

**AN EVALUATION OF THE NEEDS OF PATIENTS RECEIVING
PALLIATIVE CARE FOR UPPER GASTROINTESTINAL CANCER AND
THEIR MAIN CARER**

CLARE HELEN BYRNE

PhD 2010

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**A thesis submitted in fulfilment of the requirements of
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ABSTRACT

Background

Only 20% of patients at diagnosis of gastrointestinal cancer will be suitable for potentially curative surgical resection, and then only 5 -10% of these will survive to 5 years. Most individuals die within twelve months. Whilst the relief of physical symptoms is essential and contributes to improving quality of life, such patients are also likely to have psychosocial needs.

Psychological adaptation has been found to be positively influenced by the coping resources available to individuals e.g. physical and emotional well being, their values and beliefs, support from family and their social network. Carers' levels of psychological distress, when cure is no longer an option, can be extremely high. Evaluation and research of the organization of generic palliative care in specialist gastrointestinal cancer is limited.

Method

An exploratory case study design using contextual triangulation was used. 34 patients receiving generic palliative care for gastrointestinal cancer, 30 main carers and 28 bereaved carers were interviewed and completed measures of psychological well-being. Patients also completed the Concerns Checklist.

Findings

Whilst the main message in the literature had suggested that psychological distress manifested as depression was underestimated in patients with cancer, this study did not support these conclusions. There were however, high levels of anxiety, concerns and adjustment disorder in patients. Fisher's exact test was highly significant ($p=0.002$) for anxiety and poor disclosure in patients. Contributing factors to this are

explored. Patient anxiety was significantly correlated with total concerns ($r = 0.419$, $p = .017$)

In carers Fisher's exact test was significant for psychological distress and information ($p = .029$) with a trend for younger female carers and bereaved carers to be more anxious than older carers. There was a clear association between insensitive disclosure, unmet information needs, poor coordination of care and increased psychological distress in carers, with unresolved consequences when bereaved.

Implications Results demonstrate the need to proactively manage those affected by these cancers of limited prognosis. Individual assessment of patient and carers at an early stage of their referral to a specialist gastrointestinal cancer centre, with particular attention to psychosocial needs, use of sensitive disclosure, tailored information and coordination of care may promote positive appraisal of coping resources, improve adjustment and increase psychological well-being.

Conclusion

This study has illustrated the wide diversity amongst those affected by incurable gastrointestinal cancer. The perceptions and concerns of 92 people have been listened to, and their levels of psychological well-being measured. It offers new insight in a number of areas and in particular the association of health service care and how this increases or decreases access to coping/ improving levels of psychological well being.

The current case study using triangulation was able to reveal individual meaning as well as collaborative interpretation of the constituents and processes of living, dying, or caring for someone with incurable gastrointestinal cancer. The breadth of such an approach has not been found previously in a British study in gastrointestinal cancer, and this exploratory and explanatory approach provides evidence and a strong new insight into the effects of incurable gastrointestinal cancer upon those affected. Such

results hold potential for practical application and key quality issues which address how a specialist gastrointestinal cancer service should develop its standards of care and audit practice.

By entering the participant's world, although very briefly, this study has explored the perceptions and concerns of those affected by incurable gastrointestinal cancer, and links with coping and psychological well-being. There is a need to pursue this work with ongoing study, whilst publishing and promoting evidence of the positive outcomes for all parties involved.

Organisation of the Thesis

The thesis is structured in six main sections:

- The Preface serves to outline the rationale for the study to be undertaken.
- Chapter One is a review of the literature which identifies the concepts to be considered and attempts to set the scene for the remainder of the project.
- In Chapter Two the methodological issues are explored including the rationale for the complementary approach adopted.
- Chapter Three describes the study including the data collection methods and the framework for analysis.
- Chapter Four focuses on presentation and discussion of the three stages of analysis and results.
- In Chapter Five the study findings are discussed in relation to current theory. Conclusions and implications for practice and the limitations of the study are explored.

Preface

The reconfiguration of cancer services following the Cancer Plan (2000) and the release of national guidance for palliative and supportive care (NICE 2004) encouraged the adoption of the palliative and supportive care strategy at all stages of the cancer journey. The responsibilities that the development of a specialist cancer centre for gastrointestinal cancer might have for meeting the needs of those affected by this cancer is currently unclear and has been the focus of this work.

In an attempt to identify the psychological needs of those affected by incurable gastrointestinal cancer, the present study explored the service users perspective of their experiences of living with incurable gastrointestinal cancer or having cared for a close relative or friend with gastro intestinal cancer, and examined what they considered was important or made a difference to their psychological well being.

Gastrointestinal cancer affects one in fifteen hundred people in the UK. Despite investment in research and advances in earlier detection and diagnosis, the treatment of this cancer remains a challenge to all healthcare professionals involved, with many patients presenting with advanced, incurable disease. The role of nursing in meeting the physical, psychological, social and spiritual needs of those affected by such cancer is still uncertain. Whilst an abundance of literature exists in palliative care on the management of cancer patients at the end stage of life, whether this evidence is applicable at an earlier stage at the transition to incurable disease is less well known.

The present study arose from an interest in the psychological needs of patients with cancer and a specific interest in the needs and concerns of those presenting with incurable gastrointestinal cancer. It developed against a background in and reflections upon advanced nursing practice as well as previous research by Byrne (1997), which

identified the information needs of patients with metastatic liver cancer, and other patient concerns, including needs of their carer which required further investigation.

CHAPTER ONE

REVIEW OF THE LITERATURE

1.1 Introduction

The experience of patients with cancer is increasingly documented in the literature. Much concerns patients affected by one of the major cancers such as breast or lung, or studies involving mixed cancer populations. Most studies are undertaken by health care disciplines, particularly those working in the field of medicine, nursing, sociology and psychology. Many studies involve individuals during the early stages at diagnosis, though there is increasing evidence in the palliative and terminal phase. There are few studies involving those affected by gastrointestinal cancer which examine the perception and concerns of patients and carers in the transition to the palliative phase of their cancer when cure is no longer an option, or the consequences for those involved when bereaved. In light of this, the aim of this review is to identify other studies including those with mixed cancer types and in palliative care where the interventions and outcomes might be compared and contrasted with gastrointestinal cancer. The research methods and methodology chosen to create knowledge in these studies has been critically examined in an attempt to determine whether the findings can inform or increase our understanding of the impact of incurable gastrointestinal cancer, and whether such methodology could be useful in the proposed study. Whilst performing a systematic review might have been the ideal, it was not possible because so many studies are not comparable, principally because of their methodology. However, in an attempt to offer structure, five criteria identified by Maxwell (2002) were used in a reflexive way as a framework to judge the value of the knowledge established from the research in this review. These included:

- An assessment of the research for its descriptive validity: an accurate recording of what happened
- An assessment of the research for its interpretive validity: how accurately the interpretations reflect the individual's perspectives
- An assessment of theoretical validity which serves to question how well the account serves as an explanation of the phenomenon
- An assessment of generalisability which looks at the ability to infer from the account
- An assessment of evaluative validity looks at how knowledge from the research can be utilized.

Attention is shifted in this framework to the need for a reflexive review of the research process underpinning the generation of knowledge construction, widening the perspective, taking a critical stance as to what contributes to evidence and knowledge. Whilst summarizing the review of many studies through this adapted narrative approach does have limitations, the approach has been supported through critical synthesis of the literature by comparing, combining and contrasting it, identifying strengths, weaknesses, consensus and gaps, reflecting on its relevance to established theoretical, epistemological and ontological assumptions and its influence on the development of policy and cancer clinical practice.

The literature will be discussed in five sections:

- Part 1.2 identifies the literature search plan.
- Part 1.3 examines current cancer healthcare policy to establish the context of the study.

- Part 1.4 begins the more rigorous analysis of the literature and examines psychological distress, psychological well-being and coping.
- Part 1.5 reflects on the relevance of palliative and supportive care to the study and explores the literature on the core component of psychosocial care.
- Part 1.6 examines the literature on carers and bereaved carers in cancer.
- Part 1.7 provides a summary and identifies the research questions.

1.2 Literature search plan

Evidence based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients (Sackett et al., 1996. p.71). In order to identify the existing evidence and to identify and support the research questions a comprehensive literature search was carried out at the beginning of the study, and was subsequently updated as the study proceeded. It was considered essential to review the literature during the long process of the study in order to keep up to date and identify developments in the field, as these might have implications for the findings of this study. Literature was reviewed in this section up to 2004 when analysis commenced. Subsequent literature up to 2007 was reflected upon in the Discussion. The following databases were searched;

Cochrane Library of Systematic Reviews (regularly updated to 2007)

CINAHL (1985- 2000, regularly updated to 2007)

Medline (1985-2000, regularly updated to 2007)

PsychLit (1985-2000, regularly updated to 2007)

From previous knowledge of the literature and previous academic study, and as a senior nurse working in the field the researcher was aware of key aspects of the literature which would require review and which in turn might inform selection of other literature in order to refine the research question. At the start of the study the following search terms were used:

Palliative care

Experience of cancer patients

Perception of cancer patients

Experience of carers

Perception of carers

Experience of bereaved carers

Perception of bereaved carers

Anxiety and depression and cancer

Psychological distress and cancer

Psychomorbidity and cancer

Coping and cancer

Gastrointestinal cancer – incidence and survival

Cancer Policy

Carers Act

Carer Policy

1.2.1 Inclusion and exclusion criteria

Abstracts were read online and the search was refined by excluding studies which looked at early stage disease. Further citation and the reference lists of relevant studies were scanned in an attempt to identify further relevant studies. A strong inclusion criterion for the literature review was when a study included a method that captured the patient and/or carer experience of advanced cancer, and in particular their perception of that experience. This might be for example, a phenomenological or narrative approach. Research methods that also captured measurement of psychological distress in advanced cancer were also sought, as well as use of mixed method or triangulated approaches.

Wherever possible, attempts were made to include literature from studies undertaken in the United Kingdom (UK), as it was considered that these would most likely reflect the current healthcare system, healthcare policy and the practice of healthcare workers. However, there are a small number of studies included which are outside of this range, but which provide seminal work. Much of this complementary literature is from Scandinavia, North America, Australia, Canada and Europe and although not directly, may be comparable to the UK. Throughout the study the databases were monitored using the same search terms and additional works were noted and utilized as appropriate. The inclusion and exclusion criteria very much reflected the reflexive approach to the literature review, recognizing the exploratory, evaluation and explanatory nature of the cancer study set alongside a need for a methodology that would include a strong participant focus.

The results of the literature search were categorized into sections or domains according to their major research focus. For example the section examining the literature

on psychological distress and cancer revealed many sub-sections including an exploration of psychological distress and anxiety and depression, which then led to review of design and methods of studies examining screening measures used in cancer. An examination of coping theory and cancer resulted in an exploration of coping theory, but also the design and methods of non-cancer studies increasing our knowledge of coping theory and coping strategies.

Table 1.1: Table to illustrate one category of the Literature Search

DATABASE	Main Subject Headings	Search Refined By:	RESULTS	FINAL SELECTION
MEDLINE	Palliative care Anxiety and Depression Patients	Boolean Operator "And" Main Subject Heading in Title Only	124	23
Psych Lit	Palliative care Anxiety and Depression Patients	Boolean Operator "And" Main Subject Heading in Title Only	131	17
BRITISH NURSING INDEX	Palliative care Anxiety and Depression Patients Qualitative	Boolean Operator "And" Main Subject Heading in Title Only	83	22
CINAHL	Palliative care Anxiety and Depression Patients Qualitative	Boolean Operator "And" Main Subject Heading in Title Only	23	11
TOTAL			361	73

Section 1.5 combines both description and critique of Specialist Supportive and Palliative Care policy, but also reviews design and methods used in studies that have provided the evidence for such policy.

However, the first section (1.3 Health care policy and cancer) is predominantly descriptive, though with reflection and critique by the author (a clinician working in the environment governed by such policy). It was considered essential to use such a reflexive approach in order to demonstrate an understanding of, and provide a rationale for the context of the proposed research study by examining current policy, and whether our current knowledge base can both support its implementation and evaluate what the key issues are in cancer clinical practice in order to achieve an improved service for those affected by gastrointestinal cancer.

1.3 Healthcare policy and cancer

A major consideration in the selection of the literature was the recognition of several policy developments within the NHS. The main ones were:

- The framework for the delivery of quality in healthcare, “A First Class Service: Quality in the New NHS”, (Department of Health 1998).
- The Report of the Chief Medical Officers Advisory Group on Cancer (Department of Health 1995).
- The NHS Plan (Department of Health 2000a).
- The NHS Cancer Plan (Department of Health 2000b).
- The Manual of Cancer Service Standards (Department of Health 2000c).
- The Nursing Contribution to Cancer Care (Department of Health 2000d).
- Palliative and Supportive Care Strategy (The National Council for Hospices and Specialist Palliative Care Services 1995, 2000).
- Improving Supportive and Palliative Care for Adults with Cancer. National Institute for Clinical Excellence (NICE 2004).

- End of Life Care Strategy (Department of Health 2004).

Because of several changes in recent years that have influenced healthcare practice it was considered important to select policy literature published during the last ten to fifteen years. A reflective critique of the policy documents has explored the implications for service provision (including nursing) for working towards quality cancer care. Throughout other sections of the literature review reference and further critique has been made to these policy documents, and whether there is any empirical evidence to show that their implementation is promoting and supporting improved cancer services and really making a difference to what matters to adults with cancer and those close to them. From this, it has been possible to identify any deficit in both our current knowledge and in service development and provision.

1.3.1 The quality agenda in healthcare

The present Government is committed to place quality at the heart of healthcare (NHS Plan, Department of Health, 2000a). The framework for the delivery of quality in healthcare, “A First Class Service: Quality in the New NHS”, (Department of Health, 1998), identified a structure for developing and monitoring standards in practice (clinical governance). It stressed how organizations are now accountable for quality and that simply counting numbers and measuring activity is no longer enough. The emphasis is on what matters to patients. Healthcare professionals are being encouraged to develop a collaborative partnership with their patients, to value the patient’s opinion and contribution, and to consider the person as a whole in a more holistic healthcare approach (Department of Health 1998; Department of Health, 2000).

The seminal report from The Audit Commission (1993) claimed there was a definite communication and information void between healthcare professionals and patients. It was found that the manner in which doctors spoke to patients, and such incidents as addressing patients when they were undressed or being told bad news when they were on their own were examples of practice that needed prompt attention. Furthermore, not only were patients not getting the information they felt they needed, they also felt denied information, and many commented that any information they received was often of poor quality. In cancer care, studies and reports identified similar problems and concerns, particularly in relation to communication (Fallowfield, 1993; King's Fund, 1996; The National Cancer Alliance, 1996). Such early studies have provided a baseline within the literature against which improvements can be measured, and areas requiring further improvement identified.

From this early part of the literature review it can be concluded that:

- There has been a drive over the last decade to provide high quality personalized healthcare, with an emphasis on what matters to patients. Strategies and policy have supported this through the development of guidance and the measurement of standards in practice (clinical governance).
- It would appear that key generic issues on which the implementation of such quality initiatives depend, including communication and information, have shown only minimal improvement.
- As such, whilst the guidance might exist, the processes that assure its successful implementation appear to be less well understood and developed.

1.3.2 The NHS Cancer Plan

Cancer is high on the political agenda in the quest for quality improvement. The NHS Cancer Plan (Department of Health, 2000b) has built on 'A Policy Framework for Commissioning Cancer Service', (The Calman Hine Report, Department of Health, 1995), and developed the wider health changes inherent in 'A First Class Service' (Department of Health, 1998), and The NHS Plan (Department of Health, 2000a). The Cancer Plan, (viewed as a potential template for other diseases), identified an approach to tackle inequalities and set out a proposal for modernising the NHS through new national standards and new ways of working to prevent and treat cancer. A tripartite structure for cancer services has been implemented through the development of cancer networks, (specialist cancer centres, smaller cancer units in smaller hospitals treating common cancers and primary care). The main tools utilized were 'The Manual of National Standards (Department of Health, 2000c)', based upon the principles and recommendations of the Calman Hine report plus evidence-based "Improving Outcomes guidance" on tumour specific sites (e.g. breast, urology, colorectal, lung and gynaecology). Together, they identified the structure and process of care to provide the framework for local cancer networks to assess the quality of care they provided through performance indicators, regular patient feedback, self assessment, peer review groups and benchmarking. Recent policy has therefore emphasized the need for improved assessment of cancer patients, including all domains of physical, psychosocial and spiritual care (NICE, 2004). Guidance for the treatment of patients with specific cancers, such as colorectal cancer has mirrored these concerns, where professionals are encouraged to understand the concerns of patients from the patients' perspective. However, whilst a

structure has been developed to provide quality cancer care, as a senior nurse working in a specialist gastrointestinal cancer centre, it seems imperative to identify and understand the rationale and evidence supporting such policy in order to identify how it might be implemented locally and by whom. Because of the minimal evidence available, investigation which includes service users in the process of enquiry may reveal a structure that is more patient and carer focused. For example, whilst the emphasis is on providing a more holistic approach to cancer care by including a regular assessment of physical, psychosocial and spiritual needs in patients, exploring the experience of those affected is likely to inform who should undertake such an assessment, when and how often, as at present this appears uncertain. Furthermore, if a specialist gastrointestinal cancer centre is to be able to assess the quality of care it provides it needs to reflect a questioning culture of research. It must be able to continually provide and update the evidence of issues that are important to those affected by this type of cancer by adopting research methods that enable their participation and thus can underpin quality change in practice.

1.3.3 The NHS Cancer Plan: Review of Progress

In 2003, the Department of Health issued a three year progress report on the Cancer Plan (Department of Health, 2003). Mortality rates seemed to be falling, cancer networks were being established, services were being streamlined, cancer prevention was being addressed. However, there were still many areas that required improvement including a need for more patient information about treatment, and provision of support and care at the end of life. In what seemed to be a timely response, the National Institute of Clinical Excellence issued the manual 'Improving Supportive and Palliative Care for Adults with

Cancer' (NICE, 2004). This guidance document was to underpin the 'The Manual of National Standards (Department of Health, 2000c) as key integral components of palliative and supportive care across the whole cancer experience. This evidence based document appears key to the way services are planned and delivered by Cancer Networks. Some of its strengths lie in the inclusion in its design of a wide range of individuals who play an important role in the care of those affected by cancer. These include patients, carers, health professionals, social service and voluntary sector workers (e.g hospital, hospice and primary care, charity organizations and community self help groups). As a result of this, the emphasis is on meeting needs through the assessment and regular reassessment of the patient and those close to them as the framework for the provision of all aspects of supportive and palliative care. As an immediate consequence it is apparent that communication and interpersonal skills of those involved in order to elicit concerns and assess needs will be key.

However, implementation of this guidance has not been instantaneous, despite revision of the Manual of Cancer Services (Department of Health, 2004) to accelerate the pace of improvements and to define the characteristics of a good service based on the recommendations of the NICE (2004) guidance. At this stage the Cancer Plan was revised, and the NHS identified a range of tools to implement the NICE (2004) guidance. The aim was to improve the quality of life for all patients affected by cancer and to enable more patients to live and die in their place of choice (NHS End of Life Care Programme 2004; Liverpool Care of the Dying Pathway, 2003). Alongside these, and in order to improve the primary and secondary care interface, a decision was made to introduce a third tool for community palliative care called The Gold Standards

Framework (GSF) (Thomas 2003) across all cancer networks. Whilst the GSF had been piloted in only a limited number of areas, its aspirations and aims as a process framework to enable those approaching the end of life to be identified, their care needs assessed, and a plan of care with all relevant agencies put into place, was viewed as an essential and very practical part of implementing the NICE (2004) guidance. The Gold Standards Framework focused on optimizing continuity of care, teamwork, advanced planning (including out of hours) symptom control and, for the first time, an assessment of carer needs and staff support. A group of patients who could well exemplify these issues are those affected by gastrointestinal cancer, many of whom present at diagnosis with advanced, incurable disease with limited prognosis.

The implementation of the NICE (2004) guidance should in theory have potential benefits for those affected by advanced gastrointestinal cancer. However, it is apparent from the generic cancer and palliative care literature that there are still areas that require improvement with particular concern about the weak links between primary care, social care and palliative care providers.

As has been revealed elsewhere in the literature, communication and information seem to be key. In a specialist gastrointestinal cancer centre we need to have the evidence to show what communication processes might be effective and how this can improve the experience for those involved. This evidence will only be accurately secured and provide a firm foundation if studies are undertaken involving patients and carers.

1.3.4 The Nursing Contribution to Cancer Care

The Nursing Contribution to Cancer Care: a strategic programme of action in support of the national cancer programme (Department of Health, 2000d) set out to ensure a

coherent, seamless, high quality service – from prevention, through primary care and screening services, diagnosis, treatment, rehabilitation and palliative care for all those affected by cancer. The Manual of Cancer Service Standards (Department of Health, 2000c) complements the Cancer Nursing strategy, and recommends that each patient should have access to a named clinical nurse specialist (CNS), who can offer support and continuity of care. This nurse should know about the patient's cancer and treatment, should work closely with those who provide palliative care, and should play a central coordinating role in each multidisciplinary treatment team.

1.3.4.1 The Clinical Nurse Specialist role in cancer

Whilst nurses do seem to play a significant part in the process of caring for the large majority of individuals affected by cancer, much of this care remains hidden, almost unnoticed and invisible (Corner, 1997). Although government policy supports localness, responsiveness and convenience, and the emphasis is on primary care for cancer patients, what is striking is an apparent dichotomy of concentrating CNS expertise in secondary and tertiary cancer hospitals for it is here that disease site specific cancer CNS's have been expanded in great numbers (Hill, 2000). The growth of such specialist nurses seems unplanned and unregulated and the support and coordination role of the CNS within the multidisciplinary cancer team seems quite implicit with a lack of clarity about what it is supposed to achieve (Ackerman, 1997), and with limited guidance available from policy documents (Booth et al., 2001).

These uncertainties are set against concern about the lack of clarity of terms such as emotional care and support for patients with advanced cancer. Skilbeck and Payne (2003) critically examined the literature using combinations of the key words 'emotional

support', 'emotional care', 'end of life', 'palliative', 'terminal illness', 'advanced cancer', 'Clinical Nurse Specialist', 'emotional labour'. The results of this identified that the use of the terms emotional care and support were ambiguous and lacked clarity, and there was a presumed understanding of their use. Skilbeck et al (2003) suggested that there are complex processes involved in the development of supportive nurse-patient relationships, and that the key to getting to know the patient lies in the use of effective communication skills. A strength of this study was that it also pursued the consequences for engaging in emotional work, and that those who engage in such relationships require support themselves. They concluded that existing research fails to recognize that emotional care and support as a concept is not a fixed, stable process learnt through experience and socialization, but is moulded by the process of social interaction and by specific contexts and theoretical perspectives. They further suggest that there appears to be a need to understand better what happens when emotional care and support are delivered in different care settings, calling for further research that can capture the views of those involved.

An area of increasing evidence is how the majority of studies of both hospital and community based palliative care nursing involve the CNS working within a multidisciplinary Specialist Palliative Care Team as opposed to a CNS working as a member of a disease specific cancer multidisciplinary team, such as a Lung cancer or Gastrointestinal cancer (Department of Health, 2000c). Whilst the specialist palliative care CNS will predominantly work with patients and their carers when life is limited, the disease specific CNS will work with patients and their carers at an earlier stage of the cancer trajectory. This role normally functions from the point of referral when the patient

presents with symptoms suspicious of cancer, through diagnosis, treatment, on going surveillance including issues around cure, survivorship, recurrence and transition to incurable disease. This functional aspect of the role is considered important because the disease specific CNS should be working within the supportive and palliative care guidance (NICE, 2004). How useful palliative care CNS studies are in identifying what makes a difference to those affected by gastrointestinal cancer could not be assessed from the literature available. However, it is anticipated that much of the palliative CNS literature will be relevant in relation to for example core communication skills and an ability to accurately assess and elicit concerns.

Over twenty years ago, Watson et al (1988) provided a template for specialist nurses working with cancer patients. The emphasis was on identifying and recording the patient's health and social care needs, and evaluating their impact on that individual's daily life, including their quality of life. i.e. needs being what an individual perceives as required to be met in order to maintain or improve current states of well-being or to anticipate and manage their deterioration (Watson et al., 1988). They found that the proper assessment of a cancer patient around the time of diagnosis, including assessment of their physical, psychological and social adjustment, educates them to realise that it is legitimate to reveal any problems that develop. However, there seems to be limited evidence in the cancer literature of how the hospital based disease site specific CNS role continues to impact on the patient or carers lives in cancers other than in relation to information needs in breast cancer (Beaver et al., 1996), and no studies were found on the value of the coordination aspect of the role.

In contrast there are an increasing number of studies, many using mixed data sources, which demonstrate the effectiveness of specialist palliative care teams in primary care (Higginson, Wade and McCarthy, 1992), secondary care, including the effectiveness of the hospital specialist palliative care CNS (Jack, Williams and Oldham, 2002) as well as the role of the hospital lead cancer nurse (Kirshbaum, Booth and Luker, (2004), Whilst the focus of these studies might not inform the current study directly, the value in examining these studies was to consider whether any of the roles researched and the research methodology might inform the current study.

For example, using a two stage case study approach, which had the advantages of identifying the potential complexity of organizational and service phenomena as well as dealing with multiple sources of data (Yin 2003), Kirshbaum, Booth and Luker (2004), evaluated the role of the hospital lead cancer nurse. With an exploratory focus, information was collected about post holders in such areas as the post, working contexts, evidence of achievements. This was then complemented by an explanatory phase which examined the processes that enhanced or inhibited the development of lead nurse posts within each organization. Whilst this study yielded an abundance of observational and documentary data of the 26 participants, including 20 audio-taped interviews, from a methodological perspective it illustrated how adhering to a structured and systematic framework for recording, organizing, displaying and analyzing multiple sources of qualitative data in a series of matrices (Miles and Huberman, 1994) can promote more accurate analysis, interpretation and validity. This made both the method and the results accessible to the reader in a format that allowed a greater understanding of how aspects of the study methodology might be analytically generalized to other studies.

However, as a clinician working in the field, a major concern is the lack of evidence of how the disease specific CNS role functions. For example how effectively does this role communicate with agencies such as the same hospital specialist palliative care team, community nurses, GP's and social workers?

As a further consequence of lack of evidence in the literature, it was decided to examine the literature outside of cancer looking at models of generic advanced nursing roles. Research undertaken by Castledine (2003) and the USA Case Management literature of Zander (2002) was helpful in defining how the CNS might make a difference in cancer care, by demonstrating what it is about specialist nursing roles that makes them unique and of value. Whilst acknowledging that a specialist nurse is someone who focuses their knowledge and skill on the specific medical and nursing needs of a particular group of patients, Castledine (2003) suggested the role encompasses nine core competencies including direct clinical care, improving quality and health outcomes, evaluation and research, teaching and educating others, leading and developing practice, innovation and change, dissemination, developing self and others, and an ability to work across professional and organizational boundaries,

It seems evident that there is both a need and an opportunity to assess the relationship between the quality of CNS cancer nursing care practices and interventions and patient outcomes, and such competencies as Castledine (2003) has identified might be useful. Research that identifies the needs and concerns of individuals, and the means by which they may be assisted during the earlier part of their cancer trajectory could provide valuable insight and a forceful argument for cancer nursing as a therapeutic enterprise in its own right (Corner, 1997). Such enquiry also has the potential to be illuminating

because it is an area where the supportive and palliative care aspects of management and psychosocial care seem to be the key.

- Whilst there has clearly been a drive over the last decade to provide high quality personalized healthcare, there appear to be key generic issues of communication and information, on which implementation of such policy greatly depends, which have shown only minimal improvement.
- Roles and responsibilities to implement cancer policy (including nursing) seem quite implicit with a lack of clarity about what is supposed to be achieved and by whom, and a need for better understanding of terms such as emotional care and support for patients with advanced cancer.
- How useful palliative care CNS studies are in identifying what makes a difference to those affected by gastrointestinal cancer appears uncertain. However, a number of palliative studies have used a methodology that enables their findings to be generalized to theory, providing useful insight into what might be important in the CNS role at an earlier stage of the gastrointestinal cancer trajectory.
- Higher level competencies in communication skills underpinned by strong leadership skills may lie at the core of the CNS role within the multi-disciplinary team, reflecting a philosophy which enhances the skills of others whilst retaining the capacity for flexibility. This role has the potential to ensure that new and sustained models of cancer care will meet the diversity of individual needs, rather than be restricted by a bio-medically dominated culture.

1.3.5 Gastrointestinal cancer

- Gastrointestinal cancer is the second most common form of cancer and is associated with high mortality.
- Cancers of the oesophagus, stomach, pancreas, gallbladder and cholangiocarcinoma (collectively known as the upper gastro-intestinal cancers), led to 21,447 deaths in the United Kingdom in 2000, or 13.5% of all cancer deaths **(Cancer Research UK 2003)**.
- Primary Liver cancer (Hepatocellular carcinoma) led to 2,432 deaths in the United Kingdom or 1.5% of all cancer deaths. **(Cancer Research UK, 2003)**.
- Metastatic colorectal liver cancer led to 21,623 deaths in the United Kingdom in 2000 or 14.7% of all cancer deaths. **(Cancer Research UK, 2003)**.

Table 1.2 Incidence rates, survival rates and death rates in Gastrointestinal cancer (Cancer Research UK 2003)

Cancer site	Incidence: United Kingdom 2003		One year survival rate	Five year survival rate	Deaths United Kingdom 2003	Death rate per 1,000,000 England & Wales 2003	
	Men	Women				Men	Women
Oesophagus	4,271	2,809	27%	9%	6,919	146	87
Stomach	6,337	3,675	28%	12%	6,608	138	83
Pancreas	3,250	3,419	12%	3%	6,897	114	116
Hepatocellular	1,418	966	13%	5%	2,432	48	34
Colo-rectal liver metastases	9,250	8,400	95%	40%	21,623	394	330
Gallbladder	137	373	9%	2%	575	N/A	N/A
Cholangio carcinoma	557	469	13%	6%	1,023	N/A	N/A

Figures for incidence, survival rates and deaths are shown in Table 1.2. Poor survival figures in most of these cancers are principally attributed to the late stage at

which the disease can become apparent. Recognising that poor management in gastrointestinal cancer may be a significant factor, the emphasis is on providing quality care by experts in specialist cancer centres, supported by research evidence indicating that treatment in hospitals where clinicians manage larger numbers of patients, leads to better outcomes (Bachmann et al., 2002; Bachman et al., 2003). However, such specialist centres often cover an area of up to 100 mile radius, as was the case in the current study. No literature was identified in relation to patient and carer experience of investigations, diagnosis and treatment and the consequences of this for their psychological well being prior to their referral to a specialist cancer centre. Exploring this aspect of the cancer trajectory with those who have experienced it may help to better inform the process of gastrointestinal cancer care, and in particular the responsibilities of non-specialist hospitals managing patients in these early stages of diagnosis.

Inspection of Table 1.2 indicates that the majority of these cancers generally carry a poor prognosis. Only 20% of individuals at diagnosis will be suitable for potentially curative surgical resection, and then only 5 -10% of these will survive to 5 years. If surgery is not an option, or if the disease recurs after surgery, palliative oncological interventions such as chemotherapy, radiotherapy, or endoscopic / radiological stenting can prolong life. However, most individuals die within twelve months of incurable diagnosis (Blazeby et al., 1995; Hugh, Kinsella and Poston, 1996; Fitzsimmons and Johnson, 1998; Poston, 2004).

Since so many of these cancers present at a late stage, with limited prognosis, it is considered that both patients and those close to them are likely to have individual unmet needs. This is a group of patients which is under researched, but there is a requirement for

those specialist cancer centres involved in the care of such patients to ensure that their practice is evidence based. Whilst an abundance of literature exists on the medical management of such patients, little is known about the psychosocial needs of such individuals, and the key aspects of supportive and palliative care management which make a difference to them. Such enquiry has the potential to inform the psychosocial management of other cancers of poor prognosis.

1.4 Psychological distress and cancer

1.4.1 Background

It was not until the early 1970's that the measurement of outcomes in cancer care took account of the psychological issues of quality of life of individuals affected by cancer (Greer and Morris, 1975). With a few exceptions, outcomes had been restricted to survival time and recurrence free survival. Before this time it was also commonplace for doctors not to disclose diagnosis and prognosis to patients, though often informing other family members. As well as this paternalistic approach, there was a commonly believed assumption that because anxiety and depression were natural, inevitable reactions to cancer, psychological treatment was not feasible. Set against this model of care, systematic enquiry that included the patient perspective on care and quality of life was simply not accessible.

Research and clinical reports by such pioneers as Glaser and Strauss (1964) and Hinton (1964) and the development of the hospice movement (Saunders 1959, 1977) saw a shift from only relying on the measurement of clinical outcomes to the measurement of factors that were likely to be of direct concern to patients, such as sensitive issues relating

to disclosure of a terminal prognosis or discussion about preferred place to die with patients and their relatives.

1.4.2. Psychological distress

The disclosure of a diagnosis of cancer invariably brings with it a range of emotional responses. These may result in negative as well as positive psychological outcomes, but it is the negative outcomes such as anxiety and depression which seem to impair the individual's capacity for pleasure, reducing quality of life, including an inability to gain meaning in life and curtailing normal social interaction with others (Hopwood, Howell and Maguire, 1991; Payne, 1992; Lloyd-Williams, 2003).

The terms psychological and emotional distress seem to be used interchangeably (Callahan et al., 1998; Pini et al., 1995). Psychological distress is predominantly viewed in the cancer literature as a clinical disorder most frequently identified as anxiety and depression (Brody et al., 1997; del Piccolo et al., 1998), with minimal evidence of studies using a broader subjective state (e.g Morrasso et al., 1999). In the cancer literature it is defined as an unpleasant, emotional experience of a social or psychological nature that is tied to and interferes with the ability to effectively cope with cancer and cancer related treatment (Passik et al., 2003). In this context it seems to have been adopted by healthcare professionals to avoid a perceived stigma by patients, and refers to a non-diagnostic assessment of the patient's psychological state. However, in a study in primary care Brody (1997) revealed how the term emotional distress fails to describe patient healthcare needs. Four hundred and three patients were asked "how much effect has emotional distress had on the way you have been feeling and functioning?" 60% considered emotional distress was having some effect, whilst 18% felt it was affecting

their feelings and ability to function to a great deal. Whilst 63% felt it was important for their GP to help with their distress, only 17% of patients met the criteria for a diagnosis of psychological disorder such as anxiety or depression. What is significant here is that whilst emotional or psychological distress was a significant health care need for 60% of participants, a clinically diagnosed psychological disorder could only be applied to one third of the study sample. This study supports how the pathological model of mental health and illness is relatively underdeveloped in comparison with our understanding of physical illness (Pilgrim and Bentall, 1999). It therefore seems imperative that when assessing psychological need in patients, their own assessment of the impact of their perceived illness on functioning should be incorporated into the appraisal of health care need.

Others have also argued that the reliance in the majority of studies upon classifying people as anxious or depressed limits understanding by researchers of the scope of cancer patient's psychological distress. For instance Breitbart et al. (1995) and Folkman (1997) argue that the classification of psychological distress as a clinically distinct phenomenon of anxiety or depression ignores the many different aspects of psychological distress and even psychological well being that may occur during the course of an illness.

In identifying predictors of psychological distress in cancer, the following risk factors have been identified by Harrison and Maguire (1994) who used a checklist approach:

- previous history of mood disturbance,
- high emotionality,
- low ego strength,
- poor performance status,

- certain types of treatment e.g. colostomy,
- lack of social support,
- recent losses,
- passive or avoidant coping with a tendency to pessimism,
- unresolved concerns,
- a history of alcohol abuse,
- lack of information,
- communication problems,
- previous suicide attempts.

Much of the literature stress how aspects of both mood and malaise can be present in all stages of cancer, and this may contribute to the difficulty for health professionals in distinguishing between normal aspects of the cancer illness and anxiety and depression (Maguire, 1985; Block, 2000; Lloyd-Williams, 2003). Consequently if healthcare professionals assess depression as a normal feature of cancer, there is a risk that depressed cancer patients may go undiagnosed and untreated (Block, 2000).

1.4.3 Anxiety and cancer

Anxiety has been described as the subjective feeling of fear that encompasses dread and apprehension (Massie, 1989, cited in Holland and Rowlands, 1989). It may be vague and represent ill-defined general emotions including tension, restlessness, jitteriness, autonomic hyperactivity, insomnia, shortness of breath, apprehension and worry (Passik et al 2003). The types of anxiety most frequently encountered in cancer include reactive anxiety that is related to crises, anxiety related to medical influences such as pain, or hormone producing tumours, and anxiety that is related to preexisting anxiety disorder

that is exacerbated by the medical illness such as phobias, panic or anxiety provoked by cancer treatments or their side effects (Massie, 1989). It has been suggested (Maguire, 1995), that anxiety in cancer is induced by the patient perceiving threats to survival and well being and their uncertainty about the future. Maguire (1995) also considers how anxious patients, like depressed patients, tend to be selective in recalling 'more threatening information' given to them, and importantly, how the process of explanation can be therapeutic in itself.

A major significant area influencing level of anxiety is the stage of cancer. Whilst patients with early stage cancer can often have a long life expectancy, patients diagnosed with advanced cancer or those with a recurrence or metastatic spread have to face the emotional consequences of imminent death, and this emotional burden usually causes intense emotional reactions, including clinical states of anxiety (Galuszko, 1996).

Passik et al (2003), suggested that it is often related to existential issues, with patients fearing isolation, and estrangement from others and a risk of feeling like an outcast, with such social aspects as financial burdens and family role changes as common stressors.

1.4.4 Depression and cancer

Depression in the patient with cancer, like anxiety, is one of the most difficult psychological problems to identify. It is defined as a disorder in which mood and vitality are lowered to the point of despair, where patients report that life is meaningless and experience feelings of misery and hopelessness (Lloyd-Williams, 2003). As a simple cut off point depression is said to be significant when the sadness response (e.g. depressed mood, insomnia, fatigue, feelings of worthlessness, diminished ability to think) to a disclosure of a cancer diagnosis or poor prognosis, lasts over two weeks (Barraclough

1994). Lloyd-Williams (2003) suggested a useful concept when considering whether a patient is depressed is that the patient who blames the illness for how they are feeling is probably experiencing sadness, whereas the patient who blames themselves for their illness and how they are feeling may well be depressed.

Depression is considered by some experts to be the most common psychiatric problem in patients with advanced cancer (Lloyd-Williams, 2000), and it has long been established that treating psychiatric disorders such as depression in such patients can improve their quality of life (Maguire et al., 1985). The major concern arising from the literature is that it appears to be under diagnosed (Lloyd-Williams, 2000), and therefore remains untreated.

1.4.5 Assessing psychological distress -advanced communication skills

Block (2000) suggested that there is some reluctance amongst many healthcare professionals to initiate and explore psychological issues with their patients as they are concerned this will exacerbate the patient's distress (Lloyd-Williams and Payne, 2003). However, another reason seems to be emerging from the literature which offers some reasons why health professionals feel powerless to influence the situation and so do not intervene. Several studies (Booth et al., 1996; Heaven and Maguire, 1996; Wilkinson, Roberts and Aldridge, 1998; Lloyd \Williams and Payne, 2003) indicate that the main reason why clinicians do not pursue these sensitive issues with patients is their lack of communication and interpersonal skills to draw out and explore patients concerns and so failing to identify and meet their information needs and decision making preferences.

In a longitudinal study to investigate the effect of skills training in communication for hospice nurses Heaven and Maguire (1996) used a repeated measures design to assess

the impact of a ten week communication skills teaching programme which included individual feedback on practice tapes with patients, carers and actors. Forty-four nurses completed the pre and post and nine month follow up intervention assessments of an audio-taped recorded assessment interview. This study supported the proposal that in order to assess the needs of an individual a higher level of communication skills is required, and that video demonstration and audio feedback can improve skills. However, the advantage of the longitudinal methodology was that it demonstrated that the transfer of skills to the work-place with associated improvement and maintenance of skills over time was not guaranteed. Whilst the use of open questions improved, it did not prevent use of blocking behaviours (where they or the patient changed the focus or switched topic), which increased. Furthermore, there was little improvement in eliciting patient's concerns which by 9 month's post training had decreased below the pre-intervention levels from 51.7% to 37.5%. This was one of the first communication skills nursing studies to incorporate quantitative measures though Wilkinson (1991) had reported 50% of nurses in her communication skills study using blocking behaviours. Comparison with studies of training clinicians report changes of 25-35% (Gask et al. 1988; Maguire et al., 1989) suggesting that other factors appear to be important and need to be considered if communication skills training and maintenance of skills is to be effective (Booth et al., 1996).

In a key study examining blocking behaviours, which had clearly been identified as prohibitive to eliciting patient concerns (Wilkinson, 1991; Heaven and Maguire, 1996), Booth et al. (1996) developed the research process in this field by comparing perceived professional support and the use of blocking behaviours by hospice nurses. There was a

very definite hypothesis to this study, namely that blocking behaviours were likely to be used by nurses when patients disclosed their feelings, but used less when nurses felt they had satisfactory professional support. In an 18 month prospective study to test the impact of training in key assessment skills, 41 hospice nurses in two different hospices assessed a patient's current problems both before and after feedback training and then 8 months later. The interviews were audiotaped and were assessed by trained raters' according to the frequency of nurse responses that resulted in blocking disclosure in the patient, and the emotional level of patient disclosure. Prior to the start of each patient assessment the nurse was interviewed and completed a 4 point questionnaire to assess perception of support received.

Although only half the sample completed the study, 113 interviews were completed; 72 from nurses who remained in the study, 41 from those who left. Whilst this might have been considered a threat to the validity of the study a number of issues were taken into consideration when examining independence of interviews and links with support. These included the fact that there was no significant difference in drop out between the two hospices, and also the key finding that there appeared to be very little positive training effect that might influence the data.

The use of trained raters' in this study emphasized the importance of inter-rater reliability in the design. This was calculated through the use of two independent raters counts of four interview behaviours. The random selection of twenty-five interviews and the calculation of Spearman correlation and Wilcoxon matched pair signed rank tests demonstrated that there was high agreement with no significant difference between raters for open-directive questions ($r = 0.93$, $P = 0.469$) and psychological focus ($r = 0.93$, $P =$

0.231). Likewise, the values for blocking ($r = 0.0.64, P = 0.109$) although lower were considered acceptable for the purposes of the study. However, the use of inter-rater reliability also identified a significant trend ($P = 0.005$) for one trained rater to award higher values. Consideration was given by the researcher as to how these findings could influence the overall results. In a similar vein, acknowledging what might be perceived as a threat to validity, when the tapes from the hospice nurse were all rated by the trained rater shown to have a tendency to award lower values it was considered that disclosure of patient's feelings in the hospice data had to be considered as conservative.

Despite the training, only a weak level of improvement was measured in pre and post intervention. The number of blocking behaviours was significantly associated with patient disclosure of feelings, with greater use of blocking behaviours evident when patients disclosed feelings (Kendalls $r = 0.36, P < 0.001$). The second prediction of the hypothesis was also confirmed. Where less blocking behaviours were used, more disclosure of patient feelings and concerns were evident ($r = -0.24, P < 0.5$). Furthermore, when nurses felt supported in their professional role, both practically and emotionally, less blocking behaviours were used ($r = -0.37, P < 0.005$).

As with Heaven and Maguire (1996), this study has identified quite clearly how other important factors, such as professional support need to be recognized and provided if this fundamental aspect of care to those affected by cancer is to be improved and maintained.

1.4.6 Adjustment disorder and cancer

The American Psychiatric Association (1994 pp.1216) define adjustment disorder as 'a rather nebulous disorder characterized by a variety of clinically significant behavioural or emotional symptoms that occur as a result of some triggering event or stressor'.

Despite apparent high prevalence of adjustment disorder in up to 30% of patients with cancer (Dugan et al 1998), it was found in the literature review for this study that psychological distress in cancer tends to concentrate on the assessment of anxiety and depression. Passik et al. (2003) in exploring the relationship of adjustment disorder and depression discussed how adjustment disorder is sometimes classed as minor depression with its relationship to depression viewed on a continuum. However, there are no clear guidelines and Passik et al. (2003) expressed concern about the difference in such terms as minor depression and sub-clinical depression. Their view is that the two disorders are quite distinct with major depression viewed as symptom based where for example anhedonia might be experienced for more than two weeks (Lloyd-Williams, 2003), whilst adjustment disorder affects function in such areas as an inability to maintain normal role function, with the presence of coping inflexibility in response to their cancer as the critical component of adjustment disorder.

This coping inflexibility theory is resonant of Folkman (1997) and Folkman and Greer (2000) who argue that the emphasis on measuring symptoms of anxiety and depression reveal only part of the story of how people cope with illness. Another quite different part of the story concerns psychological well-being and the presence or not of coping processes that support it, including the individual's own resources. Antonovsky (1979) suggested that a person's coping ability is a crucial determinant of their adaptation and perception of well-being, and this aspect would appear to be crucial in adapting to a diagnosis of incurable cancer. The idea that people can experience psychological well-being despite their illness may at first seem counterintuitive, but some studies have

shown that people do experience well-being (cheerfulness, feeling positive) under the most difficult of circumstances (Folkman, 1997; Chesney et al., 1996).

- It is clear from the literature that psychosocial assessment and care is important in cancer. However, in order to assess patient need and elicit concerns advanced communication skills training is essential. Evidence is emerging that the effects of such training will only be improved and maintained if those healthcare professionals involved perceive themselves to have access to, and receive appropriate emotional support.
- In assessing psychosocial need it is apparent that just measuring anxiety and depression reveal only part of the story of how people cope with illness. Another quite different part of the story seems to concern levels of psychological well-being and the presence or not of coping processes that support it, including the individual's own resources.
- What is not clear from the literature is what strategies contribute to improved levels of psychological well-being and how can such strategies be promoted and maintained in those dealing with a life threatening disease.

