operation in an effort to avoid damage to the anal sphincters and local recurrence rates were between 25%-50% with recurrence in the pelvis commonplace. When TME is taught to surgeons their success rate will be measured by the histopathology with patients being able to avoid the necessity of a permanent colostomy.

Late Effects of Chemo-radiation	Late Effects from Surgery
<ul style="list-style-type: none"> • Second malignancies • Neurocognitive deficits • Cataracts • Dental caries • Hypothyroidism • Pneumonitis, pulmonary fibrosis • Coronary artery, Valvular, cardiomyopathic and pericardial disease • Bowel stricture • Radiation proctitis • Radiation enteritis • Bladder scarring • Infertility, impotence, premature menopause • Lymphoedema • Bone fractures 	<ul style="list-style-type: none"> • Cosmetic effects • Functional disability from limb amputation or organ (e.g., bowel, bladder or sexual organs) • Pain • Scarring/adhesions • Incisional hernia • Parastomal hernia • Lymphoedema • Systemic effects

Table 5. Showing late effects from Surgery and Chemo-DXRT.

Living with a colostomy.

It is impossible to separate our bodies from who we are and what we do in the world. Our daily activities of work, play, family and friends are perceived through our bodies in our relationships with others and in this process we learn about ourselves. Finlay (2011) suggests the body is fundamentally implicated in all lived experience. Therefore when colorectal cancer is diagnosed and another way of excreting is explained (colostomy) the individual feels that their body becomes objectified and the

individual may experience feelings of shame, disgust, not in control, anger and exposed. Firstly, in becoming a colorectal cancer patient the diagnosis initiates a process in which the individual has to come to terms with their bodily changes that the cancer will make and interpret the symptoms and try to understand the disease in their own body. Secondly, and more difficult for the patient, is the coming to terms with the colostomy and its incontinence (Annells 2006, PROMS 2012, Burch & Black, 2017).

The social taboos that surround body matter elimination in Western cultures are legion so that when a colostomy is 'raised' as a surgical procedure to eliminate faeces from the body, the individual's body image changes forever. Body image is the mental picture the individual retains of their physical being that develops from birth and continues throughout life. It is related to different factors affecting its formation and dynamics. A crisis such as the creation of a colostomy leads to an alteration in body image and an awareness of the meaning of the change in appearance and function of an individual. The intensity of emotional reactions to body changes such as a colostomy, are less related to the severity of the disability than to the assigned importance of the structure and this appraisal depends among other factors on the individual's immediate social situation and past experiences. Many factors affect this adaptation to an alteration in body image and are relevant to the patient and family. These factors include, but are not limited to: the disease process, diagnosis, treatment and medical and nursing care, both in the hospital and return to the community (Black, 2000).

In today's Western culture an individual's feelings about body matter elimination are embedded deeply within the psyche and are associated with it being a private function, best managed in one's own home and this can be related to the notion that 'dirt' is harmful, both to the individual and others. The individual with a colostomy may see themselves as a person who has transgressed certain social expectations and personal responsibilities. Throughout each culture and society, excretion and excretory behaviour are rigidly controlled and there are strong prohibitions in Western societies on the uncontrolled passage of urine and faeces. Prohibition dealing with excretion is extensive and has been equated with madness, danger or witchcraft. To excrete through a different body exit requires a specific schema for the individual and their society to understand, in order that the individual does not become a marginal member of that society. For the individual with a colostomy there is the risk that they will be placed in a liminal position and considered dangerous

within their own society (Black, 1992).

Within society a change in body image can be seen as the representation of a social body. The body in health offers a model of wholeness yet the body in sickness offers a model of social disharmony, conflict and disintegration (Sutherland et al 1952, Douglas 1966, Holden & Littlewood 1991, Bekkers et al 1996, Black 2000, Helman 2007, Black 2017). The change in body image from the raising of a colostomy is anomalous with a rite of passage and this rite of passage is not purifactory but prophylactic (Black, 1992, 2000). The individual's status within society is not being restored but redefined and passes through a transitional social state that is deemed by society to be dangerous. An individual, after stoma surgery has been undertaken, will experience anxiety and even terror in the relation to pollution beliefs. Although pollution beliefs are a cultural phenomenon, fear is exhibited by the individual in understanding how they will modify their behaviour and hide their stigma on return to their culture and the society from whence they came (Goffman 1968, Holden & Littlewood 1991, Black 2000, Kilic et al 2007, Reimer & Nichols 2011, Black 2012).

For the individual undergoing a colostomy other sources of stress arise such as the threat to body integrity, permanent physical change, loss of autonomy, loss of control and a cancer diagnosis. Kelly (1985: 517-525), one of the earlier patient researchers, graphically recalls his feelings after stoma surgery:

"The protruding stoma and its attachments looked horrible.... moreover, I now realized how uncontrollable it was and what being permanently incontinent implied..... What really alarmed me were the physiological consequences, especially the incontinence and smell..... these I believed would become the deforming characteristics of my social identity and everything about me, my relationships, the way others viewed me, would be conditioned by these".

Kelly (1985) is implying that the sudden shock and post-operative response may be profound and that the individual feels there has been an assault their body and self-image. The individual finds himself or herself in a situation, which they define as threatening and feel powerless to do anything about it.

Individuals who undergo stoma surgery will often use the term "stigmatised". This originally comes from the Greek term and it was used as a term to refer to bodily signs designed to expose something unusual and 'bad' about the moral status of the signifier. Patients today refer to what they see as a socially unacceptable sign of physical disorder but it often applies to the disgrace rather than the bodily evidence.

In this instance, stigmatisation by exteriorising the excretory organs, especially later in life can lead to an individual having problems with re-identification of themselves or developing disapproval of themselves. The sudden change caused by the equally sudden change in body image is expressed as distortion of the total self. It gives rise to confusion and negative changes in self-perception. For those individuals who had a prior high self-esteem of their physicality, the body image change and presentation of self will be far harder for them to accept. While the stoma is disfiguring to the body it may well be more disfiguring to the mind. Kelly (1985: 517-525) again describes his feelings of possible ostracism by his friends and work colleagues:

".....for the rest of the day I felt utterly wretched, sad and overwhelmed by a sense of loss and failure..... I was not upset by the loss of my bowel per se, but rather the loss of its function..... my sense of failure came from viewing my body as having been wrecked by surgery....."

Body Image.

Adaptation to the changed physical body and to the psychological body image picture that the individual holds is a complex phenomenon. Intrinsic factors such as the individuals' coping mechanisms and extrinsic factors such as the socio-cultural background of the society or community the individual comes from, will have an impact on how the individual perceives their colostomy (Porrett & McGrath, 2005).

Sharpe et al (2011) and Ang et al (2013) suggest that there are many factors that have a positive or negative effect on the individual's adaptation to stoma formation. Psychological issues are underemphasised in clinical practice and many CNSs disregard the cues the individual is exhibiting as they have little or no experience on how to deal with these issues or where to refer the individual to.

However, body image has attracted a wealth of literature from many perspectives and disciplines and body image is a fundamental element of how the individual views themselves (Bekkers et al 1996, Aron et al 1999, Helman 2007, Noone 2010, Taylor et al 2010, Finlay 2011, Van Mannen 2014, Burch & Black 2017). Kelly (1992) suggests that self and identity are in an ever-evolving process of becoming and are never thought to be complete. Shame and its effect are characteristic of individuals who undergo stoma operations, more so those for whom it is going to be a permanent situation. Characteristically, the effect of shame is to hide away, withdraw from society, and not discuss the operation or outcome. Individuals have cited the feelings of tears, frustration at their own behavioural attitudes, helplessness and

worry what others will think of them. Often the biggest fears are the lack of control of the phenomena of odour, noise and the very real impact of leakage of the appliance whilst in a public place. Holden & Littlewood (1991) suggest that bodily secretions are the objects of taboo as they may be a threat to primary discrimination as they are part of the individual's person. There is a social and cultural order that the individual belongs to with norms of conduct that have effective social sanctions and the ability to know what is and what is not one's "self" is culturally constituted. The control of excreta is a boundary that the individual and their society have drawn between themselves and the outside world and when this boundary is transgressed the individual finds it profoundly disturbing. This breakdown of the accepted boundary between self and the outside world can violate the individual's sense of worth (Black, 1992). In Western culture if an individual can define oneself as "sick" then acts of excretion that are out of place can be considered to be "forgiven" and the individual does not become socially ostracised. However, if the individual is not able to declare themselves as "sick" either because they cannot or do not wish to, incontinence objectifies the individual to a childlike state.

Colostomy disposal can affect the individual's psychological wellbeing and body image. The work of White (2002) and McKenzie et al, (2006) used a multi-centre study (n=86) of colostomy patients four months after surgery to examine the psychosocial correlates of colostomy patients across Scotland. Pouch change and disposal confidence was shown to be significantly associated with negative thinking about life with a stoma and the lack of confidence in managing social demands of their lives by avoiding social and leisure activities. In assessing the psychological distress factor of having a colostomy 45% of interviewees believed the colostomy ruled their lives, 41% of interviewees did not feel in control of their body and 23% of interviewees believed that they were not complete people because of the stoma. In work by Reimer and Nichols (2007) the authors looked at life discontinuity associated with stoma surgery from <1 year since surgery to >10 years since surgery.

Chao et al (2010) examined patients with colorectal cancer and the relationship between demographic and disease characteristics and acceptance of disability. The findings reported moderate levels of acceptance of disability. However, those individuals with shorter disease duration, stoma and lower educational level reported lower levels of acceptance of the psychological adaptation to colorectal cancer and a stoma. They suggest that the lower scores for the individuals with colorectal cancer and a stoma had less acceptance of their condition, possibly due to the

inconvenience of stoma care in daily life and negative emotions from the loss of physical wholeness. For those individuals with colorectal cancer having surgery, which may extend their longevity, the complications of having a stoma and change in their appearance is complicated by the involuntary defaecation process and leakage which brings about increased frustration and anger, lowering of self-esteem and feelings of wellbeing (Krouse et al, 2007). Persson et al (2005) concurs with a survey of 55 stoma patients, with approximately half stating that the nurse education they received was inadequate and that contributed to their difficulty in adjusting to their disease. Both these findings suggest that more attention needs to be paid to the psycho-social needs of the colorectal cancer patient with a stoma, with effort being focussed on confronting non adaptive coping ways with the stoma and body image to enable the individual to return to their daily activities quickly and successfully. Capilla-Diaz et al (2016) suggest that individuals with a stoma will often feel shame, embarrassment, changes in quality of life and roles and relationships in their social environment. This first phase of this work explored these experiences and suggests that their results show that internationally, there are many similarities in the ways in which individuals cope with having a stoma.

An individual receiving a diagnosis of colorectal cancer has immediate thoughts of possible body image change and often there is little time to adjust their thoughts as there may be the need for neo-adjuvant therapy, primary surgery or surgery and adjuvant therapy to be considered even before stoma is mentioned. Some patients will have an understanding of what the possible consequences of this diagnosis may mean prior to seeing the surgeon and will have had time to adjust their mental body image picture. However for many this will not be the case and these are often the individuals who will have difficulty in adapting their body image picture. For many the overriding concern is that the cancer is removed and death will be postponed and they will have longevity after surgery with or without a stoma (Allal et al 2000, Pachler et al 2005, Ross et al 2007, Sharpe et al 2011).

Alienation is often a term that is used by individuals with a stoma to describe a term of feeling different after their stoma surgery along with the loss of self -esteem and confidence. Feelings of shock and disgust are identified in individuals when seeing the stoma for the first time and are elevated in the individuals who have not been prepared pre-operatively for what to see or expect especially when it is an emergency case (Wade 1989, Persson & Hellstrom, 2002, Black 2004, Borwell 2009, Mols 2014, Burch & Black 2017).

This view is still common as Notter (2002), and Notter and Chalmers (2012) found. It is at this point that the individual has to accept the body has failed them and they had to be surgically altered, so removing their autonomy. In addition these patients will find difficulty in controlling the phenomena of offensive odour and sounds and therefore retreat from many activities as a means of controlling elimination and the sensory phenomena surrounding a colostomy. In addition the perception of these phenomena by the individual, actual or potential, becomes an issue, owing to the very nature of the phenomena. This can be seen in the narratives from research by Black (1992):

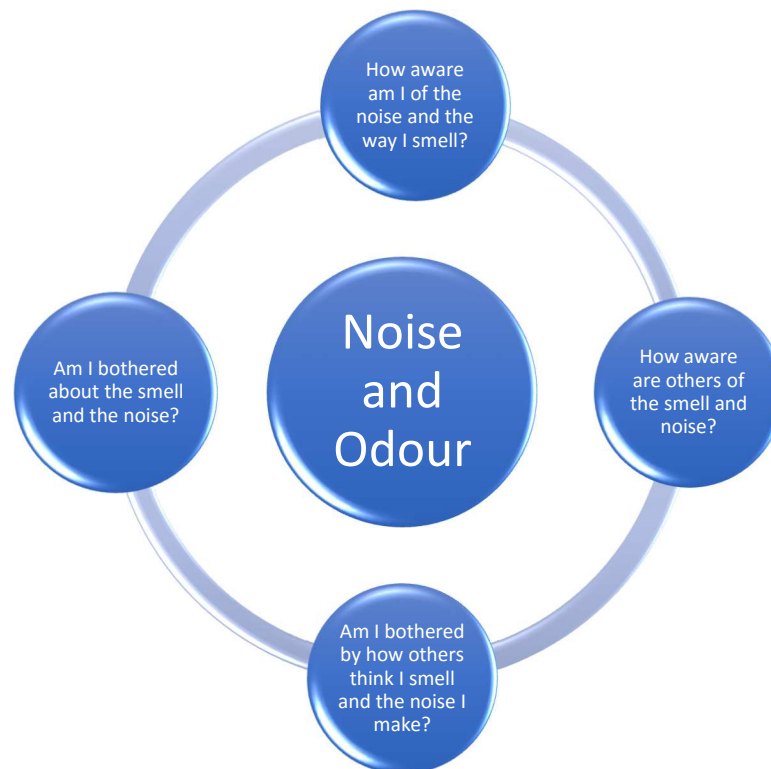
“.....every one tells me I don’t smell..... I know I do..... I know they are not telling me to protect me”.

..... “The smell seems to permeate the whole house and my wife always has a tin of air freshener everywhere.....in every room..... it’s most embarrassing when visitors are here..... she always has the windows open”.

..... “I coped with the pain, I coped with the diagnosis, but how can I be expected to carry on my job with this awful smell and the continual noise..... I’ll have to give up my job and stay at home..... We will never be able to go on holiday again”.

Although now a little dated, the issues that these individuals had are still issues today and it appears that for the permanent colostomy patient these phenomena are still restricting their day to day activities (Black 2000, Borwell 2009, Nichols & Reimer 2011, Black, 2017).

Figure 11. Multidimensional construction of body phenomena of a patient with a colostomy.



(Black, 1992).

However, as elimination and control over the sensory phenomena are learnt in private, at an early age as a controlled bodily function, the exteriorization of these structures and consequent loss of control becomes an anathema for the individual. There is now a wealth of sociological and psychological research into the effects of diagnosis, illness and major mutilating surgery on self-identity and lifestyle (Notter and Burnard, 2006). This is confirmed by the work of Nichols and Riemer (2011) who used the Ostomy Comprehensive Health and Life Assessment, a validated and reliable survey that was distributed in North America, UK and Italy (n=4097) and is a self-reported multi-item survey querying major facets of the lives of patients with a stoma (Hollister, 2011). How ostomates (people with a stoma) view their body after stoma surgery is a complex multidimensional process and this complexity limits the context and range of published body image discussions in health related quality of life studies. There is another issue for those with an altered body image. Altered body appearance may amplify this negative perception that the individual has of their body. Nichols and Riemer (2011) study of 1086 ostomates found that 36.5% ostomates had distinct negative body image feelings. Their study aimed to identify the relationship between body image, peristomal skin condition and the quality of life. However, they found that even those individuals with normal, intact peristomal skin still had a negative body image (1086) but that negativity was higher in individuals

who experienced peristomal skin problems intermittently or all the time. They were unable to determine a metric for the impact that peristomal skin problems have on the quality of life of the stoma patient establishing that non normal peristomal skin condition can be intermittent but always compounds negative feelings of body image.

The way an individual copes with a life changing event such as a cancer diagnosis and colostomy can be compared with an actor giving a performance. When an individual 'performs' they are implicitly asking observers to take seriously the impression they are seeing. The 'performance' the individual gives is socialized, molded and modified to fit the society in which the individual exists. The individual with a stoma struggles to cope with their private self as an ordinary person with a stoma and with their public identity as someone who is known to have a stoma. The stoma can become a relevant factor in some social interactions once the individual's identity as an ostomate is known. The first level of coping is the routine technical skill that is needed to keep the unpredictable and incontinent body under control. Under normal circumstances the individual does not usually have to concern themselves with these issues as growth and culture have organized these in an accepted form (Holden & Littlewood 1991, Black 1992, Kelly 1992, Bekkers et al 1996, Borwell 1997, Black 2000,).

Learning to cope at the technical level is learning control of pollution of the self and the environment and the associated uncontrollable phenomena. These are very private activities and if the individual is able to cope and manage the body technically, then the individual can 'perform' before the public audience and appear to be unexceptional. Coping can be conceptualised as adaptation following illness and use of cognitive and motor activities that the sick individual uses to preserve their identity and compensate the limit of irreversible impairment. Although able to cope technically, these skills do not make the threats associated with stoma disappear, but simply hold it in check. However anger, anxiety and depression are common even if the individual's 'front' cannot always hide the undertow of unhappiness. Goffman (1968) in the Presentation of Self in Every Life succinctly paraphrases how many stoma patients feel:

....immediately after surgery you have to learn the technological aspect of going to the toilet..... You've got to learn a new language almost, a foreign language.....its things you've never seen in your life before, names you've never heard of.... It's all strange and has got to be learned".

.... "It's a nightmare.... I wake up at night thinking and worrying about it..... I don't like to dwell in the past, but I keep thinking.... I should have done this..... I should have done that.... I hate him (the surgeon) for doing this to me..... He says forget the past: you can't, it's really hard".

At the interpersonal level of coping, in what has been the private world of the individual after colorectal surgery, has now become the public world. Managing the knowledge that others will know of the individual's status requires a sophisticated coping behaviour. To cope at the inter-personal level, individuals try to recognise the potential for problems that may expose their bodily secrets. Across the levels of coping with living and daily life there is often a discrepancy between appearance and reality. There is concealment from the 'audience' of all evidence of 'dirt' and the notion that 'dirt' is looked after in private. In trying to control 'dirt' the individual will embody several ideal standards and often the standards are maintained in public by the sacrifice of some of these standards in private. However, at the inter-subjective level of coping, the individual constructs schema, vocabularies and rhetoric's that are used to make sense to themselves of what has happened during their life event:

....."Am I going to be able to wear nice clothes again? Will I be able to go on holiday? Am I going to want to go out and meet people and do my shopping again...I felt different. I.....in hospital it was ok, but when I got home and tried going out I felt different.....exposed you could say.....that everyone knew what was under my clothes".

As this individual has expressed, they feel that everyone will know that they wear a stoma appliance under their clothes. Although it is impossible to separate the body from who or what the individual does in the world, good psychological pre and post-operative counseling and support will help allow the individual come to terms with their changed life style.

Social Capital, Health and Colorectal Cancer.

Traditionally public health research was quantitative in nature, but although this gave results that could be generalised, it gave little indication of how the individual was affected or the impact of disease on the quality of life. In recognition of this there has been a policy change within the NHS and edicts that the patient perspective must be included. This has led to an acceptance of the role of qualitative research in health care and healthcare policy. Qualitative research is the preferred term used in public health research although researchers in other disciplines such as medical anthropologists prefer to use the terms such as ethnography. In qualitative research

there are specific paradigms and specific explanatory terms in the collection and analysis of the data that all qualitative researchers aim to increase understanding and insight into real life settings. The focus is on depth as opposed to breadth, allowing the researcher to become well acquainted with a particular group of people or community, the main methods being interviews, focus groups and observation to facilitate access to the lived day to day experience of the person or community. By accessing the specific population, (in this instance colorectal cancer and stoma patients) the researcher is able to explore and understand the “phenomena” from the patient’s point of view. There is an increasing body of researchers whose work can be used to guide design and rigour of qualitative research from Husserl (1900/1967), Heidegger (1927/1962), Goffman (1961), Glasser and Strauss (1967), Kleinman (1980), Lenninger (1985), Miles and Huberman (1994) and Denzin and Lincoln (2005).

In an emerging area of interest such as social capital, qualitative research has a principal interest. As qualitative research relies on open rather than closed questioning of participants, qualitative research allows a complete exploration of ideas that are just beginning to exist. One of the foremost theorists of social capital is Robert Putnam (1993) who conceptualises social capital as “features of social organisations, such as networks, norms, and trust that facilitates action and co-operation for mutual benefit”. Using Putnam’s (1993) view, there could be seen some evidence that investment in building social capital in local communities may have positive effects on people’s health and wellbeing. However, while some effects can be found using Putnam’s (1993) view, social capital has been found to be less powerful than socio-economic status in predicting health outcomes.

In addition to these researchers, were those seeking to use in depth research to explore the impact of these lived experiences on how the individual fits into or functions within their given social setting. Also, factors which enhance or inhibit life within the social group, examines how the individual builds on or loses their social position. Bourdieu (1986) defines this as social capital. Putnam (1993) considers, while accepting Bourdieu’s work, social capital has features of social organisations, such as networks and support groups that engender trust within the group. Both Putnam (1993) and Bourdieu (1986) see benefit to the community in group membership and activity. Such activities for people with colorectal cancer and a stoma include the National support groups for those with a stoma, such as the Colostomy Association and the activities and support from Macmillan cancer care

who support all cancer patients from diagnosis onwards.

Health related qualitative research and social capital remain limited in the literature although Campbell and Gillies (2001) set out to assess Putnam's (1993) concept that social capital encompasses the important elements of community life in the UK. Their research concerned health promotion and community level interventions with interest from the current government of the time. In depth Interviews of thirty seven participants in the south of England were carried out. They argue that their findings were that Putnam's (1993) theory did not encompass all of the important elements of social community activity that may affect health including informal support networks and those that extended to national support. Their study indicated the limitations of Putnam's (1993) theory with its emphasis on formal activities within the community, it's recognition of the lack of variation within localities and the study demonstrated the complex nature of community social life when seen from an ethnographic view point. Since then studies undertaken to describe and define social capital invoke Putnam's (1993) hypothesis that social capital was the missing element in community life and that the focus on micro level processes in the community miss the important elements on health in the community (Morgan & Swann, 2004, Whitely 2008, Horlick-Jones, 2011).

The limitations of these studies of social capital and health indicate the nascent nature of research into the public health area in the years from 2004 -2006 (Morgan & Swann, 2004) research, which they argue, shows a steady interest on the impact of social capital on health. Ziersch et al (2005) used a mixed method study, formerly used in researching social capital and health. Their data illustrates that socio-economic factors which are unrelated to social capital have stronger effects on health than Putnam's (1993) theory. Previous reports by Black (1980) and Acheson (1998) into Inequalities in Health and the Department of Health report, Saving Lives: Our Healthier Nation (1999) all have the same common strand, that is, the recognition of solutions to public health issues such as cancer. These reports recognized that issues such as cancer are complex and require interventions across all sectors to take into account the broader social, economic, political, physical and cultural experiences that form people's lives. The Health Development Agency (Morgan & Swann, HDA, 2004) suggested that social approaches to the organisation and delivery of public health may have considerable benefit for health improvement especially for those people from disadvantaged areas of society and that the concept of social capital is a coherent construct that can help push forward the discussion

around the social approaches to public health in the form of screening and health promotion.

For over 25 years The public health agenda globally has been increasingly recognising that health experience and outcomes are shaped by a series of factors including lifestyle, cultural, genetic and environmental factors (WHO1999, DH 1999) and that there is a growing body of evidence that people from dis-advantaged social circumstances are prone to more illnesses, shorter life spans and greater distress (WACS study, Gordon et al, 2011) In endeavoring to bring social capital into the wider scheme of policies and initiatives to help reduce health inequalities, the concept must be redefined with measurable outputs before public health policies can reflect how the predictive power of a range of health related outcomes can be compared with the broader determinants of health (Morgan & Swann HDA, 2004). Gillies (1998) suggests that in community development terms, social capital is important as it provides a new social view of how the world works, how resources can be assessed and how improvements could be made in building stronger and healthier communities for the future such as a greater uptake in bowel screening especially among the male population.

CHAPTER 3:

METHODOLOGY.

Aims.

- To explore the experiences and quality of life of people living life long with the outcomes of treatment for colorectal cancer and colostomy formation.
- To increase healthcare professionals awareness, knowledge and understanding of the long term effects of colo-rectal cancer treatment on quality of life
- To develop a conceptual framework and model for a Care for Life Plan for patients after transition from therapeutic interventions for colorectal cancer and stoma formation.

Study Design: Setting the scene.

When planning for this study a review of published research in the field revealed that there was relatively little research into the long-term care needs of this group of patients. The two most recent surveys of 369 and 5000 patients who have had a colostomy indicated that there are some long term issues and concerns, many of which arise after treatment has been completed (Notter and Chalmers, 2012). However, the positivist methodological approach used in both these studies whilst yielding valuable insights into patients wants and needs had its limitations. Both surveys were designed for generalisations to the wider colorectal patient population covered a wide range of issues but did not focus specifically on the patient's quality of life. Nevertheless, it provided an ideal perspective on what the colorectal cancer patient may want or need after a therapeutic intervention has ceased, and can therefore be used to inform future research in this field, such as this study.

Therefore, it seemed appropriate to build on these studies but utilise a different and more in depth approach. The decision was made to utilise a qualitative design in order to gather rich and detailed insights into the variations of the individual 'lived' experience. Denzin and Lincoln (1994) and Bryman (2012) consider qualitative research to be: a more naturalistic approach which aims to increase insights into social phenomena in terms of the meanings of the people who live them. In contrast to the positivist approach used in previous studies in this field where the emphasis was on collecting data that could be numerically coded and statistically analysed (Bryman & Cramer 2008) the interpretivist paradigm focused on collecting data that could be studied in depth and was specific to the participants. The aim was not to generalise about "what" happens but to increase knowledge and understanding of

the “how and why” the phenomena occurred. As with positivist research there are different approaches that can have been used and each of these was considered before a decision as to which one to use was made. There are a variety of research methods that have grown in popularity including ethnography, phenomenology, grounded theory and hermeneutics (Laverty, 2003).

Reflecting on the various possible methods, as a medical anthropologist, I discarded ethnography as a methodological practice for this research as the ethnographic interview differs from other qualitative research interviews. In ethnography the researcher aims to capture the “now” experience of the living present, but for this study the “now “ was seen as too late with the reflective experiences of living seen as essential. Consideration of other possible methods included phenomenology, the study of the lived experience in the life world (van Mannen, 1990), initially developed by Husserl (1931, 1970) as a response to rejection of the objectivism of the natural sciences, which he argued precluded an adequate apprehension of the world (Husserl 1900, 1967). Phenomenology places emphasis on the world as lived by the individual and not the world or reality perceived by the researcher. In trying to enhance insights and understanding of the human experience as it is lived, the researcher examines and re-examines shared descriptions and discussions with the aim of uncovering new and /or forgotten meanings (Husserl, 1970). For this approach, there is an expectation that the researcher will review their own knowledge and experience in the subject prior to, during and after the subjective processes of the interviews and analysis.

The use of phenomenology in nursing research according to Lenniniger (1985) fits with Husserl’s (1900) belief in the need to move away from the positivist empiricism, the dominant mode of scientific inquiry. The argument used is that philosophy should not only have rigour but also humanism with identity and contextual independence related to thoughts, feelings and intentions. These serve as a frame of reference to life’s events, people and places and supports an in-depth study with no question higher ranked than any other and facilitating the inclusion of ambiguities and complexities that are based within the evidence collected (Giorgi, 1992, 2009). The advantage of the use of descriptive phenomenology in a study, with its philosophy of seeking to understand the ‘lived’ is that it helps construct specific and detailed experiences of the individual without ranking experiences or descriptions (Giorgi, 1992, 2009). This approach is subjective with data and analysis having a strong reliance on text and all findings being time and place specific, and not generalisable

to the whole population (Silverman, 2011). A criticism of this approach is that the subjectivity gives a narrow perspective of reality with a lack of reliability as the data is text based and there is interaction between researcher and participant. As this study was designed for a specific group, the subjectivity and lack of generalisability were not seen as problematic and the interaction between researcher and participant was seen as essential. Although traditionally seen as appropriate for individual interviews, descriptive phenomenology is being increasingly used for focus groups, (van Mannen, 2014) which reinforced the relevance of this approach for the planned study.

However, before a final decision was made, two other possible choices of approach were considered, grounded theory and hermeneutics. Hermeneutics is also based on phenomenology but differs in that it is interpretive rather than descriptive. It too focuses on verbal and nonverbal communication and communication from participants. This interpretive process concentrates on the meanings of experience and their development, accepting the influence from the participant's background on individual and social levels. Phenomenology and hermeneutics have some shared background characteristic but according to Mohanty (1989) and Giorgi (2009) the key difference in the two approaches is that descriptive phenomenology is epistemologically based and hermeneutics is ontologically based. As this study focuses on describing the lived experience and increasing knowledge, an epistemological approach is more appropriate and therefore the ontological approach of hermeneutics was rejected.

The third possibility was grounded theory. Chiovitti and Piran (2003) suggest that grounded theory is a suitable qualitative approach for those who wish to use a clinical inquiry approach to nursing practice for the purpose of theory development. Furthermore, in grounded theory methodology, information gained from participants focuses the research and influences further related questions. With grounded theory, transcription of the interviews is done immediately after each interview as this helps determine the information sought. Strauss and Corbin (1990) argue this type of theoretical sampling facilitates the exploratory nature of the research, the literature studied, and the number of participants in the study. This approach is built upon assumptions that either collectively or individually, people are constantly changing and therefore research knowledge also constantly changes. Charmaz (2014), suggests that grounded theory concerns itself with discovering the basic social process or problem in which people find themselves and to which they must respond.

Thus it is useful when there is little research or theory existing. Grounded theory studies also seek to develop consensus and ultimately to generate theory from within the data sets gathered, and was developed in reaction to the 1960's sociological stance of the time that studies should have a firm theoretical basis.

Having considered the above three options, the choice made for this qualitative research was descriptive phenomenology. It was seen as providing a unique voice during the collection of the data, bringing to the forefront the authenticity of the human experience following the journey of the patient's illness, wellness and rehabilitation. Giorgi (1992, 1997, 2009) suggests that any necessary interpretation is customary in this area of the study of healthcare, while van Mannen (2002) argued that phenomenology is a "profoundly reflective inquiry into human meaning". Similarly, Denzin and Lincoln (2011) suggest that phenomenology has much to offer in the interview in that it provides a framework that is not restrictive. In using a qualitative approach and descriptive phenomenology, the methodology facilitates working with a small number of individuals, either in individual interviews or small focus groups. This allows for more detail of the "lived experience" of people's understanding and interactions, rather than scope of larger numbers.

Bracketing.

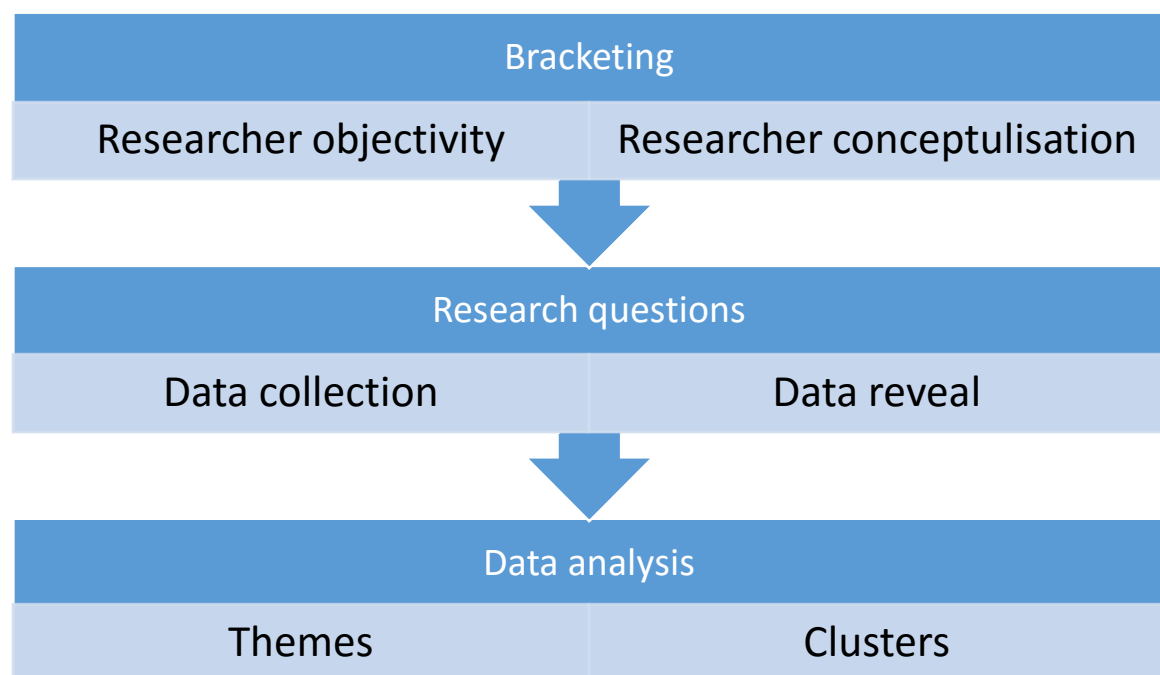
In using a phenomenological method the researcher explores social phenomena practices to increase insight and understanding (Van Mannen, 2014). Van Mannen (2014) uses Taminiaux's, (1991) argument that to explore issues, reduction is needed, consists of two opposing moves that complement each other – negativity and positivity. Negativity suspends access to the phenomenon and positivity leads back to the phenomenon. Husserl (1960) in *Cartesian Meditations*, described the epoché and reduction as the suspension of belief, and offered them as the central method used for phenomenological practice. Epoché describes the way in which the researcher needs to open up themselves to the world, recognising and releasing any pre-suppositions. Originally, bracketing (Giorgi, 1985, 2009) was used to identify researcher bias and the interviewer's perceptions prior to the study starting, during the interviews and after analysis to show that the data collected was participant driven and not researcher driven. Prior to interviewing the researcher reviewed any preconceived ideas and thoughts. Maso and Smaling (2004) suggest that the use of bracketing in descriptive phenomenological research is to allow the researcher to put aside (into brackets) their previous knowledge of the research subject. Furthermore,

they suggest that this process is cyclical and needs preparation, evaluation and feedback. Thus, bracketing supported the quality of the research method and an element of trustworthiness in the degree to which the opinions of the researcher have a role in the research. It acknowledges that the researcher's education, training and experience in the subject may alleviate any difficult discussion of subjects that could be embarrassing or taboo (Notter, 2014).

Today, it is now accepted that pure bracketing, the task of sorting out the qualities that belong to the researchers experience, is an important concept but that it is not feasible for the researcher to put aside and discount all their life experiences (Drew, 2004). Instead, the principles of bracketing should be seen as a scientific process through which the researcher acknowledges and where possible holds in abeyance presuppositions, biases, assumptions and previous experiences (Geary, 2004). The following diagram is a representation of where epoché sits in the research process.

To summarise bracketing can be seen as an essential starting point in the planning and implementation of phenomenological research supporting the researcher as they aim to minimise the impact of their own bias while at the same time conceptualising the study and completing the stages of data collection and analysis as seen below.

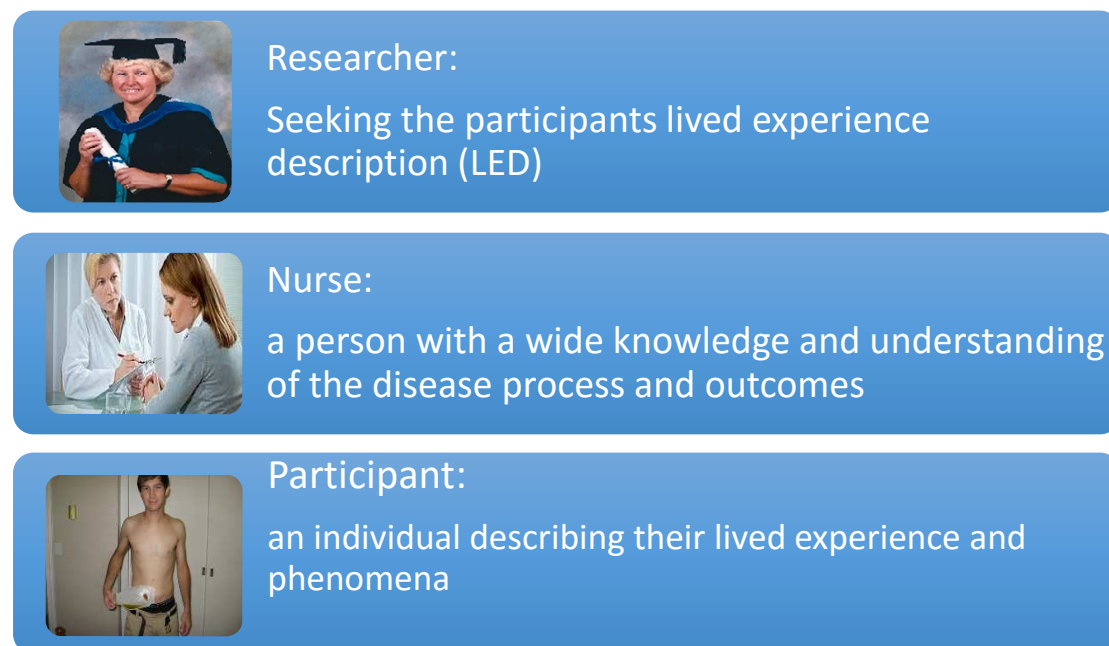
Figure 12. Bracketing.



Positionality.

For this research it was clear that for the researcher there would be several roles; researcher - seeking the participants lived world experience, nurse – a person with a wide knowledge and understanding of the disease process and outcomes of the participants and an individual - listening to and deciphering the phenomena the participants describe.

Figure 13. The Researcher's Positionality.



I have worked in this field of care for the last 30 years during which time I have successfully completed research projects utilising both focus groups and individual interviews. In addition part of my role as nurse consultant, I have played a lead role for the Department of Health in the development of colorectal cancer support groups.

Takacs (2003) hypothesises as to whether positionality causes bias to the epistemology, an important issue for this study because phenomenological research is epistemological not ontological. However, Takacs (2003) goes on to suggest that individuals live their lives in their heads although they are constantly re-confirming dialogue with themselves. Assumptions are made and based on each person's own individual positionality which may also bias how each individual perceives their world. Harding (1992) suggested that through recognising and analysing the cultures in which the researcher is positioned it is then possible to take positive steps to become more aware and objective. Bourke (2014) takes this further arguing that the act of examining the research process within the context of positionality is reflexive.

The nature of qualitative research means that the researcher is also the data collection instrument, and thus it is not unreasonable to suggest that their beliefs will be important variables in the study as a whole. Accepting this, interpretation of the data consists of two related concepts. Firstly, the way the researcher accounts for the experiences related by the participants and secondly, the way in which the participants make meaning of their experience (Bourke, 2014). Therefore, the potency of the research process is positively or negatively affected by the researcher and participant.

Patient trust is a pre- formed requisite from previous acquaintance during the participant's colorectal stratified pathway while undergoing therapeutic interventions. As the Cancer Patient Experience Survey Programme (2014) reports, although patients report very positively on their care those with Clinical Nurse Specialists (over 90%) report that the Clinical Nurse Specialist (CNS) had listened carefully to them and that they received understandable answers about their diagnosis and treatment. Patients with a CNS reported more favourably on a range of items than those without a CNS. One of the most striking findings of the 2010 National Cancer Patient Experience Survey is related to the CNS role. When the data was analysed between those patients who had access to a CNS and those who did not there was a significant difference between groups on every question in the survey. Patients with a CNS were more positive about their care and treatment plan than the patients who did not have a CNS. The most significant differences in view between those patients who had a CNS and those who did not was in respect of verbal and written information, involvement, information on financial support and prescriptions, discharge information, post discharge information and emotional support. In considering the substantial impact that having a CNS makes to patient perceptions of their care and treatment, certain groups of patients have less access to a CNS than others.

Having identified how my previous life experiences and personal beliefs could impact on the study, I needed to find a format through which they could be collated and used as a reference throughout the duration of the study. For me, the best way to do this was through a modified SWOT analysis (**S**trengths, **W**eaknesses, **O**pportunities, and **T**hreats). The modified SWOT allowed me to identify and tabulate my views. Having done this I could check that I had identified the key issues and personal reflections that could impinge on the study. I returned to this at regular intervals. Notter (2014)

suggests that concepts of health and quality of life issues will vary from individual to individual and are affected by previous and current circumstances.

Figure 14. Modified SWOT Analysis of researcher.



In order to check the analysis of the data was not skewed by my personal perceptions, the SWOT analysis was reviewed on completion of each round of data analysis. An important positive aspect identified by the SWOT analysis and evident when reflecting on the data collected was that my education, training and experience of working in the NHS allowed the discussion of intimate subjects such as sexual relationships, embarrassment of leaking or exploding stoma appliances in public and even suicidal thoughts, to be discussed without embarrassment to the interviewer or interviewee.

Data Collection.

In phenomenological research the method of choice for data collection is interviewing (Giorgi 2008). The subject being researched is both sensitive and emotive and this can raise concerns regarding the interview process. The acceptance that research

interviews are interactive recognises that in order for in depth discussion to take place there needs to be a positive relationship between researcher and interviewee (Silverman 2011). Grant et al (2011) also argues that when researching personal and emotive issues it is important for the researcher to accept that there needs to be a shift in the power base, with researchers being willing not just to parry questions, but to respond with appropriate information. The study by Notter and Chalmers (2012) identified that many patients had poor information regarding services available, imperfect understanding of the surgical procedure they had undergone, and the limited awareness of the changes it had wrought in their bodies. It seemed likely therefore, that participants in this study would have queries and questions they wanted answering. The sharing approach can facilitate the development of a relaxed atmosphere which can enhance the quality (and quantity) of the information given. However, even where interviews are participatory the relationship that develops does not indicate involvement on either part, so they are more successful where there is an overlap between the interests of the researcher and participants. This study is developed in response to a lack of information and therefore it is hoped that the aims will be of sufficient relevance for participants to share their personal experiences.

The use of a semi structured approach to both the focus groups and individual interviews necessitated the interviewer having good interviewing and interpersonal communication skills, to identify as far as possible with the interviewee's world and facilitate the discussion allowing them to take a natural course (Bryman, 2008). All focus groups and interviews were audio recorded, transcribed and anonymised.

The Phenomenological Interview.

The phenomenological interview is a means for exploring and gathering experiential material. The interview seeks to uncover narrative material or anecdotes that will give insights to a richer and deeper understanding of the "lived experience" of the interviewee. The interview is a flexible and adaptable way of eliciting information from the individual about their experiences during their illness and face-to-face interviews allow the researcher to modify the conversation to follow up interesting and specific responses. Non - verbal responses may help to understand the verbal response and the overall process has the potential of providing rich and illuminating material (Robson, 2011). For phenomenological research, Silverman (2004) argues that flexibility and freedom are essential to facilitate probing and exploration of key issues. However, as Bryman (2008) points out, without a minimal structure to guide

the interview, participants may be unsure of what is required. Therefore in this study both the focus groups and the individual interviews were based on a short topic list with prompts based on the findings from the qualitative studies previously completed. Silverman (2011) also suggests that there is a real difficulty in trying to capture “real” thought and feelings of the participant and that the researcher’s relationship with the participant is crucial. Oakley (1981) suggests that there should be a non-hierarchical relationship during the interview for the interview to be effective with joint trust and participation. Collection of data was with recorded interviews and field notes at the time of interview and on reflection after each interview. The aim of data collection was to explore with participants how they perceived their quality of life, what they think affects it, and their perceived attitudes and beliefs.

Semi structured interview.

The interviews were semi structured to ensure the major topics were covered and that the researcher had scope and freedom to gather a wider range of information. Semi structured interviews also allow the researcher to dig deeper into interesting points that the participant brings up. The semi structured interview allows more information to be produced and picking up on interesting subjects that the participant has added to the conversation. The questions were open ended allowing concepts to emerge. The actual number of interviews was dependent on the nature of the data gathered, although a term derived from grounded theory, the concept of saturation was used to indicate adequacy of data collection (Bryman 2008). Thus, using this concept, individual interviews were continued until the data collected yielded no new issues regarding quality of life. The use of a semi-structured approach to both the focus groups and individual interviews necessitated the interviewer having good interviewing and interpersonal communication skills (see Appendix 4). Using these skills the researcher can identify as far as possible with the interviewee’s world and facilitate the discussions allowing them to take a natural course (Bryman, 2008). All interviews and the focus group were audio recorded, transcribed and anonymised.

Focus Group.

Focus groups offer a degree of flexibility which combine discussion and interview and may be highly structured, semi structured or unstructured. For this study a semi structured approach was selected because this enabled the discussion to focus on key issues as perceived by the participants. They were encouraged to probe and

debate with each other their individual views and perceptions (see Appendix 5). This helped identify collective views and the degree of consensus regarding key issues, with the researcher able to minimise the dominance of individual examples and instances (Searle, 2004). Group dynamics can allow individuals to focus on, or recall what are for them, the most important topics and with the researcher acting as facilitator, they can be empowered to make comments in their own words. Thus a focus group was especially useful in studies such as this in maximising variability in the sample (Robson, 2011).

Previous focus group work undertaken with colorectal cancer patients who have a stoma has elicited many streams to investigate in relation to survivorship when therapeutic intervention has ceased (Black, 2000). Robson (2011) suggests that a common problem with focus groups may be that one or two people will dominate the discussion and it will take considerable experience, tact and sensitivity in the running of the focus groups. However, the researcher has considerable experience in this area, so this was not a problem. Also as the content of the investigation was not rigid and fragmented, the participant's story could retain its meaning.

Överlein et al (2005) suggested that focus groups can be used as an in depth method in high involvement topics such as cancer because they facilitate the involvement of all members, and group dynamics help in focusing on the most important topics. Also that it is possible to assess the extent to which there is a consistent or shared view. Participants were empowered to make comments in "their own words", and it was possible to encourage quieter participants in the group to participate fully.

The size of focus groups can vary (Morgan 1998, Kreuger and Casey 2000, Halcomb 2007) with suggestions from previous authors of anything from 6-12 participants. The focus groups were homogeneous in that all participants had recently used the health service for a specific disease, and they had all undergone body changing surgery (Kitzinger 1995, Överlein 2005, Robson 2011).

The researcher had found in previous projects that the participant preferred to be away from the hospital setting as this brought back memories that some patients wished to put to the back of their minds. For some, just coming back into the hospital was seen as traumatic. Interviews with participants about their illness experience are often best in their home setting as they feel safe and can talk with ease. The

individual interviews which were undertaken by telephone due to the geographical spread across in England, which meant the participant was in their own home, at a time and date that had been requested by the participant. With the focus group a room at the local library was used and the group were comfortable with this as they met here regularly for their support group.

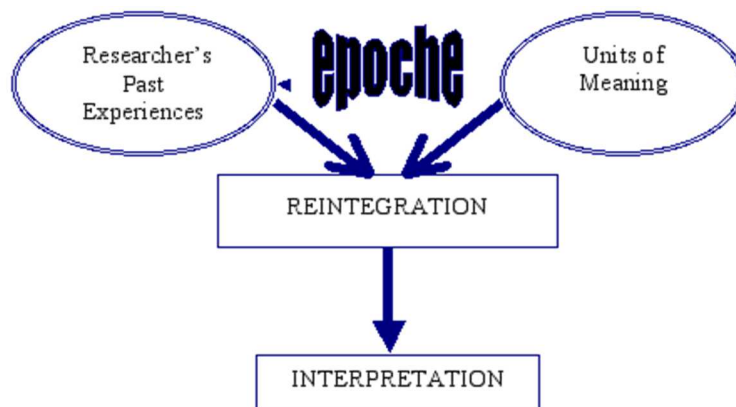
In some of the interviews after the first 10 minutes, there were some silences through which the researcher waited until conversation started again and if it seemed that a prompt was needed for the participant to continue, the researcher reminded the participant of the last sentence. This was often adequate for the participant to continue. When there seemed to be a generalisation on health care during the conversation the researcher asked if the participant could remember a particular incident rather than a generalisation.

Data analysis using a phenomenological approach.

A large amount of thick, rich data emerged which represented a source of discovery within the analysis. The researcher was aware from her life in the NHS that she did not fall into the DRIP (**D**ata **R**ich **I**nformation **P**oor) syndrome that appears to paralyse many health care organisations with too many indicators being used but poor information forthcoming. Qualitative information gained in a phenomenological interview gives specific knowledge to the researcher about the emergent themes from the participants. Therefore analysis was undertaken manually from the focus group, interviews and field notes.

The data analysis is a way to discover the emergent themes and meaningful categories that will aid a better understanding of the phenomena. Giorgi,(1997, 2009) suggested that analysis has to begin from the perspective of the participants, from where they see themselves. Reduction and epoché was undertaken as illustrated below until the researcher had thoroughly checked that the participants' descriptions, were their reality and not the researcher's.

Figure15. Epoque



Throughout analysis every effort was made to keep in mind the meaning and essences of the phenomena that comprise the participants' experience. Using the participants' individual experiences the aim was to work forward until themes developed to a saturation point whereby after that it was clear there were no new themes arising. All aspects of the participants' views were taken as equal and no hierarchy was given to the arising themes. At this stage there were 30 descriptors/feelings that the participants were saying that ran through all the interviews. As the researcher transcribed and wrote her own field notes, familiarisation with the data occurred enabling the researcher to identify the saturation point.

Recruitment Strategy.

As phenomenological research is involved with the "lived experience" of the individual, the participants are invited to take part in the study based on the criteria for the study. The researcher used groups that these interviewees would be accessing and in the largest group wrote an article asking for volunteers who meet the inclusion criteria in England. A second approach was through a local support group in a venue where a focus group could be easily arranged.

The study was seeking to understand how the interviewees felt after they were discharged from therapeutic intervention five years after they were considered "cured" and how they managed their diagnosis and stoma. All applicants that applied by email or those that volunteered via the local support group were screened in order to ensure they met the inclusion criteria for the research study. Ultimately a selection of participants were listed and replied to by the researcher.

Sample size.

The research protocol placed no constraints on the number of the sample size as it would depend on how many participants applied and the screening criteria. Large numbers were not required as it is qualitative research and importance is applied to the depth and detail that will be forthcoming. The use of the word sample here does not refer to an empirical sample as a subset of a population as this is a phenomenological methodology. Van Mannen (2014) suggests that the word sample is related back to the French root word “example” and that a phenomenological inquiry is not striving for to move from a sample to a population as an empirical generalisation. In looking for the sample there can be no logarithm or statistical criterion such as data saturation. Phenomenology is not looking for a characteristic, social group, culture or sameness. It is about what is singular to each participant in the sample and looking for the instant of insight of the participant’s lived experience. There were no final set figures as how many participants there should be in the sample as the aim was to gather enough experientially rich accounts so that the outcome of the study should contain the right amount of experiential material. However, it was anticipated that the initial sample would contain between 15-20 participants.

Table 6. Inclusion Criteria.

Male and Female.
18 years upwards.
Have had a diagnosis of colorectal cancer.
Have had a permanent colostomy.
Have reached the 5 year mark and be considered to be “cured”.
May have had chemo/dxrt.
Individual interview data collection was from June 2015 – October 2016.
Focus group data collection was February 2015.

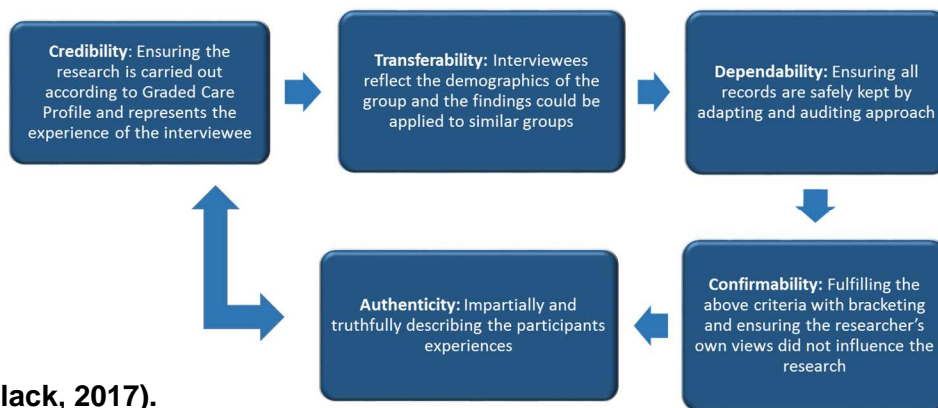
Criteria for assessing the quality of the study.

One of the main concerns regarding all research studies is the quality of the research mechanisms used to collect and analyse data. Researchers using the positivist paradigm have standardised processes to examine two key criteria; reliability and validity. The issues surrounding rigour in qualitative research have been repeatedly highlighted in the literature. Van Mannen, (2014) suggests that validity applies to

tests and measurements which are not compatible with phenomenology yet it does provide a framework from which the rigour of the processes used in qualitative research can be partly assessed (Notter, 2014). Van Mannen (2014) goes on to argue that the eidetic reduction that is accompanied by the epoché involves suspending the researcher's presuppositions and biases in regard to the phenomena that is being researched. Validity therefore presumes an informed, scholarly competence of the researcher. He also points out that reliability issues are connected with the repeatability of a study being able to produce the same outcome each time it is administered and this is unlikely to happen in a phenomenological study.

Then too, reliability assesses the standardisation of the instruments used that minimises the researchers input while validity concerns the influence that systematic errors may have in the research data itself. In the interpretivist paradigm, where the focus is on exploring in depth individual experiences and social phenomena, the application of standardised processes can be problematic. Therefore researchers in this paradigm have had to seek alternative ways of reviewing and assessing the processes used in data collection and analysis. The two most commonly used approaches are trustworthiness and authenticity (Guba and Lincoln, 1994). Trustworthiness has four components with the terms credibility, transferability, dependability, conformability and authenticity has five. In contrast to trustworthiness, authenticity, while it still focuses on the processes of research is designed to support assessing the rigour of the total study and thus considers the impact of the study on the researcher, the participants and the reader. In this study it was therefore more appropriate to discuss this in the reflection of the study as a whole. Assessment of these concepts will be assisted by the compilation of an audit that includes a reflective trail (Denzin and Lincoln 2011). However, as dissemination of the study will begin in the later stages, the researcher kept field notes and a reflective journal and some elements were assessed on completion of the research.

Figure 16. Diagram to demonstrate methodological rigour.



(Black, 2017).

Trustworthiness.

Trustworthiness indicates the believability of the research and that the researcher must maintain the context of the lived experience described by the participants in the both the focus groups and individual interviews. Trustworthiness can itself be subdivided further into credibility, dependability, transferability and confirmability.

Credibility refers to the way research data was collected and analysed and the extent to which a connection can be found between the data and the descriptions and themes that emerge during analysis (Polit and Beck, 2010).

Transferability.

Guba and Lincoln (1994) suggest that transferability is relatively recent and needs evaluation and whether the results are applicable to other contexts. Transferability is being increasingly seen that some of its elements are able to be generalizable from within one health care setting to another from the original work. In phenomenological studies which are seeking to explore and describe elements of health care, studies such as this are able to transfer from one health group to another for those researchers seeking to do qualitative studies using descriptive phenomenology.

Dependability.

Dependability relates to the extent to which the findings are plausible and can be accepted and utilised. It is based on drawing the same conclusions on the basis of the material collected (Polit & Beck, 2010) and also refers to the repeatability of the research and is based on the outcome of the material collected. In looking at the

collected data for the study, it was clear that many of the participants were saying the same.

Confirmability.

Bryman (2008) suggests conformability refers to the degree of which the researcher's opinions may have played a part in the research and the previous knowledge of the researcher is displayed in a SWOT analysis of strengths and weaknesses (Figure 14).

Credibility.

Credibility refers to the way the research was conducted (the rigour of the data collection) and is analysed and whether the study is believable to the readers. Interviews were recorded, field notes taken and correspondence used. This maximised the credibility of the data.

Ethical Considerations.

Every effort was made to apply the principles of ethics (justice, beneficence, non-maleficence and autonomy) as discussed by Beauchamp and Childress (2013) to protect those participating in the study. The practical application of these principles was through the following actions and activities. A key issue is data protection, in this study the researcher had no access to the sample data base which remains the property of the hospital linked to the Institute. However, it has to be accepted that potential participants forwarded their own contact details to the researcher. This information was securely stored in a locked, fireproof cabinet to which only the researcher had access. No transcripts contained any personal information and in addition these details were stored separately in a locked, fireproof cabinet. Only the researcher and supervisors had access to the transcripts. On completion of the study all personal details will be destroyed and the transcripts stored in accordance with Birmingham City University (BCU) policy for 5 years.

Full details of the university were included in all information, together with details of a named person for contact in case of queries. All potential participants were made aware that their participation was voluntary and that no links should be identified or made between the research and service provision. Also that they were free to

withdraw from the study at any time without prejudice. As this is a sensitive and potentially emotive field, a formal arrangement was made with a psychologist that should respondents be distressed, they could contact her for confidential help and support. Also the psychologist was available to the researcher in case the researcher felt that there were any areas with the interviewees that needed to be discussed in clinical supervision. In addition the Colostomy Association offered to provide help from one of their specialist advisors.

Prior to the study all potential participants were given written information about the aims and processes involved in the research, only when they had had time to read and reflect (7 days) could they return the informed consent and only after that were they invited to participate in a focus group or individual interview.

Ethical approval was gained from the ethics committee of the combined Institute and hospital in which the researcher was based, and from the university where the researcher was registered. Once ethical approval had been obtained the patient magazine included a short article about the study written by the applicant. The magazine is sent quarterly. The information included an invitation to participate and contact the researcher by email or work telephone number.

Bias and rigour are present in research involving people often due to the close relationship of the researcher and respondents and the notion of 'researcher as instrument' which is present in many styles of qualitative research, therefore emphasises the potential for bias (Robson, 2011). In this study modified bracketing was used to help reduce this as were the concepts of trustworthiness and authenticity,

CHAPTER 4:

FINDINGS.

Introduction.

This descriptive phenomenological study based on Giorgi's (1975) phenomenological method, consisted in total 19 participants in both the focus group and individual interviews. This was broken down to one focus group of 4 participants and 15 individual interviews across England

Table 7. Demographics of the Interviewees.

Patient	Age	Gender	Year	Bowel Cancer	Colostomy
01	75	Female	2009	APER	✓✓□
02	85	Female	2007	APER	✓✓□
03	72	Male	1977 2004	Hartmann's Procedure APER	✓✓□ ✓✓□
04	50	Female	2002	APER	✓✓□
05	83	Male	2008	APER	✓✓□
06	70	Female	2002	APER	✓✓□
07	71	Male	2006	□Five lots of surgery	✓✓□
08	75	Female	2005 2010	Anterior resection to avoid stoma APER 2010	Temp ileostomy ✓✓□
09	62	Male	2009	APER	✓✓□
10	57	Female	2011	APER	✓✓□
11	65	Female	2006	APER	✓✓□
12	80	Female	2000	APER	✓✓□
13	82	Female	2008	Hartman's procedure	✓✓□
14	70	Female	1997	APER	✓ □ Irrigates

15	80	Male	1992	APER	✓✓□
16	64	Female	2008	APER	✓✓□
17	74	Female	2009	APER	✓✓□
18	86	Male	2010	APER	✓✓□
19	76	Female	2010	APER	✓✓□

Fifteen individual telephone interviews were used instead of face to face interviews due to the disparate geographic spread. A focus group was used for one group where the participants were able to attend a central point, in order to ascertain whether focus group dynamics would elicit any different responses than from the individual interviews. The interviews were conducted with open questioning and a conversational manner to enable participants to be able to tell their own story. In this way the depth and complexity of the participant's story enabled them to lead the interview. Where necessary prompts were used (i.e., tell me more) to gain further insight and to clarify ambiguity. In seeking a richness of data about the individual's experience sampling was purposeful rather than random. The inclusion criteria were individuals who had a diagnosis of colorectal cancer and a permanent colostomy and had passed the five year finish of their treatment. As Cohen et al (2000) suggest, the interviews and data did reveal themes that go through the individual's experiences that are the outcome of phenomenological research which facilitate the emergence of themes that traverse the total lived experience description of each participant.

For each interview the researcher, as an experienced colorectal consultant nurse, needed to "bracket" her pre-understandings to enable the individual's stories to be appropriately analysed (Giorgi 1997).

Looking at the data it was evident the interviews told a chronological story for each individual, revealing that participants had taken a different time span for the transition from 'patient' to 'person'. Many of the interviewees were occupied with existential issues often wondering what was going to happen to them now they were known as a 'cancer patient'. Ratcliffe (2008) considers existential feelings as background orientations that are woven into the individual's perception of bodily being and experience of the world. Existential feelings challenge the duality of life: self-versus world, inside self-versus outside, therefore self and world are experientially related. Although the individual's body becomes absorbed into life activities and is not

consciously noted on a day to day basis, when the individual becomes ill the body comes to the fore front of the consciousness.

The overall purpose of the study was to consider and make a contribution to the 'survivorship' of colorectal cancer patients after the five year mark has been passed and to find out what SCPs for the individuals are needed as it appears from the research and the researcher's many years of experience of working with this group of individuals that they feel 'let down' or 'abandoned' when they are finally discharged from therapeutic intervention.

Phenomenological research aims to describe the lived experience and stimulate further creative insights that can be used to facilitate interpretation within praxis (Van Mannen, 2014). Thus it endeavours to explore how the phenomena being investigated impacts on the kinaesthetic, sensory, visceral and 'felt sense' dimensions of the bodily lived experience (Finlay, 2011). For the purposes of this study it had to be accepted that life threatening illness impacts on the whole person leading to an altered view of their whole body and an altered view of their world and these two perceptions are inextricably linked. Also that after diagnosis of colorectal cancer and a permanent stoma it is normal for the individual to feel that their 'world has collapsed' (Black, 2000). Seamon (2002) and Kemp (2009) have both illustrated the outcomes of these worlds collapsing changes the lived experience permanently. They argue that these changes in the physical body following diagnosis and surgery can profoundly change the individuals sense of self and world leaving them cut off from their habitual way of being. Participants in this study have all lived through this process and therefore it was important to explore with them the challenges that arose after treatment. This included reflecting on their lives as they learnt to navigate through their new world with its changing family, social and for some, working context, in the light of their permanently altered physical and psychosocial self.

The first steps of data analysis, reduction and epoché, were undertaken in light of the above and entailed repeatedly reading and listening to the data which was to minimise errors. Initial thoughts and ideas were reviewed and re-reviewed to check that it was the participant's descriptions of reality being presented. Throughout this iterative process every effort was made to keep in mind the emerging meanings and essences of the phenomena that comprised the participants lived experience. All aspects of the participant's views were taken as equal and no hierarchy was given to the arising nascent themes. At this stage there were 30 descriptors/ feelings that ran

through all the interviews. Checking transcription and field notes increased familiarisation with the data set supporting the identification of these descriptors. As the researcher transcribed and wrote her own field notes, familiarisation with the data occurred enabling the researcher to identify the saturation point.

Next the researcher examined these descriptors/feelings to try and have an understanding of how these would be categorised and reduced. The researcher repeated her familiarisation with the participant's interviews again to be sure that there were no other recurring descriptors/feelings and therefore be able to apply phenomenological reduction which involved in searching for all possible meanings without prejudicing the data with the researcher's assumptions and lengthy experience in working with participants such as these. Once identified, the researcher then started reduction of the 30 descriptors/feelings into 5 categories with each reduction having 3 parts which are descriptive statements of the participant's feelings. This process aimed to discover aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is (Van Mannen, 2014). In communicating the meaning of the data Patton (2002) suggests that the researcher uses whatever means they have available to them to find the most appropriate way of communicating and making sense of the data. The repetition of interviewee quotes were necessary for showing the context and its link to the development of the final conceptual framework.

Table 8. Interviewee's Feelings/Descriptors.

Feelings Descriptor	<u>Interviewee's Description</u>	Patient Number
Scared	"I'm scared the cancer may come back"	1
Anxious	"I'm scared of the stoma, it rules me"	1,7,13
Worry	'I worried it was asking for trouble to celebrate the end of treatment"	8, 5
Family	"I'm worried about my family"	2,3
Communication	"I'm nervous, stopped talking to my wife"	
The Future	"I worry everyday about the future even though it is 15 years on"	8,3
Coping	"I'm not coping, life has changed"	2,5,13
Burdened	"I feel burdened, overwhelmed"	2,13
Nervous wreck	"every twinge or pain makes me a nervous wreck"	13,8
Irritability	" I am annoyed with myself that I feel irritable when people ask how I am"	5, 7
Weakness	"When treatment was finished and told I was cured, I should have been over the moon but I always feel the cancer is not behind me"	9,2
Fretting	I'm always worrying I will run out of bags or they will not let me have anymore"	2,7,13
Behaviour	"My behaviour changed"	1,8
Fatalism	"Death, even tomorrow, does not bother me"	7
Avoidance	"I will not discuss my feelings with anyone"	1,7
Unwanted thoughts	"I worry every day that I may die"	13
Panic	" Every time I have a pain my heart beats fast and it is hard to breathe"	1,8
Confusion	"I would like to see my clinical nurse again but the GP said I can't"	1,2
Edginess	"I heard a programme about bowel cancer, it bought it all back, I was on edge for hours"	10,6

Stress	"My GP is not receptive to me and my queries –he says I am fine and do not need to see someone"	1,2,13
Mood	"I noticed after the end of chemo that I had bad mood swings _ I was never like this and it has stayed with me all these years"	5
Insomnia	"Every night I go to bed and worry about recurrence, how will I know, will it be to late"	2
Social Isolation	"I don't go out in case the bag works then what would I do"	2,13
Thankful	"I'm so thankful that it was caught at the time, I give thanks for every day that I am here"	5
Frightened	" I feel a failure as I don't seem to be as able as I was before the operation 12 years ago"	1,13
Anger	"I am still angry after 9 years, if I am told how lucky I am I will scream"	10
Fighting Spirit	"I responded with fighting spirit and was back at work within 6 weeks, it's not going to get me"	8
Exhaustion	" Everything I do is exhausting, I can't make plans"	1
Courage	"People praise my courage"	11,3
Strength	"People praise my strength"	11,3

(Black, 2017).

In analysing the 30 descriptors/ feelings from the interviewee's stories it became clear that there were areas where the interviewees were reporting similar feelings / descriptors about their treatment and care. Van Mannen (2014) suggests, these thematic insights from the interviewee's stories are 'insight cultivators' that aid the reflective and where appropriate the interpretive process. They give insight to the lived experience description of the stories and in the recalling of the experiences that happened to the interviewee thus enabling the researcher to see new possibilities in

the epoché. Van Mannen (2014) goes on to argue that phenomenological research can help the health care professional to increase their cognisance of individuals' challenges and needs. Also to recognise that they must be aware of the way that each individual experiences and lives through their life changing events so creating their own unique way forward. Using Van Mannen (2014) It can be considered that the individuals in the researcher's sample are out of step with the body after surgery and that health care professionals can help to recover a "liveable relation" with their psycho-physical wellbeing. Using Van Mannen's (2014) research, it could be argued that the interview data from the participants would illustrate the elements of the five identifiable phenomenological aspects of body experience that life threatening illness impacts upon.

The body experienced as an aspect of the world
The body experienced as reflective
The body experienced as observed
The body experienced as focus of appreciation
The body experienced as call

Therefore a re-examination of the 30 descriptors/feelings was undertaken to ascertain whether the 5 phenomenological aspects defined by Van Mannen (2014) were evident. Following this, a full review of all transcripts took place to check that no other occurring descriptor/feelings could be identified. This included checking the researcher's pre-identified knowledge and bias had not prejudiced the data analysis.

Once it was clear that there were no further descriptor/feelings then the process of reduction of the accepted descriptor/feelings began. It was immediately evident that each reduction had 3 parts which consisted of descriptive statements and which in combination fitted within Van Mannen's (2014) 5 aspects (table 9).

Table 9.

Analysis showing reduction of data.			
Reducing	Reducing	Reducing	Van Mannen (2014) comparison
A) Searching for reassurance	B) Constant worry	C) Physical sensations perceived as disease progression	The body experienced as observed
A) Overwhelmed by diagnosis	B) No active coping strategies	C) Self-blame and burden to others	The body experienced as reflective
A) Minimisation of the disease threat	B) Undertake distraction techniques	C) Maintain life as if everything is normal	The body experienced as an aspect of the world
A) Lack of control	B) Acceptance	C) Fate will decide	The body experienced as call
A) Cancer and stoma seen as a challenge	B) Information sought to help with treatment	C) To keep life as normal as possible	The body experienced as a focus of appreciation

Discussion of outcomes of reduction and comparison using Van Mannen's (2014) categorisation.

The body experienced as observed means that for every ache, pain or twinge that the patient feels they are unable to forget their body and what has happened to it. The patient has the inability to 'forget' their body in order to focus attention and awareness on living and the world. While the patient's body is well they have no reason to take notice of it in normal modality. However, once diagnosed with colorectal cancer and a colostomy that will form an everyday part of their life until they die, there is a permanent reminder of what has happened to them. Merleau-Ponty (1962) suggested that every individual has their own special relationship with their body and if they are unhappy with the way they look, dressed or undressed, they cannot hide from their body. They are able to hide their body and themselves from the sight of others they cannot separate their body from their sense of self.

The body experienced as reflective for the individual causes concern for them especially after surgery. The individual is aware of the phenomena of flatus and odour from the colostomy and feels that everyone that comes into contact with them will notice these uncontrolled phenomena. The individual worries that everyone who comes into contact with them will know that they are incontinent (colostomy) and so view them differently. The body appears to push itself forward and the individual is aware of the others' embodiment and therefore they feel that others are aware of their mutilated body and the phenomena of uncontrollable output, flatus and odour.

The body as observed is more noticeable for the individual as their well-being has been disturbed and become ill-being after surgery. Serious illness changes everything that the individual knows in sense, time, priorities and experience of space. The individual can no longer live in a self-forgetful world in all their other dimensions. When well-being is disturbed the individual appears to 'discover' their own body as a conspicuousness that disturbs the individual's non-positional consciousness in the form of the surgery (colostomy). In the diagnosis of colorectal cancer the individual from diagnosis until 'cured' and discharged at five years, continues to reflectively focus on the body's state of wellbeing. It is clear from the sample interviews that even after discharge, the individual continues for the rest of their life reflectively focusing on the 'what if' scenario of cancer and never returns to the non-positional consciousness. Merleau-Ponty (1963), suggests that in a sense the individual needs to 'forget' their body in order to be able to focus attention and

awareness to life, but this is very difficult for colorectal cancer patients with a permanent colostomy as for their life span there will always be the worry of the cancer returning and the uncontrollable output from the stoma.

The body of self as an aspect of the world is experienced as a non-positional consciousness meaning that the individual does not in the ordinary way notice the body much during day to day living. Non-positional consciousness is the state of pre-reflective consciousness that is presumed to underlie the individual's consciousness of day to day experiences. When the individual is well and disease free and has not received bad news about their body the individual lives in a pre-reflective mode. However, when the individual is given news of ill health there is a sudden focusing on consciousness and the individual's body or area of body comes to the forefront of consciousness.

The body experienced as call, taking the meaning of call to do with death (call as in calling hours to view the body) it can be perceived by the individual that they have 'died' as in the body no longer can be controlled or act in the manner that the individual would want. No longer can the individual return to non-positional consciousness, as they are continually able to perceive what is happening with their body and therefore remain in the state of positional consciousness with the world. Health care professionals, especially Clinical Nurse Specialists in stoma and colorectal nursing can be involved with the individual who is out of step with the body, due to the type of surgery, to recover a liveable relationship with their psycho-physical being. Increasingly the healthcare professional is becoming aware that individuals need more than surgical intervention and that the health professional must be aware and involved in the way that the individual experience and live with their problems in a different way, that can be deeply personal and unique. Different patients who receive the same diagnosis may experience their illness in fundamentally different ways due to the clinical path having different consequences and significances for each individual.

Following on from the initial epoché from the 30 interviewee's comments, thematic analysis was compared to Van Mannen's (2014) textual insight cultivators which produced five phenomenological aspects of body experiences. This information still did not adequately provide what the interviewees were really saying therefore the epoché was reapplied to bring forth a categorisation of the five themes.

The body experienced as a focus of appreciation can be seen in the patients who are keen to overcome what has happened to them and develop an effective response to having had colorectal cancer and a colostomy. The experienced physiognomy of the new 'self' often expresses the patient's character. However, if the look of others, who are unaware of the individual's dis-ease does not centre on the abdominal area it does not objectify the individual and make the body into an object.

Following on from the initial epoché from the 30 interviewee's comments, thematic analysis was compared to Van Mannen's (2014) textual insight cultivators which produced five phenomenological aspects of body experiences. This information still did not adequately provide what the interviewees were really saying therefore the epoché was reapplied to bring forth a categorisation of the five themes.

The body experienced as observed: the participant's perspective.

This meant that for every ache, pain or twinge that the patient feels they are unable to forget their body and what has happened to it. The patient still has the inability to 'forget' his/her body in order to focus attention and awareness on living and the world. When the patient's body was well they have no reason to take notice of it in its normal modality. However, once diagnosed with colorectal cancer and a colostomy that became an everyday part of their life until they die, there is a permanent reminder of what has happened to them. Half a century ago, Merleau- Ponty (1962) suggested that every individual has their own special relationship with their body and if they are unhappy with the way they look, dressed or undressed, they cannot hide from their body. They are able to hide their body and themselves from the sight of others they cannot separate their body from their sense of self.

The interviewees found that they constantly worried about the stoma and the possibility of recurrence. Insomnia was a problem for some of them and they lay awake until the early hours feeling exhausted, when they had to arise so worrying even more. Worry is a natural, instinctive reaction to bad news. However, although they were discharged as well after five years they still worried. They worried about any perceived pain that it was a recurrence, that they smelt from the stoma, that others would think they were incontinent. There appeared to be nowhere they could go for reassurance about their worries. Ending treatment is a life event as much as diagnosis was, but support for all these worries is lacking.

This fits with Van Mannen's (2014) suggestion that the patient may look at their abdomen and colostomy in a detached way or even as a curiosity and feel an existential amazement that what they are seeing is part of them. After surgery and the raising of a colostomy patients will often state that their body is rebelling when the stoma bag leaks and while trying to change the appliance the colostomy keeps working, spilling its incontinent output all over the floor. As one participant graphically describes his recall of his feelings on first seeing the stoma:

... "The nurse slowly removed the bag and kept asking if I was ok...I was dreading it and wondering what I would see...all I could see as she removed it was poo pouring out like a river of chocolate...at any other time I could have joked about the chocolate...but I just felt so embarrassed for the nurse...she was frantically mopping me and the floor with paper towel and as fast as she did there was more and more...luckily another nurse came into help...every time I saw the poor nurse I felt so embarrassed".

Over half a century ago Merleau-Ponty (1962) suggested that everyone has a special relationship with their body and if they are unhappy with the way they look they can try and change their external image but cannot hide from their surgically altered body. For some participants from this study the solution had been to focus on creating an external reality that they believed was acceptable, while keeping their own reality secret for fear of rejection:

"It is the fear that there may have to be someone else who will have to change the bag for me. I keep it a secret from everyone that I have a colostomy".

This anxious pre-occupation by the patient, that they will be treated as marginal by their community, once there is knowledge about their condition, impacts on their social interactions. If not addressed this fear can even impact on their perceptions of any consultations with health professionals:

... "I go to my GP but he seems to have little time for me and makes me feel that I am time wasting"...

This participant went on to add:

... "the practice nurse...asks me about my stoma but does not look at it".

It can also adversely affect their ability to interact with peers. This participant had joined a support group with the hope of accessing advice and help from those who had already been down the path he was now walking, said:

“...I go to the group meetings but there is never anyone there to ask”.

These comments are typical of patients for whom bodily functions such as excretion are not acceptable social subjects. Thus, as they expect others to have the same social perceptions, they place negative inferences on professional interactions and will not raise what they see as un-acceptable phenomena such as odour, noise and flatus even with those who may be experiencing similar issues.

For some participants this sense of no longer fitting into society began at diagnosis at that time with no real experience of what life would be like after surgery and they could only see the worst possible outcomes and picture themselves as social pariahs:

“...I said I did not want to be smelly and [have to] avoid social situations. I felt as if it was the end of my life and would be seen as a leper”.

This kind of initial response is not unusual, as Kelly (1985: 517-525) illustrated when he publically gave a similar description of his initial reaction to the need for a stoma:

...’ “The protruding stoma and its attachments looked horrible, more over I now realised how uncontrollable it was and what being permanently incontinent meant. What really alarmed me were the physiological consequences, especially the incontinence and smell. These I believed would become the defining characteristics of my social identity and everything about me, my relationships, the way others viewed me would be conditioned by these.”

However, it has to be a cause for concern that in the 3 decades since then, societal attitudes have changed so little that patients are afraid to face the implications of people knowing they have a stoma:

“...” I don’t know how I am going to be able to handle work...I have to stand up and give regular talks...just look how my bag blows up and the noise...well...it will show under my suit jacket and everyone will notice...what am I going to do...I can’t retire I don’t want to I’m too young”

When considering the body as observed, body image plays an important role. While profound distortions in regard to body image are rare, as the participants in this study showed, some patients continue to worry about the body and its image in relationship to its orifices, boundaries and body fluids.

...” this is not normal is it...this... coming out of my abdomen...it should be coming out of my bottom...how can I use universal changing rooms when I go to get a new dress or whatever...if they all see a bag of s...t hanging on me they will all run out...is this is what is going to define me forever now?”

Treating marginal and ill-defined states such as patients with a stoma can be compared to the sociological approach to pollution, but also edges and boundaries which are used in the order of social experience and are treated as dangerous or polluting. These rites of transition are only prophylactic and not purifactory and therefore do not re-define or restore the lost former self, but define entrance to a new status. This patient states:

...”Well I thought...what do we have here...I had no idea what it was going to look like...I presumed just a hole in my abdomen...not this red thing...but let’s be sensible...at the end of the day it’s just my bum in a different place”

It was also evident though, from some participants that problems with body image arose before surgery and were compounded by the reality of the first sight of the stoma. For some other participants the anxiety aroused by chemotherapy treatment resulting in observed change in functioning rather than just the physiology:

“...The most worrying thing was that after the second treatment I found that my colostomy output was very fluid for up to two days afterwards and often it was yellow and frothy... I could not use the closed colostomy bags as I had to take the appliance off so frequently and I asked the chemo specialist nurse what to do”.

Coping with such disconcerting changes needs to be discussed with the specialist stoma care nurse if long-term issues such as excoriation of the peristomal skin are to be avoided. This example also illustrates that care needs to be taken to check that appliances initially given are appropriate for each stage of the journey. If this is not done the patient may be left struggling long term.

The body experienced as reflective

For the individual this causes concern after surgery. The individual is aware of the phenomena of flatus and odour from the colostomy and feels that everyone that comes into contact with them will notice these uncontrolled phenomena. The individual worries that everyone who comes into contact with them will know that they are incontinent (colostomy) and so view them differently. The body appears to push itself forward and the individual is aware of the others embodiment and therefore

they feel that others are aware of their mutilated body and the phenomena of uncontrollable output, flatus and odour.

The body as experienced as reflective is more noticeable for the individual as their well-being has been disturbed and become ill-being after surgery. Serious illness changes everything that the individual knows in sense, time, priorities and experience of space. The individual can no longer live in a self-forgetful world in all their other dimensions. When well-ness is disturbed the individual appears to 'discover' their own body as a conspicuousness that disturbs the individual's non-positional consciousness of the form of the surgery (colostomy). In the diagnosis of colorectal cancer the individual from diagnosis until 'cured' and discharged at five years, continues to reflectively focus on the body's state of wellbeing. It is clear from the sample interviews that even after discharge, the individual continues for the rest of their life, reflectively focusing on the 'what if' scenario of cancer and never returns to the non-positional consciousness. Merleau-Ponty (1963), suggests that in a sense the individual needs to 'forget' their body in order to be able to focus attention and awareness to life, but this is very difficult for colorectal cancer patients with a permanent colostomy as for their life span there will always be the worry of the cancer returning and the uncontrollable output from the stoma.

For the individual, their well-being has been disturbed both through diagnosis and surgery and become ill-being after surgery. Serious illness changes all aspects of time, social and emotional priorities, context and with that their experience of space. Reflection on what is actually said at the time of diagnosis can be a constant for the rest of their life. It is not unusual for patients to be able to repeat verbatim what they were told at the time of diagnosis as the quote below illustrates:

....." the surgeon remarked that it was good that I had a family as it would be very unlikely that I would be able to have any more children after the operation as it was a 90% chance that I would be impotent after the operation. He said that it was possible that the nerves could be cut and I would not be able to have a sexual relationship with my wife ".

The impact of the combination of a cancer diagnosis, possibility of sterility and impotence with the impact the last will have on sexual relations cannot be overestimated. Entering the consultation room as an individual with an illness and leaving with information that will negatively impact on all aspects of life is devastating:

....” the nurse talked to me about the possibility of impotence...but I was 53 and only wanted the cancer gone and to have a life”

The immediacy of the cancer diagnosis tends to overrule all other issues, however, as the participants in this study revealed the long term issues of sterility and impotency increase as time from surgery extends. The same patient continues:

...” it was clear after a year when I felt better that part of my life was missing...I was unable to have a full relationship with my wife and we both felt sorry that the rest of our lives would be partially unfulfilled”.

Health professionals need to recognise that they need to probe and explore how individuals cope with such major life changes. There is ample evidence that for such personal issues as these patients find it difficult to ask for help and the onus is therefore on staff to be proactive and raise the issues of sex and where appropriate, fertility both prior to surgery and in the long term

This reinforces the reality that these individuals can no longer live in a world they have created for themselves, the normal dimensions of life are gone. They see their own body in a different way, instead of being an unconscious but accepted element of life, it has conspicuously failed them and needs to be surgically altered by a stranger if they are to survive. The current system of care takes no account of the fact that this reflection may last for many years or forever. Instead if there is no recurrence after five years they are discharged as cured. While this may be an appropriate procedure in terms of physicality this approach totally ignores the psychosocial wellbeing of the individual. It was clear from the interviews that some of the participants continued to reflect on the ‘what if’ scenario of cancer never returning to their previous position of unconscious wellness. For some participants the withdrawal of services left them feeling bereft and somewhat confused as to what to do next. The permanent colostomy was a reminder that the cancer could well return and further limit their life. This group urgently needed access to support and advice:

....there was no support.... and it was as if everyone had magically disappeared.... my good GP had retired and my new one admits to my face that he does not have the first idea of how to help me with this under carriage pain. He suggested I go to the hospital but as I am too far from the second hospital that is not a solution.... I have arthritis and “water work” problems and I have no idea what will happen if I cannot care for myself as I cannot ask my wife. It's beginning to get me down but who do I talk to about it”

This example revealed a second problem, the challenge of silence within a relationship. It is not possible to say whether or not professional intervention would have helped his wife to cope with the physical elements of her husband's colostomy. However, it is evident that without intervention this couple were left with a long term breakdown in the care and support of each other, something that must inevitably impact on their relationship. This illustrates the need for access to lifelong support and guidance for this very special group.

It has to be acknowledged that for this group of patients needing surgery for bowel malignancy, to be suddenly faced with the many stressful aspects of cancer, such as the uncertain prognosis, fear of the possible kinds of treatment, prospect of death, and significantly changed body image, life can seem bleak. The reality is that the family will also be reflecting the same issues and unless a way is found to facilitate communication there are deleterious effects on family and friendships:

... "my husband walked out of the consulting room when my diagnosis was given... the nurse went after him and he said he did not want to discuss it... he drives me to my chemo but goes to the cafeteria and reads the paper... I've tried to discuss it with him but he just says he does not want to talk about it".

Some patients cope well with psychosocial rehabilitation that needs to follow such major changes, but this group tends to be silent thus the strategies and mechanisms they have used remain unknown and unshared. For them moving on is "just what you do", but this stoical approach gives no indication of how they have learned to overcome a situation that leads many others to fail. There is an urgent need to explore both successful adaptation and the problems that prevent some patients moving on. Only when healthcare professionals are aware of the implications of the various coping styles that patients use, will they be able to offer appropriate care to all. There is a need to accept that confrontation with a life-threatening disease requiring mutilating surgery makes the pathway to normal life slow, difficult and for some it may even seem unbearable:

... "I remember being taken back to my room after surgery and sort of aware my wife was there... suddenly there was a bone shivering howl... where was this coming from was it me... then I realised it was my wife ... the consultant told her what had been found and that I had a colostomy for life"

All patients should be offered access to psychosocial intervention, shared decision making was designed to enable individuals to work with professionals making their

own choices with regard to what they do and do not need. Currently, while there may be elements of shared decision making evident in allopathic medicine there is little evidence of patients being able to debate the options regarding the wider range of services such as those designed to increase mental wellbeing. There needs to be a process through which those at risk of being trapped in reflection can be identified at an early stage and offered support and guidance. For this to be possible the links between hospital and community need to change to include issues of physical state at discharge.

The body of self as an aspect of the world is experienced as non-positional consciousness, meaning that the individual does not in the ordinary way, notice the body much during day to day living. Non-positional consciousness is the state of pre-reflective consciousness that is presumed to underlie the individual's consciousness of day to day experiences. The presentation and experience of self comes from the mundane day to day experiences that individuals all live through and is the central location that provides the knowledge that aids the individual to understand how the world is understood and interpreted. Self is linked to the individual's social context and relationships that are forged with family and others and therefore is the identity with which the individual shows the world. When the individual is well and disease free and has not received bad news about their body, the individual lives in a pre-reflective mode. However, when the individual is given news of ill health there is a sudden focusing on consciousness and the individual's body or area of body comes to the forefront of consciousness. There is often a tension between self-presentation and the socially constructed public identity that an individual has after such mutilating surgery. Although focus is on the patient, in reality it may well be that it is the close family relatives and not the patient who choose not to accept or see the way in which their world is changing:

...." I remember the afternoon well as I was much less sleepy then when the SCN came. My wife stood and looked out of the window of the room as the SCN introduced herself to us and would not face the SCN or speak to her. The SCN sat down and explained to us what a colostomy was and how it could be looked after, but my wife refused to share the consultation".

For this patient, apparent rejection by their closest loved one adds considerably to the shock and distress they are experiencing. However, many try and minimise the apparent threat of their change in body image:

... 'my husband said he would help me look after me and the stoma, but I told him not be silly as I could manage. After all I had changed the children's nappies so how difficult could it be'

Although rejection after colorectal surgery by close family or friends is not a common occurrence, for these participants' it was clear the memory of the rejection remains clear and bright over many years after the surgery. When the patient meets others in their day to day life the individual will be aware of meeting the other person via their body, with a smile, a handshake yet, as the body seems to present itself to the forefront the patient is aware of the other person's reaction to them. The individual has had to learn to be toilet trained again and needs to learn how to contain the transgression of the body boundaries that the colostomy has created. However, this anatomical difference of the individual's body is invisible in most social circumstances, hidden by dress, but is exposed when either the individual chooses to reveal their state or the appliance leaks. In these situations the patient dresses to avoid attention being drawn to the abdominal area and realises that they wonder if people will notice anything different about them and possibly comment on it. When the individual senses something conspicuous that has occurred to their body they will worry all the more. However, because the patient's wellbeing is disturbed by their change in body image, yet remains unknown to the observer, they are no longer self-forgetful of their body:

... "I don't like meeting other people so I don't go out. When I have to I dress carefully making sure my abdomen is well covered and protected and pray that I do not have a lot of wind to swell the bag and people may stare at me"

When wellness is disturbed the individual is aware of their bodily change and will often process thoughts about their own mortality. However, those that they thought would be there supporting them seem unable to do so. The hurt and distress from this passive rejection never goes. It is a continual reinforcement to the individual that they no longer meet society's expectations of normality:

... "I get undressed in the dark so that my partner cannot see my stoma bag. Luckily I can wear pyjamas to hide it all, the scars, the bag. I sleep in another room now so that I do not disturb him with my tossing around"

However, the phenomenological locus of the life world in which the individual's body, self and world are intertwined, a holistic, non-dualist approach is taken in looking at the participants' interviews. In splitting mind and body, a sense of self arises through our perception of our relationship with others. For the individual faced with living with

a permanent colostomy, their sense of body and self in daily activities changes as they avoid all talk of their stoma, surgery and relationships with others. Avoidance techniques in relation to the individual's body image, are quickly accumulated and distraction techniques are utilised:

... "I was made to look at my stomach and the thing [colostomy] as the nurse said I need to use the mirror to see how to apply the bag... as soon as I got home I moved all my full length mirrors out... I don't want to see it again... I only have mirrors where I can see my shoulders and face... below that it's not me"

Sometimes, extreme distraction techniques are used and an example of avoidance and the division of mind and body is seen with this patient:

... " [How are you managing with your stoma].... well there it is it looks ok but I don't ask it I don't care... [The nurse asks where and he points to the empty chair beside him] it's on the chair there... The thing... I suppose I have to do it each day but try not to... I don't want people thinking it is part of me of who I am".

Here the individual is talking about his stoma but he completely un-attaches himself from the physicality of the abdominal surgery and stoma because he dislikes it so much. He sees it as a 'being' that he has to make some effort to care for as if he is talking about an unwanted pet. He avoids letting anyone think it belongs to him and that he has to make some effort to care for it daily. Sartre (1956) suggests that the most common manner of experiencing the body is as non-positional consciousness or near self-forgetfulness until something happens to move the individual into explicit consciousness, such as stoma surgery. Positional consciousness means that the individual becomes aware, explicitly of their body or what has happened to it and tries to maintain life as if everything is normal:

... "It is over a long time ago..... I am well and carry on with my life.... everyone always tells me how well I look and I agree with them.... but.... it is always there at the back of my head..... but I just move forward all the time".

For participants in this section of the interviews it was clear there were recurrent topics related to identity and self. The theme that was most conspicuous was that there is evident tension between the private and public self-relating to individual identity after colorectal surgery. Subjective awareness of changes in the body, such as stoma, becomes an encumbrance, something that is confronting the individual as they have to deal with stoma care every day. Sometimes, explanation can help to heal and enable the patient to become less anxious in their relationship with their body, but as many of the interviewee's said, their discomfort, be it physical or mental,

is because they continually focus on their body image and therefore find it difficult to continue with normal activities of daily living. Sensate experiences of everyday life are taken for granted and do not figure in the individual's consciousness until there is a physical alteration to the body. Merleau –Ponty (1962) suggests that there is a special relationship that all human beings have with their body. If the individual is unhappy with their body, be it with a permanent stoma, and worries about their physical health (the effect of cancer), the patient may suppress these feelings yet cannot hide them from their own body. Even physically hiding themselves from the sight of others and the world, they are unable to separate themselves from their body and sense of self.

Fatalism: The body experienced as call is using the meaning of call in association with death (call as in calling hours to view the body) and it can be perceived by the individual that they have 'died' as in the body no longer can be controlled or act in the manner that the individual would want. No longer can the individual return to non-positional consciousness as they are continually able to be cognizant of what is happening with their body and therefore remain in the state of positional consciousness with the world. Health care professionals, especially Clinical Nurse Specialists in stoma and colorectal nursing can be involved with the individual who is out of step with the body, and help to recover a livable relationship with their psycho-physical being. Increasingly the healthcare professional is becoming aware that individuals need more than surgical intervention and that the health professional must be aware and involved in the way that the individual experience and live with their problems in a different way, that can be deeply personal and unique. Different patients who receive the same diagnosis may experience their illness in fundamentally different ways due to the clinical path having different consequences and significances for each individual.

Following on from the initial epoché from the interviewee's comments, thematic analysis was compared to Van Mannen's (2014) textual insight cultivators which produced five phenomenological aspects of body experiences. This information still did not adequately provide what the interviewees were really saying therefore the epoché was reapplied to bring forth a categorisation of the five themes. Goodhart and Atkins (2011) suggest that low mood or even depression is one of the most common side effects of cancer. Although none of the interviewees suggested that they had had treatment for depression at any time, it seems clear that this patient quote shows that they could be depressed with the situation they find themselves in:

....I'm scared the cancer will come back and that they may not get it all anyway.....I can't get it out of my head....it's there all the time...day and night, night and day....I haven't got a life anymore...I haven't got a future, I'm not coping”.

Fatigue, also one of the common late onset symptoms of cancer is still evident. Often with diagnosis and treatment the individual can be stretched to their limit and beyond and often grieving does not take place at this stage and it can take some years for the grieving process to become evident. This can be exhibited in depression that has been triggered by a momentous happening such as surgery for malignancy and a permanent stoma. The bottling up of all these symptoms can lead to a fatalistic attitude and feelings:

...”I was alive, I had finished treatment but I was disfigured. I feel dead. Some days... Not many days I feel I am in a stupor....I watch TV all day but don't know what I have watched...I might eat if I can be bothered or again I might not”

Every day many cancer patients consider that diagnosis, treatment and colostomy for colorectal cancer makes them consider their existence that has been profoundly called into question as for many of these patients the expectation of this diagnosis is a death sentence. When an occasion such as this occurs the patient will be brought face to face with their own mortality and find the collapse of the world as they know it, has gone. Some of the participants expressed a dichotomy that they found themselves with, their cancer ‘cured’ but that their self-body-world unity, relationship with others and their family, threatened as their life is derailed:

....”I know I am 'cured' because they told me that.....he knows that as well.....but every day I am convinced it will be my last day and I will not wake up....he tells me not to be silly.....he says he still loves me regardless.....but how can he with a body like this”

Sometimes an unintentional comment by a healthcare professional may aggravate the patient's mood by inadvertently trying to bolster the patient's morale and does not realise how a poor use of conversation can do more to damage the delicate thread that is keeping the patient supported and send them into a further downward spiral:

... [The consultant told me]...you should be grateful for what we have done, you are cured...many people do not get what you have. A life....go away and enjoy yourself. If only I could...every pain and twinge frightens me...how do I know if it has come back again?”

Van Mannen (2014) suggests that the modality of the body experienced as call introduces an existential element into the patient's immediate experience. The fundamental life feelings as seen in Maslow's (1954) hierarchy of needs of self-actualisation, esteem, belonging and security are tied up in the patient's body experience and are shattered with a single blow by the surgeon with the diagnosis of cancer. Cancer brings a massive shift in a patient's life and the life of their family and some will shut down emotionally to try and manage the treatment. However, for some, life and living after colorectal cancer and a stoma can be alienating and meaningless, very much without a purpose in the way it used to be. Their life, health, happiness and family has suddenly been stopped in its tracks and called into question. Their previous existence has ceased, they are looking death in the face:

... "I remember it all so clearly... I said it's my birthday tomorrow that is all I could think of. I was taken to the see the consultant in his room and could hear him speaking but didn't know what he was saying.... I looked round the room... why were all these people here looking at me... what were they doing there... they were nothing to do with me... they will be here when I have died and am forgotten"

What can be ascertained here is the participant, in describing their reaction above, of the shared landscape and shared conversation described by Merleau-Ponty (1962) was that the participant was describing that they did not recognise this person who was being told bad news. It could be recognised and described as meeting death 'face to face'. The participant was so shocked with what they were being told that they could not marshal their thoughts with the most immediate fact being that it was their birthday the next day. On discussing what happened on that day many years ago, the participant felt that they had a fundamental sense that it was them within this encounter at the hospital but yet also felt that they failed to recognise who this other was, being told bad news, experiencing an 'otherness' as described by Levinas (1981).

The role of the healthcare professional plays an important part in the call. Van Mannen (2014) suggests that there is a responsibility by the healthcare professional when the patient has an experience of the call that bursts upon their world in the most unexpected of ways. The responsibility of the health care professional is to deliver the news in the kindness of ways and Levinas (1981) suggests responsibility is experienced as 'being there' for the other. Healthcare professionals learn how to cope with this degree of responsibility when a patient experiences 'call' and learns how to cope with the imparting of the news without causing trauma to themselves or

become drained especially when working in oncology clinics where patient after patient is given bad news. It is probable that the way healthcare professionals deal with these patients in their professional lives is to be aware of their own emotional lives in addition to managing their private lives, families and friends.

Fighting Spirit: The body experienced as a focus of appreciation may be seen in the patients who are keen to overcome what has happened to them and develop an effective response to having had colorectal cancer and a colostomy. The experienced physiognomy of the new 'self' often expresses the patient's character. However, if the look of others, who are unaware of the individual's dis-ease does not centre on the abdominal area it does not objectify the individual and make the body into an object.

Although it is very common to have worries after being diagnosed with cancer and body image change, many individuals can have a "fighting spirit" from diagnosis and through treatment and onwards as they return to their normal lives. They do not want to "wallow" in self-pity and have the temperament to continue their life styles and jobs. They will often search for any other forms of treatment to be able to confidently discuss regimens with their doctor and how they want their treatment to progress:

... "when I felt better afterwards [after the surgery] I investigated on the computer what might happen next.....I had heard of chemo and wanted to be prepared.....I wrote for literature from those people who deal with colostomy. [Colostomy Association]..... knew I was going to see another doctor [oncologist] in six weeks and wanted to be prepared with questions.....I suppose all the patients are like me.....keen to know what goes on.....well it was only the best [the oncologist's news] and I was back on track.....no chemo or side effects to put up with.....but mind you I would have taken and put up with whatever he threw at me.....I have had excellent treatment from the GP and hospital".