1.4.7 Prevalence of psychological distress and cancer

Recent guidance suggests that healthcare professionals should be able to screen for psychological distress at key points along the patient pathway (NICE, 2004). However, estimating the prevalence of affective disorders in cancer populations is difficult partly because different studies use different assessment and diagnostic methods (Payne, 1998). In addition, there are numerous variables which have been long established and known to influence affective disorder, and may therefore confuse the true prevalence rate. These

include the type of cancer (Massie and Holland, 1989; Northouse, 1995); the precise definition used by the investigators, the disease stage (Barraclough, 1994 Northouse, 1995); treatment factors including undergoing treatment, undergoing different types of treatment, and being assessed at the start or end of chemotherapy treatment (Ibbotson et al., 1994); age, gender and time since diagnosis (Harrison et al., 1994) poorly controlled symptoms and, in particular, pain (Barraclough, 1994).

There is a consensus that about one in three of patients with cancer have increased psychological distress compared to one in ten of the normal population (Block, 2000). However, in the cancer population, it has been suggested that this may be an underestimation (Ibbotson, 1994; Lloyd-Williams, 2000), because of the difficulty in identification (Lloyd-Williams, Friedman and Rudd, 1999; Chochinov, 1997; Barraclough, 1994). Much of the evidence is based on the more frequently occurring cancers such as breast and lung at different stages along the cancer trajectory (Hopwood, 1991; Fulton, 1998; Kramer, 1999). Increasing evidence available from studies with mixed cancer types (Cull, Stewart and Altman, 1995; Grassi et al., 1996), have shown higher rates of depression in those with a greater level of disability and discomfort, and in those in the end stage of palliative care (Chochinov et al., 1994; Hinton, 1994; Hopwood, Howell and Maguire, 1991; Payne, 1992; Lloyd-Williams, 2003).

1.4.8 Assessing psychological distress

Lloyd-Williams, Friedman and Rudd (2003) suggested that whilst patients should be able to describe their own symptoms of psychological distress, many patients with advanced cancer are either unwilling or unable to do so, and often underestimate their distress. Proxy assessment by a close friend or relative (Addington-Hall and McCarthy,

1995) can also be inaccurate and often reflect their own distress rather than that of the patient. Similarly, inaccuracy in healthcare professionals was found by Ford, Fallowfield and Lewis (1994) who reported one investigation in which five oncologists completed self-reports on their assessment of their patients well being, including depression. When these were compared with reports the patients made themselves, the comparison indicated that the oncologist constantly underestimated depression levels.

It has long been recognised that the best way to identify depression is through a structured gold standard interview (McDaniel et al., 1995), a factor confirmed in cancer by Chochinov et al. (1997). The use of The Psychiatric Assessment Schedule (Dean et al 1983) appears to be the ideal and this was used in conjunction with DSM-III criteria (American Psychiatric Association, 1980) by Parle et al. (1996) to assess if the participants had experienced a major depressive episode, generalized anxiety disorder or adjustment disorder in the period since diagnosis.

However, less time consuming, screening measures can be useful in the clinical assessment of patients (Barraclough, 1994). Most measures are comprised of a number of symptoms or feelings on which the patient gives a response and then a score is calculated - usually by the person administering the measure. Any patient identified at risk can undergo a more detailed structured interview to assess more accurately their level of psychological distress. Whilst such a screening system could be routinely used to identify the likelihood of depression in for example, a busy outpatient clinic, studies have shown that they are not ideal for diagnosing depression in patients with cancer (Sellick and Crooks, 1999; Lloyd-Williams et al., 2001). Many instruments have been validated on physically well patients, and in cancer many have been validated with patients affected

by early disease or those undergoing active treatment with limited application in palliative and terminal care (Lloyd-Williams, 2003).

Thus, whilst the likely occurrence of psychological distress is acknowledged in the literature, its prevalence is less well understood, with concern of the consequences of under diagnosis and under treatment, and few studies assessing those affected by gastrointestinal cancer. It is apparent that the best way to identify psychological distress including depression is through a structured gold standard interview, but evidence is emerging that less time consuming, screening measures can be useful in the clinical assessment of patients. In those affected by all cancers, including advanced gastrointestinal cancer where life is limited, use of such instruments might become an important issue in relation to the requirement to regularly assess for psychological distress at key points along the cancer trajectory.

1.4.9 Validity of screening measures

Where screening tools are used by clinicians, the number and range of quality of life issues raised and discussed has been found to increase (Ryan et al., 2005). The selection decision on the most appropriate clinical tool should be based on validity, reliability, responsiveness to change, feasibility and acceptability to patients (Lloyd-Williams et al., 2003). They stress how crucial the issue of validity of screening measures is because validity assesses whether the measure actually measures what it is supposed to measure. The assessment of validity is measured against a predetermined gold standard (McDaniel et al., 1995). Examples of gold standards are a rigorous clinical interview or a method such as the Present State Examination (Wing 2007), a semi structured interview where responses are coded and by means of entry into a computer data programme a psychiatric

diagnosis can be obtained. A number of cut-off thresholds are selected and the thresholds analysed for:

- (i) sensitivity – the number of patients scoring at this threshold or above who are actually true cases
- (ii) specificity – the number scoring below a threshold who are true non-cases
- (iii) positive predictive value (ppv) – the probability that a score at the threshold or higher would be a true case
- (iv) negative predictor value (npv) the probability that a score at the threshold or lower would be a true case

Bowling (1995), Gibbon (1998) and Lloyd-Williams (2003) suggested a number of criteria that should be achieved when assessing validity. Knowledge and application of these criteria appear essential when considering use of a measure of psychological distress and include:

- **Face validity:** are the questions reasonable and do they appear to be measuring what it is claimed they are measuring? Is the measure relevant, reasonable and acceptable for those who will be using the measure
- **Content validity:** do the components of the measure assess all aspects of the variable to be measured? Each item should reflect at least one of the content areas being measured. The number of items should reflect the importance given to each variable and be balanced.
- **Criterion validity:** can the variable be measured accurately? Can the scale be correlated with another measure, which is suitable and can be predefined as a 'gold standard'?

- **Construct validity:** this is based on a theory or assumption of the association and correlations of some items of the scale and is then examined to establish if they are correct. This is usually required when a gold standard is not available.

Breitbart et al. (1995) and Payne (1998) reiterate how the problem with identifying valid and reliable measures of psychological distress for use in clinical practice is also relevant to their use in research with palliative and terminal care patients.

It is therefore apparent from other cancer and palliative care studies that a key issue in developing knowledge about those affected by advanced gastrointestinal cancer is to be able to undertake studies that assess levels of psychological distress. However, the decision on the most appropriate clinical tool should be based on validity, reliability, responsiveness to change, feasibility and acceptability to patients. The application of these criteria across a range of measures should help to refine this process.

1.4.10 Examples of screening measures and their use in cancer

1.4.10.1 The Hospital Anxiety and Depression Scale (HADS)

This scale measures both anxiety and depression and gives an index of state and a cut-off for probable clinical levels. Maguire and Selby (1989) and Selby (1992) have recommended the HADS scale for use with patients with cancer because it is short and does not contain any somatic items. Several studies have used the HADS to measure anxiety and depression (Fulton, 1997; Payne, 1992). The HADS has been reported by Ramirez et al. (1995) as a valid instrument when used in newly diagnosed patients, whilst Hopwood et al. (1991) also report it is valid and effective for patients with advanced breast cancer.

However, concern has been expressed about using the HADS as a single measure for anxiety and depression in palliative care patients (Urch, Chamberlain and Field, 1998; Lees and Lloyd-Williams, 2001). In a study of 100 patients receiving palliative care, with a prognosis of 6 months or less, Lloyd-Williams Friedman and Rudd (2001), found that two items of the depression sub-scale were consistently given a high score. These were those related to subjective well-being and activity, ('I still enjoy the things I used to enjoy', and 'I feel like I've slowed down'). Lloyd-Williams et al. argued that it is understandable that palliative care patients respond positively because of their physical disease, and that these two items are therefore poor discriminators for depression in patients with advanced metastatic disease. However, it might also be argued that because patients are so overwhelmed by fatigue at this stage of their disease, these aspects do influence their psychological state. Urch, Chamberlain and Field (1998) illustrated one of the practical considerations when working with debilitated terminally ill patients, finding that the HADS was too long and complicated for those involved to understand and complete.

Le Fevre et al. (1999) and Lloyd Williams et al. (2001) have suggested that the combined score of the two scales is more appropriate. Le Fevre (1999) identified 20 as the 'at risk' category for psychological distress, with a sensitivity 77%, a specificity of 85% and a positive predictive value (ppv) of 48. Lloyd-Williams et al. (2001) found the optimum threshold was a combined cut-off of 19 with a sensitivity of 68%, a specificity of 67% and a positive predictive value (ppv) of 36%.

1.4.10.2 Beck depression inventory

This consists of 21 items with a four point scale response, totalled to achieve a score. It was developed with psychiatric patients and has thresholds for both research and clinical use. A 13 item shortened version has been validated with medical patients, and correlated well with the original scale. It has been used extensively with patients with chronic medical conditions such as back pain (Poole 2006), but its use in cancer appears limited, though one study (Chochinov et al 1997) did demonstrate it to be an effective measure of depression in this population. However, its use in palliative care is questioned. Valentine and Saunders (1997) challenged the use of the Shortened Beck Depression Scale (BDI-SF) with a terminal cancer population as it includes somatic items very closely related to cancer symptoms.

1.4.10.3 The General Health Questionnaire¹² (Goldberg 1992)

The GHQ-12 (Goldberg 1992) is a shortened version of the validated GHQ-30 (Goldberg, 1978). The scale was designed to give a general indication of psychiatric caseness rather than a definite diagnosis of depression (Goldberg et al., 1997). The GHQ-12 has been shown to perform well by comparison with the longer version of the GHQ30 in detecting psychiatric disorder (Goldberg et al., 1997). Each of the 12 items asks whether the respondent has experienced a particular symptom or item of behaviour recently, using a four point scale; "less than usual", "no more than usual", "rather more than usual", or "much more than usual." The scale is self-administered and takes about 5 minutes to complete. Selby (1989) suggested that the GHQ30 works less well with cancer patients and Le Fevre et al. (1999) found that the GHQ 12 did not perform as well as the HADS in identifying cases for depression in a palliative care in-patient setting.

1.4.10.4 The European Organisation into Research and Treatment of Cancer

Quality of Life Questionnaire (EORTC QLQ-C30)

This is a generic questionnaire for assessing quality of life in patients with cancer. This instrument has been developed by The European Organisation into Research and Treatment of Cancer (EORTC) Quality of Life Study Group. The questionnaire was designed to be supplemented by questionnaire modules specific to a particular cancer or treatment. Modules are being developed according to strict guidelines published by the EORTC and are available in lung, breast, head and neck cancers, colo-rectal, pancreatic cancer (Fitzsimmons and Johnson, 1998), oesophageal cancer (Blazeby et al., 1995) and gastric cancer (Blazeby, Conroy and Bottomley, 2004b). However, the modules for hepato-biliary cancers including primary and metastatic liver have not yet been completed and tested in the international field. Whilst the disease specific modules should improve the sensitivity of the core instrument to monitor the outcome effects of curative, palliative and adjuvant treatments, there has been concern expressed that the EORTC QLQ- C30 and its modules have limited scope for measuring psychological levels in patients with cancer (Skarstein et al., 2000).

Whilst the process of development and testing the psychometric properties of tools is documented in the general population, in early stage cancer, in those receiving active treatment, and in increasing evidence in palliative care, there seems to be uncertainty about their viability in the gastrointestinal cancer population. Table 1.3 illustrates the advantages and disadvantages of measures explored for inclusion in the proposed study. If such measures are to be of value in clinical practice, and for the proposed study, they need to be able to indicate whether a patient has symptoms of psychological distress,

rather than being a diagnostic tool. In selecting an instrument for those affected by advanced disease there is also the requirement that the tool will be minimally burdensome, easy to administer and score. This is of particular importance because it is apparent that using one measure on its own may not accurately reflect whether symptoms are due to the cancer or to psychological distress. A further advantage of exploring the validity of measures has been the identification of tools validated with a general population that might be used effectively with a presumed well population, such as carers in the proposed study.

Table 1.3 Advantages and disadvantages of measures explored for inclusion in the proposed study

Measure	Uses	Advantages	Disadvantages	Use in proposed study
The Hospital Anxiety and Depression Scale (HADS)	Measures anxiety and depression. Validated in early advanced breast cancer	Short and does not contain any somatic items	Concern about using it as a single measure in palliative care.	Combined scores may be more valid Second data source useful. Minimal use in carers.
Beck depression inventory (BDI)	Chronic medical conditions (e.g. back pain)	Short	Limited use in cancer, includes somatic items closely related to cancer symptoms.	Could be used with carers
The General Health Questionnaire12 (GHQ 12)	Gives a general indication of psychiatric caseness rather than a definite diagnosis.	Self-administered and short	Validated on general population. Does not perform as well as the HADS in a palliative care setting	Could be used with carers
The European Organisation into Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ - C30)	A generic questionnaire	Validated in a range of cancers	Has limited scope for measuring psychological levels in patients with cancer	Not suitable

1.4.11 Concerns and psychological distress in cancer

An area of assessment that seems useful in exploring the wider aspects of psychological distress is the assessment of concerns in the cancer literature. It has long

been established that people with cancer have a variety of concerns and that these have an influence upon psychological distress (Maguire et al., 1980). However, there is currently little empirical knowledge about the nature of those concerns and their relationship with psychological distress in individuals affected by gastrointestinal cancer. Thus, the literature on the association between cancer patients' concerns and psychological distress in the newly diagnosed (Harrison et al., 1994; Parle, Jones and Maguire, 1996) and in a limited number of studies in palliative care patients (Heaven and Maguire, 1997, 1998), including when patients are dying (Morasso et al., 1999; Maguire et al., 1999) have been explored.

Many of these studies use a triangulated approach, capturing data through both quantitative measures and qualitative interviews. Heaven and Maguire (1997) effectively used such an approach to show how psychological, social and spiritual concerns are less likely to be divulged by patients, but that these are important aspects of assessment as they are more associated with psychological distress. Likewise the use of different data sources examining the physical and psychological needs of patients dying from colorectal cancer, (Maguire et al., 1999), demonstrated how the prevalence of affective disorders in patients was 22%, which was lower than the 33% reported in studies of patients with advanced breast cancer (Hopwood et al., 1991). Significantly, Maguire et al. (1999) found that carers had a greater prevalence of affective disorder. Such a methodological approach gives emphasis to capturing data with an individual perspective as well as a statistical measure. Nevertheless, patients had unresolved problems with pain and several unresolved concerns including their illness, physical strength and inability to do things. This relationship between concerns about symptoms and psychological distress has been

identified by others in relation to fatigue (Weisman and Worden, 1977), breathlessness (Bredin et al., 1999), and pain (Derogatis et al., 1983).

Morasso et al., (1999) found that patients with a decreased functional state, unmet needs relating to symptom control, occupational functioning, emotional support, nutrition, sleep, self-fulfilment, communication and emotional closeness, all showed significantly higher psychological distress. In a key study, exploring maladaptive coping, Parle, Maguire and Jones (1996) identified that patients with 4 or more concerns had a greater tendency to develop anxiety and/or depression.

This thought provoking aspect of the literature has demonstrated the importance of assessing the wider aspects of psychological distress in patients and how use of additional tools can contribute more accurately to assessing individual psychological need. This does not just refer to the use of two measures, but rather to the use of a combination of data sources in a triangulated approach. Key studies have shown how psychological, social and spiritual concerns are less likely to be divulged by patients and how concerns and levels of psychological distress can vary in cancer populations, but can also be an indicator of distress in the individual in the future. Taking this into account, the use of a multi-method approach in the case of those affected by gastrointestinal cancer would appear to have potential for strengthening the research process.

1.5.11.1 The Concerns Checklist (Harrison 1994)

This checklist was developed with lymphoma patients. They were asked open ended questions in order to identify their main concerns. It has been shown to be reliable and clinically useful with other cancer groups (Devlen, 1984; Heaven et al., 1997, Maguire et al., 1999). It is a 13 item measure. Concerns include current illness, physical symptoms,

treatment, feeling different, feeling upset, inability to do things, future, job, finances, relationship with partner, relationship with others, sexuality, and amount of support.

In a study by Heaven and Maguire (1997), forty two nurses from two hospices in England were asked to interview patients and assess their concerns before and after training, and nine months later. Interview transcripts were then rated to identify concerns disclosed. Within twelve hours of each interview a research nurse used the Concerns Checklist (Harrison and Maguire, 1994b), and a semi-structured interview to elicit patients' concerns, and requested patients to complete the HADS and the Spielberger State Anxiety Scale (Spielberger 1983).

Results showed that patients were highly selective in what they disclosed and there was a high tendency to disclose physical symptoms. Overall 60% of concerns as determined by the interview remained hidden and concerns about the future, their loss of independence and appearance were not disclosed in more than 80% of patients. Those patients who were more anxious or depressed were less likely to disclose concerns. There was a correlation between anxiety and depression and low disclosure of concerns. Disclosure difference correlated significantly ($p < 0.001$) with the anxiety ($r = 0.4942$) and depression ($r = 0.3901$) subscales of the HADS and with the total score ($r = 0.4338$) of the HADS. It also correlated with the Spielberger State Anxiety Score ($r = 0.5150$).

The nurses registered and documented only 40% of the concerns disclosed to them at interview, and less than 20% of concerns were identified appropriately. It was also found that nurses were very selective about which categories of concerns they registered, and sometimes interpreted and documented concerns that were not actually disclosed at interview. Physical worries of pain, nausea and vomiting, appetite, weight loss

predominated in the interview, whilst concerns over their cancer, bowel function, treatment and emotional worries were not registered. The patient's main concern was identified and recorded in only 45% of cases. Thus the study highlighted that open or semi-structured interviews may not cover the range of issues, or convey to the patients areas that may or should be discussed and that a more proactive or structured approach may be needed.

This study has added to our understanding of what communication and interpersonal skills and techniques can promote disclosure of concerns in patients, and like Booth et al. (1996) has highlighted that there are other support facets essential for achieving and maintaining effective communication other than development of communication skills training. In considering the relevance of this study both as a research methodology and for assessing the needs of those affected by advanced gastrointestinal cancer in a specialist tertiary cancer centre, there are issues that require further exploration. For those healthcare professionals involved on a daily basis in assessing patient need, it is apparent that creating a healthcare environment and culture that invests in support to healthcare professionals has the potential to achieve more accurate assessment of patient need, and the identification of those at risk or experiencing psychological distress. Whilst such an investment could be interpreted as a key quality initiative, with the potential for improving quality of care and even quality of life for both recipient and healthcare professional, a study that specifically focuses on using and testing the mixed methodology of checklist, interview and measure of psychological distress to explore the perceptions and concerns of those affected by gastrointestinal cancer should have the potential to provide a more critical insight into capturing their

needs, and how such needs might be more accurately assessed and met by healthcare professionals in a specialist cancer centre.

1.4.12 Information and levels of psychological distress

Through examining a number of studies using in-depth interviews with patients (Byrne, 1997), and with patients and carers (Wilson Pateman, Beaver and Luker, 2002) and Beaver Luker and Woods (2000)), it was evident how research participants were able to interpret and describe their experiences.

Byrne (1997), in an exploratory qualitative study explored the information needs of patients with metastatic liver cancer, and found most patients had complex, unmet needs. A key variable was managing uncertainty. Patients valued talking with a clinician who could directly address their concerns, and had the strategies and skills to meet their individual information needs, also reported by Ford, Fallowfield and Lewis (1996). Other issues included what information to give and at what stage of the adaptation process, as too much or too little information can result in increased risk of anxiety and depression (Fallowfield et al., 1990). This need for an individualised approach has been addressed across the cancer literature (Beaver et al., 1996; Fallowfield, 1995; Taylor, 1988; Maguire, 1998 and Chan and Woodruff, 1997). It does appear that patients with cancer adjust and cope better with their situation if they perceive they have received appropriate information (Butow et al., 1996). Byrne (1997) also found that patients perceived carers' information needs to be different from their own. A number of patients in this exploratory study had inoperable disease, and indicated that more specialist support would have been welcomed after the acute phase of care when the patients returned to the community and as the disease progressed. The National Cancer Alliance (1996) (in a study designed to

capture the patient's perspective) argue for a link person in order to ensure continuity and to anticipate the needs of individuals living with cancer.

Recent qualitative studies examining support roles in primary care have reiterated the importance of access to information. Wilson et al. (2002) in an interview approach found that both patients and carers had unmet needs for psychological support related to information about nutrition, and that carers, as in Beaver Luker and Woods (2000) study, especially those not resident with and not related to the patient who had greatest information needs. Unfortunately, such studies seems to suggest that unmet information needs among cancer patients and their carers may reflect the failure of healthcare professionals to provide, interpret and reinforce the information available. This reflects another aspect of the wider issues in relation to competence in advanced communication skills, as it has consequences for both assessing and meeting individual's information needs.

From a methodological perspective, whilst these studies each employed a small sample, this had the advantage of allowing the interviews to be in depth. The analysis was by a team of researchers in the patient and carer studies which increased the reliability of the findings by reducing the potential bias of the single author study.

1.4.12.1 Decision making

It has been suggested that patients' attitude and coping resources and their ability and willingness to be involved in decisions about their management may well be influenced by previous experience of disclosure and information received (Faulkner and Maguire, 1994; Beaver, Bogg and Luker, 1999). A study, though with small sample size, in patients newly diagnosed with colo-rectal cancer (Beaver et al., 1999) identified only a

significant minority of individuals wanted to be involved in decisions about their care. This may be influenced by the difficulty in translating scientific data from clinical trials, where evidence is still emerging about best treatment options and under what circumstances, into language that can be understood. Rothenbacher Lutz and Porzolt (1997) demonstrated how most patients with advanced cancer wanted a collaborative or active role in decision making but 28% desired a passive role. Again, this reinforces the need for healthcare professionals have skills to ascertain both involving patients in decision making, and to assess their individual information needs at all stages of cancer, as it has been highlighted that different ways of describing the outcomes of treatments may have a dramatic effect on patient treatment decisions (Poston and Byrne, 2006).

- At this stage of the literature review it can be seen how the core issues of an individualized approach and effective skills in communication are emerging repeatedly as necessary and complementary if quality cancer care is to be provided.
- Different research methods have shown how assessment of need may not be possible through one source, and demonstrate the value of using multiple data sources not only to widen the perspective of a research study, but also how such approaches might be beneficial in the clinical environment.
- Whilst patients are encouraged by policy to be involved in decision making about their care, and there is evidence emerging that patients with advanced cancer want a collaborative approach to decision making, it is also apparent that the emphasis has to be on healthcare professionals' communication skills utilized through

individual assessment and reassessment of the patient's desire to be involved in decisions about their care.

1.4.13 Psychological distress, concerns, and gastrointestinal cancer

Since curative surgery is not an option for many patients with gastrointestinal cancer, and given the high incidence of recurrence and poor prognosis, these patients are likely to have physical and psychosocial needs. In attempting to meet these needs, healthcare professionals may begin by trying to alleviate the physical symptoms such as pain, jaundice, weight loss. Fitzsimmons and Johnson (1998), in a grounded theory approach examined the perception of quality of life between health professionals and patients with pancreatic cancer. A key finding was that whilst the health professionals attributed changes to symptoms, patients did not. In fact the two factors that appeared to be linked to the quality of life were perceived threat and the maintenance of control, an aspect also elicited by Parle Jones and Maguire (1996). Fitzsimmons and Johnson (1998) also argued that the coping strategies available to the individual mediated between these factors and the quality of life. Thus psychosocial factors in the face of poor prognosis appear to be a key issue.

In a longitudinal study with 141 patients with gastrointestinal cancer, Nordin and Glimelius (1999) examined the possibility of predicting anxiety and depression 6 months after a cancer diagnosis and interviewed patients soon after diagnosis, at 3 months (if incurable), and at 6 months. The interview comprised structured questionnaires to assess anxiety and depression, coping and subjective distress. Their findings indicated that anxiety and depression assessed close to diagnosis was predictive of a similar status 3 and 6 months later. The number of patients in need of psychological intervention, however,

was small. The addition of data on coping strategies and subjective distress did very little to improve the prediction. Whilst distress seemed to decrease for most patients independently of psychological support from health care staff, some individuals had high levels of either anxiety or depression or both, not only soon after diagnosis, but also during follow up. Because of the longitudinal approach it can be suggested that for these individuals, psychological intervention may be necessary, and this study strongly reinforces the importance of on going assessment. This gastrointestinal cancer study is resonant of the longitudinal study with a mixed cancer group of newly diagnosed patients by Parle, Jones and Maguire (1996), who identified that the occurrence of 4 or more concerns at diagnosis was indicative of increased psychological distress in the future. Again, the benefit of a longitudinal approach is reflected in the findings of a more recent palliative care study by Lloyd-Williams and Riddleston (2002) which suggests that screening palliative care patients for depression at referral or first assessment may be useful in assessing depression within the palliative care setting.

The findings of these longitudinal studies, some of which involved those affected by gastrointestinal cancer, reinforce the suggested guidance (NICE, 2004) of the benefits of an initial assessment at diagnosis and ongoing assessment of psychological need throughout the cancer trajectory. However, as has been broached, there are resource implications, not yet clearly defined.

1.4.13.1 Qualitative approaches in Gastrointestinal cancer research

A qualitative approach was used by Rozmovits and Zeibland (2004) who chose to explore the lived experience of patients with colorectal cancer and the impact of the disease through the use of narratives. Their sample was taken from patients attending

support groups. It could be argued that Rozmovits and Zeibland (2004) attempted to reduce bias through the use of narratives since they allowed participants to talk about the issues that were important to them and not issues which were the predetermined interest of the researcher. They aimed to recruit a maximum variation sample in order to identify the broadest range of experiences. Higginbottom (2004) states this is in keeping with qualitative research methods, since the purpose of this research is to understand the patient's experience and not to create generalizable findings. What was also notable about this study was a more pragmatic approach where the authors remained flexible in their research design by re-interviewing one participant whose reversal of colostomy operation failed. Litva and Jacoby (2002) acknowledge that the social world is constantly changing, thus the researcher must remain flexible in their research design and adapt to changes as they arise.

The benefits of using a qualitative approach, where little is known, is reflected in this recent exploratory study which has helped us generate knowledge about how people interpret and experience their world affected by one of the gastrointestinal cancers. Information from professionals, management of physical symptoms, the importance of family support and the development of coping mechanisms were issues important for patients. However, the usefulness of this study may be compromised because whilst there was a lot of evidence of approaches to increase validity, the importance of reflexivity was overlooked, and it was not possible to identify how the researchers own beliefs may have introduced bias into the study or even shaped the results, and as such reflexivity will need to be an essential component of the proposed study.

1.4.13.2 Quantitative approaches in Gastrointestinal cancer research

Those studies which adopted a quantitative methodology tended to use questionnaires to collect their data. Quantitative methodology enables causal relationships between variables to be examined and analysed to determine statistical probabilities and the certainty of a particular outcome (Duffy, 1985). In quantitative methodology, the researcher remains detached from the facts to prevent bias and attempts to control the events by isolating variables and implementing controls (Duffy, 1987). The research begins with a hypothesis, which then, through measurement, data is generated and by deduction allows a conclusion to be drawn (Greenhalgh, 1997b). The strength of quantitative methodology is in its reliability; that the same measurements should yield the same results time after time (Greenhalgh, 1997b). According to Douglas (2003), quantitative methodology however, does not explain the rationale behind peoples' behaviour.

Klemm, Miller and Fernsler (2000), aimed to describe the demands of illness in people with gastrointestinal cancer. Questionnaires designed to measure the demands of an illness were completed. The international sample was generated via an online support group. Klemm et al. (2000) added strength to their study through the use of a previously validated questionnaire. However, there are several flaws to this study. There is no power calculation to determine a sufficient sample size for this study, whilst the sample was selected from an on-line support group and therefore, not truly random or representative of a wider population. It could therefore be argued that this reduces the applicability of the results. As with the qualitative approaches, this study in gastrointestinal cancer which adopted a quantitative methodology has revealed some key findings including that younger patients had statistically higher demands of illness scores, compared with older

patients and because of the method utilized this was not due to chance alone. However, what we can also learn from this study is the limitations of such an approach, as it is not possible to explain the rationale behind peoples' behaviour.

Because of the potential benefits, but also limitations of a single method approach gleaned from these recent studies in Gastrointestinal cancer, it was decided to examine how use of mixed sources of data, found to be effective in previous communication skills training studies (Heaven et al., 1996; Booth et al., 1996), has been used in a very limited number of gastrointestinal cancer studies.

1.4.13.3 Mixed method approaches in Gastrointestinal cancer research

In contrast to the qualitative approaches, Maisey, Norman, Watson et al. (2002) focussed on identifying the relationship between quality of life and survival in patients with advanced colorectal cancer. Maisey et al. (2002) retrospectively analysed the data of four previous randomised controlled trials of patients receiving chemotherapy. 501 patients were included in the study and ethical approval and consent were obtained. The knowledge created from these studies highlighted how factors such as coping skills, family support, information from professionals and existential concerns can affect quality of life.

Maisey et al. (2002) employed a large sample in their study. This increased the power of the study, that is, the ability to detect a statistically significant result when they exist (Mayer, 2004). The authors used a previously internationally validated questionnaire; the EORTC QLQ-C30, and whilst they state that there is a statistically significant relationship between quality of life and survival in colorectal cancer, because of the quantitative nature of the retrospective data they are unable to explain why this

relationship exists. This is a drawback to this study, where there was no opportunity to include for example a qualitative interview approach with a sub-sample of the study participants enabling the triangulation of data. The access to such data might have also overcome the concern expressed that the EORTC QLQ-C30, fails to capture adequately the psychological aspects of quality of life in patients affected by cancer (Skarstein et al., 2000).

Different research approaches have generated knowledge about the impact of gastrointestinal cancer mainly concerning physical and psychosocial issues which the quantitative study identified were highest amongst younger patients (Klemm et al., 2000). In conjunction with the quality of life aspects in gastrointestinal cancer, there appears to be a limited amount of predominantly qualitative generic cancer research evaluating the experiences and organization of care in the community of those affected by this type of cancer. What is not evident in the literature is what factors influence the levels of psychological distress or well-being in this population, and in particular those with the cancers of poor prognosis (such as oesophagus, stomach, bile duct, pancreas, liver and advanced colorectal cancer). This seems to be an area that requires further in depth study since it is apparent from the literature that in order to both measure levels of psychological distress and to identify what influences its occurrence or otherwise, it will be necessary to adopt a methodology that can capture both the participant perspective (e.g. through interview) and their level of psychological distress (e.g. using a measure). Furthermore, the benefits of including a checklist and adopting a longitudinal approach creates potential for a more robust study, and one that might be useful in other cancers presenting with limited prognosis.

1.4.14 Coping strategies

Hinton (1964) challenged the accepted theory at that time that depression in people with cancer was accounted for solely by the prospect of dying, as many other patients in the same situation did not experience depression. When considering this in the context of those affected by incurable gastrointestinal cancer it was considered essential to explore some of the models of coping. Freud (1933), from a psychoanalytical perspective, defined coping as individual using unconscious defence mechanisms to deal with internal threat and conflict. This definition of an unconscious approach to coping was generally accepted until new models started to emerge over fifty years later. These new ideas defined or conceptualized coping as a conscious response to external stressful or negative events (McCrae, 1984; Moos and Schaefer, 1984; Krohne, 1989).

1.4.14.1 Stress and associated concepts

Cannon (1932) was one of the first to suggest that stress was a disruption to the body's overall equilibrium writing about the 'fight or flight response', whilst Selye (1952) also described stress in terms of physiological symptoms such as an increase in pulse and blood pressure, as seen in those with recognized medical conditions. Selye supported his model by illustrating how such symptoms could be replicated in laboratory animals and concluded that these symptoms were due to failing homeostatic mechanisms. He assumed that all biological organisms could only exist if the conditions they lived in were maintained at a constant, or if they were able to adapt to the challenge of new conditions. He called these responses The General Adaptation Syndrome (GAS) which has become known as the stress response.

However, the explanation of the stress response by Seyle is rather reductionist as it excludes any psychological factors that might influence the adaptation process. When under stress there can be a large variation in the performance of skilled tasks (Lazarus and Eriksen, 1952), with some managing to improve their performance whilst others achieve significantly worse. This conclusion suggests that because humans are thinking and rational organisms, the stressor must be monitored and modified by influences from the mind. Therefore, performance will be influenced by previous experiences, motivation and coping (Lazarus and Eriksen, 1952), which appear to be conscious fundamental requirements for how an individual responds to a stressor.

The most frequently applied model of psychological adaptation in health, including cancer, is the transactional model of stress and coping of Lazarus and Folkman (1984), which focuses on the coping processes that help manage or reduce aversive states. It goes some way to explain how some individuals may cope less well than others and experience psychological distress. Lazarus and Folkman define coping as:

‘constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources’ (Lazarus and Folkman, 1984 p.141).

The model describes how coping, stress and other factors are related, and illustrates how coping is viewed as a response to stress and is consequentially linked closely to it. Stress and other associated factors will now be explored in the context of the present study and coping theory of Lazarus and Folkman (1984).

Motivation includes the conscious effort in deciding how to react to a stressor, and has become known as appraisal. Lazarus and Folkman (1984) consider how appraisal is important because it precedes the behaviour seen in response to a stressor. They describe the subtle differences within the appraisal process, namely primary and secondary appraisal, where primary appraisal identifies the stressor and its potential, whilst secondary appraisal identifies the actions that can be taken to minimize the effect of the stressor. Primary appraisal is further sub-divided into three types, dependant upon whether the stressor is appraised as irrelevant, benign positive or stressful. Irrelevant appraisal is interpreted as no need for action, benign positive is appraised as a stressor likely to cause benefit, whilst stressful appraisal leads to a requirement to reduce the harm a stressor may cause by making use of a coping mechanism. Coping is therefore, the mechanism utilized to deal with a stressor.

In this model physical and psychological adaptation has been found to be positively influenced by the person's appraisal of the coping resources available, which are categorized as:

- **Positive reappraisal** - optimism, self confidence, confidence in e.g health care professionals
- **Helplessness** - feels helpless, no action taken
- **Acceptance** - acceptance, conditional sacrifice
- **Distraction** - distractive action, postponement of worry, thought displacement

1.4.14.2 Coping strategies classification

Whilst it is acknowledged that different coping strategies may be used in different situations, Lazarus and Folkman (1984), classify these strategies as:

- **Problem focused strategies** which are those aimed at changing the objective situation by reducing the demand or increasing resources.
- **Emotion focused strategies** which aim to limit the negative experience of stress without changing the external situation. The use of defense mechanisms such as denial as a means of dealing with stress falls into this category. Whether a strategy is successful often depends upon the context of the situation as a whole.

Individuals begin by appraising their situation, evaluating the personal significance of the event and then assessing their assets for coping. Coping is the way in which an individual responds cognitively and behaviourally to regulate stress. If coping strategies are available to resolve the stress, then coping ceases. However, where the stress does not resolve, further appraisal and attempts at coping are necessary. Coping is thus process orientated, and therefore is ongoing and continuous rather than a consequence of a particular event. This is a crucial aspect of this model because cancer likewise, is not a single, stressful event. It has diverse demands and multiple demands simultaneously and changes over time. The needs of individuals with cancer would appear to require continuous appraisal and reappraisal, as demonstrated in cancer adaptation in key studies by Parle, Jones and Maguire (1996), Derdiarian (1986), and Sardell and Trierweiler (1993). It is further supported by Northouse (1995) who found four predictor variables that influenced the adaptation process. These were social support, uncertainty, symptom distress and hopelessness. Stress can lead to negative emotional states. If people are unsuccessful in attempts to cope, then they are more likely to experience these states and to experience them to a greater extent. Thus, people with fewer resources would be less likely to cope successfully with stress.

1.4.14.3 Meaning based coping

The decision to include a non-cancer study (Folkman, 1997) that was one of the largest prospective studies of the effects of caregiving and bereavement on mental and physical health was a pragmatic decision. It was very much influenced by the strength of the study design as well as its contribution to developing the traditional theory of coping of Lazarus and Folkman (1984), of which so many previous coping and adaptation studies had referred to (e.g Parle et al., 1996).

Folkman (1997), in a longitudinal study with the partners of men with AIDS, using interviews and questionnaires, identified the presence of both positive and negative psychological states. Through this mixed method approach, multiple sources of data were collected which enabled her to examine what kinds of coping processes support positive psychological states and the theoretical significance of positive psychological states in the coping process. Both positive and negative psychological states were assessed through caregiving and bereavement and compared with a community sample of urban university students not experiencing unusual stress (Horowitz et al., 1988).

Folkman (1997) added strength to her study through the use of a range of previously validated questionnaire promoting internal validity (Mayer, 2004), and enabling statistical measures of significance. For example she was able to demonstrate that bereaved caregivers positive states of mind were significantly lower than those of the community sample four weeks following their partner's death ($F(1,151) = 24.80, P = < 0.0001$), and remained significantly lower until five months following their partner's death ($F(1,137) = 4.41, P = 0.04$), and was not due to chance alone (Newman and Roberts, 2002). However,

at subsequent assessments the scores of bereaved caregivers did not differ from the scores reported by the community sample.

A further strength of the method selected was that Folkman (1997) was able to add explanation to these statistical findings through triangulation with qualitative data from interviews. Four types of coping processes were associated with positive psychological states during care giving and bereavement. These were:

- **Positive reappraisal:** appraising a situation in a positive light can result in positive affect
- **Goal directed problem focused coping:** acknowledging that the situation is uncontrollable, and that the disease is progressing over time, effective problem focused coping contributed to positive psychological states by allowing individuals to experience some personal control and sense of accomplishment
- **Spiritual beliefs and practices:** individuals who reported spiritual beliefs and practices used more positive appraisal and problem focused coping in dealing with stressful events
- **Infusion of ordinary events with positive meaning:** e.g being with a group of friends, going out on a trip. Such events led to feeling connected and cared about, feeling a sense of achievement and self esteem, and having an opportunity to be distracted from every day cares

Folkman (1997) suggests that there is a common underlying theme to these types of coping, namely searching for and finding positive meaning, and how meaning can be created despite on going stressful events. Linked to this positive psychological states lead back to appraisal and coping. Positive reappraisal processes can help an individual

redefine and focus on positive meaning, which can help to re-engage in efforts to cope with the ongoing stressor and positive effect can promote goal directed problem focused behaviours.

Whilst recognizing the strengths of this study a potential flaw in the generalisability of the findings has to be considered in that the applicability of the results may be limited by the characteristics that distinguish the caregivers from caregivers in traditional studies of caregiving and bereavement, including fundamentals such as gender and age. However, taking into account generalizing to theory and what can be generalized to what it is because of its strengths of design the study could be replicated in a range of other caregiving populations. Application of the design adopted by Folkman (1997) including a prospective longitudinal approach, use of both self report and clinical observation, use of both qualitative and quantitative analyses and frequent and regular assessments during the months leading up to and following bereavement could add a valuable contribution to our knowledge base in the bereaved. Ultimately, this study has highlighted not only the definite existence of positive psychological states in the coping process, but also a study design that could be adapted to help others to learn more about coping processes that achieve and sustain positive psychological states in stressful contexts, such as when confronted by incurable cancer either as a patient or as a caregiver.

Folkman and Greer (2000), in defining the variables that research indicates contribute specifically to psychological well being in serious illness, suggest that when further appraisals and efforts at coping take place, such as in terminal disease, meaning based coping helps the person relinquish untenable goals and formulate new ones, make sense of what is happening, and appraise benefits where possible. This type of coping can

also generate a positive effect, which provides a 'psychological time out' from the distress and motivates further coping. It can have positive and negative effects, as individuals may feel dispirited in changing their goals, but happier from achieving the aim of their new goal. Meaning based coping appears to contain a strong component of the spiritual aspect of palliative care (Clark, Hockley and Ahmedzai, 1997).

Holland and Rowland (1998) studied the religious and spiritual beliefs of patients with malignant melanoma to identify how their beliefs contributed as a coping resource. They found that those who admitted a reliance on religion claimed that it provided an active cognitive framework which helped them deal with their existential crisis. However, Folkman and Greer (2000), emphasize how appraisal and coping processes are influenced by characteristics of the person and the environment, and depend very much on the individual to appraise the situation realistically, choose appropriate coping strategies and use them effectively. Variables such as situational demands and constraints, whether the situation is changeable or controllable, and whether there are resources for coping when other demands might be competing for resources are all crucial personal and environmental aspects of appraisal and coping.

1.4.14.4 Coping and incurable cancer

Payne (1990) and Parle, Jones and Maguire (1996) acknowledge how the complexity of cancer experiences necessitates different coping responses. Payne (1990) in a grounded theory approach demonstrated how women used a complex range of coping strategies when receiving palliative chemotherapy for advanced breast cancer. Thinking positive/fighter, acceptance, fearfulness and hopelessness were the four main strategies the women favored. Similar coping strategies of fighting spirit, denial, helpless/hopeless

and stoic acceptance have previously been described by Morris, Greer and White (1977) in a study of women with primary breast cancer.

In a key prospective study, involving 673 newly diagnosed cancer patients, Parle, Jones and Maguire (1996) interviewed participants at intervals of 4 to 8 weeks and one year later to assess the effects of their appraisal, coping responses and resolution of any concerns on their psychological well being. This study was with patients with cancer assessed by their clinician as likely to survive for at least two years, and whilst it is not comparable to the proposed study population, it was included in the review in recognition of a methodology that captured the complexity and the diversity of demands which arise from the diagnosis and treatment of cancer. The researchers were skilled in assessing psychiatric disorder and used The Psychiatric Assessment Schedule (Dean et al., 1983) in conjunction with DSM-III criteria (American Psychiatric Association 1980) to determine if the patient had experienced a major depressive episode, generalized anxiety disorder or adjustment disorder in the period since diagnosis. This was repeated 12 months later.

In an attempt to reduce bias and threat to the individual, patients were interviewed in their own home. The Concerns Checklist (Harrison et al., 1994) was used to measure concern appraisal, whilst a semi-structured interview developed with lymphoma patients by Devlen (1984) was used to assess coping response by asking patients what if anything they do to manage each concern. Coping efficacy was assessed by asking the patient to what extent the nominated coping response had resolved the concern. The study was strengthened by the use of several data sources which promoted both qualitative findings and statistical measures.

Whilst the most frequently reported concerns were ‘the illness itself’ and ‘not being able to do things’ the relationship between concern appraisal and affective disorder were able to be measured through logistic regression. This revealed that patients with high concern appraisal were more likely to have a concurrent affective disorder ($P < 0.001$) and a subsequent affective disorder ($P = 0.004$), a finding previously identified by Harrison et al. (1994). Initial coping efforts soon after diagnosis appear to provide significant evidence for patients to base their beliefs about their ability to cope in the face of what may be a chronic series of demands. It would therefore appear that those who are assessed at diagnosis as struggling to show coping efficacy with evidence of helplessness are likely to need increasing psychological support as their cancer trajectory proceeds.

Classic work by Weisman and Worden (1977) examined the psychological and social profiles of patients who had died from cancer, based on the recollections of their nearest living relative and correlated patient’s length of survival with the medical profiles. An expected rate of survival score was devised from such clinical findings as the patient’s age, histology, and treatment received. Those who were perceived to use negative coping responses such as isolation or perpetuating a cycle of need, and those who demonstrated depression and poor relationships with others in the palliative and terminal stages of their cancer had statistically shorter survival times. Those who were perceived to have a more accepting and adaptive attitude and who were able to maintain reciprocal and mutually respectful relationships demonstrated significantly correlated longer survival and better quality of life. Whilst the reliability of studies that use the caregivers perceptions as a source of data is questionable as they confound respondent’s and the patient’s level of psychological distress, this study supports the outcomes of the

Pettingale (1984) study which indicated that the coping response of denial and negative appraisal are correlated with earlier demise.

What seems to be missing in the cancer literature is evidence of what it is that contributes to an individual's negative or positive appraisal of a cancer experience, resulting in ability or inability to activate problem based coping strategies and emotion focused strategies which might activate coping resources. What influences individuals to adopt the strategies they do? An influential piece of work nearly forty years ago gave some partial answers. Hinton (1967) identified that patients, and those close to them often experienced depression when they did not acknowledge and work through their impending loss. Hinton (1967) also identified other losses in the dying process such as loss of health, loss of role, loss of family and loss of sense of belonging. Death threatens to take away everything that a person has valued, and the perceived anticipatory grief is an important though not an easy task. More recently, Sheldon (2003) suggests that from the moment a person learns of their incurable cancer diagnosis, they see themselves differently, as do those around them. The losses they experience in relation to their social world are concerned with their engagement with the world outside home and with the roles and relationships within the family. Whilst social pain alongside physical, psychological and spiritual pain has been acknowledged in palliative care (Field 2000), Sheldon (2003) suggests it is one of the least understood aspects of palliative care. Finding out what may be involved as both the patient and those around them 'struggle with a changing identity' in for example the family, or at work (Sheldon 2003), and what healthcare professionals can do to support those involved and reduce the impact is an

important aspect of advanced cancer care that a lack of evidence in the literature suggests requires further exploration.

- The transactional model of stress and coping of Lazarus and Folkman (1984), which focuses on the coping processes that help manage or reduce aversive states has shown how appraisal of resources in coping is important in both patients and carers. Furthermore, appraisal and coping appear to be ongoing and continuous rather than a consequence of a particular event, and cancer likewise, is not a single, stressful event. When considering the assessment and reassessment of psychological need in patients and carers this model can help us understand how lack of resources can lead to negative emotional states. What the resources are and how we help those affected by gastrointestinal cancer to identify them or increase them to promote positive psychological states, appears to be uncertain from the current literature available. The importance of communication skills that can accurately assist patients to assess their resources appear to be key.
- In addition to this, there appear to be benefits in helping the person relinquish untenable goals and formulate new ones, to make sense of what is happening, and appraise benefits where possible in meaning based coping. However, it is surmised that helping an individual talk about such issues in a form of working through their concerns in anticipatory grief will no doubt require advanced interpersonal and communication skills. Currently there is a lack of evidence to guide and educate healthcare professionals in this area.

1.5 Specialist Supportive and Palliative Care

1.5.1 Palliative care.

Palliative care, developed through the hospice movement (Saunders, 1959), is an active approach to managing the whole patient and family and their problems, as an individual approaches the end of life. Relief of suffering is a fundamental goal of palliative care, reflecting a humanistic and compassionate concern for the comfort of those affected. The Royal College of Physicians of the United Kingdom registered palliative care as a specialty in medicine in 1987, with the World Health Organisation (WHO) supporting Palliative Care as an integral part of healthcare (WHO 1990). More recently the WHO definition of palliative care has been summarised by Sepulveda et al (2002):

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;

- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (Sepulveda, et al. 2002).

Higginson and Hearn (1997) elaborated that active total care refers to the holistic approach, rather than specialist palliative care services taking over the total care of the patient, and that the emphasis should be on relief of distressing symptoms such as pain and quality of life within the framework of a coordinated service. This interpretation is important because it encourages adoption of the palliative care approach by the patient's generic professional health carers, whether in primary or secondary care. It also helps to characterize the responsibilities of 'specialist' palliative care services (e.g Macmillan Nurse, Palliative Care Consultant) as a resource for specialist support in, for example, managing difficult symptoms such as pain or intractable vomiting, or in providing complex psychosocial care.

1.5.2 Supportive care

The subtle differences of supportive care within the palliative care philosophy refers to care that is designed to help the patient and their family cope with cancer and its treatments at all stages of the cancer trajectory, maximizing the benefits of treatment, but also living as well as possible with the effects of the disease. Thus, the palliative care

philosophy of well coordinated, patient centred care incorporating psycho-social care, quality of life, an holistic approach, inclusion of the patients family and carers, open and sensitive communication, patient autonomy and choice are encouraged to be incorporated throughout the cancer experience (NICE, 2004). The guidance also provide a source of expert opinion on a variety of issues including setting up palliative care services in the acute sector, clinical guidelines for managing cancer pain, as well as strategies on how psychosocial support services should be organized within the NHS and across boundaries into the community and voluntary sectors.

1.5.3 The purpose of psychosocial care in supportive and palliative care

The principal concern with the psychological and social aspects of cancer is to alleviate the emotional distress which affects patients (Jeffrey, 2003). Psychosocial care, an integral part of palliative care, is defined by the National Council for Hospice and Specialist Palliative Care Services (2002),

Psychological approaches are concerned with enabling patients and those close to them to express thoughts, feelings and concerns relating to illness, assessing their individual needs and resources and ensuring that psychological and emotional support is available. A range of informal and planned interventions may be used to relieve psychological distress, e.g. anxiety, anger, low mood and intrusive thought. For some patients this will also include the recognition and treatment of specific psychiatric disorders such as depressive illness.

1.5.4 Access to psychosocial care in supportive and palliative care

Whilst the NICE (2004) guidance provides the evidence that access to psychosocial care can be beneficial to those affected by cancer, uncertainty seems to exist as to how this specialist aspect of care should be provided. In a survey of 166 hospices in the UK Lloyd-Williams, Friedman and Rudd (1999) found that whilst all units had access to a chaplain and the majority (75%) to social workers, less than 10% had regular access or support from psychologists or psychiatrists. The consequences of the manpower shortage of both these professionals and the length of time before a patient was seen resulted in services being rarely utilized, and hence local service guidelines, protocols and evaluation were also poorly developed. Whilst the current drive to improve cancer services aims to incorporate specialist psychological services (NICE, 2004), such services are being developed at a Network level and as in other aspects of key skills development such as advanced communication skills training, it is the complex issues of access to expert manpower, time and investment which appear to be restricting development of, and access to, such services for all those affected by cancer.

A model that promotes access to expert psychosocial care is described by Payne and Haines (2002) who endorse the provision of a clinical psychologist within the framework of the 'specialist palliative care team' (SPCT) rather than being a member of every cancer multidisciplinary team. The benefits of such an expert appear to have consequences for the development of specialist palliative care services. As well as providing psychological assessment and interventions with patients and families, Payne and Haines (2002), stress how the psychologist within the SPCT has the potential to become a major educational resource for improving counselling and communication

skills, as well as for facilitating team working, service delivery, and service evaluation. It has to be acknowledged that such an expert role might also identify and promote new areas of research into the psychological aspects of cancer, an area that remains underdeveloped.

However, despite identifying a potential model (Payne et al. 2002), little seems to have changed in the provision of access to expert psychological care, with no evidence of such a model implemented available in the literature. The complexity of the situation is also compounded by uncertainty as to whether resources should be used to prevent clinically significant distress and improve quality of life in the many or should be concentrated on treating significant distress in the few? As well as this it is not clear whether group, as opposed to individual interventions should be adopted and how healthcare staff can be helped to identify need and provide support?

1.5.5 Psychosocial care – implications for nursing practice

It has been suggested that because clinical nurses spend more time in direct patient contact, are able to observe patient behaviour, as well as the intimacy of some nursing tasks, patients may feel better able to express concerns or psychological distress (McVey, 1998; Pasacreta and Massie, 1990). Whilst acknowledging psychological aspects as key components of any nurse's role, studies have illustrated how there is a need for further training of healthcare professionals in specific assessment of psychosocial needs.

Lloyd-Williams and Payne (2003), using a qualitative interview approach identified concern in 17 specialist palliative care nurses working in a hospital or community setting regarding their lack of skills in assessing anxiety and depression in patients with cancer. The advantage of this in-depth methodology was that it was able to explore each nurses

understanding of depression as a symptom, their assessment of depression, treatment issues and general issues regarding psychosocial care. The constant comparative approach to analysis ensured accurate coding and the identification of major themes.

Whilst this study both demonstrated the complexity of the skills deficit in those often presumed able to assess depression in cancer, it could be argued that it might have had greater impact across cancer and palliative care by including other healthcare professionals engaged at the frontline in assessing psychosocial need, including for example the disease specific cancer CNS and the General practitioner. The fact that all participants thought the assessment and treatment of depression was not as high on the palliative care agenda as physical symptoms, that depression in cancer can be difficult to assess, and that there is a stigma attached to mental illness were recurrent themes. To have included the ward nurse, the disease specific cancer CNS or the General practitioner might have given some insight into whether these healthcare professionals experience the same difficulties as the specialist palliative care nurse, why depression is not assessed at an earlier stage of the patient's cancer trajectory and why other healthcare professionals including GP's need persuading to both refer for specialist assessment and/or prescribe treatment. It might have also offered some insight into why patients often need so much encouragement to commence treatment. However, this would have required not only negotiation for access to invite participation, but also the negotiation of ethical approval in multiple sites. Whilst the conclusions of the study cannot be generalized to other healthcare professionals, there is scope for generalizing the findings to theory, and as such it is extremely useful both to other specialist palliative care nurses and where

interpreted as relevant to their practice, other healthcare professionals. Furthermore, this study adds to our knowledge

There also appears to be lack of clarity about roles and responsibility in this aspect of psychosocial care. A review of District Nursing services by the Audit Commission (National Audit Office, 1999), noted a lack of consensus among District Nurses about the nature of their role including the validity of referrals requesting psychological, supportive, education or assessment visits likely to lead to inter-service referral, rather than referral to perform a physical task.

It has been suggested that it might be necessary to strengthen the Macmillan nurse role as a resource for District Nurses by providing training and support in the management of psychosocial issues and intervening in challenging cases (Grande, Barclay and Todd, 1997). However, whilst it is suggested that additional training may be needed to enable District Nurses to maximize their role in encouraging disclosure of concerns, whether the Macmillan nurse is ideally placed to provide that training has to be questioned (Lloyd-Williams et al. 2003). Although there is a drive in the NICE (2004) guidance to implement psychosocial care for all patients with cancer, there would appear to be a need for assessment of competence and education across all healthcare disciplines. Evidence emerging in the literature (e.g. Lloyd-Williams 2003) indicates that those working in traditional specialist support roles, even with advanced communication skills may not necessarily have the skills to undertake psychological assessment.

It is apparent from these recent qualitative studies that we cannot presume a level of psychological assessment and the addressing of psychosocial needs through such aspects of care as providing information, without adequate educational input and supervision for

District Nurses in the community and Specialist Palliative Care Nurse working in primary, secondary and the voluntary hospice setting (Lloyd-Williams et al., 2003; Wilson et al., 2002; Beaver et al., 2000; Booth, 1996).

- Whilst evidence of the philosophy of palliative care in the terminal phases of cancer appears to be increasingly effective, there seems to be an ongoing challenge about meeting the psychological needs of those affected in earlier stages of cancer, with great uncertainty as to how this specialist aspect of care should be provided. The situation in gastrointestinal cancer equally lacks clarity.
- Whilst potential models have been identified, as in other aspects of key skills development such as advanced communication skills training, it is the complex issues of access to expert manpower, time and investment which appear to be restricting development of, and access to, such services for all those affected by cancer. Those working in traditional specialist support roles, even with advanced communication skills may not necessarily have the skills to undertake psychological assessment. With the revelation in the literature that such advanced skills are only maintained and effective with ongoing emotional support to providers, this has further resource implications.
- This is clearly an area of great concern, with little apparent resolution to date. Whilst it is likely that those affected by gastrointestinal cancer would benefit from psychological assessment, the proposed study will have the potential to provide the evidence to support and justify the need for the resources for this development in a specialist gastrointestinal cancer centre.

1.5.6 Patient and carer expectations of specialist palliative care

The effectiveness of a qualitative approach in studies with patients and carers (Jarrett, Payne and Wiles, 1999) as well as bereaved carers (Beaver, Luker and Woods, 2000), is reflected in the clear identification of a need for better understanding about the primary and secondary care interface. Likewise there is a need for more effective communication between different healthcare professionals and clarity about roles and responsibility when planning care. Interviews with participants in both studies revealed a confusion regarding who was the lead person when care was being planned.

A further number of studies using an interview approach with patients and their caregivers found that different healthcare professionals believed care of terminally ill patients was their respective domain (e.g. Jarrett, Payne and Wiles, 1999; Beaver, Luker and Woods, 2000). Why the Macmillan Nurse visited less regularly than the District Nurse caused some confusion. Whilst specialist palliative care nurses such as Macmillan nurse are given a high profile in the provision of palliative care services, Beaver, Luker and Woods (2000), suggest that the type of service they provide may need to be differentiated and made more explicit to service users. What continues to be misunderstood is that their role as 'specialist' is often in an advisory capacity to other healthcare professionals, rather than to give direct care to the patient (Payne, Smith and Dean, 1999). Furthermore, Beaver, Luker and Woods (2000) found that information provision was a major area of concern, especially for carers, who would have appreciated more educational input from healthcare professionals. Timing of response to an information need was important, with carers suggesting that access to an immediate response was preferred.

It is apparent that different services need to collaborate to ensure that their different roles and specific practices result in seamless care. How such roles as a Clinical Nurse Specialist in a tertiary cancer centre communicates with a patient's Macmillan Nurse in the community is uncertain, and no studies pertaining to this were found. However, two studies: Wilson et al. (2002) and Luker et al. (2003) used qualitative interviews to explore the views of cancer patients and their carers in relation to hospital discharge planning and the role of district nurses. Both studies identified lack of clarity and understanding about the role of both District Nurse and Macmillan Nurse in cancer care, with no written information available about roles and responsibilities. Stereotypical views predominated, with the district nurse being viewed as someone who was always busy, was only involved with tasks, such as wound care, that other, older, sicker people had greater claims on their time, and that the Macmillan nurse was only involved when someone was dying (Luker et al., 2003).

Luker et al. (2003) using pre and post discharge conversational interviews captured the perspective of 71 patients and carers. Use of this longitudinal qualitative approach, demonstrated that whilst they appreciated supportive, non-task visits from the District Nurse, participants in the study questioned the legitimacy of such visits, and it is suggested that there is a need to publicise to patients and carers that psychosocial concerns and information are legitimate use of healthcare professionals time (Luker et al., 2003). Whilst this study identified a lack of understanding of roles by patients and carers, the study might have been strengthened by widening the data sources to include both ward based health professionals (including for example the disease specific CNS or the specialist palliative care nurse) involved in planning and providing information about

discharge with the patient and their carer and also the perspective and experience of the District nurse receiving such a referral, and whether the District Nurse felt equipped to care for this patient and carer. This would have had the advantage of evaluating the outcomes of the healthcare professionals input into planning and delivering care measured against the patient and carer perspective of what actually transpired. However, this would have been a much larger study and would have had major resource implications. However, inclusion of the District Nurse perspective might also have informed the argument that all cancer patients and their carers (Payne, Smith and Dean, 1999; Luker et al., 2003) would benefit from better planning including a holistic post discharge assessment followed by, if necessary, ongoing assessment and case management, with the aim of establishing service users' preferred levels of participation in self monitoring and self care, as there is strong evidence that carers want to be self-reliant (Payne, Smith and Dean, 1999). Worth, Tierney and Watson (2000) argue that there is an information gap in the post discharge period related to increasingly shorter hospital stays, and that primary care services (particularly District Nurses) should accept a greater role in filling this gap. However, if community nurses are to meet the information needs of patients and carers there must be a robust interface with nurse colleagues working in secondary and tertiary cancer units to ensure that a two way system of appropriate and accurate information is available. Perhaps research that includes service provider perspective in primary and secondary care might better inform this process.

1.5.7 Referral to specialist palliative care

Another important issue and concern about palliative care is how individuals, including healthcare professionals, access specialist palliative care in the first instance (Bestall et al., 2004; Ahmed et al., 2004), as it is not clear exactly how people are eligible for palliative care services. Ahmed et al (2004) undertook a systematic review and identified a number of factors that restricted access to receiving palliative care. These included lack of knowledge and education amongst health and social care professionals, patients and carers and a lack of standardized referral criteria. People from minority ethnic communities, older people, and people with non-malignant conditions as well as those socially excluded such as homeless people were most likely not to receive a timely referral for palliative care.

Although small, a further qualitative study, (Bestall et al., 2004), also highlighted a need for improved access to education about how and when to refer patients for specialist palliative care and a need for standardized referral criteria. Thirteen patients, 3 GP's, 6 community nurses and 12 healthcare professionals in specialist palliative care were interviewed. Another key finding in this study was that whilst patients expressed general satisfaction with care, they wanted to be able to be supported at home in their final days. These findings indicate that further education is required to improve communication between generic community healthcare professionals and specialist palliative care teams.

1.6 Carers and Cancer

One of the most important areas of supportive and palliative care in cancer is the consideration of the family's needs before and after death. The emergence of 'informal carers', usually a family member or close friend, who provide unpaid assistance for their

dependant relatives living in the community (Heaton, 1999), became specifically recognized on the generic health and social care policy agenda with the launch of the Carers (Recognition and Services) Act 1995 (Department of Health, 1995, 2000). In palliative care, whilst 90% of patients spend the majority of the last year of their life at home (Seale and Cartwright, 1994), and whilst a desire to remain at home is mutually held by patient and carer, it has long been established that one reason for admission to hospice or hospital is a breakdown in the support to carers in community care (Addington-Hall, 1998). More specific advice to support the family and friends of cancer patients was made in the Cancer Plan (Department of Health 2000b) with further policy calling all carers needs to be better understood and met in the Supportive and Palliative Care guidance (NICE 2004). However, whilst a glut of literature on informal carers exists in gerontology, disability and dementia, Nolan, Grant and Keady (1996) suggested that there are still significant gaps in our understanding of family care. Brandon and Jack (1997) expressed concern that caring relationships are rarely seen as reciprocal and tend to be interpreted as unrewarding and damaging, with an emphasis on the physical burden of caring.

1.6.1 Carers and levels of psychological distress

Generic cancer and palliative care studies incorporating measures of psychological distress and looking at the experiences of carers have helped to inform the factors which predict psychological distress in carers in palliative care (e.g Higginson, Wade and McCarthy, 1990; Addington Hall and McCarthy, 1995; Higginson and Priest, 1996; Davis, Cowley and Ryland, 1996; Grande, Todd and Barclay, 1997; Payne, Smith and Dean, 1999; Rose, Webb and Waters, 1999; Eriksson and Laurri, 2000). Several studies

have found that carers levels of anxiety in palliative carer are extremely high (Higginson et al., 1990; Payne et al., 1999). It has been suggested that distress in carers may be related to the medicalisation of death and the carers unfamiliarity with what in the past would have been regarded as a natural part of the life cycle (Neale, 1993), as well as the carers anticipation of bereavement (Payne et al., 1999). However, the literature also suggests an association between psychological distress and such factors as lack of access to information, a need for better communication, and support from healthcare professionals (Payne et al., 1999).

1.6.2 Carers, information needs and psychological distress

The emphasis on information need in carers was prevalent in a number of qualitative studies (e.g. Davis et al., 1996; Grande et al., 1997; Rose et al., 1999; Beaver et al., 2000), as well as studies adopting mixed methods (Payne et al., 1999). Carers indicated that they would have welcomed more information and support at an earlier stage, (Payne et al., 1999), someone to talk to (Beaver et al., 2000), that their information needs are different to patients, and should be assessed on an individual basis (Rose et al., 1999), and that a need for emotional support may be at a lower level than a need for information (Eriksson et al., 2000). Rose et al. (1999), also found that understanding details related to the illness seemed to help carers cope with the situation, and fear of not knowing what to do or expect greatly increased carers stress, as did poor coordination of care (Beaver et al., 2000). Information was a major area of concern, especially for carers who would have appreciated more educational input from healthcare professionals. Timing of response to information need was also important, as carers felt they needed an immediate response. A more structured appointments system for healthcare professionals

home visits to increase carers opportunity to seek information and reassurance, and if they did not reside with the patient, to make sure they were there, were also important issues for carers (Beaver et al., 2000).

Whilst all the above studies have generated knowledge about the impact of cancer on carers , and have emphasized the importance of information, Payne et al. (1999), added strength to the internal validity of their study through the inclusion of previously validated questionnaires (Mayer, 2004). Payne et al. (1999) used a cross-sectional design to identify the concerns of informal carers in palliative care. Thirty-nine carers, (15 male and 24 female), in two separate areas in England completed a semi-structured interview, and two previously validated questionnaires, (The General Health Questionnaire (GHQ) and The Caregiver Strain Index (CSI)). Strength was also added to the qualitative data collection through the use of an interview schedule previously used by Hinton (1994) which focused on carers' concerns and satisfaction with the caring role. It was pilot tested and found to have face validity with carers involved in providing terminal care in the home environment. Ethical approval was obtained for both sites. Scores of the questionnaires were analysed by age (above 60yrs and below 60yrs) enabling correlation of the data to assess whether any relationship on the GHQ and the CSI by age or gender could be identified. The interviews were analysed and coded into clusters that described the experience of carers and their needs. Transcripts were first analysed by two of the authors and then discussed and agreed with the first author. Investigator triangulation promotes reliability of coding and reduces the potential bias of a single author and improves the reliability of the study (Mitchell, 1986).

- The majority of carers were experiencing psychological morbidity. Thirty three (84%) scored above the threshold (5) for psychological distress on the GHQ, with 16 (41%) scoring over 8 (range 1-12) on the CSI.
- Carer strain and psychological morbidity were found to be moderately correlated ($r = 0.51, P = <0.001$). The p-value was also calculated for age and carers scores on the GHQ and CSI. This demonstrated that age was moderately negatively correlated with scores on both the GHQ ($r = -0.48, P = 0.001$), and CSI ($r = -0.54, P = 0.002$).
- Like age, gender was also found to be moderately correlated to carers scores on the GHQ ($r = 0.51, P = 0.001$), and the CSI ($r = -0.35, P = 0.02$), showing that female carers experienced more psychological morbidity and strain than male carers.

The strength of using a statistical measure shows that this result is statistically significant, that a difference exists between younger and older carers and between female and male carers and is not due to chance alone (Newman and Roberts, 2002).

From the qualitative perspective three main themes emerged. These were:

- life restrictions
- emotional consequences of caring
- support received.

Events and activities that restricted the carers' own life were particularly evident in the disclosure of young carers. The emotional consequences were portrayed as anxiety about the future and uncertainty of coping with death. Support received by carers varied, with family and friends relied on most often, though there was a perception that visits of both

family and health professionals were viewed as for the patient and not themselves, despite the fact that regular contact with, and access to healthcare professionals was perceived to be of great support.

From a methodological perspective whilst this study confirms previous studies that carers in palliative care experience psychological distress, the key aspect of this study is that it refines those findings by including a measure that revealed that young carers and female carers have greater levels of measured distress and caring burden, and may require additional physical and emotional support in their caring role.

The authors acknowledge some limitations to the study, including the fact that it is a small study undertaken in two areas. However, the fact that they undertook analysis of the data by site and were able to demonstrate similar responses improves its validity and goes some way to counteract this. Furthermore, they discuss their concern that the sample represented an over optimistic account of carers needs because of selection bias in that there were some healthcare professionals reluctant to request the participation of carers of patients with very advanced disease. As such, there is caution expressed about the generalisability of the study.

Whilst the authors do explore the limitations to their work, they do not examine how their own beliefs and use of a previously developed interview schedule may have introduced bias into the study, Litva and Jacoby (2002), state that reflexivity is important in qualitative research, since it allows the researcher to account for how they may have influenced and shaped their results. Whilst Payne et al. (1999) did pilot and achieve face validity with their interview schedule they could have attempted to reduce such potential bias through the use of narratives allowing participants to talk about the issues that were

important to them and not issues which are the predetermined interest of the researcher. Importantly, they do acknowledge the fact that the study does not allow inferences about patterns of causation or changes over time, and that a longitudinal study may better inform this.

1.6.3 Non-spouse carers

When reviewing the cancer carer literature, it was found that there was an emphasis on carers who are spouse or family rather than carers who do not live with or who are unrelated to patients. One study (Wilson et al., 2002), found that these carers had information needs that were difficult to satisfy because of their lack of family and or legal status, resulting in uncertainty about their rights. Luker et al. (2000) and Woods et al. (2002) highlight the ethical complexities of awareness, of who knows what with regard to a patient's condition and prognosis. They suggest that issues of confidentiality are perhaps even more ethically challenging when dealing with carers who are not family, but who may have the same information needs for future planning. The issue of those carers who are non-resident with the patient who have visits from healthcare professionals is another area of concern identified by Luker et al. (2000). Who and why were they visiting, and what were they doing? The issue of how to keep these carers informed without compromising patient confidentiality is particularly challenging.

1.6.4 Healthcare professionals and support to carers

Grande et al. (1997), in a community study examining the dilemmas of patients and carers in the last year of a patient's life, suggested that the best way of helping carers may be to help patients' to come to terms with their increased need for outside help. Whilst services may be available, Grande argued that it is their timely integration that is crucial

in order to sustain patient and carers throughout the cancer experience, rather than being a belated response to a crisis.

The aspects of better communication between healthcare professionals, patient and carer, to supply information and coordinate care in order to anticipate and meet needs is echoed by Davis et al. (1996), who explored the experiences of patients suffering from a terminal illness and their carers. Using a semi-structured interview in a survey method, their results suggested that it was usually a spouse or the daughter who was the main carer, and that most patients preferred to retain their independence of the support services as long as possible. They concluded that a number of these limitations could have been reduced if earlier diagnosis had been made or if support services had been called in earlier. Burden of care in this context appears to be related to lack of support and information, despite a willingness to care.

Many studies involving carers suggests a need for a mediating role between patient and carer, but who is best placed to act in such a role is not clear. Reflecting on the aspirations of the NICE (2004) guidance and concern that both patient and carer needs for information and emotional support are not being met, it is apparent this is clearly an area of cancer care that still requires further evaluation and attention.

Twigg (1989), has suggested that the attitude of healthcare professionals who view the carer “not as a person in their own right, but merely as an appendage to the patient” or even “a coworker” may contribute to increased levels of psychological distress. Whilst carers are apparently recognized in policy, (Department of Health, 2000b; NICE, 2004) previously recognised uncertainties as to whether carers are providers or users of services (Heaton, 1999), or whether they should be acknowledged as experts in

their own right (Nolan, 1996), appear to still prevail. In palliative care it has been suggested that their specific needs need to be regarded as a distinct entity and that they should be assessed as secondary patients (Finlay, 1999). Inclusion of carers needs in the NICE (2004) guidelines and operationalised in the Gold Standards Framework for Palliative Care (Thomas, 2003) appears to acknowledge their importance in the last year of life, but whether this will eventually also include carers in earlier, supportive stages of cancer care has yet to be demonstrated.

1.6.5 Carers and the stage of cancer

Payne et al. (1999) have suggested that there is a major flaw in the literature concerning carers. They consider that other than in caring for the cognitively impaired, there are few studies that explore carers experiences of caring in specific illnesses or medical diagnosis. Payne et al. (1999) are concerned that the carers role in different disease trajectories and levels of support are likely to have major impact on the level of stress a caregiver may be subject to. They suggest that in cancer, contributing factors such as the uncertainty of outcome, the stage a cancer presents, treatments available and response, may require the carer to have intensive involvement for a short period of time, then a period of remission, even cure.

Of relevance to the current study, Payne et al. expressed concern about the needs of carers of patients with advanced disease and limited prognosis, who require an intensive period of adjustment to palliative and terminal care. Thus, anticipating both the patient and carers needs and equipping and preparing carers to care in such a short space of time is likely to require intensive assessment, and support by healthcare professionals if a crisis is to be avoided. However, it is not possible from the current evidence available to

identify what it is and who should support carers to care, and importantly to achieve satisfaction with the care they provide.

1.6.6 Carers, psychological issues and gastrointestinal cancer

In the literature examining psychosocial issues in carers and gastrointestinal cancer only a very limited number of studies were found which focussed on the psychosocial and physical impact of gastrointestinal cancer on patients and their carers. Northouse, Mood, Templin et al. (2000) used a quantitative approach to compare patients' and spouses' patterns of adjustment to colon cancer. This was a longitudinal study which used several instruments to obtain data. 56 patients were recruited from consultant lists of patients with colorectal cancer.

Key issues emerging from this study included that patients may be more accepting of their situation than their spouse and that spouses are vulnerable, however the longitudinal nature of the study demonstrated that these problems were reduced over time (Northouse et al., (2000). Another key methodological issue was how Northouse et al. (2000) aimed to develop a deeper insight into how couples adjust over time again through the use of a longitudinal study. Northouse et al. (2000) stated five of the seven scales used to measure levels of adjustment have previously documented reliability and validity. Furthermore, they used confidence intervals to show the statistical significance of their results, which quantify the precision of the result. However, they recruited a small sample of only 56 participants and they acknowledge that it may have been insufficiently powered to detect some effects. They also acknowledge that some pre-existing conditions may have accounted for changes in the study, rather than illness alone. As a result it may not be appropriate to generalize these findings to a wider population.

There seem to be a number of key issues emerging from the carer literature. Whilst recent policy and guidance appear to acknowledge their importance in the last year of life, who should provide care to carers at an earlier stage of the cancer trajectory seems less certain.

- Exploratory qualitative studies in the cancer and palliative care literature have had the advantage of capturing carer experiences. Findings suggested an association between psychological distress and such factors as access to information, better communication, and support from healthcare professionals. Of significance to the proposed study, there is an indication that carers would have welcomed more information and support at an earlier stage of the cancer trajectory and not just in the final stages, in order that they might plan and anticipate need in the patient.
- The advantages of both mixed method and longitudinal approaches have been demonstrated in the literature where the vulnerability of younger, female carers, with greater levels of measured distress and caring burden were found suggesting they may require additional physical and emotional support in their caring role.
- A limited amount of evidence suggests that if carers needs are to be met, there may be a need to help patients come to terms with their increasing need for outside help. The evidence to show why patients hold back on accepting external support is limited. However, it is apparent that as in so many other aspects of supportive and palliative care, helping patients come to terms with this reduction in their independence through for example, meaning based coping, (as previously discussed), will very much depend on the assessment and support skills of healthcare professionals involved to enter into what may include a mediating role

between patient and carer. This is clearly an area of cancer care that requires further evaluation and attention, and may have further resource implications.

1.6.7 Bereaved Carers and cancer

Studies which examine the consequences of the caring experience in cancer and describe what factors hinder or promote adjustment to their loss and bereavement are limited (Fakhoury McCarthy and Addington Hall, 1997; Cameron and Parkes, 1983). There is a lack of research to guide evidence based practice to identify those who might be at risk of poor adjustment once bereaved. Bereavement is viewed as something separate, after the event, rather than on a continuum of the cancer trajectory.

1.6.7.1 Bereavement theory

In order to better understand bereavement it was decided to explore bereavement theory and grief in the context of coping and adaptation. It was considered that this might help to establish whether there was any relationship between coping as a carer and coping when bereaved, and thus, whether theories of coping such as Lazarus and Folkman (1984) influence the bereavement process.

It has long been acknowledged that death is a most powerful stressor in life, and can result in both somatic and emotional distress in those closely associated with the person who has died (Freud 1917; Lindemann 1944). The sociological literature (e.g Walter, 1999) and the psychiatric literature (e.g Bowlby, 1996; Parkes, 1996) proved to be helpful in exploring terms used when discussing the loss of a close relationship including bereavement, grief and mourning. Bereavement is defined as the reaction to the loss of a close relationship, whilst grief is defined as the emotional response caused by a loss including pain, distress and physical and emotional suffering (Walter, 1999 pp xv). A

further important term is mourning which refers to the psychological and behavioural expression of grief, often influenced by cultural and gender differences (Walter, 1999; Firth, 2001). However, what also seems to be apparent is that all these aspects are inextricably interlinked (Walter, 1999; Small, 2001).

One of the most influential theories of bereavement of the twentieth century is the developmental theory summarized by Walter (1999 pp. xiii) as something that can eventually be 'resolved' by 'detaching', 'letting go', and 'moving on' to new relationships. This theory assumes that grief associated with bereavement is a process, and there are certain stages to be worked through to achieve a positive change in the bereaved individual. Failure to move on is interpreted as abnormal grief. This theory has its roots in the psychoanalytical work of Freud (1917), where mental pain, typically repressed, needs to be brought to the consciousness so that psychiatric symptoms can be relieved. In the early part of the twentieth century, in his 1917 text 'Mourning and melancholia', Freud analysed aspects of depression, the results of which offered the basis for a number of theories of grief and their resolution. Whilst acknowledging the difficulty of grieving where there is an inner need to both carry on a bond with the deceased and at the same time let go of the relationship, Freud stressed the important need for this process he called grief work, in order that mental energy and emotion could be channelled into the bereaved individual's recovery and future relationships. Lindemann (1944) went on to develop Freud's grief work, whilst other theorists, such as the psychiatrist Bowlby (1969, 1979), developed the relationship aspect of Freud's work in attachment theory where attachment in human relationships and the breaking of this relationship through separation and loss were explored in an attempt to understand the effects of bereavement.

Working with young children separated from their parents, he identified how bereavement could trigger intense feelings of distress and behavioural emotional responses, and argued that whilst children might protest, then despair and yearn, they eventually protect themselves by detaching from the mother, and as such all forms of mourning lead towards detachment as a means of survival. However, what was also emerging from this ongoing work (Bowlby, 1980) was that where these strong attachments exist there is also evidence of creative adaptation to change. He discovered that widows and widowers progressed through phases when coming to terms with their loss and reach a state of mind in which they retain a strong sense of the continuing presence of their partner'. Bowlby (1980) suggested that this is a common feature of healthy mourning which explicitly refutes Freud's views that the function of mourning is to detach the survivor from the dead person. Parkes (1986, 1993), another psychiatrist working with the bereaved also sought to understand the major impact of loss, and how it challenged the normal psychosocial world of the bereaved. He supported Bowlby's view at this stage that individuals progress through phases in coming to terms with their loss. He describes how prematurely bereaved widows whilst at first too shocked to remember much about their spouse then began to recall and enjoy more memories, leading to a richer, rather than an attenuated sense of their dead husband.

1.6.7.1.1 Continuity theory

Theories of bereavement continue to evolve. Building on the work of Bowlby (1980) and Parkes (1986) whose ideas suggest that previous strong attachments can facilitate creative adaptation to change allowing the individual to retain a strong sense of the person they have lost, continuity theory also challenges the idea of moving on and letting

go of the deceased person. The purpose of grief is to integrate the dead into the survivors ongoing life, and not to sever ties (Walter, 1996).

1.6.7.2 Stress and coping in bereavement, implications for this study

This focus on the psychological rather than the physiological changes was first proposed by Holmes and Rahe (1967) who proposed that what helps us understand stress is to focus on the sources which trigger the stress reaction. They suggested that any life change such as bereavement can be a stressor which challenges the adaptational capacity of individuals resulting in both physical and psychological responses

Having explored the transactional model of stress and coping developed by Lazarus and Folkman (1984) (as discussed in Section 1.5.13.1) it could be considered that the death of a close relative or friend is likely to result in stressors, triggering a stress response of problem focused and emotion focused coping. Taking into account the psychological factors in the appraisal and response to stress, Stroebe and Schut (1999) developed this theory in bereavement, in their dual processing model. This model proposes that there is no one way to grieve and that individual's fluctuate between restoration focused coping where they attempt to deal with everyday life, and grief focused coping where they allow themselves to express distress. Over time, they suggest that the individual tends to utilize more coping responses associated with a restoration focus. Whilst links can be made here with the continuity theory of bereavement, what is not clear from the literature is what strategies contribute to improved levels of coping that enable adjustment from grief focused coping to restoration focused coping including the integration of the deceased into the individuals life. Furthermore in order to promote this adjustment and psychological well-being how can such strategies be promoted and

maintained in those adjusting to their anticipated loss when a carer and their loss when bereaved. From a gastrointestinal cancer perspective are there experiences of support and service provision to both the patient and the carer that promote adjustment in the carer when bereaved? How do we assist carers to achieve positive psychological states when caring which may equip them to cope when bereaved?

1.6.7.3 Bereavement research

Post bereavement interviews are an established means of documenting the effect of caring, loss and adjustment (Cameron et al., 1983), and a small number of large studies have utilized this approach (Addington-Hall et al., 1995). Concern has been expressed about the reliability of such proxy reporting in relation to perceived patient experience (Higginson et al., 1994; Fakhoury et al., 1997), but Beaver et al. (2000) and Rogers et al. (2000) claim that it is the information about carers' own first hand experience and accounts of caring for a person with terminal disease which are both valid and valuable in this under researched area.

The use of post bereavement interviews have been subject to expressions of concern that they might be intrusive and cause distress. However, Seamark et al. (2000) found that this method caused no or only mild distress in 80% of participants. Only one interview was terminated because of excessive grief, but 75% of those completing the interview found the interview helpful or very helpful and viewed it as an opportunity to talk through the process of dying, vent anger, it was the first chance to speak openly about the death, and it was worth doing if it was helpful to others. This suggests that such a method may also be therapeutic as in telling their story in bereavement counselling.

1.6.7.4 Bereaved carers and psychological distress

In a small, but significant study in a large teaching hospital in Canada, Cameron and Murray-Parkes (1983) looked at adjustment in 20 carers whose relative with cancer had died in a Palliative Care Unit (PCU), and who had received pre and post bereavement support. They were compared with a control group of 20 carers whose relative had died of cancer in other wards of the same teaching hospital.

It could be argued that a strength of this study was that it was a controlled trial that tested an intervention of the palliative care unit using multiple sources of data including demographic information, the amount of warning of the pending death as well as an interview and a health- adjustment inventory of 32 questions. This covered psychological aspects of bereavement and mental health at two weeks and one year post bereavement.

The results showed that:

- 75% of the control group claimed their personal health had deteriorated since bereavement compared to 40 % of the PCU group.
- 50% of the control group were taking night sedation, and almost as many were taking tranquillisers, as compared to 20% and 5% of the PCU group respectively.
- Signs of continuing psychological stress and persisting grief as well as expression of irritability and anger were evident in 85% of the control group compared to 5% of the PCU group.

The PCU group reiterated appreciation of care that had been given, particularly effective pain control, and how this contributed to their peace of mind since bereaved. In both groups those who were aware at least 4 days in advance that the patient was going to die had a better overall outcome. What has to be considered about this study is how it is

one of the first studies that identified how healthcare professionals can contribute to the experience of positive psychological states in carers when bereaved through effective strategies including inclusion of the carer in the patient's dying process. It is an aspect of positive psychological states that is very reminiscent of Folkman's (1997) adapted theory of coping, and is an area that requires further investigation.

In a much larger study, Fakhoury et al. (1997) conducted analysis on a sub-sample of 1858 carers from the Regional Study of Care of the Dying survey of cancer deaths in 1990 in 20 health districts in England. Results demonstrated statistically significant associations between bereaved carers' self-rating health status, psychosocial function, their experience of bereavement related health problems, and their perceived satisfaction with professional services. McCorkle et al. (1998) in a study with lung cancer patients of poor prognosis and their spouses that bereaved peoples' psychological distress can be positively influenced depending on how their loved one was cared for during the terminal phase of their illness. In a similar vein, Wiles et al. (2002) found that medical error or negligence was a risk factor for complicated bereavement and a reason for referral for counselling, an aspect not identified in other studies.

The relevance of these studies is that they identify clearly some of the consequences that are experienced by the bereaved dependant upon their experience of professional care to the patient and support to themselves. Kissane, McKenzie and Bloch (1997) suggested that since family functioning appears to be emerging as pivotal to adaptive grief outcome, it is recommended that an assessment of family issues as a part of good clinical care in order to identify families at risk of suffering maladaptive grief, and offering psychosocial intervention when indicated.

1.6.7.5 Bereavement support

Whilst recommended methods are available, and bereavement support appears to be long established as an effective and integral part of palliative care there appears to be great diversity in uptake. Only 18% of bereaved individuals partake of current supportive interventions offered (Addington-Hall et al. 1998), and high numbers fail to complete counselling contracts.

It has been argued that bereavement support in palliative care is not as advanced as other aspects of palliative care (Payne and Relf, 1994) with some indication that the organisation of palliative care services (Beaver, Luker and Woods, 2000), as well as the needs of the families may need further evaluation and research (Bromberg and Higginson, 1996). Cameron et al. (1983) suggested that post bereavement support with those who 'had been there sharing it all with you' can reduce the incidence of maladjustment. More recently similar findings have been substantiated by Field et al. (2006), in a hospice setting where pre-bereavement support and continuity between this and bereavement support positively contributed to the person's experience of bereavement. It might therefore be presumed that carers response to District Nurse and GP counselling post bereavement should be effective.

However, the development of bereavement care in hospices does not appear to have had a major impact on other healthcare professionals (Field et al., 2007), and as with other aspects of palliative and supportive care such as communication skills training and end of life care, perhaps there is an opportunity for hospices to identify a model for pre and post bereavement care to be integrated into the end of life care package that might be transferable to other settings in primary care and acute trusts. Again, as with

communication skills training, and psychological assessment there appears to be a need for developing competence through education and training in this essential aspect of care of the dying, though time and resources may be the greatest challenge to overcome.

Studies of the effectiveness of primary care teams in bereavement support are still in their infancy (Payne, 2001). In a study exploring the experiences of counsellors providing a service in GP practices, Payne (2001) found that bereaved people were often referred when they had what were interpreted by the GP as complicated or abnormal grieving reactions, and for some, time had elapsed since the death. Counsellors also recalled that when a person had been referred for generic counselling for another reason as discussion progressed experience of past bereavements were found to be a major contributing factor to their current distress. Thus, it would appear that psychological issues related to loss and bereavement may have wider and ongoing consequences if left unresolved.

Birtwistle et al. (2002) in a survey of 307 community nurses found that older age, higher qualification, and district of employment was associated with greater interest in bereavement and more proactive care of bereaved people. Costello (1995) suggested that District Nurses are well placed to assess the bereaved for health problems and refer at risk people to more specialized services. However, there is concern (Birtwistle et al., 2002) that when District Nurses assess bereaved people, whilst they are able to provide practical support and information, mental health issues may not always be assessed as the District Nurses may not feel competent to assess mental health issues with bereaved people, as previously recognized in assessing and meeting the information needs of carers (Beaver et al., 2000; Payne et al., 1999).

Birtwistle et al. (2002) suggested that with the changing social structure of families, bereaved people may turn to healthcare professionals when in the past they would have turned to family, community or the church. However, the role of District Nurse as bereavement counsellor cannot be presumed, and there are important implications for the education and emotional support of nurses working in bereavement support, as in the studies examined in relation to communication skills training and levels of competence for assessing psychosocial needs in patients (Skilbeck et al., 2003; Booth et al., 1996). Furthermore, from an organisational perspective there are resource implications for continuing professional care of carers and bereaved carers, as this is not normally assessed in estimates of workload (Finlay, 1999).

- Whilst carers' own first hand experience and accounts of caring for a person with terminal disease are both valid and valuable in this under researched area, there is a lack of evidence to guide practice in for example a specialist gastrointestinal cancer unit, to identify those who might be at risk of poor adjustment once bereaved. Overall, the responsibility does not seem to lie with those involved in cancer care at an earlier stage, with bereavement viewed as something separate, after the event, rather than on a continuum of the cancer trajectory.
- It is apparent that bereavement theory and grief in the context of coping and adaptation may be useful as a provision for considering whether there is a relationship between coping as a carer and coping when bereaved. What is not clear from the literature is what strategies contribute to improved levels of coping that enable adjustment from grief focused coping to restoration focused coping including the integration of the deceased into the individual's life.

- From a service provision perspective, it seems essential to identify what these strategies are and how they can be promoted and maintained in those individuals adjusting to their anticipated loss when a carer and their actual loss when bereaved. Are there experiences of support and service provision to both the patient and the carer which promote positive psychological states and adjustment in the carer when bereaved?
- A similar theme explored in a small number of studies suggests that post bereavement support with those who ‘had been there sharing it all with you’ can reduce the incidence of maladjustment. Whilst no evidence of this advantage could be found in gastrointestinal cancer, it is apparent that this is an area that requires further investigation if a specialist gastrointestinal cancer centre is to ensure that it is meeting the needs of carers when in their caring role and when bereaved.

1.7 Summary

Whilst the 2000 Cancer Plan (Department of Health, 2000b) appears to have achieved some impressive results in streamlining cancer services, a number of concerns in relation to the implementation of aspects of the Palliative and Supportive Care guidance (NICE, 2004) appear unresolved. Whilst demographic and epidemiological trends indicate that the proportion of the population living with cancer in remission or with managed relapses is set to increase, for those affected by incurable gastrointestinal cancers, boundaries between diagnosis, treatment and palliation are likely to remain blurred, and for the majority, their time will remain limited.

This review has focussed on key domains that may contribute to identifying the impact of gastrointestinal cancer on normal functioning and quality of life in patients, carers and bereaved carers since the need to understand the experience of cancer from this perspective is considered a priority to inform practice. Whilst there is evidence that psychosocial care is beneficial and its lack can be harmful, the literature has revealed few studies that specifically evaluate the needs of a population of patients with gastrointestinal cancer that is no longer curable, and few that evaluate the needs of their carers. Consequently, there seems to be a lack of knowledge of the relationship between coping ability and well-being in such patients and their carers' both during the caring phase and when bereaved. Whilst a small number of studies in the gastrointestinal cancer of colorectal cancer were identified, whether these studies can be generalized to the other gastrointestinal cancers requires further investigation with such patients and carers. A study in this cancer population could serve as an exemplar for other cancers, as the emphasis is on supportive and palliative care from the time of diagnosis in a disease of limited prognosis.

A number of studies in palliative care have added to our understanding of how communication skills, interpersonal skills and techniques can promote disclosure of concerns and contribute to assessing psychological distress in patients. However, they have also highlighted that there are other facets such as professional support to clinicians which are essential for achieving and maintaining effective communication other than just training in communication skills. To assess the importance of this key aspect of cancer care with those affected by incurable gastrointestinal cancer has the potential to improve our knowledge in this key area of cancer care.

Although professional support roles in cancer are accepted and encouraged in the literature and reflected in policy guidelines, there is very little hard knowledge about elements that are beneficial or the significance of the primary/ secondary/tertiary interface, where communication and exchange of information appear to be key. There also appears to be a need to identify whether the management of patients and their carers (in cancers that present as advanced disease) contributes to their levels of psychological distress or psychological well being. It appears likely that factors (such as information and coordination of care) may be important for adjustment when bereaved.

A review of the studies in each domain has identified a variety of methodologies and research methods employed to generate knowledge, regarding different aspects of the literature review. Several authors chose to adopt qualitative methodology, using interviews, narratives or focus groups to describe the experience of patients and their carers and the meaning they ascribe to their situation. Through the use of description and interpretation, qualitative methods are able to provide a picture of what is actually happening (Duffy, 1987). The researcher is concerned with the dynamic nature of reality and attempts to achieve a holistic view of what is occurring, including subjective data (Dootson, 1995).

Thus, both qualitative and quantitative methodologies were identified from the literature review, which have generated knowledge in relation to identifying the research question. The qualitative studies have provided an insight into the lived experience of participants, whereas the quantitative studies provided numerical data to illustrate the relationship between variables. The authors adopted various strategies to improve the quality of their research, yet the review has identified a number of flaws in the studies,

which question the trustworthiness of the results. Therefore, it is important to consider if there are any alternative methodologies which can generate knowledge regarding this topic.

The major domains identified throughout the literature were the psychosocial and physical impact of cancer and the effect on quality of life. The qualitative studies provided an in-depth account of the patient and carers experience, whereas the quantitative studies used numerical data to explain the association between variables. The critique of the studies identified some flaws in the research design, which suggest that the quality of results may be compromised and the findings should be interpreted with caution.

Methodological triangulation could generate knowledge about this topic and possibly reduce some of the inadequacies associated with a single methodology. Therefore, in order to ensure that clinical cancer practice remains evidence-based, utilising the full body of knowledge in this area, future research should consider the use of a mixed method approach. Furthermore, there is evidence that a longitudinal approach may also have benefits.

Key questions that cannot be answered from the literature:

- What is the level of psychological distress in patients with gastrointestinal cancer and in their carers’?
- What strategies influence their resources for coping and well-being?
- What would improve meeting the needs of bereaved carers in this population?
- Does meeting the needs of carers improve their resources for coping when bereaved?

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CHAPTER TWO

METHODOLOGICAL CONSIDERATIONS

2.1 Introduction

The review of the literature concluded that there was:

- a likelihood of psychological distress in patients with cancer,
- a limited number of studies involving patients with gastrointestinal cancer,
- a need for further information about carers both before and after death of their relative/friend
- little evidence to inform what the needs of these patients and carers are following disclosure of incurable diagnosis and what supports the ability to carry on.

2.1.1 Proposition: It therefore seemed important and necessary

- to explore the needs of patients and carers affected by these cancers
- to measure their levels of psychological distress
- to elicit from them what they consider would help
- this information will inform policy, service provision, and clinical practice.