Once finally discharged they are able to continue their inquiring into cancer and will often want to help others who may be finding it hard to move on in their lives after treatment:

... "when I was diagnosedI thought ok, well, how am I going to approach this....we enjoy our life (with his wife)and love our holidays abroad and no way are they going to stop.....I am sure people who have stomas go away when they are well.....they do don't they?.....I must look into how to do this.....I go to stoma days (open days) and talk to the companies....I need to find what will suit me bestI have seen over the years how the bags change".

As these individuals become aware of the changes that are going to take place within their body and integral with their identity of their self, they may feel deceived that this invasive illness can cause so much disruption and change the relationship with their body as they have previously known it. By being proactive with what the diagnosis and outcome may do to their identity, they look to define their situation themselves rather than the situation defining them. These individuals have made a conscious decision that becoming ill may change their identity but that they are going to appreciate their own new embodied being:

...."I am a lay preacher and I will continue.....my health is good at present.....we have been married 60 years and I definitely expect some more [years].....I had no psychological or emotional problems.....I back at Am Dram [Amateur Dramatic] now and the choir.....yes there was fear of the unknown but nothing seems to be unknown these days with a computer.....it's a minor inconvenience.....my bum is in a different place now where I can see it".

The primary appreciation of one's body is disturbed when colorectal cancer and a permanent colostomy are diagnosed. For many, body dissatisfaction is common before it is changed by stoma surgery and then there can be repulsion. However, for many the cancer diagnosis and colostomy is not going to stop their lives. The patient's self-esteem and underlying beliefs about themselves place them high in Maslow's (1954) hierarchy. For these patients they believe that this "blip" in their life will not keep them from doing what they want:

..." we have always travelled...had a good life you know...I did query it with the stoma care nurse and she was most keen for us to carry on...she said wait until 3 months when I would start to feel better and start planning something nice...she said she would sort out a travel certificate in the appropriate language and give me a list of insurers...how good is that...it would be such a waste if we can't use our staff flights...that's why we go away so often...I've got no worries about managing abroad"

Self-esteem is very important as it is a major part of who the individual is and body image is the mental picture of who they are and there can be an intensity of feelings when they are faced with permanent body change. The intensity of emotional reactions to body change are related less to the severity of the disability than to the assigned importance of the structure and this appraisal depends, among other factors, on the individual's immediate social situation and past experiences. A patient states:

..." well let's look at it this way.....there are people out there far worse off than me...what have I got to moan about...nobody is going to see it...it's not as if I have lost a leg or been facially disfigured is it".

Many cancer patients have to go through a period of re-ordering their environment after surgery and recovery and say they are left with a sense of loss and vulnerability associated to the physical changes that they have been through. Nothing will quite be the same again for them; many patients say they are not going to let cancer and colostomy defeat them and throw themselves into resuming normal activities as soon as is reasonably possible. Many will have a "fighting spirit" and want to turn their new found life to helping people and charities associated with the same problem that they had. Travel is not a problem and they have learnt what to take with them in the form of extra supplies and for some, extreme sports are not a bar to what they wish to do. This patient states:

"I get out and about a lot but do find that I have to sit for twenty minutes every 2 hours or so due to the dragging pain in my perineum and I like to go abroad. Not so far now as I am older but I am not going to be stopped by this".

Toombs (1993) suggests that illness is a state of disharmony, disequilibrium, disability and disease which incorporates a loss of the familiar. All the participants in this study, although five or more years past the discharge point still were very much aware of the impact of their diagnosis and mutilating surgery and could still iterate their feelings of initial despair for some of them, that carried on all through their lives to those who although were shocked at the beginning turned themselves around used a 'fighting spirit' to carry on with their lives. For some participants in the study group, those with a colorectal cancer diagnosis and a permanent colostomy, their loss of normal bowel function was a greater problem than the cancer diagnosis. They felt that the colostomy caused them to lose their confidence, motivation in their daily activities and the taken for granted control of bowel function that they were taught as young children. For some, this resulted in a diminishment of their life and social isolation and connectivity. These participants lived experience descriptions following their own chronology extends over many years since their initial diagnosis and it became clear that even those who were between ten and twenty years since diagnosis could recall as if it all had happened recently..

..."I am a lay preacher and I will continue.....my health is good I have many more [years].....I had no psychological or emotional problems.....I back at Am Dram [Amateur Dramatics] now and the choir.....yes there was fear of the unknown but nothing seems to be unknown these days with a computer.....it's a minor inconvenience.....my bum in a different place now where I can see it".

In theme 5 the participants' story is told chronologically but in looking at the narrative analysis it is a progressive account of his illness and recovery leading back to his community to lead a normal and productive life. He tells of what he wants from the rest of his life and how he has returned to his hobbies stating clearly that he will get on with his life. It may seem to other participants that this individual is very lucky and they can never hope to be the same as the diagnosis and colostomy is too much to bear. This participant has emerged from a difficult time in his life and is willing to share it with others in an altruistic way and continue and to show that life can go on. Narratives offer a way into the participant's life story and understand how the stories un-fold over time (Finlay, 2011). In finding a 'story line' for the overall analysis of all the participants in this study, initially seemed overwhelming, but once the first reduction and analysis of the quotes came about, the traumas of the majority of the participants was becoming clear. Their stories were similar once they left the intensive care of the hospital healthcare professionals at the five year mark. Recurring themes were 'lost', 'cast adrift', 'who do I turn to', 'who will understand that I am worried'. As for many people at this stage of the cancer trajectory, post five years, they are considered to be the worried well and commonly the GPs do not know how or what to do to help them. This participant bears this out:

"I go to my GP but he seems to have little time for me and he makes me feel I am time wasting....I go to the group meetings but there is never anyone there to ask....they are not medical....I have my yearly old age check but the practice nurse is so young she doesn't seem to know much about what I am talking about.....she asks about my stoma but does not look at it."

This is also borne out in the literature in the work done by Corner (2014). She suggests that Improvements in survival are a result of earlier diagnosis through screening, public health initiatives and new and different treatments. Yet the complexities of living with cancer are not reflected in the cancer survival statistics and the typical cancer trajectory is becoming less predictable than 20 years ago when there was a relatively stable understanding of the course of illness for individuals. However, the picture now is of a changing scenario where the good news over cancer survival statistics masks what is now a longer illness trajectory that is increasingly unpredictable in terms of the health outcomes for these individuals. For those whose cancer recurs, multiple treatments are becoming available that can prolong the duration of living with active cancer over months or even several decades on from primary treatment. It becomes clear that there is a need to develop an understanding of what it is like to live with cancer beyond primary diagnosis and

cancer treatment and how the NHS should respond is therefore an important agenda.

What was apparent from some of the participants' narratives was the hopelessness and helplessness at the diagnosis of cancer more so than the need to have a permanent colostomy. Even though a few participants who described this in their narratives realised they had lived beyond the five year point, felt that there was no clear demarcation for them between life threatening disease and terminal disease. For them they were imbued through their social and educational positions in life that a cancer diagnosis means that they will die and die in pain. A cancer diagnosis increases the individual's thoughts about their mortality which will remain with them to a greater or lesser degree for the rest of their lives. The thought of impending death due to a cancer diagnosis does not always affect the patient but can have a profound effect on the patient's relative as the participant stated:

"My wife said she needed to know when the SCN would be coming and wanted to avoid seeing her as she said she felt that the surgeon and the nurse had signed my death warrant and how would she cope with the house and children if I died".

For many patients and their relatives the diagnosis of cancer suddenly brings to the forefront of consciousness the fact that they are mortal and there will be a time for them to die. However, for the majority of the participants, facing a life threatening illness such as cancer and its consequences, once the initial days and weeks go by, they return to their non-positional consciousness. Ramussen et al (2007) suggests that cancer patients meet silence in others and also in themselves and use this as a coping mechanism. However, even pushing to one side the thought of death, as the majority of the participants did, does not take away the threat of mortality, but the participant has the ability form strategies to restore embodied control in their everyday life. However, for most of the participants in the study, they had overcome their diagnosis and treatment episode with their own strategies. The thoughts of death that they felt would define their lives were put to the back of their minds and they made the decision to continue with living. Some though, who were coping with the threat of mortality were finding their biggest difficulty was coping with the colostomy, physically and mentally. They were disembodied and although the literature suggests that there are four stages of re-embodiment (Taylor et al 2010, Thorpe et al 2014), those being disembodiment, restoring embodiment, reclaiming control and managing embodied control, it was clear that through their narratives, several participants had not and could not move beyond disembodiment. The way an

individual copes with a major life event such as colorectal cancer and colostomy may be compared to an 'actor' giving a 'performance'. When such an individual 'performs' they are implicitly asking their observers to take seriously the impression that they are seeing. The 'performance' the individual gives is socialised, moulded and modified to fit the society in which the individual exists. The individual with a stoma struggles to cope with their private self as an ordinary person with a stoma and with their public identity as someone who is known to have a stoma. The stoma becomes a relevant factor in some social interactions once the individual's identity as someone with a stoma is known. A participant in the focus group, FG (a), shows how this affects them:

"I come here because the group leader has helped me such a lot, but as soon as I walk in a room anywhere else they all know I have a stoma by looking at me". [FG (b) asks how people know as the stoma cannot be seen]. FG (a) replies....."well I know they know, they must do because I know and I make noises and smell.....I don't go out anywhere now and have to rely on my son to get the shopping....everyone in the store will look at me and say here comes the dirty lady.....I would not be able to cope with that".

It appears that the major consideration in terms of adaptation to having a colostomy would be the length of time the grieving process takes the individual. There are several stages, five, that have to occur for the individual with a stoma will have to go through to construct a new identity. Realisation of what has happened to them will be characterised by avoidance or denial of the loss followed by the experience of unreality or blunting. Next comes alarm as the individual becomes anxious about the colostomy and how to care for it. Searching is characterised by panic and pre-occupation with loss followed by a period of grief for the body part that has gone and feeling that the individual has been mutilated especially when they see the stoma. Lastly, is resolution this is when the individual makes the effort to construct a new social identity. Unfortunately, a few of the participants in the study only reached stage 4 of 5 of their re-embodiment and stopped there. Learning to cope at the technical level is learning control of pollution of the self and the environment. These are very private activities and if the individual is able to cope and manage the body technically, then the individual can 'perform' before the public audience and appear unexceptional. At the intra-subjective level the individual may be able to cope technically, but these skills do not do not make the threats associated with a stoma disappear, but simply hold it in check. Focus Group (FGc) stated:

"It's a nightmare... I wake up at night thinking and worrying about it all the time....I don't like to dwell in the past, but I keep thinking.....I should have done this....I should have done that. I hate him (the surgeon) for doing this to me.He says forget about the past.....you can't, it's really hard".

Reflecting on the above findings.

At the inter-personal level of coping, what has been the private world of the individual after stoma surgery now becomes the public world. Some of the individual's social circle will know of the individuals change in status due to surgery, others will not. Managing this knowledge requires a sophisticated coping behaviour. The aspects which affect the individual with a stoma are that the individual now has a difference which impinges on the private self, but which does not usually affect the public self. To cope at the inter-personal level, individuals try to recognise the potential for problems and to keep their own bodily changes secret. At these various levels of coping of life events, there is often a discrepancy between appearance and reality. There is concealment from the audience of all evidence of 'dirt' and that 'dirt' is looked after in private. In controlling 'dirt' the individual embodies several ideal standards and often these standards are maintained in the public arena by the sacrifice of some of these standards in private.

At the inter-subjective level of coping, the individual constructs schema and an explanatory model that is used to make sense of what has happened to them during this time period. In this crisis approach, the individual's body alteration leads to an internal reaction and uses an explanatory process or model to move from identity to self. It is this negotiation that helps the individual with a stoma to move from societal reactions to internalisation of self to disclose their new identity. Many individuals and health care practitioners have pre-conceived ideas about patterns of illness and how it is interpreted and treated and Kleinman (1980) in his work with explanatory models distinguishes aspects about episodes of sickness and treatment that individuals use either consciously or sub consciously and these are:

The cultural construction of illness as a psychosocial experience

Establishment of general criteria to guide the health seeking process and to evaluate the treatment approach

The management of particular illness episodes by communication and labelling

Healthy activities and therapeutic interventions, medicine, surgery, healing rituals and counselling

Management of therapeutic outcome and appropriate treatments for the condition

These five care points or notions about sickness and illness have been determined by Kleinman (1980) as 'explanatory models'. Often the cultural construction of illness is a personal and social adaptive response as is seen in the lived experience descriptions (LED) of the participants. The malfunctioning of the body and the psychological process involved becomes disease, while the psychosocial disruption becomes illness. Illness will invoke cognition, valuation of the symptoms and possible breakdown of family and social interaction. Therefore, illness is the shaping of disease into behaviour and experience is created by personal, social, and cultural reactions to the disease. The lay explanatory model is put together in response to a particular episode of illness and is not the same as general beliefs about illness that may be held by the individual's particular society, which may be idiosyncratic and changeable and influenced by culture and personality. By contrast, the medical model is based on scientific evidence to deal with that particular set of symptoms. The doctor and patient, each using their own explanatory model, must come to an agreement about the interpretation of each other's model, the individual's subjectivity of their own disease and the doctor's view of the disease process. Any contradictions must be resolved by negotiation so that compliance of the prescribed treatment may take place. Explanatory models are a way of constructing reality and imposing meaning on chaos but may be hazardous if accepted as reality, rather than a way of organising what is seen by the patient as chaos after a diagnosis of colorectal cancer and permanent colostomy (see Figure 17).

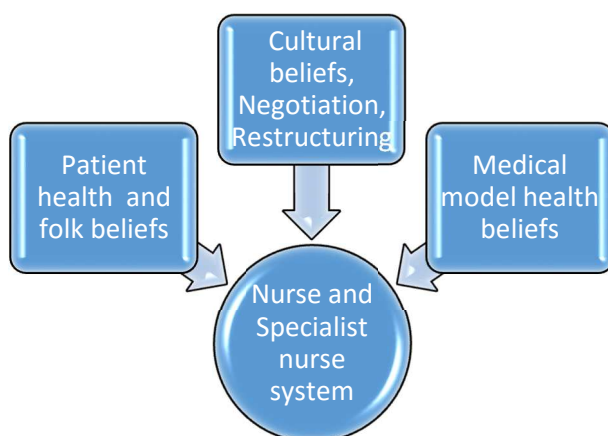


Figure 17. Constructing reality and imposing meaning on chaos.

The clinical process is one way for the individual to adapt to worrying news and circumstances and the adaption process is often reflected in the words ‘managing’, ‘coping’, and ‘adapting’. The way the individual constructs the news given to them about their diagnosis is a personal and social adaptive response.

Presenting the participants’ stories and their complexities was challenging for this study in keeping faithful to the embodied lived world and to produce a new, conceptual framework to support this group of patients after final discharge. However, although still nascent, a growing number of studies are beginning to take notice of the fact that cancer is moving towards to being recognised as a chronic illness and noticeably, individuals are living a considerable time after primary treatment has finished. In their work, *Implementing Survivorship Care Plans for Colon Cancer Survivors*, Mayer et al (2014) suggest that many patients find transition from acute treatment to survival, difficult. They suggest that survivors may not know the significance of surveillance and which tests need to be done and when, who to see and when to go for follow up once treatment is over with many of their study not receiving the recommended follow up care for colorectal cancer. One of the few papers on long term follow up for colorectal cancer and what it should be is by Figueredo et al (2003). A systematic review was conducted to evaluate the current literature of the different programmes of follow up after curative resection of colorectal cancer where five year survival was reported. They suggested that follow up programmes for patients with curatively resected colorectal cancer do improve their longevity with good, organised follow up programmes. The visits should include blood tests, chest x-rays, liver imaging and colonoscopy although there is no clear definition which tests or their frequency is optimal. An Australian study by Brennan et

al (2014) suggests that there is a lack of long term outcome data about survivorship care plans and whether there is any significant benefit later in the individual's longevity. They suggest that further research is needed to evaluate the long term effects of a care plan on the increasing number of cancer individuals moving onto the longevity stage of the cancer trajectory.

More recently, from the UK, Corner (2014) states that there is very little data from the few studies of the well-being of those with a cancer diagnosis and experiencing longevity past the five year point, and these suggest that while, in general, individuals report that they are in good health, a substantial minority experience long-term physical, social and economic consequences. This leads to an extensive use of health services as a result. It is noted from her research that there are few services targeted at supporting long-term cancer patients or ways to help the minimization of potential physical or emotional consequences which prevent individuals to return to productive lives following treatment. Perceived neglect of the issues surrounding longevity in cancer patients led to a movement in the USA (Hewitt et al, 2005) promoting the concept of cancer survivorship, which was recently acknowledged in the Cancer Reform Strategy for England (DH, 2007). As the population of cancer survivors is increasing by 3% every year, health care professionals involved in planning and delivering cancer longevity care have access to tools, resources, information, and data useful for planning individualised longevity care plans. There will be challenges to implementation, but there are indicators that holistic care and services can be both cost-effective and used to improve care and quality of life for survivors. However, there will be implications for nursing practice as much of the longevity care will be undertaken in the community or at the GP practice. As the goal of post treatment longevity care is to promote the health of the cancer individual. Nurses have significant roles in the planning and delivery of survivorship care for cancer patients. Although there are no clearly defined pathways of these nursing roles, nurse specialists in colorectal and stoma care and the role in which they support this group of patients are well suited to deliver care for life plans in the community or GP practice. The specialist nurse role has clear resonance with theories and practice of nursing, where the essence of specialised nursing knowledge is directed towards helping individuals regain health. at a time when they are unable to, or lack an appreciation of the importance of doing so. With the impressive improvements in survival rates of several of the main cancers, survivors need support in understanding and recognising late effects including secondary malignancies, cardiac dysfunction, functional decline, psychosocial morbidity and

other co-morbidities associated with age related cancers. Some late effects are avoidable by early detection or risk modification.

CHAPTER 5:

COPING STYLES.

The main aim for the study was to develop a conceptual framework for patient centred care after the transition from “patient to person. However, as the previous chapter indicates, although there are themes that go through the individuals experiences it was evident that reduction and analysis would be needed.

It became evident from the interviewee’s stories that there are many disease and stoma issues that are still unresolved in their lives even after they have been given the “all clear” at 5 years by the consultant surgeon or oncologist. Recovery and acceptance after colorectal cancer diagnosis and permanent colostomy are known to be influenced by many factors including gender, age, stoma, diagnosis, pre and post-operative care and advice (Haughey and McGrogan, 2017). These complexities and the effort of trying to return to a normal and productive life in the community can become very difficult for the individual and their families. Interviewees had been asked to describe words to state how they were feeling at the time of interview in regard to their life, diagnosis and stoma. Many of the interviewees, at the time of being discharged from the end of successful treatment, felt that they should be experiencing relief, peace and time for celebration but it was obvious that many of the group did not have this experience. Instead they stated that they felt that they had dropped into a big hole and were still continually falling. Some felt that they were alone with no one to turn to and some were even more worried than they had been with the original diagnosis

The interviews are also a chronological story for each individual and each had a differing amount of time since the transition from ‘patient’ to ‘person’. Much has been written about the psychosocial and physiological problems that an individual with colorectal cancer and a colostomy may encounter but there is little to nothing about what the impact of this diagnosis means or does to the individual and their partners. These stories from the participants are here to show how little healthcare professionals realise about what this impact is and how it goes on for years in the individual’s life right up in some cases to their death. Dow (2003) suggests that substantive research into the experience of ‘surviving cancer’ is long overdue and this view is supported in the nursing literature as far back as the 1970s. Carter (1989) stated that “these lives need to be valued and specifically catered for”. If as health care professionals, we are preparing these individuals for longevity after the cessation of therapeutic intervention we need to have insight as to what this longevity involves.

The purpose of the study was to understand how individuals feel after they have reached the five year mark and beyond, after the diagnosis of colorectal cancer and a permanent colostomy and to make a contribution to patient centred care after the transition from patient to person. It is recognised within the UK, that at five years if there has been no recurrence or metastatic spread and scans show no progression or unexplained changes, the individual is considered to be 'cured'. Invariably they are told to go away and enjoy life. For many of the patients that were interviewed there were and have been long lasting repercussions from the surgery, adjuvant therapy, physical and psychosocial repercussions. All these individuals seek help from where ever they can as there is no accepted way they can refer themselves back to hospital and the team and invariably the GP cannot answer the individuals query.

Survivorship Care Plans (SCPs) only cover the time from diagnosis and during the time until discharge. These are made up of two elements, a receipt of a written summary of the cancer and a receipt of instructions of who to see for routine follow up. Chrischilles et al (2015) in their research found that only one in four individuals reported that they had received a SCP with both elements and were certain about their doctor who was caring for them. At the seven-year survey post-surgery, older individuals reported that they had not received a SCP. In the study the authors recognise that many cancer patients lack adequate support to successfully move from "being a patient to a survivor". Individuals need more than a SCP that is only active in the early stages of diagnosis and treatment. Arora et al (2011) reported that over 60% of post treatment 'survivors' in their study lacked the help they needed to improve their health once their treatment ended or the support needed and moreover, that the clinician did not understand how the treatment had affected their quality of life.

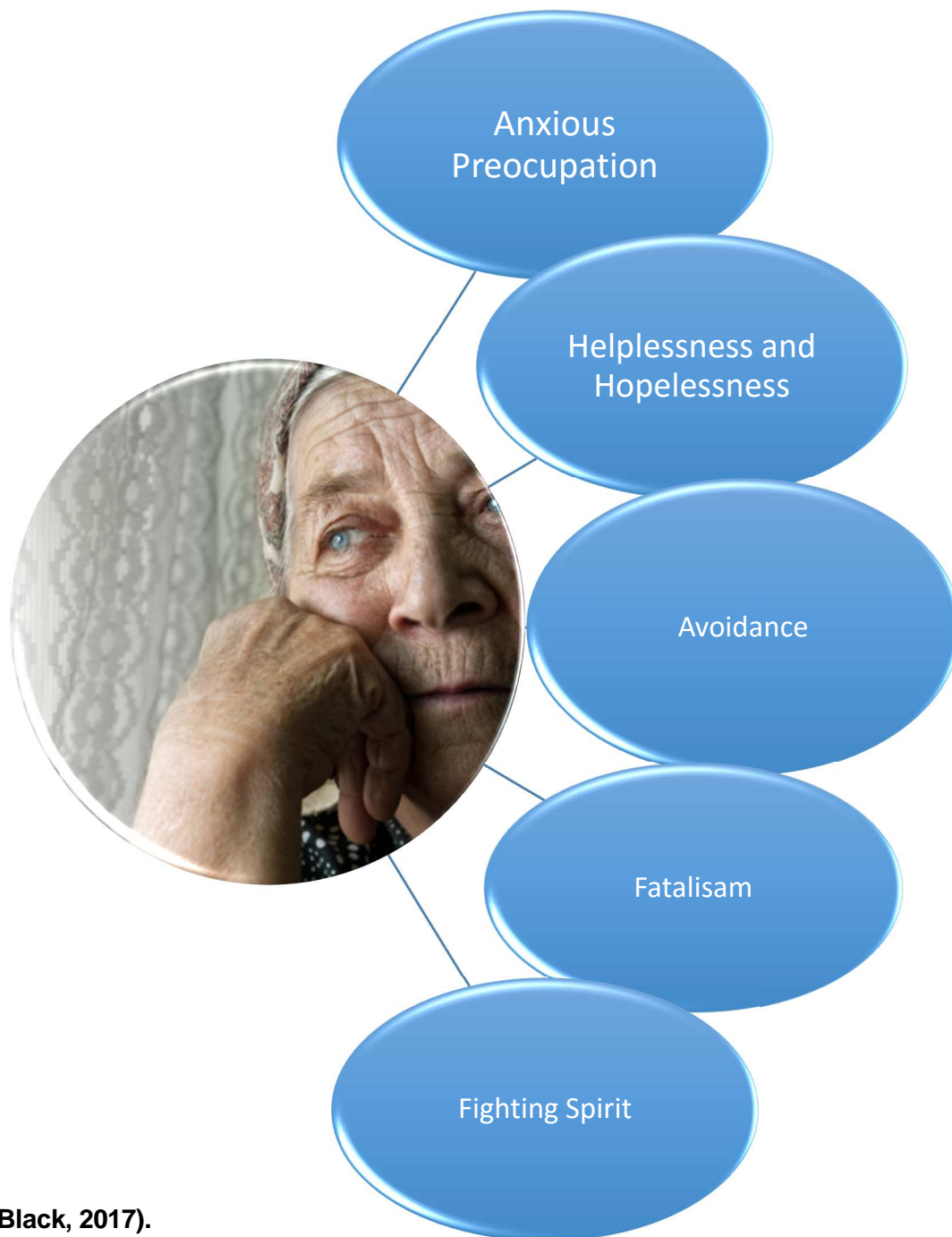
Elation by the individual on completing treatment for colorectal cancer and a colostomy, is often coupled with the anxiety of losing contact with the medical team and specialist nurses or conversely never wanting to see them again which suggests an association between somatic anxiety and psychological distress. As increasing numbers of people are being treated for cancer successfully today, it therefore follows that more will survive to pass the five year mark (CRUK, 2012). In coping and passing the five yearpoint (the world wide accepted time scale that the cancer has been 'cured') these individual's lives need to be catered for and valued. If as Rodgers and Knafl (2000) describe, concepts are the building blocks of theory therefore concepts can be viewed within a socio-cultural and emic context.

Historically and metaphorically, survival has been associated with war or laws of nature and in cancer it is metaphorically aligned with war, fighting battles and survival (Chapter 8). One of the first people, Mullan (1985), described his personal experience of cancer and how this might affect an individual holistically and evolve over time. From then the concept of 'survival' after treatment for cancer started to take hold in the literature, yet no definition was given. Aziz and Rowland (2003) suggest that cancer is now classed as chronic disease with physical and psychosocial outcomes and 'survivorship' can be defined as a process starting at diagnosis, involving uncertainty, a life changing experience and has a pluralism of negative and positive aspects along a continuum. There is lack of general agreement in the literature as to when an individual begins to think of themselves in the terms of 'survivor' (Little et al 2000, Leigh 2001, Vachon 2001, Ganz 2005). However, other writers suggest that to be termed a 'survivor' the individual must live for at least five years after the diagnosis of cancer (Carter 1989, 1993). For many individuals the experience of a colorectal cancer diagnosis and permanent stoma, is without doubt, a memory that remains vivid in the individuals head combined with the sudden realisation of vulnerability and mortality. Mullan (1985) compares 'survivorship' with nature and of having three seasons - acute, extended and permanent. Carr (2004) suggests 'survivorship' is waiting and wondering all the time. This criteria was adopted by the National Coalition for Cancer Survivorship in the United States of America as their criteria of membership. Anyone with a history of cancer from diagnosis and for the remainder of their life is where the 'survivorship' idea in the UK originated (Leigh & Logan, 1991). In defining how 'survivorship' is described, medically it means after treatment has finished but if looking to establish a timeframe this could be any time from 2,5 or even 10 years after diagnosis or when a cure is achieved. Many support groups disregard this time frame and a 'survivor' is any one after a diagnosis of cancer regardless of recurrence or persistent disease. To find a linguistic term for life after a cancer diagnosis that is harmonious with all concerned – patients, healthcare professionals, voluntary support organisations, it appears strange that what has been accepted is an oxymoron – surviving cancer.

Table 10.

2nd Analysis showing categorization of data.			
Reducing	Reducing	Reducing	Categorizing
A) Searching for reassurance	B) Constant worry	C) Physical sensations perceived as disease progression	Anxious Pre-occupation
A) Overwhelmed by diagnosis	B) No active coping strategies	C) Self-blame and burden to others	Helplessness and Hopelessness
A) Minimisation of the disease threat	B) Undertake distraction techniques	C) Maintain life as if everything is normal	Avoidance
A) Lack of control	B) Acceptance	C) Fate will decide	Fatalism
A) Cancer and stoma seen as a challenge	B) Information sought to help with treatment	C) To keep life as normal as possible	Fighting Sprit

Figure 18. Patient coping styles identified from 2nd analysis and epoché.



(Black, 2017).

As the literature revealed and the participants interviews concurred, there is little data or research on what the needs of the colorectal cancer patient with a colostomy are after they have reached the five year mark and effectively been told they are 'cured'. Even a decade ago, Lotfi-Jam et al (2009) were discussing the increasing recognition that cancer survivors require continued care, beyond diagnosis and treatment. They too, concurred with the researchers' findings that this group of patients are at increased risk of second and recurrent cancers, treatment related side-effects, other

co-morbid health conditions, as well as psychological difficulties and social isolation. As has been indicated by the participants, current care is suboptimal and does not adequately, if at all, meet the needs of this population. Jefford et al (2012) noted that colorectal cancer survivors expressed high levels of satisfaction in interviews after receiving an SCP in a nurse-led consultation during their primary treatment time. However, Jefford et al (2012) noted in their paper, that in a pilot study of colorectal cancer survivors where SCP use was considered feasible, it was found to be resource intensive and estimated that 1–1.5 h and some as much as 4 hours were required for a nurse to complete SCPs and then staff with clinical experience had to verify the accuracy of the SCP. Due to the heterogeneity of these studies from America and Australia, it was suggested that current health-care funding models do not allow for remuneration for this considerable time.

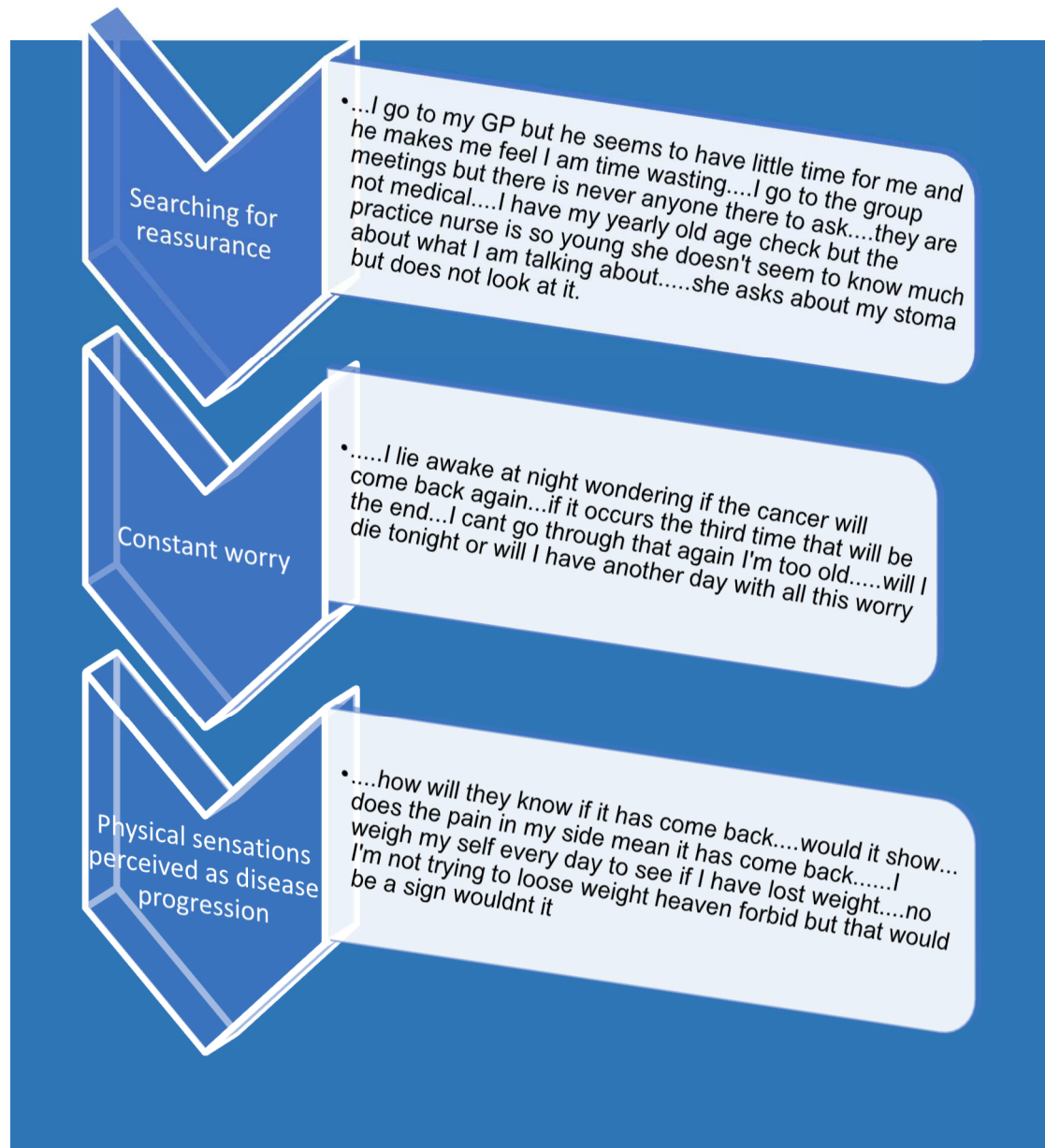
The collective view from the focus group was useful in gaining an over view of the participants' feelings that led to the individual interviews offering more opportunity to delve deeper into what their needs are and whether they are being met. Also Van Mannen (2014) suggests that the interview schedule is the traditional method used in phenomenological research. With the second epoché and analysis from the individual interviews the researcher was able to begin to identify common themes that the participants were expounding. To avoid the description-interpretation continuum the researcher chose to utilise description from the participant's description of their feelings/descriptors rather than interpretation as that may bring into the research external theories. Thematic analysis of the data enabled the five themes to emerge which were embedded in all the participants' lived experience details. The emerging five themes are evidenced below starting with extracts of the three parts of each theme followed by a patient vignette to illustrate the theme overall.

Theme 1: Anxious Pre-occupation / The body experienced as observed.

The interviewees in this category found that they constantly worried about the stoma and the possibility of recurrence. Insomnia was a problem for some of them and they lay awake until the early hours feeling exhausted, when they had to arise so worrying even more. Worry is a natural, instinctive reaction to bad news. However, although they were discharged as well after five years they still worried. They worried about any perceived pain that it was a recurrence, that they smelt from the stoma, that others would think they were incontinent. There appeared to be nowhere they could

go for reassurance about their worries. Ending treatment is a life event as much as diagnosis was, but support for all these worries is lacking.

Figure 19. Anxious pre-occupation.



All the lived experience descriptions and quotes have been freely given and are anonymous for confidentiality as directed by the Nursing and Midwifery Code of Practice (NMC) 2015). This interviewee expressed the areas of social isolation, not coping, fear and fretting:

Diagnosed in 2007 aged 75.

I am 82 now and was diagnosed in 2007 with colorectal cancer. I have been married for 63 years but my husband is switched off about the cancer and the treatment, but my son is a 'rock'. My diagnosis and hospital stay won't be easily forgotten. I didn't know what a colostomy was but after the surgeon had described what it meant I said that I did not want to be 'smelly' and avoid social situations. I felt as if it was the end of my life and I would be seen as a leper.

In all it was an awful experience and the experience with my stoma makes me dread that I will ever have to go into hospital again. It is the fear that there may have to be someone else who will have to change the bag for me. I keep it a secret from everyone that I have a colostomy.

I remember how scared I was on discharge from hospital as no one had watched me change my bag as the SCN was always busy elsewhere. I was given an appointment to come back in two weeks, to see the oncologist. I had no idea what that meant. I went to the appointment with my husband but he did not want to come in with me and went to have a coffee in the cafeteria. The oncologist asked me why I was there. I thought it a strange question so I told him it was because I had been given an appointment. He said most people say they are there to be cured. He explained I would need some treatment as some nodules (lymph glands) needed some medicine to make sure that I would be ok. I was an active, social, person before the operation and I wanted to continue like that. He said there may be some side effects from the medicine but they would not be too bad. He gave me some papers to read about the treatment but they were quite complicated.

I started my treatment at the local hospital and I had to go for six months. My husband did say he would take me each time which I was really grateful for especially as after the first three times as I started to feel unwell. He would go and sit in the cafeteria and read his paper. As I went through the treatment I found that my appetite started to go down, and had a metal taste in my mouth and started to experience tingling in my hands and feet (peripheral neuropathy). The most worrying thing was that after the second treatment I found that my colostomy output was very fluid for up to two days afterwards and often it was yellow and frothy. I could not use the closed colostomy bags as I had to take the appliance off so frequently and I asked the chemo specialist nurse what to do. It was explained that the best person to

ask was for me to see the SCN who could give me some drainable appliances to make the chemo sessions easier. I said that I had tried to contact her but the SCN had not replied to her phone call. The chemo nurse said she would see what she could do and returned at the end of the session with some drainable stoma appliances for me. I don't where she got them from. Without the help of the chemo specialist nurse I did not know how I would have managed to go on. In between treatment sessions I saw the oncologist and had scans and blood tests. I don't really know what these are for as no one tells you anything.

When the 6 sessions had finished the oncologist explained that everything had gone well and that he was happy to pass me back to the surgeon to see me through the next four and half years until they think I am cured of the cancer but that I will have the colostomy for ever. I was so glad to have finished that awful treatment.....I sort of.....thought that the colostomy would be gone too.....No-one told me it would be there forever”.

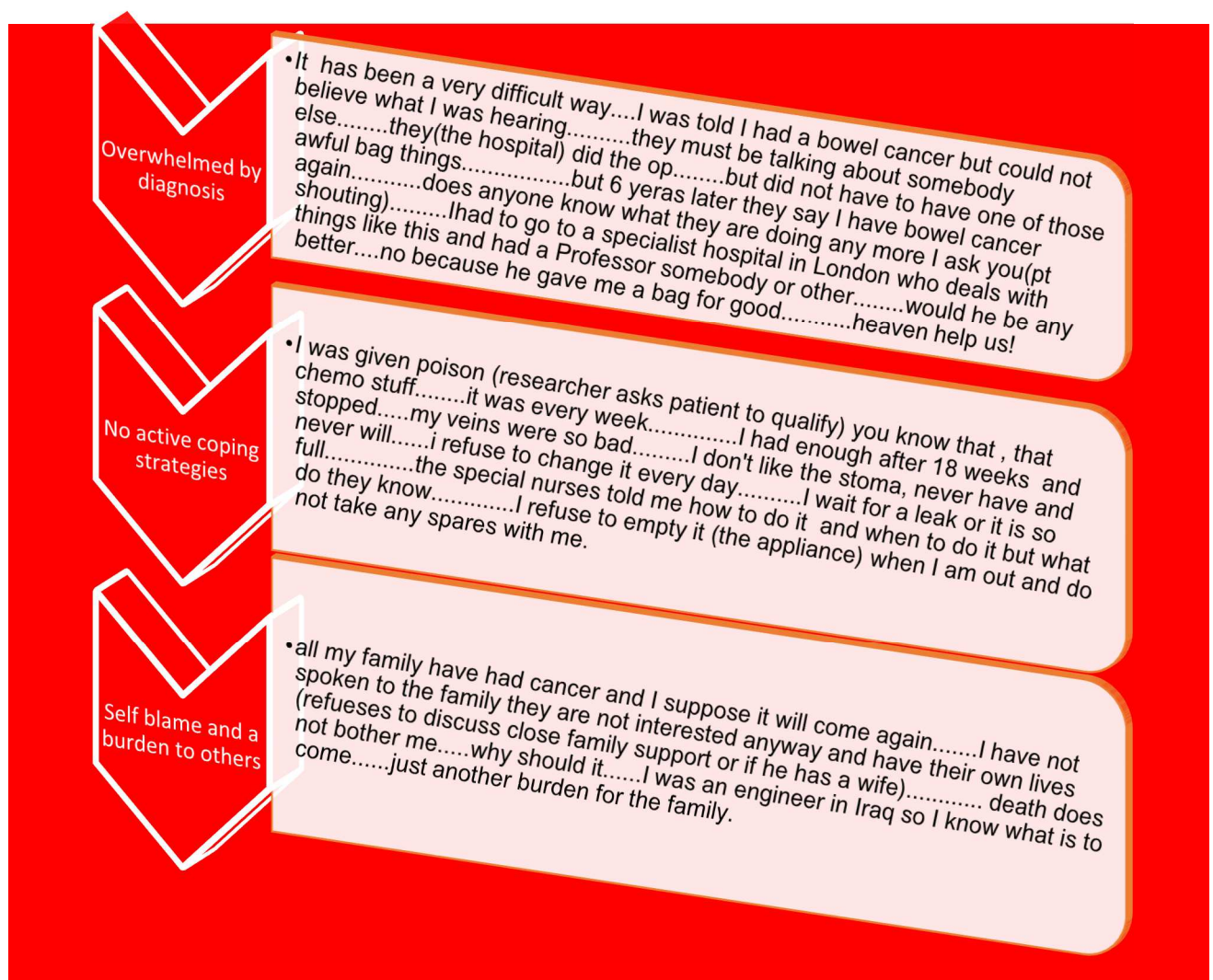
After finally being discharged for ever I still have strange things going on... split nails, always cold to the bone and ‘tingly’ feelings in my hands and feet. I tried to see the SCN but nothing came of that and I made an appointment to see the GP but did not find it helpful as he didn't really know what I was talking about. I'm now 84 and my husband is 87 and I really feel that I need some help and support but no –one is interested. Friends have said to use a computer to help with my problems and treatment, but I don't have one and wouldn't know where to start. Someone told me about the Colostomy Association and I left a message but they did not reply to me.

I was in the local library one day, I go there for some peace and quiet, and I found an advert for a support group for people with stomas. I decided to go and see and thought I don't have to go back if I don't like the people. I was surprised to find others like me with many of the same problems. I went back again and over the last 2 years it has helped me to deal with some of the problems I have had been and only wish I had known about it before. I never knew there were such things. There are still things I wish I could have information about or see someone face to face who knows what I am talking about. I would like to see someone every year. Not because I am ill just to have like an annual MOT and to know that there is time to discuss my worries, Someone to see my stoma and skin and tell me its ok. Even if the stoma nurse was still there she wouldn't see me now as she never saw me in the first place.

Theme 2: Helplessness and Hopelessness / The body experienced as reflective

For some of the interviewees, the original diagnosis was overwhelming, even though they had a feeling about what they were going to be told. The barrage of information coming at them is overwhelming and they are not able to form coherent coping strategies to deal with the diagnosis and treatment regimen. For many the thought of having a permanent colostomy is also overwhelming and they feel that they will never be able to continue with their life as they know it. They feel that they will be a burden to their spouse and that that no one will want to be near them as they will smell (Black, 1989, 2000).

Figure 20. Hopelessness and Helplessness.



An example of feeling burdened, stressed, family worries and poor communication is identified below in how this patient feels about what has occurred:

Diagnosed in 1977 aged 39 (1) and 2004 aged 60 (2).

"I was unfortunate to have had a diagnosis of colorectal cancer twice in my life. In 1977 after being married to my childhood sweetheart and having had two children, I attended my GP with some bleeding that I noticed after going to the toilet. I was referred to the hospital to see a surgeon, who in 1977 was just a general surgeon and undertook a variety of surgical procedures including abdomino-perineal resection and colostomy. The surgeon enquired what I did for a job and if I had any children. At that time I was Clerk of Works for the local council and had two young sons My wife had not come to the consultation and the surgeon asked if I would like a few days to go home and discuss this (with his wife). I declined and said that my wife was very private person and would not discuss anything like this with me or him (the surgeon) so I just said to go ahead and operate. It was more important that the cancer was removed than worry about how I would be later.

I still remember well how awful my recovery was with all the drips and a tube in my perineum so that there was difficulty in sitting and how painful everything was. I still have flash backs when I talk about it and I clearly remember having a near death experience just after the operation, of being above his bed an drifting upwards and trying to pull himself back to the bed. I had a SCN in 1977 which I think was far reaching for my hospital as I now know that SCNs were only established in the UK in the early 1970s. I remember the stoma bag I was given in 1977. A Hollister bag that was 16 inches long would you believe. I changed it once a week. I emptied it by pushing the faeces out through the open end, a horrible task. I was in hospital for 6 weeks and needed 6 months off work. I was advised to have chemotherapy and radiotherapy as I was so young to be sure that all the cancer was gone. The radiotherapy was given to the very painful underneath (perineal area) within a few weeks of surgery. I have always had motorbikes but since the surgery and radiotherapy I couldn't ride it easily due to the pain underneath. Also bus journeys were difficult and uncomfortable and in the car I had to always take a cushion with me.

Unfortunately in 2004 I was again diagnosed with colon cancer and was referred to a centre of excellence for specialist attention. The whole system was different this time round. Within 2 weeks of seeing my GP, I had an appointment with a professor of colorectal surgery. After tests and returning for the results I was told I needed bowel surgery again but that they would be able to leave the colostomy where it was. I went

in on my surgery day, early morning, as I had my bowel cleaning medicine at home. The SCN was told me my stay would be short and nothing like before (for the first diagnosis). I was in hospital for 8 days and had to take 6 weeks off work. When I saw the SCN she asked if I had considered irrigation. I did not know what she meant. She explained it to me and I thought I'd give it a go as I was still working and it would make life easier at work. I could not start immediately until the bowel had settled down and I liked the small stoma appliance, very different from the big old bag I had been given.

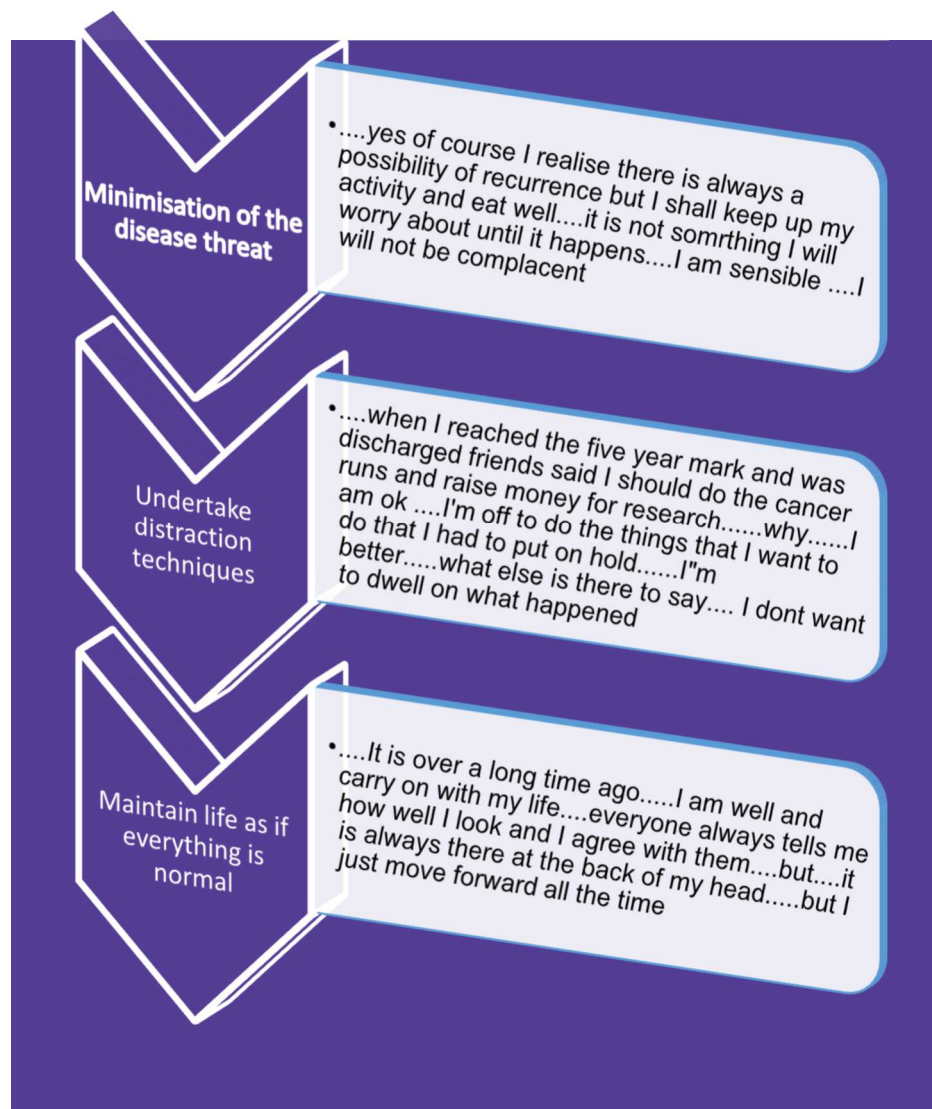
At both times after both operations I tried to have the attitude of "get on with it". Unfortunately my wife was also suffering as between my two bowel ops my wife had been diagnosed with breast cancer and had undergone mastectomy and chemo like I had. I have to say that since my first surgery my wife had never seen my stoma. We are a very private couple but my wife did not want to know. I don't talk to my family either as it is my own private business. I was discharged quickly after the second operation and I was seen for the next four years at the hospital then told finally to go to my GP if I had any worries.

There was no support and it was as if everyone had magically disappeared. My good GP had retired and my new one admits to my face that he does not have the first idea of how to help me with this under carriage pain. He suggested I go to the hospital but as I am too far from the second hospital, that is not a solution. I have arthritis and "water work" problems and I have no idea what will happen if I cannot care for myself as I cannot ask my wife. It's beginning to get me down but who do I talk to about it".