2.2 The philosophical implications of the research questions

Psychological distress in people with cancer is increasingly being tested with standardised instruments, as well as with interviews (Devlen, 1984; Heaven and Maguire, 1997; Morasso et al., 1999; Maguire et al., 1999; Lloyd Williams and Taylor, 2004). The assumption is that the diagnosis of cancer is associated with morbid emotional states (e.g. anxiety and depression). Quantitative measures of anxiety and depression are then typically used, not only to establish the individuals current morbidity, but also as an

outcome measure associated with such factors as coping process and support. Much of the research focus has been on establishing the reliability and validity of instruments to measure anxiety and depression in different groups. However, from a coping theory perspective, Folkman and Greer (2000) suggested that the emphasis on measuring these symptoms reveal only part of the story of how people cope with illness. It fails to include psychological well-being and factors associated with resilience such as coping and support. Little is known about the needs of people affected by incurable gastrointestinal cancer, and by themselves quantitative approaches might contribute to the making of a psychiatric diagnosis but will not give insights into the process of change and adaptation/maladaptation from the point of being given an incurable diagnosis onwards. It therefore seems crucial to explore what it is that contributes to psychological distress and/or well-being in these individuals. The emphasis will not be on making or excluding a psychiatric diagnosis, but rather on an approach that incorporates measures in conjunction with qualitative methods (such as interviews) which the literature has revealed can more widely capture and assess each individuals' unique response to cancer. The use of the two approaches should offer a perspective for theoretical triangulation, a biomedical pathological account and an existential account of the lived experience.

2.3 The rationale for a complementary approach

The combining of research methods is currently much more prevalent in the social and behavioural sciences than it was 20 years ago and has been a cause of ardent debate between those who have adhered to one or other perspective (Bryman, 1984; Guba and Lincoln, 1994; Coyle and Williams, 2000). These debates have centred around several

conceptual issues relating to the production of knowledge and the research process and in particular the quantitative and qualitative debate. A summary of the issues is explored.

2.3.1 Combining quantitative and qualitative research methods: the debate

In order to answer the research question the philosophical views which underpin research must be considered. There are two major paradigms; the rationalistic paradigm and the naturalistic paradigm which underlie all research (Dootson, 1995). A paradigm is a world view of a subject which includes its underlying philosophy and the assumptions inherent in that view (Khun, 1970). It is these assumptions which should guide the research process, by providing a philosophy within which research questions can be developed (Munhall, 1989).

Quantitative research is usually characterized by isolating, defining and categorizing specific variables in an objective manner. Qualitative data are often collected in a predetermined way usually with a tested instrument in the form of a questionnaire which requires unambiguous answers. The aim is to test a hypothesis decided upon before the data collection commenced. The testing of the hypothesis is clearly defined in standard statistical analysis which examines the relationship between variables, and tends to be enumerative and deductive.

The naturalistic paradigm views science as a process of understanding human behaviour; views the individual as a whole and believes that reality is multiple, interrelated and determined within context (Haase and , 1988). Within this paradigm are different branches such as ethnography, phenomenology and grounded theory, which have different slants concerned with describing the situation, including meanings, feelings and beliefs (Duffy, 1987).

Conversely, qualitative data are usually collected in the form of in-depth interviews or participant observation, with the aim of maximum exploration of the data. In this process the data itself becomes the outcome of the research and tends to be analytical and inductive. Generally, quantitative research has a narrow focus observing specified variables, whilst qualitative research has a broad focus searching for patterns and inter-relationships between unspecified variables. The researcher in a quantitative paradigm is considered to be a detached observer aiming to assert no influence on the collection of data. Conversely, the qualitative researcher often considers their involvement as an important implicit facet in shaping and collection of data using flexible and reflective research skills.

Quantitative research tends to be enumerative and deductive assuming an objective reality exists which can be accessed. Generally, the aim is to identify from a sample population the number and type of people in a general or parent population who are likely to have a particular characteristic. In contrast, the qualitative researcher is mostly analytical and inductive in the research process and formulates theory through concepts and categories not through their incidence and frequency. Quantitative enumerative deduction has a long tradition associated with the 'hard sciences' and is therefore generally viewed as a reliable method of obtaining scientific fact. Qualitative methods have a much more recent history of use, gaining popularity in the 1970's. The data and theory generated from qualitative analytical induction have therefore been criticized as unscientific and subjective. Conversely, constructionists of the qualitative paradigm criticize numerative, inductive methods for creating a particular 'type of truth' rather than uncovering 'the truth' and severely doubt the possibility of social sciences to isolate laws

of human behaviour (Brannen, 1992; Bryman, 1984; Capaldi and Proctor, 1999). It is this underlying ontological view which has created tension between the amalgamation of quantitative and qualitative methods.

2.3.2 Combining quantitative and qualitative methods: the rationale for a complementary and pragmatic approach

According to Corner (1991) there has been an attempt by some authors to suggest that quantitative methodology represents the logical positivist approach to research and qualitative methods are synonymous with phenomenology or ethnography. Bryman (1984) was critical of the tendency to place quantitative and qualitative methodologies within a specific paradigm and argues that epistemological and technical issues should not be used interchangeably. Such confusion regarding qualitative and quantitative research has led to the debate as to whether it is feasible to use both methodologies together in research. However, combining the two may help to solve the developing polarity in social science research and offset the individual inadequacies of individual approaches (Corner, 1991).

The opposing ontological views which the quantitative and qualitative methods adhere to would seem to make any combination in a research study impossible. However, Hammersley (1997), and Woolgar (1997) have argued that the contrasting features of qualitative and quantitative research are overstated principally because of the antagonism between the two traditions. Whilst there are differences, they are not as rigidly defined or problematic as has been traditionally argued (Bryman, 1984; Woolgar, 1996). Hammersley (1997) suggested that many methods do not fit neatly into one category, added to which there are many philosophical variations between the extreme

philosophical stances. The important thing is to select a research method according to judgement and the purpose of the research with the aim of ensuring as accurate a representation as possible and not by adherence to a philosophical stance (Hammersley, 1997).

Yardley (2000) suggested a 'middle way' forward. This pragmatic way accepts the relationship between objects and representations can be contorted by other forces such as the research process or human distortion of the facts. The emphasis is placed upon obtaining a fuller picture of the research topic and gaining different views of the truth, but not necessarily a truth (Begley, 1996). Complementary approaches can allow the researcher to function from a position of practical application to the research problem rather than from a position of a theoretical paradigm view which limits the choice of methods. However, Hammersley (1997) reminds us that any eclectic view must acknowledge the theoretical underpinning of the methods chosen as they are relevant to the way the research is carried out and the interpretation of the data. With this in mind the main paradigms in this mixed method case study design have been explored with the aim of illustrating how they complement and inform each other.

The two principal paradigms are:

- **case study and triangulation**

with important influences of

- **reflexivity**

In the following sections case study and triangulation are explored with reference to the contribution of reflexivity throughout.

2.4 Case study research

2.4.1 History of case study research

Case study research developed out of the influential Chicago School of Sociology in the 1920s and 1930s in the USA (Yin 2003). This early work utilised records, interviews and participatory data, with the primary aim of understanding the social context from the perspective of the participants. It was increasingly used in other disciplines such as anthropology, geography and economics (Yin, 2003). Case study research grew less popular in the 1930s with the emergence of statistical analysis, which could be applied to large amounts of quantitative data.

2.4.2 Definition of a case study, and rationale for its use

Yin (2003 p.13) defines a case study as 'an empirical enquiry that investigates a contemporary phenomenon within its real life context, especially when the boundaries between phenomenon and context are not clearly evident'. Case study is an in depth research strategy rather than a method. Its focus is on a particular 'case', whether that be an individual, a group, an organisation or a society (Meiher and Pugh, 1986; Stake, 2000; Yin, 2003). This research approach is distinct from the clinical case study of an individual, although it can focus on an individual patient (Yin, 2003).

The key characteristics of case study research as a strategy and the rationale of how they are applied to this study are now explored.

An important design component when considering whether a case study is going to answer the research questions is the decision to use a single or multiple case approach (Yin, 2003). In a single case study design the focus is on an individual or single unit, (e.g a hospital or school), whilst a multiple case study approach uses data from multiple

sources (e.g a number of hospitals, a number of schools) and is useful when comparison of cases is potentially fruitful (Yin, 2003).

In a single case approach Lee (2002), interviewed and observed patients and professionals in a single day hospice. The data collection was guided by theoretical propositions and the analysis was guided by pattern matching to the theoretical propositions. The results of this single case study challenged the theoretical literature which had suggested that working within a team structure assured interprofessional working.

In a pertinent study, Bergen (1992) used a multiple case design to evaluate the nursing care of terminally ill patients in the community. Each case consisted of three patients, a district nurse and a continuing care nurse working in one health authority. The case was an instance drawn from a class (Alderman et al., 1980), the class being nursing care of the terminally ill in the community and the instance being how effective nursing care teams are at providing continuing care based on patient needs. Whilst Bergen (1992) sought to evaluate practice, it was also acknowledged how information gained about this population could be both exploratory and descriptive as so little work had been undertaken previously. Bergen (1992) suggests that findings were not intended to be generalised to the community outside the area, but other community nurses could assess the interpretation of the study and consider how it might be applied to their practice. However, the generalisability of the findings were promoted by the fact that Bergen (1992) based her theoretical framework on nationally agreed standards of care, utilised by community nurses as a quality measure or audit tool i.e. generalisation was to theoretical propositions rather than to populations. If other nurses measure the quality of care by

these standards, the results of Bergen's study could be used as a measure of the effectiveness of care delivered.

2.4.3 Case study research and nursing

Meiher and Pugh (1986) suggested that because nursing is such a diverse occupation the flexibility of case study research is valuable. Sharp (1998 p 785) refers to the climate of developing research based practice, and states 'by definition case studies take place in the practice setting, and so can be carried out by practitioners in a way which other more remote forms of research cannot'.

Another example, (Kent and Maggs, 1992) used case study research to evaluate pre-registration midwifery education. Their case was multiple and focused on six colleges of midwifery offering pre-registration training. Rather than evaluate cause and effect, this study sought to describe and explore pre-registration midwifery. In relation to external validity and generalisability this multiple case sought to generalise outside the case (in contrast to Bergen 1992) as it was looking at evaluating pre-registration midwifery in general rather than in one region, but was also able to identify regional variations in the provision of pre-registration midwifery.

In a longitudinal key study in palliative care looking at the complex and differing patterns and processes of service delivery by Macmillan nurses Skilbeck and Seymour (2002), Clark et al. (2002), Corner et al (2003) and Skilbeck and Seymour (2003) used and built upon a case study strategy with great effect. Not only did the prospective, longitudinal, comparative case study approach reveal the processes, it was also flexible enough to look at structures and outcomes. The links between these elements were made because case study promotes the drawing together of evidence from different complex,

changing context sources collected by different methods, often by comparing the data to prior propositions derived from relevant literature. Resources were a major aspect of this study design since it incorporated both a number of organisations as well as a number of skilled researchers.

From these examples it can be seen that case study research has the potential to explore the reality and complexity of practice and policy issues with a view to learning not only about the specific setting under study but also deriving theoretical indicators which may apply to other settings (Yin, 2003).

For this study the proposed single case design was adopted as pragmatic approach to an in depth investigation of patients, carers and bereaved carers affected by incurable gastrointestinal cancer treated in a specialist cancer centre in the North of England. Whilst it might at first be considered that patients referred from smaller units in a one hundred mile radius to the specialist cancer centre are multiple sources of data, Yin (2003) proposed that these are in fact sub-units of data embedded within a single case, the single case being the specialist cancer centre.

A multiple case design was considered, because it had the potential for being a more robust study with the advantage of substantial analytical benefits. These included for example, direct replication and/or the different contexts of each case, whereby external generalisability might be increased. However, the geographical limitations and the time constraints of negotiating access to other specialist gastrointestinal cancer centres in the United Kingdom was beyond the means of the single part-time researcher. Despite this, the single case study was viewed as worthwhile in contributing to knowledge and theory

building and as a means of identifying future investigations in the entire field of caring for patients with gastrointestinal cancer.

It is important to stress that a case study is neither a data collection tactic, a method or design feature alone but a comprehensive research strategy (Meiher and Pugh, 1986; Yin, 2003). Its use with triangulation as a methodology was considered for this study as a means of supporting the person focused approach of the study as well as a means of analysing multiple subunits of data in an embedded, single case design. This was an important aspect for this study where the literature had supported the proposition that use of both qualitative and quantitative data could be useful.

Case study can describe, explore or explain (Yin, 2003), which was viewed as essential with the evaluation of service and exploratory and explanatory component of the study. This was important in the context of considering whether the single case was a revelatory case explaining what might contribute to good or less good service provision as well as how this might reveal the complex reality of what contributes to the well formulated theory of stress and coping.

It would appear then that case studies are appropriate to study complex social situations where there is a likelihood of multiple variables (Bergen, 1992). There is evidence of their effective use in cancer and palliative care in single case (Lee, 2002) and in multiple case design (Bergen, 1992; Cowley et al., 2001; Skilbeck et al., 2002; Kirshbaum, Booth and Luker, 2004). What is also apparent from the literature is that the response to a diagnosis of incurable gastrointestinal cancer is likely to be multi-faceted and multidimensional, and so a flexible approach to research is required. A case study approach values situational factors and this 'contemporary' aspect of this study, dealing

with the real world of those involved, which currently appears ill defined and uncertain, may be captured through a case study approach.

From the perspective of cancer patients and their carers, there may also be scope to describe, evaluate and explain what Yin (2003) refers to as ‘causal links’ in real life interventions such as whether healthcare support they receive, and from whom, is appropriate or not, with an emphasis on explanation rather than cause and effect.

In order to gain deeper insight into this population (of cancer patients and their carers) it is thus argued that use of a single case study approach that uses mixed methods such as triangulation has the potential to capture multiple perspectives in multiple sub-units of analysis, to recognise and reveal more about the complex situations these people find themselves in when confronted by incurable cancer and should provide a means of exploring the breadth of process and outcome experienced in a flexible, but rigorous approach. It is this use of a range of data collection methods in a case study approach which appears to be the key to capturing complexity (Skilbeck et al 2002) as well as capturing different perspectives and context and these are viewed as valuable research components to meet the aims of this study.

2.4.4 Validity and case study research Yin (2003) describes a matrix of case study design that identifies the attributes of the case to study in terms of embedded design, which in this study relates to multiple sources or subunits of data within a single case and is significant and guided the current design.

An application of all quality control components of the study is demonstrated at the beginning of Chapter Four (Section 4.1.1). The framework for assessing reliability and validity and establishing rigor and quality within the case study included:

- **construct validity** through the use of triangulation in relation to methods, providing both multiple sources of evidence and a chain of evidence.
- **external validity** of the findings by identifying a theoretical framework or theoretical proposition prior to entering the field (Yin, 2003). The theoretical propositions in this study were drawn from conclusions from the literature which led to the development of a theoretical framework (see Table 2.2) which in turn guided both selection of data collection methods and analysis. Analytical rather than statistical generalisation was the focus of the study. Because of the use of mixed methods, triangulation of qualitative and quantitative data was possible resulting in a wider explanation of the findings.
- **internal validity** by creating a structured technique for analysis and logical inference which helped to improve the validity of the study and provided an audit trail as advocated in qualitative research practice (Koch, 1994). The structured technique for analysis in this study included the development of matrices of categories (e.g Table 4.5) and placing evidence within such categories, including frequency of different events.
- **reliability** was demonstrated by description of clear research questions and an appropriate research design, including how all data were collected and analysed, such that the study could be repeated.

Three critical concerns of the validity of case study have been repeatedly acknowledged (Hamel, 1992; Yin, 2003), and it was considered essential to acknowledge and explore these from a perspective of potential disadvantages of a case study approach,

and to explain how these challenges were overcome when applied to this study. These were:

- the representativeness of the case (linked to sample),
- the rigour in the collection and analysis of data associated with bias on the part of the researcher and the research participants (relationship of researcher and reflexivity)
- generalisability (linked to theoretical generalization and analytical induction)

These concerns will now be explored:

2.4.3.1 The representativeness of the case

The literature describing how the case study sample should be drawn is limited, particularly when a mixed method is considered. Since the literature review and the propositions in the theoretical framework had suggested that data collection would benefit from a mixed method approach with the inclusion of quantitative measures, the participants were selected by purposive sampling, viewed as a valid case for both qualitative and quantitative data and one that would enable statistical measures to be applied.

2.4.3.2 Bias on the part of the researcher and the research participants

One of the traditional issues with research has been the belief that it is essential that the researcher has no effect on the research and equally that the research environment has no effect on the researcher recognising how values, assumptions and the presence of the researcher may impact on the data (Bryman, 1984). The investigator tries to maintain a detached, objective view and adopts 'bracketing', where previous experience and knowledge, is put to one side (Duffy, 1986), The possibility of becoming enmeshed with

participants could lead to the researcher having difficulty in separating their own experiences from those of their subjects (Sandelowski, 1986) resulting in subjectivity. More recently, in qualitative research, the use of reflexivity assumes that the researcher should engage in self-critique and self appraisal and be able to explain how their experience has or has not influenced all stages of the research process. In nursing (e.g. Lipson, 1991; Burgess, 1984; Hand, 2003), researchers have found that reflecting upon roles and agenda, and their own beliefs about a phenomena are considered an important part of qualitative study research

In the present study, reflexivity, a fairly recent, evolving development in social science research, has been included, but rather than using it to accord the study the appearance of academic rigour, it is proposed that because we are all influenced both consciously and unconsciously by our social world, true objectivity is not always possible or even desirable (Sandelowski, 1986). It is considered that relationships between researcher and participant are essential for fostering a collaborative approach and an aid to contributing to participants not feeling exploited (Finch, 1984), in what Heron (1981, p. 60) described as 'co-operative enquiry'. In practical terms it is difficult for a clinical nurse who is also a researcher to interview a participant who is also a patient and deny their professional life role (Spencer, 2003). It could be argued that to deny this aspect of their clinical professional / client relationship might also be unethical.

As such, reflexivity has the potential for collecting a richer vein of data, and is viewed as valuable in studies in which 'natural history' is central (Hammersley, 1997). The strength of the non-hierarchical, interactive relationship in reflexivity is that the researcher and the participant can co-construct valuable and meaningful data (Duffy,

1986), within a transparent reciprocal format in what Lincoln and Guba (2000) term a moral tilt towards revelation. The issues and application of reflexivity are explored further in the interview approach (Chapter Two, Section 2.9) and in Reflexivity (Chapter Five).

2.4.3.3 Generalisation and case study

Sharp (1998) argued that case study research is often underestimated, because of a fundamental confusion about two distinct logical bases upon which generalisations can be made: empirical and theoretical.

Empirical generalisation is concerned with showing that some relevant characteristic of a sample is typical of the population, but this does not require the researcher to say anything about the reasons for the relationship.

Theoretical generalisation, by contrast, is based on identifying some general principle concerning the phenomenon in question and seeking to explain the relationship.

Case study researchers have devised methods to overcome problems with generalisation, suggesting that it is not whether it can be done at all but from what can be reasonably generalised to what (Yin, 2003; Burns and Grove, 1997; Woods, 1997).

Yin (2003) compared the case study to an experiment in that:-

- it is aimed at generalising to theoretical propositions, not to populations
- the investigator's goal is to expand and generalise theories (analytic generalisation)
- making a case is more concerned with persuading the reader that it is reasonable for the results to be generalised, which can often be achieved through rich description of the context in which the study occurred in order that readers can judge the relevance of the findings to their own practice situation.

Sharp (1998) suggested that what is important about these explanations is that they are generated from a number of models or theoretical schemata used by social scientists to organise, order and explain phenomena. Within the present study it is anticipated that the reader will identify how for example, coping theory and coping in patients and carers affected by gastrointestinal cancer are associated or linked and will then examine how this can be theoretically generalised to their own area of clinical practice e.g coping strategies used by other cancer patients and carers, or those affected by Parkinson's Disease or Stroke. However, the relevance of the findings to any other practice situation ultimately has to rest with the reader (Simons, 1971).

2.5 Triangulation

Methodological triangulation, where methods associated with both quantitative and qualitative methodologies are used in combination in research, is gradually gaining popularity and acceptance (Douglas, 2003). Triangulation has developed as a way of combining traditional research methods, in an attempt to overcome the deficiencies and bias that can occur when using a single method (Duffy, 1987). Triangulation can be used to examine the same phenomena from multiple perspectives, to enrich our understanding, by allowing for new or deeper dimensions to emerge (Jick, 1979) and can improve the validity of data and the analysis (Bryman, 1984). However, there are many difficulties associated with triangulation such as the cost and time implications of employing multiple methods (Mitchell, 1986). In addition, it has been argued that the philosophies of the two paradigms are too opposed to be mixed (Phillips, 1988). However, much of the literature supports triangulation, but stresses that one paradigm will always dominate (Powers, 1987). Therefore, before embarking on triangulation, the researcher should

consider their underlying philosophical assumptions, or their work may become confused and useless

Therefore, it is reasonable to suggest that triangulation of qualitative and quantitative methodology could be an appropriate research methodology to generate knowledge for this topic area. Although the literature review included studies which used both interviews and questionnaires (e.g. Payne et al., 1999; Mullens et al., 2004) they acknowledge that their findings may be limited to some degree by the small sample employed. If methodological triangulation is used successfully to study patients with gastrointestinal cancer, it can be argued that a fuller picture could be obtained. Mixing methods may be of value for researching questions about social experience and lived realities. Thus, where studies identified a relationship between psychological distress and concerns, (e.g. Parle et al., 1996), the addition of qualitative methods helped to explain and interpret this relationship. Similarly, the findings from the qualitative studies could be generalized to a wider population, if quantitative methods were also employed. Indeed, the use of mixed methods in nursing research is endorsed in the literature.

Cowman (1993, pg 788) describes triangulation as 'a combination of multiple methods in a study of the same object or event to depict more accurately the phenomenon being investigated'. Methodological triangulation is not a new concept in research. Adopted from a navigational technique whereby two known or visible points are used to plot a third, it has its origins in the social and behavioral sciences, the term being first used by Campbell in 1956 (cited in Breitmayer, 1993). Use of more than one research method was advocated as a means of overcoming weaknesses inherent in much of the

research of that time (Campbell and Fiske, 1959; Denzin, 1978; Morse, 1991) to confirm or cross validate the findings of each in an attempt to validate results.

In contrast, Fielding and Fielding (1986), Bryman (1988), Knafl and Breitmayer (1989) and Shih (1998) favour triangulation for completeness. They suggested that combining methods just to increase validity is naïve, as the differences between data sets can be as informative and as valid as any similarities. In using triangulation for completeness a more holistic view is gained of phenomena under study which can add to the investigator's depth and breadth of understanding (Begley, 1996). Rather than to confirm existent data, extra data are expected to contribute an additional piece to the puzzle (Knafl and Breitmayer, 1991), in what Jick (1983) considers to be a more complete, holistic and contextual portrayal of the units under study. This is an important consideration in this study of those affected by gastrointestinal cancer where the situation appears to be complex and little is known. Such an approach could be useful for exploring and acknowledging the uniqueness of the individual experience, and what contributed to this experience.

2.5.1 Approaches to triangulation

Denzin (1978) identified two approaches, - within and between method:

Within method triangulation uses multiple single method data sources. For example Shih (1998) used semi-structured interview, observation, listening, clarification and explanation to enhance validation.

Between method or contextual triangulation collects quantitative and qualitative data using different techniques to look for common or different themes (Mitchell, 1986; Duffy, 1987). It is suggested that this approach has the following advantages:-

- Statistical findings from the quantitative method can validate themes arising from qualitative data and vice-a-versa.
- It can enhance the analysed data by illuminating different aspects of the 'problem', explaining differences and contradictions in the data, and should allow complex, causal links to become apparent and explained.
- A wider perspective of a phenomenon can be achieved which may uncover anomalies and paradoxes and present a new view of the area under scrutiny resulting in a more meaningful idea for accomodation and for completeness.

Sandelowski (1995) uses the term 'accomodation' to imply 'peaceful coexistence' of the different research traditions whilst preserving the integrity of each. Baum (1995) captures the essence of the approach. He argues that drawing data from different sources encourages analysis of complex data to move beyond 'painting by numbers' towards a 'rich tapestry of understanding'. Between method triangulation can be either simultaneous or sequential. The approach is determined by the theoretical framework driving the research. Where theory is inductive, qualitative methods predominate, supported by quantitative. If a deductive approach to theory is utilised, then quantitative methods take precedence. In this study because so little is known about those affected by gastrointestinal cancer it was considered that inductive theory would likely predominate, though at a later stage when data is compared and contrasted a deductive approach could be used when appropriate.

2.5.2 Triangulation- precision and rigour:

The crucial issue when combining methods seems to be the need for precision (Sandelowski, 1995). Areas of concern when qualitative and quantitative methods are combined have been identified (Mitchell, 1986). These include:

- the combined analysis of numerical and textual data elicited in the same study.
- the interpretation of divergent results obtained from the different approaches.
- the difficulties in delineating concepts clearly.
- the value ascribed to results obtained from different methods.
- the difficulty in estimating the contribution of each method when results are being assimilated.

Whilst acknowledging these concerns it appears that there are methods that promote precision and rigour through quality control. Firstly, it seems to be important that the research questions are clear and focused, explicitly detailing why mixed methods were selected to meet the aims of the study (Morse, 1991; Cutcliffe and McKenna, 1999). Secondly, in an attempt to consider and exclude method slurring and avoid the 'sloppy mishmash' threatened by Morse (1991), Leininger (1992, p.2-4) argues that no attempt should be made to blend, jumble or mix methods across paradigms as this process is considered likely to lead to "inaccurate and confounded research outcomes". By adhering to the research paradigm for each method, including the important aspect of single unit of analysis (Sandelowski, 1995; Yin, 2003), methodological integrity can be maintained.

Whilst each method should have limited interaction between the units of analysis during the data collection, at the further stage of comparing and contrasting data, findings

can be examined to assess whether they contradict or complement one another (Field and Morse, 1985), and it appears that it is at this point that the richness of data of a mixed method approach should begin to be appreciated. For example, in this study it is considered that healthcare research interview data will give some insight into individual's perceptions and views and psychometric measures may provide a more structured, yet narrower view on psychological well-being. An advantage of between method or contextual triangulation is that together, analysis of these findings may evaluate the whole healthcare experience more fully and result in greater understanding (Rose and Webb, 1997). Thus, the aim of combining methods is not just to ensure validity. Rather it contributes to interpreting the reality of the complex, inter-related aspects of individual perception and experience, service provision and care in what Silverman (2001) calls a true state of affairs.

2.6 Outcome measures - standard instruments

The issues surrounding the measurement of anxiety and depression as a measure of psychological distress in patients with cancer, their carers and bereaved carers has been discussed in Chapter One. Whilst it was considered that the inclusion of such measures would enable comparison with the literature and might identify whether measures of anxiety and depression play a useful part in the management of those affected by gastrointestinal cancer, the aim was not to specifically identify cases of a psychiatric diagnosis of anxiety or depression. Rather, it was to identify those who might be at risk of psychological distress, and who might require further psychological assessment. In keeping with the case study approach using multiple sources (Yin, 2003) and methods of data collection in triangulation (Begley, 1996) it was considered that the addition of such

data would add to a more complete, holistic and contextual portrayal of the units under study.

2.6.1 The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)

Whilst acknowledging the potential threat to reliability and validity, (as have many other studies cited in Chapter One), and the limited number of studies that have used HADS with carers (e.g. Glasdam et al., 1996) it was decided to use the HADS to allow for comparison in patients, carers and bereaved carers. By also using the Active Interview approach (Holstein and Gubrium, 1995), (see below) and the Concerns Checklist (Harrison, 1994), (see below) it would be possible to further identify and explore some of the issues relative to the experience of patients affected by upper gastrointestinal cancer. In examining the experience of carers and bereaved carers the use of the HADS would enable comparison of levels of anxiety and depression with patients, and the active interview data from carers and bereaved carers should also inform this process.

Le Fevre (1999) and Lloyd Williams (2001) have suggested that the combined score of the two scales is more appropriate, but whether this is applicable to this investigation is uncertain. However, combined scores will be examined during analysis to assess whether they improve the identification of those 'at risk'.

2.6.2 The General Health questionnaire 12 (GHQ12) (Goldberg 1992)

The GHQ-12 (Goldberg, 1992) was considered for this study and selected with the aim of assessing a general indication of psychiatric caseness rather than a definite diagnosis of depression (Goldberg et al., 1997). As discussed in Chapter One it was considered that the GHQ-12 was not suitable for patients, and so was used only with carers and bereaved carers.

2.7 The Concerns Checklist (Harrison 1994)

The inclusion of the Concerns Checklist in this study was primarily to complement the active interview, and to identify any gaps in the interview process. It was decided to incorporate the Concerns Checklist into the present study, not primarily to achieve a further quantitative measure, but in order to compare the results with the interview data and thus complement and cross validate them through the process of triangulation. However, taking into account the study by Parle et al. (1996) looking at maladaptive coping in cancer (discussed in Chapter One) it was considered that comparison of the interview data, patient concerns and levels of anxiety and depression through triangulation might be a further means of evaluating the complexity of the real world of living with incurable gastrointestinal cancer.

2.8 Interview approach

The researcher had used an interview approach in a previous qualitative study (Byrne, 1997) and found it an effective means of capturing the individual's perspective. An active interview approach using the guidelines described by Holstein and Gubrium (1995) was viewed as commensurate with the aims of this study to capture the perceptions and

concerns of those affected by incurable gastrointestinal cancer, and appropriate for the case study design as a means of contributing to triangulation.

Furthermore, the contribution of reflexivity to the case study design is also captured through the use of an interactive interview approach. The researcher, a senior clinical nurse working in the field of cancer, considered that an interview approach that promoted 'cooperative enquiry' with the interviewee (Heron, 1981), and that used reflexivity within the interview was an aid to contributing to the participants not feeling exploited, which was an important ethical consideration. Again, with the emphasis on 'context' and the real world of participants (Yin, 2003), this interview approach was viewed as 'not merely a neutral conduit', eliciting meaning by apt questioning to a 'vessel of answers' but rather a method for assembling actively and communicatively, meaning in an interview encounter (Holstein et al., 1995).

The following characterise the active interview approach:-

- participants are perceived not so much as 'repositories of knowledge - treasuries of information awaiting excavation' – but as 'constructors of knowledge in collaboration with interviewer' (Holstein et al., 1995 pp.4).
- it is a form of interpretive practice involving respondent and interviewer as they articulate ongoing interpretive structures, resources and orientations, with what Garfinkel (1967), calls 'practical reasoning'.
- as opposed to the conventional view of interviewing where the passive respondent engages in a minimalist version of interpretative practice, the active conception of the interview invests the respondent with a substantial repertoire of interpretative methods and stock of experiential materials.

- the active view eschews the image of the vessel waiting to be tapped in favour of the notion that the subjects interpretative capabilities must be activated, stimulated and cultivated (Holstein et al., 1995 pp3).
- the artfulness of the interview can be seen as a drama:- its narrative is scripted in that it has a topic or topics, distinguishable roles, and a format for conversation. It also has a developing plot, in which topics, roles and format are fashioned in the give and take of the interview.

2.8.1 The active interviewer

It was considered that by having personal contact in the interview would provide the medium whereby the interviewer motivates the respondent to give accurate and full information and allows detection of any disparity between the spoken word and non-verbal expressions (Robson, 2002). Fielding (1994) showed how response rates and the extensiveness of response were greater for experienced than for inexperienced interviewers, and identified key skills of the interviewer:

- an ability to listen, to reflect back and to be able to pick up on cues in order to probe more deeply (Holstein et al., 1995), and similar to basic counselling skills such as active listening, paraphrasing, and summarising (Egan, 1986).
- to be a clear communicator, who uses positive non-verbal cues, and is skilled at creating a safe environment (Rose, 1994).
- to be flexible and alternate between an active and passive role continually making decisions regarding the sequence and phrasing for questions in light of responses received (Rose, 1994).

In addition, characteristics such as race, age, social class and religion have to be considered. Fielding (1994) suggests that 'much of what we call interviewer bias can more correctly be described as interviewer differences, which are inherent in the fact that interviewers are human beings and not machines'.

2.8.2 Interview Guidelines

Interview guidelines offer an aide memoire, agenda or checklist to ensure the issues of interest are raised and the interview is kept 'on task' to answer the research questions. The focus is on selected issues or topics arising from the literature or phenomenon and are reflected in the research aims. Less structured or open interview guidelines adopt neutral questions with the aim of encouraging narrative. Pertinent to the case study strategy selected for this study (Yin, 2003), this approach is used when there is a lack of previous information as it affords latitude to explore wide dimensions of a topic. It can also offer respondents more of a feeling that their particular perspective is being taken into account, which is also in keeping with the qualitative approach.

2.8.3 Structure of Interview guidelines

For the current study, the literature and the propositions derived from the literature as well as preliminary open interviews with four patients, four carers and two bereaved carers were undertaken to explore their experiences of gastro-intestinal cancer. Each individual was asked to recall their experiences through significant events and stages of the cancer journey and exchanges with healthcare professionals. Key themes and topics that repeatedly arose modified the content, approach and the order for the interview guidelines (See Table 2.1).

Table 2.1 Key themes of framework for interview guidelines

Patients	Carers	Bereaved carers
Response to incurable diagnosis	Response to incurable diagnosis in patient	Response to incurable diagnosis in patient
Their cancer journey	Their cancer journey	Their cancer journey
Significant support Mechanisms	Significant support Mechanisms	Significant support Mechanisms
What could be better	What could be better	What could be better
The future	The future	The future

2.8.4 Recording Interview data

It is advised that interviews should be tape-recorded in order to capture the full conversation and allow later transcription into textual narrative offering a means to return again to the data and also to assist the data management process.

2.9 Ethical considerations

There is little research on ethical issues involving people with terminal disease (Clark Hockley and Ahmedzai, 1997; Seymour and Ingleton, 1999). Some suggest that the principle of autonomy should be no different with dying people than with any other research participant (Mount et al., 1995; Copp, 1999). In contrast, De Raeve (1994) argued that individuals in this population require protection and that research with the dying can never be justified.

Of serious consideration in the proposal for this study was the fact that it would be researching a group of patients and carers in whom the patient was likely to have died before the research was completed. Furthermore, it also involved a group of recently bereaved carers. Whilst the research had the potential to benefit other patients and carers, research ethics as defined in the Declaration of Helsinki (World Medical Organisation

1996) stipulate that the individual interests of research participants outweigh any potential benefits of research to society as a whole. The preliminary and pilot work was extensive for this study and enabled reflection and modification of the research design to ensure it was ethically justified. Throughout this exploratory phase continuous assessment of risk of harm (maleficence) and benefit (beneficence) was made and evaluated through reflection and discussion with not only the clinical supervisors, but also other expert clinicians, experts in the field of cancer research and importantly patients with incurable gastrointestinal cancer and their carers.

During the 10 preliminary and 2 pilot interviews with patients, and carers known to the interviewer in her capacity as a cancer nurse, issues and concerns were identified by participants that required professional intervention once the interview had been completed. The researcher considered that to have not intervened would have been unethical and unprofessional.

Whilst the literature review had identified the potential benefits of a longitudinal study and the researcher had considered interviewing carers firstly when a carer and subsequently when bereaved, because of the need to seek professional support for a small number of participants in the pilot study the researcher had to acknowledge there was a risk of bias if these carers who received professional intervention were then interviewed when bereaved. Recognising that this might occur in the main study, it was decided to recruit a separate sample of bereaved carers who had experienced caring for a person with incurable gastrointestinal cancer. It was also acknowledged that to have interviewed carers before and after death of the patient in a longitudinal approach might have offered a different insight to the study but might not have met the aims of the study.

When considering whether to involve patients and carers with whom the researcher had been professionally involved, there was concern about undermining their autonomy because they may feel obliged to take part in research by virtue of their need for health care. There was also concern about bias on the interviewer's part in influencing the interview or restricting the participant's true opinion of their experience. During the design phase of the study the researcher sought the expert opinion of two Professors of Ethics and Palliative Care at different Universities in the UK. Whilst they both acknowledged the potential for bias they also suggested that not to include these individuals would also introduce bias, and would be equally unethical. Furthermore, and perhaps more importantly the researcher discussed at length the implications with patients, carers and bereaved carers in the preliminary and pilot interviews. Each considered that the nurse researcher's prior knowledge contributed to their experience in the research interview and they all stated that they felt they were encouraged and supported to give opinion freely and did not in any way feel obliged or restricted.

Participants known to the nurse researcher identified benefits of taking part in the research, and these were also revealed by participants not known to the researcher. These included the opportunity to talk about their experience, (many for the first time), the right to make a personal decision to take part in research and for many, the knowledge that they were contributing to research that might be of benefit to others in the future. These self-identified benefits for participants in research in end stage cancer have been detailed by Barnett (2001) and included a restoration of a 'sense of purpose'. Likewise, Crighton et al. (2002) found that not only did individuals appreciate an opportunity to talk through

their experiences but they also valued the opportunity to share such experiences with an educated listener who wasn't family.

Of the 92 participants only 12 were known to the researcher in her professional capacity.

Further discussion over this ethical issue with participants is explored in Section 5.5

With the experience of the preliminary and pilot interviews, as well as the nurse researcher knowing 12 of the participants professionally, it was recognised that all participants might be vulnerable at times during the research procedures, particularly since many of them might not have been asked to express their feelings about their experiences of healthcare before. It was decided to identify a set of safety rules that would show evidence of how the interviewer equipped herself with strategies to support all the participants in anticipation of any distressing event during the interview.

Sensitivity and understanding by the interviewer, in this case a practising cancer nurse, was implicit. This allowed for any support or help to alleviate distress caused by the interview to be offered

The rules included the following:

- an explicit explanation about the focus of the interview and the outcomes of the study were provided to each participant
- it was also critical to stress and explain why the participants needed to be interviewed individually, rather than together and hence may not have support
- there was an option to discontinue the interview at any time
- the interviewer would assess each distressing situation and offer to stop recording the interview or move onto another aspect if preferred

- if the interviewer had concerns about the content of any distressing situation she offered to explore this with the participant once the recorded interview was completed and involved other family, friends and healthcare professionals as necessary and appropriate
- the interviewer made every attempt to finally conclude the meeting with the participant with a less emotional and where possible topical or humorous subject of conversation, so that the experience came to a pleasant conclusion
- a contact number of the researcher was left with participants in case of query about the interview or any action taken to resolve a distressing event.

However, whilst these support mechanisms are important, accounts of this type of research show that there is normally very little distress involved (Barnett, 2001). On the contrary, participants appear to welcome the opportunity to share experiences and discuss the care they have received (Holland et al., 1987; Fallowfield, 1995; National Cancer Alliance, 1996; Rose and Webb, 1997; Payne et al., 1999, 2002; Luker et al., 2003; Woods et al., 2003). Furthermore, it has been shown that even when interviewees appear angry or sad, most said they enjoyed their interview experience (Lipson, 1994; Byrne, 1997; Crighton et al., 2002; Chapple, Zieblauds and McPherson, 2006).

In conclusion, it would appear that the theoretical and empirical evidence suggests that research in this participant group may be conducted without compromising the ethical rights of individuals, and indeed that research may support individuals. It was considered that whilst the acuity and awareness of factors in relation to participant autonomy and non-maleficence were of ultimate priority, the safety rules established supported the ethical justification to proceed with the study. The potential benefits of the proposal set

against the ethical risk was supported by Liverpool Local Research Ethics Committee, who granted ethical approval for the study (Appendix One). Research governance approval was also received from the University Hospitals Trust in which the study was undertaken (Appendix Two).

2.10 Summary:

The study was influenced by several methodological issues:-

- to select a method(s) that would answer the research questions
- Because of the complexity of individuality, the use of case study method using contextual triangulation was considered appropriate.
- to ensure validity and rigour by using triangulation incorporating both qualitative and quantitative data.

This study incorporates both quantitative and qualitative methodologies in a case study approach as a means of illuminating the experience of people affected by incurable gastrointestinal cancer and to identify the relationship of their experiences to their levels of psychological distress. The use of a multi-method approach reflects a pragmatic decision to adopt the most appropriate methodology to address the research problem under study. The choice of using both quantitative and qualitative methodologies was made from a philosophical and methodological stance with the aim of capturing the perspective of participants (Hammersley, 1997), and is illustrated in Table 2.2.

It is acknowledged that combining or triangulating qualitative and quantitative methods is controversial, because the research paradigms stem from such different perspectives (Brannen, 1992; Dootson, 1995; Sim and Sharpe, 1998) and the characteristic language

of opposites used to describe them contributes to and perhaps exaggerates this dichotomy (Duffy, 1987; Dootson, 1995; Corner, 1991; Sandelowski, 1995).

It was considered that in this study the decision to use mixed methods was appropriate to the research questions and enabled the inclusion of data from a variety of sources. In addition it was hoped that working in this way had the potential to contribute to the increasing number of published research studies which combine research methods in a pragmatic, orientated way (Corner, 1991; Payne et al., 1999; Maguire et al., 1999; Walshe et al., 2004). By adopting an eclectic approach the aim is not to ignore the quantitative and qualitative methodological issues, but to use these in a complementary manner whilst also recognising the theoretical orientation of each method.

Table 2.2 Theoretical Framework

Review of the literature and proposition	Methodological considerations and Complementary approach	Data sources and type	Analysis Results and Dissemination
<p>Literature:</p> <ul style="list-style-type: none"> * a likelihood of psychological distress in cancer patients * few studies in gastrointestinal cancer, * a need for further information about carers before and after death of friend * what helps people cope?. 	<p>Methodological considerations:</p> <p>Need to capture lived perspective and experience</p> <p>Need to measure psychological distress</p> <p>Each method has advantages</p> <p>Pragmatic approach</p>	<p>Data source:</p> <p>Patients Carers Bereaved carers</p>	<p>Analysis:</p> <p>Maintain rigour</p> <ul style="list-style-type: none"> • Descriptive • Statistical • Single units of analysis • Compare and contrast across data • Emergent associations • Analytical induction - generalise to theory • Compare with literature/theory
<p>Proposition:</p> <ol style="list-style-type: none"> 1. explore needs of a sample of patients and carers 2. measure levels of psychological distress 3. elicit from them what they consider would help 4. results should inform policy and clinical service. 	<p>Complementary approach</p> <p>Prospective case study design</p> <p>Between methods contextual triangulation</p> <p>Reflexive influence.</p>	<p>Data type:</p> <p>Quantitative: Measures of psychological distress HADS GHQ12</p> <p>Qualitative: Interviews Concerns Checklist</p>	<p>Dissemination:</p> <p>Feedback to multidisciplinary team</p> <p>Feedback to patient support group</p> <p>Publication/Presentation</p> <p>Development of policy and protocols , review through clinical audit</p>

CHAPTER THREE

THE STUDY

3.1 Design

In order to meet the aims of the study a case study design using contextual triangulation incorporating self reporting psychological scales, and interviews was selected.

3.2 Method

3.2.1 Ethical approval

Ethical approval was received from the University, the Local Regional Ethics Committee (Appendix One) and the Director of The Research and Development Committee at the participating University Hospital NHS Trust (Appendix Two).

3.2.2 Recruitment

Participants were recruited from a large University Hospital Trust in the North of England. All medical Consultants involved in the care of patients with gastro-intestinal cancer (no longer amenable to cure) gave permission to invite eligible patients and their main carer to participate. The Directorate / Services Managers in Medicine, Surgery, Gastroenterology and Outpatients at the Trust also supported the study and gave permission for The Clinical Nurse Specialists and Nurse Practitioners to act as the gatekeeper and identify patients and carers who satisfied the inclusion criteria. Recruitment was staggered over an eighteen month period to facilitate the interview workload and the transcription of tapes.

3.2.2.1 Inclusion criteria:

Adults of 16 years of age and older who were diagnosed with recurrent or inoperable cancer of the oesophagus, stomach, pancreas, liver (primary or secondary), or gallbladder, were invited to participate in the study, along with their main carer.

A separate group of bereaved carers aged 16 years and over, who had been the main carer for a patient who has died from gastro-intestinal cancer during the previous 3-9 months, were also invited to participate in the study.

3.2.2.2 Exclusion criteria:

In the patient sample, those individuals with a previous diagnosis of other malignant disease, or not expected to live for at least six months. In the bereaved carer sample previously interviewed carers who had subsequently become bereaved were not included.

3.2.3 Participants

34 patients with gastrointestinal cancer no longer amenable to cure, 30 carers of these patients and 28 bereaved carers of similar patients participated in the study. The participants represented 20% of the annual number of patients referred to a specialist Cancer Centre in a University Hospital Trust in the North of England. The sample reflected the tertiary referral pattern to a specialist cancer centre with patients referred from a radius of one hundred miles. Based on both medical expert opinion and the researcher's clinical experience of working with such patients for over 10 years, an examination of the patient characteristics and needs of the eventual sample indicated that they were no different from the population referred to this specialist cancer centre.

3.2.4 Consent and Ethical Issues

A letter of invitation plus an information sheet and a reply slip were sent to potential participants. The written information included the study aims, expected outcomes, and the issues of confidentiality and consent (Appendices Three to Five). It stressed the requirement of participants to be interviewed individually rather than together. Once a reply slip had been returned, the researcher telephoned the participant to arrange a date and time for a meeting to complete the psychometric measures and participate in the interview. This telephone contact provided opportunity for the researcher to ensure that each participant met the inclusion / exclusion criteria and enabled them to ask any questions about the study and what their participation would entail. A suitable time and place, either in their own home or in the hospital setting was arranged. Privacy for the interview was discussed, and a suitable environment arranged to ensure the patient and carers' comfort. At this stage the participants GP was notified in writing of their entry into the study (Appendix Seven).

3.3 Measures

The HADS (Zigmond and Snaith, 1983), Concerns Checklist (Harrison, 1994), and GHQ12 (Goldberg, 1992) were selected for this study as they were considered to be valid and reliable.

Table 3.1 Methods of data collection

	Quantitative data	Quantitative data	Qualitative data
Patients	HADS		Active interview Concerns checklist
Carers	HADS	GHQ12	Active interview
Bereaved Carers	HADS	GHQ12	Active interview

3.3.1 The Hospital Anxiety and Depression (HAD) Scale (Zigmond and Snaith, 1983)

The HADS (Appendix Eight) was used with all participants in the study, and was completed before the interview. Data was scored according to protocol with cut off points of 0-7 (normal), 8-10 (borderline) and 11-14 (at risk) (Zigmond and Snaith, 1983).

3.3.2 The GHQ-12 (Goldberg, 1992)

The GHQ12 (Appendix Nine) was used with carers and bereaved carers and was completed before the interview. Data was scored according to protocol with cut off points of 0-3 (normal), 4-12 (at risk) (Goldberg, 1992).

3.4 The Concerns Checklist (Harrison, 1994)

The Concerns Checklist (Appendix Ten) was used with patients, after the interview had been completed.

3.5 The Interview

All participants were interviewed by the researcher, using the interview guidelines (Table 2.1).

3.5.1 Preparatory Phase

The interviewer underwent further education to refresh her skills in interviewing skills from an expert in the field, including taped interviews and feedback sessions. Then, as noted earlier, the interview guidelines were developed from preliminary interviews with participants in the same population.

3.5.2 The Pilot Study

Two pilot interviews were tape-recorded using the interview guidelines in order to:

- assess the appropriateness of the interview guidelines.
- test whether data would be generated to answer the research questions.
- gain some experience in the active interview approach.

These resulted in modifications to the guidelines and identified the need to encourage and explore through techniques such as probing or reflecting back in order to gain richer, deeper conversation. The importance of using a sensitive microphone was also realised as a result of poor quality data reproduction during the pilot phase. Practice in using the tape recorder was also of value.

3.6 The interview process

The interview started by obtaining written informed consent (Appendix Six) and demographic details of age, gender, cancer diagnosis, occupation and other dependants. This initial process served as a means of establishing rapport with the participant. They were then asked to complete the questionnaires (HADS, GHQ12), followed by the active interview. This order was maintained throughout the study as there was concern that completing the questionnaire after the interview (which might include discussion about worries and concerns), could influence responses in the questionnaire.

Using the interview guidelines (Table 2.1) as a framework, questioning was as open-ended as possible so as to gain spontaneous information rather than a rehearsed position, and such phrases as ‘Can you tell me.....’, and ‘I would like to hear.....’ were used. Respondents were encouraged to answer in their own words about their experience of their cancer, and with sensitive probing the interviewer tried to elicit underlying attitudes, beliefs and values.

3.6.1 Interview Location and Length of Interview

Attempts were made to control external factors through the selection of the location for the interview. Only three of the ninety two participants were interviewed in the hospital setting. Potential interruptions of home interviews were avoided by explaining the importance of privacy to family members prior to the interview and seeking their assurance that the participant would be undisturbed. Equally in the hospital setting a private uninterrupted location was assured. The interviews lasted one hour on average. About 5 minutes was spent before the interview in social discussion to relax the participant. Some time was spent after the interview to ensure the participant was not distressed.

3.6.2 Recording and Transcribing of Interviews

All subjects agreed to their interview being tape-recorded and then transcribed. As part of the preparation for interview each respondent was assured that at any time during the interview they could stop it.

3.6.3 Confidentiality and assured Anonymity

Each participant's data was given an identification number. The list of names and ID numbers was kept separate from other data. All tapes, interview notes and completed scales were assigned the ID number. The ID number was used in the SPSS analysis. For practical reasons the researcher enlisted the assistance of a transcriber. Only the researcher and the transcriber had access to the tapes and the transcriber was only aware of the ID number.

3.6.4 Participant codes

The transcribed interviews were coded. Participants were coded as:

P = Patients, number 1-34.

C = Carers, number 1-30.

BC = Bereaved Carers number 1-28.

R = response identifying the location of the quote in the participant's interview text.

Coding checks were made by the two supervisors and an independent researcher and found to be legitimate. Patients and carers described their prospective experiences of living with incurable gastrointestinal cancer. Bereaved carers recalled their retrospective experiences of caring for someone living and dying with this type of cancer.

3.6.4.1 Response rate

The response rate in this study was very favourable.

- 34 patients who were approached participated in the study.
- Of the 34 carers of the above patients, 30 participated, but 4 did not. One was in hospital with depression, one felt too angry about his wife's situation to complete

the interview, one was doing his university exams, and one did not arrive for the pre-arranged appointment.

- Of the 30 bereaved carers approached 28 participated. The two who did not participate responded to the letter of invitation, but when approached to make an appointment to meet, declined, and gave no reason.

3.7 Data Management and Analysis

3.7.1 Data management framework

The drawing of conclusions and their verification was the major remaining analytic task which followed the data collection process (Robson, 1995). Multiple methods of data collection frequently result in problems with management of large and diverse data sets (Tierney, 1998; Vallis, 2000). It was recognised that the case study design using multiple sources and types of data selected for this study could cause similar challenges, especially for the single researcher. A data management framework based on Yin (2003) and Miles and Huberman (1994) was identified for use in the study. The units of analysis were the individual patients, carers and bereaved carers (92 in all) and analysed in three stages as presented in Table 3.2:

Table 3.2 The three stages of analysis

Stage of analysis	Data	Chain of evidence
Stage One: analysis of the demographic data, interviews, HADS, GHQ12, and Concerns Checklist.	34 Patients- Interviews, HADS, Concerns Checklist demographics 30 Carers – Interview, HADS, GHQ12, demographics 28 Bereaved carers – Interview, HADS, GHQ12, demographics	Chapter Four Tables 4.2, 4.3 and 4.4 Descriptive analysis of measures. Chapter Four Table 3.3 and 4.5 Checklist matrix showing first & second level coding of interview data in three major themes Chapter Four Tables 4.6, 4.7 and Appendix Nine Frequency and number of concerns
Stage Two: single unit analysis of each patient, carer, and bereaved carer	P31-34 individual scores, concerns & themes C1-30 individual scores & themes BC1-28 individual scores & themes	Chapter Four Tables 4.11, 4.12, 4.13 Case Dynamic Matrices showing single unit analysis of triangulated data for each participant
Stage Three: compare and contrast units of analysis	Compare and contrast analysis of main themes. Compare and contrast analysis of coping response. Compare and contrast: patient and carers, carers and bereaved carers. e.g. Do the same themes emerge, or is each individual coping responses and coping resources	Chapter Four Tables 4.14 – 4.63 Emergent association, not causal networks. Compare and contrast, demographic data, HADs, GHQ12, concerns, main themes and coping response across patients, carers and bereaved carers Analytical induction, resonant of Lazarus and Folkman

3.7.2 Stage One of analysis: analysis of the separate data sets

The individual data sets, namely the interviews, psychometric measures, demographic details and other documented evidence were each analysed.

3.7.2.1 Psychometric measures and demographic data

The HADS and GHQ 12 measures were scored according to their protocol and data was entered into SPSS along with participant code, demographic data, diagnosis and such

issues as time since diagnosis in the case of patients and carers and time since bereavement in bereaved carers.

3.7.2.2 The Concerns Checklist (patients only)

Responses to the Concerns Checklist were analysed and displayed in matrix fashion (Appendix Eleven) to demonstrate concerns expressed, their frequency and by whom. Any deviant cases were also tabled.

3.7.2.3 Interviews

The researcher explored the use of a software package to assist analysis of interview data, but decided against this preferring to create analytic files. These consisted of copies of coded data segments from the transcripts. Each file contains the copies of data relevant to particular codes or patterns of codes. The organisation of the analytic files changed as analysis proceeded, and new patterns were tried or old ones discarded. Throughout, complete transcripts were kept and any selected data or quotes were coded in such a way that the true context in which they occurred could be referred to. The Miles and Huberman (1994) methods of analysis in conjunction with Yin (2003) were selected. However, it has to be stressed that while these techniques provide useful tools, they need to be used flexibly or they may undermine the strengths of qualitative research by overly mechanistic data analysis (Robson, 1995).

The suggested general approaches to qualitative data analysis emphasise the importance of ongoing analysis during data collection. The researcher was conscious of themes developing and emerging throughout each interview. These contributed to and were recorded as first level coding in analysis reflecting the co- construction theme of the

interview technique (Holstein and Gubrium, 1995) with the researcher / analyst engaging with the data of the participant's experience.

3.7.2.3.1 First and second level coding of interviews

First level coding of interview data led to a vast number of codes, and these were then amalgamated under broader categories, themes or patterns in **second level coding**.

Having sought to make data manageable through summary and coding, it was necessary to display the data, and present it in such a form that valid conclusions could start to be drawn. Matrices are data displays which seek to bring relevant data together in a way that will encourage the drawing of conclusions. Miles and Huberman (1994) describe a checklist matrix as a format for analysing field data on one or more major variables or general domains. The fundamental principle of this method of display is that the matrix includes several components of coherent variables, which in this study was considered to be the main themes.

Another indicator for the use of a checklist matrix suggested by Miles and Huberman (1994), is that the variable can be unbundled easily into distinct indicators or components. In this particular study it was considered that this could refer to such aspects as disclosure of diagnosis and the interpersonal skills influencing the communication process, or prognosis and the future in the major theme of uncertainty. An advantage of using a checklist matrix to display the data was that it facilitated comparison of multiple units of analysis, as well as giving structure to field data, which could then be compared and contrasted with the same variables in the literature (Miles and Huberman 1994).

Table 3.3 Checklist matrix showing examples of first and second level coding of patient interview data

First level coding	Second level coding
Communication, Information exchange. Coordination of care- management, anticipating need. Roles (GP, DN, Macmillan). Hospice.	Individualised approach with sensitive communication
Response to a terminal diagnosis Time, timing, timeliness, waiting Prognosis The future Dying Chemotherapy. Work, Benefits (DHSS) How will it affect others? Concern about others.	Uncertainty
Crawling along Feeling drained The worst thing Blame it on getting old Reminder Humour So tired, but can't sleep Social side of food and drink	Fatigue

Data was selected for entry into each matrix according to certain "decision rules" (Miles and Huberman, 1994; Yin, 2003). In particular the proposition, the aims of the study, the data types and the intensity of the patient's response or their judgement or ratings, became the crucial decision rule for entry into the matrix. Table 3.3 shows how the checklist format made data display more systematic, enabled verification, and encouraged comparability. It also permitted simple quantification. The decision rules contributed to the quality control aspect of the study, and it was hoped would reduce the risk of colleagues or readers drawing dubious conclusions about the data displayed. A further attempt to support the data displayed, was made by requesting an independent researcher to review a number of matrices and the data displayed, along with the decision

rules and field notes, to check the procedural accuracy of the work. It was hoped that this again would serve as an important check on the confirmability of the procedures used.

A larger checklist matrix (Table 4.5) more fully demonstrates the three major themes and coding categories from analysis of the 92 interviews. Within each main code all items appearing under a particular sub-heading were then collected together, with interview code and line numbers appearing next to each quote. This allowed identification of where the item appeared in the main transcript, along with the identification of the context of any particular phrase or comment. The frequency and percentage of each theme was calculated and is illustrated in the matrix.

3.7.3 Stage Two of analysis: Single unit analysis (each patient, carer, and bereaved carer)

Once the interview data had been analysed and coded it was possible to triangulate the themes from each participant with their quantitative data in single unit analysis. Case Dynamic Matrices, (Chapter Four, Tables 4.11 - 4.13), were used to display this stage of analysis, and as a means of identifying how the themes appear to be dynamic, influences, stresses or forces that contribute to each unique single unit of analysis (Miles and Huberman, 1994; Yin, 2003). Displaying the data in such a way was an attempt to increase confidence in the qualitative interpretation of the relationship of interview themes to levels of psychological distress. Miles and Huberman (1994), stress how the test of any matrix is what it helps you understand. Once the matrices were developed it was found to be useful to do what they call a "squint analysis". This involved a quick scan down rows and across columns to see what components of the matrix struck the

analyst as important. Then it was possible to verify, revise and when necessary disconfirm that impression through further review or even return to the transcripts. Patterns and themes started to emerge and clustering began to develop. Tufte (1986) describes what the reader needs from displays:

"What we are seeking in graphic and tabular displays of information is the clear portrayal of complexity, not the complication of the simple; rather the task of the designer is to give visual access to the subtle and the difficult - that is the revelation of the complex". Tufte (1986 p.80).

3.7.4 Stage Three analysis: Comparison and contrasting of units of analysis

In this stage of analysis the qualitative and quantitative data from each participant was compared and contrasted. Yin (2003) argued that this stage of analysis is the most difficult aspect of case study research as it involves much more than simple aggregation across the themes and variables, and there are no shortcuts. 'Pattern matching', where cases are compared against an 'ideal' model has been suggested as a technique to use (Yin, 2003). The researcher became conscious during data collection that there were participants with low levels of anxiety and depression who expressed satisfaction with the service provided and demonstrated coping responses and resources that enabled them to adapt to their situation. This appeared to offer 'an ideal model' or what Miles and Huberman (1994) describe as the 'critical case', which could validate and exemplify the main findings. It was possible to identify both similar and different patterns which

identified for example positive or negative aspects of communication, support, service provision and personal coping resources.

Statistical methods were then used to assess whether there was a measurable or significant relationship between such interview themes and other data such as demographic data and levels of psychological distress.

The statistical methods and their rationale for use will now be explored.

3.7.5 Statistical measures

3.7.5.1 Bonferroni correction

The level for significance used was at the 5% level (0.05). The Bonferroni correction is a safeguard against multiple tests of statistical significance on the same data, where 1/20 hypotheses tested will appear to be significant at the $\alpha = 0.05$ level purely due to chance (Perneger, 1998). The Bonferroni correction states that if an experimenter is testing an independent hypotheses on a set of data, the statistical significance level that should be used is n times smaller than usual. For example, when testing two hypotheses, instead of a p value of 0.05, one would use a stricter p value of 0.025.

The sample size is so small that for categorical variables the Bonferroni correction was not used to relate qualitative data, to the demographic variables, and therefore these analyses should be seen as exploratory.

Because of the small numbers in the study:

- it was not possible to do multi-variate analysis
- where appropriate, borderline significance was discussed.

The following statistical measures were used:

- **McNemar test** looks for change or differences between two paired categorical measures. It was used to determine whether the (i) patient and carer gender and (ii) patient and carer age were significantly different from one another.
- **Chi-square test (X^2)** (with continuity correction) is used to look for differences in proportions in categories between two groups. It was used to determine whether the proportions of (i) carer and bereaved carer gender and (ii) carer and bereaved carer age were significantly different from one another.
- **Chi-square test (X^2)** was also used to determine whether carer and bereaved carer experience of (i) disclosure, (ii) information, (iii) fatigue, (iv) children/other dependants (v) coordination of care were significantly different from one another.
- In addition, **Chi-square test (X^2)** test was used to determine whether carer and bereaved carer coping response were different.
- **Fisher's Exact test** is used when numbers on a 2x2 table are too small for X^2 . It looks for differences in proportions between two groups. It was used to determine whether patient, carer and bereaved carer experience of (i) disclosure, (ii) information, (iii) fatigue, (iv) children/other dependants (v) coordination of care and anxiety were different.
- **Fisher's Exact test** was also used to determine whether carer and bereaved carer experience of (i) disclosure, (ii) information, (iii) fatigue, (iv) children/other dependants, (v) coordination of care and psychological distress were related.
- **A two way ANOVA** was used to investigate the relationship between the variables of age, gender and (i) anxiety (ii) depression and (iii) psychological distress in carers and bereaved carers.

- **A paired sample t-test** which assesses whether the means of two assessments on the same individuals are statistically different from each other was used to compare levels of anxiety and depression in patients and their carers.
- **An independent sample t-test**, which assesses whether the means of two groups are statistically different from each other was used to compare levels of anxiety and depression and psychological distress between carers and bereaved carers.
- **Spearman's Rho**, is a non-parametric method used to provide information on the strength of relationships between pairs of continuous or ordinal variables. It was used to investigate the relationship between the number of concerns and (i) patient anxiety and (ii) patient depression.
- **The Kappa test** looks for agreement between two paired measures. It was used to determine whether the patient and carer experience of (i) disclosure, (ii) information, (iii) fatigue, (iv) children/other dependants (v) coordination of care were similar. The Kappa test was also used to determine whether the patient and carer coping response were related

In this section of analysis the focus was on moving from descriptive summation into explanation by drawing conclusions from the data. Examining emergent associations of themes and their relationship with such aspects as demographic data, coping response and psychological measures promoted the building of an explanation in what Yin (2003) suggests 'stipulate a set of causal links'. This immediately calls to mind independent and dependent variables and almost seems to reinforce a cause and effect process. However,

an important aspect of the 'meaning establishment task', (Miles and Huberman, 1994), was clarifying the conceptual importance of those conclusions, and in particular how they tied into the established theory illustrated in the literature. More specifically, Yin (2003) suggests that the most effective use at this stage of analysis is where explanations have reflected some theoretically significant propositions. For example in the current study the very resonant principles of Lazarus and Folkman (1984) have helped in the design. As a result themes emerging led back to Lazarus and Folkman and coping theory. The gradual building of an explanation appears to be similar to the process of refining a set of ideas. Robson (1995) considers that the process is very similar to analytic induction, which stresses the value of identifying a decisive negative case. In support of this, Yin (2003), stresses the importance of entertaining other plausible or rival explanations incorporating the following:

- Relevant evidence
- Major rival interpretations
- Own expert knowledge

In applying this approach, the result of the explanation building process was not simply the analysis of each individual unit of analysis, but a chain of evidence of compared and contrasted units of analysis, which can be seen throughout the study in examples in tables and appendices in the Results section, with further comment in the Discussion. It was considered that by using such an approach and including display of matrices in the text that the reader or another researcher could reconstruct how the analysis developed, check the translation, and allegiance of constructs and follow the logical validity of conclusions (Kratwohl, 1991).

3.8 Summary

This research project was undertaken to gain insight into the perceptions and concerns of patients and their carers affected by life threatening gastrointestinal cancer. There were three phases:

1. The preparatory phase involved development of a framework for interview guidelines, and the identification of suitable measures of psychological well-being.

2. In the main part of the study, and following two pilot interviews, thirty four patients, thirty carers and a separate sample of twenty eight bereaved carers completed measures of psychological well being and were interviewed. Patients also completed the Concerns Checklist.

3. Transcripts were coded and then analysed to identify perceptions and concerns, and measures were scored and analysed to assess psychological well-being. The data was then triangulated to enable comparison and contrasting of units of analysis.

CHAPTER FOUR

RESULTS

4.1 Introduction

As discussed in Chapter Two, when using a mixed method design it is important to maintain rigour in analysis (Sandelowski, 1995; Yin, 2003).

- Section 4.1.1 describes the Quality Control strategies used.
- In Stage One of Analysis the results deal predominantly with descriptive data with no comparison or contrasting across data sources or data types.
- In Stage Two, single unit analysis begins to compare and contrast data within the set for each patient, carer and bereaved carer.
- Section Three extensively compares and contrasts across all data sources and types and compares and contrasts with the literature.
- The Summary draws together the key findings for further exploration in the Discussion.

4.1.1 Quality Control

Before presenting the results the steps taken to ensure quality of the data are described. These fall into three parts:

4.1.1.1 Data Collection, entry and screening.

Around 30% of the data from the HADS, GHQ12, and Concerns Checklist and the descriptive measures entered onto SPSS were checked for accuracy of scoring and entry into the data sets. No errors were found. Univariate descriptive statistics were used and examined for out-of-range values and plausible means and standard deviations. Each variable was checked for skewness, kurtosis and outliers.

4.1.1.2 Reliability and validity of the HADS and GHQ12

Cronbach alphas were computed to check for internal consistency of the HADS and GHQ12 and compared to those in the manuals (Table 4.1). They ranged from 0.67 to 0.87, which was lower than those in the manual but alpha's over 0.6 are deemed to be reasonably reliable (Gibbon, 1998), and only the HADS depression score fell below 0.70.

Table 4.1 Internal consistency of the scales as assessed by Cronbach alpha

	HADS anxiety manual value 0.93	HADS depression Manual value 0.90	GHQ12 Manual value 0.82 - 0.90
Patients	0.72	0.67	N/A
Carers	0.80	0.73	0.86
Bereaved carers	0.85	0.80	0.87

4.1.1.3 The Quality of the Qualitative Data

The five key principles for quality control suggested by Miles and Huberman (1994) were applied to the qualitative data and interpretation of the compared and contrasted units of analysis.

4.1.1.3.1 Objectivity and confirmability

To meet the criteria for objectivity and confirmability the methods and procedures were described in detail including relevant "backstage information" in Appendices (e.g. Patient information sheet, Summary of Concerns checklist), and Checklist matrices displaying data. This provided a chain of evidence demonstrating how data was collected, processed, condensed / transformed and displayed for specific conclusion drawing. The researcher tried to make as explicit as possible personal assumptions, values and biases, and affective states, and how they might have come into play in the study. Study data was retained and made available for reanalysis by others.

4.1.1.3.2 Reliability, dependability and auditability

Clear research questions, and an appropriate research design were both described. As noted above, the researcher's role and status were also explicitly described including her professional relationship with the participants. Findings were examined to assess whether they showed meaningful parallelism across data sources (participants, contexts and time). Data was collected across the full range of appropriate settings, times, respondents, as suggested by the research question. Coding checks on a sub-sample of nine transcripts were made by the academic supervisors and an independent researcher. They considered that the codes identified were legitimate.

A further check to the reliability of the qualitative categorisation was a comparison of responses between the carers and patients on factual issues, such as recall of time-table of diagnosis, the disclosure and to a lesser extent the coping strategies they adopted. In the latter, one would expect some differences but there was an overall reasonable level of concordance and agreement. This reasoning does not apply to comparison between carers and bereaved carers as they are different samples and so differences may be due to sampling issues or different needs and issues related to different points in the cancer journey.

Comparisons of patients and carer coping strategy responses for togetherness, carry on as normal, avoidance and inability to activate a coping response were made using the Kappa test. All indicated significant levels of concordance. The details are discussed in the relevant sections of the results.

4.1.1.3.3 Internal validity, credibility and authenticity

To try to ensure the findings actually made sense (face validity) they were subjected to four principles:

- Descriptive -what happened in specific situations was described. Thick

descriptions such as quotes and narratives (Denzin, 1989) were used to specify everything that a reader may need to know to understand the findings.

- Interpretative- what it meant to the people involved (participants and researcher).
- Theoretical - concepts and their relationships used to explain actions and meanings, including the available literature, are stated.
- Evaluative - judgments of the worth or value of actions and meanings were included. Special attention was given to uncertainties and rival explanations.

4.1.1.3.4 External validity, transferability and fittingness,

To support external validity, transferability and fittingness, the characteristics of the samples needed careful description, including the limiting effects of sample selection.

The present sample is considered to be reasonably representative of the population of patients and carers using this specialist cancer centre.

Four carers and two bereaved carers refused to take part, and so some bias due to self selection is possible. One carer did not arrive for the pre-arranged appointment, one carer was in hospital with depression, one was too angry about his wife's cancer management to talk about it and one was doing his exams at university, and his father, the patient had suggested at the last minute that he not attend. Two bereaved carers who had responded to the invitation to participate gave no reason for declining an interview appointment, just that they had decided against it. Given the reasons for declining it might have been more likely that the results for carers would show higher levels of distress and problems with coping.

Use of "thick description" enables readers to assess the potential transferability of the theory to their own setting. A range of readers experienced in the field (i.e. 2 Clinical Nurse Specialists, a Consultant in Palliative Medicine, 2 Surgical Oncologists

and 1 Medical Oncologist), were asked to read and comment on exemplar anonymised transcripts and interpretations to assist with both face validity and transferability. Narrative sequences were preserved.

4.1.1.3.5 Utilisation, application and action orientation

Emphasis on how the findings might be used to encourage debate or change service provision to patients with gastro-intestinal cancer and their carers has been kept at the forefront of the analysis.

In conclusion, the data is considered to be robust and reliable and reasonably representative.

4.2 STAGE ONE OF ANALYSIS: The Participants.

4.2.1 Sample characteristics

There were 92 participants: 34 patients, 30 carers and 28 bereaved carers.

Full details of the sample are in Tables 4.2- 4.4.

4.2.2 Patients:

- 34 patients participated, 21 male and 13 female. Age ranged from 30-81 years.

Mean age was 63 years. 21 patients were married. 4 male patients were divorced (1 lived with a female partner, 1 lived with his mother and step-father, 2 lived alone).

9 patients lived alone, (1 bachelor lived alone, 3 males were widowed living alone, 5 females were widowed, (3 lived alone, 1 lived with son, 1 with daughter).

- 32 patients' main carer was their next of kin. 1 patient's daughter, who was her next of kin, had terminal breast cancer, and the patient was cared for by her daughter in law. 1 patient was cared for by her sister where her son was next of kin.
- Cancer diagnosis: 4 oesophagus, 3 stomach, 6 pancreas, 3 hepatocellular, 14 colorectal liver metastases, 2 cholangiocarcinoma, 2 gallbladder.

- Days since incurable diagnosis given to date of interview ranged from 87 to 199 days, mean 136 days.
- Survival time from date of interview ranged from 40 to 870 days, mean 107 days.
- Survival time from date of incurable diagnosis ranged from 135 - 1027 days, mean 201 days
- 3 patients were in employment.
- 5 patients had dependant children, (one had four, three had two, one had one).
- 5 patients had been caring for an adult dependant prior to diagnosis interview.
Two female and one male patient had been caring for their spouse with long term mental health problems. Another man had been caring for his wife who had had a stroke. One male had been caring for his elderly mother. Three of these roles reversed following diagnosis, with the dependant claiming to be the patients main carer, and interviewed for the study.
- 2 male patients had been bereaved of their wives during the 12 months prior to their interview

Table 4.2: Details of patient sample (n=34)

Sex M = male F = female	Age in years	Diagnosis (type of cancer)	Days since incurable diagnosis	Survival days from date of interview	Survival days from incurable diagnosis	Main carer
P1 F	63	Metastatic liver	124	434	558	Husband
P2 F	72	Metastatic liver	153	270	423	Husband
P3 F	47	Gallbladder	122	45	167	Husband
P4 M	55	Oesophagus	92	572	664	Wife
P5 F	57	Hepatocellular	155	238	393	Husband
P6 M	68	Oesophagus	119	307	426	Sister
P7 F	79	Stomach	154	870	1027	Daughter
P8 M	76	Metastatic liver	93	42	135	Wife
P9 M	74	Hepatocellular	187	40	227	Step-daughter
P10 M	30	Metastatic liver	199	152	341	Mother
P11 M	36	Oesophagus	123	372	495	Wife
P12 F	63	Metastatic liver	124	162	286	Husband
P13 F	73	Metastatic liver	196	795	981	Son
P14 F	63	Gallbladder	122	120	242	Husband
P15 F	78	Cholangio	135	89	224	Daughter-in-law
P16 M	63	Metastatic liver	187	300	487	Son
P17 M	46	Pancreas	93	91	184	Mother
P18M	53	Metastatic Liver	125	82	207	Wife
P19 M	73	Pancreas	127	83	210	Wife
P20 F	74	MetastaticLiver	189	454	643	Sister
P21 M	80	Pancreas	121	204	327	Wife
P22 M	71	Metastatic liver	123	172	295	Wife
P23 M	65	Metastatic liver	185	210	395	Wife
P24 M	64	Hepatocellular	94	223	317	Wife
P25 F	57	Metastatic liver	127	324	451	Daughter
P26 M	55	Pancreas	87	355	442	Partner (F)
P27M	70	Cholangio	185	312	497	Wife
P28 M	67	Metastatic liver	94	475	569	Wife
P29F	77	Pancreas	154	102	256	Husband
P30 M	70	Pancreas	85	760	845	Wife
						Carers NOT interviewed
P31 M	47	Metastatic liver	124	183	307	Wife In hospital
P32 F	46	Stomach	127	120	247	Husband. too angry
P33 M	81	Oesophagus	135	420	545	Son unavailable
P34M	53	Stomach	188	176	364	Son at university

4.2.3 Carers

- 30 carers participated, 9 male and 21 female.
- The age range was 32 – 78years. The mean age was 58 years
- All carers, except one were related directly or by marriage to the patient. 19 were caring for their spouse, (12 wives, 7 husbands), 1 female carer was living with her partner, 2 mothers were caring for their sons, 1 sister was caring for her brother, 1 son was caring for his mother, 1 son was caring for his father, 1 daughter was caring for her mother, 1 step-daughter caring for her step-father, and 1 daughter in law was caring for her mother-in law.
- 24 carers lived in the same house as the patient, 4 lived nearby, 1 lived within 20 miles of the patient, and 1 lived 200 miles from the patient.
- 4 carers had a history of depression, 2 had cancer, 1 had had a stroke and 2 had emphysema.
- 10 carers were in paid employment.
- 3 carers were caring for another adult dependant.
- 7 carers had child dependants (1 had 4, 1 had 3, 3 had 2, and 2 had 1).

Table 4.3: Details of main carer sample (n =30)

Sex M = male F = female	Age in years	Relationship to patient	Dependants other than patient	Occupation	Carers current health needs
C1 M	65	Husband	0	Retired RGN	None
C2 M	68	Husband	0	Retired	Depression
C3 M	55	Husband	0	Pub Manager	Tests for cancer
C4 F	53	Wife	0	Housewife	None
C5 M	50	Husband	0	Baker	Depression
C6 F	60	Sister	1	Housewife	None
C7 F	51	Daughter	0	Unemployed	Depression
C8 F	76	Wife	0	Housewife	None
C9 F	46	Step-daughter	4	Cook	None
C10 F	51	Mother	3	Cleaner	None
C11F	35	Wife	2	Housewife	None
C12 M	57	Husband	0	Retired	None
C13 M	51	Son	0	Unemployed	Disabled
C14 M	64	Husband	0	Retired	Emphysema
C15 F	54	Daughter in law	2	Secretary	None
C16 M	39	Son	3	Chartered building surveyor	None
C17 F	57	Mother	0	Housewife	None
C18 F	53	Wife	1	Housewife	None
C19 F	70	Wife	0	Retired RGN	None
C20 F	72	Sister	0	Retired	None
C21F	78	wife	0	Retired	None
C22 F	65	Wife	0	Consultant Obstetrician	None
C23 F	65	Wife	0	Retired	Recent stroke.
C24 F	69	Wife	0	Retired clerk	None
C25 F	32	Daughter	1	Nursery Nurse	None
C26 F	36	Partner	0	Vaccine Inspector	None
C27F	63	Wife	0	Psychologist	None
C28F	70	Wife	0	Housewife	None
C29F	76	Husband	0	Retired	None
C30M	68	Wife	0	Retired	Stomach cancer

Main carers NOT interviewed

F	44	Wife of P31	4 children	Housewife	In hospital with depression
M	55	Husband of P32	None	Retired	Not interviewed too angry to talk
M	52	Son of P33	Wife & 2 children	Taxi driver	Not interviewed
M	21	Son of P34	None	Student	Not interviewed at patients request

4.2.4 Bereaved carers

- 28 bereaved carers participated, 6 male and 22 female.
- The age range was 27 - 88years. The mean age was 53 years.
- Time bereaved ranged from 91 – 271 days, mean 182 days
- All bereaved carers were related to the patient. Sixteen had cared for their spouse, (14 wives, 2 husbands); 4 were sons; 6 were daughters; 1 was a step daughter and 1 was a daughter in law.).
- 22 bereaved carers were in employment, 3 were retired, 2 were homemakers and 1 was unemployed.
- 15 bereaved carers were caring for child dependants, (5 for 1 child, 5 for 2 children, 5 for 4 children).
- 2 bereaved carers, both with 4 children were caring for the deceased parent's spouse, 1 bereaved carer with 2 children was caring for the deceased parent's spouse. In these 3 cases, the deceased patient had originally been the main carer in the relationship.

Table 4.4: Details of bereaved carer sample (n=28)

Sex M=male F=female	Age in Yrs.	Relationship to patient	Patients cancer diagnosis	Days bereaved	Dependa nts	Current health needs	Occupation
Bc 1 M	45	Son	Metastatic liver	265	1	none	Engineer RAF
Bc 2 F	27	Daughter	Oesophagus	162	0	depression	Unemployed
Bc 3 F	52	Wife	Cholangiocarcinoma	121	0	depression	Housewife
BC4 M	49	Son	Stomach	233	4	depression	Legal executive
Bc 5 F	53	Wife	Pancreas	257	1	none	School inspector
Bc 6 F	49	Wife	Oesophagus	129	0	none	Salaries clerk
Bc 7 M	49	Husband	Metastatic liver	271	1	none	Architect
Bc 8 M	79	Husband	Pancreas	132	0	none	Retired Engineer
Bc 9 F	65	Wife	Stomach	242	0	none	Day Nursery Owner
Bc 10F	58	Wife	Oesophagus	164	0	depression	Cook
Bc 11F	88	Wife	Metastatic Liver	159	0	Stroke	Retired
Bc12 M	42	Son	Oesophagus	241	2	none	Teacher
Bc 13F	59	Wife	Pancreas	237	0	none	Company Director
Bc 14 F	72	Wife	Pancreas	97	0	depression	Salaries clerk
Bc 15 F	55	Wife	Metastatic Liver	265	0	none	Retired Civil Servant
Bc 16 F	40	Daughter	Stomach	99	2	none	Nurse
Bc 17 F	44	Daughter	Stomach	91	2	depression	Housewife
Bc 18 F	52	Step-daughter	Pancreas	157	2	depression	Class room assistant
Bc 19 F	53	Wife	Hepatoma	136	2	depression	Class room assistant
Bc 20 F	57	Daughter	Metastatic Liver	167	1	none	Radiographer
Bc 21 F	49	Daughter	Stomach	172	4	depression	Area Manager
Bc 22 F	43	Wife	Stomach	259	4	none	Teacher
Bc 23F	69	Wife	Hepatocellular	160	0	none	Dance Teacher
Bc 24 F	61	Wife	Gallbladder	128	0	depression	Travel agent
Bc 25 F	37	Daughter-in-law	Gallbladder	120	4	none	Housewife
Bc 26 M	38	Son	Cholangiocarcinoma	129	4	none	Regional manager
Bc 27 F	70	Wife	Oesophagus	258	0	depression	Book keeper
Bc 28 F	38	Daughter	Stomach	260	1	depression	Building society manager

4.2.5 Summary characteristics of participants

- The gender differences are similar to other studies in several ways:
 - (a) there is a higher ratio of male to female patients (21 male:13 female) which is similar to published figures for this cancer population (HMSO 2003).
 - (b) the ratio of 21 female (70%) to 9 male (30%) carers and 22 female (78%) to 6 (22%) male bereaved carers is higher than the national figure of 58% female (HMSO 2002, for all carers), but this is expected for this cancer population (HMSO 2003).
- The number of carers with dependant children/other dependants, 14 (29%) is slightly more than the national figure of 26%, (HMSO 2002).
- The proportion of bereaved carers with dependant children/ other dependants, 15 (53%), is double the national figure (HMSO 2002). This might be explained by the number 12 (43%) of female bereaved carers.

4.3 STAGE ONE OF ANALYSIS: Qualitative data

The 92 interviews produced a vast amount of qualitative data. As described in the Method there were 3 stages of analysis.

4.3.1 Interviews: First and second level coding

These produced major themes as illustrated in Table 4.5. Three main themes emerged that were common to the three participant groups were:

- The need for an individualised approach to information with sensitive communication
- Living with uncertainty.
- What supports the ability to carry on?

It is not possible to say whether other participants did or did not experience such themes, only that they did not recall these aspects in their interviews. The frequency, importance and emphasis given by participants governed the scoring of themes.

Whilst it is not usual to score qualitative data, it is increasingly used to give emphasis to qualitative findings (Miles and Huberman, 1994). During the process many of the same themes were emerging in the three participant groups. In order to display the results, compare and contrast qualitative data and to examine association, frequency was viewed as a complementary and useful process.

Table 4.5: Checklist Matrix showing main themes emerging from the data

Patient group n = 34	Carer group n = 30	Bereaved carer group n = 28
<p>MAJOR THEMES</p> <p>1. The need for an individualised approach with sensitive communication 24 (72%) Response to incurable diagnosis 15 (44%)</p> <p>2. Living with uncertainty 28 (82%) Prognosis, the future, dying 28 (82%) Chemotherapy 9 (26%) Time, timing, waiting 5 (15%) Will I be in pain 5 (15%) Work, benefits (DHS) 4 (12%) Patient / carer issues It's more difficult for those you leave behind, how will they cope? 22 (65%) Their life is on hold 4 (12%) Children 14 (41%) Need to get house in order 8 (24%) Fatigue – the worst thing 25 (73%) Reminder 7 (21%). Frustration 7 (21%) Crawling along 6 (18%) So tired, but can't sleep 4 (12%) Chemotherapy 6 (18%) Social side of food and drink 6 (18%) Nutrition and carer 4 (12%) Coordination of care 9 (27%)</p> <p>3. What supports the ability to carry on? 34 (100%) Strategies adopted with carer We talk, we deal with it together 6 (18%) We talked, now we carry on as normal 8 (24%) Avoidance, we don't talk about it 17 (50%) Inability to activate coping responses 3 (9%)</p> <p>Personal Acceptance 8 (24%) Stay positive 4 (12%) Family and friends 14 (41%) Staying in charge 5 (15%) Spiritual 9 (27%) / Inspiration 3 (9%) Access to alternative medicine 3 (9%)</p> <p>Professional – access to expertise GP 7 (21%) District Nurses 11 (32%) Macmillan Nurse 12 (35%) Hospice 8 (24%) Cancer Nurse Practitioner 7 (21%)</p>	<p>MAJOR THEMES</p> <p>1. The need for an individualised approach with sensitive communication 22 (73%) Response to incurable diagnosis 18 (60%)</p> <p>2. Living with uncertainty 29 (97%) Prognosis 18 (60%) Someone to talk to - Information 19 (63%) I feel I can't contact anyone 10 (33%) Chemotherapy 4 (13%) Work, Benefits DHS 3 (10%) Carer / patient issues Gatekeeper, it's their agenda 7 (23%) Getting house in order 4 (13%) Setting goals 5 (17%) The parent of the dying child 2 (7%) Patient fatigue 4 (13%) Own health Fatigue 6 (20%) I need to stay well 7 (23%) Own health on the back burner 8 (27%) Children as carers 7 (23%) Children 15 (50%) When to tell 3 (10%)</p> <p>Coordination of care 12 (40%)</p> <p>3. What supports the ability to carry on? 30 (100%) Strategies adopted with patient We talk, we deal with it together 5 (17%) We talked, we carry on as normal 7 (23%) Avoidance, we don't talk about it 17 (55%) Inability to activate coping response 3 (10%)</p> <p>Personal Sense of achievement 5 (17%) If patient is dealing with it well 5 (17%) Family and friends support 9 (30%) Information resource to others 11 (37%) Previous life/cancer experience 10 (33%) Spiritual 6 (20%) Counselling 2 (7%)</p> <p>Professional - access to expertise GP 6 (20%) District Nurse 8 (27%) Macmillan Nurse 8 (27%) Hospice 5 (17%) Cancer Nurse Practitioner 6 (20%)</p>	<p>MAJOR THEMES</p> <p>1. The need for an individualised approach with sensitive communication 23 (81%) Response to incurable diagnosis 17 (61%)</p> <p>2. Living with uncertainty 27 (98%) Prognosis 17 (61%) Someone to talk to-information 16 (57%) Anticipating need 8 (29%) The dying process 11 (39%) Bereaved carer / patient issues Gatekeeper, it's their agenda 13 (46%) Resolution of issues 6 (21%) Own health Fatigue 8 (29%) I needed to stay well 8 (29%) Now exhaustion 5 (18%) Loss of weight 4 (14%) Children 14 (50%) Access to specific support 6 (21%) Children are support 7 (25%) Children as carer 8 (29%)</p> <p>Coordination of care 12 (42%)</p> <p>3. What supports the ability to carry on 28 (100%) Strategies adopted with patient We talked, dealt with it together 15 (54%) We talked, carried on as normal 3 (10%) Avoidance, didn't talk about it 6 (21%) Inability to activate coping response 4 (14%)</p> <p>Personal Sense of achievement 7 (25%) If patient dealt with it well 2 (7%) Family and friends support 15 (54%) Previous life/cancer experience 7 (25%) Spiritual 7 (25%)</p> <p>Professional – access to expertise GP – 11 (39%) District Nurses 10 (36%) Macmillan Nurse 14 (50%) Hospice 7 (25%) Cancer Nurse Practitioner 5 (18%)</p> <p>Since bereaved Nothing will ever be the same again Setting goals 3 (11%) Caring for a parent left behind 5 (18%)</p>

4.3.2 THEME ONE: The need for an individualised approach with sensitive communication

Theme one was a core element and featured throughout the results. For many participants, (24 patients (72%), 22 carers (73%), and 23 bereaved carers (81%)), the communication and interpersonal skills of healthcare professionals were repeatedly commented on. This was especially so in relation to disclosing the cancer diagnosis, or breaking other bad news. Participants repeatedly identified the following necessary components for effective communication:

- assuring privacy
- showing compassion and concern,
- assessing if the patient wanted a spouse or friend with them during the disclosure
- assessing how much the patient wanted to know
- giving the patient and their carer time,
- maintaining hope
- assuring on going support and availability from healthcare professional.

4.3.2.1 Response to an incurable diagnosis

Response to the incurable diagnosis was recalled by 28 (82%) patients, 24 (80%) carers, and 22 (79%) bereaved carers. The theme of an individualised approach with sensitive communication featured strongly in this important aspect of care.

4.3.2.1.1 Patient disclosure

Participants' responses indicated that they knew how such issues as breaking bad news, disclosure and giving information should have been managed (P5 R50-53, P12 R5-7, C26 R2). Some participants said that the language used, such as "there's nothing we can do" (P28), left them feeling hopeless and abandoned, "shunted into a siding" (BC 7).

Some participants recalled disclosure of incurable diagnosis handled sensitively, (P1 R15-17, BC 8 R5-6), with experience of some or all of the following components:

- the doctor asked to see us together
- we weren't rushed, he gave us plenty of time
- he held my hand
- he seemed to understand I might be upset
- he said he wasn't giving up on me
- he said to call if we had any questions afterwards

However, the inclusion of recall in participant interviews appeared to be more common when they felt things had not gone well, (P5 R50-53, P12 R5-7, BC 9 R2-3, BC19 R2, BC12 R.6, BC14 R37-49), and was associated with more criticism of those healthcare professionals involved. 11 patients (32%), 15 carers (50%), and 13 bereaved carers (46%) described situations when they had not been told in an ideal way, and expressed some distress at this. Their experiences included some or all of the following:

- I was on my own
- I wasn't expecting it
- there were no curtains round, he just stood at the end of the bed
- he told me in such a cold way
- he just said 3-6 months and that was it
- it took away all my hope
- I was left on my own afterwards
- it was left to me to tell my husband
- we never saw him again

The following quotes illustrate the data:

No, I don't mind being told, because I accept it. It was the way that they said it. He didn't even sit down, he told me from the end of the bed. But there was just nobody there. It was the most cruel thing that ever happened to me. P5 R50-52

Disclosure of inoperable and therefore incurable disease had great impact on participants. This appeared to be most severe when the patient had experienced a lengthy period of inconclusive investigations before diagnosis was made (P32, BC13, BC14), and when the patient found themself in a position where they had to tell their carer themselves.

I thought I am supposed to be in intensive care. The next thing I know he's sitting there. I said they have opened me up and sewed me up again. He went don't be so ridiculous. I said I am telling you they have opened me up and sewed me up again. I just knew, I don't know why. I felt I had had to tell him. Nobody else came near. P32 R26

4.3.2.1.2 Consequences for carers if patient told diagnosis alone:

11 (37%) carers and 9(32%) bereaved carers recalled being excluded at the time of diagnosis or when bad news was told to the patient.

and the doctor asked us to stand outside the room, outside the ward and closed the doors. He (the patient) said can't she stay, and he said no, out. He cleared the room.

C4 R33

Carers stated that the patient should not be told their diagnosis of cancer when alone for a number of reasons:

- it caused the patient distress,
- it excluded the carer from supporting the patient at the time
- it excluded the carer from information given to the patient at the time
- it increased the chance that the patient adopted avoidance or denial strategies, which in turn denied the carer a means of establishing information and professional support vital to their own needs as a carer

- it increased the probability of feelings of isolation and uselessness in the carer and patient conflict

For example, without access to information and an appropriate healthcare professional, carers appeared to feel helpless and even hopeless (C5 R12, C26 R2, BC 7 R7, BC2 R6).

Only the junior, I had 5 minutes with one day. Other than that, that's it. I just don't know. I don't know, I don't know what to do. Scared. In March, she could die in March, I don't know. They have told her, but I don't know. (*inaudible, getting upset*) At the end of the day though, I just feel so useless that I can't do nothing for her C5 R12

The analysis suggested that when the patient had been told their diagnosis alone, they were more reluctant to talk or to share information with their carer. It was not clear whether this was because they could not recall information due to the shock, they didn't know, or because they were trying to protect their carer. However, where instances of these were apparent, the carers clearly experienced frustration. When denied information they felt less able to support the patient such as to talk with each other or express how they might feel about the incurable diagnosis (C5 R12, C26 R2, BC2 R7) or how they should manage the future together. It could be argued that this could be a source or certainly a factor that encouraged avoidance or collusion.

.... and I had gone away for these three days, and when I come back he had been to the hospital and they had actually told him. It was just leaflets around the place. It was like he wouldn't talk about it either. C26 R2

4.3.2.1.3 Consequence for carers knowing diagnosis before patient

Whilst the majority of patients in this study seem to indicate that they did not wish to be alone when they received their cancer diagnosis, it was also apparent that carers' did not wish to know the diagnosis before the patient. (C3 R7-19, BC 16 R..). One carer recalled how knowing his wife's cancer diagnosis four days before she was told led

him into an uncomfortable and stressful situation of collusion, and suggested how the situation might have been managed more effectively:

He should have said nothing and waited the four days and told us both together or waited even until we got to the cancer centre. C3 R7-19

From these examples it can be identified that the consequences of health professionals excluding the carer from disclosure, (intentionally or otherwise), has led to a greater possibility of collusion between the patient and their carer. Again, whilst this might not be intentional on the part of the patient, the combination of a desire to protect the carer, trying to remember all the information, and having the courage to divulge such sensitive news has the potential to promote a state of denial and avoidance.