Theme 3: Avoidance / The body experienced as an aspect of the world.

Often cancer individuals or family members are ashamed of their anxieties about their loved one's diagnosis and treatment even when they have been told that they are "cured". They feel that they do not want to upset the family and friends by expressing their on-going anxieties about the possibility of recurrence and fret that they are holding up their own recovery. For many post cancer anxiety is short lived. However, for some this will continue through their lives and will undertake activities to avoid family and friends asking how they are or how they are coping. Even after many years post treatment discharge individuals still employ distraction techniques to avoid the discussion of how they feel and how they are doing.

Figure 21. Avoidance.



This patient talks of stoicism and the need to carry on as normal.

Age 52 at diagnosis in 1994.

I had been to see my GP because I was concerned about my bowel habit change and had noticed occasional bleeding after having my bowels open. He referred me to my local District General Hospital (DGH) to see a colorectal surgeon. I had private health insurance from my job and asked to be referred to the same surgeon as the wait would be shorter. I had my tests MRI, CT, and routine blood tests.

The result of the tests showed I had a low rectal cancer that would require abdomino-perineal resection and a permanent colostomy. Any other treatment would not be known until the results came through. I was admitted the next day at 10am to the

private hospital having starved from midnight. I had a bowel cleanser to be taken by mouth and only clear fluid was allowed for the rest of the day until the operation early the next morning. I was taken to theatre at 8am for surgery. On my return from theatre to my room my wife was already there although I felt too dozy to talk and just wanted to sleep. Later the surgeon came along to explain to both of us what had happened at the operation and how it had gone and that the stoma care nurse would be seeing me in the afternoon to talk about my colostomy and recovery. I don't remember much about what was said but I do remember one thing feeling quite strange as if I was watching myself from afar and it was the awful howl that I could hear and I could not make out what it was or where it was coming from as I was sure it was not me.....I suddenly realised it was my wife but I could not understand why".

My wife found the shock that I had a colostomy too much as it was the one thing she had feared most and said she would not be able to cope. The surgeon said again that the stoma care nurse (SCN) would be along later and would explain more to us and how life would go on. I remember the afternoon well as I was much less sleepy then when the SCN came. My wife stood and looked out of the window of the room as the SCN introduced herself to us and would not face the SCN or speak to her. The SCN sat down and explained to us what a colostomy was and how it could be looked after, but my wife refused to share the consultation. I felt that I wanted my wife to be involved to an extent as if I was ill she would have to help. I felt embarrassed for the SCN as she was so helpful and was explaining about the different ways of caring for my stoma. I was only 52 and would be going back to work, a high powered job in the city and needed to know how to train the colostomy.

My wife said she needed to know when the SCN would be coming and wanted to avoid seeing her as she said she felt that the surgeon and the nurse had signed my death warrant and how would she cope with the house and children if I died.

I was discharged home and the SCN made an appointment to visit. At the first visit my wife was there but refused to acknowledge the SCN and spoke indirectly to her via me. I was so embarrassed about her rudeness. Surely this lovely nurse was here in our home talking to me about positive things and how life would return to normal. I was interested in irrigation as I thought it would be easier as I often have to stand up and present to people in my job and I worried about the noises and odour the colostomy may make when working. Also my wife wanted to know exactly at what

time the nurse would visit. Later I realised why she wanted to know this. My wife, on my return home, refused to sleep in the same bed and put up a camp bed down stairs. Before the nurses visits she spent 2 hours hoovering the carpet so that the marks from the camp bed would not be seen by the nurse. When I was able to start to learn to irrigate my wife always made sure she was out of the house.

I was managing my irrigation procedure and colostomy and looking forward to returning to work and one day on the off chance the SCN was passing and knocked to see how the irrigation was going. My wife had gone to stay at her sisters for a week and I answered the door in a dishevelled state to be honest I was still in my pyjamas and dressing gown in the afternoon. I asked the SCN to come in and excuse my state. I suddenly thought -- I am pleased she is here now we can talk.

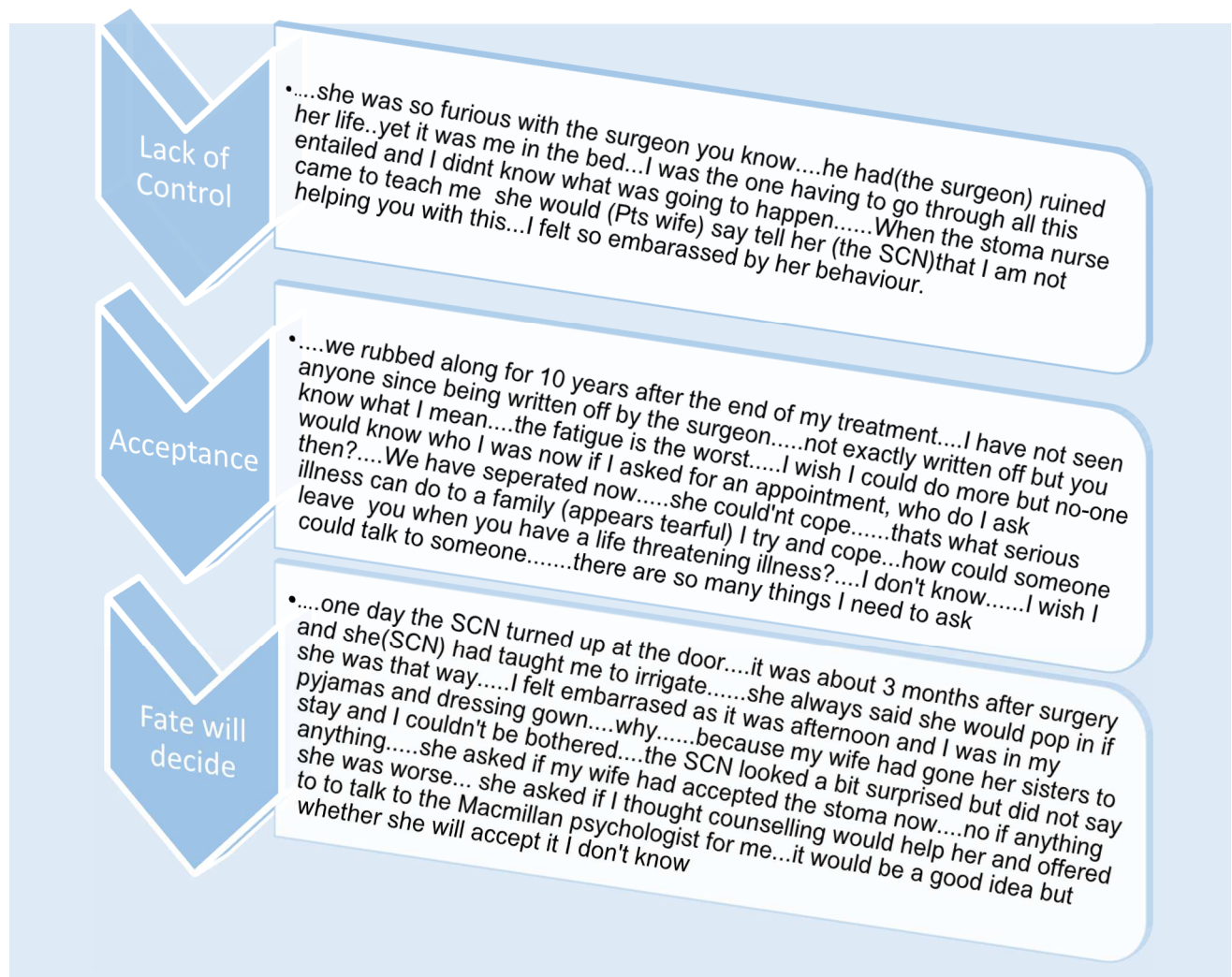
I wanted to tell the SCN about my wife's strangeness, I can't think of a better way to describe it and how worried I was. I have to say that she has always been highly strung and somewhat obsessive about cleanliness and the thought of me and my colostomy sent her over the edge. I probably never really took much notice before but because I was at home for 3 months recovering it all became noticeable. We discussed what help could be accessed for her and the SCN advised me how to set the wheels in motion. When she returned from her stay with her sister I said that this needed to be sorted and we should see the GP together and discussed her behaviour. She was referred to the psychologist for an assessment and treatment plan. The psychological treatment helped immensely and we enjoy our retirement and now. I strongly feel that there is a need for some outside support after the five year mark as the GP considered me to be well and cured. I had times when the irrigation did not seem to be working well, causing accidents and I did not know who to ask. It would have been nice to talk to someone and discuss this but I'll look on the internet. You know, people are now living longer with cancer and they still need support, not just for the first five years, but for the rest of their lives.

Theme 4: Fatalism / The body experienced as call.

Goodhart and Atkins (2011) suggest that low mood or even depression are one of the most common side effects of cancer and although none of the interviewees expressed thoughts of depression or treatment for depression at any time, it seems clear that the patient quotes show that there could be depression with the situation the individual found themselves in. Fatigue, also one of the common late onset

symptoms of cancer is still evident. Often with diagnosis and treatment the individual can be stretched to their limit and beyond and often grieving does not take place. The bottling up of all these symptoms can lead to a fatalistic attitude and feelings.

Figure 22. Fatalism.



Age 66 at diagnosis 2008.

This patient talks of fatalism and lack of control.

Where do I start? What do I say to you? I don't know, I don't.....really don't know what to do. I'm not good at the moment but don't know what is wrong. It's not my body really I have been given someone else's. It's like looking at a dead body (researchers asks to qualify this). Well this is not what I was born with is it so I must be dead. I hate going out but I want to but can't. Everyone will see I have a bag of poo stuck on me. They will know. You.... You are my only contact. I wanted you to

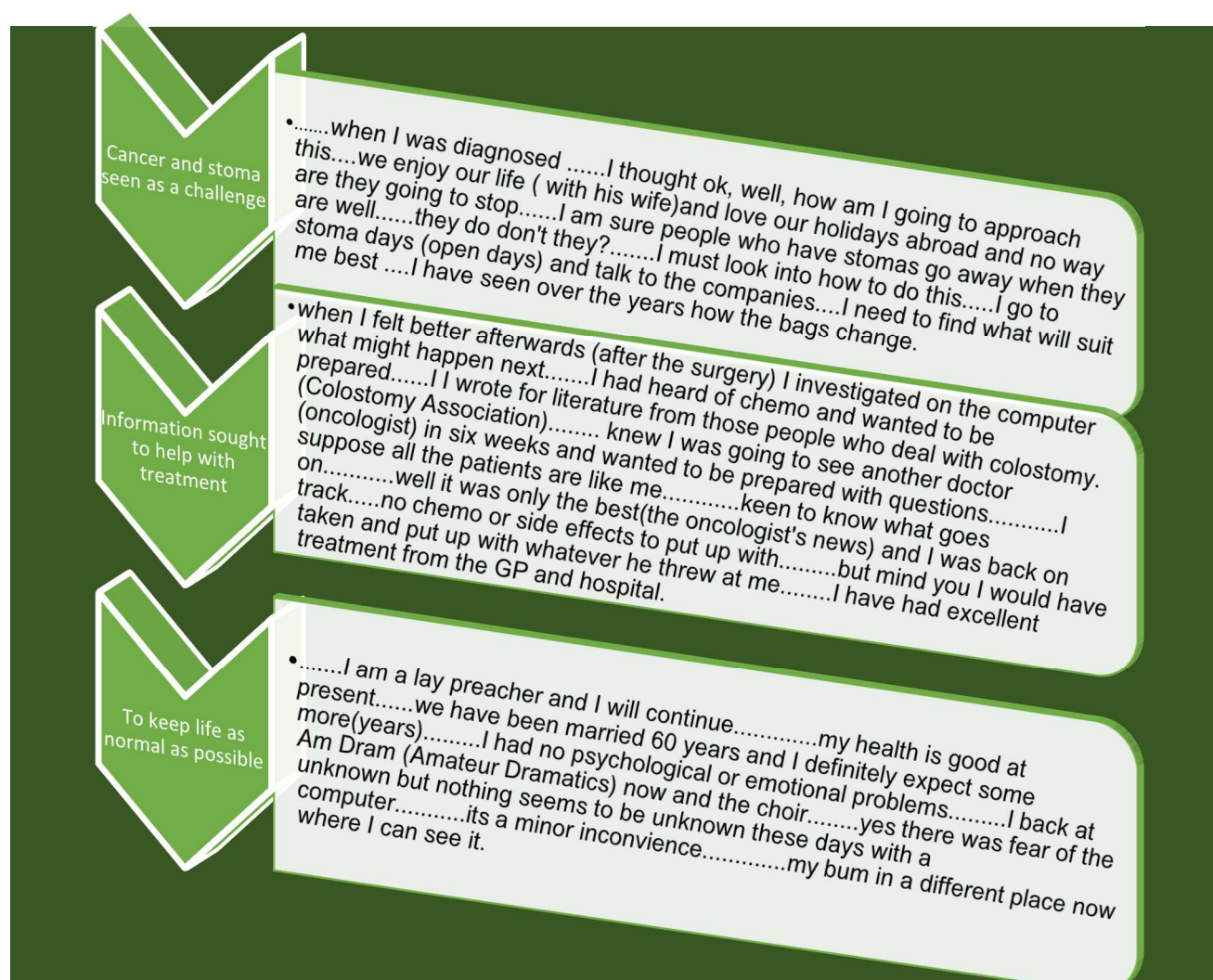
ring me. I want to go out as I have always enjoyed it but it is so difficult now. I would like to have some support but do not know how to find it or what there is. Are there not some type of support groups for these people like me? My stoma care nurse did not tell me anything. They were very unsupportive to my needs and I felt that they did not like helping me. I think they classed me as one of those difficult patients, you know. I have never been back to see them or them me.....well you know what it is like when they think you are difficult. I don't want this bag and cancer.....why me what have I done to anyone. I feel so miserable and down.....am I going mad? Sleeping is difficult and I am always so tired. I worry about going to sleep in case the bag works and then I get up to check it then I can't get to sleep again and so it goes on. You know.... People say pull yourself together as if it is something that will go away or that I am being lazy...it's not that....it's?? Never mind it doesn't matter and you don't want to hear all my troubles. You would think I would have been happy when they said I was all clear and don't want to see me again. I wasn't. Everyone said I should be happy but I feel the opposite. Why is that? I see my GP sometimes and he just says get yourself back to what you were doing before... throw yourself into something you like doing and you will enjoy life. As if. People tell me having got through cancer and colostomy I have achieved a lot. Really what do they know? I am angry... I think I see that now. This is probably the first and longest time I have told anyone how I feel. I feel threatened all the time that tomorrow I will know the cancer has come back and what will happen then? I talk to myself a lot myself in the house. They say it's the first sign of madness but who's to know I do it.....only you now. It makes it seem that I have a partner and I am talking to them. It's not about the day I have had.....it's about what I have said to you. The tiredness, the change in me and wondering what is happening to me. Do you know...I feel like what rape must feel like (researcher queries this).... Well I have been assaulted haven't I in the most awful way I don't mean the cancer ... the hole in my stomach where all this muck comes out. It makes me feel vulnerable but I cannot tell you to what. My body has let me down... at 66 I should have been active and enjoying my retirement but look at me now. I know my friends and relatives want me to get back to me.....if only I could remember what that was. It's not that simple though is it I've been this me for 7 years now I don't know who me is now. Because I told everyone I was discharged they all seemed to think I was off to conquer the world....if only I could then and perhaps I would not be this me. It's like I have had a body transplant. I am struggling to work out who I am now.(Patient crying now) I shouldn't cry and worry about how I look and what other people might think about me..... I suppose I should be grateful for the treatment I have received to take the cancer away.....but I find it so hard. I

feel useless to everyone, I am useless and also I am ugly because this is not a normal body.....how will I ever be accepted by everyone or go out again.

Theme 5: Fighting Spirit / The body experienced as a focus of appreciation.

Although it is very common to have worries after being diagnosed with cancer and body image change, many individuals can have a “fighting spirit” from diagnosis and through treatment and onwards as they return to their normal lives. They do not want to “wallow” in self-pity and have the temperament to continue their life styles and jobs. They will often search for any other forms of treatment to be able to confidently discuss regimens with their doctor and how they want their treatment to progress. Once finally discharged they are able to continue their inquiring into cancer and will often want to help others who may be finding it hard to move on in their lives after treatment.

Figure 23. Fighting Spirit.



Age 60 at diagnosis 2000.

This patient was not going to let it get her down and took the diagnosis as a challenge.

When the diagnosis came it was a bit of a shock.....no... really it was a big shock. I didn't think there would be anything vitally wrong with me and had not really thought it could be cancer. I'm a retired nurse and midwife so understand these sort of things, but I'm a pragmatist as well and thought ... here goes let's get on with this. I had not long retired and was looking forward to doing all the things you can do when you have retired. I may be single but I have lots of good friends and they were all shocked when I told them then realised I would not be wallowing in self-pity as I would want to get back to my plans. I had quite a complex lot of surgery and treatment to follow. My pelvic floor muscles became much weaker and they removed the posterior vaginal wall. I had this dear young stoma care nurse who came to see me to explain what the surgery entailed. She started to tell me how the removal of the posterior wall would affect me during sex. She was obviously feeling quite awkward about discussing this. After all it was done at the hospital I had worked at for many years. I always say better the devil you know. (Patient laughs). In the end I said to her (stoma care nurse) don't worry about it, I don't have a partner so this area of your teaching does not worry me. She scuttled off, quite relieved I am sure.....I think the other stoma care nurses in the department had sent her on purpose (laughter). I did have adjuvant therapy as the oncologist felt I would have a better chance especially as I had just started my retirement. I need to get something out of this life after all my time caring for others. I have got some neuropathy from the chemo.....we know that capcitateabine does that but I'm not going to let it bother me too much. All these years on I still have days when I feel tired and know I have pushed myself too hard. I have tried to research it a bit and I think it is what called cancer fatigue is but I just listen to my body and rest. After all I may be retired so can rest if needs be without a problem during the day. I get out and about a lot but do find that I have to sit for twenty minutes every 2 hours or so due to the dragging pain in my perineum and I like to go abroad. Not so far now as I am older but I am not going to be stopped by this. I had some lovely stoma care and colorectal nurses. Such sweeties. The stoma care nurse asked if I would like to consider irrigation and explained it to me....what a good idea that was. It meant that I did not have to wear a bag all the time.....but still have to cover the stoma as it can put out some mucous. I only do every 2-3 days which suits me. It's great when I go away. I go to our local stoma group meetings every two months. It's not so much for the support or to see

people.....I try to help the others..... I suppose that's the nurse in me (patient laughs). Sometimes when I am sitting at home perhaps reading in the quietness I think about what has happened to me and if I would have managed quite as well if I had not been a nurse.....and I also wonder if the cancer will return and I have to go through treatment all over again. But then I get up, tell myself not to be so morbid and go and find something to do.....but I suppose it's always there in the back of the mind of all people diagnosed with cancer about if or when it may return. This is getting very morbid isn't it? This is not me normally. It's a challenge and I accept challenges..... I suppose we nurses do.

Life changing and uncertainty are two terms associated with the diagnosis of cancer and 'survivorship'. For many individuals, after the shock of diagnosis and treatment plan, the individual will review and assess their life and their priorities. Even with today's advancements in the treatment of colorectal cancer, individuals and their families still consider it a 'death sentence' as opposed to surviving and having a relatively normal life after treatment has finished. For some it's a transformational period and evidence that individuals make positive life changes after such a diagnosis is seen in the literature (Mullan 1985, Armstrong 2001, Carr 2004, DeMarco 2004,). Social connectivity, family relationships, intimate relationships and everything that makes up the individual's life are all affected by a diagnosis of cancer which is an extreme experience involving body image change as well as the possibility of a shortened life and disruption of the individual's sense of identity. In the older individual given the diagnosis of colorectal cancer and its subsequent outcome, the effects of treatment and adjuvant therapy can leave them with psychological and physical issues such as depression, anxiety about recurrence, fatigue, pain, cognitive impairment and find it harder to overcome these issues in combination with exacerbation of other co-morbidities.

With the diagnosis of colorectal cancer and a permanent colostomy come the positive effects and negative effects of a cancer diagnosis. The positive is the chance that death will be defeated at least for the noticeable future and there may be the chance of a normal life span. The negative is that the alternative to survival is death. For the ageing population the diagnosis combined with co-morbidities can create complex problems for the surgery and for the rehabilitation and for some this is just another hurdle that may not be overcome. The individual's cancer trajectory is unique to that individual and Carr (2004) suggests that the lived experience of cancer is poorly understood by those not afflicted. For many of the individuals, description of

what they are going through or feeling cannot be adequately described and can be “beyond the scope of language” (Little, 2000).

As the five year longevity rate begins to rise, a researchers' need to understand the connection between the somatic disturbance and the physical upheaval that a colorectal cancer diagnosis brings. It was thought that human beings were goal directed and there was no explanation of how these goals were pursued due to the lack of attention to the strategies that human beings use. From the researcher's own group of participants came the diagram that the individuals use to cope after a cancer diagnosis. Cancer related distress has been negatively associated with positive health behaviours yet it is seen that repetitive or frequent thoughts about cancer are not necessarily distressing to the individual. Harper et al (2006) suggest that a cancer diagnosis and treatment may offer a 'teachable moment' to be captured by the specialist nurse to help the individual to evaluate their priorities and begin to think about behaviour change. Discussing and talking about change at this time in an individual's life is a prerequisite for behaviour change and a time for the individual with cancer to reflect upon what is important in their life.

The cancer survivorship vision recommends that cancer patients should be assessed following initial treatment and then be assigned a level of risk of developing consequences of treatment or further disease. An individual care plan would then be drawn up addressing the whole range of needs an individual might have after treatment with the aim of minimising risks and supporting the patient to manage on-going conditions. Stratifying patients for follow up according to their risk can ensure that patient needs are better met and that resources are used more efficiently. At the end of treatment, patients no longer have routine follow up appointments but are educated to self-manage their condition, but if they do have any worrying symptoms, concerns or issues they are able to contact their specialist nurse or clinical team. The rationale for risk stratified pathway is that it will be responsive to individual needs e.g. can facilitate access to specialist care when needed. It aims to embrace the consideration of consequences of cancer treatment using Patient Recorded Outcome Measures (PROMs, Picker Institute, 2009).

Table 11. The five shifts in care are:

1. A greater focus on recovery, health and well-being after cancer treatment.
2. Holistic assessment, information provision and personalised care planning.
3. Supported self-management
4. Away from clinical follow up to tailored support that enables early recognition of the consequences of treatment and the signs and symptoms of further disease.
5. Measuring experience and outcomes

However, even with the use of PROMs and SCP none of this work goes beyond the finalisation of treatment and the discharge of the patient, as one patient put it “abandoned to fall into the great black void.”

Chapter 6.

Living beyond colorectal cancer: Linking the findings to policy and practice and the need for change.

Although a small scale study, this has shown in a bigger context, the descriptors/feelings that colorectal cancer patients exhibit as seen in the researcher's study. However, the psychological outcomes of mutilating surgery (stoma) can be severe and long lasting so impeding the patient in managing self-care, therefore this needs to be set against the continual worry that the patient may feel if they fear their cancer has not fully gone. Therefore, this section has to incorporate findings from the study.

Worldwide, 54.5 million people have been diagnosed with cancer within the last five years and 45% of these individuals will be alive after five years and some for several decades more (Cancer Research UK, 2007). For many individuals the elation of completing treatment and arriving at the five-year mark is coupled with the anxiety of not seeing any of the clinical team again. For many individuals the fear that the cancer will return is overriding and this 'fear' can initiate 'symptoms' of worry, insomnia, nausea and lack of concentration. For many of the individuals whose treatment is over they have expected to feel elated as they left the consultation, but feel the opposite and some individuals will ask to come back to clinic in 6 months to see the team for reassurance. However, the fear of recurrence is not only the prerogative of the individual undergoing treatment or who has finished treatment, it is often a major concern of the spouse or partner as well:

"my wife said she was scared...scared of what I asked....she just cried...I told her I would be ok...I'm not going to let it get me down...she then said it wasn't now it was later... that it would return and I would die and how would she cope...every time she looked at me she felt she would not see me again" (Fatalism).

Looking back, as early as 1989 in Wade's (1989) research, adaptation to life after a colorectal cancer diagnosis and a stoma depends on the length of time it takes the individual to work through the grieving process and the factors make it harder to adapt. The loss of a body part has a distinct psychological consequence and bodily changes alter the way the patient and their family perceive their body with it's change of bodily function. Wade (1989) pointed out that for those who lose the natural bowel function, the loss of what they see as part of their body gives rise to grief prior to the operation and/ or post operatively. This interviewee said:

..." my stoma care nurse did not tell me anything. They were very unsupportive to my needs and I felt that they did not like helping me. I think they classed me as one of those difficult patients" (Fatalism)

The type of information and advice given before surgery, emotional support, and the opportunity to discuss problems, can help in the reduction of and possible prevalence of psychological problems that having a cancer diagnosis and a permanent colostomy entails:

...” the stoma care nurses... what I can say... they were sweeties....did everything to help me...gave me written and oral information and were happy to explain again and again” (Fighting Spirit)

This kind of support and information given by the healthcare professional is necessary and valuable to patients about to undergo major surgery. Other members of the patient's family, will also require support. Cancer commonly causes loss of bodily function, damage to the individual's body image, and a threat to life. Fear and grief are likely to be shown and are not uncommon especially as the surgical treatment for cancer is often mutilating. However, some of the participants in the study stated in their lived experience description, both avoidance and/or obsessive preoccupation with the loss of the part of the body (bowel/stoma) can be problematic. What the participants showed in this study can be compared to the grieving process demonstrated by Maguire & Parkes (1998) and ties in with this study's coping styles exhibited after the 2nd analysis. Any person that has undergone surgery that leads to the loss of a part of the body should be asked by the specialist nurse about the effects that it is having on them and their families and the kind of emotional support that they may require. General conversation and counselling should be directed rather than free flowing allowing the patient to demonstrate whether they are experiencing “blunting” by avoidance of discussion about what has happened to them, moving on to fear and insecurity about their families that the diagnosis of cancer will have on them in the long term. Overt preoccupation with the stoma as the main part of their life is shown by anxiety, panic and feelings of loss. By giving the patient time to talk they can feel supported and learn how to gradually and with effort, construct a new social identity.

Table 12. Parke's Five Aspects of Grieving compared with Second Reduction and Analysis.

Realisation (Helplessness & Hopelessness)	Characterised by avoidance or denial of the loss followed by experiences of unreality or blunting.
Alarm (Anxious pre-occupation)	Characterised by anxiety, restlessness, fear, insecurity.
Searching (Avoidance)	Characterised by acute episodic feelings of anxiety and panic and a preoccupation with the loss.
Grief (Fatalism)	Characterised by feelings of internal loss and mutilation.
Resolution (Fighting Spirit)	Characterised by efforts to construct a new social identity.

(Parkes, 1972 /2010).

This study showed how individuals varied in the degree of confidence and flexibility with which they coped with a cancer diagnosis and bowel stoma. Studies (Wade1989, Schag et al 1994, Parle et al 1996, Maguire and Parkes 1998, Montreux study 2003, Nichols &Reimer 2011, PROMS 2012) have all shown that the intensity of distress following the onset of cancer and its eventual outcome, is determined by such factors as these and also by the degree to which the individual feels that the eventual outcome of treatment and the losses caused by the cancer have made them different from others. This, in turn, can give rise to depression, problems of sexual adjustment, and other significant psychological difficulties that the individual and their families will need to overcome. Maguire and Parkes (1998) suggest that individuals can be termed 'avoiders' or 'sensitisers'. Avoiders need to be given the opportunity to discuss and talk through the implications of their surgery, loss and the outcomes, and will need reassurance about the normality of the grieving response and the emotion they will be experiencing. Sensitisers want full discussion and disclosure of what is to happen to them and will appreciate the offer from the specialist nurse to have contact with others (same gender, age and operation) to see how it is possible to continue their life after surgery. Adaptation to living with a permanent colostomy may seem to be an adjustment that the majority of patients conquer, but in reality how does the individual cope with the fear of recurrence for the rest of their life when often the greatest challenge for some is living with a stoma:

...".yes of course I realise there is always a possibility of recurrence but I shall keep up my activity and eat well....it is not something I will worry about until it happens....I am sensibleI will not be complacent" (Avoidance)

In one of the more recent studies, Taylor et al (2010) used grounded theory to understand the experience of fear of recurrence and how it can affect individuals recovering from curative colorectal cancer surgery. This study period only covered the first 12 months after surgery with individuals interviewed on four occasions. As to be expected at this early stage in recovery many of the participants expressed anxiety about if and when their cancer might return. This anxiety led to some individuals in the group needing to achieve a more dependable and controllable body by 'guarding,' a process the individual takes in adopting new behaviours to be aware of any changes in the body and then immediately seek a clinical decision. By contrast, others in the group did not feel the risk of recurrence to be personally threatening and felt they were able to assume strategies to manage any concerns and that curative surgery had given them the boost they needed to return to a normal life. In one of the more recent studies Taylor et al (2011) follow up article on this study mirrored the early work of Wade (1989). Interestingly, rather than the description of "coming to terms" with surgery, Taylor et al (2011) describe four conceptual stages that individuals go through in the first year after surgery:

Table 13. Conceptual Stages during First Year of Surgery.

Disembodiment	Emotional process.
Restoring embodiment	Physical process.
Reclaiming control	Social process.
Managing embodied control	Self- managing the body.

(After Taylor et al, 2011).

Looking at these outcomes it is evident that nothing new had been added to Parkes (1972 / 2010) work. Despite the inclusion of specialist nurses and MDT approach there has been no change in the struggles experienced by patients in the first year after surgery.

It was disheartening to find this study of individuals who make up a homogenous group and who have had surgery at 5, 10, 15 or more years ago, many who are still going through the steps of recovering as described by Taylor et al (2011). Thus they still have a need for support (or to know that support is available to them when they

'feel' something is wrong). It is accepted that after a first cancer, it is very probable that a second primary cancer may occur at a later stage in their lives (Taylor et al, 2002). However, individual longevity after primary treatment may be influenced more by the late effects of cancer treatment and other non-cancer morbidities rather than recurrence or another primary cancer. Recurrence of colorectal cancer declines with time after primary therapy to less than 1.5% at five years and 0.5% at 8 years with non -cancer co-morbidities having more influence in the individual's quality of life and longevity than the cancer diagnosis. Denlinger and Barsevick (2009) suggest that colorectal cancer 'survivorship' should shift from observing for recurrence to caring for the individuals who have co-morbidities and receive appropriate preventive long term care. The majority of individuals with longevity reported at least one symptom attributable to their cancer treatment such as hand and foot neuropathy from the effect of the chemotherapy they were given after surgery, and as many as 70% had co-morbidities (associated with age related onset) that needed care input:

...."wellI, may be cured of the cancer but I don't have a job....the pins and needles in my feet overtime stopped me having any feeling (result of chemotherapy)....I could not pick up small things....I have to wear steel toe capped boots...health and safety you know....I asked if a letter from you would make a difference and they said 'no'... I have to wear the boots or find another job."
(Anxious pre-occupation).

Although the trajectory of care remains intensive in the early years after curative treatment for colorectal cancer with visits to the surgeon and decreasing visits to the oncologist, It was evident that these colorectal cancer 'survivors' receive minimal to no counselling for co-morbid conditions yet the evidence of the impact on QoL from such co-morbidity is clear (PROMS,2012)) . Whilst clinical dialogue is high in the early years, this study matches the findings by Denlinger and Barsevick (2009), rates of preventive care decrease after the 5 year mark. This studies participants also reflect Horlick-Jones (2011) suggestion (from his own experience of being diagnosed with cancer) while cancer is often treated as being a chronic disease, it does not take away the fear of recurrence. He contends that the anxiety arising from this fear is wide spread and can lead to enhanced bodily awareness with the interpretation of "mundane sensations as a symptom of pathology". It was evident from the interviews in this current study that this fear together with the lack of access to professional support had left some interviewees with an on-going question of "have I got it again". This reveals that there had been no change since Lee-Jones et al (1997) significant review that found that the fear of recurrence of cancer remains universally present. Also that some individuals never get over this and that it is a

“sword of Damocles that continues to hang over the individual and their family for the rest of the person’s life” with nothing available currently, to alleviate this.

Horlick-Jones’ (2011) ethnographic study aimed to make some sense of his experience and to try and understand the logic involved in his fear of recurrence has given additional insights to the cancer trajectory. As a professional with medical knowledge he worried that his level of fear of recurrence of the disease was higher than that of his fellow patients with their greater dependence on medical experts. His study revealed that while his fear was not uncommon it seemed that patients with little knowledge of the disease process did have some protection from fear that arose from knowledge of cancer probabilities and outcomes (Horlick-Jones 2011). He argues that there is a need for support for all individuals fits with Humphris and Ozakinici (2008) who explicitly acknowledge that fears of recurrence of cancers are realistic and need to be addressed. However, most of these studies discuss cancer patients as if they are a homogenous group with a standard set of needs, but as the previous chapter in this study reveals this is not an actual reflection of this patient group. There is heterogeneity within the group as illustrated by the five coping styles. Until these are recognised and integrated into care provision patients will continue to struggle once treatment has finished and access to specialists becomes limited:

...“I have not seen anyone for 14 years....that is since I was finally discharged...I worry about all the pains I get...they don’t last long enough to get to the doctor but what would he know anyway....You know what would be good....a yearly MOT...a check-up so I could talk to someone and they could eyeball me....it would put my mind to rest.” (Anxious pre-occupation)

In the UK there are 2.5 million people living with cancer (NHS England, 2016) and this is rising by 3% every year. In England alone, there are 200,000 people living with and beyond colorectal cancer (NCSI, 2013). Long term colorectal cancer ‘survivors’ with a stoma have contributed to many studies regarding their QoL using tools such as Health Related Quality of Life (HRQOL). However, a review of these studies shows that few if any, have focused on QoL after the five-year point. McMullen et al (2008) used a one page open ended questionnaire based on HRQOL and asked respondents’ what the biggest challenge the individual had to come to terms with, their cancer diagnosis or the formation of a stoma. They reported discomfort and complications during and post treatment took a considerable toll on the individuals but were related more to the cancer treatment and the fear of recurrence than the stoma. Long- term complications included fatigue, radiation enteritis, infections and

diarrhoea. Further challenges associated with co-morbidities were chronic obstructive airways disease, diabetes or cardiovascular disease and these complicated the day to day care of the stoma serving as a reminder that they had cancer as well. However they gave few suggestions on how to alter care to support these patients.

Other research tools that assessed as suitable to use for colorectal cancer patients are the European Organisation for Research and Treatment of Cancer (EORTC) module and Quality of Life Questionnaire – Colorectal 29 (QLQ-CR29) along with the QLQ-CR30 core questionnaire. The EORTC QLQ-CR29 demonstrates sufficient validity and reliability to support its use to supplement the EORTC QLQ-30 to assess patient reported outcomes during treatment for colorectal cancer. While this did demonstrate that health related quality of life outcomes are important, this gave few practical recommendations. Over all, QoL studies agree that cancer related fatigue affects approximately 40% of colorectal cancer individuals as long as 10 years after treatment has finished (Deimling et al, 2007). This has been attributed to the debilitating use of chemo -radiation, the presence of other co-morbidities and psychological stress. For those individuals that are diagnosed at a later stage in the cancer staging, QoL appears to be worse emotionally, cognitively and socially. Neuropathy after some chemo-therapies have been associated with a poor quality of life and are also a co-morbidity. It appears that measured fitness and self-reported fitness of colorectal cancer survivors is poor when measured against those in the population who do not have colorectal cancer. It is important that the needs of colorectal cancer survivors after the five-year survival period have a supportive, continuing rehabilitation programme as the aging population is increasing along with the increasing rise in colorectal cancer:

...."why is my GP not interested in me....I know I am not the best specimen at 79....diabetes, poor kidneys, breathing problems and then the big C...do you know I learnt to manage my stoma well and am happy about that....yet sometimes I don't know what to do about the sore skin....when I see him (the GP) he says he doesn't know (about the stoma) go back to the hospital....he never asks if I have any worries to do with the big C." (Anxious pre-occupation)

The Department of Health (2012) compiled a report from a pilot survey using Patient Reported Outcome Measures (PROMS) aimed at collecting detailed information on the quality of life of cancer survivors. Yet again this used cancer registries between one and five years post diagnosis. The results do contribute to cancer care revealing that at one year post diagnosis, the fear of recurrence and dying were 47% and 27%

respectively. At the five year point these percentages had only decreased slightly to 42% and 22% respectively. Those who had been treated for colorectal cancer reported difficulty in controlling their bowels or stoma and were twice as likely as other cancer sites to report a lower quality of life. Included in the Department of Health (2012) PROMS survey looking at the Quality of Life of cancer survivors (breast, prostate, colorectal, NHL) using EQ-5D-5L (2011), there was room for free text answers. The overall sample size was 4866 and 1056 of all four groups of cancer added free text. The free text comments were divided into three broad themes: participant's experience of cancer diagnosis and treatment, participant's experience of living beyond cancer and comments that were perceived to be unrelated to living with or beyond cancer (Corner & Wagland, 2012). Of the four cancer groups there were 258 free text replies from the colorectal cancer group. However, it has to be a cause for concern that 7 years on, a recent literature search revealed no further follow up studies have been published. This, despite the evidence from DH (2012) that there were long term issues regarding health wellbeing and QoL that need to be considered if service provision is to adequately support these patients.

The DH (2012) study revealed often older people were given a diagnosis with insufficient time to explore this diagnosis and all that it entailed. Also there was little support offered in adjusting to their changed health status. This included organisational problems, delays in treatment, unreliable hospital administration services and unacceptable delays from GP to specialist referral. This finding was reflected in this current study as this participant indicated:

... "At the consultation I was given the diagnosis and told what was to happen... I was dumbstruck... it's not what I expected... the brief conversation with the doctor was abrupt to say the least... I just sat there... he asked if I had any questions and if not to leave the room and I would get a letter when to come in... I was offered no support emotional or otherwise... there were no nurse support people.... I sat at the bus stop and tried to make sense of what had just happened" (Hopelessness & Helplessness).

Other participants reporting on their experiences of living beyond cancer showed that there were indeed a wide range of ongoing problems for those living more than five years beyond the end of treatment. The problems that negatively impacted on quality of life included on going physical problems from either the surgery or consequences of chemo-radiation included treatment, psychological and social problems:

....there was no support and it was as if everyone had magically disappeared. My good GP had retired and my new one admits to my face that he does not have the first idea of how to help me with this undercarriage pain. He suggested I go to the hospital but as I am too far from the second hospital, that is not a solution. I have arthritis and "water work" problems and I have no idea what will happen if I cannot care for myself as I cannot ask my wife. It's beginning to get me down but who do I talk to about it". (Helplessness & Hopelessness)

For those that had treatment for colorectal cancer they reported bowel and urinary incontinence (with or without a stoma), constipation, sexual difficulties and impotence, cognitive problems, fatigue, peripheral neuropathy in those that had had chemo therapy especially Capecitabine, poor body image and worry about recurrence and death.

Unfortunately this theme produced the most experiences where participants believed they had been poorly prepared for the impact that cancer would have in the first five years and in living beyond cancer. Lack of information about coping strategies and the experience of their aftercare left many feeling that they had been 'cast adrift' by the health care system because, as yet, there is nothing established to help these long term 'survivors'. Those participants that had work, family responsibilities or were caring for older relatives, felt that not enough interest was taken in their circumstances and social situation either during or after treatment had finished and they had effectively been discharged from care. For many, the lack of preparation by the health professionals for the side effects of their treatment meant that they adopted their own strategies including focussing on the positives of their lives and their families, adjusting work routines, increasing physical activities and leading a 'healthier' life.

For the older patient, co- morbidities often related to their advancing age it was evident that physical, psychological and social problems had continued for many months and years after completion of treatment. The participants indicated that they had been given little to no information about what to expect as time went on about the impact the cancer would have on their lives. Corner & Wagland (2012) suggest that such comments are to be expected arguing that cancer patients are not receiving optimal levels of information about life about the post five year point. Similarly, Armes et al (2009) longitudinal study of patient's supportive care needs beyond the end of cancer, reports that more people are living with cancer and do need continued access to care and support at the cessation of treatment. Looking at the transition from treatment to discharge self-management, this study's findings

concur with those of Arnold (1999), Maher (2007) and Armes et al (2009) that some patients continue worrying about long term coping alone:

...“I am afraid of dying...a fear...especially if the cancer comes back...how will I know if it has...no one sees me now...I wish someone would sit down and talk with me...perhaps then the fears will go and I will live” (Fatalism)

Again this demonstrates that despite major medical advances, for this patient group there have been no changes in patient needs and wishes for over 30 years. Indeed, one of the most significant predictors of unmet needs in this study was the fear of recurrence of the cancer or of another cancer. This concurs with other studies by Sneeuw et al (1992) and Scharloo et al (2005) that there is an association between fear of recurrence and psychological distress therefore reducing the quality of life of the patient.

Also with Corner and Wagland (2012) analysis element free text study of the PROMS (2012) which showed that participants reported that they lacked information on utilising strategies for dealing with their ongoing problems which may have occurred many months or years after the end of primary treatment. They suggest that there should be change in the way cancer patients are supported as part of the Department for Health for England Cancer Survivorship Initiative. Their belief is that data the DH PROMS (2012) programme has the potential to provide data for this and that preparation for life after cancer is urgently needed. There is a growing recognition that that people living with cancer and beyond need support all through the different phases of cancer from diagnosis and primary treatment, living with the effects in the community and longevity to death. The National Cancer Survivorship Initiative (NCSI) (2007) was launched with the intention of improving outcomes for those living with cancer and to increase the understanding of the needs of those living long term and how they can be supported. The free text in the PROMS (2012) survey has shown how rich data can provide insight into the needs of cancer patients and help to support improvements. Much of the free text dealt with the positive and negative effects of initial diagnosis and at various stages of the cancer trajectory of those having surgery for bowel cancer and how they can be supported. In a recent paper on addressing the needs of cancer survivors: issues and challenges, Corner (2014: 443) suggests that:

...“the well-being of cancer survivors suggest that while, in general, individuals report that they are in good health, a substantial minority experience long-term

physical, social and economic consequences, and make extensive use of health services as a result. There are few services targeted at supporting long-term cancer survivors or minimising the potential physical or emotional consequences to enable individuals to return to productive lives following treatment.”

Much of the free text of the PROMS (2012) survey dealt with the positive and negative effects of initial diagnosis and at various stages of the cancer trajectory of those having surgery for bowel cancer:

Table 14. Positive and Negative replies from Patient's PROMS 2012 Free text replies.

Support from hospital staff, negative and positive.
<i>...”Specialist nurses were fantastic...were there at the beginning of the process, right through to the end of treatment...Can always call if I am at all concerned or worried”.</i>
<i>...”Little support from the designated clinical nurse specialist.... I only support people after the operation...That was said when I had 9 months to wait for my operation”.</i>
Experiences of living beyond cancer, positive and negative.
<i>...”It may have been worthwhile having discussion with patient and partner prior to surgery to outline the scale of the surgery involved and what the needs of the patient are likely to be”.</i>
<i>...” I have nothing but praise and gratitude for the nurse led cancer follow up team. Their positive attitude and cheerful kindness has helped me to remain positive too”.</i>
Lack of emotional support, positive and negative
<i>...”Advice, information, treatment, follow ups and care has been wonderful throughout –I cannot suggest any aspect that needed to be improved...knowing that I could and still can directly contact the colorectal nurse specialist has been a major support factor, and at critical moments, a great help”.</i>
<i>...”I have recently been discharged from the hospital follow up system...this a relief and should give me confidence that all is well, foreseeably, but in fact I feel a bit lost...it might be helpful if there was a group to join, to share experiences and worries with fellow sufferers.”</i>

Table 15. Areas where the free text PROMS 2012 showed negative/ positive answers.

initial GP visit
investigations,
Diagnosis
co-ordinated care
role of health professionals
surgery,
in patient care
Communication
adjuvant therapy
discharge
community support

(PROMS, 2012).

The participants raised issues of lack of preparation of the physical and psychological impact of the cancer treatment, lack of aftercare provision, the impact of co-morbidities and the on-going physical, psychological and social problems faced. This correlated with this current study but the emergence of the coping styles illustrates the different ways in which individuals learn to cope. Some felt that the lack of information regarding the outcomes of adjuvant therapy compromised their capacity in decision making and denied them patient choice.

...." I had these awful feelings in my feet and hands...like tingling....I couldn't pick up small objects easily or do small things easily.....I mention this at each cycle(chemo session) and they just say it will go when treatment is finished....treatment has finished and I have been back to work for a few months now....I am going to have to retire as I am finding it so hard to type as my fingers have no feeling....it's like they belong to someone else....the times I have dropped stuff in the supermarket"
 .(Anxious pre-occupation)

While for others:

...."I am a lay preacher and I will continue.....my health is good at present.....we have been married 60 years and I definitely expect some more(years).....I had no psychological or emotional problems.....I back at Am Dram (Amateur Dramatics) now and the choir.....yes there was fear of the unknown but nothing seems to be unknown these days with a computer.....it's a minor inconvenience.....my bum in a different place now where I can see it." (Fighting Spirit)

The NHS promotes choice and that patients should be given all the information needed to make an informed choice about their treatment and care. A lack of clear, full information regarding treatment options and side effects restricts the patient in their decision making. For some this left them with the feeling that they had been rushed along a path they did not want to take. Thus they had focussed on that point of time seeing it as the end of life as they knew it:

...."the surgery and stoma have ruined my life.....I know it was cancer....but I was bullied into surgery and its outcomes.... no information, not told how it would affect me.... I hate the stoma...always have...always will". (Fatalism)

The challenge here is knowing how to support these patients enabling them to move forward. It might have been different for patients with a different coping style:

...."Do you know...I feel like what rape must feel like (researcher queries this).... Well I have been assaulted haven't I in the most awful way I don't mean the cancer ... the hole in my stomach where all this muck comes out. It makes me feel vulnerable" (Hopelessness and Helplessness)

These differences indicate the importance of assessing individual coping styles at the point of diagnosis and utilising them throughout the patient's cancer pathway.

NHS commissioning of services.

Cancer Commissioning.

The responsibility for commissioning services is shared across 3 different organisations. Although from a patient perspective how this works may not appear to be overtly linked to their care, nevertheless it is key to the provision of all NHS services and therefore needed to be included here.

Table 16. Professional Led Follow Up.

NHS England	CCGs	Public Health England
<p>NHS England commissions specialist cancer services for adults including specified rare cancers, specified complex surgery or interventions for more common cancers, chemotherapy and radiotherapy. It also commissions all cancer services for children and young people including radiotherapy services.</p> <p>NHS England also commissions primary care contracting and cancer screening programmes.</p>	<p>CCGs commission services for patients with common cancers, GP referral, diagnostics, follow up and surveillance, rehabilitation and survivorship and palliative care/end of life care.</p> <p>CCGs also have a duty to support quality improvement in primary care.</p>	<p>Public Health teams in Local Authorities are responsible for health improvement for their populations and health promotion initiatives. This includes raising awareness of cancer symptoms, behavioural and lifestyle campaigns to prevent cancer and general health and wellbeing advice and initiatives.</p>

(NHS England, 2016).

As with everything within the NHS there has to be financial support for new innovations and extra work loads. Some examples of financial and non-financial levers and incentives which should ensure that patients have access to a range of high-quality services come from the core function of NHS commissioning. Contracts support this by giving a robust framework through which a commissioner can set clear standards for a provider and hold it to account for the quality of care it delivers.

Table 17. Examples of financial and non-financial levers and incentives for providing longevity care for the cancer patient.

Quality Premium Payment.	Payment to CCGs for improvement in quality of services commissioned.
Commissioning for Quality and Innovation (CQUIN)	Payment to incentivise quality and innovation improvements over and above the baseline requirements set out in the NHS standard contract.
Quality Outcome Framework (QOF)	Payment mechanism for GPs for quality care against set of indicators -for example the Cancer Care Review.
Best practice tariffs (BPT)	To incentivise care with specific high quality cost effective treatments.
National and local	Enhanced service schemes

Table 18. Non-Financial Incentives.

Clinical Commissioning Groups (CCGs) outcomes indicator set	To give clear comparative information about the quality of health services commissioned by CCGs and the associated health outcomes.
Commissioning for value / pathways	Support CCGs to understand where there are outliers and focus improvements for best effect.