4.3.3 THEME TWO: Living with Uncertainty

28 patients (82%), 29 carers (97%), and 27 bereaved carers (98%) identified this as an important issue. The main uncertainties for patients were:

- prognosis and what the future held
- palliative chemotherapy
- fatigue
- concerns about carer and family
- work, eligibility for DHS payments
- coordination of care

In carers and bereaved carers the same uncertainties as patients emerged plus others pertinent to their role as carer. These included:

- anticipating need
- access to information
- someone to talk to

- needs of children
- carers own health
- other social responsibilities.

4.3.3.1 Living with Uncertainty and Prognosis

4.3.3.1.1 Patients and prognosis

Only 5 (15%) patients wanted to know a definite prognosis. Whilst all patients in this study knew they had incurable cancer, 23 (68%), of the 28 (82%) patients who commented on prognosis did not want to know their prognosis (in relation to an estimation of time left). 7 (21%) of these 23 preferred just to know that their situation would be managed appropriately. The responses of 16 (47%) patients suggested that giving them a specific length of time would reduce their coping capacity and 'Not knowing' appeared to be a constructive coping mechanism, if accompanied by assurance of appropriate care (P1 R17-19, P14 R46-47)

I am just not that sort of person. I couldn't cope with it if somebody said you have got X amount of time. I do know some people ask but I don't want to know, I think really it would be policy to find out if the person and the family want to know, but I don't think it should just be said. (P1 R18-20)

Not wanting to know linked to avoidance appeared to be important to some participants, who used it as a coping mechanism. The quote below appears to indicate that it can be an effective resource.

I mean I don't want to know an awful lot, I am not one of those people, I don't want some consultant to say to me, yes next Thursday night, well how long have I got, I don't want that, I mean I don't know how long I have got, I have got a rough idea, but I have improved in the way that I psychologically can handle it. I'll keep it, if I can feel as well as I can for as long as I can. P18 R27

However, when an avoidance strategy was adopted by patients, it was sometimes associated with the carer being restricted in having access to, for example, information and support.

Some patients (P17, P27, P24), seemed to indicate that they did not want to know their prognosis for fear of being told about their demise, including pain. The pain issue appeared to be related to knowledge or previous experience of associations of cancer with severe pain. A dilemma faced by some patients was the need for information to help decision making. However, there were examples where patients appeared to avoid asking in case they were told more than they wanted to know.

No I like to forget about it. I say to myself well how much pain I'm going to get, how long is it going to take you know things. Others, I have seen them like you know I've seen them deteriorate, is that going to happen to me you know things like that? P24R4-8

5 of the 16 patients who had said in interview that they did not want to know about their prognosis did however, express a need to know whether they would be in pain in the context of the future and dying.

I'd like to know will I be in pain, how will it be? P27 R12

In the following example the important issue for the patient is to have information that will help make decisions to get their affairs in order.

It is something that I would like to have sorted out in my mind Well it is up to a point because I don't know how optimistic everybody is really as to whether I am going to get better or not to go back to work. P25 R20

And Yes. I don't think I would like to know when, because, you know, you would be expecting it, but I mean if they turned round and said to me you have only got 12 months to live, that's it, then I would pack work in, and stop at home. P11 R58-63

The following quote illustrates a missed opportunity by the health professional to explore with the patient his information needs in relation to concerns about the future (in this case his employment) thus compounding his dilemma rather than helping it. It also demonstrates a need for health professionals to be pro-active to anticipate information needs in patients.

Oh, I asked him about going back to work, you know what I mean. He said are you intending going back, you know. He said people don't usually go back to work. Well it's okay if you can afford not to go to work, you know, it's not too bad is it really, but you have got to work to live really haven't you? P26 R77- 83

4.3.3.1.2 Definite prognosis

Another aspect of sensitive communication related to prognosis was that whilst patients might ask how long they have to live, being given a definite time can be something that is so shocking that on reflection they wish they had not asked. There is some indication that coping resources such as hope were threatened in patients who were told their prognosis in a blunt manner.

It's like the doctor like he sacked me didn't he? He just said there is nothing I can do for you. You know you won't live to see next Christmas. P5 R47

This needs serious consideration by health professionals working with this cancer population, and demonstrates a need to explore the question with the patient to truly assess their information request before answering directly.

It's good to know, but sometimes you ask a question off the top of your head without really thinking about it. Yeah, and when I was told my life expectancy was probably months, I think that was a bigger shock than finding out that you had cancer that couldn't be cured. P3 R25

In a number of cases it was highlighted how not knowing a specific time for prognosis could be more beneficial to both the patient and the carer and how it even supported the carrying on as normal strategy of coping.

I remember he (*the patient*) said 'don't ask because you'll change completely towards me' BC 6 R7-8

This identifies a further coping strategy used by participants i.e. "carrying on as normal", and may explain a little more the rationale for not wanting to know prognosis.

I was determined to enjoy the time we had together and we did. It was lovely.

I didn't ask that because I didn't particularly want to know and I don't always believe them any way because how long is a piece of string you can't possibly say, and if you were to say, it would ruin things for you BC23 R3-4

4.3.3.1.3 Accuracy of prognosis

Most participants experience of prognosis was completely incorrect. There is evidence that when they were given a prognosis of 3-9 months or 6-12 months, they interpreted their actual prognosis as the lower figure.

I would have spread that out over a long period of time and I think the shock of the family would have been less because they were all expecting me to be dead in 3 months type of thing, because that was basically what we were told it could be as short as that. P30 R46 - 47

4.3.3.1.4 Accuracy of prognosis and consequence for carers and bereaved carers

Patients being told a definite prognosis also seemed to accentuate distress in both carer and bereaved carers. It appeared to contribute to their sense of uncertainty, hopelessness, and helplessness, and reduced their capacity to cope (C5R57,BC 9 R2,BC 19 R3).

.....and to me, that's, what I had to deal with when we came home, not that he was cowardly or anything like that, but his anguish and my anguish.

The next day he said to me well that's one day off my 6 months. And I thought what a way to have to spend the rest of your life. I think sometimes ignorance is bliss.

BC 19 R3.

Even in those for whom disclosure was managed well (C1, BC 23) and unlike the patients who seemed to view disclosure and prognosis as separate issues, carers and bereaved carers recalled response to diagnosis and prognosis as inextricably linked. This may indicate that from the start carers were appraising the situation, and inwardly exploring the necessary resources to deal with the cancer journey ahead.

Whilst a similar number of carers (24 (80%)) to bereaved carers (22 (79%)), commented on response to diagnosis and prognosis, the vivid recall by the bereaved carers many months after the disclosure, emphasised how this experience had affected them.

.....he just sat on the bed and said it was the most difficult place to get cancer in and that they very rarely survived and that with John's condition they didn't really expect him to survive after Christmas, this was the September. BC 9 R2-3.

The first shock was when he got the tumour, the second shock was to know it was cancer, the third was to know he had such a bad liver, and the fourth was to know he only had 6 months, so as far as I was concerned, it was four shocks. BC19 R3

This was particularly apparent in those who recalled how their relative had been unwell for some time prior to diagnosis and when both an incurable diagnosis and prognosis were discussed at the same time in an insensitive and inappropriate manner.

he said (*patient*) I want to know how I can put weight on. And he (*the doctor*) just turned straight to him and said you are dying Mr..., you are dying. And aren't we all. So we were both, I couldn't speak, ...it was like a kick in the teeth. BC 14 R37-45

This emphasizes how a combination of factors rather than a single factor seemed to be associated with levels of psychological distress. It is not only what is said, but how it is said, and the ongoing relationship with the healthcare professional which seems to be important (BC 9 R2-3, BC19 R2, BC12).

The surgeon came through to see us, he said he has got three months, But as it happened, he didn't, he had 12 months. Although of course you know, you are so shocked you never actually say anything, do you, and then he walked away and you never see them again. We were just left high and dry. BC13 R1

4.3.3.1.5 Prognosis and palliative chemotherapy

Prognosis was viewed by individuals as an important issue in relation to palliative chemotherapy, which was considered as a means of buying extra time, and was thus a coping resource. Again, most patients did not want to know their prognosis in the context of chemotherapy. Those who had been told a definite prognosis seem to express an added burden associated with waiting to see whether the chemotherapy had worked or not. The context of chemotherapy and a fixed lifetime seems to set up a mathematical scenario where numbers and months take precedence over every other aspect of life, in what seems to be a countdown to death. The consequences of giving

a definitive prognosis for some seems to reinforce hopelessness, which might also reduce the capacity to activate coping mechanisms.

I said I won't be here doing this next Christmas Billy, and I had been told I won't. I mean the chemo might not work. (P5)

And he said no, he said you are having no more chemo. He said that nearly killed you last time. So I said well how long have I got? And he said well you have had 12 months. He said I will give you 2 – 12 months to live, and each time I went, I went down. P28 R13-16

4.3.3.1.6 Carers and palliative chemotherapy

Carers recalled their reaction to the stopping of chemotherapy in the patient, and the significance of sensitive communication and interpersonal skills for the patient's psychological health.

And what it did, it gave Dave the impression that he was just written off, off you go, go away and die, and I was blazing mad, I really wanted to go and tell him exactly what I thought of him. Because I mean, if he gets depressed, I think he could go down hill quicker, and I think that is horrendously important. C18 R 104-106.

Carers were naturally protective of the patient. This carer expresses throughout her interview that it was her husbands wishes / agenda that were important, not her own.

No, as I say the Macmillan etc is always there in the background, if necessary, but I would only, I mean I would never consider them, that is for Dave to consider. When he is ready or when he wants, or if he never wants, well that's fine too, um, but we know, I know that they are there. C18 R37

4.3.3.1.7 Patients who did want to know prognosis

An important finding in this study was that whilst most patients did not want a finite prognosis, there were 5 individuals, (15%), (P34, P16, P17, P15, P10), who did. Their request for information appeared to be related to the quality of life issue of autonomy, maintaining independence, and not wanting to be a burden to their carers, - also evident in plans they made for their care when dying. Four of the five patients were living alone with no resident carer.

Family, no, we don't discuss it. No, only as far as my plans are concerned.
I don't, but I have got the bed booked at Nightingale House (*hospice*). P16 R29-34

Under the circumstances requesting prognosis could be considered as a problem focused response in these individuals. For some (P10 R13, P34 R30-31) their request also seemed to be influenced by their desire to achieve certain objectives before dying.

(*Daughter*) who is 18 is different and of course she was even younger than that, she was 16 when I was first diagnosed and she was devastated. She was very, very, very upset and a year or so later developed anorexia. So I don't know, she has already been in therapy at the Eating Disorder Unit, so I will look for help there. I need to know so I can make sure its available because she is so very upset by what is going on. P34 R30-31

4.3.3.2 Living with uncertainty and information

4.3.3.2.1 Patients and Information

15 (44%) patients had a need for further information. As has been discussed in the previous section on prognosis, it is apparent that many patients did not ask for more information, in case they were told more than they wanted to know. 5 (15%) patients who did ask for further information, (P34, P16, P17, P15, P10), were those previously discussed who lived alone and required further information in relation to prognosis and maintaining independence.

The results of The Concerns Checklist (Section 4.4) indicated that many patients had concerns which might have been helped and resolved through appropriate information. The implications of this are discussed in Stage Three of Analysis where this aspect of living with uncertainty will be explored further when coping strategies are examined. However, this appears to emphasise a requirement by healthcare professionals to proactively, but sensitively, explore with patients their individual information needs, in order to elicit and address their concerns about such issues as the future or their current illness. It was apparent that patients do not know what questions to ask, and may not have the coping resources and hence do not feel equipped to deal with the information supplied.

4.3.3.2.2 Carer and Bereaved carer information need

24 carers (80%) and 15 bereaved carers (54%) said they had wanted more information and someone to talk to. Thus, the information needs of over half the sample had not been met. It is interesting to note that 24 (72%) patients expressed concerns about how their carer would cope with the future, indicating that both they and their carer had information needs. The main information need in carers was for information that would help future planning and constructive action in supporting the patient. This was a problem focused strategy to cope with uncertainty.

4.3.3.2.2.1 Carers and restricted information

The consequences for coping and restricted information for carers is reflected in the following quote:

I don't know, don't ask, don't ask because I've no idea. And then you're sitting on your own and you're thinking Oh God what's going to happen next. C24R48

Restricted access to information and avoidance by the patient did result in avoidance strategies being adopted by some carers (C11 R21-25, C18)

You know, I mean I don't know what will happen, how he will become ill, and I am very much the type of person that needs to know things so I can deal with them, you know, it's just so uncertain, so now I try to block it out, I try not to think about any of it. Yes, I find it creeps into my mind, and I physically push it away. I don't want to know. C11 R21-25

A strategy for some carers who did not reside with the patient and who were not present at diagnosis was "to go behind the patients back" in order to secure information (C6 R22-42, C25 R19, C16 R54).

Yeah, it was whispered conversations with the nurse before my Dad came back because he would not have been too impressed with me asking questions, because whilst we were there together I was the silent partner. I would just sit and listen. Yeah I think somebody needs to acknowledge that I might have different questions, like does he need somebody to look after him, what is he going to need? C16 R53-54

Carers who did not live with the patient, who were not always included in disclosure of information about the patient's condition, and who had other responsibilities appeared to have particular information needs (C25 R30, C9 R48-R53)

I mean mum's very sort of open, but I mean at the moment we don't know whether this time next year mum will be here. Well we feel as a family we feel we would like to have more information. C25 R28-29

This identifies the dilemma carers sometimes found themselves in. Carers have a different information agenda. These appear to be issues that cannot be reconciled because of the uncertainty, as nobody knows when the patient is going to die. However, what also seems evident is that these carers do not know who to approach to meet their information needs or to raise concerns with.

Other carers however, acknowledged that their closeness with the patient led to them “being in one another’s pockets”, (C4), which inhibited them seeking access to information from professionals (C15, C7, C11, BC7).

You see when we go to clinic I'm there and she's there, there's never a chance to sort of talk to someone on your own and you need that (C7 R49)

4.3.3.2.2 The need for a proactive approach to information and carers

Some carers felt that professionals should anticipate and make opportunities to meet the specific information needs of carers, by adopting a proactive approach. There also seems to be a need for carers to have the uncertainty acknowledged by healthcare professionals as part of a supportive strategy, and as an opportunity for raising potential concerns and anticipating need.

Well the feel is that perhaps there should be more not you having to ask, but they should come to you. Because I think she was quite pleased that the cancer nurse practitioner got in touch with us. It's somebody out of the family to talk to, because no disrespect to the GP, but I think you need that specialist knowledge C15 R41-47

4.3.3.2.3 Access to expert information

There were a number of concerns raised by bereaved carers about access to information in the ward environment. There appears to be an implicit comment that

the information they required could only be met by someone with expert knowledge of the patient and the specific cancer.

I mean they didn't seem to want to give you any information on the wards. They seemed to be more, whether it's this confidentiality of hospital, I don't know, but they weren't as forthcoming, you know. In fact the only things we found out when he was on the wards was what we overheard, you know. BC 13 R 79 - R84

Carers and bereaved carers did not expect this level of knowledge from ward staff. (BC7 R27-34, BC13 R79-84). Whilst they may not have had the information, some participants said they perceived ward staff unsure about how to deal with sensitive questions about cancer from carers in relation to the patient's condition, and using the issue of confidentiality to avoid answering requests for information:

And so I felt that there was no-one I could personally turn to, to ask a question, a serious question. I mean to ask it of a Sister on a ward was unfair because they were doing their best in a given circumstance. But who could I speak to? I think the key word is information. All the time the key word is information. BC7 R27- R34

4.3.3.2.2.4 Information and social service support

Some carers felt confused and did not know who to contact about social services support and financial allowances.

we have never claimed nothing, not that type of thing, so it was like, even where do you go in there, you know, where do you hand the forms in like, type of thing?

C26 R57-61

This tended to occur more with patients who adopted avoidance as a strategy and deferred professional support (P26, P23), with the consequence that access to such information was not available to them, or often their carer also.

She said to me well we can get you these people, but you'd have to pay so I thought well what do you pay with? (C23 R6)

4.3.3.2.2.5 Information and supporting children

A need for guidance in supporting their children, and how to provide them with information seemed to be a core issue for most carers dealing with children, no matter what their age.

.....or because the children were there I couldn't show that I was upset so I kept a stiff upper lip. I suppose really during that period I didn't cry, the only time I cried was with Eric when I wasn't with anybody else. I don't know whether that's the right thing or the wrong thing. (C30)

Such practical aspects as living at a distance seemed to prohibit talking about the situation, particularly over the telephone. Participants suggested access to information for children from sources other than the patient and carer themselves (P1, P5, P22, C22, P30, P34, BC1, BC5, BC7, BC22), and how their experience of health service provision could be improved.

I think one tends to forget that children are just as worried as anybody else is and they tend to be pushed to the background by the doctors. I think it would be very useful if they could speak occasionally to a person like a nurse specialist, my children don't trust me. To be able to talk to somebody, they can ask the questions and they could get an answer.

P30 R30- R33

Even those carers who were able to talk to their children demonstrate the complexity of supporting children, and the lack of support for both informing them and for post bereavement support. This seemed to apply to both the carer with adult children and the carer with dependant young children (BC2, BC7, BC10, BC12, BC13, BC14, BC18, BC19, BC21, BC22).

I think it's very important that children are talked to, in a formal way too, so they are very aware that they are being spoken to and that their needs are being taken on board, because if it's informal they feel it's just like any passing friend who will pat their arm and say your parent is ill and we understand, but if it's formal it saying to them 'You matter. Your opinion matters, and what can we do to help you?' (BC5 R79-80)

4.3.3.3 Living with uncertainty and Fatigue

4.3.3.3.1 Patients and fatigue

22 (65%) patients identified fatigue as an issue in relation to living with their cancer.

Fatigue was associated with the following themes:

- frustration with not being able to do normal activities
- increasing dependence on carer
- a reminder of the illness and the inevitable end
- being a burden and “kill joy” to others
- the effects of insomnia
- guilt about not being able to help through basic acts of giving and sharing food, and accepting and enjoying that which is given
- not feeling able to respond enthusiastically to the carers ideas for comfort, or normal socialising.

The effects of fatigue appeared to be tied up with issues of normal roles, sharing, demonstrating appreciation of others, nurturing and survival. The following quotes illustrate the data.

Yes, or tired. That's when it brings it back to me that I am sick, But if I am feeling normal then I hardly ever think about it

P10 R36

I had to give up (*membership of organisations*) . I gave them all up. I gave a lot of them up simply because I couldn't cope with them, getting too tired so I just gave up. So, I am at home more and I am not a sort of reader and I just watch television if I am at home and this creates problems. P30 R29

The tiredness is driving me mad, it's driving me round the bend because I have always been hyperactive, and I love being like that. I can't clean my house, or anything. I am frightened of people cleaning around me, it's driving me mad. P32 R29

Euphemisms such as ‘crawling along’ (P8 R53) featured in the narratives with the experience of fatigue having wider implications other than physical tiredness for those affected. Most associated fatigue with progression of their disease, withdrawal from normal family role, working activities, (P24 R.), reduced socialising with friends (P8 R22-27), and an increasing dependence on others, particularly their carer (P30 R29)..

If I go out for a drink, I don't enjoy it. I can only drink a couple of glasses these days. Yes, I feel sometimes I tend to spoil their night. But when I have said this,

they say oh, no, don't feel like that. But I tend to sit there thinking now am I going to get indigestion tonight. That sort of thing, you know. P8 R22-27

Not being able to eat a meal prepared by their carer was a source of anxiety as they recognised the distress this often caused in the person most dear to them

Pat says to me what would you like tonight. I just can't think. I was always quite happy to eat what was given me..... I mean if I can't eat anything, I will say well I am sorry I just can't eat it. And she will throw it away. P8 R24-25

Oh yes. I worry sick about him. You see he says I pick on him. Because I can't eat, he won't eat. He puts his dinner out, he puts me like a little bit out and when I stop, he stops. I have got enough to worry about without worrying about you. I feel guilty, so it's awful isn't it. Yes. It makes it a lot worse. P32 R60

Insomnia was often blamed for fatigue, with various strategies to improve sleep and increase energy described.

A bad night is probably sleeping for about 2 or 3 hours and then tossing and turning. There are a lot of things going through your mind, you know, not being able to relax and I will come down and make a cup of tea and sit around, you know. P3 R34-44

However, many patients and carers described insomnia and negative thoughts and worries going around their mind, as is typical in various stressful circumstances including depression.

And that's how, not every day, it isn't every day, it isn't every night, but now and again I have got up for a couple of minutes to have a smoke, I couldn't sleep, and I'm organising funerals. P1 R35

4.3.3.3.2 Causes of fatigue

Very few patients or carers appeared to understand the cause of fatigue, and the data demonstrated an information need that should be anticipated by health professionals. Some had strategies to deal with it, but most appeared to accept it as a consequence of their progressive disease. Conserving energy and resting as well as supplements and sweet drinks were the favoured strategies used.

I don't think there is anything that can be done for it it's just a question of living with it you know, but I mean I just find ways around it sitting down perhaps to do things that I would have stood up to do P25 R57

Both patients and carers used the euphemism 'getting old' as a reason for fatigue, no matter what the age of the patient, and humour was often used as a means of defusing the situation.

Well yes, but I mean that's just normal. Because I mean, I am not likely to play in Wimbledon but not many of us do, so it's just the part of growing old really. P31 R120

Whilst still acknowledging the gravity of the situation, joking about it seemed to make it more tolerable.

I have obviously slowed down, I used to play cricket and obviously I don't play cricket anymore, - there again neither do the England team. P18 R8

4.3.3.3 Carers and fatigue

In carers there was evidence of recognition of fatigue in the patient and remedial action taken to improve the patients situation. Whilst encouraging them to rest and conserve their energy carers often found patients reluctant to let them take on physical tasks normally performed by the patient. This sometimes led to disquiet, since it seemed to emphasise to the patient both their progressive disease and their loss of independence and even seemed to threaten their self-esteem.

A major issue for carers was providing food that would increase energy and which might therefore prolong life in the patient. Carers related how they tempted the patient with various foods, but few carers expressed understanding of the consequences of cancer for suppressing the appetite. This was clearly an information need in many carers, and illustrated a requirement for health professionals to be more pro-active in explaining the consequences of the cancer in these fundamental but important aspects of the carers role.

Some carers recalled the mutual distress it often caused between the patient and themselves, particularly if food had been prepared and then left almost untouched.

He didn't want anything, so then you go in the kitchen and think my goodness he's going thinner and thinner and not eating anything, what are we to do, we've tried the supplements. He can't even stand at the bathroom sink. C8 R20

Only a few carers recognised fatigue in themselves, but whilst acknowledging this, most considered their own physical and emotional needs to be 'on the back burner', or of secondary importance to those of the patient. Like patients, periods of insomnia appeared to be associated with negative thoughts.

The depression comes when the light goes off at night and you lie down to go to sleep, and then you are a prisoner of your own thoughts then. And you sort of dwell inside your own head, or if I go up to have a bath and I think I'll lie here for 20 minutes in the water, but then your brain starts working then, because he's not there to see, so that's OK. C18 R16

4.3.3.3.4 Multiple demands on carers and fatigue

If the carer had other dependents such as children or was caring for a disabled parent there seemed to be added risk of stress and fatigue. In the following example the carer is not only looking after her dying adult son, but she is also in the process of completing a divorce, and has financial worries. Furthermore, she is trying to care for her young daughter (the patient's sister), whose response to her brothers pending death is to withdraw from normal relationships with him.

My daughter, I think she sort of is going away from him because she knows that he is going to die. They have always been really close. Yes, she sort of looked up to him, and he spoilt her rotten, it's just the way it is. (C10 R25-34)

Other carers (C9, C13, C17, C23,) and bereaved carers (BC2, BC10, BC17, BC21) described a catalogue of associated demands such as multiple loss, poor health or increase in physical and emotional demand such as caring for a disabled parent. The effect of these multiple demands on carers is explored later in the results when coping strategies are explored.

4.3.3.3.5 Bereaved carers and fatigue

Whilst some bereaved carers acknowledged the progressive fatigue experienced by the patient, in contrast to carers they also cited experiences of their own fatigue. Most remarked how they only acknowledged it in themselves when bereaved (BC8 R75-78).

Some describe the exhaustion, loss of weight, insomnia and the physical and psychological consequences, (BC 8, BC19, BC 21, BC 24).

Yes, yes physically and mentally drained I am feeling at the moment. I don't want to do my job and I am thinking well may be I need a change of work that doesn't help because I am fed up with my job at the moment. May be I think I a lot of mums grief is still in there. Some days I just can't be bothered getting out of bed C21 R41

The physical burden of caring was not an issue for the high majority of carers during their time of caring. Those who did reflect on this aspect of the caring role tended to be those that had opted to care for the patient "in their own way". Their admission of tiredness was not stated with reluctance, as they claimed satisfaction in caring, and in the fact that they had 'got to the end of another day' (C2, C21, BC8).

Others discussed how their work, which was previously well within their capabilities, had become stressful and more arduous, (BC 4 R58, BC 21 R41, BC 24, BC28).

Yes, yes, because for the first time ever last month I was having problems with blood pressure, which I have never had before. I have never had a day off sick in the last 25 years, you know the same as my dad. I think it's a combination of the job, what's going on with my dad and everything else on top of it. BC4 R58

These are all recognised signs of depression.

Those bereaved carers who recalled these post bereavement symptoms had witnessed or experienced the following experiences during the time of caring for the patient:

- poor disclosure
- carer not included in disclosure
- patient told prognosis without requesting it
- multiple additional stress sources (previous recent loss or bereavement, caring for disabled parent left behind).

- protracted diagnosis
- fatigue in the patient
- carer had no access or limited access to information
- poor co-ordination of care.

Conversely, other bereaved carers showed evidence of adaptation to their loss, acceptance and recovery, despite their sadness at the period 4 to 5 months post bereavement.

You know how it is, you're driving along and there is no one to pass you a wine gum, just small things like that and there were lots of little things that can set me off no problem at all, but it's all healing tears BC 23 R30

Such bereaved carers had witnessed or experienced the following experiences during the time of caring for the patient:

- good disclosure
- carer included in disclosure
- patient not told prognosis without requesting it
- multiple sources of support, professional, family, social, spiritual
- fatigue in the patient
- carer had access to information
- good co-ordination of care.

4.3.3.4 Living with uncertainty and coordination of care

A major professional issue in relation to living with uncertainty for participants in this study was the coordination of patient care. 9 patients (27%), 12 (40%) carers and 12(42%) bereaved carers identified coordination of care as an important issue. It was apparent from their experiences that they valued knowing that their individual case, including investigations, monitoring and treatment decisions about their care, was

planned and managed in a timely and appropriate way. Participants recalled instances from pre-diagnosis to bereavement when they considered their care and support had been sub-optimal because of poor planning and management by healthcare providers, and this appeared to be associated with increased psychological distress..

I mean you build yourself up to going in, and then all of a sudden, bang, you have got to wait until the next day, and go through the same process again. P4 R71 – 75

4.3.3.4.1 Coordination of care and protracted diagnosis

The present study focused on the time from incurable diagnosis. However, 5 (15%) patients, 7 (23%) carers and 10 (36%) bereaved carers recalled the pre-diagnosis period of investigations. This was often protracted and lengthy, because of the insidious nature of gastrointestinal cancer. Sometimes symptoms mimicked other less sinister conditions, and this along with many inconclusive investigations, appeared to compound disbelief when the cancer was diagnosed. The situation was further compounded if other aspects of care were viewed as below standard. This was normally in a hospital setting and was recalled by individuals as being due to a shortage of resources. Such a catalogue of events appeared to result in an underlying unease or threat to the confidence and uncertainty the individual had in healthcare workers providing care in such a poorly coordinated system.

I mean we had another week of worrying, and he thought that's it it's in my liver, it's gone right through me. He said I will refer you to the oncologist. It won't cure you. It felt as though I had had a smack across the face. C4 R24-34

As illustrated, carer frustration was often recalled as perceived by the patient in their narrative and was normally related to delayed diagnosis and poor co-ordination of care (P4 R 74-76). In one case, the carer declined to be interviewed on the day arranged, because he felt so angry about his wife's situation. His perceived frustration is reflected quite strongly in his wife's narrative, which also captures her sense of loss.

No, he doesn't want to know. No, he doesn't want to know, he's angry. Yes, very angry. We have got too much of a good life and too much going for us, we shouldn't be in this position pet. He's taking early retirement this year. It's no good taking retirement on his own now is it? He just feels like we've been let down after all these months of tests and now nothing can be done. P32 R60

The incidence of 8 bereaved carers (29%) recalling protracted investigations, delayed diagnosis, and limited treatment options was also very high, especially given the time since bereavement (BC 2R6, BC3 R2-8, BC13 R1, BC14, BC18 R7, BC24 R8, BC26 R21-35, BC 22).

Oh no, I think it's something that needs, it's something that needs sorting out, yes, definitely. When Keith went in the first time, it took them about 6 months to find out what was wrong with him. BC13 R1

It was apparent that protracted diagnosis was a source of both unresolved concern and psychological distress for these bereaved carers. Whilst at an early aspect of care on the cancer journey, it appears to remain significant and was associated with negative appraisal of their experience. It would appear that those who witness protracted diagnosis are at greater risk of psychological distress when bereaved. This risk factor should be assessed by healthcare professionals involved in both management of patients and their carers and in bereavement support.

4.3.3.4.2 Coordination of care and delay in treatment

Time and timing were influencing issues in coordination of care. Participants expressed concern when delay occurred considering this might be associated with a less favourable outcome.

Well it's obvious to me, they tell you have got cancer say December and they don't do it until February, it's a couple of months really isn't it, you know. Once it's started, it bloody well starts, you know P26 R98-100

Delay also had other consequences. Some patients expressed concern about the consequences of delay for their carer (P4,P25, P26, P28). This was often related to hospital appointments where the patient felt the carer was not only inconvenienced by the

appointment, but also by the delay.

They kept saying another hour and Margaret was there with the baby you know sort of hanging around so we had to go up again on the Tuesday. So having gone up Monday come back on the Tuesday evening you know from there. P25

4.3.3.4.3 Coordination of care: Communication between healthcare professionals

Sometimes participants implied that delay in treatment had come about because of poor communication between healthcare professionals.

Most probably he was waiting for Mr.C to write to him, who wouldn't give me any more chemo. So I thought well, September, nothing happened, oh well, he had decided he can't do nought, so he don't want to see me, but you know, after 3 or 4 months you think he's not bothered, you know. P28 R32- 38

Poor communication between healthcare professionals also reduced participants confidence in the system of care and seemed to be related to who was coordinating and managing the patients care to achieve the best possible care, as well as access to information.

Various people appeared, physiotherapists, palliative care team, a range of different doctors, all different every day. At no time did anybody and this is from day one right through to her death, did any doctor or nurse sit down with us and say this is what's happened to you so far, this is what Mr so and so has done this is what we've done, what's happening to you now, probably because no one person knew. BC7 R2

4.3.3.4.4 Coordination of care and support in primary care

A major professional issue in relation to living with uncertainty was access to support and information from healthcare professionals in the community. The primary care roles of GP, District Nurse and Macmillan Nurse, feature in many of the interviews, but with little consistency in patterns of support, and with limited specific cancer information to both patients and carers. Overall, participants expressed poor understanding of the roles and services available in the community.

Well, as for the Macmillan nurse and the District Nurse, I don't want to be waiting in for them, you never know when they're going to call, it lacks structure. I don't know what the Macmillan nurse does and what the District Nurse does. What are the different functions? I can't stop in every day P17 R11

Many bereaved carers commented on Macmillan nurse getting involved at too late a stage (BC6, BC12). However, resisting support from the specialist Macmillan nursing service or avoiding the hospice was common with many patients where avoidance or carry on as normal was used as a coping response (P1, P7, P11, P18, P26, P27)

they do very good work but that's not for me (P1)

This lack of professional input consequently denied carers access to information and support to meet the needs of the patient. The carer (C11), with children in this situation had the added frustration of no access to specialist support in meeting their specific needs.

However, again there appeared to be misunderstanding about roles and specialist palliative care services such as the Macmillan Nurse or the hospice, often related to previous bad experience with cancer in the family, and an association with palliative care and imminent death. This identified the need to proactively promote and explain support roles available to patients and their carers, as some demonstrated both misunderstanding, but of concern, limited alternative support.

We went to the hospice, but it gives me the creeps, yes the chapel of repose, people creeping about, that's how it makes me feel, and the GP's not someone to talk to

C8 R23-27

Support from the District Nurses and the GP were, however, mostly welcomed and seen as less threatening to patients, though they were sometimes viewed as a less knowledgeable resource for carers (BC1, BC6, BC14). This was often because participants perceived that the GP and District Nurse had been left out of the communication loop and were not kept properly informed by the specialist cancer centre.

Oh I thought that was a lack of communication really. I think if he did know he would have made a phone call or something because he is a nice Dr, he is very caring C7R75

No-one, not a soul, haven't spoken to his GP, nobody's approached me. You're the first person that we have come in contact with. He's had no support C9 R21

Where the insidious nature of these cancers had led to a lengthy investigation period prior to an eventual diagnosis the relationship with the GP or hospital consultant often suffered and affected trust and confidence not only in these professionals, but more generally (P32). This was also evident where a patient, referred from a district general hospital had experienced delay in diagnosis and insensitive disclosure of diagnosis and often viewed other staff, including those in the specialist cancer centre as incompetent. (P12).

4.3.3.4.5 Coordination of care and anticipating need

A small number of patients (P11, P7, P18) recalled how they did not like the uncertainty that was associated with waiting for symptoms to reoccur preferring to anticipate a problem and deal with it as soon as possible.

They said if you have any symptoms, get back in touch, so I said well I didn't have any symptoms the first time, when I was originally scanned. I mean if I hadn't pushed it, I would just be waiting for symptoms to appear. You see, I don't want shocks, because probably by then it might be too late. P11 R52-56

Added to this, such patients appeared to feel more in control if they had a contact number and a follow up outpatient appointment.

When they discharged me, well the last meeting. So I haven't heard anything since. Well I have been saying, I have been saying to myself well why haven't I got another appointment. P7 R25-28

Access to information in relation to anticipating needs was frequently cited as a major source of concern to carers and bereaved carers. Many carers fell back on family and friends support, and often expressed that they should not have to wait until a crisis when professional help is provided. Rather, health professionals should be visiting more regularly in order to anticipate needs in the patient.

After the second week of chemotherapy Sue was unwell, she was terribly dehydrated, complaining of pains in her legs and I just didn't know. I rang the hospital and they said there's nothing we can do. I rang my GP and it was half day closing, so I rang the locum who said we're very busy here, so if you're concerned dial 999. BC7 R1-R2

Many participants identified problems with out of hours support, not knowing who to turn to.

I had just come home and the wound was leaking blood and pus. So he phoned the ward and said what am I to do. Oh we can't accept her back now. Get in touch with the GP and if you get no joy, bring her back into casualty. P12 R32

4.3.3.4.6 Coordination of care and chemotherapy

Patients receiving chemotherapy had both concerns about the coordination of their treatment and their support needs, which they implied could not always be met by the traditional community team of GP or District Nurse.

As I say it is a little bit sort of scary doing this chemo yourself you know and having the line. I hope nothing goes wrong with it, because it is an hour's journey to get there, and the district nurses who don't know an awful lot about it. I probably know more about the actually process than they do. P25 R72

In this situation there were examples of patients and carers turning to a previous source of support they had found beneficial.

I get good support I've got the Stoma Therapist, and the Nurse Specialist. She found out a little bit about the chemotherapy for me. I was concerned as I said you know every time I've been to see somebody I've been told a different thing. I've wanted to know how they thought it was going to work when it didn't work the previous time? P25 R21

Their experience suggests that support to patients receiving chemotherapy in the community is less well established than other hospital based support roles, and that communication between the multi-providers of care to patients with gastrointestinal cancer is inadequate.

I felt it was not, it wasn't her patch, as it were. They should have had someone at the chemotherapy center. I did phone the CNS at the surgical unit in the end because I was getting worried, his temperature kept on going up, so I did phone her. I think that is bad, because the chemo unit closes down at weekends, and I didn't know you could phone one of the wards. C27 R23-26

4.3.3.4.7 Coordination of Care and the Clinical Nurse Specialist Role

The expertise of a hospital based senior clinical nurse as a key resource and coordinator of the cancer journey was a valued role but only experienced by a limited

number of participants. Significantly, these participants recall of events indicate that having the CNS present at disclosure was a key time for establishing a trusting relationship. The main aim of the role as perceived by participants was to work with the patient and carer to assess and meet their needs in such areas as information and to involve other healthcare professionals to establish support on the cancer journey, from the point of diagnosis.

She was there at the outset. We met her with the surgeon I remember after he had told us how bad it was she stayed with us and talked it through and sort of helped us move on, and she rang the GP, and arranged the nurse to visit, and she's been there for us. P7 R41

The use of the term 'she made it happen', and 'I knew she would sort it out' were examples of comments participants recalled. This individualized approach seemed to make a positive difference to participants who often recalled how the CNS worked in a proactive way, and had the authority to work across disciplines to ensure appropriate patient outcomes were achieved. This professional support was recalled by some participants as a means of reducing uncertainty and fear associated with their incurable cancer, and seemed to promote adjustment.

Some carers recalled how it helped and equipped them to care for the patient.

What I liked was when I came in at visiting in the afternoon, she would often come over and check that we both knew what was going on. It was like she looked after us both. C20, R23

Other issues that supported the patient and the carer were the way the CNS continued to be available by telephone following discharge from hospital, was frequently seen in the clinic setting, and could be called upon as an expert resource to GP's and the primary care team.

Some bereaved carers recalled how when the CNS was trusted by the patient it helped the patient and carer talk together and with their children.

It was amazing really. She became like a friend overnight. She knew my situation, separated from my husband, and coming home to care for him. She helped us talk and they were the most amazing months, it was as if we had never been apart. She found time for us, and helped us include Rachel who really struggled with the whole thing. BC5 R12

Others recalled how the CNS retrieved the situation for them when disclosure or coordination had been managed inappropriately at a referring unit.

I remember clearly after all the bad experiences I'd had at the other hospital, she was there for me all the way through. I'd just have to call and she lightened the load, I could talk about my worries, we'd even have a laugh. She helped me live with it, put me in touch with the nurses nearer home. P12 R 35

The role also seemed to promote access to and acceptance of palliative care services e.g. District Nurse, Macmillan Nurse and hospice as the cancer progressed. Bereaved carers recalled how this forward planning helped the dying process, which was then well managed, with effective symptom control and psychosocial support. This appeared to contribute to psychological adjustment and peace of mind when bereaved. There was evidence in these participants of satisfaction with support and care provided, both by health professionals and how they were assisted as carers to provide care (BC 23 R19 BC 8, BC 27)

She (CNS) had said to me she would set everything up, and from the beginning when the district nurses started coming they said now remember just pick up the phone and if we are not there, there is somebody in the office and the message will get to us and we will be around and they were and that's how it was. I found all the nurses unbelievably good, and they carried on and came to see me afterwards as well BC23 R19

The key points emphasised were::

- being supported to care in the way they wanted to
- good disclosure
- feeling included
- information needs met

- good co-ordination of care

4.3.3.4.8. Coordination of care, the CNS role and carers

In this study carers considered they had less access to the CNS than patients, as they did with other healthcare professionals such as the District Nurse or Macmillan Nurse. The carer tended to view their role in terms of patient need rather than their own needs as a carer. It is apparent from this study that in order to provide support for someone with cancer there are also many carer concerns that need to be proactively addressed.

Yes you think you are immune to all kinds of things and then it happens to you, it's a different feeling, especially when it's the one you love. It's horrible. You need help to support you. The fear of life is there. I feel there should be more time and sympathy offered. The quality of life is important, we should support the patient as well as the person who cares for them. C22 R3-5.

There appeared to be certain barriers, often emotional, to providing help and information to carers and for many, help received was largely reactive after a crisis rather than anticipated.

I mean we are not complaining but I mean, when the patient says I feel fine, perhaps they should speak to the carers as well because the carers know what's really going on. Just keep the hope and support going. GP's are too busy, and often don't know. C22 R5-8.

4.3.4 THEME THREE: Strategies that support the ability to carry on

In this theme participants perceptions of their coping responses and access to coping resources are explored.

4.3.4.1 Coping strategies

This phase of analysis identified strategies adopted by participants recalled in a “relationship” format of patient and carer. During analysis it was identified that three of these responses were very similar to the carer coping responses identified by Rose et al (1997). These were:

- Togetherness
- Carry on as normal
- Avoidance

However, a further response was also evident in the data. This was a restricted response, where some participants appeared to have an ‘inability to activate a coping response’.

Within the responses adapted after Rose (1997), it was also possible to identify more detailed emotion and problem focused processes of coping response and resources similar to those identified in the modified model of coping (Folkman, 1997). These appeared to demonstrate that appraisal and coping processes were influenced by both characteristics of the individual and their environment, and that some individuals experienced what Folkman (2000) describe as ‘well being’, despite their experience of incurable gastrointestinal cancer.

Participants did not always adhere to one strategy, but had a unique combination of strategies according to their appraisal of different situations on the cancer journey. What is demonstrated is how each participant recalled how they perceived their use of coping strategies as a patient, a carer or a bereaved carer, affected by incurable

gastrointestinal cancer. How strategies adopted were influenced positively or negatively by their experience and appraisal of sensitive communication, living with uncertainty, plus the resources they perceived were available to them, such as personal resources, family support, access to information and professional support are also illustrated.

What was apparent was that the experience of patients often appeared to influence the strategy adopted between themselves and their carer, a finding that was also evident in the bereaved carer experiences. For example, in many cases, how a healthcare professional spoke to a patient at disclosure influenced the direction and tempo of the patients cancer journey including their coping response and therefore their carer. In the previous section it has been illustrated that patients who perceived poor disclosure had unmet concerns and information needs in relation to their illness, the future, how their carer would cope and not being able to do the things they used to. Furthermore, the inclusion, or not, of the carer at this early stage of disclosure, and the coping response of the patient seemed to influence the carers' appraisal of coping resources available to them.

Coping responses will now be described.

4.3.4.1.1 Togetherness

Table 4.58 (Section 4.7.3.1) demonstrates how use of this strategy was recalled by 6 (18%) patients, 5 (18%) of their carers, and 15 (54%) bereaved carers.

4.3.4.1.1.1 Togetherness and positive appraisal

On first examination this appeared to be the ideal coping response. There was strong evidence of patient and carer trying to work together in partnership (P10, C10, P20, C20, P21, C21,

P25, P25, P30, C30, P32, C32, P32, BC4, BC5, BC7, BC8, BC9, BC11, BC12, BC16, BC15, BC16, BC 19, BC20, BC22, BC 23, BC28).

We dealt with it together and I was supportive to him and he realised at that time he thought the diagnosis wasn't very good and that he would have about 6 months to live and he wanted to get everything ready for me, and the children were very supportive although my son lives in Peru and my daughter in Nottingham C30 R4

In many instances neither party recalled coping alone, neither party was superior to the other, but looked upon one another as a coping resource. This resulted in emotion focused and problem focused responses through an ability to communicate and to identify needs in each other (P10, C10, P20, C20, P21, C21, P25, C25, P30, C30, BC4, BC5, BC7, BC8, BC11, BC15, BC16,

BC20, BC22, BC 23).

We talked to one another about it. We discussed about what the Macmillan nurses had said and done, about the doctor and you know and Eric, he just needed to get financial things sorted out C30 R15

The strength of relationship, knowing one another and expressing understanding of what the other might want was evident in this coping response.

He went to the hospice for a fortnight. The Macmillan Nurse thought it might be an idea and it was fine but we knew he wouldn't go again. I said you don't want to go back again and he said no I want to stay here with you so I said fine and you know of course there was tremendous help.

BC 23R14 -17

For some of those who had experienced good disclosure and well managed co-ordination of care together, there was positive appraisal and confidence in healthcare professionals with access to professional involvement and support. This seemed to

enable a problem focused response by both patient and carer of constructive action, information seeking, and making plans for the future, including terminal care (P10, C10, P20, C20, P30, C30, BC4, BC5, BC8, BC11, BC12, BC20, BC22, BC 23).

I felt the confidence of it was great because I felt (CNS) is brilliant and she is the most caring person I have met, she gives that impression obviously she can't remember all these cases it's illogical, but she gave that impression and you felt that was a security
P30 R16-20

In this category there was also evidence of an emotion focused response through positive beliefs, spiritual and inspirational support, and previous experience (P10, C10, P20, C20, P21, C21, P25, C25, P30, C30, BC4, BC5, BC8, BC11, BC16, BC20, BC22, BC 23, BC28). This appeared to be at a level of emotional adjustment which Folkman (1997) refer to as meaning based coping demonstrating evidence of adjustment and acceptance

It might sound to other people very cynical and cold and calculated, and whatever but it's an acceptance. We've got a faith, although my Dad never went to church but he lived his life as a Christian. My Dad always said it's the only inevitable part of life. He knew things were going to be okey, and that's why I feel okey BC20 R13

The combination of problem solving and emotion focused use of social skills and social support with inclusion of family and friends was also evident as a resource for many participants adopting the coping response of togetherness, (P10, C10, P20, C20, P21, C21, P25, C25, P30, C30, BC4, BC5, BC8, BC9, BC11, BC20, BC22, BC 23, BC28), with some awareness that this social support was an essential component of coping as a carer.

I had my family and a few close friends, because John didn't want a lot of people involved anyway. But if they haven't got those friends around them, they do need more. I mean really it could send you quite loopy. Just think of the effect it would have on you if you were alone having to cope with all that and then afterwards you were alone as well. It is very lonely. Even me and I'm surrounded by people it is very lonely without John. BC9 R58-59

4.3.4.1.1.2 Togetherness and negative appraisal

Negative appraisal was also evident in some participants when they perceived that they did not have access to resources to resolve or cope with a situation. This negative appraisal was predominantly associated with the two previous major themes of sensitive communication and uncertainty. For example, younger, female carers with

multiple responsibilities often experienced such negative appraisal. These contributory factors to psychological distress are illustrated in the following quote.

Someone has to stay strong which means I have to stay strong for my baby, my Mum and my two sisters, and sometimes you would just like to let go and let someone take the burden for a couple of hours to give yourself a break. I mean my husband gets fed up because he gets it all you know. C25 R 10

For some couples the lack of resources caused problems in their relationship of togetherness. For example an important minority of bereaved carers (BC7,BC9,BC12, BC 15,BC19, BC22) recalled how protracted diagnosis and/or poor disclosure reduced the capacity for togetherness.

'Well John, she said, you know there's nothing I can do for you I am just paying you a visit. They were her very words and on the way down she said to me 'You just have to face these things you know and get on with it'. What she said was so unnecessary, it did John no good at all BC9R9

Whilst some patients who adopted togetherness wanted to know their prognosis and this appeared to contribute positively to their psychological adjustment (e.g. P10), if the disclosure was poorly managed, this had repercussions for carers.

He didn't mean it in a bad way, that's his way of doing it. He realized that Richard wanted to know the truth, there was no padding about it, you have got a few months to live. And that was the fact you know that I had to deal with too C10 R20

4.3.4.1.2. Carry on as normal

Table 4.54 (Section 4.7.3.2) demonstrates how use of this strategy was recalled by 8 (24%) patients, 7 (23%) of their carers, and 3 (11%) bereaved carers.

4.3.4.1.2.1 Carry on as normal and positive appraisal

Some participants recalled talking together around the time of diagnosis and then sought to get on with their lives as normally as possible, (P3, C3, P4,C4, P5, C5, P7, C7, P12, P15, C15, P29, C29, P31, BC1, BC6, BC27). As with the previous coping response of togetherness, carry on

as normal appears to be a positive appraisal of their situation with patient and carers apparently taking constructive action.

She didn't really talk about it much. So I said as long as you feel alright, you have just got to take each day as it comes and get on with your life, and she quite agreed. She wouldn't come back with me, she wanted to stay by herself and carry on as normal.

C15 R15

Positive appraisal of family and friends as an emotion focused coping resource was identified as beneficial (CP3, C3, P4, C4, P5, P7, C12, P15, C15, P29, C29, P31, BC27), and spiritual beliefs and practices appeared to influence an emotion focused response of acceptance, and were also considered beneficial (C4,P5, P29, C29)

I mean they all help, Yes, prayers help. A bit of comfort. I mean I am not surprised that people have sent cards. They are having Masses said, there was a Mass said in Lourdes, there have been candles lit a couple of times in Lourdes, so someone has got to listen, someone is listening. C4 R83-84

There was also positive appraisal and confidence in healthcare professionals, in particular the role of the Cancer nurse practitioner, Clinical Nurse Specialist, and Macmillan nurse (P3, P4,C4, P12, P15, P29, C29, P31 BC27), with emotion focused and problem focused responses, such as talking to professionals and seeking information. However, this positive appraisal was predominantly recalled by patients, with only a limited number of carers perceiving themselves to have access to this professional resource (P3, C3, P4,C4, P5, P7, P12, P15, P29, C29, P31, BC27).

It was nice for me to talk to the nurse (cancer nurse practitioner) on the phone, you know about different things, you know, although me and my husband discuss it now and again, we don't actually discuss what's going to happen to his Mum in the future.

C15 R64

4.3.4.1.2.2 Carry on as normal and negative appraisal

Whilst carry on as normal appears to be a positive response, negative appraisal of their situation is apparent in some participants. This appeared to be related to resources issues reflected in the two previous themes and in particular in relation to sensitive communication and uncertainty.

4.3.4.1.2.3 Carry on as normal and fatigue

Getting their house in order was often dictated by the patient, particularly where the patient had held responsibility for finances and paying bills. Taking on this responsibility reminded the carer of the patient's increasing fatigue, loss of role and inevitable end (C3 R47, C5 R, C4 R61-64)

I wake up in bed and when she's not there, and I come down and she's messing about with all the paperwork, and she wants to get on, what's got to go to whom, (inaudible) and I say don't mither with that, she says it's got to be done. Rita has always done that side of it. So I'm like back at school. C3 R47

Fatigue, discussed previously, was viewed as a high concern by patients and in particular how it related to increased dependence on their carer. Adopting a 'carry on as normal' strategy was an attempt to defer this dependence on their carer, in a problem focused response, helping the patient cope themselves, as well as providing a coping resource for their carer. Some participants, however, seem to be admitting that it is a struggle to carry on as normal, or to accept reversed or altered roles, despite obviously trying to, and that carrying on as normal is associated with negative appraisal of their situation, which seems to be associated with psychological distress.

Last week, I didn't want to get dressed, it was me, I just felt horrible, I was so tired, I felt horrible, I went to hell, you know, stayed in my dressing gown, which isn't me, and I said to Billy I said don't let me do it too often. Now and again, but... And he said okay. Because I have got to get up and get dressed and get on with it. P5 R 17-20

4.3.4.1.2.4 Carry on as normal and carer exclusion

Often the carry on as normal strategy was agreed tacitly and initiated by the patient. If this included 'not talking about it' and 'not making a fuss', if the carer had also been excluded from the communication system it caused a problem. Some carers had been excluded from disclosure of diagnosis when the patient was told their prognosis (C3, C4, C5, C12). They had expressed concern that their spouse had received their diagnosis of cancer and prognosis when alone (C3, C4, C5, C12). Their lack of inclusion at this initial

stage and limited access to health professionals as a coping resource appeared to be associated negative appraisal of coping resources which prevented them activating a coping response. Instead, such experiences appeared to trigger negative emotion focused responses such as not feeling able to take action to seek information, (C3,C4, C5,C7,C12,C15, BC1, BC6), a lack of confidence to make plans (C3,C4,C5, C7, C12, BC1), and fear about the future (C3,C4, C5,C7,C12,BC1), even helplessness (C3,C5, BC1 BC6).

See I wasn't, all we got told that is just the tumours were there and it'd gone to his liver, but I wanted to know more. But I didn't, I didn't know where to go, who to ask? And I think myself personally, I should have been spoken to by someone, is there any questions you want to ask about George's disease? And like you know, how long he's got to live. BC 6 P32

This combination of negative appraisal appears to be compounded if the individual has limited social skills (C3,C5,C7), or a history of depression (C5, C7, BC27), or has experienced recent multiple loss (C4).

I think Billy needs it more than me actually because I am stronger. Billy's weak. And Billy lately has been crying every week. He has got depressed and upset every week. He feels inadequate, he doesn't feel he is doing enough and I am going Billy, you are. You can't do any more. P5 R101-103

Whilst some participants admitted to carry on as normal, their recollection sometimes appeared to be more associated with the next strategy of avoidance.

Yes and when I came home from work that day we just talked about it and he said, what I've got to do Pat, I've just got to get on with it. We told no-one. We just kept it to ourselves and we just got on with it. We just tried to act normal, we just tried to do the same things. We never went out, we just stayed in, like we never went out anyway but we just tried to live each day and not to change BC 6 P6

4.3.4.1.3 Avoidance

Table 4.55 (Section 4.7.3.3) demonstrates how avoidance was recalled by 17 (50%) patients, 15 (50%) of their carers, and 6 (21%) bereaved carers.

4.3.4.1.3.1 Avoidance and patients

She more or less treats it as I do. I shove it out of my mind. I haven't got cancer. I'm in perfect health. I take the dog out, I do all the jobs around the house. This is my way of

copied with it. I think if you dwell on it, sit in the corner with a cup full of gin and bite your nails down you'd be dead the following week. In my mind it's just not there. P23 R3

4.3.4.1.3.2 Avoidance and patient concerns

9 (26%) patients who avoided talking about their cancer with their carer, did express concern about the future. Others had concerns about how they would die, and if they would be in pain (P18,P19,P24,P27). Their response of avoidance seems to be associated with negative appraisal of what they might be told if they were to seek information about the future and other concerns.

she's building up now for August to go to New Zealand like you know so we talk about things like that in the future the positive things. We never talk about you know if anything might happen, no I like to forget about it. P24 R2

A contributing factor to this appears to be concerns about how their carer might cope caring for them if they were told they would be distressed or in pain.

I say to myself well how much pain I'm going to get, how long is it going to take you know, and how she's going to cope. I haven't spoke to anyone about it. It's just at the back of your mind like you know because if you know people that has had it as I've known a couple of people P24 R3

Some patients had had previous experience of poor disclosure, or had been given prognosis without requesting it, and this appeared to influence the decision to avoid seeking further information, even though this in turn restricted access to support.

After the way I was told it was so advanced, it depends what's going to happen next. I don't want to be given a catalogue of a whole series of stages. I think I'll treat it as it comes. So while, while I can be light hearted about the fact that I have got cancer and that I am going to die. Um, I don't really want to know the gory details. To be honest. It's the cowards way out, but what the hell. I don't panic, I don't feel frightened and I don't want to change that. P18 R89- 99

Sometimes it appeared that the patient wanted to literally avoid what the future had to offer, and use of avoidance seemed to be a means of postponing worry and distancing their carer from reality. Previous patient experience of terminal care in the

role of carer, or loss, and the effects felt once bereaved appeared to contribute to the adoption of this avoidance strategy by the patient.

She was literally incapable of anything from about the August until she died in the January, and I was having an hour off a day, and my parents were living here as well and I was looking after them P16 R10

Sometimes the patient seems to adopt avoidance in an attempt to minimize the situation, which might be viewed as avoiding reality.

Again, I could get knocked down by a bus I suppose, but knowing that something could happen in the near future. I just basically carry on and forget about it, and when I need to know, I will get told, won't I? P11 R108-109

This illustrates the need for healthcare professionals to anticipate information needs in individuals with incurable disease, and to take a proactive approach to explore with them and their carers their fears and concerns, in an attempt to increase their coping resources and positive appraisal.

4.3.4.1.3.3 Avoidance in patient and carer exclusion

The adoption of avoidance by 13 (38%) patients who experienced diagnosis when their carer was not present or was excluded (P6,P8,P14,P16,P19,P22,P23,P24,P26,P33,P34,BC13,BC14) seems quite significant. This appeared to happen when disclosure was unplanned and unstructured, and emphasizes the importance of planning disclosure and coordination of patient management.

But the sister in the hospital told me well after the first week. I didn't tell the wife, of course no, or none of the family, I kept it, you know. No, but she said it was a major operation.

P19

R12

Avoidance was prevalent in those patients living alone, who appeared to use it in what they seemed to considered was a positive response, in an attempt to maintain independence.

I know when my sister comes down with her husband, they stop here for about a week, I am glad to see them go, I am used to being a loner, you know and make my own decisions. P6 R61-63

It was also used as a strategy for not burdening their carer (P1,P2,P8, P16,P18,P23,P24).

To be quite frank with you, I would rather walk across the road and have a heart attack in the middle of the street quite frankly and have done with it. No, we don't discuss it. No. I have the bed booked at Nightingale House (*hospice*). I can't see any alternative, they have all got their own lives to lead. P16 R29-37.

One of the major concerns to carers was where the patient wanted to maintain their independence to either protect them or to 'avoid all the fuss', it often led to the total exclusion of the carer. This in turn led to frustration and even helplessness in the carer

I don't think he minds the nurses going to talk but he will not have any of us. He wants to do it himself, he wants to carry on doing that. C6 R78-87

4.3.4.1.3.4 Avoidance in patient and carer's health

When the carer had health care needs, (P2,P14,P23,P26), use of avoidance by the patient in an emotion focused response seemed stronger, but what it also demonstrated was how avoidance reduced the scope for problem focused action in seeking access to support and information to both the patient and the carer. Again, carer exclusion at disclosure and poor coordination of care with no support instigated, might have contributed to the patient's negative appraisal and adoption of avoidance. The following example shows the patient's response when his partner needs care and support after major surgery, and how he appears to put his own needs secondary to her needs.

I am more inner, I keep things tucked in myself rather than talk. Well with Alison, she was bedridden for a couple of months, she was really bad. So I was made up coming home, at the same time out of hospital to help her, but my condition like was getting worse with not having the operation for the cancer. P26R87-90

Rather than talk to their carer, patients often recalled talking to other family members, friends or health professionals about their concerns about their care r (P1,P2,P8,P14,P16,P18,P23,24). This was frequently when the carer had physical or mental health problems (P2, P14, P23)

No, (*hasn't talked to wife*) because I don't want to worry her. I've had a chat with my son when he was over at Christmas, over what would become of her. She'd be living here, by herself. And, we decided, my son and I, that if I pop off, then we sell this place, and buy her a small bungalow that she would be quite happy in. P23 R14

4.3.4.1.3.5 Avoidance in patient and healthcare professionals

The lack of understanding about the role of palliative and supportive care services was evident in the way in which some patients deferred involving palliative care services, as if involving them was an admission of reaching the terminal stage of their life. (P1,P6,P11,P18,P19,P23,P26,P27,BC13, BC14,BC18).

I know they are very good and have got a tremendous reputation, to get in touch with either Marie Curie as a patient or Macmillan nurses as a patient, because I want to keep, I know I have got cancer but I don't want actually, it seems like um hardly a quantum leap, but once you start using the services P18 R47.

Some patients however, avoided or felt unable to talk about their cancer at all, even when skilled health professionals were involved (P6,P11,P19,P26, P27,P28),

A couple of times we tried, but I think even she (*Hospice Doctor*) has agreed with me that this is just Kevin's way of dealing with things and you know, if he wants to talk he will. We have silences. We have silences. He has said a few things here and there to give me a clue as to how he is feeling, but now we just don't talk about it at all really, you know, it's like pushed to one side, it's just get on with things. C11R10-12

4.3.4.1.3.6 Avoidance in patient: consequences for carers and bereaved carers

The negative emotion focused response of avoidance associated with not talking and distancing seems to have been adopted by patients to reduce their stress and to make life more bearable for themselves. Many also felt it would reduce exposure to stress for their carer by avoiding reality which might prove to be overwhelming if confronted. However, carer and bereaved carer narratives demonstrate the multiple and diverse repercussions the use of avoidance had. This strategy inhibited emotion focused and problem solving approaches, such as talking to professionals, acquiring

information, seeking support from friends and planning for the future care of the patient as well as perhaps children and other dependents.

He is like the victim, as it were, he's the one, but he won't talk, and it would be nice just to talk to someone. I think that the carer is put in secondary position which is fine by me, but in an ideal world, it would be nice to have had the opportunity, your husband is going to go through this, this is what might happen and when, and you will feel pretty shattered or whatever. C27 R32-33

4.3.4.1.3.7 Avoidance and negative appraisal of coping resources in carers

Some carers seemed to react to the patient's strategy of avoidance with a negative emotion focused response of helplessness and inability to activate any coping response (C8 R12-15, C14 R14-17). This sometimes occurred when the carer had serious health problems of their own such as a stroke or depression (C2, C23, C24), or when the carer admitted that they felt they had always had a difficult relationship with the patient (C2, C8, C14, C23). It was a source of distress for a significant minority (C8 R12-15, C14 R14-17).

We don't have a lot in common, he's a mans man C8 R12-15,

Different as chalk and cheese C14 R7,

Our lives are sort of empty. Yes, hospital and her illness C2 R119

The situation was exacerbated if the patient adopting avoidance had information needs, or if the carer with healthcare needs themselves had been excluded from disclosure, access to information and professional support. Again, this seemed to accentuate the negative appraisal of their situation which appears to be helpless and hopeless resulting in no positive action being taken.

I found that I'm now looking after him and I am not 100% myself. I'd had the stroke over a year ago and I had a very active job, and now I can't drive and get out. Everything has altered. It's like ooh it's just like in two years everything has been taken off both of us do you understand? C23 R2

Carers recalled how the patient adopting avoidance also used other emotion focused strategies such as anger.

Not good, I was the target for the anger, and I think the anger was due to the fact that it had spread, but I got the target, I got the flack. C1 R18

Some carers felt the patient's illness had altered their attitude to them with some remarking on the patient almost resented them.

Sometimes she will be lovely and I will feel very close to her, and then other times she has got this sort of barrier between us together, and she is looking at me as if I am all to blame, and she is telling me as much. She has said that she has supported me for years, and now I am more or less pretty useless to her when she needs me most C2 R86

Those carers with mental health problems did express concerns about how they would cope (P2R R84, P5R.), This seemed to emphasise their feelings of inadequacy and was reflected in their case scores for anxiety and psychological distress.

Yes, she has always been a strong person, and I have relied on her as my strength, now, when she should be relying on me at her side, I feel I am not there for her.

C2 R65

4.3.4.1.3.8 Avoidance and coping strategies in carers

Positive emotion focused and problem focused strategies perceived by carers as useful to overcome the effects of avoidance in the patient (and the consequential exclusion of access to professional support and information), included seeking information and support through their General Practitioner (C1,C2,C6,C11,C16, C22, C24, C27), the hospice (C11,C16), the Cancer Nurse Practitioner or Clinical Nurse Specialist at the hospital (C1,C6,C11,C27), the Internet (C27) and patient volunteers (C27).

Yes, it's a good resource yes. To have someone, well like the CNS, she has always been very helpful. And she always said if I can help, and she did help a lot, because I was able to phone her quite freely, so that was a very good thing, but it's a big strain on her. Yes, but as soon as he changed, left the surgical unit I felt as if I was on my own almost. . C27 R23-26

And, just get on with it, but no, the one thing I would say the hospital system could help with is just having that point of reference, someone the carers can call. C16 R57

4.3.4.1.3.9 Avoidance and carer acceptance

There were instances where carers appeared to support the strategy of avoidance with the patient in an emotion focused acceptance response, with some signs of conditional sacrifice, genuine love and affection, and their own needs as secondary (C18, C19, C26, C28).

Carers were naturally protective of the patient. This carer expresses throughout her interview that it was her husbands wishes / agenda that were important, not her own.

I think it probably comes from the fact that Dave is absolutely primary in my life and always has been since the day we met and that's 34 years ago, so if I can sort of give the appearance that I am coping, I am fine, there is no need to worry about me then that has lightened the load a bit for him, and I think it, I think it worked. C18 R11-15

Use of avoidance in this situation by the carer seems to be as an emotion focused positive coping mechanism, but it also seems to have repercussions, which she admits to, in that it restricts access for the carer to express her own needs for information and support, and even her fears about the future

The depression comes when the light goes off at night and you lie down to go to sleep, and then you are a prisoner of your own thoughts then. And you sort of dwell inside your own head. I wouldn't want him to see how, how really desperate sometimes I can get, he must know inside that I have my moments, but he doesn't see it, I don't let him see it. C18 R16-21

The consequences of the carer supporting avoidance by the patient also led to avoidance of uptake of specialist palliative care and support which might be a coping resource for the carer.

Macmillan nurses, Dave doesn't want to go down that road, well no not at the moment and I have to support him in that. For his own reasons. When he is ready or when he wants, or if he never wants, well that's fine too, um, but we know, I know that they are there. C18 R35-38

4.3.4.1.3.10 Avoidance and bereaved carers

Six (20%) bereaved carers recalled how they had gone along with the patients strategy of avoidance. As in the carer narratives, what was evident from their experiences was how they perceived the patient's negative appraisal of their cancer experience had

contributed to the patient adopting this coping response. They each recalled caring for someone who had experienced some or all of the following: protracted diagnosis, poor disclosure, given blunt prognosis without requesting it, and poor co-ordination of care.

Some bereaved carers recalled being excluded from disclosure, or witnessing badly managed disclosure, and poor coordination of care, and how the patient's sense of helplessness and hopelessness triggered the negative emotion focused response of avoidance from then on.

Well, he just wasn't, you know, until then he was the model patient and making everybody laugh, but till then, we feel as if he went into depression and nobody bothered, nobody helped in any way. We were just told that they couldn't do no more for him so take him home, you know. And that's what happened. BC14 R19

What also seems to be apparent is a sense of helplessness and hopelessness in the carers experience.

He said I don't want to go on like this, you know, and I don't want to live any more. And he said well that's up to you dad, you know, do what you want to do. But that was the only moment he spoke and then after that he went back again into his silence and wouldn't speak, and we just didn't know what to do. BC14 R51

In a similar situation some bereaved carers recalled a loss of confidence in health professionals by the patient if there had been protracted diagnosis, hopes raised for treatment, but incurable disease and limited prognosis actually diagnosed. This seems to emphasise a need for health professionals to be skilled in adopting caution, and to keep the patient and their carer informed of the uncertainties and concerns associated with the pre-diagnosis period of investigations and the staging process in upper gastrointestinal cancer, as well as the high risk of recurrence after treatment.

This seemed to result in negative appraisal of their situation by the patient with reluctance to accept professional support, and avoidance of talking to their carer.

They (*Macmillan nurse*) came out before he went in for the stent, and Keith sent him packing. He said kiss of death. He sent him packing. Because I was hoping to talk to him myself. BC13 R68-69

Consequentially, the carer recalled negative appraisal of their own situation, feeling alone, with nobody to talk to, and with limited access to resources, such as support and information.

4.3.4.1.4 Inability to activate a coping response

This section examines how some participants responded to multiple demands on their emotional and problem focused coping resources. Table 4.61 (Section 4.7.3.4) demonstrates how inability to activate a coping response was recalled by 3 (9%) patients, 3 (10%) of their carers, and 4(14%) bereaved carers.

4.3.4.1.4.1 Inability to activate a coping response: Patient concerns about carer

Two patients expressed concerns about their illness, fatigue and how they would die. Three patients expressed concern about how their carer would cope (P9,P13 P17). They seemed to recognise that their carer was already under a lot of stress because of recent bereavement and loss and that their cancer diagnosis would compound the situation.

Oh yes, you see to put you in the picture, Dolly (my step-daughter) and her mother had a row. She was very forceful, Rosa, and they had this row, and for 6 months they hadn't spoken, so of course Dolly felt a little bit guilty about that because she wasn't there to see her die. Dolly won't let the sun shine on me now. P9 R50-53

However, two patients (P9, P17), also acknowledged some emotion focused responses in themselves such as acceptance, support from friends and family, and learning from previous experience of cancer in the family.

I don't know, I think it's something that comes with illness, I think you find there's a lot you can cope with. You know that there's a strong possibility that you might go early, you start cramming them all in. You start realising there are things you want to do. It doesn't really frighten me. P17 R10

What was surprising was that one patient felt his own cancer was helping his mother adapt to her recent loss of his brother.

She's very strong. I mean not just because of me, but because of my brother, who was killed. She can face things, she is going to be upset, it's no good pretending, I think this happening to me, I don't know whether it has helped her to get out of the rut over Patrick dying. It's given her something else to do, Patrick, Patrick all the time. Whichever way I think it has helped. P17 R13

However, what was also evident in patient narratives, which might have been significant for their carers, was lack of information, limited access to professional support as a coping resource, and poor coordination of care. If the patient was not receiving information or support, it was unlikely that the carer was either.

They don't tell you why and what it means to you. But I don't like asking, but if somebody sat you down and you understood it was alright to ask, spend time with you, odd things that crop up, that are bothering you about how you are progressing. P17 R8-9

In the hospital, she talked to me, and the way I understood it was, which could be a misinterpretation, was that I would get a visit from a Macmillan nurse every week. Well I never even seen a Macmillan nurse after that. P9 R28-30

Patients often highlighted how their carer had more responsibilities than just to them, perhaps still working (P9), or had other members of the family to care for (P17). Patients were concerned when their carer had been exposed to recent death, personal loss, or tragedy (P17, P9, P13).

I was a bit worried on account of Martin you see, because he is such a loner. I am afraid of leaving him on his own. I worry about that, yes. Since his car accident, he doesn't want to know, he doesn't want to listen to me when I have talked to him he cuts me off like P13 R18-26

Extra concern was raised if the patient knew there were unresolved issues for the carer such as recent bereavement (P9, P17), which might be compounded by the patients own incurable illness.

She worries me a little bit because you know, because she is going to have a terrible time I think because my own personal belief is that it's a little bit of guilt complex and that's why I am getting all the love that she should have been giving her mother and vice versa, but I don't know, I just worry for her sake. P9 R50-57

4.3.4.1.4.2 Inability to activate a coping response: negative appraisal in carers and bereaved carers

Some carers and bereaved carers, (C9,P13,C13,C17,BC2,BC10, BC17, BC21), seemed overwhelmed by their negative appraisal of their situation. An accumulation of demands on their emotional, physical and even material resources seemed to influence their inability to activate coping responses, which in some cases appeared to spiral into helplessness.

It's just been one thing after another, since my Mum died so suddenly, and we hadn't got on and I feel so bad about that. I work full time, and with my kids and my husband working so hard I am determined we'll have a holiday this year, but it will all depend on Joe and how he is. I've seen nobody at Joe's I don't know who to contact to tell me anything, but sometimes I think I'd rather not know. C9 R12

This perception of lack of support was also linked to perception of poor coordination of care, and was evident in carers, (C9,C13,C17), and bereaved carers, (BC2,BC10,BC17).

You see all the adverts and we have always given to Macmillan, but where were they when we needed them? BC2 R8

One carer who had disability, including depression from a road traffic accident head injury, was caring for his mother. She had had a stroke 25 years previously and now had incurable cancer with many side effects including faecal incontinence from radiotherapy to her bowel. Although she had visits from the District Nurse and was about to attend the hospice as a day patient, his lack of financial and social support and his reduced social standing in his role as a carer, seemed to compound his feelings of deep seated bitterness and helplessness resulting in feelings of isolation.

Well you get that way, It's what have you been doing today, well I have been to the match, where have you been? Oh in the house looking after my mum. They just ignore you and walk away as if you're a reject. They haven't had our troubles, they have had easy times. Well, now I am getting used to it. I would just rather be on my own, and be a loner. I have just got that way. I know it sounds sad, but I have gone past it. It's something, It's sad that, I have just looked after her, I have had nothing, so it just means nothing. C13 R17

4.3.4.1.4.3 Inability to activate a coping response: multiple loss and consequences for carers

A huge challenge recalled by carers and bereaved carers was trying to activate an emotionally focused coping response to caring for somebody close to them with terminal cancer on top of recent bereavement or loss.

Losing my mum first might have affected me in a different way than may be it would have affected somebody else because dad had been quite sad since he lost my mum earlier and at that point he didn't want to live and I kept him going through lots of things you know he turned to alcohol at first, that was his release valve, and I got him over that and he had been quite jolly, but then for him to be struck down by this, it was too much, I felt there was nothing I could do. BC21 R4

Carers and bereaved carers who had experienced lack of access to information and support as well as multiple loss identified how they had found it difficult to enjoy normal socialising during their time as a carer (C9, C13), and when bereaved (BC2, BC10, BC17, BC21)

But if I wanted to move away now I'd feel so guilty for leaving Mum. And if I'm having a laugh it's like someone in my brain going 'hang on a minute' BC2 106-107

4.3.4.1.4.4 Inability to activate a coping response: multiple loss and consequence when bereaved

Once bereaved, some carers demonstrated classic signs of depression accompanied by an apparent physical exhaustion (BC 2, BC10, BC17, BC21). All these participants had a history of depression

I just get on with things. I get extremely tired and I know I'm getting tired and looking back now the way my job has been over the past few weeks I don't know how I fitted my dad in I really don't know how I managed to do what I did for him, but I did but now on reflection I think how did I cope. I am feeling tired now though BC21R36

Such participants did not have access to bereavement support, but had to seek counselling from their GP (BC21, BC2, BC17). This could be difficult and might inhibit the participant activating this response if there had been difficulties with the patient's management by the GP and the community team (BC2, BC10).

They are not going to come up with any answers so what's the point? BC2 R103

The need for general guidance over bereavement seems to be evident in some of the narratives, including those who have had previous experience of loss, but have also had limited professional support whether choosing to withhold from support (C9, BC21), or because none was offered during their time as a carer (BC2, BC10,).

So I think keep work going, keeping dad going, losing dad, and people don't have grieving time you know it's back into work carry on with your life and I know that's going to carry on for a long time but I don't think I've had time for me and I am not sure how much time you need. BC21 R37

The need for bereavement support also appears to be related to unresolved issues from previous loss, and may contribute to an inability to activate a coping response to their current situation (C9, BC2, BC13, BC17, BC21

May be I think I a lot of mums grief is still in there
Yeah because I put aside my grief for my mum to be with my dad because he was grieving so badly and he needed me so my grief for my mum got buried and part of me feels guilty about that that I miss my dad more BC 21 R44-47

4.3.4.1.4.5 Inability to activate a coping response: Carer and bereaved carer need for guidance about supportive and palliative care

Some bereaved carers felt they had discouraged patient access to palliative and supportive care, thinking they could manage on their own, and perhaps because they were trying to protect the patient.

I don't know whether it is the denial thing. The Macmillan nurses are related to this cancer and I really didn't want to know and I really didn't want to put dad in the situation where he felt I'm dying of cancer. It was easier not to but, yes I still don't know what their role is. BC21 R34-35

As a consequence there seems to be some evidence of negative appraisal of this with feelings of regret and guilt when the carer realises how the patient had benefited from hospice support.

He said I've had a lovely day and he said I can't describe what I mean but it was just lovely they were talking and we said some prayers and we sang a hymn and oh it was just lovely. His voice it sounded more like my mum would say like at peace I can't really describe it but he was definitely different that night but then he only went twice which I felt a bit sad about afterwards because he'd had a such a lovely time. BC21 R28.

As has been illustrated in other themes, this emphasised the lack of knowledge and understanding and access to information about palliative and supportive care, and the stigma she, like others attach to palliative and supportive care.

4.4 STAGE ONE ANALYSIS: The Concerns Checklist

The aim of using the Concerns Checklist with patients, was to check whether the interview technique had adequately assessed patient concerns (Heaven and Maguire, 1997), and to explore the relationship of the number of patient concerns and their anxiety score on the HADS (Parle et al., 1996). The results of analysis of the Concerns Checklist are displayed in Table 4.6 and 4.7 and in a larger matrix in Appendix Nine).

The four most frequent concerns reported by patients in this study were the same as those identified in studies in advanced colorectal cancer by Maguire et al. (1999), and in the coping in cancer literature by Parle et al. (1996).

Table 4.6 The Concerns Checklist – patient's most frequent concerns

Concern	Number of patients
Not being able to do the things you used to do	22 (65%)
Your current illness	21 (61%)
How you are feeling physically	20 (58%)
The future	14 (41%)
Your relationship with your partner / main carer	4 (12%) No, but..... 20 (60%)

Table 4.7 Frequency of total concerns

Number of Concerns	Frequency	Percent	Valid Percent	Cumulative Percent
0	3	8.8	8.8	8.8
one	5	14.7	14.7	23.5
two	3	8.8	8.8	32.4
three	8	23.5	23.5	55.9
four	7	20.6	20.6	76.5
five	1	2.9	2.9	79.4
six	2	5.9	5.9	85.3
seven	2	5.9	5.9	91.2
eight	2	5.9	5.9	97.1
ten	1	2.9	2.9	100.0
Total	34	100.0	100.0	

4.4.1 The most frequent patient concerns

The most frequent concerns are illustrated in Table 4.6 and are now explored. The significance of concerns to levels of psychological distress and coping response are explored later in Stage Three of Analysis (Section 4.7).

4.4.1.1 Not being able to do the things you used to

This concern was reported by 22 patients (65%) and was very much related to the interview theme of fatigue as well as loss of role, loss of self-esteem and loss of control. Many felt a lack of support on how to adjust to the consequences of their cancer of reduced energy levels and increased dependence on others. Comments such as 'I can't be quite the person I was' (P5) and 'Yes, very frustrating, I take it out on everyone' (P32) confirm the effect of fatigue on the patient including their loss, but they also clearly have implications for carers, dealing with the patients altered role in life. These factors were confirmed in the carer interviews in relation to managing fatigue.

4.4.1.2 Your current illness

Twenty-one patients (61%) expressed concern about their current illness, and in each situation the concern seemed to be related to an individual and unique information deficit. What this meant for each patient was different, and ranged from

why tests hadn't been done more frequently, to concerns about what was going to happen in the future? This is an important finding because not only does it confirm the findings in the interviews about a need for an individualised approach to communication and assessment of information, but this information deficit also seems to have implications for dealing with uncertainty- it restricted patients in adjustment to their diagnosis and activating a coping response. The issue of adjustment was apparent from the contrast in comments from those patients who did not consider it a concern, where acceptance was expressed, and also acknowledgement that the situation was unavoidable and that everything had been done.

4.4.1.3 How you are feeling physically

This concern was reported by 20 (58%) of patients, and confirmed the previous concern of 'not being able to do' and again, was very much related to the interview theme of fatigue and the consequences this had for patients and carers. Of interest, one patient expressed concern about nausea, and another indigestion, whilst most talked about the effects of fatigue. Likewise the concern 'the effects of any aspects of treatment on your body' in 13 (38%) patients was not associated with body image, but was much more associated with the effects of fatigue and acknowledgement and information need in relation to the side effects of stent placement or chemotherapy.

4.4.1.4 The future

Of the 15 patients (44%) who reported concern about the future, there is a marked comparison with the interview theme of sensitive communication and information. As discussed in Section 4.3.3 concern about their illness and the future are interrelated. Key issues that would help to resolve such concerns as 'how long have I got?' (P3), 'will I be in pain?' (P24), and 'how will I die?' (P27) are all dependent on healthcare professionals adopting a proactive approach to use of sensitive communication and

assessing and meeting individual information need, as illustrated in the interview themes.

4.4.1.5 Your relationship with your partner

This concern was reported by only 4 (12%) patients. However, 20 of the 30 not reporting it added to their responses 'no but...' in that they were concerned how their carer would cope, both with caring for them as they became more dependant as their illness progressed, and how they would cope after they had died. This was therefore clearly a 'concern' to them although because of the way the questionnaire was structured they scored it as not being so. Therefore, 24 (72%) patients had concerns about their carer/ relationship.

This response seems to have wider implications about assessing and acknowledging with patients their relationship with their partner / carer. The interview themes confirmed patient concerns about how their carer would cope, and how their carer would be supported, which may be beneficial to discuss with both the patient and the carer to promote adjustment to their situation. This seems to be a key aspect of psychosocial assessment.

4.4.1.6 Other concerns

Four concerns, (i) feeling upset or distressed, (ii) feeling different from other people, (iii) how you feel about yourself and (iv) any other concerns, which were noted by a smaller number of patients. For example, comments in relation to the concern 'how you feel about yourself' are very striking: 'I want to be the person everybody knows' (P3), and 'I'm the same person inside' (P25), illustrate what Yin (2003) refers to as 'deviant cases', which by their difference, emphasise their need in a case study approach of acknowledgement. They also confirm a need by healthcare professionals

to assess each individual's personal loss in order to promote adjustment when confronted by incurable cancer.

4.4.1.7 Concerns Checklist Summary

Overall, the Concerns Checklist and the interview themes were found to be congruent, giving reasonable support to the validity and reliability of the two sources of triangulated data. Furthermore, the findings support the potential use of the Concerns Checklist as a valuable means of assessing patients in a busy clinical setting.

The results of comparing and contrasting the Concerns Checklist, the data measures and with interview data will be reported in Stage Three of and offers some explanations about why patients felt concerned or not. For example, the concern 'your relationship with your partner' was marked as not a concern by those patients who adopted avoidance or carry on as normal strategies with their carer (e.g. P2, P8, P11, P16).

4.5 STAGE ONE ANALYSIS: Measures

4.5.1 The HADS in patients

Table 4.8 presents the number of patients falling into the three categories of the HADS. On first scrutiny, the indication of levels of anxiety and depression in patients appear to be low. The mean for both scales is within the 'well' category and only 7 and 1 patients respectively fall into the 'at risk' category (with scores of 11 and over) for anxiety and depression respectively.

Table 4.8 also presents HADS combined score, but of concern is that only 5 patients fall into the 'at risk' category of 19 and over. This combined scores therefore identify fewer patients who might be regarded as 'at risk'. For this reason the combined score data is presented for completeness but is not used in comparisons during analysis.

Table 4.8 Hospital Anxiety and Depression scale in patients (n=34)

	Well Score 0-7	Borderline Score 8-10	At risk Score 11 and >	Mean	Median	SD
Anxiety	17 (50%)	10 (29.4%)	7 (20.5%)	6.85	7.50	4.12
Depression	27 (79.4%)	6 (17.6%)	1 (3.1%)	5.29	5.50	3.34
Combined Scores	(0-18) 29(85%)		(19 and >) 5 (15%)	12.2	11.0	6.5

The low number of patients screened as 'at risk' for both anxiety and depression was not as anticipated from the literature where it is suggested that psychological distress in cancer is underestimated and may be as high as 50% with 27% experiencing depression in advanced cancer (Lloyd-Williams et al., 2004).

4.5.2 The HADS and GHQ12 in carers

Table 4.9 presents the results on the HADS and GHQ scales for the carers. Compared with the patients there are far more carers falling into the 'at risk' categories. As found for patients, the HADS scores for the carers show a high level of anxiety, but lower level of depression. As in the patient group, use of combined scores in carers was not useful as it identified that only 14 carers would be identified in the 'at risk' category. Again the combined score data is presented for completeness but is not used in comparisons during analysis.

Table 4.9 HADS and GHQ12 results in Carers (n=30)

HADS	Well Score 0-7	Borderline Score 8-10	At risk Score 11 and >	Mean	Median	SD
Anxiety	6 (20%)	4 (13.3%)	20 (66.6%)	11.37	12.0	4.860
Depression	22 (73%)	5 (16.6%)	3 (10%)	5.63	5.0	3.764
Combined scores	(0-18) 16 (53%)		(19 and >) 14 (47%)	17.0	17.0	7.8
GHQ12	Well (score 0-3)		At risk (4 and >)	Mean	Median	SD
Psychological distress	8 (27%)		22 (73%)	5.47	5.0	3.693

4.5.3 The HADS and GHQ12 in bereaved carers

Table 4.10 presents the HADS scores for the bereaved carers. There were still high levels of anxiety and depression. The same pattern of higher anxiety than depression was found. Combined scores showed that 14 bereaved carers (50%) would be identified in the 'at risk' category, which is comparable to the case score for anxiety. On the GHQ12 (cut off threshold 4 and above) the bereaved carers showed the same high level of psychological distress as carers.

Table 4.10 HADS and GHQ12 results in bereaved carers (n=28)

	Well Score 0-7	Borderline Score 8-10	Case Score 11 and >	Mean	Median	SD
Anxiety	10 (35%)	3 (11%)	15 (54%)	10.43	11.0	5.146
Depression	16 (57%)	5 (18%)	7 (25%)	7.64	6.50	4.548
Combined Scores	(0-18) 14 (50%)		(19 and >) 14 (50%)	18.1	18.5	8.5
GHQ12 results	Well (score 0-3)		Case score (4 and >)	Mean	Median	SD
Bereaved carers	8 (28%)		20 (72%)	6.61	7.50	3.8

The implications for these scores will be assessed in Stage Three of Analysis when they are compared and contrasted with the interview themes and the literature to examine emergent associations.

4.6 STAGE TWO OF ANALYSIS: Single units of analysis

Stage Two of analysis examined the preliminary relationship of the scores of the quantitative measures to the interview themes for each patient, carer and bereaved carer. The relationship of the single units of analysis were illustrated in case dynamic matrices. Dynamic refers to demands, requirements or strains (Miles and Huberman, 1994), which were the consequential processes found in the three major themes and how these appeared to relate to the outcomes of levels of psychological distress in each single unit of analysis. The matrices, (Tables 4.11, 4.12 and 4.13) illustrate the unique combination/pattern of each patient, carer and bereaved carer. If each of the 92 rows is looked at one at a time, clusters of associations emerge, with participants explaining how things happened as they did, and what appeared to be associated with what.

The extremes of a good experience and poor experience in gastrointestinal cancer were identified by comparing and contrasting, for example, BC 7 and BC23 in Table 4.13. Whilst each bereaved carer admitted to a very close relationship with the patient and use of togetherness as a coping response, it is possible to begin to identify how their separate perceived experiences appear to be associated with their levels of psychological distress. BC7 experienced poor coordination of care, had information needs, felt hopeless and helpless, with no support to his children, and had an 'at risk' score for anxiety. BC23, on the contrary, experienced good disclosure, experienced effective professional and family support to care for her husband, and had some acceptance and adjustment when bereaved with normal score for anxiety. The extremes of experience appeared to allow for stronger inference, where a major theme such as poor coordination of care and support to children was experienced.

However, most comparisons were much more subtle, and emphasised the uniqueness of each single unit of analysis. For example the experience of P3 and P5 in Table 4.11 appear to have some similarities on first examination. They both had normal scores for anxiety and depression, they both had 7 concerns each, both used carry on as normal as a coping response, and both had professional and family support. As such it might be expected that they would have similar themes from their interviews. However, on closer scrutiny P3 experienced good disclosure, was satisfied with support and care, and was planning ahead, whilst P5 experienced poor disclosure, was told her prognosis without requesting it, and had worries about how her husband with depression would cope. So whilst some comparison can be made, there is also a contrast in their experience and their needs, which emphasizes the uniqueness of each patient, carer and bereaved carer.

A further example of how very different experiences were associated with increased levels of psychological distress was found in comparing and contrasting the experience of C21 and C25 in Table 4.12. Both had case scores for anxiety, and both adopted togetherness with the patient, but whilst C21 was accepting of her husband's fate, that everything had been done, she had some concerns as to whether she would cope with caring for him as she wanted to do it on her own as she was a bit of a loner. In contrast C25 had experienced exclusion from disclosure, poor coordination of care, lack of support and information, had a young baby and was trying to support both her mother (the patient) and her two sisters.