However, as well meaning as these incentives are, the recovery packages cannot be put into place unless staff are aware of NHS recommendations and what their role is. Reports need to be cascaded down to all staff dealing with cancer patients and

implemented. During the interviews the researcher found no patients had ever had any written information from diagnosis, treatment and post treatment and living with cancer. However it must be noted that there have been changes and patients diagnosed today should receive written information about their disease and care. For many of the participants in this study survivorship care plans (SCPs) were not in existence at the time of their diagnosis of colorectal cancer. For some, the more recent participants there had been access to a SCN, and two mentioned colorectal nurse specialists. However, once their five year point was reached all were told “just contact your GP if you have any problems” and were then left to cope on their own. Therefore, most of the participants described similar side effects and expressed the need to seek advice. Clearly they had unmet needs which due to lack of immediate access to a specialist nurse, added to their distress and increased the cost to the NHS as this patient states:

....”I can never get any help when I have problems with my stoma....I’ve been discharged for 10 years now but at times my skin breaks out.....I make a doctor’s appointment....he doesn’t know and sends me in to the practice nurse....she doesn’t know....she says contact the hospital.....I ask for a home visit from the stoma care department as I can’t easily get to the hospital....they don’t do home visits now.....what do I do”. (Helplessness and Hopelessness)

This mirrors findings from previous studies, for example several of the colorectal participants in the PROMS (2012) free text study stated that they would have liked more follow up support and to know their precise regime of follow up. They wanted to leave therapeutic care knowing that they were not vulnerable but knowing whom to contact to access specialist services.

Another concern expressed by participants was the difficulty to renew prescriptions particularly where they wanted to change appliance or accessories. If they were using a dispensing appliance company (DAC) they could free phone the DAC and the DAC would request the prescription from the GP. This was where for many of the interviewees, the delay came as the GP would often be very slow in sending the prescription back to the DAC, often taking up to 4 weeks:

....” I seem to spend all my life ringing and reminding the practice about my prescription...they don’t seem to think it is a problem...they obviously do not need to wear a bag...I cannot be left without any... the Doctor said to me did I really need to use bags every day.....perhaps he should have a stoma and see what it is like being permanently incontinent....it takes so long to do this process...going to the chemist is no better” (Anxious pre-occupation)

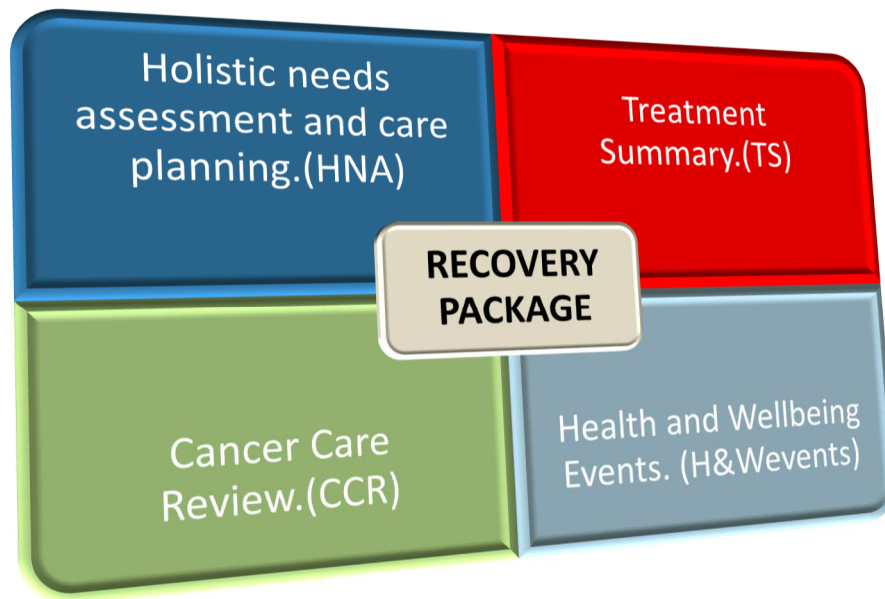
For some of the interviewees this was problematic as in their own words they were not the “best at remembering” to allow time for the GP to return the prescription, so found themselves very short or even without stoma appliances. Participants were concerned about the lack of GP involvement at all the stages of their cancer trajectory and this was also a finding of the PROMS (2012) study. For the older participants the interviews suggest that co-morbidities which may have been exacerbated by primary treatment or adjuvant therapies, continue to be problematic for years after treatment:

....” My heart problems are worse...I had chemo and the one they gave me said I could have worse heart problems...I did and they stopped it for a while and then started it again...I’m between the devil and the deep blue sea” (Anxious pre-occupation).

Yet another example of this study matching the PROMS (2012) survey. These findings are significant because cancer survival and longevity has improved considerably over the last 15 years. As a result cancer survival and longevity is at its highest point with significant improvements made in treatment over the last 15 years. The number of people living with cancer in the UK has risen by 400,000 in the last five years - taking the total number of people living with cancer in the UK to 2.5 million. (NHS England, 2016). Today, it is estimated more than half of people receiving a cancer diagnosis will now live ten years or more. These positive outcomes have been driven by scientific improvements in how to treat and control cancer. It is therefore now imperative that policies and strategies be developed and implemented to enable long term care provision to match the acute treatment options. Only that way can individuals be supported through their cancer diagnosis and health needs to live well during their longevity.

The five year forward view 2015 - 2020 emphasises the importance of taking a whole person and whole pathway approach to the commissioning and provision of cancer services. Therefore it is important that the needs of people living decades or more after cancer treatment have their quality of life included as a key component of NHS commissioning and an effective recovery package be developed and delivered on a national basis. NHS England (2016) has produced guidelines of the areas that need to be considered for inclusion in such a package.

Figure 24. Recovery Package.



(NHS, 2016 Recovery Package).

This package has four pillars. Firstly, the NHS (2016) state that all cancer patients should be offered an HNA and care plan at the diagnostic consultation, again at end of treatment and whenever the patient's needs change or at any other time at the patient's request. They argue that effective assessment of the patients' needs and care planning can lead to early interventions, diagnosis of consequences of treatment, improved communication and better equity of care. The HNA and care plan are meant to ensure that the patient's emotional and social needs are met in a timely and appropriate manner. Also, that resources are targeted to meet those patients with the highest level of need.

The HNA requires input from the range of healthcare professionals involved in the patient's care at any time along the cancer trajectory and after therapeutic intervention has finished. This should create a shared understanding between patient and healthcare professionals about what to expect during recovery and after, identifying any specific needs. A service specification such as that used by the London Cancer Alliance of an HNA is given in the appendices (Appendix 2, 3.) The government recommends that running consecutively with the HNA there should be a Care Plan (CP) that has been developed as part of patient/professional discussion. This should support shared decision making, enabling appropriate interventions, including support and information, and referral to other agencies if needed to be included in care provision. They argue that the combination of HNA and CP should

help to minimise or reduce complications and prevent psychosocial concerns from escalating, so supporting self-management. It is accepted that many of the participants in this study were diagnosed and treated in the years before such comprehensive planning existed. Nevertheless it has to be pointed out that no participant had received any of the support mechanisms that NHS (2016) confidently describe as being the fore runners for this new package. For example:

...“I was told by the hospital to report to the surgical ward 4 days prior to my operation....I had some blood taken and some other tests then given an enema of soap and water....I was told to put on the gown for theatre and off we went....I remember coming back with tons of wadding wrapped round my abdomen.....a few days later it was taken away and a junior (nurse) put a bag over what she called a stoma...I was discharged at 4 weeks and told a district nurse would come to the house...I’m luckily not stupid and had watched the junior change the bag every 3 days so felt I could manage” (Fatalism)

The second pillar, the treatment Summary (TS) should provide important information for GPs, including possible treatment toxicities, information about side effects and/or consequences of treatment, signs and symptoms of a recurrence. It also needs to indicate whether they are at risk of developing comorbidities such as cardiac disease, osteoporosis and diabetes, as well as any actions to be carried out by the GP. In order to discuss the person’s needs. The first treatment summary should be completed within six months of a cancer diagnosis and should include post-treatment support, financial impact of cancer on the patient, patient awareness of medication and prescription charges and exemptions. It should indicate possible late effects of the specific cancer and its treatment and the information needs necessary to facilitate self-management (NHS England, 2016). To support implementation of this treatment summary, cancer care reviews of treatment and needs carry eligibility for QoF points for GP practices. The importance of noting this is that QoF carry financial incentives, hopefully encouraging GPs to play a bigger role in long term care. Something that the findings from this study suggest is urgently needed:

....“My daughter took me to the GP a few days after I was finally discharged home after being in and out of the hospital for five years....I needed to give him new details for the bags and other bits....also I wanted reassurance from him that I was doing ok and that I could rely on his care now....he was polite when we went in....he asked what he could do for me....I was a bit taken aback and I said you do know what has happened....he said no....he said he had not had been given any information and had not had a discharge letter....I felt so let down” (Hopelessness and Helplessness)

The third pillar, health and wellbeing events has been included to provide an opportunity to inform and educate patients about the clinical and holistic aspects and ongoing management of their health in regard to their cancer and longevity. These

events also serve to impart information about local facilities, supportive care and opportunities that are available to individuals and their families in the community where they live. Although every individual with cancer should be offered the opportunity to attend a health and wellbeing event during and at the end of primary treatment, this is not yet in practice. Also it has to be remembered that many patients fear being 'labelled' as a result of attending such events, while others do not like group activities. However, for those who do want support:

...."the hospital stoma nurse asked if I would like to meet someone who had started off like me....I could have a visit to my house or I could go to the next function day they would be putting on....she explained it was for stoma patients to meet others in the same way....the nurses got someone to come in and talk then there would be tea and cakes and then I could talk to the nurses or other patients...I went....they were all so welcoming like a big family but with all the answers to my questions" (Fighting Spirit).

Conversely though, social 'get together' of similar people is an anathema to some:

..." what could be worse....a room of people with bags on their stomachs smelling and making uncontrolled noise....no...I might find there is someone there who recognise me...how appalling would that be....I don't need a label I know who I am" (Avoidance)

Although not labeled as health and wellbeing events for the last two decades in stoma care, CNSs have held regular patient open days each year, not only to allow patients to see current products, but also to try and capture the 'lost ostomist', patients who for whatever reason have fallen under the 'radar' of the local stoma care department. Within the last decade these local support groups for stoma patients have started to include the patient who has had colorectal cancer surgery but no stoma as they realized that this group of patients also need lifetime support. Often at these support days there may be a speaker about nutrition, exercise, makeup, and fashion for those worried about a stoma showing and often complimentary therapies.

To widen this approach and following government recommendations such as Macmillan and Maggie's centres, they are putting on sessions and days for cancer patients and their families. Whilst these may not always address specific colorectal cancer concerns they do provide the opportunity for patients and their families to share their experiences, to support each other and move forward.

The final pillar should be the Cancer Care Review (CCR) informed by the Treatment Summary. It needs to be completed by GP or Practice Nurse and should include

discussion of the patient's current needs. It covers many of the issues included in the treatment summary but the focus is on checking for current issues and concerns. Thus these reviews should be held at regular intervals. Recognising, that in some instances encouragement may be needed to get these reviews completed, some commissioners in England see a need to have local incentive schemes to improve quality, timing and/or frequency of the CCR. Then too, the cancer care review will also be eligible for Quality Outcomes Framework (QOF) points.

The recovery package will only function well standardising care across the country once the challenges of late diagnosis have been addressed. It is a cause for concern that despite all efforts within England there remain some marked variations in the proportion of patients who are diagnosed with cancer at an early stage. For colorectal cancer, there is a nearly a threefold variation between the highest and lowest performing CCGs (Cancer Research UK, (2014). Early stage cancer treatment is significantly less expensive in terms of personal, psychosocial and financial impact on the individual and demonstrably less expensive for the NHS than treatment for advanced disease as the colon cancer and rectal cancer diagrams below demonstrate.

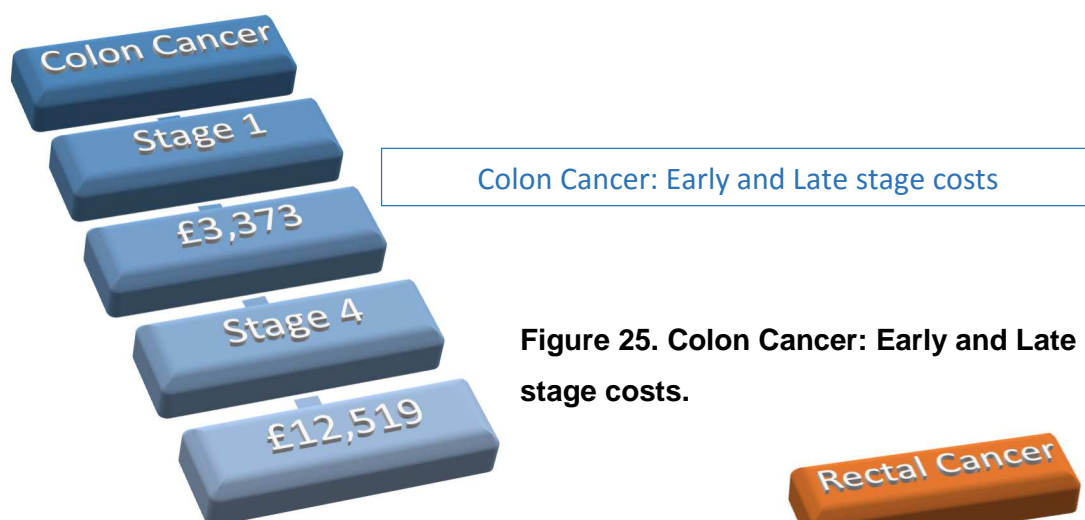


Figure 25. Colon Cancer: Early and Late stage costs.



Figure 26. Rectal Cancer: Early and Late stage costs.

(Cancer Research UK, 2014).

In addition, the cost of recurrence can be significant and planners should be aware that it needs to be taken into account when modelling overall cancer treatment costs. The twin costs of financial and health impact of recurrence re-emphasise the importance of ensuring that all patients are offered the most effective treatment choices possible. Until the inequalities in time and stage of diagnosis are addressed, late diagnosis will remain a major driver of NHS cancer treatment costs. As the figures above illustrate, treatment for stage 3 and 4 colon and rectal cancers cost the NHS nearly two and a half times the amount spent on stage 1 and 2 colorectal services (Cancer Research, 2014). The significant savings that could be realised if all CCGs achieved the same level of early diagnosis would fund care and support after the five year cut off point. For colon cancer, savings of over £24 million could be realised and for rectal cancer, savings of nearly £10 million could be realised (Cancer Research, 2014).

In the light of the increasing numbers living long term with cancer and the fact that the current recovery plan as described above is another example of care in the first five years, the need for change in provision is clear. The findings from this study showed that participants wanted and needed much longer term support, therefore the next logical step for this research was to utilise the descriptions of their lived experiences to develop a conceptual framework that can be responsive to what will be an increasing population requiring long term guidance and support.

Implications for training and education of healthcare professionals for a Care for Life Plan in the NHS.

The NHS promotes choice and states that patients should be given all the information needed to make a decision about their treatment and care. A lack of clear, full information regarding treatment options and side effects restricts the patient and their family in their decision making. The National Service Framework for Older People (NSF, 2001) and the Living Well in Later Life (2006) have no mention of cancer and the complexities of care for these individuals. The only mention of cancer in both documents is a referral to the National Cancer Plan (DH, 2000). Yet the NSF considers the older person to be from 50 years if they are retired and finished child rearing, while cancer screening indicates that 50 years onward is often the time that diagnosis of colorectal cancer occurs along with the older person who develops age related cancer. Even today, 18 years on from the ideals of the Cancer Plan (2000), few services are targeted at supporting the long term cancer 'survivor'

and in too many areas the reality of supporting cancer services fails to match the level of the commitment stated in the Cancer Plan (2000). However, despite the best efforts of the NHS, cancer patients across the country are still lacking support after they have finally been discharged from hospital treatment at the five year mark due to under investment within the community. Furthermore, there are too many variations in the quality of post cancer care across the country that leaves cancer patients and their families frustrated by a postcode lottery.

Family doctors, practice nurses and community nurses play a crucial role in helping people reduce the risks of cancer with health education and should have a greater role in supporting the individual after treatment has finished in providing support for patients and their families in living with cancer. The Cancer Plan (2000) introduced new joint training across health care professionals in communication skills and made it a pre-condition of qualification to deliver patient care in the NHS that staff are able to demonstrate competence in communication with patients. For nurses and doctors working with cancer patients they were given additional training in communication skills in the provision of providing psychological support. In conjunction with Macmillan education and training, frontline healthcare professionals, those who had a major role in the cancer multidisciplinary meetings, attended two day workshops in Advanced Communication Specialist Training (ACST) to help them prepare their communication skills to discuss the aspects of cancer, treatment options and on-going care in a way that the patient is able to understand and therefore make a well informed decision about their care.

Armes et al (2009) suggested that there is growing recognition of cancer patient's needs as it was becoming clear that with improved treatment factors, cancer patients were living longer beyond the end of their cancer treatment. Health professionals will need to consider how to improve care for these patients during their longevity stating that there needs to be development of individualised care plans based on the patient's needs. This would help to ensure that those who may experience unresolved needs can be supported. Armes et al (2009) considered that in 2009 there were predictors of unmet needs and more information was needed by the patients on follow up care, rehabilitation and self-management, stating that current models of follow up care often failed to meet the patient's needs. This has been confirmed by the researcher's work into what the interviewees were saying about how they feel 'let down' after their discharge at 5 years because they felt that there is

no one to whom they could seek advice from if they wanted reassurance about their health or stoma.

The main focus of the National Cancer Survivorship Initiative (NCSI, 2007) introduced in 2007 was to diagnose and focus on treating cancers, although, at this stage in time, one of the underlying aims of the initiative was to enable cancer patients to live a long and healthy life as possible. Franklin (2007) suggested that Improvements in cancer screening, detection and treatment have resulted in increased 5–10-year survival rates in many cancers, with colorectal being one of them, and are now considered chronic diseases. In the UK there is a limited knowledge of the needs of cancer patients and how they manage their longevity and whether there is the infrastructure within the NHS in place to meet these on-going needs. With a medical model in place in the NHS that is disease focused, more emphasis is put on detecting recurrence rather than a patient centred care model. In the work by Armes et al (2009) they suggest that 30% of cancer patients have 5 or more unmet needs at the end of their treatment with most frequent being the fear of recurrence. Psychological needs and recurrence made up 20% of the patient worries and many had fears about dying. Other areas of need were emotional problems (Sherman et al, 2012), changed relationships with healthcare professionals (Corner et al, 2013) and changes in social support and financial difficulties (Sammarco 2001, Shewbridge et al 2012).

Individuals with a history of cancer that have been discharged from their primary treatment at 5 years have the right to continued medical follow-up with basic standards of care that include the specific needs of long-term cancer 'survivors'. These long term cancer individuals should be able to access specialised follow-up clinics that focus on health promotion, disease prevention, rehabilitation, and identification of physical and psychological problems Essentially this care is patient-centered and coordinated, including responsiveness to the individual's needs, communication and information sharing with the focus on recurrences, metastasis, second cancers, and late effects of chemo- radiation, whilst helping the individual to improve their quality of life. Each individual should have access to and receive care following their primary cancer treatment. Due to the heterogeneity of cancer and late effects there will be a need for specific services that will vary from individual to individual.

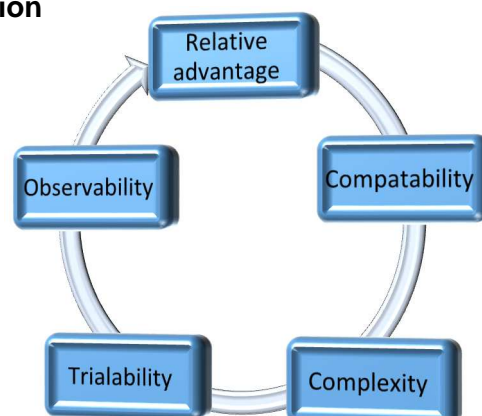
To be able to develop and quantify the ongoing needs of the individual once primary

treatment has finished and discharge at the 5 year mark reached, it is important to have a detailed knowledge of the constituent group (those living with a cancer diagnosis) to be able to identify their needs over the long term. Therefore an organized plan for living after cancer treatment needs to be instigated offering the individual practical guidance and hope that the individual will continue with longevity. A Care for Life Plan lasts until recurrence, a second cancer, or death. Currently, even after the National Cancer Plan (DH,2000) and the work of Davies (2009), Armes et al (2009), Richards and Corner (2011), PROMS (2012), Brennan et al (2014), Tessaro et al (2013), Mayer et al (2014) and Corner (2014), where all authors have described the need for ongoing care for individuals after primary cancer treatment has been finished, there are 22,824 men and women in England (Macmillan, 2017) who have 'survived' from 15-21+ years post treatment for bowel cancer, but have not been given a Care for Life Plan or have any organized care. Although this phase of care has only recently gained a wider public attention, there appears to be relatively little experience and research on how to deliver such a programme for this section of the population.

Educating the work force.

It has become clear that there is a need to increase the effectiveness of post treatment cancer care after the five year mark by adopting and implementing a suitable framework of on-going care. When trying to instigate changes in care a suitable way must be found to change clinical behaviour and break down resistance to change within the health service. A suitable way to do this is to use Rogers (2003) theoretical approach, diffusion of innovation (figure 27), which is a theory of social and cultural change developed 50 years ago. According to Rogers (2003) it is a process, not a discrete event and there are five elements that will help to determine whether adoption or diffusion of a change in clinical care will occur.

Figure 27. Diffusion of Innovation



(Rogers, 2003)

New concepts of innovation need to come from outside the current system that is in place if change is to occur, but new processes need to come from inside the current system. Resistance to making changes in what is known as survivorship in cancer care invariably comes from clinical opposition as the common statement is “it is already being done”. As all the participants in the researcher’s study have shown, care after the five year mark is not being addressed. In the process of diffusing innovation in clinical change and addressing the long term care and support of cancer patients, understanding Roger’s (2003) theory plays an important role.

Relative advantage is considered by Rogers (2003) to be the degree to which the innovation is considered to be better than the idea it supersedes. However, as yet there is nothing available for the cancer patient who has exceeded their five year mark to support them within the community. Table 20 (page 169) demonstrates the number of colorectal cancer patients, male and female, who are alive and well 15-21 years after diagnosis. Organisations are seen to adopt innovations at different rates and innovators are able to imagine the possibilities while early adopters can make a connection between the new practice and what is needed to reach that level. Others known as early majority adopters and late majority adopters will follow as they see the advantages to the innovation.

Compatibility considers the degree to which an innovation will be perceived by healthcare professionals to be compatible with their current practice, past experiences and needs of the potential adopters. Creating an awareness among healthcare professionals that longevity in cancer patients is something that is separate from oncology care and the current survivorship programme supported by MacMillan Cancer (Richards et al, 2011) will be a challenge. Most healthcare professionals and patients will quite rightly feel that the focus of care is immediate treatment and control of the disease and that survivorship care comes from a history of the medical model. One centre of excellence director in discussing the cultural shift that needs to take place among healthcare professionals describes the cancer patient after treatment and on maintenance surveillance visits as “they are not dying, they’re not in active treatment so there hasn’t been a lot of emphasis on the resources they need” (Tessaro et al, 2013).

Complexity concerns the difficulty or ease to which adopting the innovation may be. When a clinical innovation is put forward it’s adoption is more likely to be accepted if it is simple and well defined and shown to the appropriate healthcare professionals who are involved with the subject there is more likelihood that it will be adopted. The

process for change in healthcare organisations is often slow and will require time, commitment and effort. Invariably there is resistance to change in health organisations if the innovation is perceived as 'difficult', education and training raises awareness of the needs of this group of individuals who are currently lacking support during their longevity after cancer treatment.

Trialability is defined as how the innovation may be trialled and modified and allows healthcare professionals to explore implications and potential outcomes. It also allows flexibility of change and input from all healthcare professionals to the innovation.

Observability is the degree to which the innovation is visible to others both from within the project group and to those outside including the individuals to whom this innovation is aimed. Dissemination of the innovation and outcomes should also be shared within education and training programmes.

An early adopter of longevity was Bristol Clinical Commissioning Group (CCG) who considered what the needs of the cancer patient were once regular treatment and therapeutic interventions finished to enable the patient to have a good quality of life. The process of recovery after any cancer and its treatment is lengthy and cancer rehabilitation is now becoming recognised as a critical part of care pathway of the cancer patient and efforts are being made to remove the 'disconnect factor' that is prevalent between reaching the five year mark and the continuing of life after the five year mark. A consequence of poorly coordinated care is poor quality care. Cancer patients may not receive necessary non-cancer care if their cancer diagnosis shifts attention away from other care that is routine but necessary. As early as 2004 a study by Earle and Neville (2004) focused on the care experience of Medi-care patients in America who had survived 5 years past their diagnosis of colorectal cancer. They found that colorectal cancer patients were less likely than controls to receive appropriate and timely follow-up for heart failure, necessary diabetic care, immunisations and other preventive services. They suggested that a collaborative approach to follow-up is needed.

Figure 28. Diffusion of Innovation theory.

Diffusion characteristics	Themes	Strategies for change
Relative advantage-perceived as better than before.	Creating awareness.	Widespread education.
Compatibility-consistent with values, habits, experience of potential adopters.	Making the cultural shift.	Find the best fit for survivorship care within the organisations professional culture.
Trial ability-experiment before commitment.	Trial and error.	Flexibility and change in models of care that work.
Observability-tangible results.	The bottom line.	Funding and organisational support-internally and externally.
Complexity-ease of use in understanding or using innovation.	Change can be hard and slow.	Education and training for healthcare professionals to improve performance.
Innovators and early adopters.	Champions / Beacons	Identify leaders, time and commitment.

(Tessaro et al, 2013).

In an early paper by Figuerado et al, (2003) looking at devising a practice guideline for follow up of patients who have had a curatively resected colorectal cancer they conducted a systematic review of the literature they found six randomised trials and two published meta-analyses. Of the six randomised trials comparing one follow up programme to a more intense programme, only two trials detected a statistically significant benefit to the patients from the more intense follow up programme. As with most of the papers, the follow up programmes being looked at were only for the five years until discharge from clinical care. In two more recent papers on care plans for colorectal cancer patients (Brennan et al 2014, Mayer et al 2014) suggest that there

exists a lack of long term outcome data about the impact of survivorship care plans that are used during the five year cancer trajectory or whether there are benefits in care follow up later in survivorship. Mayer et al (2014) suggests that although patients may find the transition from acute care to extended care – up to five years – find the transition difficult. They suggest that the patient may not be aware of the importance of surveillance in the following years after the cessation of the acute treatment phase. Neither of these papers considered the needs of the colorectal cancer patient after the five year point is reached nor what these patients may need for the rest of the cancer pathway,

Corner (2014) suggests that while there have been many studies of QoL among individuals undergoing cancer treatment there is relatively little research into the long-term care needs of people after treatment for cancer. Very few studies have systematically studied the health and well-being of people treated for cancer during their longevity following initial treatment. There are no published studies that have been undertaken, for example, among UK cancer survivors and just a handful of studies internationally.

A key commitment of the Cancer Reform Strategy UK (DH, 2007) was to establish a National Cancer Survivorship Initiative (NCSI). A core focus of the NCSI was research and development of evidence as to what the needs of cancer survivors were and how effectively to deliver this. The paper by Richards et al, (2011) suggested that if there were to be improvements for cancer survivors several questions needed to be answered. Among these were;

Table 19. Understanding the Needs of Cancer Survivors.

-
- **How many people are currently living with a cancer diagnosis,**
-
- **What specific or concerns do these people report,**
-
- **What care are these people receiving in the community or hospital,**
-
- **What are their preferences for future care,**
-
- **What are the risks of late consequences of cancer treatment**
-

(Richards et al, 2011).

Khan et al (2011) explored the perceptions and preference of care by cancer patients in a qualitative study and the study suggested that there is a need for support, information and ongoing needs in this population. They reported minimal involvement by their GPs and that the GPs lack the necessary expertise to cope with problems arising in cancer management. In the paper by Richards et al (2011) it summarises that new models of care are needed to optimise the QoL of cancer patients who are experiencing longevity. In table 20, the number of patients surviving from five to twenty one years after diagnosis of colorectal cancer in England can be seen below. It therefore seems imperative that these thousands of patients should be supported in their longevity and not be left to cope on their own.

Table 20. Colorectal Cancer longevity since diagnosis in England. 1995-2015.

England	5-10 years survival	10-15 years survival	15-21 years survival
Male	32,354	17,264	11,519
Female	26,790	15,565	11,305
Male and Female	59,144	32,829	22,824

(MacMillan Cancer Support, 2017).

It appears from the literature searching and the researchers own knowledge, that there is a fragmented delivery system for those who have suffered from cancer. Cancer patients, as with other individuals with chronic conditions, face a well recognised set of challenges—dealing with symptoms, disability, emotional upheaval, difficult lifestyle adjustments, and the need to obtain helpful medical advice. When undergoing primary treatment, cancer patients often see multiple specialists—surgeons, medical oncologists, specialist nurses. Assuring coordinated, multidisciplinary care for continuity along the pathway can be difficult to implement and may affect subsequent longevity. A focus on continuity of care is central to quality of care of the cancer pathway throughout the cancer care trajectory.

Currently, within the NHS there is a lack of continuity for the patient between secondary and primary care in the NHS as tertiary centres lack oncology input and comprehensive rehabilitation services for the cancer patient and their longevity.

Early intervention in the community with rehabilitation can minimise the effects of primary treatment of cancer and offer support to the newly discharged cancer patient who has reached the five year mark and is expecting to have support as they extend their longevity. The concept of continuity of care for cancer patients has been defined by Lauria (1991: 1762) as:

“The systematic assurance of uninterrupted, integrated medical and psychosocial care of the patient, in accord with the patient’s wishes, from assessment of symptoms in the pre-diagnostic period, throughout the phase of active treatment, and for the duration of post treatment monitoring and/or palliative care”.

Optimal care for longevity after cancer treatment is characterized by an organized plan for follow-up that is shared with patients so they can take responsibility for their care.

The PROMS free text survey concurred with Armes(2009) and colleagues that patients need to be fully informed about the effects of treatment and have access to advice and post treatment support services. When therapeutic intervention has finished patients need to be informed of what further contact and information is available and that they understand that there is a possibility of potential psychological problems related to recurrence and death, may occur. For many patients there may be the need to access advice about their financial problems, state benefits, return to work and social services. In reviewing the interviewee’s descriptors/feelings and quotes they revealed that many of the interviewees were expressing similar thoughts about their diagnosis, treatment and longevity.

The nursing role and education.

Nurses would appear to be very well suited to providing a Care for Life plan, as the emphasis in nurse education and training is on patient assessment, symptom management, psychosocial care, and care planning. Clinical nurse specialists in the appropriate cancer arena, are ideally placed for the continuum that these individuals need to aid their longevity. The interaction between the health care professional and the patient depends on the level of training the health care professional has had. Much of the medical consultation at appointments is with a doctor and their role and training has been a long term medical model that is focused on disease and treatment. However, nurses are the largest component of the NHS workforce and frequently the subject of significant changes and challenges in terms of their clinical role. Of all the developments in nursing, the role of the specialist nurse has been one

of the most exciting, but also one of the least understood and valued by management, where it is often considered as an expensive role that can be discarded. Clinical nurse specialists deliver high quality, effective and person-centered care (RCN, 2010). In keeping with national studies of CNSs, it was found that as much as 51% of their work is performed in the outpatient setting or on the telephone (Leary et al., 2008). The RCN report (RCN, 2010) analysis of their data and the wealth of information obtained, show that there are discrete patient outcomes from CNSs' practice. Below shows the top five interventions:

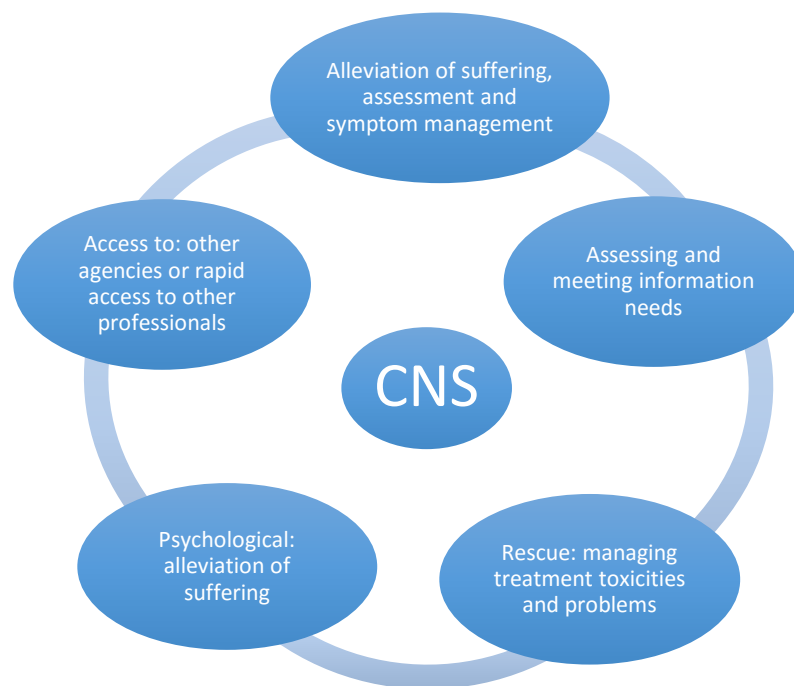


Figure 29. CNS top five interventions. (Black, 2017).

Since the Calman Hine report (1995) into cancer care and the Improving Outcomes in Colorectal Cancer report (1997) confirming the need for the specialist nurse role in colorectal care, CNSs appear to represent significant benefits to an organisation, including patient outcome and the Clinical Nurse Specialist: adding value to care (2010) study, examines the cost benefit ratio. The study found that the outpatient work done by CNS's is worth approximately £72,128 pa per full time nurse , and saves consultant spend of £175,168 per nurse by freeing up consultant follow up appointments. Telephone consultations reducing the number of GP appointments save approximately £72,588pa, The prevention of unscheduled care is poorly recognised in the work that CNSs do because the specialist area is not the focus of national research even accounting for the cost savings in an over extended, cost

stretched NHS.

Although the colorectal/stoma CNS is primarily based in the hospital and meets the patient immediately at the start of the cancer trajectory after referral from the GP, there is limited follow up once the individual returns to the community. At this stage it is after surgery or completion of other therapies that the individual has less contact with the CNS and health care team. Up until the five year mark there will be hospital visits as an outpatient and after year 2 these appointments gradually decrease in frequency until the discharge point is reached. Even during this time the individual begins to notice the decreasing support from the CNS and team and will have no further contact after five years unless the individual makes a concerted effort to contact their CNS with their query. As one of the interviewees stated:

" When I was discharged finally at 5 years I was sad even though everyone was pleased with me...I was worried what would happen now...who do I contact...who do I talk to. The CNS was lovely and said I could ring at any time but I know from my experience how busy they are all the time with new patients...I am cured so how can I worry them...I was just told to go to my GP if I had any worries". (Anxious pre-occupation)

Although many of the hospital CNSs do home visits, especially during the first 3 months after surgery, this is becoming less and less as hospitals consider that it is not their role to support the Clinical Commissioning Groups (CCGs) financially with domiciliary visiting and likewise the CCGs do not see home visits by an experienced CNS cost efficient. Hospitals consider that patients who make it to their outpatient appointment can be seen by the CNS at the same time, not taking into account the considerable burden that the CNS may have that day with other patients previously scheduled in. Likewise, this can be a problem for the patient who has a need to see the CNS and is asked to wait until they are free to see them, often more than several hours after their appointment. Many patients consider that they cannot wait and decide not to contact the CNS and see if the problem resolves in its own time. The therapeutic relationship built up over the five years with the individual's CNS appears to have dissolved at this stage in their care and this can add to the psychological distress that the individual feels. One interviewee stated:

..." I had a lovely CNS, so caring....the time she spent with me and my family...exceeded all...I have managed to get through this due to her...her kindness, compassion...she always said to ring if there was a problem...or come to the nurse clinic...I am so scared as we are moving up country and there will be no one who knows me.' (Anxious pre-occupation)

From the researcher's experience the feelings of this individual are not unusual. The

support the CNS gives even only by telephone can make a difference to a patient when they feel that they have a problem. However, although a decade ago the Cancer Reform Strategy (2007) outlined the need for a National Cancer Survivorship initiative to improve ongoing support for the individual's longevity and that this may mean a different kind of care and support currently available to cancer individuals. Pledge 4 from the Cancer Reform Strategy (2007:5) states:

“Whether you are living with or beyond your cancer, high quality information and support tailored to your personal needs will be available”

The Cancer Reform Strategy (2007) recognised firstly, the role and skills of the CNS and that in time they will adapt to reflect new care pathways. Secondly eight key areas to be addressed to improve the longevity of the post cancer individual. These are:

Table 21. Eight Key Areas to Improve Longevity.

Communication and information sharing towards choice and decision making.
Continuity of care with co-ordination beyond the hospital environment.
Psychological support.
Supportive and palliative care.
Appropriate training for healthcare professionals.
Understanding the financial elements of cancer.
Measuring patient experience to improve QoL.
The critical importance of the CNS.

(Cancer Reform Strategy, 2007)

Individuals who have reached the five year mark post cancer treatment and have been discharged to the community may have a range of physical, psychological, social, spiritual, financial and information needs. At the time of writing the Cancer Reform Strategy (2007) it was recognised that current services then, frequently did not meet the needs for these patients and the patients are poorly integrated into their

GP service as they are considered 'cured'. As many patients with cancer are elderly and have other co-morbidities and other problems, services for these individuals need to be well integrated into GP and primary care services. Currently, for many of the patients, once discharged at five years, if they need to see the CNS with a problem that the GP cannot solve this will require a new appointment with a referral letter from the GP to the hospital and a wait until a new appointment comes through.

Implementing the Care for Life Plan in secondary and primary care.

It is clear from the literature and the interviewees that CNSs in cancer care are key workers treating and managing the health concerns of cancer patients and work to promote health and wellbeing in the patients they care for during their therapeutic relationship. CNSs use their skills, expertise, education and training in cancer care to provide physical and emotional support for the patient and family, coordinate care services and to inform and advise patients on clinical as well as practical issues, leading to positive patient outcomes. They also reduce treatment costs, increase efficiency, drive innovation and provide valuable information for service redesign as well as enable multidisciplinary care and communication between different teams (Macmillan, 2018). The cancer trajectory is complex and often disjointed involving care interventions from various multi-site professionals such as oncologists, surgeons. Patients should have access to high quality, effective care and the CNS has an important role in ensuring that the patient's needs and expectations are met.

It has become clear from the literature and the interviewees that current models of care are not identifying or meeting the needs of all patients living with cancer and that there needs to be an adaptation in the way post five year individuals are cared for. The CNS, also known as the patient's key worker needs to become embedded in the acute sector practice and then extended into the primary sector using their specific skills and specialist knowledge of cancer to continue support and management of these patients in their longevity. Although, currently, most CNSs in cancer tumour types are based in the acute sector, very few work with services in the in the community. For those that do they are able to build partnerships between different healthcare professionals based in various settings. They also recommend patient referrals to the most appropriate services back to the hospital setting according to the individuals specific need because as CNS has knowledge and information about what support is available and appropriate. Also the CNS possess excellent skills and expertise about their specific tumour group and are able to use this knowledge to ensure that the individual experiences the best possible care and

support.

Reviewing the extensive literature available in relation to the role of the CNS, it has clearly become an established and recognized role in the NHS supporting the cancer patient in making their cancer trajectory as smooth as possible. The National Cancer Survivorship Initiative (NCSI, 2008) established several work streams in the area of survivorship. Of those that have an importance to the colorectal cancer patient and their ongoing needs are:

1. Assessment, care planning and immediate post treatment approaches to care. The development and testing of a standardized model of post treatment follow up care that would enable equality and consistency in the delivery of survivorship care.
2. Managing active, progressive and recurrent disease. Creating a responsive service that takes into account the individual health needs of survivors and carers.
3. Late effects of treatment. The development of an assessment framework for identifying and managing late consequences of cancer treatment.
4. Self-management, the testing of self-management programme measuring the long term outcomes on patient and provider.

(Davies, 2009)

In 2008, the NCSI had already recognized the need for a pathway for the patient to support them through treatment and this emerged as the Recovery Package. The Recovery Package is a set of essential interventions designed to deliver a person centered approach to care for people affected by cancer. This includes Holistic Needs Assessment (HNA) and care planning, Treatment Summary (TS), Health and wellbeing events, Cancer Care Review (CCR). The focus of the work involved in managing late effects of treatment is to help patients manage or limit their psychological and psychosocial functions. As these problems are often late effects of treatment and may not show until after final discharge it is important that the patient knows who to contact or have a planned schedule of care (Care for Life Plan) that enables them to know when they are to see a healthcare professional. Self-management by cancer patients is important but cannot replace a Care for Life Plan that gives confidence to the patient about what will be happening to them over the next years. New models of care are needed to optimise health-related quality of life among cancer 'survivors'. However, up to now this area of cancer support and

research has been relatively underdeveloped both within the UK and elsewhere. Although there may be challenges for gathering information on long-term health outcomes of cancer patients the PROMS (2012) free text study showed where the inefficiencies were in care and support of the patient, both in and outside the hospital environment. The number of research groups pursuing questions related to long term cancer survivorship is small at present and investment in this area is needed (Richards et al 2011, Corner 2014). Research that will address the area of longevity in the cancer individual post five years and development of research in this field should remain a high priority.

The role of the CNS, although at the moment, confined to the acute sector, is in an ideal position to take the Care for Life Plan forward by educating colleagues and ensuring that the patient is given one at final discharge. The CNS then needs to liaise with the GP and ensure that they have a copy of the Care for Life Plan and reassure the patient and family that they are still available but the continuing care will come from the primary sector at specific organised times. Cancer CNSs also help empower patients to self-manage their conditions leading to reduced costs for healthcare providers through hospital appointments, emergency admissions and consultant time. In taking a holistic approach to treatment and longevity the CNS can provide a continuing package of care linking up different health and social care services together to improve the cancer care process for patients.

Table 22. Components for CIPS - a Care for Life Plan.

Co-ordination	Between specialists and primary care providers to ensure that the individuals health needs are met - health promotion, immunisations, screening for both cancer and noncancerous conditions, and the care of concurrent conditions.
Intervention	Consequences of cancer and its treatment such as medical problems, sexual dysfunction; pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; concerns related to employment
Prevention	Prevention and detection of new cancers and recurrent cancers
Surveillance	Metastasis, recurrence, second cancers, metachronous cancer

(Black, 2017).

Essential to a Care for Life plan is a patient-centered approach, including responsiveness to a patients' needs at the time of appointment, effective communication and information sharing to appropriate other agencies and encouragement of the adoption of healthy lifestyles and activity. A Care for Life plan has a focus on identifying any cancer recurrence, second cancers, and late effects of other treatments such as chemotherapy and radiotherapy; ensuring access to effective interventions and helping patients to improve their quality of life and longevity. Every individual should receive a Care for Life plan following their treatment, and not just for the five years until they are discharged from therapeutic intervention. The need for specific services will vary from individual to individual because of the heterogeneity of cancer and late effects from oncological treatment. All individuals of early or late stage cancer and those whose treatment was limited, require follow-up care. Tierney and McKinley (2002:11127) as cancer suffers themselves, suggest that:

.... "Providers must try to understand the impact of cancer on their patients' lives and the lives of their patients' caregivers. They should focus on both the negative and positive effects of cancer and its treatment, and be as energetic and considerate in treating the cancer patient (and hopefully, survivor) as they are in treating the cancer itself."

When there are changes in practice in nursing it will often be a transformational nurse leader who will want to move forward with innovation within their practice area. The majority of nurses who work within the colorectal cancer area are often more experienced nurses who have a role as clinical specialist nurses. The specialist nurse has evolved since the 1980s and through theory development, research and practice the nurse has helped patients to positively affect their health status. These new roles as clinical nurse specialists emerged to provide particular services based on evolving scientific knowledge for particular disease based populations. With the role of specialist nurse came the improved relationships between the patient and practitioner responsible for their care. This relationship between patient and specialist nurse has been shown to improve the quality of care given to the patient and the ability to keep the patient at home as the patient will have twenty four hour telephone access for questions and queries. If necessary the specialist nurse can arrange a community visit or a walk in appointment to the nurses own clinic which saves precious time in A&E waits and unnecessary admissions. Hamric (1983) suggests the definition of the specialist nurse is someone who exercises judgment, demonstrates leadership potential, is assertive and creative to act as an advocate, be a change influencer and have effective interpersonal skills with the MDT. The specialist nurse can engage quickly in relationships with patient and family but remains objective. The specialist nurse needs to be an analytical thinker who is highly motivated and can work autonomously without being told what to do. Doody and Doody, (2012) suggest that effective nursing leadership is a vehicle through which healthcare delivery and consumer demands can be fulfilled. However, today nurses are now facing unprecedented challenges, but there are opportunities to change care and push forward with innovations. Today in health care organisations, innovators need to have an adaptive, flexible leadership manner. Bass (1985) labelled this type of adaptive leadership as transformational, under which diffusing of innovation theory in clinical practice can take place.

Transformational leadership is a process that motivates followers by appealing to higher ideas and moral values. In a paper from the University of York Center for Reviews and Dissemination, Wong and Cummings (2007) looked at a systematic review of the relationship between nursing leadership and patient outcomes and suggest that from the few studies currently available, transformational nursing leadership improves patient satisfaction with health care and reduces adverse events and complications. Transformational leaders make it safe for staff to risk and extend the boundaries of thinking, doing and care and is viewed as the most effective model

of leadership. That being said, it seems that one of the best ways of teaching health care practitioners the need for the cancer patient to have continual therapeutic interventions after the five year mark, using the Care for Life plan, is to work with the specialists nurses in colorectal and stoma care as well as other nurse cancer specialists. However, to understand and extend the boundaries of current colorectal teaching early adopters are needed. In the diffusion of innovation theory (Rogers, 2003), suggests that approximately 14% of the population, which after innovators, are first to try new ideas. Early adopters rely on their intuition and vision and have above average education level, such as specialist nurses who are often educated to Masters Level. For the acceptance of any new idea to be successful it needs to attract innovators and early adopters to enable diffusion to be taken to the early majority and late majority and then on to those who consider that the current system has worked well so why change it

From the researchers' study, all the interviewees reported various problems after the five year point which they felt that no-one took responsibility for. Some of these were physiological and some psychosocial problems that had not been addressed. Some of the research group participants felt that their specialist nurse would be able to discuss with them many of the issues that had arisen with them, yet some of the participants stated that their nurses were diffident and not competent in discussing certain issues. Some of the participants of the study clearly said that their nurses lacked time to sit with them and discuss on going issues and said that the nurses said that they had no specific training and education in colorectal and stoma issues. Specialist colorectal and stoma care nurses are key members of the multidisciplinary team and cancer nurses' perspectives are essential to inform future developments in long term survivorship care provision, not just through the first five years. Cancer centres also need to implement a model of care that continues past the five year mark and provide improved training and educational resources for nurses to enable them to deliver quality survivorship care and meet the needs of all cancer survivors. Tjandra et al (2007) in their paper on the follow up of colorectal cancer patients after curative surgery suggest that there are strong arguments for replacing follow-up with low-intensity monitoring regimes and self-management by individuals of their on-going condition through dedicated education and support programs.

A Systematic review of evidence relating to self-management and self-care programmes in cancer settings indicate that well-planned education and support, help individuals cope with their illness and increase their sense of self-efficacy. Self-

management programmes appear to work best when fully integrated into clinical care and when patient learning is supported and reinforced by health professionals. However, such programmes have yet to be introduced systematically as part of on-going support packages for cancer survivors. As many as two-thirds of all individuals who have had a cancer diagnosis use at least one healthcare service in any given year, and 40% of people 15 years post-diagnosis still receive some kind of cancer-related care and support. Doody and Doody (2012) suggest that effective nursing leadership is a vehicle through which healthcare delivery and consumer demands can be fulfilled. However, today nurses are now facing unprecedented challenges, but there are opportunities to change care and push forward with innovations. Today in health care organisations, innovators need to have an adaptive, flexible leadership manner. Bass (1985) labelled this type of adaptive leadership as transformational, under which diffusion of innovation theory in clinical practice can take place.

CHAPTER 7:

**THE WAY FORWARD: THE
DEVELOPMENT OF A
CONCEPTUAL FRAMEWORK
TO PROVIDE CARE FOR LIFE.**

The findings from this study gave rise to concerns regarding the quality of life and ongoing medical support, with a clear lack of continuity for this vulnerable group of patients. It is recognised that in cancer care, continuity of service provision is important to assess and monitor health status and physical and/or psychological changes experienced (PROMS, 2012). However, as the previous chapters have illustrated, few participants had received any comprehensive post treatment care after the five year point. They have been in effect, lost to follow-up, with some having had little post-treatment care from either their cancer or primary care providers. It was disheartening to find that despite all the NHS advice and recommendations nothing appeared to have changed for decades. When considering their care, a useful analogy is that given by Goodhart and Atkins (2013) who describe the initial diagnosis of colorectal cancer and the need for a stoma as a “boat” that has been damaged, lost its maps and provisions and the fear is that the “boat” will sink. Then into view comes the cancer care team as the “lifeboat” to rescue the patient and support them through treatment. However, using this metaphor it would seem that as the UK NHS standard of care is for a fixed 5 years follow up after cancer treatment (NHS, 1997), it is known that adjustment time varies between patients. For some, the “lifeboat” does not actually reach the shore. Thus, some of those living for decades after their original diagnosis can be said to be in a ‘boat’ that while afloat has become rudderless, leaving them helplessly drifting.

It has to be accepted that there are so called Survivorship Care Plans (SCPs) designed to support patients, but the problem is that these have been designed to cover the 5 years during which the patient has contact with the NHS. In consequence, they do cover the time from diagnosis up to and including the five year discharge point, but at the point in which the patient is expected to become totally self-caring, the lifeline they have learned to rely on is removed. Yet, for this group, the results of cancer care and treatment are increasingly being cited as leading to chronic conditions (Sisler, 2012). This in itself is contradictory for most chronic conditions and illnesses, the NHS care provision recognises the need for long term follow up including clinical reviews, while this group, with acknowledged major physical, social and psychological issues, are being left to fend for themselves (AHRQ 2007, Foster 2009, Richards et al 2011, PROMS 2012).

Disappointingly, there was a second issue they should have received a SCP made up of two elements, a written summary of their cancer and its treatment, together a set of instructions regarding whom to see for follow up. This fits with Chrischilles et al

(2015) research which found that only one in four individuals reported receiving a SCP with both elements. Also that while 25% were certain they knew which doctor who was caring for them, this left 75% who were not clear about their ongoing care. Then too, most of the older individuals reported not receiving a SCP and there was a lack of adequate support for transition from “being a patient to a person.” Interviewees in this study revealed that in addition to not receiving a SCP at any point in their care with most had not heard of them:

....”I was in for six weeks then sent home....I was given some bags and told to go to the GP to get more....I had no idea how to manage or what would happen next....I didn’t see anyone after I went home....I had a visit a year to the hospital for 3 years and that was that....no one talked to me....I was left high and dry to get on with it” (Helplessness and Hopelessness)

Also as Chrischillies et al (2015) the participants in this current study reported that barriers impacting on achieving a good quality of life included: a fragmented and poorly coordinated cancer care system and health care professionals with a lack of knowledge and experience. Most had no idea whom to contact for follow up care and had not been given mechanisms to initiate communication with specialist care providers. They had had little access to a lack of access to psychological support and that included help with key personal issues such as sexuality and intimacy:

....”as soon as I arrived home my wife said she had sorted the bedrooms....I asked what did she mean....she said I would be restless at night what with the bag and keep wanting to pee... I said it would be ok but she insisted as I would need my rest....I quickly worked it out....I was her excuse to leave the marital bed and she made it clear not to expect her to return’ (Fatalism).

It does have to be noted a few of the interviewees had nothing but praise for the way they had been treated “many years ago”, but that for most there had been no long term successful therapeutic relationships with healthcare professionals. None described what Kitson et al (2013) suggested are core areas identifiable for successful relationships between patients and healthcare professionals. These include patient participation and involvement in decision making, the healthcare professional having appropriate knowledge and expertise, and the context within which care is delivered being considered and factored in. All these issues are inherent within patient-centred care and are described within health policy, medical, and nursing literature. Kitson et al (2013) do go on to point out that as different professional groups tend to focus on different areas, a lack of an all-encompassing approach negatively affects the patient and professional relationships so limiting the implementation of individualised care.

Participants in this study also said that there had been little engagement either for them or for their families in the processes involved in the planning and delivery of their own care. They had been expected to “accept and follow” the doctors decisions. This medical model left little room for negotiation or discussion of the consequences of the treatments proposed an approach found still to be in vogue by (Bucknall et al, 2016) this despite all recommendations that cancer care should be personalised with all decisions based on informed choices. Transitions between acute and community settings are supposed to be planned in partnership with patients and their families (NICE 2015). However, the participants interviewed for this study seemed unaware of this describing their experiences of poor communication which included finding out that their primary care health care professional had no record of them. At the five year discharge point it is essential that the patient knows what is happening, but as the following quote illustrates participants in this study literally had no idea of what was happening:

....there was no support and it was as if everyone had magically disappeared. My good GP had retired and my new one admits to my face that he does not have the first idea of how to help me with this under carriage pain. He suggested I go to the hospital but as I am too far from the second hospital, that is not a solution. I have arthritis and “water work” problems and I have no idea what will happen if I cannot care for myself as I cannot ask my wife. It’s beginning to get me down but who do I talk to about it”. (Helplessness & Hopelessness).

Then too, when thinking about how to help this group with care for life, it was a concern that they were still struggling with practical problems arising regarding stoma care:

....”I can never get any help when I have problems with my stoma....I’ve been discharged for 10 years now but at times my skin breaks out.....I make a doctor’s appointment....he doesn’t know and sends me in to the practice nurse....she doesn’t know....she says contact the hospital.....I ask for a home visit from the stoma care department as I can’t easily get to the hospital....they don’t do home visits now.....what do I do”.(Helplessness and Hopelessness)

These two quotes clearly illustrate the need for a Care for Life Plan particularly as over the course of data collection such experiences were seen as “normal”. It is accepted that this phenomenological study did not have large numbers of participants, but the frequency with which similar comments were given and the almost unanimous acceptance that lack of support and expertise are to be expected once initial treatment is completed demonstrates the need for the problems felt by this group. It is important that the new proposed Care for Life Plan is clearly differentiated from current proposals and short term survivorship care plans. Indeed,

the need for this influenced the choice of terms used in the development and descriptions for the new model and led to rejection of the terms survivors.

The starting point.

To develop a conceptual framework that is efficient and effective consideration needed to be given to how it could be slotted into existing services, identifying and implementing the constituent elements needed to deliver care for life. The plan needs to be accessible, acceptable and appropriate for all colorectal cancer patients who have reached the five year discharge point. It needs to be incremental, as the three iterations of analysis had led to the identification of the five coping styles presented, all of which had different psychosocial implications. Therefore, the decision was made to start by reviewing psychological and psychosocial models of care available as these could then be linked to the five coping styles to address the challenges identified by the participants.

Searching the literature in this field, Beck's (1967/2008) Cognitive Theory of Psychopathology, although now almost 50 years old, appeared to be a better fit with the participants' lived experience and descriptors/feelings than any other model or approach considered. Beck's Cognitive Model of Depression (1967/2008) conjectures that dysfunctional beliefs are created by earlier experiences and that activation of these beliefs creates negative effects and feelings about the individual (Allen, 2002). Beck (1967/2008) illustrates how these early experiences can lead to the formation of dysfunctional beliefs which may lead to negative self-views of aspects such as body image. A key part of Beck's (1967/2008) theory is that beliefs fall into specific fields, which separates them from other known disorders such as panic and anxiety. He considers these indicate polar reasoning, selective abstraction and overgeneralisation. For the purposes of this study, the early experiences have been classified as the diagnosis and treatment phase for colo-rectal cancer. Using this, then the three specific fields can be considered and linked to the findings of the study illustrated with quotes from participants within each of the coping styles.

Polar reasoning is extreme, and sees a 'lapse' from perfection is considered to be a failure, in this study it is illustrated as the body having had to be surgically altered as it 'failed' in its normal functions, failure leaving them with a stoma, giving them an unchosen, and unwanted permanently altered body image. Abstraction suggests that

any successes are ignored and the individual is left with sadness. In this study, this can be seen in the description:

....'yes I well know I am cured....they said so and don't want to see me again....but I feel like I was assaulted....I've lost my identity....I don't recognise this body anymore....I feel vulnerable.(Avoidance).

For these participants, the successful outcome of their treatment had not been celebrated, instead they dwell on the negative outcomes and reminders of the need for surgery and treatment. Thus, no matter what they have managed to do since their treatment, the permanent effects of cancer and cancer treatment are seen to have limited what they could have done. They reflect on what was, on what might have been, rather than on moving forward with the success of the treatment as a positive resolution.

...."when people know I have had cancer they say how lucky I am as I am better....better?... yes I am here but not with a normal body....cut up, poisoned and incontinent....I hate the stoma, always have ,always will....you call that lucky?" (Fatalism).

Overgeneralisation refers to the self-belief that the individual will fail in a specific area therefore, and having done so will continue to fail in all other aspects of their life. For this group, it refers to their belief that having had their body fail in its normal functioning and needing to be surgically altered by someone else in order to survive, they have lost their ability to succeed on their own. The stoma is a visible reminder of their loss, and because they always see and feel it, this keeps the memory of their failure current, which in turn affects how they see and act:

...."every day....day after day year after year I change the bag....it is there to constantly remind me of the cancer....I can't get away from it...I thought life would get back to normal once it was all over....it hasn't....it doesn't regardless of what people say'. (Anxious Pre-occupation)

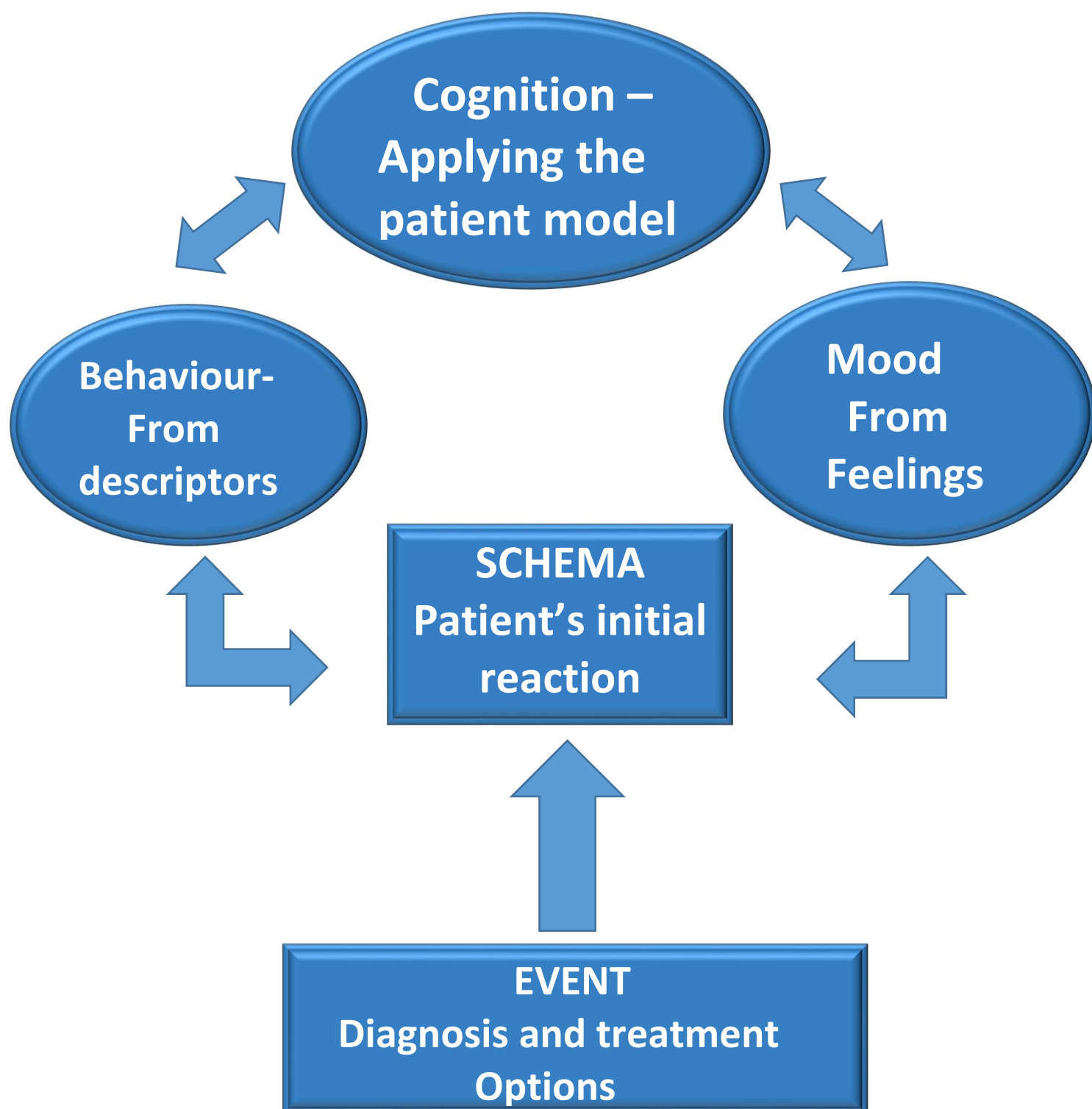
Using Beck's (1967/2008) theory and main argument that an individual has a poor self-image and body image, (as with these participants), then their negativity of self-perception could cause various degrees of depression. Beck (1967/2008) argued that this has social implications when faced with groups or meeting others (even family members). Building from this self dis-satisfaction increasingly impacts on willingness to engage in any social interactions leading to rejection of opportunities and ultimately social isolation. He also argued that although not necessarily exhibiting overt symptoms of depression when another or new negative effect

occurs, vulnerable individuals may show an increase in depressed mood which in turn impacts on both verbal and nonverbal interactions.

Sato and McCann (2000) tested whether Beck's (1967/2008) theory which had led to a development of a sociotrophy - autonomy scale using solitude, independence and achievement, did in practice indicate the presence of depression. They found two areas, independence and achievement (evidence of autonomy) did not relate with depression but that sociotrophy which did included solitude. It was decided therefore that the next step was to use Beck's (1967/2008) theory to develop a schema that illustrated how the theory could be applied to this patient group.

Although it has to be noted that in this current study, some reporting their isolation and rejection of social activities, when asked, did not see themselves as depressed. Nevertheless, it has to be accepted that some may have a degree of undiagnosed depression, as they have little contact with health professionals, reporting only seeking medical advice when a physical issue needed treatment.

Figure 30. Schema to show the Effect of Cancer Diagnosis on the Patient.



(Beck, 2008, adapted by Black 2016).

Beck's (1967/2008) model illustrates how early experiences (diagnosis and treatment) can lead to the formation of dysfunctional beliefs which may lead to negative self-views such as body image (mutilated due to colostomy). Although

thoughts of loss and failure are predictors of depression the majority of the interviewees did not consider that they were depressed even though they disliked the colostomy and had fears about cancer recurrence.

The cognitive triad (Figure 31, page 197), developed by Beck (1967/2008) and illustrated by McLeod (2015) suggests that the negative thoughts about self, the world and the future, thoughts that the interviewees often describe, are predictors of depression. Although Beck (1967/2008) suggests that feelings of depression are related to failure (the weakness of having colorectal cancer) and loss (removal of bowel and colostomy) this was not evident in the interviewee's stories.

Therefore, while this was a good starting point it did not address all the issues and further study into the elements to support this care for life plan were continued. The often complex daily routines needed to change the appliance served as a permanent reminder of their difference from their peers (as the coping styles in chapter 6 indicated), for those who could be classed as vulnerable individuals this then led to an increase in depressed mood. This correlates with much of the quality of life (QoL) literature which shows that patients with colorectal cancer and a stoma who accepted and could cope with their stoma, did not have a poorer QoL (Grumann 2001, Harisi 2004 Allal 2005, Yoo 2005, Arndt 2006, Campos-Lobato 2011, Varpe 2011,). However, for those who struggled with the concept of, and practical implications of a stoma, social isolation and reduced QoL were evident (Jess 2002, Pucciarelli 2008, Yau 2009).

Asked if they had had professional help to cope with the problems they encountered and that impacted adversely on their lives, the answers were on the whole, not positive. As most of the participants had had surgery before many NHS trusts had CNSs in post, it was perhaps not surprising to find that some did not mention these nurses when discussing their own past care. Still, the overall lack of professional input was a source for concern. Disappointingly, there were contrasting views from those who had encountered CNSs, some having found them very helpful with others reporting the converse:

....'there was little support from the stoma nurse specialistshe said she would see me after the operation as she does not see people before operation... there were so many things I wanted to know before the operation". (Anxious Pre-occupation)

...."I had nothing but the best support both pre and post op....the stoma nurse saw me on the day I arrived on the ward and after the consultant round to sit and talk with

me about what had been said....she left pamphlets and told me to write down any questions I might have and she would do her best to answer them....she saw me 3 times a week until my discharge and that she was sure I could self-care". (Fighting Spirit).

However, here it has to be noted that the CNS needed to be contacted in a timely manner if s/he was to enable care plans to be re-assessed and pro-actively transferred to the appropriate community contact. The lack of this not only occurred at ward level within their initial discharge, but also at an outpatient level when the patient was given their final discharge. This is not acceptable, healthcare professionals have the responsibility of fully understanding referral processes and knowing the time required to arrange for an individual patient's needs to be addressed so promoting a safe and for the patient, a good transition to the community.

The Care for Life Plan has to be based on good, coordination between care providers from different disciplines, it is essential for the improvement of the quality of care offered, in particularly for patients with the type of chronic disease discussed here. The way in which GP's and hospital specialists interact has important implications for any healthcare system in which the GP will be playing the role of gatekeeper to on-going care. However, the time after the patient has reached the five year mark seems to have become lost, with patients left to only seek help in what they see and an urgent or emergency situation. Patient experiences and preferences have proven to be increasingly important in discussing healthcare policy, but this group appear to have had no voice. Perhaps because they, as the study found, they have low expectations so do not seek out help until they can no longer cope alone. Berendsen et al's (2009) study focused on the transition of care at the primary – secondary interface, with reference to the impact of the patient's ability to make choices about their secondary care. They explored experiences and preferences of patients regarding transition between primary and secondary care, what the patient perceived to be necessary regarding their illness/treatment and searched for ways that the information supplied could make it easier for follow up care. Their key finding was that it was important to receive a clear diagnosis in language that they could understand and to be informed of what they could expect with their treatment, was evident in this study:

...."I was concerned that I may not be monitored close enough when I was discharged from final care....I hoped to have aftercare....a good contact with someone....I don't know who as I did not know who was out there....but someone I

could contact if I was worried....would my GP understand". (Anxious Pre-occupation).

Of considerable concern was that some participants indicated that they had received inadequate information about their treatment much as Berendsen's (2009) study had found almost a decade ago. However, it has to be remembered that the duty of candour did not exist within the NHS when the researcher's participants had their diagnosis and treatment. Again as with Berendsen (2009) a considerable number of patients in this study reported being dissatisfied with the length of time it took for the GP to be given information from the hospital on final discharge, in some instances it had taken several months and in others it had not been sent at all. In addition, interviewees reported that they felt insecure when suddenly discharged from the specialist's care with no clear referral route back to their GP. Interestingly, discussing communication and information giving, yet again responses matched with Berendsen's (2009) study with many participants reporting patients preferred receiving information from nurses during their hospital stay or at the outpatient clinic. Reasons for this included clarity of the instructions, more extensive information, easy access to information and the thoroughness of nurses. Unfortunately, even today, there are in some organisations, mandates such that nurses must only follow physicians directives, an approach based on institutionally recognised power and hierarchical structures (May, 1993). In these organisations there can be a serious lack of information addressing the problems the patient may face after discharge, especially in the time that elapses before the specialist has reported back to the GP (Rubin 1986, Black 1994a, 1994b, 2009, 2013, 2015).

It is accepted that involvement of the patient and family in communication during transition of care may help to improve the transfer of clinical information and prevent adverse events such as psycho – social and post chemo-radiation complications following discharge (Rutten et al 2005, Rowland et al 2006, Khan et al 2011). The literature also argues that patients who actively participate in healthcare decision-making have been found to have better health outcomes and more positive experiences of care, but it seemed from this study that much work still needs to be done in this area, and that the planned care for life plan needs to include a clearer strategy for inter-professional communication (Rachman et al 2002, Arnetz et al 2004, 2010, Coleman et al 2004, 2006, Weingart et al 2011).

This transition of care described by the Picker Institute (2013) which would be appropriate for this group and would offer patient centred care, has four principles:

Table 23. Transition of Care

1. Coordination and integration of care: information, communication and education
2. Physical comfort: emotional support and alleviation of fear and anxiety
3. Involvement of family and friends: practical help and support
4. Transition and continuity and access to care: respect for patients' values, preferences and expressed needs

(Picker Institute, 2013).

Accepting that patient engagement involves participation in decision-making and other aspects of their care (Wellard *et al* 2003, Longtin *et al* 2010) then the conceptual framework has to include self-care management strategies (Richards *et al*, 2011) through which patients can monitor their own progress and needs. Sahlsten *et al* (2008) describe four attributes of patient participation in a nursing context that seemed appropriate for this Care for Life Plan and these attributes were firstly, an established relationship, secondly, the nurse surrendering some power and control. Thirdly, shared information and knowledge and fourthly active mutual engagement in intellectual and / or physical activities. However, patient willingness to participate, and freely share and discuss their condition and differences in expectations were identified as barriers to the therapeutic relationship therefore affecting the transition of care (Thorpe *et al* 2014, Thorpe 2017).

Therefore, this plan was designed to include strategies that explain why participation in the development of this plan is important and it encourages the sharing of information. The proposed plan also has to address a finding by Arora *et al* (2011) that was also evident in this study that the clinicians did not understand how the treatment had affected the individual's quality of life. It was evident from the descriptions given by the interviewees that something more than the short term SCP is needed for individuals to navigate their way into total self-care after the first five years and to enable them to maximise the rest of their lives. The participants also made it clear that they still saw themselves as living with cancer and for this it seems that the Care for Life Plan needs to include strategies to help the individual accept this during their continuing longevity:

...."you can't cure cancer can you....even though it's 10 years....so there is a chance it might rear its head again...how would I know....I don't see any one and the GP.....well when I insist on seeing him....he just tells me the pain is adhesions....just how does he know....he doesn't examine me, he barely acknowledges me....tells me to go home and take Panadol." (Anxious pre-occupation)

Other interviewees who reported being comfortable with their treatment after initial diagnosis and the support from their cancer care team once they were finally discharged found life difficult with no means of contact to the team they had learned to trust and rely on. As time passed they missed the ease of access and support they had been accustomed to:

..." I just want someone to ask...when I have a pain I have not had before...is it the cancer again...you know what...I would like a yearly check...MOT I call it...it would put my mind at rest....also know I was going to see someone...I've seen no one for 14 years". (Anxious Pre-occupation)

Most agreed with this participant wanting contact of some kind with a health care professional 'just to ask'. Even though they had all been assured they were cancer free they wanted and needed on-going reassurance that whatever they were feeling was not a return of the cancer. For some this was because they had had few symptoms before diagnosis, so remained unclear regarding what was a 'warning and what was just part of getting older' and this fits with the PROMS (2012) report on the Quality of Life of Cancer Survivors in England where patients openly stated that they required long term caring and high quality care. Linked to this, there were several recommendations about continuing care, appropriate for the Care for Life Plan. All patients need to be fully informed about potential side effects of their treatment, whether it will be likely to occur immediately after treatment or potentially later in the cancer trajectory. They should have information on how to access post treatment support services. When the patients reach the point where they no longer have access to the healthcare professional team, they need to be aware that there may still be the possibility that psychological issues may occur and that there are services that they can access for help. Also patients need to be made aware that there may be social and financial issues that can have a continuing impact during this post treatment period. For example, even though they have finished primary treatment and have been given the all clear at the five year mark, some may not be able to return to employment and will need to know how to access social services and what their rights are concerning work and inability to return to work after cancer treatment. Although the aim is for personalised after care which encourage patients to self-

manage, but this approach needs to be accompanied by easy access to a team of healthcare professionals from whom psycho–social support can be provided.

It was evident from listening to the interviewees and reading the field notes that there were commonalities in each of their stories such as those given above, that matched the PROMS (2012) free text report. However, it was also clear that there appears to have been no significant change in post-acute care services and support for these long term surviving cancer patients. The descriptions of the impact of treatment upon co-morbidities and the physical, psychological and social problems that they had encountered were moving, with repeatedly reports that they had been given no preparation or knowledge regarding the impact and long term outcome of their cancer treatment. It is accepted that a cancer diagnosis is a life changing and life-threatening even, but for this group the added news that a permanent colostomy was needed had not only come out of the blue but had been a second major shock. Most reported that they had no understanding at all of what a colostomy was, what it looked like or how it would affect their life. For many there had been tears at the diagnostic consultation as they had been waiting but hoping that it would not be cancer, yet here had been the moment of truth. For this group many years had passed since their original operation and treatment, so not surprisingly, some felt their memory had disguised the pain and terror they had gone through so long ago.

Others still remembered their feelings, and the shock and dismay that went with 'being handed down a death sentence' as at that time they had believed that as there was no cure for cancer they would die a painful death much as Tritter and Calnan's, (2002) study found. Several of the interviewees did accept that the teams that can be found in the NHS today were not in existence at the time of their surgery and treatment, accepting this as their reason for having had no support. Indeed, it has to be noted that it was not until 1997 when the NHS Executive produced the far reaching document *Improving Outcomes in Colorectal Cancer* (NHS,1997) that questions were posed regarding what the colorectal cancer patient might need and want, whether they would benefit from having more information, whether stoma patients did indeed have special needs and what the most beneficial way of giving them information would be. Despite this, in reality interviewees gave repeated examples of problems in communication and information which fitted with the report which while citing the problems gave no indication or strategy on how to answer the issues the reports raised (National Cancer Alliance, 1996).

In the researcher's current study it was evident that while the themes that emerged covered the key issues, the interviewees had not told chronological stories they moved backwards and forwards through their cancer journey revealing that each had required differing times and different strategies to achieve transition from 'patient' to 'person'. It was discouraging to find that despite all that has been written about the psychological, psycho-social and physiological problems that an individual with colorectal cancer and a colostomy may encounter none of this had been translated into practice. Thus, despite the fact that over a decade ago Dow (2003) suggested that substantive research into the experience of 'surviving cancer' was long overdue, a view in existence in nursing literature since the 1970s. While, almost 30 years ago Carter (1989) stated that "these lives need to be valued and specifically catered for" and that health care professionals preparing these individuals for longevity after the cessation of therapeutic intervention needed to have insight into what post cancer longevity involves and in consequence what each individual's needs. Not one of the participants in this study gave an example of this type of support, but most described wanting it. This was yet another unchanged patient perspective for a decade, and matched Armes et al (2009) findings, although they reported one third of participants in their study at baseline, reported five or more moderate to severe unmet needs while in this study it was the majority of those interviewed who cited unmet needs.

The 30 descriptors/feelings that emerged in this study revealed no examples of mutually constructed patient/nurse relationships that could transition across to the primary care setting. On the contrary, the majority of the interviewees reported that in addition to long-term lack of support, they had received little to no patient/nurse relationship during their five years prior final discharge. It was evident from the interviews and field notes that descriptors / feelings included beliefs of the individual that were still clearly associated with the original diagnosis and subsequent treatment. Most of the interviewees also revealed that they had had, and indeed, still have negative beliefs about themselves, what had happened to them and how it had impacted on their families.

An additional search for useful elements for the Care for Life Plan had identified other elements needed and the diagram for the conceptual framework was therefore reviewed and reconsidered. The addition of the use of the Cognitive Triad (Beck 1967) seemed appropriate, as this clearly demonstrates the results of a negative self-view and linked clearly with the experiences articulated by some of the

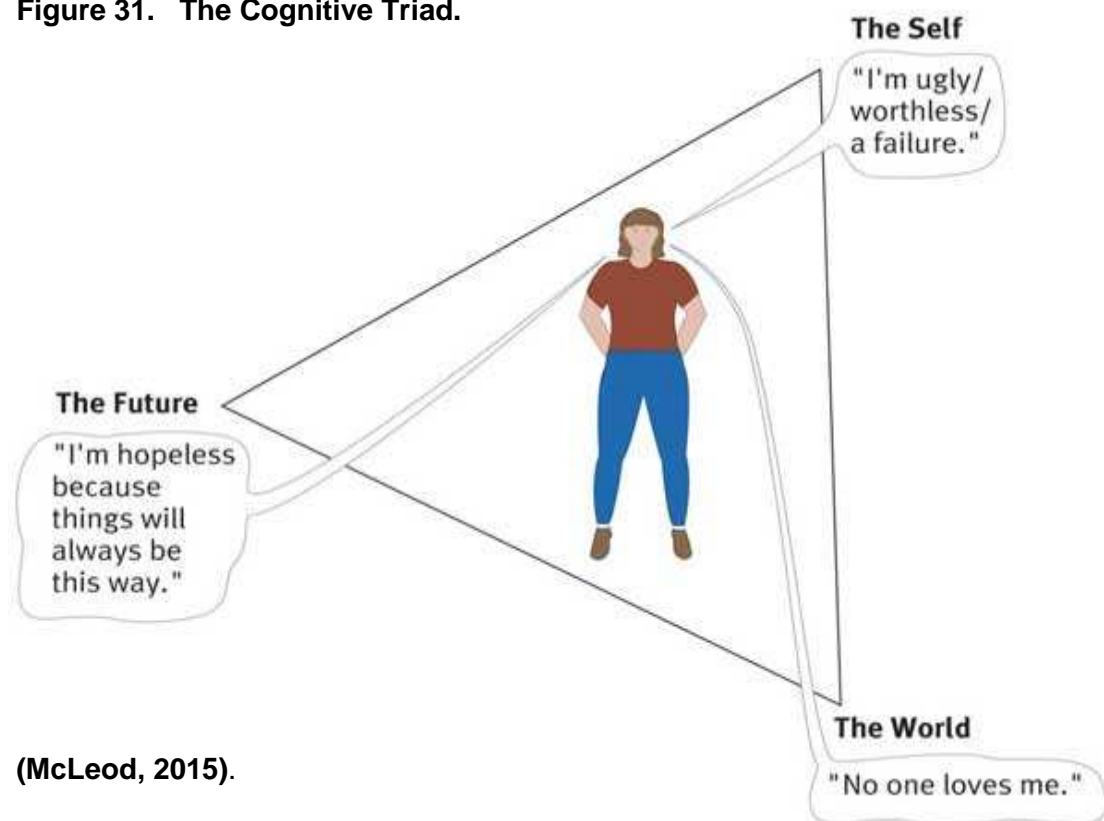
participant's, particularly when they thought about the future in relation to their diagnosis. :

...."I lie awake at night wondering if the cancer will come back again...if it occurs the third time that will be the end...I can't go through that again I'm too old.....will I die tonight or will I have another day with all this worry" (Fatalism)

In the cognitive triad The Future reflects the interviewee's descriptor /feeling of Hopelessness and Helplessness. The Self reflected the descriptor/ feeling of Anxious Pre-occupation and The World reflected the descriptor/feeling of Fatalism.

The cognitive triad was studied and taken further by McLeod (2015), and it is this late version that has been used in this study.

Figure 31. The Cognitive Triad.



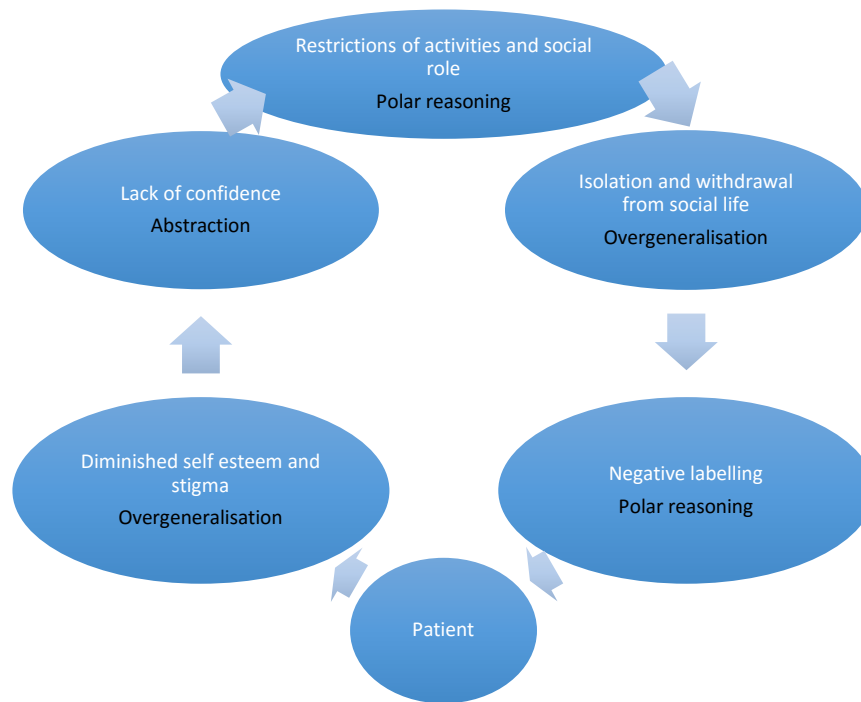
However, there were still some areas not needing resolution to develop the Care for Life Plan. McIntosh and Fischer (2000) reviewed whether there were actually three distinct negative thoughts as seen in figure 31, could actually be found, but found in reality, the research showed there was no clear separation within the, negative thoughts, they were singular, one dimensional and not discrete. Notwithstanding this, the triad does demonstrate the nature of the negative descriptions given by some participants in this study. It therefore seemed appropriate to see whether the redesign of the Negative Triad could be used and adapted to illustrate the views of

participants from the more negative coping styles that emerged from within this study. It seemed appropriate to therefore to consider whether the triad could be linked to the Negative Cycle (McLeod 2015) which uses the negative feedback between self-esteem and perceived stigmatisation as described in Beck's (1967) original work. In practical terms, this suggests that the negative feedback between self-esteem and the perceived stigmatisation by the stoma patient, in turn affects the future, forming a repetitive circle that continues to impact on life. This Negative Circle developed as an adaptation from the cognitive triad of Beck (1967) and negative triad (McLeod 2015) could offer a useful tool for the healthcare professional to use to examine how the patient is faring at different post-operative stages.

The Negative Circle for colo-rectal patients after discharge from treatment.

Becoming a cancer patient appears to trigger off a process in individuals in which the patient is constantly interpreting their symptoms, the disease and the information they are being given. Although Beck (1967, 2008) and McLeod (2015) provided an appropriate starting point, and did offer explanations for some of the findings it did not fully indicate how individuals formulate and reformulate information. Yet this is a crucial issue for these patients that is neither static nor rational, as they transition from contact with specialist health care to total self-care. It continually changes as more knowledge is gained and life experiences are absorbed and integrated into their perceived world. The negative circle was therefore modified to illustrate how the feedback and information processing occurs with this group, with the negative feedback between self-esteem and perceived stigmatisation by the stoma patient addressing the self, the world, and the future as described in Beck's negative cognitive triad.

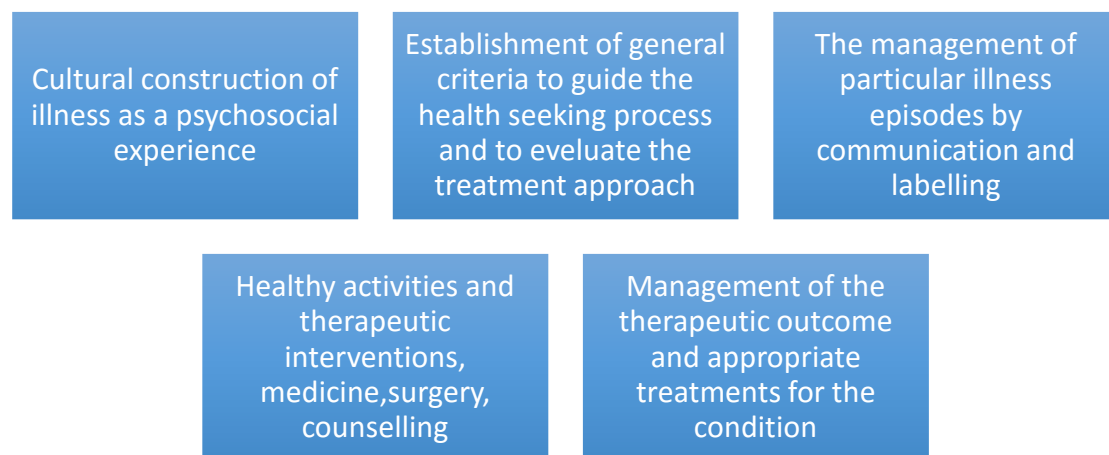
Figure 32. The Negative Circle.



(Adaptation by Black, 2017).

This circle can only be used effectively if health care professionals recognise and accept that both they and their patients have preconceived ideas about patterns of health and illness based on their own culturalisation which determines how they interpret information, how they respond and for patients ultimately, how they are treated. Over three decades ago, Kleinman (1980) when trying to describe patterns of behaviour used Explanatory Models (EMs) to suggest that “disease affects single individuals, even when it attacks a population; but illness most often affects others as well (family, social network, even at times an entire community).” This statement true then, is still particularly apt for colorectal cancer patients with stomas. Kleinman (1980) distinguished five core points used to describe these, the elements involved in episodes of sickness and treatment.

Figure 33. Core points forming Explanatory Models.

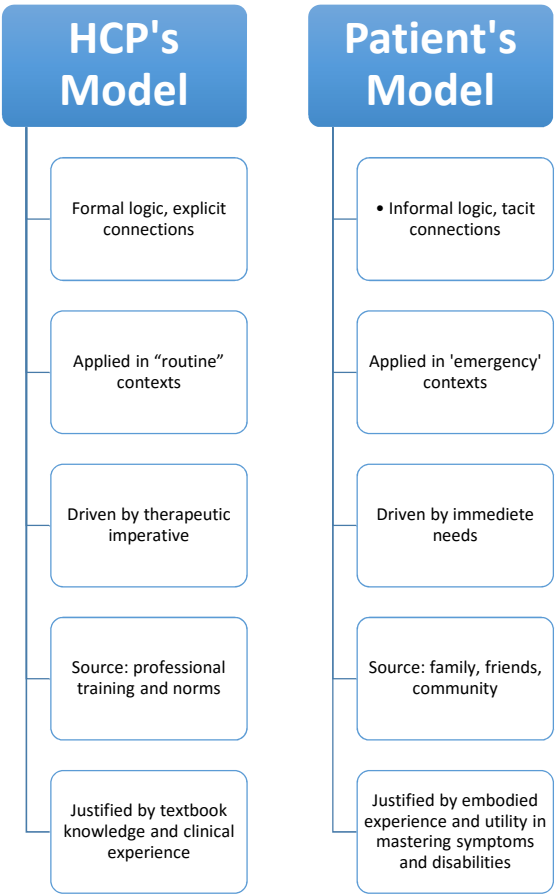


For this patient group the cultural construction of illness is very personal and the social adaptive response formed from the information the patient has been given will be informed by the social and cultural context in which they live. The malfunctioning of the body and the psychological process involved, involve cognition, valuation of symptoms and without support can lead to difficulties in and sometimes, limitation or breakdown of family and social interactions. For this group, the outcomes of treatment can lead to the shaping of the disease into behaviour patterns, partly because of the changed physical functions they have to adapt to and the experience of the disease process created by personal, social and cultural reactions to their specific disease (Kleinman 1980, Black 1989, 1992, Holden & Littlewood 1991, Helman 2007, Capilla-Diaz et al 2016).

In this study, the EMs described by the interviewees were partly conscious and partly outside their awareness. These individual EMs were based on a cognitive (reasoning) system that directed the individual's reasoning. Their discussions revealed implied knowledge that previously they have not openly shared, instead they have remained implicit, and something they had not been able to articulate. Although EMs are a way of constructing reality and imposing meaning on chaos, their use may be hazardous if they are accepted as 'reality' rather than a process that helps organise information. For instance, a patient with a colorectal cancer diagnosis requiring a permanent colostomy, will try to make their own schema from what they know of world views that will in part be idiosyncratic based on life experiences influenced by their knowledge of current health care. Inevitably, for

each patient the EMs will change as s/he acquires more knowledge and life experiences from their own treatment, popular health ideology and medical knowledge. Acceptance of this approach lead to the development of two explanatory models, one for the professional and one for the patient (Kleinman 1980, Black 1992, Helman 2007, Capilla-Diaz et al, 2016).

Figure 34. The Expert and Patient models of understanding the cancer diagnosis.



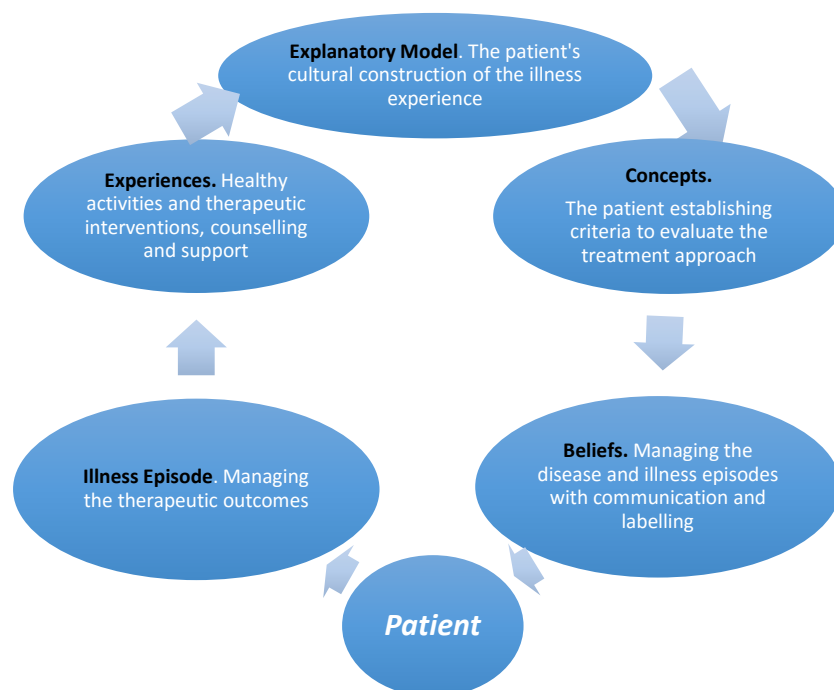
(Adaptation of Explanatory Models by Black, 2017).

Patient and family EMs address what they consider to be the most salient concerns and disclosures of a given health problem with both the patient and family as they try to rationalise possible treatment goals. These EMs for specific illness episodes are developed to cope with the specific health problem. Individual patients may choose to withhold their “lay” EMs as they may worry or fear that their EMs will be criticised or seen as inappropriate from the professional medical point of view. It is has to be noted that patient EMs will alter as they move from surgery, through other treatments to discharge, and will differ in clinical and home settings as there are different issues

and constraints for these patients in the two settings. For long term appropriate support there is value for the professional to elicit the patient's EM in their own home setting, and for researchers to seek for environments out in the acute sector, such as their home, or a neutral setting for focus groups or individual interview. Then too, it has to be remembered that the patient and family EMs do not have a single reference point but represent semantic networks that loosely link the variety of concepts and life experiences they have lived through. The individual uses these drawing upon their beliefs regarding causality and the significance of their illness together with the specific treatment options, which may be available to them.

Up to this point, much of the work used has focused on negative influences, but while this is appropriate for some patients, as chapter 6 revealed, there were more positive outcomes and therefore consideration had to be given to this group and to explanations that would show how they used and processed information to find ways to move forwards that did not adversely affect their quality of life. Therefore the explanatory models were utilised to construct a second, more positive circle.

Figure 35. The Positive Circle using core points from Explanatory Models.



(Black, 2017).

In listening to and categorising the descriptors/ feelings given by the participants and in noting the way in which they expressed their feelings in this study, the second analysis and epoché had enabled identification and patterns of the responses that linked to the five coping styles. Central forming the conceptual framework are outcomes reported by the participants including, but not exclusively, physical and psychological outcomes, confidence levels in self-management, existential worries, social connectivity and the lack of “someone to talk to for reassurance”.

The 30 descriptors/ feelings that led to the emergence of the five coping styles were Anxious Pre-occupation, Helplessness and Hopelessness, Avoidance, Fatalism and Fighting Spirit. These recognised but accepted differing responses to the emotional impact of being given a colorectal cancer diagnosis and that how the individual responded to and coped with, creates feelings of uncertainty, planning for the future and the possibility of becoming a burden for the family, varied across the five coping styles. Those participants who had support through their cancer trajectory perceived that their ongoing QoL was influenced by the positivity with which they had been supported. However, for many, the impact of the cancer and its treatment, side effects and difficulty in self-management of the colostomy, by being uninformed, impacted upon their strategies to cope which showed in the form of Anxious Pre-occupation, Avoidance and Helplessness and Hopelessness.

For a few, the negative impact of a cancer diagnosis caused them to ask existential questions that were unable to be answered, so causing them to fall into the group of the participants who said that there was “nothing left for them” (Fatalism). By examining the descriptors/feelings after the second epoché and analysis it became possible to identify the factors that would help to mitigate and make up the conceptual framework such as the negative and positive circles, the recovery package, subduing the effect of stigma, cultural beliefs and experiences and the five coping styles. However, the most important mitigating factor comes from the professionally led involvement of the CNS. This direct care involves being present at the Event (diagnosis), Involvement (patient choice), Partnership (patient and family) and Education (other HCPs, patient and family). Work from the free text comments of the PROMS (2012) study similarly suggested that patients need quality aftercare, named key worker (CNS), help in developing strategies and ongoing contact with a key worker to avoid the lacuna at the end of treatment. As far back as 2012 the PROMS (2012) study was stating that there is an urgent need to place greater emphasis by cancer services to supporting individuals at the end point of their

treatment to enable them to have a life after cancer. They suggested that individuals are ill prepared for the physical consequences of cancer surgery and treatments and supporting these individuals after the five year end point is paramount. It is disheartening that 6 years later we appear to be no further forward despite all the research that has been forthcoming. Therefore, the proposed Conceptual Framework and Care for Life Plan that follows aims to put in place all the areas of concern for the participants in this study, although possibly being too late for these participants, but nascent for future individuals.

The Conceptual Framework.

Developing a conceptual framework and treatment plan to support the colorectal cancer patient with a permanent stoma there is the need to re- examine the relationship between the healthcare professional and patient. Today this relationship falls mostly with the Clinical Nurse Specialist (CNS) who becomes the lynch pin for the patient and their family:

....” I can only praise the nurse led cancer/stoma team....always a positive attitude even when I was at the bottom of the void I felt I fallen into....now knowing I can still directly call them [10 years post-surgery] has proved invaluable to me and the family” (Fighting Spirit).

An effective relationship between the patient and CNS has been shown to improve the QoL of the stoma patient and the CNS (Bekkers 1996, Montreux Study 2003, Nichols & Reimer 2008, 2011). In this study apart from the few examples such as the one cited above, the lack of the CNS for the majority of the participants showed in their outcomes and the initial descriptors/feelings. Today, as the role of the CNS is at the centre of the cancer trajectory it is essential that they accept their role in providing support for the patient and their family as the patient transitions from ‘patient to person’, not just when they are receiving active treatment or recovering. A diagrammatic representation of how the CNS role should work is shown below:

Figure 36. How the CNS Role Works.

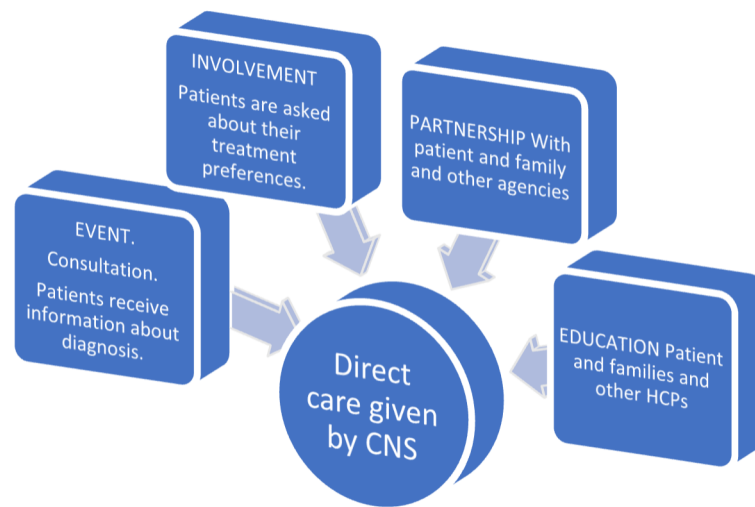


Figure to show extent of involvement of the CNS towards the patient and other HCPs. (Black, 2017).

However, it became clear, on re- reviewing Beck's Cognitive Theory of Psychopathology (1967), Kleinman's (1980) EMs, Black's (2017) Negative and Positive Circles and the initial descriptors /feelings of the researchers study group, that none of these offered a full framework, but that elements from each could be combined to offer a framework that would become conducive to use. Taking elements from each it could be shown that a clear model could be made to help the healthcare professional understand and support the patient through the cancer trajectory to beyond the five year mark.

As a medical anthropologist, I was drawn to Kleinman's (1980) explanatory models and Holden & Littlewood's (1991) anthropology of nursing work which demonstrates a rich and interesting field. In their work, Holden & Littlewood (1991) use the example of excretion as the schema that classifies people as either being in or out of 'control' of themselves as excreta is part and not part of the individual, passing from the internal to the external via the margins of the body. Excretion in the modern world is rigidly controlled through laws associated with "civilised" disposal of excreta and the private act of excretion. Therefore a diagnosis of colorectal cancer that leads to a permanent colostomy is a personal violation that upsets the individual's public, personal and cultural categories and these categories are not easily revised as has been shown in the researcher's study.

Nurses are considered to be mediators of pollution and therefore are allowed access to the private physical body and all its functioning (Thompson, 2013). However, it is crucial that they demonstrate acceptance and empathy by ensuring that their verbal and non-verbal communication is appropriate. Initially after surgery the patient with a colostomy will be cared for on a ward by nurses of varying status, supported by the CNS who will check the colostomy and initiate teaching of self-care, to be continued by the ward nurses. Nurses by virtue of their job, become intimately involved and identified with containment of personal pollution. Comments such as this patient made must be picked up and support given, although some time ago, this approach to care has stayed with the patient and left difficult memories:

... "After the operation I was sickened....how could this happen to me...if I don't do it so what...I'm going to pull the sheet over my head and not look at or talk to anyone....the specialist nurse came to my bedside and took the sheet from my head...she said come on you and I are going to the bathroom...pick up your towel and I will get the rest of your equipment... we went to the bathroom and she said I am going to show you how to look after yourself...I was stricken...she took off the smelling disgusting bag and wiped my skin then washed it and dried it...she put on a clean bag and gave me clean pyjamas...how could a stranger do such an intimate thing for me... dealing with my poo...I wasn't a new baby I was an adult who could not control the most basic of things and a young woman...a stranger does this for me". (Anxious Pre-occupation)

Sickness is a state where the individual has transgressed social codes and the individual with a colostomy may be rejected because of their uncontrolled bowel output and when the ward nurse changes the appliance patients will often respond more to a nurse's facial expression than to verbal communication (Bach and Grant, 2011). When an odour is particularly offensive, or if the appliance has leaked into the bed, it can be difficult to conceal feelings of shock and disgust, but such expressions of emotion will only exacerbate the sense of shame and stigma felt by the patient (Goffman 1963, Salter 1997, Black 2000, 2004, 2012, 2017) All patients undergoing stoma formation will, at some stage, feel stigmatised, making them reluctant to show their stoma to their partners, family, and friends and could isolate themselves from previous recreational and social activities (Owen, 2008; Noone, 2010). (Quinn and Earnshaw, 2011; Taft et al, 2011) suggest that stigmatisation from having a stoma correlates with poorer patient outcomes, low self-esteem, and decreased overall health. Therefore, it is imperative for the CNS to teach ward staff and other healthcare professionals to recognise the implications of stigma and provide effective interventions to lessen the effect.

Although profound distortions in body image are rare, there are many anxieties about the body and its image in relationship to its orifices, boundaries and bodily fluids. Stigmatisation by exteriorising the excretory organs, especially in later life. Can lead to an individual to have problems with re-identification of themselves or developing disapproval of self. This was first pointed out long ago as Kelly (1985:517-525) stated:

“The protruding stoma and its attachments looked awful and I suddenly realised how uncontrollable it was. I now realised ‘I would be permanently incontinent’”.

This distortion by the sudden change in body image is expressed as distortion of the total self. It gives rise to confusion and a negative change in the way the individual perceives themselves. In an individual whose previous self-esteem was high, or those who take particular pride in their appearance and how others perceive them, the body image change and presentation of self, brought about by a stoma, will be far harder to accept. Perception by the individual before diagnosis of colorectal cancer and colostomy is built into organised patterns for which the perceiver is responsible. As perceivers, elected stimuli on senses are schematically determined and this produces a schema for living. As time goes on these experiences accumulate and a system of labelling is used within the schema. However, the individual who undergoes stoma surgery will have to modify their structure of assumptions to accommodate the new experience and body image change (Salter 1997, Black 2004, Borwell 2009, Black 2017).

The individual will feel that they are ‘dirty’ due to the permanent incontinence and that the stoma will be a permanent reminder of the individual’s un-wholeness and mutilated state. Therefore the individual has to quickly form new schema framework to enable them to return to their own society and continue with their normal life. Management of phenomena which are now uncontrollable, noise, odour, smell have to be learnt and interpreted into the individual’s existing structure of assumptions (Holden & Littlewood 1991, Black 2000, Helman 2007, Borwell 2009, Black 2014, 2015). This assimilation can only take place when the new experience lends itself to assimilation into the existing structure, or when the schema of past assumptions is modified to accommodate the unfamiliar. However, in the early days after a colostomy has been formed, the individual will often ignore the cues which are discordant with the individuals previous assumptions of body function control, therefore learning new body control function may be delayed. Occasionally, negative sanctioned beliefs can be associated with the pollution belief after stoma surgery

especially if the formation of new schemata does not take place as the individual is still within the negative circle.

It has been known since 1975 when Douglas (1975) suggested that there is no justification for assuming that terror or mild anxiety is involved in the emotions and beliefs which are associated with bodily pollution. In the researchers study it is seen in the descriptors/feelings and quotes that a cancer diagnosis and stoma unleashes the existential questions of 'why me', "why this disease", 'why now', but these questions cannot be reduced to biological or material facts. To try and answer these questions the individual uses explanatory models to place the diagnosis and outcomes within the individual's own framework of understanding.

As Richards et al (2011) summarised, new models of care are needed for individuals to support extending their longevity after their primary treatment for cancer has finished and discharge at five years takes place. Certainly today, changes and supportive care after five years, are needed by these individuals and those that follow on and yet at 2017 there is still nothing substantial to support this group of people in their cancer trajectory. Summarising the literature given before (Beck 1968, Kleinman 1981, Holden & Littlewood 1991, Bekkers 1996, Montreux study 2003, Nichols & Reimer 2008, Richards 2011, Black 2017), it would seem that the following actions are needed:

Table 24. The Shift in Care needed to Support Patients through their Cancer Trajectory.

A shift in the approach to care and support for people affected by cancer to a greater focus on recovery and health and wellbeing after cancer treatment.
A shift towards holistic assessment and personalised care planning. Follow up based on individual risks, needs and preferences.
A shift towards supporting self-management to empower the individual to take on responsibility for their condition.
A shift from single model clinical follow up to tailored support that recognises consequences of late treatment effects.
A shift from measuring clinical activity to measuring patient experience and outcomes.

This ties in with the researcher's study that all the participants noted that there was no support for them after the five year mark. Fenlon and Foster (2011) concur with

this study's findings that support for the cancer 'survivor' requires a supportive infrastructure.

....there was no support and it was as if everyone had magically disappeared. My good GP had retired and my new one admits to my face that he does not have the first idea of how to help me with this under carriage pain. He suggested I go to the hospital but as I am too far from the second hospital, that is not a solution. I have arthritis and "water work" problems and I have no idea what will happen if I cannot care for myself as I cannot ask my wife. It's beginning to get me down but who do I talk to about it". (Helplessness & Hopelessness).

When a diagnosis of colorectal cancer is given it brings with it a mass of information from many sources that together with life experiences that the patient has to try to make sense of. They need to work out the meaning of what they are being told and it may impact on the many aspects of their behaviour which automatically, implicitly implies something else (possibility of death). If the boundary that the individual draws between themselves and the world (diagnosis) breaks down, possibly from the lack of support, the individual finds this profoundly disturbing and will often immediately deal with the information by emotionally denying it. The taboo of excretion in Western society leads to the fear of incontinence (Holden & Littlewood 1991, Black 2000, Helman 2007, Borwell 2009, Capilla-Diaz et al 2016, Black 2017) and through that to the individual becoming ostracised and embarrassed which in turn can lead to the lack of social connectivity as this patient said:

..."I had the pleasure of being invited to a formal do...at a posh place and would be meeting some influential people that would be good to network with...what to wear bothered me...I decided to go for trousers rather than a dress or skirt ...as I moved forward to shake hands I felt this warm, wet, viscose fluid start to run down my thigh and lower leg...what to do...I wished floor would open up.... It was impossible to go anywhere else at that moment....I shall never ever forget my embarrassment...I refuse all invitations now" (Avoidance).

The individual's feelings about bodily elimination are that it is a private function, best managed in one's own home and is related to the common notion that 'dirt' is harmful, both to the individual and to others in the community or society in which they live. Often the individual with a stoma sees themselves as a person who has transgressed certain social expectations and personal responsibilities (Littlewood & Holden 1991, Black 1992, 2000, 2012). Prohibitions around dealing with excrement are extensive and in the past were equated with madness, danger or witchcraft. (Douglas, 1966). Although times have changed, they have not necessarily bought with them an acceptance of the normality of the excretion process. It remains something not to talk about or publically acknowledge. To excrete through a different

body exit requires a specific schema for the individual and their society to understand and to accept in order for the individual not to become marginalised by their society. The body when healthy offers a model of wholeness but the body in sickness offers a model of social disharmony, conflict and disintegration (Black, 1992). The change in body image brought about by stoma surgery is anomalous with a rite of passage and this rite is not purifactory but prophylactic as demonstrated by Black (1992, 2000). In seeking to provide a framework it is important that the implications of a colorectal cancer diagnosis and a permanent colostomy are recognised from the individuals view point. The threat to body integrity, permanent physical change, loss of autonomy and control are some of the uncertainties that the individual and their family will have to address.

If this is recognised then the nurse/patient conceptual framework cannot redefine or restore a lost former status but can empower and define the individual's entrance to a new status. What has become clear from the participants' lived experience is lack of support after discharge at five years (NHS, 2014). Today, the conceptual framework has to be designed not only for this group, but to support all those being diagnosed today and those already on the journey. It was therefore very disappointing to find that even in 2017 colo-rectal cancer patients and indeed cancer patients in general, are still not receiving basic input from a SCP, and that neither is the utilisation of the distress thermometer and HNA (Appendix 3) recommended by the NHS (2014) is being routinely used. The conceptual framework therefore also has to include these key initial phases, even if only in outline as care needs to be continuous for life. The diagrammatic representation below was developed from the models discussed previously.

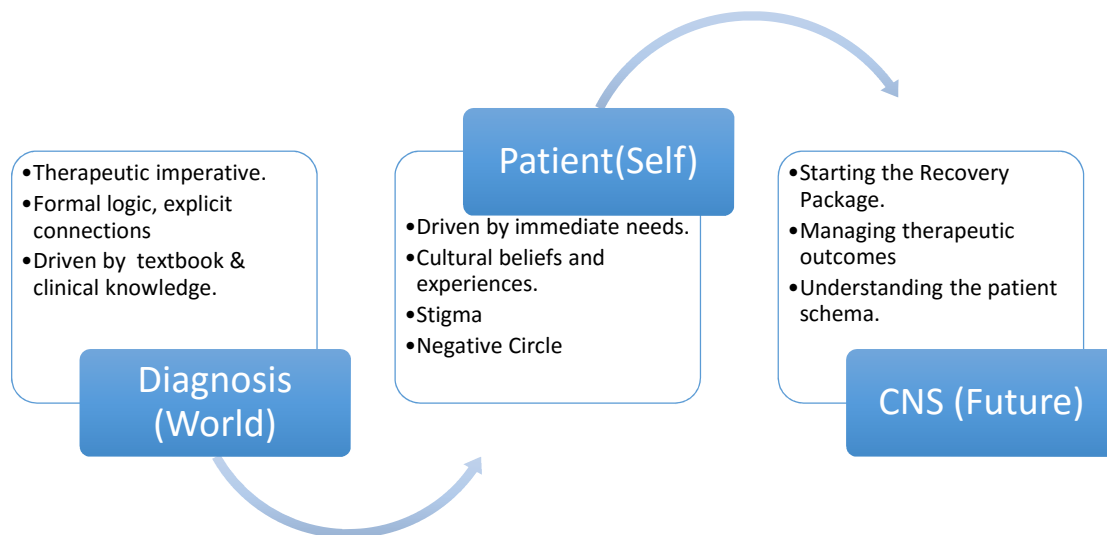


Figure 37. Phase 1 - 3. Beginning the conceptual framework incorporating Beck's Triad and Negative Circle.

It has to be accepted that for the participants in the study that recent government recommendations are too late for them to gain any immediate help. However, it is important that the CNSs in future, in working and supporting the colorectal patient, access the framework that leads to the Care for Life Plan and does not leave the patient in limbo after the first consultation wondering where future help will come from. It is widely accepted by patients and healthcare professionals that in today's health service, much more is expected by the patient and that these newer patients differ from those who were in the researchers study. Nevertheless, although diagnosed and treated 5, 10, 15 years ago, the participants expected to be kept safe and hopefully 'cured' with their surgery for colorectal cancer. Their expectations overall were that they hoped to not die too soon from the disease but to be given a longer life expectancy. Healthcare professionals, and at that time some CNSs, struggled to meet the increasing complex needs of the colorectal cancer patient as medicine advanced. Managing the stoma and the problems that could arise, were left to the Stoma Care Nurse so leading to a disjointed and fractured service (Wong & Cummings 2007, Odle 2008, Davies 2009, Brennan et al 2014, Thorpe et al 2014).

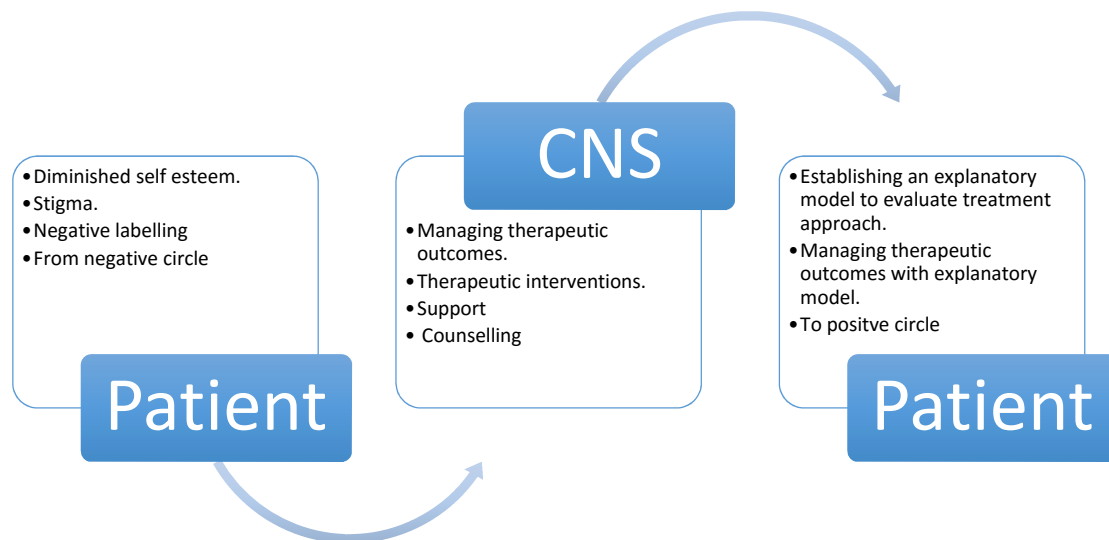
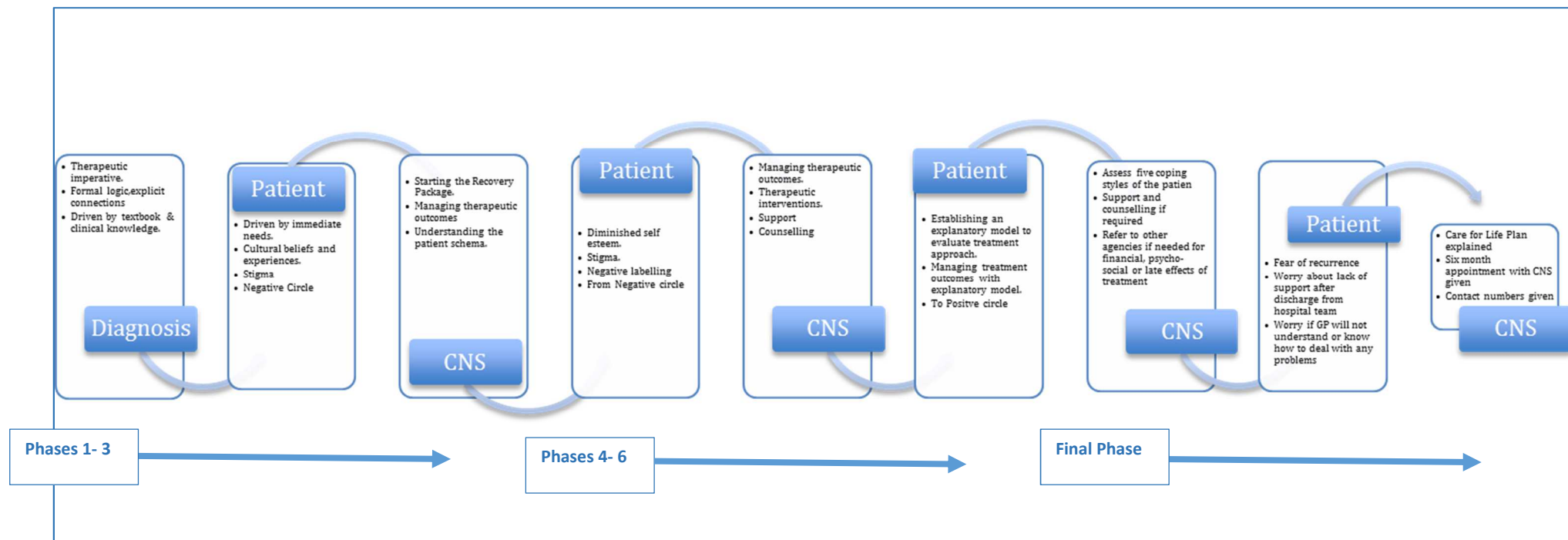


Figure 38. Phase 4-6. Adapting to a conceptual framework

Phase 4-6 shows that with the support of the CNS, with the CNS and patient working in tandem together to establish a rapport, they are able to discuss and mediate the effect of the negative circle and work towards a positive circle that will help in the patient's on going care and recovery. At this stage of the therapeutic relationship the CNS is able to assess how much anxiety the patient is undergoing. In referring back to the original HNA and distress thermometer the CNS can optimise and re-order the negative circle to become a positive circle, so mitigating the effects of the negative circle. However, there have been several needs assessment tools particularly focused on the gap between the perception of the cancer patient in regard to the services they feel they need and these have been developed with the express intention for use with cancer "survivors" (Boneveski et al 2000, Hodgkinson et al 2007). In further studies employing these tools, the outcomes are poor with 50% of participants stating they have unmet needs of support and coping with the main areas being psychological and fear of recurrence. In the prospective longitudinal study by Armes et al (2009) of the supportive care needs of patients beyond the end of cancer, they report that the studies they viewed, many did not predict the future needs of the cancer patient and few had robust measures in place that included measures to record psychological distress and the fear of recurrence in the late stage of the cancer trajectory. Armes et al (2009) suggest that their study has shown recognition of cancer patient's supportive needs during and after primary treatment and that health care professionals need to consider how these needs can be met to improve care for these patients in their longevity. Nearly a decade on, it is disheartening to see that there has been no forward motion to establish criteria and a

comprehensive framework for patients on the cancer trajectory. Unfortunately, too many healthcare professionals feel that if the all clear has been given at the five year mark then there is no need for further input to the patient and their families. Yet as this study has shown and the individuals who participated in this study, there is a need for ongoing support from knowledgeable and experienced health care professionals and providers.

Figure 39. Complete Conceptual Framework.



Conceptual framework incorporating Phases 1 & 2 of the cancer patient pathway enabling the CNS to incorporate and guide the patient through the negative and positive circles and 5 coping styles during treatment towards the discharge and Care for Life Plan.

Design elements of the Care for Life Plan.

In designing the Care for Life Plan it was important to have all the necessary elements in an acceptable form for the individual so they could feel that they were not in the constraints of the medical model that they had spent so long with. It was clear that as cancer is considered to be a chronic illness now, deciding how to devise an acceptable brochure for continued care or self- management required a new model of care as managing a chronic illness is a time consuming and complex process. The Care for Life Plan needs to show a systematic provision of individual and staff education and supportive interventions initiated by health care staff to increase individual's confidence in managing their health problems. Also there needs to be the element of regular assessment of progress, problem solving support, and goal setting for those individuals who need or request such interventions. However, within the literature it is clear that there is no clear self-management plans for this group of individuals although there are discussions about such needs (AHRQ 2007,Foster et al CREW study 2016). The use of self-management programmes can help to reduce costly health crises and improve health outcomes for individuals such as the proposed Care for Life Plan.

When deciding on planning a self-management individual support programme, an initial, major consideration has to be as to where the programme will be positioned. For these individuals who have been discharged at five years from any further therapeutic interventions as they are now considered 'cured', yet still need support, secondary care will not be suitable as it would continue to reinforce the medical model. Therefore, it seems appropriate that the Care for Life Plan should be part of the cancer individual's trajectory within the primary care sector. Yet this may have important ramifications in relation to staffing, data support, administration, co-ordination with other agencies and training of staff. Other decisions about disseminating the Care for Life Plan to the primary sector are understanding what is needed at each yearly appointment, information support, staff training at all levels within the practice and communication with individuals. It seems sensible, therefore, that the Care for Life Plan is one way to improve health outcomes for individuals who have undergone colorectal surgery and have a permanent colostomy and may have undergone adjuvant therapy, to be able to have the support they need to manage their illness effectively over their longevity.

At the time of writing this thesis a major challenge for this primary care model is the lack of clear-cut mechanisms for primary care practices to be reimbursed for the staff time and other resources needed to provide self-management support. Staffing addresses the people who actually are going to provide the support to this group of individuals. As discussed earlier in this thesis (Chapter 6), individuals with colorectal cancer and a permanent colostomy are minimal in each GP practice with a few GPs only seeing less than five in their whole practice lifetime. Within the primary care model, self-management support responsibilities can be delegated to a practice nurse who can devote more time and attention to self-management support. The Care for Life Plan timetable shows that only 2 out of six planned visits over six years are GP orientated as the majority of visits are nurse led. Competencies of the practice nurse would be in stoma care and colorectal care and the importance of interpersonal skills, with time tabled extra time to be able to sit and to focus on an individual's goals rather than solely on the disease. Similar types of self-management programmes for other chronic illnesses distinguish between generalists and specialist nurses, seeking "broad rather than deep" backgrounds such as masters-level nurses (AHRQ 2007, Kings Fund 2015). Some emphasize motivational skills and the ability to foster self-efficacy rather than individual dependency. Other attributes include empathy and compassion, as well as computer and telephone communication skills (AHRQ, 2007).

In the PROMS report (2012) a large proportion of the interviewees gave their experience of living beyond colorectal cancer with comments indicating that there was a lack of aftercare provision, care for on-going physical and psychosocial problems and the inability to form coping strategies as they did not know what to expect once the final discharge came. Lack of information on side effects from adjuvant therapies cause unnecessary worries and restricts their capacity for decision making. This concurred with the researchers study about living after colorectal cancer and colostomy:

...."if I had known how awful life would have been after I was discharged I would not have done it.... I had thought that all these problems would resolve especially after I had been discharged for good.....there is no support... you are just left to get on with it as best you can....I don't like the stoma...never have....never will" (Hopelessness and Helplessness)

Although all the researchers' subjects were post the five year point, many of them more than 10 years, some had been given all the information they needed during

their treatment but felt that they would have liked support, when needed when living back in the community:

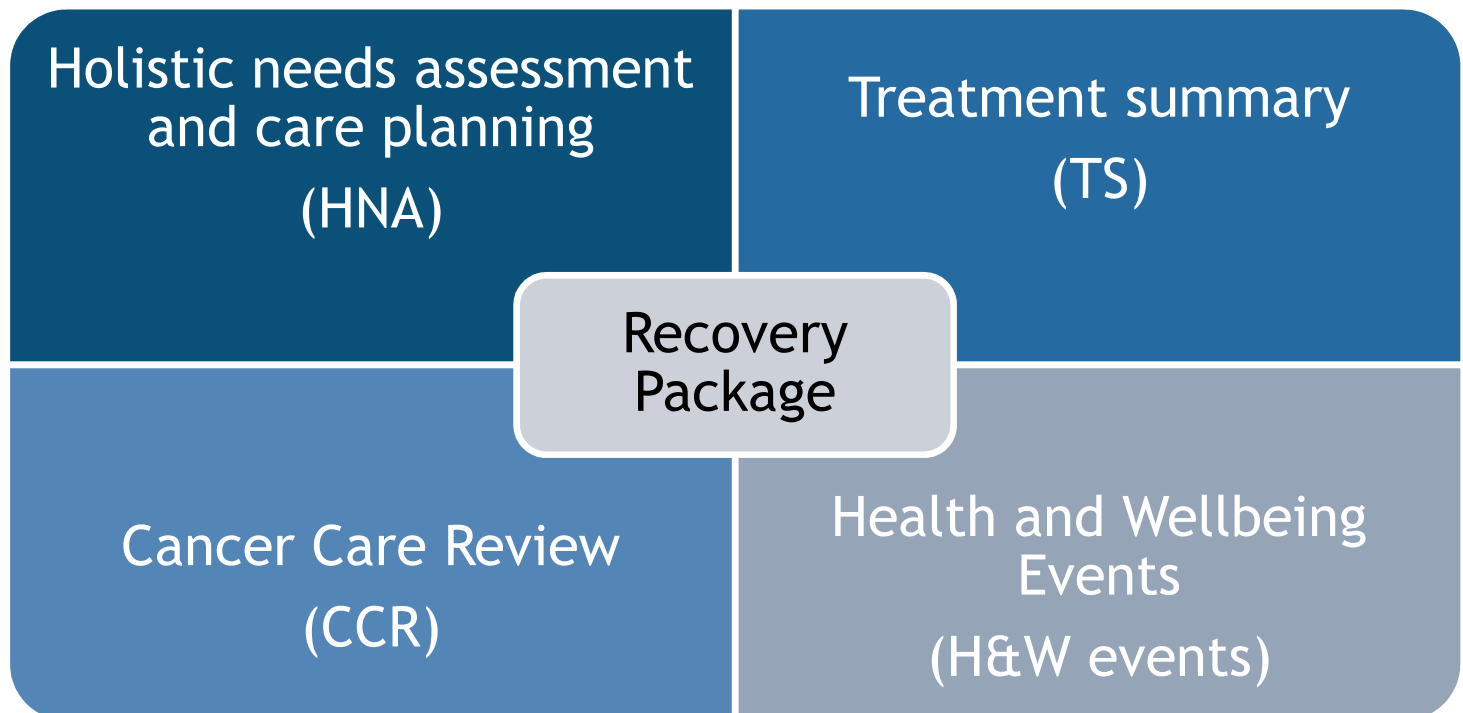
....” The nurses were sweeties....they worked very hard and showed me compassion and care...what more can you asked for.....I had written literature and they answered my questions and spent time with me...it is a bit of a shock when you find yourself on your own once you have finally been discharged....there is no one to turn to....if I felt I had a problem I would go to the GP but I would have liked to know I was going to be seen regularly” (Fighting spirit).

In searching the literature and listening to my interviewees and from my long, previous experience in colorectal nursing, it became clear to me that to successfully manage their longevity, these individuals need a plan that would help them to continue with their life and provide support. The brochure had to move away from the medical model and be pleasant to look at. In colour psychology the colour blue is one of trust, responsibility and honesty. It is sincere, reserved and quiet, and doesn't like to make a fuss or draw attention, so this drew me to a photo of mine that had a clear blue sky with white flowering cherry trees on green grass, which to me, is reminiscent of spring and new awakenings or new beginnings. This was based on a blue background on the cover and throughout the majority of the brochure. Text had to be as 'jargon free' as possible as this was for individuals and their families, not for the medical profession. Page 2 reminds the individual of the recovery package that should have happened (not for the interviewees in the study as they were mostly operated on before this became standard). Page 3 shows the CIPS programme which the individual will be involved in and describes the 4 components; Co-ordination, Interventions, Prevention and Surveillance. Page 4 includes the GP summary that was sent to the individual's GP. Pages 5 and 6 follow the lines of the Holistic Needs Assessment (HNA) enabling the individual to make notes or indicate any changes that may have occurred to their daily activities of living (Roper, Logan & Tierney 2000, Tierney & McKinley 2002) since their last visit. Page 8 indicates where the individual may find other areas of support and organisations. The last page supplies all the important telephone numbers the individual may need to support them through their longevity.

In designing the Care for Life Plan it was clear that there is still an absence of extensive evidence on the most effective ways to design self- management support programmes. This is a challenging situation for providers to deliver self-management plans as they will need to know where the remuneration and training will come from, make decisions about how to structure and evaluate their programs, which features

to include, and whether the programmes will be useful for meeting their goals and the individual's needs in the primary care setting.

Extract from Care for Life Plan Patients Booklet (please see appendix for full document).



Your HNA will have been done at the diagnostic stage 5 years ago and up dated as you finished your treatment. The HNA and Care Plan (CP) has enabled you to seek help where and when necessary in the last 5 years. The HNA is still active after you have been discharged from hospital care and using it helps those involved in your care to provide advice and care when needed. This can be used any time along the cancer pathway and this creates a shared understanding among HCPs that you come into contact with about your expectations over the coming years and ways in which they can help you. Running consecutively with the HNA is your Care Plan that was developed around the discussion you initially had with your specialist nurse or HCP.

Your Treatment Summary provides important information for your GP, including possible treatment toxicities, information about side effects and consequences of treatment, signs and symptoms of recurrence and any co-morbidities. Also it will include any issues that you may have discussed that the GP can refer you to other agencies to keep continuity of care. Also he will be aware of the late effects of cancer and its treatments.

Administration of the conceptual framework and Care for Life Plan.

The NHS (2014) currently has an information sharing project with cancer patients and plans such as holistic needs and distress thermometer have been utilised as the SCP. The distress thermometer forms a key part of the Holistic Needs Assessment (HNA), (Appendix 3) and is a tool used by specialist nurses to report their patient's level of overall distress at the time of administration. It should lead into a discussion with the CNS if possible or healthcare professional about how to best support the patients on going needs. The distress score is a broad indicator of how someone is feeling or coping overall. It is recommended that a score of 5 or above is used to trigger a more in-depth discussion about specific support needs, which can be determined by further discussion with the patient or relatives. The communication between the healthcare professional and the patient is valuable to enable plans of action in place as may be necessary. It is not always possible to address every problem that causes distress but listening and understanding are always helpful and as this paperwork sits in the patient's notes, and can be returned to at a later date by the specialist nurse and cause of distress reviewed.

The Independent Cancer Taskforce (2015) published its recommendations on the strategic direction of cancer services in England. The document was explicit in its acknowledgement of the role of Clinical Nurse Specialists (CNSs) and recommended that their numbers should be increased. Hamric & Spross (1983) suggested that the CNS shows a strong motivation towards high achievement and in the UK the CNS is expected to be working at Masters Level, either having achieved their Masters or be working toward it. The CNS is a nurse who exercises judgement, is assertive, demonstrates leadership qualities, acts as an advocate, is a change agent and has effective interpersonal skills. Significant factors that demonstrate the CNS role are that they affect the needs of a specific population (colorectal cancer) and the expectations of society. The CNS sets their own case load and has a commitment to quality patient care and is able to recognise the negatives and positives that may affect their goals in relationships with their patient group and their colleagues. Although there is a distinctive focus to the role, the remit of the CNS also includes leadership, educational, developmental and advocacy components. The CNS is well placed to offer guidance and direction in the provision of specialist care, be a resource to others and empower the patient with a cancer diagnosis.

The CNS is well placed to influence care delivery organisation and systems as they work closely with other members of the multi-professional team and have clearly defined groups of patients where improvements and initiatives can be made. Good communication skills are a major part of the CNS role, yet it is not uncommon for outpatient departments to be staffed by healthcare assistants who see many patients each day but do not have the skill or knowledge to communicate with the cancer patient who has immediate worries about their disease or treatment. This then can cause communication difficulties when the healthcare assistant has little understanding of the patient and where they are in their cancer trajectory leaving the patient feeling unsupported. Therefore it is important that healthcare professionals and patients have the Care for Life Plan explained to them to ensure that the patient knows they will be supported when they leave the therapeutic interventions of the hospital and return to primary care to continue with their longevity.

However, other decisions about how the Care for Life Plan will be delivered include factors such as appropriate staff to deliver the programme in the primary care setting such as GP surgeries, understanding of the content of the Care for Life Plan and the population served. Protocols on whom and how the programme will be delivered need to be discussed and how communication between primary and secondary care teams regarding information sharing, will need to be discussed. Interventions needed by the patient should be patient centred at the time of need and provide support and joint decision making, motivation and confidence building. Primary care should take into account that a dedicated staff member is needed to provide continuity and who has the psycho-social skills to support the patient. Likewise, disease specific information and understanding of toxicities from adjuvant treatments are essential.

To combat any feelings by healthcare assistants that they feel inadequate in dealing with the cancer patient or the patient with a stoma because they may be faced with difficult questions or embarrassing questions, the CNS should mentor the healthcare assistant and be aware of what their needs are by giving them support within the clinic setting and in coping with the colorectal cancer patient. Lunch hour teaching sessions and study days also help to give the junior nurse and healthcare assistant a greater understanding of what this group of patient's needs are. It is at such times as these that the conceptual framework and Care for Life Plan can be discussed and emphasis placed on the need to ensure that if the patient is being given their final check-up at five years and is to be discharged, the Care for Life Plan is initiated. De Vocht (2011) suggested that a breakdown in the therapeutic relationship of patient

and nurse happens when a junior healthcare professional is put in a position of having a difficult discussion with a patient asking about, dying, sexual issues and refusing treatment. Some of this study's interviewee's reflected on their experience of lack of communication and information during their cancer trajectory as they did not have a CNS during their care. This then had pushed them into the negative circle and found it took several years to adjust, as had been reported in the PROMS (2012) free text report.

The Care for Life Plan is about long term care and follow up. However, most cancer CNSs are based in the acute sector but have close links with primary care by either running satellite clinics or do home visits. This is particularly important as this sector assumes a more prominent role in the support of the person with cancer. This can be seen in some CCGs with the empowerment of cancer patients living with and beyond cancer who are experiencing outcomes of long and aggressive multimodal anticancer therapies characterised by significant acute and long-term toxicities. A programme such as the Care for Life Plan, a new model of care, provides this support and recognises that the patient will become self-managing in their longevity. Self-management can be defined as "the systematic provision of education and supportive interventions by healthcare staff to increase the patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem solving support" (AHRQ, 2007). The adoption of a plan such as the Care for Life Plan helps to avoid crises requiring hospital admission and, as it appears from the study, there is someone available to talk to about any worries.

In reviewing the interviewee's descriptors/feelings and quotes, they revealed that many of the interviewees were expressing similar thoughts about their diagnosis, treatment and longevity. Clinical nurse specialists would appear to be very well suited to supporting the patient who is experiencing thoughts from the negative circle and helping them to move towards the positive circle by discussing and understanding the explanatory models used by the patient. As the emphasis in nurse education and training is on patient assessment, symptom management, psychosocial care, and care planning, it would follow that the clinical nurse specialist in the appropriate cancer is ideally placed for the continuum that these individuals need to aid with longevity. In considering all the above requirements, protocols and education of primary care staff to be able to deliver the Care for Life Plan, it was becoming clear that there was a need to move away from a pedagogical healthcare

approach to a patient centered care approach that addresses the needs and concerns of the individual. The Care for Life Plan removes the institutionalization of the medical model that the individual has been under during their treatment phase and supports them with a move to self-management through their longevity.

Figure 40. Components for CIPS - a Care for Life Plan.

Co-ordination	Between specialists and primary care providers to ensure that the individuals health needs are met - health promotion, immunisations, screening for both cancer and noncancerous conditions, and the care of concurrent conditions.
Intervention	Consequences of cancer and its treatment such as medical problems, sexual dysfunction; pain and fatigue; psychological distress experienced by cancer survivors and their caregivers; concerns related to employment
Prevention	Prevention and detection of new cancers and recurrent cancers
Surveillance	Metastasis, recurrence, second cancers, metachronous cancer

(Black, 2017).

Essential to a Care for Life plan is a patient-centered approach, including responsiveness to patients' needs at the time of appointment, effective communication and information sharing to appropriate other agencies and encouragement of the adoption of healthy lifestyles and activity. A Care for Life plan has a focus on identifying any cancer recurrence, second cancers, and late effects of other treatments such as chemotherapy and radiotherapy; ensuring access to effective interventions and helping patients to improve their quality of life and longevity.

This Care for Life plan addresses the unmet lack of continuity following the individual's treatment, and not just for the five years until they are discharged from therapeutic interventions. The need for specific services will vary from individual to individual because of the heterogeneity of cancer and late effects from oncological

treatment. All individuals of early or late stage cancer and those whose treatment was limited, require follow-up care. Tierney and McKinley (2002:11127) as cancer sufferers themselves suggest that:

.... "Providers must try to understand the impact of cancer on their patients' lives and the lives of their patients' caregivers. They should focus on both the negative and positive effects of cancer and its treatment, and be as energetic and considerate in treating the cancer patient (and hopefully, survivor) as they are in treating the cancer itself."

This Care for Life Plan is the first to fully accept the statement above, made 15 years ago, and look at the life time challenges of this group of individuals. It has been developed in the light of the lived experience descriptions shared by the interviewees and was seen as essential that it could be used as a response for this group as well as having a role for all colorectal cancer patients.

Chapter 8:

The Lexicon of cancer,

The Road to Empowerment:

**Involving the patient at the
centre of their care.**

The road to empowerment, The Lexicon of Cancer: involving the patient at the centre of their healthcare.

The concept of cancer survivorship appears in articles in cross discipline literature frequently in this millennium due to the longevity of life and the much improved techniques of surgery and adjuvant and neo adjuvant therapies (Doyle, 2008). However, the concept of cancer survivorship does not appear to have a precise definition or be supported by a conceptual framework.

The use of Metaphor.

Metaphors can help to illustrate complex issues and can illuminate a description of cancer to the lay public. However, they are also capable of creating or perpetuating stereotypes and stigma. In oncology, the military metaphor is perhaps the most well-known, with the metaphor 'war on cancer,' and the importance for cancer patients to have a 'fighting spirit'. In cancer, particularly, there is a need to balance the instinct to fight, with words of healing and success in the psychosocial dynamic of care.

Metaphors have spread through daily language, and patients are often unaware of the use or power of metaphor. Lakoff and Johnson (1980) suggest that the metaphor goes beyond language and into the realms of thought and action. They define "the essence of metaphor as understanding and experiencing one kind of thing while experiencing it in terms of another." Czechmeister (1994) suggests that the metaphor is a 'two-edged sword,' that although metaphors are fundamental for expression, they are also capable of creating confusion, stereotype, and stigma within a population. Czechmeister (1994) also highlights the use of the metaphor, particularly within nursing and the need for nurses to communicate with patients "in language as free of stigmatizing and frightening metaphor as possible."

Metaphors can add clarity and depth of meaning to a situation. In the patient / doctor relationship when discussing illness and disease, there is often a substantial discrepancy between the patient's everyday notion of illness and the medical concept of disease. The cancer patient may understand the notion of illness in the framework of their lived experience, but may only understand the medical conception of disease in a medical model which for the patient is disconnected from the actual meaning of the situation. Even when the doctor attempts to convey knowledge about the disease process, the patient and the doctor rarely share the same understanding. It is here

that that healthcare professionals will often use metaphors to bridge the gap between illness and the patients lived experience and the world of therapeutic intervention. The metaphor offers both the patient and the physician a common language and shared understanding, offering both simplification and connection.

Metaphorical language can be more tangible than the factual information that is being given by the clinician. Metaphors add clarity and depth of meaning in the relationship between the patient and the disease and the disease and the clinician. However, there must be an awareness that there is a substantial discrepancy between the patient's everyday notion of illness and the medical concept of disease. The patient will understand the notion of illness in the framework of their lived experiences, but also has an understanding of the medical conception of disease in a scientific framework. However, this is invariably disconnected from the actual meaning of the situation. Metaphors can bridge the gap between the illness experience and the world of technology and treatment.

Of all diseases, the word cancer evokes even the calmest patient and most caring health professional to think about fighting when they are faced with this diagnosis. It is as if it is an instinctive reaction to the news. However, the health professional needs to think how to reconcile the patient's natural instinct and expressions used to fight the disease and the healthcare professionals words of encouragement in regard to acceptance of the diagnosis and the path that the disease will take. This is particularly important when the cancer does not react to therapy as may have been expected and the patient approaches the end of their life. We have inundated our language with bellicose metaphors. Clinicians will tell patients that there are many therapeutic options at their disposal and many patients are told that there is a new "magic bullet." For many people this language comes naturally, but for some the use of metaphor in disease such as cancer does not come easily as they prefer the correct scientific language. Many cancer patients and healthcare professionals will call their experience with cancer a 'journey'. Therefore the healthcare professional will need to think how best they can reconcile their language with that of the patient and relatives.

As the English language is scattered with metaphors many healthcare professionals find ones that suit the patient they are caring for but often by carefully listening to the patient the healthcare professional will hear a metaphor that the patient uses and the consultation can be carried on with these types of metaphors. These metaphors are

the ones that work best for the patient. If there has been no metaphorical conversation the patient can be given one to help with the 'story' but the healthcare professional needs to carefully check with the patient that they are able to picture what is being said and whether the metaphor works for them. Metaphors help bring the patient's subjective view of illness into the forefront of the medical consultation and give meaning to the conversation, therefore allowing the doctor and patient to strengthen the therapeutic alliance around a shared vision.

Symbols and metaphors have a significant function within the physiological world of the body and are important when describing bodily dysfunctions that cause psychological distress. Much seminal work by Kleinman (1980) was carried out prior to the millennium, suggests that symbolic reality is formed by the individual acquiring language and systems of meaning. Socialisation by the acquisition of language and symbolic systems plays a major role in the individual's response to their social situation and how they react to illness. The internalisation of symbolic reality plays an essential role in the individual's orientation of their own inner world. Symbolic reality allows the individual to make sense of their experience and helps to shape their clinical reality and social reality. Healy (2005) suggested that "the patient has to start by treating illness not as a disaster, but as a narrative, a story" Stories are like antibodies against illness (Healey, 2005) and people have a fluid view about their lives which constantly changes depending on circumstances. When people are diagnosed with colorectal cancer and will need a permanent colostomy it will change a person's bodily and psychological life. The researcher has found over the years that the patient will make a narrative about their current state after their surgery and it is suggested that the "story" is vital to the therapeutic progress. This "story" the patient tells themselves about their new condition may make the difference between permanent psychological wounding, reclusive retreat from society and effective psychological and social adjustment (Parker et al, 2000).

Clinical reality is the individual's beliefs, expectations, norms, behaviours and communicative transactions that are associated with illness, healthcare seeking, healthcare professional relationships, therapies and evaluation of the outcomes. The social reality is how the individual expresses and tries to understand clinical phenomena, which is clinically constructed. In using metaphors in cancer there is a dichotomy between two aspects of sickness: illness and disease. Disease refers to a malfunction of a biological or psychological process whilst illness refers to the psychological process the individual constructs to understand the meaning of what is

happening. However, if communication and interpersonal reactions especially within the family unit, illness is shaping the disease into behaviour and experience. Disease therefore affects a single individual even though others in society may have it, but illness affects the family, work and the individual's social networks. Personal, family and cultural beliefs and experiences are powerful influences on disease and illness. The concept of cancer survivorship appears in articles in cross discipline literature frequently in this millennium due to the longevity of life and the much improved techniques of surgery and adjuvant and neo adjuvant therapies (Doyle, 2008). However, the concept of cancer survivorship does not appear to have a precise definition or be supported by a conceptual framework.

The term 'survivorship' first appeared in medical literature in the 1960s associated with life after myocardial infarction (Lew, 1967) and historically is recognised that the term is associated with war or the laws of nature. By the 1980s survivorship was becoming associated with cancer and the individual's life during and after treatment. Mullan (1985), a physician, published his account of having cancer in 'Seasons of survival: reflections of a physician with cancer' and described how having cancer affected an individual holistically. Today cancer is classed as a chronic disease and it is recognised that there are physical and psychological sequel to the individual's longevity after therapeutic intervention has ceased. Doyle (2008) suggests that within the literature there is a lack of consensus as to when and how an individual becomes a cancer survivor, be it at diagnosis of the disease or when all treatment is finished and the bio medically designed 5 year stage is passed. There is a duality in the term cancer survivor as there are positive and negatives to be overcome. For some after treatment has ceased there is the gratitude for "surviving" the treatment and having arrived at the end of interminable hospital visits, bloodletting and scans. For others there is the effect of the treatments impairing their lives even more in the form of long term effects of fatigue, cognitive impairment and poor quality of life.

Healy (2005) suggests the impulse to fashion one's own self-affirming story out of the disease/ illness dichotomy, although considered a relatively new phenomena, helps the individual who has been diagnosed with a life threatening illness such as colorectal cancer and has a colostomy, will need to "reinvent" themselves and will start to treat the disease and illness as a story or narrative. These narratives have been called antibodies against illness and pain. This disease / illness narrative will be fluid and will be revised and reformed as the individual passes along the trajectory to wellness and longevity. Kleinman (1980) also suggests that although the individual

'rationalises' their illness into fluid narratives, healthcare professionals use disease to reformulate the sick person's illness experience with taxonomy, theoretical models and expectations of what the clinical setting can offer or do for the individual.

However, Holden and Littlewood (1991) suggest that the 'cancer patient' starts a process when a diagnosis of colorectal cancer has been given, to envisage how the disease affects their own body. Individuals will visualise the cancer with words such as wild, sick, mutant and will see chemotherapy as chemical warfare inside the body. Western societies find diseases such as cancer need to be anthropomorphised as a "virtual" human enemy against which the clinician will 'wage war' to 'fight' it with everything they have in their 'arsenal'. The individual will be urged to 'fight' cancer to psychologically encourage them that there is hope although society knows there is no cure. Even after death individuals are the subject of eulogies describing the 'fight' they had against the cancer and how they 'struggled to win' but were eventually 'defeated'. Often this terminology can be psychologically upsetting for the individual and the family, especially when treatment has not worked and the clinician states that it has failed. Often when "the going gets tough" for the individual due to therapy, illness or co-morbidities they will be told 'to soldier on' when treatment has been completed they are then in the position of 'soldering on' alone, something that the armed forces do not generally do. They do at least guard each other's backs, but after treatment has finished, even this has gone. Nurses assist this story making by contributing to conversations that enable this bridging to occur.

Since the initiation of the war on cancer, there have been significant advances in understanding, prevention and treatment. However, there is no victory yet in the cancer process, yet the military metaphor has been the most prevalent metaphor used in medicine for many years. Another metaphor used in the cancer disease trajectory is that it is a journey but there is no metaphor to say where this journey is going or where it will finish. Understandably, metaphors may help to bring the patient's subjective view of illness into the forefront of the medical consultation and help with an understanding of what is going to happen to them, it may also enable the doctor and patient to strengthen their therapeutic alliance.

Yet, conversely (Montaigne 2003, Healy 2005, Wasserstein 2007) suggest the use of these metaphors by clinicians and the public can inadvertently cause long term psychological damage. Also if cancer is a 'battle' to 'survive' then there will be losers. This terminology suggests that the individual has control over the disease if the right

attitude is applied and if death occurs then they must have 'lost the battle'. The continuing use of 'terminal' in cancer discussions is cold and hard- hearted for the individual and the family to hear when perhaps the individual will live another 6,12 or more months.

Perhaps the clearest example of that was one given by a dying patient that the researcher was working with, a patient who has been living with cancer for eight years in one form or another refrained from using the terms fighting, battling and survival. As she stated she has been living with cancer and from the start disliked the clinical and media terms of cancer as a war. Having been told how 'brave' she was she wondered if those that had died should have put up a better fight. Cancer is a disease process and with the help of clinicians she had been determined to carry on living with it. The unpredictability and chaos of cancer as a life threatening disease can be terrifying, but her belief in the clinicians that would lead her from A-Z, would either cure her or she would die. Self -enquiry and moving away from metaphors and clichés gave her a more realistic way of viewing and coping with the cancer as it was important to help her retain this perspective for as long as she could. However, as she approached the end stages of life she then questioned herself whether she had lost the attitude that had enabled her live with her disease until this point.

Sontag (1978:86) probably has done more to de-mythologise cancer with her book, *Illness as Metaphor*. As a cancer patient herself, she showed how the metaphors used by health care professionals and the lay public, can perpetuate the individual's suffering:

.... *"Nothing is more punitive than to give a disease a moralistic meaning."*

She described *Illness as a metaphor* and compared the 19th century illness tuberculosis to today's societal affliction, cancer. She described how metaphors and myths surrounding certain illnesses such as cancer add greatly to the individuals suffering and often inhibit them from seeking appropriate medical care. In her attempt to demystify cancer Sontag (1978) suggests that cancer is not a curse, punishment or an embarrassment, it is a potentially curable disease if treatment is abided by. She also points out that cancer is not a curse, but curable, and she remains an advocate for patients to seek good treatment. However, today the metaphors of dread associated with discussions of cancer have still not dis-embedded the term 'survivorship' and these terms continue to put a cultural gloss on cancer.

The road to empowerment.

There have been repeated calls to engage the patient and public and involve patients to be at the centre of their healthcare not only in the United Kingdom (UK) but also from an international perspective (Francis 2013, Bristol Royal Infirmary 2001, WHO 2008-2009, Boger et al 2015). Even though self-management has received growing attention as an effective approach for long term condition management (Boger et al, 2015), self-management support is still evolving. By developing a stronger patient and public involvement (PPI) the organisation and delivery of healthcare is now central to health reform across the western world economies. Even though self-management support may be in its infancy in the UK it is clear that 30% of the population of the UK with long term conditions accounts for 70% of National Health Service (NHS) spend which equates to £7 in every £10.

Although it is now well recognised that the involvement of patients in planning and service delivery should be at the heart of routine healthcare, there is the consideration that for some patients that they may not want to be involved. However, teams and organisations may be interested and committed to involving the patient and the family they may be diffident in involving the patient and family members (NIHR 2015, Crawford et al, 2002). By involving patients in their continuing healthcare it is suggested that PPI can have a number of benefits such as self-care and shared decision making. Yet current models of PPI are rooted in a medical and mechanistic way which are paternalistically led by the concerns of clinicians about the reality of practice combined by the rhetoric coming from government as to why they should change and support self-management (Tritter, 2009). The use of self-support is the assistance that is given to those patients with long term conditions such as colorectal cancer to help them manage their health on a daily, weekly, monthly and life time basis. Patients who invest in self-management of their health problem equates with the patient moving away from being a passive recipient of instructions from specialist nurses and doctors to having the knowledge, skills and confidence to make their own informed decisions. Many patients are keen to take on their own long time care as it frees them up to live a normal life but secure in the knowledge that they have a point of contact when they have a query. Traditionally, within the UK the majority of patient involvement in their own healthcare takes place at the level of information giving and feedback (Tritter & McCallum, 2006) with shared forms of decision making, which has been found to have proven health benefit (The

Health Foundation, 2012:9), not to be the norm. As one patient with colorectal cancer in that study said:

“....healthcare professionals give you such broad, useless information at times when one is only concerned in getting through the next stage of treatment.....but there must be some parameters in which I could work when I had been discharged for good”.

This compares with the participants in this study:

“ I saw the consultant and he told me what he was going to do....I had no one with me and I had not expected to be told that I would need radical surgery....he said he would get on with it immediately and I would have a phone call as to when to come in....I went out into the waiting room in a daze....had that really just happened to me....who could explain it all....surely there must be a choice or some information for me to make a decision”. (Anxious preoccupation)

For the colorectal cancer patient with a colostomy during their treatment and follow up phase (the first five years) there is involvement with the stoma care nurse and the colorectal nurse and they have tool kits such as the Holistic Needs Assessment (HNA), the Distress Thermometer (DT), the quality of life questionnaire for cancer patients from the European Organisation for Research and Treatment of Cancer (EORTC-QLQ- 30), the Montreux study (2003).

However, once the five year point is reached there is little for the patient in the way of “organised” support and as many of the interviewees said, they feel that that they have been cast adrift. Although huge advances have been made in colorectal cancer treatment over the recent years and the longevity of the patient is increasing, a by-product is that the colorectal cancer patient now needs supporting for many more years after their primary treatment phase. Shanfield (1980:130) suggested that the experience of having cancer as:

“....a permanent one, characterised by easy recall of initial feelings and emotions associated with the illness...a continued concern for one’s own mortality and enduring sense of vulnerability”

In this study similar sentiments were expressed by the participants.

In the literature, a clear consensus exists that having a colostomy allows involuntary output of faeces, resulting in bodily function and appearance distortion. The resulting problems and quality of life are specific to the condition and need to be measured by

specific tools because a generic tool is not sensitive enough to measure the impact on daily life that colostomy has and the challenges the patient has to undergo. However, in searching the literature it appears that it is still difficult to distinguish a stoma patients health related needs post operatively, during the rehabilitation phase, undergoing adjuvant treatment, during the five year follow up and the continuation of life when therapeutic intervention has ceased. It appears for many of the stoma patients, the pouching system which is daily, a major factor in a patient's life produces many problems such as leakage, sore skin, odour and possible visible detection especially if there is a parastomal hernia:

....” How do I go on with my social life.....look at me.....nobody else wants to....this hernia makes me look like I am pregnant but lopsided....I can't see to get the bag on and it is hit and miss....then accidents and leakage happen” (Helplessness and Hopelessness)

The core purpose of any involvement activity for patients and public is to improve the health and the experiences of services for colorectal cancer patients and their families as well as the wider public and community.

The National Cancer Survivorship Initiative vision is to support all those patients who have had a cancer diagnosis, treatment and beyond (NCIN, 2010). As part of the NCSI vision the NHS is working with patients, clinical teams the Department of Health and voluntary agencies to improve the effectiveness and service quality for those living with and beyond cancer (PROMS 2012, NCSI 2013, Corner 2014).

As the advances made over the years in cancer treatment have yielded better survival rates for patients, the by-product of this research and treatment is that patients are living longer and need support for many more years after their primary treatment has finished. Treatment for colorectal cancer leads to very specific side effects that can remain for the lifetime of the patient. These may be, among others, bowel function, sexual function, psychological issues, stoma related issues and these may affect activities of daily living. Many colorectal and stoma patients have on-going needs yet encounter fragmented and poor care co-ordination in follow up:

....’in the end I go to the GP....he doesn't want to examine and tells me to go and see the Practice Nurse....she says she has never dealt with stomas before....she says go to the hospital.....all that care I had in hospital certainly does not extend to the community” (Anxious preoccupation)

Many will find a lack of care or support once they have reached the five year mark. Long term support and care planning is needed as it has been seen that there are a whole range of unrelated conditions that can arise due to the long term effects of treatment. In enabling risk stratification to work, there needs to be better identification of the patients who are likely to suffer long term effects of their treatment well after their five year point. There is undoubtedly a growing demand for cancer aftercare services as a result of increasing incidence with better survival rates. Routine 1 to 5-year follow-up of cancer survivors within the NHS costs in the region of £250 million per year out of a £6 billion per year budget. Follow up through a medical model uses consultant outpatient appointments and timely, appropriate diagnostic tests. Research shows that the case for routine follow-up as a method to pick up early recurrence or disease progression does not appear to be a strong or cost effective. For lower-risk patients, a stronger emphasis on holistic care planning to sustain recovery, manage the consequences of treatment and reduce the risk of recurrence should be affordable without compromising early recurrence detection (AHRQ 2007, Armes 2009, Gordon 2011, Ang et al 2013).

Across Western countries, health service reforms have put emphasis on public and patient involvement by the patient, of their disease process. Increasingly the participation of patients and public in this service development and evaluation, especially in cancer, have been the central mainstay to this. This shift in health policy – cascading down from government, Clinical Commissioning Groups (CCGs), Hospital trusts and patient groups – generates considerable debate (Tritter and McCallum, 2006) and the shaping of self-management or user involvement is specific for “a ladder of Citizen Participation”. Tritter and McCullum (2006) in their work compare the relevance of Aronstein’s (1969) framework to current healthcare developments in the English NHS. Since the demise of Community Health Councils (CHCs) in 2002 there has been response from other areas to the growing pressure from communities for nationally provided self-management groups for various illnesses. Section 11 of the Health and Social Care Act 2001 directs a more user involvement approach and requires NHS organisations to engage with end users in planning, participating, evaluating individual treatment decision making. It was clear from the participants in this study that user involvement had not extended to them and that they found difficulty in engaging with NHS organisations.

One of the early adopters of self - management was the Expert Patient Programme (EPP) which began in a large scale Department of Health (DH) research project in

2002. The idea of the EPP is creative thinking that aims to give people more control over their conditions through cognitive therapy courses. Such conditions are diabetes, arthritis or Chronic Obstructive Pulmonary Disease (COPD). This begs the question of why not the colorectal cancer patient who now has the possibility of longevity after treatment and that cancer is now considered to be a chronic condition.

The organisation of follow up and continuing care for colorectal cancer survivors between health providers and government is complex and highly variable with many patients saying that they have multiple providers for example – primary and secondary care, specialist nurses that can be as many two or more with lack of co-ordination between all parties (Sisler et al, 2012). This lack of support for the long term survivor of colorectal cancer (five years and onwards) appears to be relative across the developed world (Leropoli et al, 2010). In a study from Australia to determine the preferred methods of support for long term survivors of colorectal cancer focus groups and telephone interviews were employed. There was a strong interest in peer support using a one to one telephone model and a face to face support group. The use of the internet was the least preferred.

The one to one telephone format was seen to be private and less daunting. One patient said:

“....I think it's more personal...and I find it hard to express myself in a group, whereas prefer if I can maybe just talk one to one with somebody who's been through it...I think it is easier to communicate when you are in your own environment”.(Leropoli et al, 2010:462)

Which fits with findings from this study:

“....I don't want to share my private....and personal information with everyone....there may be someone there from my street, area...community who knows me....but they won't know about the op and outcomes...I don't go into the doctor with a group of people I don't know....it is me and the doctor....it is confidential” (Anxious pre-occupation).

Telephone peer support has many advantages as it overcomes travel and geography difficulties or physical restrictions. Anonymity, privacy and comfort are considered important. Face to face support formats were also useful formats enabling participants to share their experiences with others. However, there were some participants who did not want to support the study (Leropoli et al, 2010). Peer support programmes allow participants to engage with others to discuss problems in their

disease trajectory at various times within their continuing life span, but barriers such as lack of awareness of such support programmes, stigma and caution in self-referral

It is recognised that a cancer diagnosis disrupts time and as Sontag (1991), Tritter and Calnan (2002) and Walter and Emery (2006), report, the image of cancer in society causes it to differ from other chronic diseases. Time becomes central in understanding the meaning of survival after a cancer diagnosis and is an essential aspect to the flow of life that has been disrupted by a cancer diagnosis (Ramussen & Elverdam, 2007). As the participants related, time is a difficult concept to develop in cancer survival to enable complexity and analysis to be measured. Insight into how time is measured in cancer patient's survival may be gained from social sciences and particularly anthropology. Van Manen (1990) suggests that time is a fundamental way in which people talk about and arrange their lives. In the work by Ramussen & Elverdam (2007), they found that cancer patients found the diagnosis of cancer changes the perception of time, comes unexpectedly and as a surprise. Their knowledge of everyday life becomes inadequate at such times. For these patients time becomes a 'before' and 'after' with the diagnosis of cancer a symbol of disruption of time as they knew it. Many survivors will re arrange time by dates of diagnosis, treatment and end of care as specific time related dates. Schutz (1982), suggests that we have two time areas – inside time, within ourselves which can rush forward or stop and outside time, the time we recognise such as a second, minute, hour, day. A participant describes this as:

....it all stops in an instant (inner time) and you think what now? How, why...It all goes so fast" (Fatalism)

However, understanding the appropriation of time, cancer survivors have similar experiences in the process of surviving and perceive time in different ways. Often after treatment has finished and the individual is discharged from care, cancer survivors can benefit by sharing their experiences with others in a supportive environment as part of the therapeutic process and on-going support. The time trajectory through which the cancer survivor passes is continually changing and an ongoing process and understanding the way the cancer survivors manage their time can provide a deeper insight into that individual's priorities and values.

Baravelli et al (2009) were concerned that the number of bowel cancer survivors were increasing in line with the increase seen across all cancers and many survivors

have on going needs but encounter fragmented, poorly co-ordinated follow up care, as this study shows, that nothing has changed. Survivors of colorectal cancer now represent the third largest group of long term cancer survivors in Western societies. In the United States the Institute of medicine report strongly recommended the use of survivorship care plans (SCP) to address the four elements of management which are – prevention of recurrent and new cancers, surveillance for new or recurrent cancers, as well as medical and late psychosocial effects, interventions for physical and psychosocial consequences of cancer and its treatment, and the co-ordination between specialist and primary health care providers (Hewitt et al, 2005). Although the Baravelli et al (2009) study suggested that there was strong support for SCPs from patients and health care professionals there is differing opinion as to the content by both groups:

....” I would like to see in future for these new patients something....not sure what exactly.....but something they can be given with information about who they can contact and see...if there is a problem you know...I know how difficult it was just to get to see the stoma care nurse” (Hopelessness and Helplessness).

Although the outcome was that there is support for SCPs in many of the Western societies the Baravelli et al (2009) report did not state how far the bowel cancer survivors were after their primary treatment.

Feurstein (2007) states that over the years there have been various definitions of what constitutes a cancer survivor. Survivors have been defined as those who were first diagnosed with cancer to those who have lived for 5 years or longer after treatment. Of all the definitions used for what a cancer survivor is none of them appear to be an evidence based definition. Feurstein (2007) examines the work of Mullan (1985), a doctor who was diagnosed with cancer and his effort in trying to describe the course of cancer. Mullan (1985) felt there was a widespread belief that once diagnosed and treated the patient was either” cured” or “living with the overt or covert disease”. Mullan (1985) proposed that overttness or coverttness descriptions of having been diagnosed with cancer did not realistically succeed in representing the trajectory of cancer and suggested that the term ‘survival’ was more appropriate as it would apply to those who were cured and those with continuous disease.

In the Cancer Survivorship Briefing Paper (Corner and Richardson, 2007) agree that the term ‘cancer survivor’ is widely interpreted, but in this paper the authors use a definition as someone who is in remission or is not undergoing active treatment or is

living with progressive disease. They agree that survivors face a range of often unmet needs for the rest of their lives such as physical, psychological, spiritual, social and financial. Therefore the challenges are how to address these needs for those living with cancer. Work from the Picker Institute, (Coulter and Ellins, 2006) suggests that post primary treatment support programmes can increase the quality of life, psychological functioning and reduce disability of a cancer patient.

It therefore is important that patient care packages for cancer patients should include a post treatment care plan with rapid re-entry information on how the patient or good GP can do this. Summary letters of all treatment to patient and GP. Community based post treatment support programmes and a mechanism for identifying late effects of cancer treatment. However for the bowel cancer patients with a colostomy added information on other subjects such as how to contact a stoma care nurse and dietary information would be helpful:

....” Having had such good care in hospital for the five years, I presumed, naively, that this would continue into the community....this became obvious when I had a problem with the stoma bags and needed advice....I rang the GP and his reply was to go back to the hospital if I had problems....they did not give nutritional advice as they did not know what I had done in the operation” (Hopelessness and Helplessness).

For many of cancer patient survivors there is the need to be able to recognise and support the patient with late effects of cancer treatment which may not present until some years later yet cause a debilitating effect. Although there are programmes such as the Expert Patient Programme and Macmillan’s Living with Cancer programme, this only gives support for a while and for some of the patients as was seen from the researcher’s interviews, it is often much later up to 10 years onwards that patients would like to access some help, especially as they become older. Participation in self-help and support groups provide a setting for sharing information and experiences and can also be beneficial for carers as well. However, if patients fall through the net, move house or have been well for years after treatment but now need to seek help and advice, it may well be hard to find a way to access support (Foster et al 2009, Okamoto et al 2011,):

....’ I pushed on for 10 years without seeing any oneand I can tell you there were times I was desperate..... then I saw an advert in the library about a group starting.....it was for those with stomas....I thought this may be the answer I need...I went along and go every 2 months now....I have made some friends who understand what I am talking about....why could this not have been here years ago?” (Hopelessness & Helplessness)

The National Cancer Survivorship Initiative (NCSI) (DH, 2010) strongly asserts that the patient requires support from health care professionals to enable the patient to self – manage their care. However, doing this in a paternalistic way will not achieve the intended outcome and “Consumer led” services are considered in the Cancer Survivorship Briefing Paper to be the way forward as it feels it will meet the needs of the survivors and as such may be the best way forward (Carlowe, 2009).

This current study confirms that there are many unmet challenges of a colostomy and colorectal cancer individual's survival are many, and much observation and research is undertaken in the first years after surgery where there has been increased interest in the problems of this group. These are adjustment to the stoma, psychological adaptation, sexual function, socio- economic worries and the ‘learning to live with’ problems that not only occur in the first five years, but for many, last for ten and more years. Much of the research undertaken has shown that the physical and mental quality of life for the colorectal cancer survivors is inferior to age matched individuals without cancer (Denlinger and Barsevick, 2009):

....” I worry...all the time...day and night....will it come back....how will I know....will it be too late when I know....I sit here all day wondering....I wont see friends or go out.
(Anxious pre-occupation)

Five year survival rates for colorectal cancer are 66% and the use of chemo-radiotherapy has helped to improve survival and local control. However, with this improvement comes the potential for late and long term effects that will affect the quality of life of the individual. The use of Oxaliplatin in adjuvant therapy has been shown to cause peripheral neuropathy and dose limiting toxicity (Cersosimo, 2005). The side effects of Oxaliplatin affect the fine motor skills of the fingers by numbness, pain and parathesias. This can also occur in the feet causing numbness and difficulty in walking. As many as 92% of colorectal cancer survivors who have this form of adjuvant treatment will develop some degree of sensory neuropathy. For some of these individuals peripheral neuropathy will be a long term and permanent effect. For patient such as those in this study this issue needs to be considered when planning lifelong support and therefore has been included in the Care for Life Plan.

Patients who have undergone treatment for rectal cancer- 13-50%, report symptoms of diarrhoea up to ten years and more after treatment has ceased which has limited their activity and negatively affected their quality of life. Their life is distorted by at

least three bowel movements per day or more, with frequency, urgency and tenesmus (Schneider et al, 2007). Both pre and post-operative treatment for rectal cancer increases the risk of bowel dysfunction with or without a stoma for at least five years after surgery and longer. Long term anorectal dysfunction after radiotherapy may include reduced reservoir capacity, incontinence, pad wearing and night time disturbances that may persist for ten years or more. However many long term survivors consider that bowel dysfunction such as this is normal and do not know how or where to seek help.

Fractures and risk of bone damage after radiotherapy is increased after neo and adjuvant radiotherapy for rectal cancer in older women and up to 65% with increased incidence in pelvic fractures. For the survivors of colorectal cancer there should be long term monitoring of bone density and treatment for osteoporosis (Baxter et al, 2005). Urinary and sexual dysfunction are recognised complications of treatment for rectal cancer and up to 38% of individuals still have symptoms of urinary incontinence post five years. The severity of urinary incontinence increases with time from 18% at 3 months to 31% at five years (Rauch, 2004). The use of total mesorectal excision (TME) for rectal cancer has shown that permanent sexual dysfunction is minimised but the use of abdomino-perineal resection (APER) has been shown in quality of life research to still be associated with lower sexual function even after five years (Leander-Martling et al 2000, Harisi et al 2004, Herdman et al 2011) .

In promoting long term colorectal cancer care for individuals there is the need for access to information for the individuals who have to contend with the risk of cancer recurrence, the effects of cancer therapies and non-cancer co-morbidities. Non-cancer co-morbidities exert more influence over the individual's quality of life in long term survival than the original cancer diagnosis (Delinger and Barsevick, 2009). While there may be Patient Care Plans (PCP) at the time of colorectal diagnosis for the duration of primary care, cancer survivors are living longer after the initial five years and need help and advice when they develop a range of late occurring adverse health conditions. There is a need to listen to what cancer survivors are saying and the problems they are experiencing:

“it would help if I was given information at my discharge about what the following years might be like....they seem so keen to get rid of you..... There seems to be a total lack of preparation about what to expect, who to go to, who I can call on....there

is no help for us with long term effects after colorectal cancer". (Hopelessness and Helplessness)

It is known that up to 70% of colorectal cancer survivors living more than five years' experience co-morbid conditions, in consequence, strategies are needed to help prevent functional decline. Those who support the argument say that there is limited access and difficult navigation through the healthcare system to find what they need for maintaining quality of life in their longevity, but this remains a theoretical problem. Survivor's voices can lead to change and in this there is empowerment but as yet most of the research is tokenistic. As yet in many of the developed world countries it is increasingly becoming recognised that there is a need for survivorship support through the life span, not just in the early years of treatment. Implementation of better co-ordination of care in the primary, secondary and tertiary areas is needed with an increase in the collaborative efforts between academic researchers and health departments to enable cancer survivors to know that they will be cared for through their life span.

There is still no standard definition of 'long term survival' for adults following a cancer diagnosis (Foster et al, 2009). As most papers assess quality of life with an attempt to summarise findings, this is limited by variation, definition and measurement. To properly understand the experience of long term survivorship after a cancer diagnosis there is a need to enable long term survivors to be able to describe their own experiences (Foster et al, 2009). Now that people are living longer and many cancers can be seen to be age related cancers, consideration must be given to the impact of age at diagnosis and the impact that other co-morbidities may have in this population. Understanding the implications of long term survival among older people after a cancer diagnosis and treatment, it is imperative that the development of educational strategies to help survivors and health care professionals are understood in relation to the impact of age at diagnosis. This study is a first step in providing effective support of those survivors experiencing problems when therapeutic intervention has ceased and formal services may not be readily available or even be in place. For many of the survivors there will be long term difficulties and these long term consequences need to be continually monitored and effective tools devised to help people self-manage these problems as they occur.

Chapter 9:

Reflexion and Reflexivity.

In my reflexion and reflexivity I focused on my self-awareness and openness during the research processes undertaken in this study. I sought to provide an understanding of the lives of the participants through giving descriptors of their lived experience. As a result I needed to take into account my subjectivity and positionality and how this had impacted on this research. My understanding of reflexivity in this account is that I had to accept that I had formed my own social construction of the reality of the lived experience description (LED) of my participants. The information I had gained and my understanding of what I was told was through my negotiated constructionism, enabling me to try to interpret what I listened to and discussed because my role was central to the research process and not distanced from it. My positionality was and is related to how my experience and professional position led to but also influenced the research

Throughout this study, as a nurse consultant in this field, it was distressing, depressing and disheartening listening to my participants and knowing from personal experience, that we have not moved forward despite all the research and literature available. To find that the barriers facing cancer individuals and their providers still include a fragmented and poorly coordinated cancer care system and health care professionals that lack experience, made me question where the service is going. The absence of a locus of responsibility for follow-up care after the five year mark is reached should have been addressed years ago, as should the poor mechanisms for communication. To find that there was little to access psychological support, despite it being cited in government reports such as PROMS (2012) left me wondering just what it will take to improve the care for this group, and why healthcare professionals that are in contact with, are not noticing or responding to what seemed to me to be clear issues. It meant that there was no change from Arora et al's (2011) report that over 60% of post treatment 'survivors' in their study lacked the help they needed to improve their health once their treatment ended. Also that clinicians did not understand how the treatment had affected their quality of life.

It was extremely hard to accept that 100% of the participants had had no post treatment support after the five year mark. For some of the interviewees there was nothing but praise for the way they had been treated many years ago, but that was then, but others reported that they could not remember a single successful therapeutic relationship with health professionals from the time of their diagnosis. Whilst, it is recognised that memory feats are not always accurate, nevertheless for participants to sit and think and then be unable to recall successful and supportive

relationships was for me very disappointing. Richards et al (2011) suggested that a key commitment of the Cancer Reform Strategy (2007) to establish the National Cancer Survivorship Initiative (NCSI) (2010) was because of the realisation that not enough attention had been given to the long-term consequences of a cancer diagnosis. Their points fit with Foster and Fenlon's (2011) argument that unrecognised problems of cancer patients after completion of primary treatment, included loss of confidence and general lack of support, and that support for the cancer 'survivor' requires a supportive infrastructure. As Richards et al (2011) suggested new and innovative models of care are needed as individuals extend their longevity. Sadly, despite these views being over five years old, this current study found no evidence of any attempt to support this group who no longer received active treatment, reinforcing the need for this study. As one patient said:

“there was no support and it was as if everyone had magically disappeared. My good GP had retired and my new one admits to my face that he does not have the first idea of how to help me”. (Fatalism)

For me one of the most difficult things to do, was to step back from my subjectivism and the different roles I needed for the study. As a health care professional who had worked in this field for many years, there was anger at my peers, objectively I knew that they are too thin on the ground and cannot do everything that they wish to, but subjectively I felt that these participants had been repeatedly let down by colleagues. I had to make sure that these feelings did not show in my interactions, and here my professional training was very useful. I had had many years of learning to listen non-judgmentally, but to repeatedly hear of poor service and care and not be able to change it was not easy. It was important from the beginning that participants were aware that I was a professional who understood the treatments that they had undergone, and on reflection, I think it was because of this that they felt safe enough to sit with me and tell me what they had seen and experienced since the time they had been diagnosed. I needed to repeatedly go back to my modified SWOT and bracketing and use these to help me remain focussed on the participant's descriptions. I was part of the social world in which my study was based. The gamut of emotions that I experienced as the study progressed could have led to the inclusion of much more bias and subjectivity in the findings. At the beginning I accepted that because of my choice of approach I needed to identify and record my perspective, but it was only towards the end of the study that I was clear on just how essential the process of self-evaluation was if I was to remain true to the context of the interviewees. I am so grateful that I did do it, even though it seemed time

consuming at the time. I used the documentation throughout the study to reflect back and forth through the research process and challenge my perceptions, checking to see how what I was thinking compared with my position at the start of the study and whether my changes in perception and mood, were impacting on the findings.

Reflexivity is more complex than reflection, for me searching to identify what it meant in terms of this study, I saw it as bending back on myself, I liked Lipp's (2007) description of it being the way in which the researcher examines the way in which the research acts or impacts on the world and the world acts or impacts on the research. As a consultant nurse in colorectal and stoma nursing I have worked in this field of care for the last 30 years during which time I have successfully completed research projects utilising both focus groups and individual interviews. I needed to look back on these and see if viewing them differently affected my perceptions. I needed to include my actions from my lead role for the Department of Health in the development of colorectal cancer support groups in the early years before the expert patient programme and the survivorship care plans. Bending back on myself was a salutary experience. I could no longer just accept that I had carried out my different roles I needed to explore what the outcomes meant in terms of my development and perceptions. Also, how they had affected my lived experience and how that impacted on my choice of study, my data collection and analysis.

This descriptive phenomenological study was based on Giorgi's (1975, 2009) phenomenological method with individual telephone interviews due to the disparate geographic spread. Focus groups can help participants in a group discussion to feel empowered and I was able to gain insight into ways that that meaning was made in context of what was being said and conversation flow. Therefore, a focus group was used for one group where the participants were able to attend a central point. The interviews were conducted with open questioning and a conversational manner to enable participants to be able to tell their own story. In this way the depth and complexity of the participants' story enabled them to lead the interview. Where necessary prompts were used (i.e, tell me more) to gain further insight and to clarify ambiguity. In seeking a richness of data about the individual's experience sampling was purposeful rather than random. Looking back at this, the approach chosen was appropriate, I am grateful to all those who participated and so freely shared their positive and negative experiences, they were so willing to talk to me hoping that what they shared would help others. I was determined to do justice to their trust and commitment, and have developed the conceptual framework and model from all the

things they shared with me, and from my professional expertise. Looking at it critically I believe that I have stayed within context and I will share the main outcomes with participants and with the Colostomy Association.

There was one unexpected finding, that at the time I found unacceptable, most of the interviewees reported being pre-occupied with existential issues which included wondering how they were going to be treated by other health professionals now that they were classified as a 'cancer patient'. Their fear was that any signs and symptoms that they developed would be seen in the light of the cancer and could be misconstrued. Ratcliffe (2008) argues that such existential feelings challenge the duality of life, self-versus world inside, self-versus world outside, and that self and world are experientially related. The participants in this study showed just how essential it is that issues such as this, are explored early in the cancer trajectory. Sadly, it was evident that for some interviewees, many years on they were still adversely affecting their quality of life. To sit with them and hear how lack of appropriate guidance had actually damaged the lives of this group referred to as 'survivors' was difficult and depressing. These findings made me all the more determined to complete and publish the study. The results need to be broadcast to all those who work in this field. They must learn to listen and help with the wider implications of a cancer diagnosis if they are to meet their professional responsibilities and deliver high quality, effective and appropriate care.

Reflecting on the study, I found myself in agreement with Finlay's (2011) suggestion that healthcare professionals are drawn to phenomenology for its holistic appreciation of everyday human experiences. Also, as they listen and observe, understanding comes from the discussion of how the person's world is lived and experienced. This study does reveal that qualitative research enables the less tangible meanings of the individuals' social worlds to become illuminated and allows the researcher to hear and explore the perceptions and experiences of the service user. For me, one of the challenges was to free myself from the literal meaning in which I found so difficult to listen to, and to intuitively find the implicit meaning by focussing on the phenomena. I had to repeat the cycles again and again to check that I remained in context.

It had to be accepted that I and the participants are of the same order, in that we are all living, experiencing human beings. I needed to reflect on each stage to make sure that I did not internalise the emotions the interviews revealed and allow them to

dominate data collection and analysis. The gathering of the data involved engaging with the 'others' language, using lay terms not the medical language I am more used to, as we explored the stories they told the experiences they have lived. As a consultant nurse in this area of work, what I was hearing from the participants was sadly a repetition of previous discussions with patients who had had difficult treatment experiences. Over the years I had heard these lived experiences, indeed they had led to my choice of study and the wish to develop something more than the current survivorship care plan (SCP). Nevertheless, secretly I had hoped to hear more positive examples than I did, and I had to deal with my sense of professional disappointment and let down. It was important that I understood and accepted my positionality in this research. I was proved correct in the belief that because the recruited participants were aware of my credentials they would be able to talk freely, believing I would understand what they were saying and would not have to query any medical terms that they used so allowing free flow of the conversation. However, I had not taken into account of the impact it would have on me, and this is something that I would warn future researchers about. I needed to debrief with my supervisors, and had one of them not worked in the field this would have been extremely difficult. It made me understand why they and the ethics committee had insisted on access to support for me as well as for the participants. This approach really does have a much greater impact on the individual than expected. I had carried out research before, but this study has reinforced for me the realisation that this type of research should not be carried out by junior researchers without a background of patient support and counselling. By actively exploring my positionality at the start of the research I was able enter into a dialogue with participants and use each participant's presentation of self to help revise my pre-understanding and come to make sense of the phenomena described. However, I could not carry alone the outcomes of their outpourings and I really have learned the importance of informed support.

Reflexivity was an ongoing vital component of the research process, not just an initial awareness-raising activity. To be able to bend back on myself, reflexively, I needed to identify and then reveal my pre-suppositions so that they could not emerge unexpectedly if I was exposed to a powerful enough trigger. Otherwise, these presuppositions could have possibly therefore influenced the research. Accepting and gaining understanding into what the participant was saying came from shared perceptions of shared the world in which we (myself and the participants) lived in. I needed to manage my interactions with participants and the world and actively explore how these interviews affected them as well as my pre-suppositions and

knowledge. It was apparent to me, after the first epoché, that in order to understand afresh the phenomena I was researching, I needed to undertake a second analysis. This second epoché and analysis did help me to find five themes that helped me to understand the nature of their human experience of having colorectal cancer and a stoma for life. My goal was to understand how the nature of their experiences after colorectal surgery and when the five year mark had been reached affected them. Also to consider how they responded to the hospital advice, that now the time is to 'go out and enjoy yourself'. I wanted to know what the participants needed during this phase of their life and to try to understand the many and varied ways in which their lives had been lived. I believe that I have been able to do this and from this have developed a care for life plan that I hope will help. However, for me this is just the first step in the journey, I now need to pilot this and then refine it in the light of the final. I have finally accepted that this is a very rewarding way to work, but that it does not stop. Everything I have done has pointed to the next steps needed and to future research, and I do hope I am able to continue this research with this group and ultimately improve their quality of life.

Chapter 10:

Conclusion.

This study was developed following my long experience of caring for colorectal cancer patients with a permanent colostomy, listening to, and trying to respond to their needs. It was apparent that despite all efforts, there was and is an apparent gap in the available literature, current government policies and recent reports regarding this particular group of patients. There was also little detail on what patients following discharge need, and how these can and should be catered for. Existing literature appears to concur with the general assumptions of some oncologists and/or surgeons that once these patients have finished their treatment they can be told to 'go off and enjoy yourself'. Nearly all of the participants in this descriptive phenomenological study reported being told this, but for them this had not led to feelings of happiness and relief (as the literature suggests), instead for them, there had been non-expressed feelings of being 'cast adrift', 'cut off', 'looking at a void', or 'a black hole'. They stated repeatedly, that over time they asked themselves 'who do I turn to' and felt that 'no-one cares anymore'. Many of the interviewees described how physical, psychological and psycho-social problems had developed that they had been unable to address with professional support and help. These had not been so evident to them on completion of treatment when their focus was on recovery, but had increasingly impacted on their lives since being discharged from treatment. Also for some, although they acknowledged there were support groups for stoma and colorectal patients, they did not wish to join such organisations, just wanting to return to their community to lead what they remembered to be an active and normal life. These findings must be shared with the professionals and programmes such as the care for life plan developed in this study used to support this group through the remainder of their life, just as MS, cardiac and other patients with long term disease trajectories are supported.

This was not really a surprising finding, with so much of today's literature concentrating on the early experiences of having a colostomy and the initial outcomes of a diagnosis of colorectal cancer. Indeed, as far back as 1952, Sutherland et al (1952), Orbach (1965), Devlin et al (1971), Thomas (1984), Wade (1989), Rubin (1986), Klopp (1990), Kelly (1991), Salter (1997) were writing about the early effects of living with a colostomy in a time when appliances were not as refined as they are today, and not all health authorities had stoma care nurses. However, by now with recognised longevity, this should have changed. It has to be accepted that patients from this era may not have seen a stoma care nurse or know what these specialist nurses could offer. It is therefore all the more important that instead of being sent home to manage what they often reported to be a faecal,

incontinent stoma, with sore surrounding skin without anyone from whom they felt they could seek advice, they need to be given access to long term support, guidance and help. These patients may never have had help choosing an appropriate stoma appliance and have spent the majority of their life 'making do' with material, yoghurt pots and bandages, they are now reaching an age when other additional comorbidities which can compound their existing problems may be arising. Over three decades ago Rubin's (1986) survey among GP practices about the aspects of stoma care in general practice found that stoma patients showed enormous physical, psychological and social traumas. His report argued that the primary care team could and should make an important contribution to their care, but that there was an apparent lack of uniformity in the quality of care provided by general practices. The Care for Life Plan, developed from this study addresses his criticisms and would address the issues cited by participants. It has been designed to cause minimal effect on the practice workload, given the low prevalence of stomas in a practice population. Patient satisfaction would undoubtedly improve and the needs of a vulnerable group of patients would then be much more likely to be met. The plan also address the lack of practical advice found in today's literature and the absence of sustainable systems designed to help stoma patients across the years of their longevity. Particularly as this study found was that the participants appeared not to have ever been offered even the initial NHS recovery package and stratified follow up recommended.

This study revealed that for the participants, supportive self-management was poorly defined or absent in their experience of follow up after cancer care, possibly not surprising in view of the little research evidence detailing how people self-manage problems and how they might be supported in practice (see supporting literature). Nor were there any clear indicators as to whether self-management was associated with enhanced quality of life, or greater confidence in managing problems. This group demonstrated that for some of them, self-management had not worked well. As has been seen in this study, the end of treatment had been challenging with for many, the worry of how they will cope with possible problems now they have been 'cast adrift' and how they can resume 'normal life'. In a country that prides itself on the NHS, for one group to be denied the reassurance provided by healthcare staff rather negates the much vaunted inclusive nature of the service.

This has to be a concern as advances in cancer prevention, diagnosis and treatment

mean more people are living cancer beyond the cessation of cancer treatment thus, this group will rise in numbers exponentially each year. While these increasing longevity rates are to be celebrated, as the participants in this study illustrate, it is essential that changes are made to enhance the experiences and needs of those who have completed their primary cancer treatment (DH, 2007). The findings from this study support previous research over a decade old, that health professionals may be unaware of who is struggling with problems (Maher & Makin, 2007), and that the issues faced by those who have completed treatment still have not been addressed. There was clearly a significant impact on the lives of the study group who have had to learn to live with a colostomy and altered body image. Most reported that they had wanted help to come to terms with their cancer diagnosis and colostomy, but had found very little support from health professionals once they had completed treatment for cancer. Also very disappointingly, those that had experienced support, reported it had been offered based on assessment for recurrence rather than on their health and support needs. This despite the fact that user involvement (and this includes support) is embedded in the United Kingdom's National Health Service policy. The participants reported that the current NHS left them with challenges they had to face alone. The care for life plan would address this and with its capacity to influence planning, service delivery, research and / or practice, it can help improve quality of life for this long term group of patients.

The lack of recognition of the needs of this group leads to another question that is equally important. This group were found and contacted. As has been identified by this research there is no way that these patients were identified if they had not come to the GPs notice. The implementation of a standard care for life plan would mean that all of them would be found through the medium of the GP practice, and help and advice could be given to enhance their lives and those of their families and close ones who may be struggling to support them. As a nurse consultant who has worked for decades in this field, their long-term care has always been a concern for me. During this time, my consultant nurse role entailed sitting on several Department of Health bodies, and the RCN forum as well as participating in the major Calman Hine (1995) report for cancer surgery. It was therefore a major concern that this study revealed that despite national and international dissemination strategies and publications, arising from all this previous work, so little evidence and knowledge appeared to have filtered down into practice. It is accepted that many of the policies and reports contain little practical advice or guidance; nevertheless the result has been a group of

patients left as one participant stated 'living in a void'. Having put so much effort into participating in a wide range of government level bodies with so little positive output, it raised questions about national, regional and local dissemination and implementation. It was evident that there was an overwhelming need for a way forward for this group of patients who had been 'cast adrift'. As national bodies had not addressed the problem in the last few decades, then this study has to be disseminated in a way that not only identifies the care needed but also a format that could be easily integrated into current health care services without major cost. Thus the conceptual framework developed was based on both theory and practice, such that it can be accepted as appropriate by both national bodies and health care professionals. The design and content arose directly from the findings from this study, and from previous research. It is feasible and appropriate and the next step has to be a pilot implementation, possibly in the Trust with whom it was discussed and who are national and international leaders in this field.

The five coping styles derived from the 30 unifying comments revealed in the first epoché, and then further refined during the iterative analyses of the five themes common to all participants. These embodied the life journey participants had to go through or, even after many years of longevity were still experiencing. It has to be a cause for concern that the participants also made it clear that most healthcare staff they encountered had little or no idea of the problems and worries that concerned them, particularly after they were given the 'all clear' and are discharged into the community. Very few of the participants, were given any details about the Colostomy Association, Expert Patient programmes or any other support groups that could be accessed either during their 5 years of treatment or during their longevity. It has to be accepted that it is easier to investigate the patients in the 0-5 year's quintile because they are under the umbrella of the hospital. Also that it is far harder to locate and track participants who have been discharged into the community and are often widespread across the UK, however, this does not negate the responsibility to search for, find and safeguard this group as whole.

The conceptual framework and model for care developed from this phenomenological study have a format that will facilitate the successful delivery of long term support by healthcare professionals and enable patients to accept a changed sense of embodied self. For GPs and practice nurses this is not seen as an onerous task, because NHS statistics show each practice only has a few of these patients (on average less than 10 Patients per practice (Rubin 1986, Black 2000,

Black 2009). Recent DH guidelines are that each GP patient should be seen yearly around their birth date for a checkup under the auspices of quality outcome framework (QoF) financial guidelines. Therefore the addition of this framework and model on the practice workload would be minimal, and a hitherto unrecognised vulnerable group of patients would thus be relatively easily accessed and supported. The Care for Life Plan would assess coping and to make it relatively simple to make referrals to appropriate other agencies as necessary. This in turn should positively impact on patient satisfaction.

With any new initiative such as this it is essential that all health professionals involved understand the concepts behind the framework as well as its use in practice. Therefore the description of the framework and model in this study includes the theoretical background to its development as well as the practical aspects. It is likely that the majority of assessments will be by practice nurses and it is anticipated that as these nurses have already undergone additional training, only a minimal additional input will be needed. This is in part because the format has been developed to enable all patients to make informed choices and therefore contains notes sections as well as explanatory guidance for patients and health care professionals. Notwithstanding this, the study has long term implications for the training, and understanding by healthcare professionals of the problems of the presumed 'well patient' post colorectal cancer diagnosis. They need to recognise and accept that problems of coping with a colostomy and the associated problems of peristomal skin damage, appliances, constipation and diarrhoea will be forever. The patient requires access to receptive and understanding healthcare professionals able to give advice when problems occur. Indeed, many of the participants in the study said that what they would like most is an annual MoT as such, even if they had no problems at the time of being seen, as they would feel that there was someone who 'cared'. Service user involvement is embedded in the United Kingdom's National Health Service, but this study revealed a major concern that needs resolving. It was very sad to find that the lived experience descriptions from the participants showed how uncaring they have found the health service and its professionals to be.

Prior to the development of the conceptual framework, the proposed model was discussed at the academic institute, of a national centre of excellence in bowel surgery, where it was well received. The inevitable division between doctors and nurses was apparent at this stage, with senior nurse researchers accepting that the qualitative descriptive phenomenological method was appropriate as to formulate the way forward in-depth

information was essential. They also confirmed the lack of appropriate research in this area and the need to address the long-term effects of stoma formation following a cancer diagnosis. Interestingly neither group could suggest how the 'lost ostomates' should be found. However, as GPs now receive payment for specific annual assessments, the 'lost ostomates' may come to light. For this project to be delivered across a wider area, the correct stakeholders from the organisations must be committed to all stages of implementation. This will need to include all of the information and deliverables that are expected as the project progresses. It will also stipulate the project boundaries specifying what is, and what is not included within the scope of the project. Written confirmation of the results the extended project will produce and the constraints that may occur need to be made, this needs to include recognition and acceptance of intellectual copyright before actual work begins. For the staff working on this next phase, training will be given prior to the start of data collection as a careful balance of practices and processes is essential.

The voluntary organisation for colostomy patients, who have been aware of the study since its origins, agreed with the findings and outcomes. They acknowledged that while patients are under the care of health care professionals they have access to information and help if they have problems, but the biggest failing is what the patient does for help once discharged from therapeutic intervention. This conceptual framework and model therefore were seen as addressing one of their major concerns. One of the integral elements of this study and of the method for data collection and analysis used, was the partnership between researcher and participants. In consequence all those interviewed were fully aware of the aims of the study and as partners were given the opportunity to have a précised copy of the final study report, Some accepted this offer, but the majority declined, just being happy to help in the hope that the study would improve the possibilities for long term access to specialist support and care.

The whole aim of the study was to make sense of these stories and experiences in a meaningful way with a view to learning more about what the participants needed, or in this case lacked, to effect change, whether that be in terms of influencing policy and practice or enhancing understanding at an individual, institutional or national level. For any such study as this, the rigour of the processes used and the impact of the study have to be considered before any recommendations can be made. Trustworthiness was addressed in the methods chapter, but authenticity could only be reviewed after the study was complete. Polit & Beck (2011) suggest that authenticity refers to the need to do justice to the actual experiences of the

interviewees and can be divided into five divisions; fairness, ontological authenticity, educative authenticity, catalytic authenticity and tactical authenticity. All of these issues were of importance to this study so have been considered. Fairness is a check that the interests of everyone involved in the study (interviewees) are protected without prejudice. It also reviews whether the interviewee's story was told within context and without major bias. In this study, this could not be separated from ontological authenticity. Only if the meanings, feelings, sense of being and lived experience of the participants were carefully and truthfully reported within context, and insights given were from the raw data could fairness be maintained. Then too, every effort was made at every stage to check the processes used and that the researcher's own biases had not led to the analysis focusing on the researcher and not the participants. The use of reflection and reflexivity were essential for this, and the structure of the processes used for data collection and analysis also protected the data gathered.

Educative authenticity which examines whether the research will contribute and/or add to the body of knowledge already available, were also important for this study, as was whether it would further health care professionals understanding of the subject. The decision to develop a conceptual framework and model based on data collected and with a theoretical underpinning has led to an output which can be utilised by both healthcare professionals and lay readers, such as the participants. It also considerably increased the knowledge and understanding of the researcher so on a personal as well as an overall level there is an element of educative authenticity in this study.

Catalytic authenticity concerns whether the study stimulates other healthcare professionals, health researchers to further advance the study or complement it with other work. Also whether for general readers and the researcher there is a wish to increase or change actions. For the professionals the study offers a wealth of information and insight into the lived experience of this vulnerable group of patients. It also has a model for practice that they can take and use in daily practice. It clearly needs piloting and more research to refine all elements. For the patient groups, the Colostomy Association will take and disseminate it, which may well lead to both individual and association level activities. For me, as the researcher, it has led to a determination to do justice to their trust, and to bring about a sea change in attitude to this group, stimulating colleagues to consider looking at other ways that could help in care provision of this particular group of people. Tactical authenticity which refers

to the ability of the research to empower wider actions cannot be distanced from catalytic authenticity as described above. In this instance they are intertwined when aiming to improve the lives of this neglected group of patients. There is every determination to seek further funding to continue the research and for the participants and patient association there may be new activities or support groups that they may feel that they would like to establish and/or participate in. For readers of the research the hope is that they will see the work as described by this group and understand the importance of the whole service working together to change and improve the care offered. By accepting the conceptual framework and model, they can improve the health access and health care of the whole group, through the development of new policies or procedures to facilitate implementation within their own areas of work.

In reflecting on the research experience I believe that I could to a degree, count myself as an insider with the participants. Although not having experienced colorectal cancer and a stoma I had experienced cancer twice with unfortunately, also a lack of an SCP and absence of a Care for Life Plan. I found I could strongly associate with the feelings these participants reported, yet the participants knew nothing of my personal history. I believe that this was correct, the focus was to develop a model to improve their care. My life experiences helped me to explore and gain good insight into their lived experience, but it was important not to add to their concerns and issues by relating my issues. Apart from this, I made every effort to be transparent with my participants in my positionality in this research. I feel very privileged by their trust and have gained so much from them. The rich data about their journey through disease and in their longevity was humbling. Nevertheless I believe that I have found what they need to maintain and enhance quality of life for their futures. I believe that my reflexive account has clarity and can support the claims that there needs to be more than a SCP for cancer patients and there is a need for the Care for Life Plan I have developed.

Dissemination of the study outcomes has begun, with the initial presentation being to the European Association for Cancer Education in Newcastle UK. It has also been presented at the Frontiers Course. St Mark's Academic Institute. UK. This is a three day course for colorectal doctors from across the world showcasing the best and most advanced colorectal surgical techniques and thus provided a second opportunity for a combined national and international dissemination. Further presentations have been planned for the:

- World Council of Enterostomal Therapists (WCET). This world meeting held every two years is a conference specifically of stoma care nurses from developed and emerging countries with more doctors attending now.
- European Council of Enterostomal Therapists (ECET). Held on alternate years to WCET. A conference for stoma care nurses from Northern and Western Europe.
- Association of Stoma Care Nurses UK. (ASCNUK). The UK meeting of stoma care nurses held yearly.
- Colostomy Association yearly conference. National voluntary charity for people with colostomies.
- Frontiers. A conference held by St Mark's Hospital (centre of excellence for gastro intestinal care) annually, for doctors worldwide.
- Beating Bowel Cancer. A UK charity for patients, doctors and nurses.
- Association of Coloproctology. A tripartite meeting for doctors (with a nursing chapter) held around the world.

Publications are in the process of development for the British Journal of Nursing, Gastrointestinal Nursing Journal and for Tidings the Colostomy Association patient magazine. These three publications have been selected as offering the widest access to nurses with an interest in gastrointestinal nursing. However, it is accepted that wider peer reviewed journal access is needed and therefore future planned articles include on-line journals such as research gate and open access journals, for example the International Journal of Nursing Studies and medical interest journals such as GUT – Journal of GI surgery for doctors.

Recommendations.

This study has yielded the lived experience descriptions and thoughts and feelings of colorectal cancer patients with a colostomy who amongst other perceptions feel “cast adrift’ now that they have no recourse to intensive healthcare input. Also that there is no-one now to turn to for help and advice. The consensus from the findings was such that the following tentative recommendations have been made:

- There needs to be policy recognition that this patient group needs lifelong access to specialist care and support. This needs to entail a protocol that directs healthcare professionals to instigate the Care for Life Plan on final discharge from therapeutic intervention (currently five years after diagnosis) starting with an initial appointment 6 month review. This should include a formal discussion of the future

possible guidance for patients and family. The Care Plan list need to be annually reviewed to ascertain what the patient may have indicated to be a current issue,

- GPs and Practice nurses should access the Patients Recovery Package, the Treatment Summary and Cancer Care Review completed on discharge from therapeutic intervention. There needs to be recognition that the yearly check up by either the GP or Practice Nurse should take into account the patient's co-morbidities and the effect these may be having on the patient. (Note: Dealing with cancer fatigue can be one of the hardest issues).
- CCGs and GP practices need to go through their medical records and identify patients with colorectal cancer and a colostomy. Therefore, practice nurses need to attend a recognised course for stoma care which leads to competence in recognising common problems for this patient group.
- There needs to be recognition of the possibility of social isolation amongst long term patients in this group, and this should be addressed with information on support groups or patient liaison and visiting i.e the Colostomy Association. This needs to include a formal assessment of possible emotional and psycho sexual issues with referral to appropriate agencies as necessary

The final word has to be from two cancer patients:

.... "Providers must try to understand the impact of cancer on their patients' lives and the lives of their patients' caregivers. They should focus on both the negative and positive effects of cancer and its treatment, and be as energetic and considerate in treating the cancer patient (and hopefully, survivor) as they are in treating the cancer itself."

Tierney and McKinley (2002:11127).

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