Table 4.11 Case dynamics matrix showing single units of analysis of patient data

Patient	Anxiety 11-14 -risk	Depression 11-14 -risk	Number and type of Concerns	Individualised approach and living with uncertainty	What supports the ability to carry on?
P1	8	2	4: Current illness, feeling physically, will husband cope? Wants info alternative med	Good disclosure, fatigue, chemo, arranging funerals	Avoidance carry on as normal, talks to daughters & friends. Avoids Macmillan
P2	9	7	4: Feeling physically, not able to do, will husband cope? Info alternative meds, diet	Husbands depression. Fatigue. Diet, alternatives, Luckier than some	Avoidance with husband. Talks to both daughters. Spiritual. Nurses & Hospice,
P3	7	5	4: Current illness, feeling physically, not able to do, feel about self,	Good disclosure, satisfied with care. Planning ahead,	Carry on as normal, staying normal, talk about the future. Sister/Hospice support.
P4	3	1	3: Current illness, not being able to do, the future.	Uncertainty, the future, wife is angry, poor co-ordination of care	Carry on as normal in togetherness.
P5	8	3	4: Current illness, feeling physically, not able to do, how husband will cope?	Poor disclosure, prognosis alone. Uncertainty, fatigue, future, chemo	Carry on as normal in togetherness, but husband has depression, daughters, hospice
P6	0	7	No concerns.	Brother had same cancer, knows what to expect. Independent	Avoidance, One day at a time, Deferred help from sister & nurses
P7	7	2	1: Current illness.	Disclosure a shock. Feel no different than 12 months ago.	Carry on as normal, avoidance, we don't talk, CNS is support
P8	2	7	2:Feeling physically, Not able to do.	Fatigue, everything done, war veteran, every day a bonus	Avoidance. We don't talk. Mans man. Food conflict with wife.
P9	5	6	3: Current illness, how feeling physically, not able to do.	Fatigue, Wife died suddenly recently – grieving. Step daughters guilt	Inability to activate a coping response carer won't talk.
P10	12	5	3: Feeling physically, not being able to do, how mother will cope.	Fatigue, had extra 12 months. Wants to sort out Mums divorce & finances	Togetherness, we talk, CNS role, inspired, spiritual, hospice.
P11	4	0	4: Current illness, the future, effects of treatment,, how wife will cope	Uncertainty, sudden recurrence, Info needs, chemo, young wife and family	Avoidance, we don't talk, deferred access to support. Health visitor
P12	11	7	3: Current illness, not being able to do, the future.	Poor disclosure, told alone, restored confidence later, CNS role	Carry on as normal. We don't talk, Better off not knowing
P13	14	7	7: Current illness, how feeling physically, not able to do, effects of treatment, relationship with son, how feels about self – depressed, the future.	Stroke in past, diarrhoea, clawed hand. Used to be a dressmaker.	Inability to activate a coping response We don't talk, son has mental health problems. Going to hospice
P14	1	5	1: not being able to do.	Fatigue, talks to daughters and nurse	Avoidance, excludes husband,.
P15	9	6	2: how feeling physically, effects of treatment.	Independent, Uncertainty lives alone, daughter has advanced breast cancer.	Carry on as normal We talked,now carry on as normal. Lifeline. Good family
P16	2	2	No concerns	In control, house in order, good life,	Avoidance, with carer Linked to hospice
P17	9	9	3: How feeling physically, how mother will cope, future- how will I die?	In formation needs, wants to know more. Chemo. Independent	Inability to activate a coping response Brother died recently, will Mum cope?
P18	2	7	4: Current illness, not able to do, future-how will I die, how will wife cope	Suddenness of diagnosis. Comradery, of chemo. It's so unfair for wife	Avoidance, don't talk, carry on as normal, a day at a time.Deferred support
P19	13	6	3: Current illness, the future, feeling upset or distressed.	Dr-poor communication skills Uncertainty about diagnosis	Avoidance, did not tell wife. A day at a time. Carry on as normal, holidays.
P20	4	3	1: Not being able to do.	Everything has been done Illness taking over, fatigue.	Togetherness, spiritual strength, sister as carer ,GP, Macmillan, District Nurse
P21	4	4	1: Not able to do	Fatigue, realist, good life, private, good nephew	Togetherness, acceptance, want to do it our way, deferring support.
P22	4	1	2: Current illness, support for wife and children	Uncertainty. Wife is Doctor, might want to know more.Alternative meds	Avoidance, carry on as normal, alternative medicine, prayers.
P23	1	0	4: Current illness, feeling different, future-will wife cope?	Uncertainty, support to wife when I've gone?	Avoidance, I shove it out of my mind, do not discuss with wife.
P24	10	8	5: Current illness, effects of treatment, future-not able to do.	Uncertainty. How will it be? Pain, dying?	Avoidance, don't talk to wife, talks to sister, try to be normal. Holidays.
P25	8	8	10: Current illness, feels physically, effects of treatment, upset/distressed, future, not able, money, feel about self/different,	Told diagnosis alone Uncertainty. Needs info - chemo, work & finance	Togetherness with daughters, spiritual Glad husband not here to witness
P26	12	5	6: Current illness, not being able to do, work future, how feeling physically, money,	Told diagnosis alone, coordination of care , delayed surgery, infection	Avoidance, avoids talking with carer, has deferred Macmillan support
P27	9	4	8. Current illness, not being able to do, work future, effects of treatment, feeling different, feel about self, feel distressed	Uncertainty, pain, how will I die? Fatigue. Unfinished work	Avoidance, but his agenda, avoidance, denial, deferred support of Macmillana
P28	9	10	1: How wife& grandson will cope?	Poor disclosure & chemo, retrieved at cancer centre. Life experience.	Avoidance, carry on as normal, we don't talk, feels depressed. Hospice
P29	3	3	4: Current illness, how feeling physically, not being able to do, work (housework)	Uncertainty, fatigue. Good life, good family	Carry on as normal, acceptance, spiritual strength
P30	11	9	4: Not being able to do, future, how feeling physically, feel different to other people	Told prognosis-incorrect. Wife has had cancer. Fatigue having to give up	Togetherness, acceptance, spiritual, CNS support, Macmillan- gloom.
P31	6	1	6: Current illness, not able to do,alt med, feel physically effects of treatment, future,	Uncertainty, Wife in hospital with depression, the chemo mountain	Carry on as normal, children supportive, worse for relatives, Macmillan support.
P32	15	16	8: Current illness, not able to do, future, how feel about self, different, feeling physically, effects of treatment, work,	Protracted, delayed diagnosis, Fatigue, uncertainty Chemo	Togetherness in anger, depression. And conflict. No future
P33	9	6	7: Current illness, not able, future,son, money feel about self/ different others	Uncertainty. Fatigue. Lives alone.	Avoidance, carry on as normal
P34	2	8	No concerns	Asked prognosis. Independent, fatigue, children, giving up work,	Acceptance, life achievements, spiritual, has planned community/ hospice care

Table 4.12 Case dynamics matrix showing single units of analysis of carer data

Carers n=30	Anxiety	Depression	GHQ 12 (at risk >4)	Transcript themes Individualised approach and living with uncertainty	Transcript themes What supports the ability to carry on?
	11-14 at risk	11-14 at risk			
C1	2	0	1	Satisfied with cancer centre care. Target for pts anger Carries the brunt- info and support to daughters	Avoidance, he and wife don't talk, daughters -talk openly. Having counselling
C2	16	9	12	Very tearful, I prayed I would die first. Feels excluded. Suicide attempts in past, depression Feels wife blames him.	Avoidance, wife avoids talking, She was always the strong one Helpless, hopeless, Daughters support.
C3	12	7	7	Tearful, was told patients diagnosis before her at DGH. Getting house in order. Feels helpless. Own health ?cancer	Carry on as normal, but she's the strong one, we talk, Goals. Hospice & family
C4	19	9	10	Excluded from disclosure, Need to know info Coordination poor. Sudden death of mother, & father has Alzheimers.	Carry on as normal, Togetherness, Son had Ca in past. Strong spiritual strength, Children
C5	12	4	6	Tearful. Wife told diagnosis and prognosis on her own. He has limited access to info. History of depression	Carry on as normal, we talk, she's the strong one, feels helpless and hopeless. Scared.
C6	2	0	1	Patient independent, He lives alone. Won't discuss diagnosis with carer. It's so hard, frustrating.	Avoidance. Excluded by patient, we don't talk. It's always been like this. Has spoken to GP.
C7	16	7	11	Diagnosis like a death in the family. Responsibility for info to siblings Need to know number to ring , what to look for?	Carry on as normal. Don't talk, pt confides in CNS, takes the weight off shoulders. Brothers-no support
C8	7	5	8	Diagnosis- don't understand. Don't know who to ask? Not included in visits to hospital or hospice. Food a big issue.	Avoidance, we don't talk, not a lot in common, he's a man's man. Talk to sisters, a lot of time in kitchen
C9	14	12	4	Multiple grief. Recent death of estranged mother- feels guilty. Patient is step-father. What to expect, who will care?	Inability to activate a coping response. Husband is supportive. No contact with GP, hospital, nurses
C10	18	8	8	Confidence in medical team. Watching your son die. Dominant husband, children a worry. Finances, divorce..	Togetherness, acceptance. Trips abroad, sorting divorce. Spiritual. Knows who to contact, ANP role
C11	16	7	9	Needs information. I need to know for children & future. Husband has blocked access. Chemo. CNS & HV involved.	Avoidance- he won't talk. He has refused GP, DN's, Macmillan, hospice support. Spiritual.
C12	15	4	5	Poor disclosure, conflicting results. Poor coordination of care, Retrieved at cancer centre. Needs more info re: future	Carry on as normal- only talk if she wants to. Trusts CNP- but can't talk as wife is always there.
C13	14	14	8	Conflict, own health not good, RTA, depression. Angry with DHS, loss of self esteem. Mum has CVA & cancer.	Inability to activate a coping response. Feels helpless. Acceptance- who else will do it?
C14	15	7	11	Excluded from disclosure, unable to do much - emphysema info needs- why she didn't agree to chemotherapy?	Avoidance, different as chalk and cheese, she talks to friends, seems to be coping. Family support
C15	8	1	0	She didn't ask, so I didn't ask. Info needs re: future, should not need to ask, CNP role helpful. Lives at a distance.	Carry on as normal. She has lifeline, maintaining independence
C16	8	1	0	Father very secretive, has never involved him, frustrated, confronted him. Previous marriage counselling has helped	Father uses avoidance so contacted hospice for info & support. Wife supports
C17	11	8	8	Multiple loss, Watching your children die. 1 st son in RTA, now 2 nd son dying. Info needs- don't know who to ask?	Inability to activate a coping response. Support from husband. Distraction of work & dogs
C18	11	2	5	Poor disclosure, mothering instinct, Patient's agenda, but needs access to info. Depression comes on, fear of unknown	Avoidance, but strong relationship. Confident. Good GP, no to Macmillan
C19	12	4	5	Poor disclosure, will not discuss future, coded messages Uncertainty, poor hospital communication with family & GP	Avoidance, don't want any mores support whilst he won't talk. 4 daughters, 1 a nurse.
C20	5	6	4	Good disclosure, good support all along. Worried about patient's son- mental health problems.	Togetherness, acceptance, spiritual. Good support from hospital, CNP and community team.
C21	12	3	3	Philosophical, Everything's been done I just hope I can look after him till he dies. I know whom to contact. Had innings	Togetherness, loners, acceptance, upbringing, hard times. Goals, sense of achievement. Nephew good
C22	7	4	2	Poor disclosure, excluded, carer is Doctor. Needs someone to talk to. Pt. doesn't talk. Son has mental health problems.	Avoidance, alternative medicine, keep the hope going. Wants counselling- might help
C23	15	14	12	Own health- 2 nd CVA at patients disclosure. Angry, lost independence. No DHS support. Her needs 2 nd to pts needs.	Avoidance, don't talk. Worked as HCA, no help for her now. Loves company, he doesn't. Son in USA
C24	13	5	4	MRSA & isolation was depressing. Only just retired. What's going to happen next? Uncertainty, the future?	Avoidance, distraction, Good family and friends support. Good GP, Cancer support group
C25	12	2	5	Excluded at disclosure. Poor coordination, & support. Needs access to info. Trying to stay strong for mother and sisters	Togetherness, we talk. New baby. Hope, spiritual. Husband supports. Identifies ideal CNP role.
C26	12	7	5	Excluded at disclosure, no access to info. Poor coordination Own health. Need to know about the future, what to expect	Avoidance. He won't talk. Carry on as normal- holidays/goals. Good family, GP, District
C27	9	4	4	Misinterpreted aims of treatment. Carer is psychologist. Her needs feel 2 nd to patients. Wants to talk to other carers	Avoidance, we do talk. I want support, he doesn't CNP support. Good GP. Deferred Macmillan.
C28	19	9	6	Devastated at first. Macmillan a constant reminder. Cancer centre retrieved situation. Also caring for deaf grandson.	Avoidance, distraction. Life experience - death of deaf daughter Support from hospice /GP.
C29	1	5	0	My mind started to prepare. Not had a chance to talk, but the less I know the better. It will happen.	Carry on as normal- don't talk, acceptance. Strong relationship, support of family. Calm, peaceful life
C30	8	1	0	Own cancer in remission. Husband well managed- CNS. Well informed. Doom & gloom of Macmillan was worst.	Togetherness, talked, acceptance, CNP role. Friends are a bundle of love around them. Spiritual strength.

GP = General Practitioner
DN = District Nurse
HV = Health visitor
CNS= Clinical Nurse Specialist

RTA = Road Traffic Accident
CVA = Cerebro-vascular accident (Stroke)
DHS = Department of Health and Social Security

Table 4.13 Case dynamics matrix showing single units of analysis of bereaved carer data

Bereaved carer N=28	Anxiety 8-10 borderline 11-14 at risk	Depression 8-10 borderline 11-14 at risk	GHQ 12 (case >4)	Transcript themes Individualised approach and living with uncertainty	Transcript themes What supports the ability to carry on?
BC1	5	5	3	Poor disclosure, told alone. Uncertainty, difficulty planning to anticipate needs. Everything was done. Euthanasia.	Carry on as normal, Didn't want to talk. Surgeon & CNS role. District Nurses not in loop
BC2	17	10	8	Grief and conflict. Lost brother to HIV just before father diagnosed. Poor disclosure, unemployed, no support, angry.	Inability to activate a coping response Unresolved issues. Where was the support?
BC3	20	15	11	He had really good care, extra time. Grief. Wept throughout interview. How can I live without him?	Togetherness, we talked, just miss him so much. Sister is support. Family good. CNS role, Surgeon
BC4	13	4	9	Good disclosure. Exceptional care because of CNS, who also prevented collusion in family. Anticipated needs	Togetherness, strong friendship. CNS role. Delayed grief, miss him even more. Work suddenly difficult
BC5	11	10	3	Separated from husband. Came back to care. CNS role kept her informed, anticipated needs, she stage managed care.	Togetherness, we talked, resolved issues. CNS role helped. Satisfied, but concerned about daughter.
BC6	4	3	1	Shock, but don't ask how long as you'll change towards me -just wanted me. At my wits end, needed someone to talk to	Carry on as normal - I carried on working as he wanted. Wish I'd had DN's & Macmillan earlier
BC7	11	4	3	Poor co-ordination of care, no key person for information. Felt helpless, hopeless, powerless. No support to children.	Togetherness, we talked, own determination to care. Unresolved issues. CNS role identified.
BC8	5	6	2	Good disclosure. Wanted to care for her in his own way. Just the 2 of us. Exhausted, weight loss.	Togetherness, we talked. DN's & daughter helped him care Misses her, but satisfied, Recovering now
BC9	6	4	9	Poor disclosure, poor co-ordination. Frustrated by her own standards v. nurses lack of care, no understanding of fatigue	Togetherness, we talked, protective towards him. Unresolved anger CNS retrieved to some extent
BC10	16	16	12	Multiple grief. Son who had died with HIV. Soon after husband diagnosed and died in a short time. Limited support	Inability to activate a coping response, son makes himself known. Lives with daughter- conflict.
BC11	9	5	5	Good care because daughter was so involved with DN's. Took the burden off her. He wasn't ill for long.	Togetherness, acceptance Lot of work for daughter He died peacefully at home. Now, feel I'm not alone
BC12	10	5	7	Agrieved. Poor disclosure, demolished hope, co-ordination poor. Felt angry/ lost. Presumed to care for disabled mother.	Togetherness, but needed more proactive approach, needed information Holistic hospice helped
BC13	12	14	10	Protracted diagnosis, poor disclosure, told prognosis, Poor co-ordination, getting him home/ hospice. No information	Avoidance, Talked just once. Need for manager /co-ordinator. More emphasis on comfort.
BC14	6	5	4	Poor disclosure, poor coordination, left him hopeless. Poor hospice & community experience-lacked knowledge fatigue	Avoidance, denial. Couldn't talk. Taking Prozac. Has grieved already. Resolution- had to tell hospice
BC15	9	11	9	Agrieved delayed diagnosis, hopeless from start. Crying out for understanding- counselling should be CNS - knew case.	Togetherness, we talked. Miss him so much. CNS made things happen- got him home. Spiritual - art.
BC16	0	7	4	Poor disclosure, informed before patient. Young children. Worked 3 nights throughout. Burden. 6 siblings- little help	Togetherness, talked. Prior experience of collusion. Husband great help CNS latterly. Satisfied
BC17	17	7	7	Multiple exposure to death during previous months. Death of step-mother very quick. Own health - might be cancer	Inability to activate a coping response. Daughters wedding - as step mother deteriorating. Felt robbed.
BC18	14	9	10	Agrieved. Poor disclosure, false hope. Father depressed at loss of independence & uncontrolled symptoms. Euthanasia	Avoidance. Colluded with father not telling disabled mother Stressful. Minimal sibling support.
BC19	7	13	10	Agrieved. Poor disclosure, told prognosis. Coordination poor Family not there in time. Is it worth living? Own ill health	Togetherness, but hopeless, helpless. Future like a black hole. No such thing as moving on- unresolved
BC20	7	5	1	Had a good innings, fatigue a problem Also caring for mother. Tired, working, own family needs- on back burner	Togetherness with father, acceptance. Was able to be there for him. Community team. Now - satisfied.
BC21	13	8	11	Multiple loss, father soon after mother. Felt hopeless, his mental anguish. Poor death. Carried on working. Exhausted.	Inability to activate a coping response. Wish we had talked as he wanted. Now regrets, guilt. Can't get out of bed.
BC22	13	11	10	Agrieved, protracted diagnosis 'all in his mind'. Limited support for children. Finances-worry. Own needs secondary	Togetherness, we talked, carried on as normal for children. Having counselling need to be strong
BC23	3	1	0	Good disclosure, always included in decision making. Cared for him at home, hospice not for him. Good death.	Togetherness, acceptance in family. Talked, carried on as normal. Church, friends. Sad but healing tears
BC24	17	18	12	Agrieved, Protracted diagnosis, misinformed, poor disclosure, Died so quickly. Overwhelming grief	Avoidance, didn't talk. Son and family good, but feels suicidal, there's no future.
BC25	12	8	9	Insidious onset, traumatic diagnosis. Cancer centre helped. Frustration. A lot of things remained unsaid	Avoidance, even denial. He didn't want to talk. Concerned about husband, children are a support
BC26	4	0	1	Hopeless from the start, poor disclosure. Retrieved at cancer centre. CNS role. He died in my arms.	Avoidance. Dad wouldn't talk. Now acceptance. Stayed strong for wife, children & Mum. On Prozac
BC27	12	4	5	Good disclosure, professional care and attention. He had an extra 12 months. I carried on working, now retired.	Carried on as normal. Still feel him here with family Prozac stopped me crying
BC28	18	5	9	Coordination of care, At first got angry with her, cut the strings, pushed her away, didn't want her to be in pain	Togetherness, strong relationship. CNS, support and info. made it easier, Now stress of work, exhausted.

GP = General Practitioner
 DN = District Nurse
 HV = Health visitor
 CNS = Clinical Nurse Specialist

RTA = Road Traffic Accident
 CVA = Cerebro-vascular accident (Stroke)
 DHS = Department of Health and Social Security
 HIV =

4.7 STAGE THREE OF ANALYSIS: Comparing and contrasting single units of analysis

In the first part of cross case analysis, statistical measures were used to examine gender and age distribution, and the relationship of gender and age with measures of anxiety, depression and psychological distress. The statistical measures were undertaken after the analysis of the qualitative data to avoid contamination. Comparison was made of HADS scores and Concerns in patients, HADS scores in patients and carers, and HADS scores and GHQ 12 scores in carers and bereaved carers.

The second part of cross case analysis illustrate what themes and which coping responses were associated with high or low levels of psychological distress by comparing and contrasting both quantitative and qualitative data, and through statistical measures. The numbers of participants experiencing depression were below those required to obtain statistical significance, and it was therefore decided to omit depression from the second part of the analysis. However, where depression occurred it was commented on in its context.

In paired comparisons e.g. patients (n=34) with carers (n=30), the lower number i.e. 30 was adopted.

4.7.1 Statistical measures

4.7.1.1 Gender and age distribution

Table 4.14 illustrated the gender variables for patients, carers and bereaved carers whilst Table 4.15 illustrates the age variables for patients, carers and bereaved carers. For these analyses age of 54 years was selected because 50% were below and above this age

(mode: 55yrs, mean: 56 yrs). The sample size was too small to look at 20-30yrs, and 30-40yrs.

Table 4.14 Gender variables for patients, carers and bereaved carers

Gender	Patients	Carers	Bereaved carers
Male	21	9	6
Female	13	21	22

Table 4.15 Age variables for patients, carers and bereaved carers

Age	Patients	Carers	Bereaved carers
< 54yrs	8	11	17
> 54 yrs	26	19	11
Mean age	63yrs	58yrs	53yrs

4.7.1.1.1 Patient and carer gender

McNemar test $p = .108$. Table 4.16 demonstrated that there was no significant difference in the gender distribution in patients and carers.

Table 4.16 Patient and carer gender

		carer gender		Total		
		female	male			
Patient gender	female	4	8	12		
	male	17	1	18		
Total		21	9	30	McNemar Test	.108(a)

a Binomial distribution used.

4.7.1.1.2 Gender distribution in carers and bereaved carers

$X^2 = .555$, $p = .656$. Table 4.17 illustrated no significant difference in the gender distribution in carers and bereaved carers.

Table 4.17 Carer and bereaved carer gender

	Value	df	Asymp. Sig. (2 sided)
Pearson Chi-Square	.555 ^b	1	.456
Continuity Correction	.198	1	.656

4.7.1.1.3 Age distribution in patients and carers

McNemar test $p = .180$. There is no significant difference in the age distribution in patients and carers.

Table 4.18 Patient and carer age

		carer age < > 54		Total
		<54yrs	>54yrs	
pt age < > 54	<54yrs	4	2	6
	>54yrs	7	17	24
Total		11	19	30

McNemar Test .180(a)

4.7.1.1.4 Age distribution in carers and bereaved carers

$\chi^2 = 3.354$, $p = .117$. There is no significant difference in the age distribution in carers and bereaved carers.

Table 4.19 Carer and bereaved carer age

	Value	df	Asymp. Sig. (2 sided)
Pearson Chi-Square	3.354 ^b	1	.067
Continuity Correction	2.460	1	.117

4.7.1.2 Age, gender and anxiety in carers and bereaved carers

Two-way ANOVAs were used to investigate the relationship between anxiety and the variables of age, gender, and whether carers were bereaved.

Table 4.20 Age, gender and anxiety in carers and bereaved carers

	Carer				Bereaved carer			
	<54yrs		>54yrs		<54yrs		>54yrs	
	Mean anxiety	Std Deviation	Mean anxiety	Std Deviation	Mean anxiety	Std Deviation	Mean anxiety	Std Deviation
Male	11.33	3.06	10.17	6.85	8.60	3.91	5.00	3.31
Female	14.75	2.96	9.85	4.47	12.17	5.95	9.80	4.44

Table 4.21 shows that there were no significant main effects for gender ($F_{1,54} = 1.95$, $p = 0.16$) or for carer type ($F_{1,54} = 1.09$, $p = 0.30$), nor a significant interaction ($F_{1,54} = 0.40$, $p = 0.52$).

Table 4.21 Tests of Between-Subjects Effects
 Dependent Variable: total HADS anxiety score

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	66.243 ^a	3	22.081	.886	.454
Intercept	4612.931	1	4612.931	185.021	.000
Carer type	27.250	1	27.250	1.093	.300
Carer gender	48.697	1	48.697	1.953	.168
Carer type * Carer gender	10.067	1	10.067	.404	.528
Error	1346.326	54	24.932		
Total	8321.000	58			
Corrected Total	1412.569	57			

Table 4.22 shows that for age there was a trend for younger carers (and bereaved carers) to be more anxious than older carers ($F_{1,54} = 3.4$, $p = 0.071$), but no significant interaction with carer type ($F_{1,54} = 0.41$, $p=0.527$).

Table 4.22 Tests of Between-Subjects Effects
 Dependant variable: total HADS anxiety score

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	108.920 ^a	3	36.307	1.504	.224
Intercept	6517.337	1	6517.337	269.962	.000
Carer age	82.073	1	82.073	3.400	.071
Carer type	26.377	1	26.3777	1.093	.301
Carer age * Carer type	9.800	1	9.800	.406	.527
Error	1303.649	54	24.142		
Total	8321.000	58			
Corrected Total	1412.569	57			

4.7.1.3 Age, gender and depression in carers and bereaved carers

Table 4.23 illustrates how two-way ANOVAs were used to investigate the relationship between depression and the variables of age, gender, and whether carers were bereaved.

Table 4.23 Age, gender and depression in carers and bereaved carers

	Carer				Bereaved carer			
	<54yrs		>54yrs		<54yrs		>54yrs	
	Mean depression	Std Deviation						
Male	6.33	6.81	5.33	3.14	7.20	5.63	5.00	-
Female	6.75	3.37	4.92	3.77	8.00	4.40	7.40	4.90

Table 4.24 shows there was no significant main effect for age ($F_{1,54} = 0.13$, $p=0.72$), but a trend for bereaved carers (mean 7.6, SD 4.5) to be more depressed than carers (mean 5.6, SD 3.7) ($F_{1,54} = 3.0$, $p = 0.089$) (see Table 4.25).

Table 4.24 Tests of Between-Subjects Effects

Dependant variable: total HADS depression score

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	67.057 ^a	3	22.352	1.256	.299
Intercept	2458.778	1	2458.778	138.188	.000
Carer age	2.251	1	2.251	.127	.723
Carer type	53.516	1	53.516	3.008	.089
Carer age * Carer type	5.790	1	5.790	.325	.571
Error	960.823	54	17.793		
Total	3557.000	58			
Corrected Total	1027.879	57			

Table 4.25 Carer and bereaved carer, depression mean and Std Deviation

Carer type	Mean	N	Std. Deviation
Carer	5.63	30	3.764
Bereaved carer	7.64	28	4.548
Total	6.60	58	4.247

Table 4.26 Tests of Between-Subjects Effects
Dependent Variable: total HADS depression scores

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	159.836 ^a	3	53.279	3.314	.027
Intercept	1543.114	1	1543.114	95.995	.000
Carer type	4.919	1	4.919	.306	.582
Carer gender	56.779	1	56.779	3.532	.066
Carer type * Carer gender	59.160	1	59.160	3.680	.060
Error	868.043	54	16.075		
Total	3557.000	58			
Corrected Total	1027.879	57			

Table 4.26 shows there was no significant interaction between age and carer ($F_{1,54} = 0.33$, $p = 0.571$). However, there was a trend for female carers (mean 7.16, SD 4.364) to be more depressed than male carers (mean 5.00 SD 3.546), ($F_{1,54} = 3.5$, $p = 0.066$). See Table 4.27.

Table 4.27 Carer and bereaved carer gender, depression, mean and Std Deviation

Carer gender	Mean	N	Std. Deviation
Female	7.16	43	4.364
Male	5.00	15	3.546
Total	6.60	58	4.247

Table 4.28 shows a trend for an interaction between carer type and gender ($F_{1,54} = 3.68$, $p = 0.060$); female bereaved carers (mean 8.6) were most likely to be depressed compared to female carers (mean 5.6), male carers (mean 5.6) and male bereaved carers (mean 4.0).

Table 4.28 Carer and bereaved carer gender, age and depression

carer gender	Carer type	Mean	Std. Error	95% Confidence Interval	
				Lower Bound	Upper Bound
female	carer	5.619	.875	3.865	7.373
	bereaved	8.636	.855	6.923	10.350
male	carer	5.667	1.336	2.987	8.346
	bereaved	4.000	1.637	.718	7.282

4.7.1.4 Age, gender and psychological distress in carers and bereaved carers

Table 4.29 Age, gender and psychological distress (GHQ12) in carers and bereaved carers

	Carer				Bereaved carer			
	<54yrs		>54yrs		<54yrs		>54yrs	
	Mean GHQ 12	Std Deviation	Mean GHQ 12	Std Deviation	Mean GHQ 12	Std Deviation	Mean GHQ 12	Std Deviation
Male	4.67	4.16	6.00	4.98	5.20	4.49	1.00	-
Female	7.13	2.70	4.38	3.48	7.27	3.95	6.90	3.35

An ANOVA was also used to investigate the relationship between GHQ12 and carers and bereaved carers, age, and gender as illustrated in Table 4.29.

Table 4.30 shows no significant effects were found for age ($F_{1,54} = 0.852$ $p = 0.36$), carer or bereaved carer ($F_{1,54} = 0.852$ $p = 0.36$) or the interaction between age or carer type ($F_{1,54} = 0.000$, $p = 0.99$).

Table 4.30 Tests of Between-Subjects Effects
Dependent Variable: GHQ12 total score

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	31.097 ^a	3	10.366	.723	.542
Intercept	1977.867	1	1977.867	138.011	.000
Carer age	12.206	1	12.206	.852	.360
Carer type	12.206	1	12.206	.852	.360
Carer age * Carer type	3.666E-05	1	3.666E-05	.000	.999
Error	773.886	54	14.331		
Total	2905.000	58			
Corrected Total	804.983	57			

Table 4.31 shows there was no main effect for gender ($F_{1,54} = 1.75$, $p = 0.192$) or interaction between gender and carer ($F_{1,54} = 2.06$, $p = 0.157$).

Table 4.31 Tests of Between-Subjects Effects
Dependent Variable: GHQ 12 Total score

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	64.421 ^a	3	21.474	1.566	.208
Intercept	1355.838	1	1355.838	98.864	.000
Carer type	.559	1	.559	.041	.841
Carer gender	23.931	1	23.931	1.745	.192
Carer type * Carer gender	28.185	1	28.185	2.055	.157
Error	740.562	54	13.714		
Total	2905.000	58			
Corrected Total	804.983	57			

4.7.1.5 Comparison of HADS scores in patients and carers

Because of the relationship between patients and carers a Paired Sample t-test was used to investigate any differences in levels of anxiety and depression. Significantly higher anxiety scores ($t_{29} = 4.7$, $p = 0.001$) and total scores ($t_{29} = 3.3$, $p = 0.003$) were found for carers. However, there was no significant difference in depression scores ($t_{29} = 0.75$, $p = 0.459$), indicating that the main difference is anxiety. The higher incidence of anxiety in carers (mean 11.37) (as illustrated in Table 4.32) was also revealed in the numbers falling into the at risk category (score over 11); 20 of 30 carers (66.7%) compared to 7 of 34 patients (20.6%).

Table 4.32 HADS means and SD in patients and carers

	N	Mean	Std. Deviation
patient anxiety score	34	6.85	4.120
patient depression score	34	5.29	3.344
carer anxiety score	30	11.37	4.860
carer depression score	30	5.63	3.764
Valid N (listwise)	30		

4.7.1.6 Comparison of HADS and GHQ12 in carers and bereaved carers

Because the carers and bereaved carers were not related an Independent Sample t-test was selected. The Levene's test was used to examine equality of variances. No significant differences were found and so equal variances were assumed.

Table 4.33 shows how no significant differences were found between carers and bereaved carers on the HADS anxiety score ($t_{56} = 0.71$, $p = 0.478$). A trend was found for the depression scores ($t_{56} = 1.84$, $p = 0.071$), suggesting higher levels of depression in bereaved carers. No significant differences emerged for the GHQ 12 scores ($t_{56} = 1.16$, $p = 0.252$).

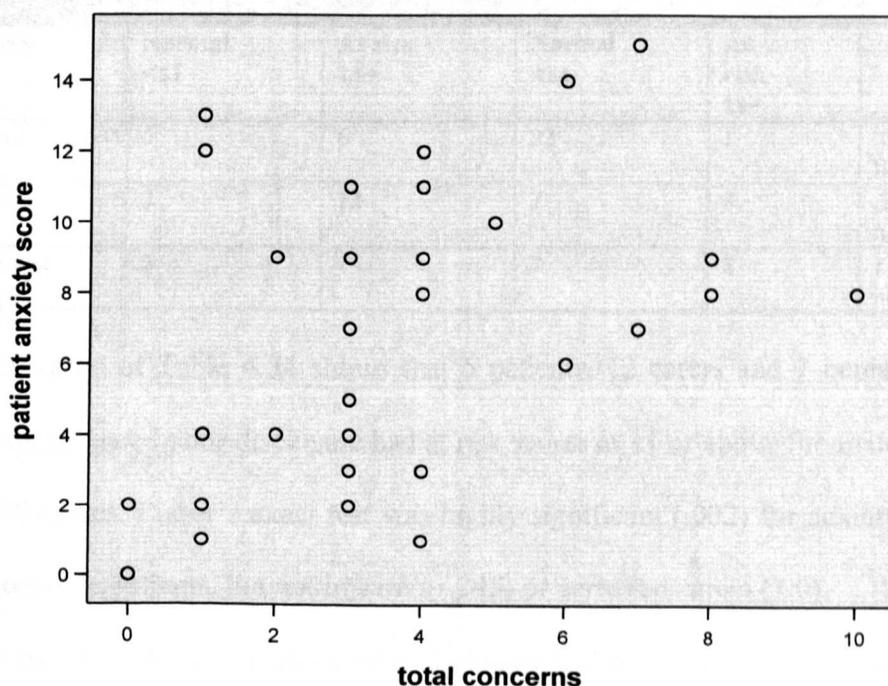
Table 4.33 HADS and GHQ12 means and SD in carers and bereaved carers

	N	Mean	Std. Deviation
carer anxiety score	30	11.3667	4.85999
carer depression score	30	5.6333	3.76447
carer ghq total	30	5.4667	3.69280
bereaved carer depression score	28	7.6429	4.54781
bcarer anx total	28	10.3793	5.05974
bereaved carer GHQ total score	28	6.6071	3.80389
Valid N (listwise)	28		

4.7.1.7 Comparison of HADS and the Concerns Checklist

Spearman's rho was used to look at the relationship between the variables of total number of concerns and patient anxiety and depression. Patient anxiety was significantly correlated with total concerns ($r = 0.419$ $p = .017$). Depression was not ($r = 0.017$, $p = 0.992$). This suggests that an increasing number of concerns as measured by the scale is associated with increased anxiety but not depression. Parle et al. (1996) suggests that 4 or more unresolved concerns can predict later onset of anxiety and depression in patients with cancer, which if applied to this study (as in Figure One), would identify 15 (44%) patients, at risk of anxiety and / or depression.

Fig 1 Scattergram of patient anxiety and total concerns



4.7.2 Comparing and contrasting measures and main themes

In this second part of cross case analysis statistical measures and descriptive measures are used to compare and contrast the patient, carer and bereaved carer main themes, levels of coping and measures of psychological distress.

4.7.2.1 Single units of analysis and poor disclosure

11 patients (32%), 15 carers (50%), and 13 bereaved carers (46%) experienced dissatisfaction with disclosure (Table 4.34).

Table 4.34 Patient, carer and bereaved carer experience of poor disclosure and levels of anxiety

Anxiety	Poor Disclosure-Yes		Poor Disclosure -No		Fisher's Exact
	Normal <11	At risk 11+	Normal <11	At risk 11+	
Patient	5	6	22	1	.002 highly sig
Carer	3	12	7	8	.245 not sig.
Bereaved carer	6	7	7	8	1.0 not sig.

Examination of Table 4.34 shows that 6 patients, 12 carers and 7 bereaved carers who experienced poor disclosure had at risk scores at 11 or above for anxiety in their HADS scores. Fisher's exact test was highly significant (.002) for anxiety and poor disclosure in patients, but not in carers (.245) or bereaved carers (1.0).

Eight patients who experienced poor disclosure had concerns related to 'their current illness, the future, how their carer would cope, and not being able to do the things they used to do'. This emphasised both poor disclosure and unmet information need. There were indications that patients did not seek information about these concerns for fear of being told more than they wanted to know.

4.7.2.1.1 Patient and carer disclosure

Kappa score $p = .02$. There was significant agreement between patients and their carers in the experience of poor disclosure (Table 4.35).

Table 4.35 Patient poor disclosure, carer poor disclosure

Count	carer poor disclosure		Total
	experienced poor disclosure	did not experience poor disclosure	
pt poor disclosure experienced poor disclosure	8	2	10
pt poor disclosure did not experience poor disclosure	7	13	20
Total	15	15	30

Measure of Agreement	Value	Asymp. Std. Error(a)	Approx. T(b)	Approx. Sig.
Kappa	.400	.158	2.324	.020

4.7.2.1.2 Carer and bereaved carer disclosure

There was also no significant difference in proportion between carers and bereaved carers in the experience of poor disclosure (Table 4.36). Therefore the data have a reasonable level of congruence.

Table 4.36 Carer and bereaved carer poor disclosure

	Poor disclosure		Corrected
	Yes	No	
Carer	15	15	$X^2 = 0.0$
bereaved carer	13	15	$p = 0.993$

Table 4.37 shows that 13 carers and 10 bereaved carers who experienced poor disclosure had at risk scores for psychological distress on the GHQ12. However, the Fisher's exact test did not reveal any significant differences for psychological distress and poor disclosure in carers (.215) or bereaved carers (.686).

Table 4.37 Carer and bereaved carer experience of poor disclosure and levels of psychological distress

GHQ12	Poor Disclosure-Yes		Poor Disclosure -No		Fishers Exact
	Normal <4	At risk 4+	Normal <4	At risk 4+	
Carer	2	13	6	9	.215 not sig.
Bereaved carer	3	10	5	10	.686 not sig.

4.7.2.2 Single units of analysis and information needs.

Table 4.38 shows that 15 patients (44%), 24 carers (80%), and 15 bereaved carers (54%) experienced unmet information needs.

Table 4.38 Patient, carer and bereaved carer information need and levels of anxiety

Anxiety	Information need -Yes		Information need -No		Fisher's Exact
	Normal <11	At risk 11+	Normal <11	At risk 11+	
Patient	13	2	14	5	.426 Not sig.
Carer	6	18	4	2	.141 not sig.
Bereaved carer	7	8	6	7	1.00 not sig.

Two patients, 18 carers and 8 bereaved carers who had unmet information needs had at risk scores at 11 or above for anxiety in their HADS scores, but Fishers exact test revealed no significant effects for anxiety and unmet information needs in patients

(.426), carers (.141), or bereaved carers (1.00). However, 20 patients had “concerns about their carer” in relation to how they would cope with the caring for them, which could be interpreted as an information need in patients.

4.7.2.2.1 Patient and carer information needs

Table 4.39 presents the comparison of patients and carers information need. Kappa score $p = 0.192$. No significant agreement was found between patients and their carers in the experience of information need. This suggests they have different sets of needs, with more carers having unmet needs.

Table 4.39 Patient and carer information need

	carer information need		Total	
	experienced information need	did not experience information need		
pt information need	11	1	12	
has information need does not have information need	13	5	18	
Total	24	6	30	
	Value	Asymp. Std. Error(a)	Approx. T(b)	Approx. Sig.
Measure of Agreement Kappa	.167	.119	1.304	.192

4.7.2.2.2 Carer and bereaved carer information needs

Table 4.40 compares information needs between carers and bereaved carers.

X^2 , $p = .062$. Carer and bereaved carer experience of information need differs, with bereaved carers having less need for information than carers. The trend indicates higher needs in carers, which might be expected as ‘caring information needs’ have reduced with the bereavement.

Table 4.40 Carer and bereaved carer information need

	Information need		Corrected
	Yes	No	
carer	24	6	$X^2 = 3.471$
bereaved carer	15	13	$p = .062$

Inspection of Table 4.41 shows that 22 carers and 20 bereaved carers had at risk scores for psychological distress on the GHQ12. Fisher's exact was significant for psychological distress and information in carers (.029), but not bereaved carers (.410), indicating that carers with at risk score of 4+, had a higher need for information than those with normal score.

Table 4.41 Carer and bereaved carer information need and levels of psychological distress

GHQ12	Information need -Yes		Information need -No		Fisher's Exact
	Normal <4	At risk 4+	Normal <4	At risk 4+	
Carer	4	20	4	2	.029 significant
Bereaved carer	3	12	5	8	.410 not sig.

4.7.2.3 Single units of analysis and fatigue

Table 4.42 presents the data related to fatigue. 25 (74%) patients, 6 (20%) carers and 8 (29%) bereaved carers experienced fatigue. Examination of Table 4.42 reveals that 5 patients, 6 carers and 5 bereaved carers who experienced fatigue had at risk score for anxiety. Fisher's exact was not significant for fatigue and anxiety in patients (1.0), but there was a trend for fatigue and anxiety in carers (.074). No significant effects were

found for for anxiety and fatigue in bereaved carers (.686). Whilst one might expect carers to experience more fatigue, 80% carers denied experiencing fatigue.

Table 4.42 Patient, carer and bereaved carer experience of fatigue and levels of anxiety

Anxiety	Fatigue -Yes		Fatigue -No		Fisher's Exact
	Normal <11	At risk 11+	Normal <11	At risk 11+	
Patient	20	5	7	2	1.0 not sig.
Carer	0	6	10	14	.074 almost sig
Bereaved carer	3	5	10	10	.686 not sig.

4.7.2.3.1 Patient and carer fatigue.

Kappa score (0.842) indicates that there is no significant agreement between patients and their carers in their experience of fatigue (Table 4.43).

Table 4.43 Patient fatigue and carer fatigue

		carer fatigue		Total
		carer experienced fatigue	carer did not experience fatigue	
pt fatigue	experienced fatigue	4	17	21
	did not experience fatigue	2	7	9
Total		6	24	30

		Value	Asymp. Std. Error(a)	Approx. T(b)	Approx. Sig.
Measure of Agreement	Kappa	-.022	.111	-.199	.842

4.7.2.3.2 Carer and bereaved carer fatigue

Carers may feel that denying their fatigue at this time is a positive way of coping. However, as shown in Table 4.44 there was no significant difference ($X^2 = 0.649$) between carer and bereaved carer in the proportion experiencing fatigue.

Table 4.44 Carer and bereaved carer fatigue

	Fatigue		Corrected
	Yes	No	
carer	6	24	$X^2 = .207$
bereaved carer	8	20	$p = .649$

Thus, fatigue may not be such an issue in carers. If fatigue is a hidden issue it might be revealed in looking at the relationship with psychological distress.

Table 4.45 Carer and bereaved carer fatigue and levels of psychological distress

GHQ12	Fatigue -Yes		Fatigue -No		Fisher's Exact
	Normal <4	At risk 4+	Normal <4	At risk 4+	
Carer	0	6	8	16	.155 not sig.
Bereaved Carer	3	5	5	15	.651 not sig.

However, Fisher's exact was not significant for psychological distress and fatigue in carers (.155) or bereaved carers (.651), which indicates there was no difference in proportion between the two groups. Thus taken together the fatigue issue may not seem to be a major problem to carers nor one that causes distress to the majority.

4.7.2.4 Single units of analysis and poor coordination of care

Table 4.46 shows that 9 patients, 12 carers and 12 bereaved carers expressed concern about poor coordination of care.

Four patients, 9 carers and 4 bereaved carers who experienced poor coordination of care had at risk scores for anxiety. Fisher's exact showed a trend for relationship between patient anxiety and poor coordination of care, but was not significant for carers (.694) or bereaved carers (.125). Both patients and carers appear to have the same views on coordination of care, but it appears to be related to more anxiety in the patients.

Table 4.46 Patient, carer and bereaved carer experience of coordination of care and levels of anxiety

Anxiety	Poor Coordination - Yes		Poor Coordination -No		Fisher's Exact
	Normal <11	At risk 11+	Normal <11	At risk 11+	
Patient	5	4	22	3	0.061 trend
Carer	3	9	7	11	.694 not sig.
Bereaved carer	8	4	5	11	.125 not sig.

4.7.2.4.1 Patient and carer and poor coordination of care

Table 4.47 shows Kappa score ($p = 0.005$) which indicates that there is a strong agreement between patients and their carers in their experience of poor coordination of care. As with the data on disclosure with patients and carers it shows strong congruence with patient, carer and recall and views of coordination of care. This means that it is probably reasonable in this instance only (i.e. coordination of care) to use surrogates for patient experience.

Table 4.47 Patient and carer poor coordination of care

		carer poor coordination of care		Total	
		experienced poor coordination of care	did not experience poor coordination of care		
pt poor coordination of care	experienced poor coordination of care	6	1	7	
	did not experience poor coordination of care	6	17	23	
Total		12	18	30	
		Value	Asymp. Std. Error(a)	Approx. T(b)	Approx. Sig.
Measure of Agreement	Kappa	.478	.159	2.820	.005

4.7.2.4.2 Carer and bereaved carer and poor coordination of care

$X^2 p = 1.0$. There is no difference between carers and bereaved carers in the proportion experiencing poor coordination of care (Table 4.48).

Table 4.48 Carer and bereaved carer coordination of care

	Poor coordination of care disclosure		Corrected
	Yes	No	
carer	12	18	$X^2 = 0.0$
bereaved carer	12	16	$p = 1.0$

Table 4.49 shows that 9 carers and 8 bereaved carers who experienced poor coordination of care had at risk scores for psychological distress. Fisher's exact was not significant for carers (1.00), or for bereaved carer (.691) psychological distress and poor coordination of care.

Table 4.49 Carer and bereaved carer experience of coordination of care and levels of psychological distress

GHQ12	Poor Coordination -Yes		Poor Coordination -No		Fishers Exact
	Normal <4	At risk 4+	Normal <4	At risk 4+	
Carer	3	9	5	13	1.00 not sig.
Bereaved carer	4	8	4	12	.691 not sig.

4.7.3 Comparing and contrasting single units of analysis and coping strategies

This stage of analysis explores adaptation to their cancer experience, and development of coping strategies by each patient, carer and bereaved carer. Through this technique it was possible to identify what appeared to contribute to their individual choice of strategy. The emphasis was not based on cause and effect, but from conclusions from the data, both how they tied into established theory in the literature, and in particular how resonant they were of Lazarus and Folkman coping theory. Both positive and negative appraisal of their situation with emotion focused responses and resources were illustrated.

Cross reference was also made to the two other main themes of an individualised approach with sensitive communication and uncertainty, and their sub themes (e.g. poor disclosure, information, fatigue, children, coordination of care) to demonstrate how these were associated with the coping strategy adopted.

The three tables below demonstrate the levels of anxiety and depression in patients and carers, and the levels of anxiety, depression and psychological distress in carers and bereaved carers in relation to their coping response.

Table 4.50 Patient, carer and bereaved carer levels of anxiety and coping response

		Togetherness	Carry on as normal	Avoidance	Inability to activate a coping response
Patient anxiety	<11	3	7	15	2
	11>	3	1	2	1
Carer anxiety	<11	2	2	6	0
	11>	3	5	9	3
Bereaved carer anxiety	<11	8	2	2	0
	11>	7	1	4	4

Table 4.51 Patient, carer and bereaved carer levels of depression and coping response

		Togetherness	Carry on as normal	Avoidance	Inability to activate a coping response
Patient depression	<11	5	8	17	3
	11>	1	0	0	0
Carer depression	<11	5	7	14	1
	11>	0	0	1	2
Bereaved carer depression	<11	11	3	4	2
	11>	4	0	2	2

Table 4.52 Carer and bereaved carer levels of psychological distress (GHQ 12) and coping response

		Togetherness	Carry on as normal	Avoidance	Inability to activate a coping response
Carer GHQ12	<4	3	2	4	0
	4>	2	5	11	3
Bereaved carer GHQ12	<4	7	2	2	0
	4>	8	1	4	4

Each coping strategy will now be discussed. For each strategy a case ordered effects matrix (Miles and Huberman, 1994) was constructed to illustrate the individuality of the participants. Examination of the matrices also shows the congruence between the HADS and the GHQ12. Given the methodological approach of the study, it was not felt fruitful to statistically correlate the two scales in terms of frequencies above and below threshold. However, inspection does indicate quite high agreement.

4.7.3.1 Togetherness

Despite adopting this apparent positive coping response of togetherness and talking to one another and trying to work together, at risk scores for anxiety, depression and psychological distress were also evident in this group of participants. Examination of Table 4.50, 4.51, and 4.52 show that frequency of above and below threshold were fairly equally distributed for anxiety and for the GHQ12 scores. However, in all three groups far more participants who adopted togetherness had below threshold depression scores – 21 (<11) v. 5(>11). This supports the view in the literature that togetherness (of emotional and practical support) can reduce risk of depression. At risk scores for depression occurred in one patient (P32), and 4 bereaved carers (BC3, BC15, BC19, BC22). These 4 bereaved carers were young females and under 55 years of age.

- At risk scores for anxiety occurred in 3 patients (P10, P30, P32), 3 carers (C10, C21, C25) and 7 bereaved carers (BC3, BC4, BC5, BC7, BC12, BC22, BC28). 2 carers and 4 bereaved carers were female and under 55 years of age.
- At risk scores for psychological distress occurred in 2 carers (C10, C25), both of whom were female and under 55 years of age, and both of whom had children and were trying to cope with other social dependants and responsibilities.
- At risk scores for psychological distress occurred in 8 bereaved carers (BC3, BC4, BC9, BC12, BC15, BC19, BC22, BC28), 5 of whom were female and under 55 years of age.

At risk scores appeared to occur when participants found that despite adopting what they thought was a positive problem focused approach they had negative appraisal of a situation and did not have access to resources to resolve or cope with it. Negative appraisal of resources was predominantly associated with the two previous major themes

of sensitive communication and uncertainty as identified through the interviews. Examination of Table 4.53 indicates that delay in diagnosis, poor disclosure and poor coordination of care also appeared to have repercussions and was associated with case scores of psychological distress in carers and the bereaved. The findings demonstrated that despite adopting togetherness as a strategy, carers and bereaved carers under 55 years of age, and female carers who continued to have multiple demands on their coping resources had at risk scores for psychological distress.

Table 4.53 Case-ordered effects matrix showing comparing and contrasting of single units of analysis (at risk scores, patient concerns, positive and negative appraisal) in patients, carers and bereaved carers who adopt a coping strategy of togetherness

Participant	Anxiety At risk >11	Depression At risk >11	GHQ12 At risk >4	Number and type of Patient Concerns	Positive appraisal, emotion focused, problem focused response/resources	Negative appraisal, emotion focused, problem focused response/resources
P10	12	-	-	3: Feeling physically, not being able to do, how mother will cope?	Togetherness. Mutuality . Surgeon gave him extra time, Good support Consultant /CNS	Trying to sort out mothers divorce & finances.
C10	18	-	8		Togetherness, spiritual strength	Watching son die. Divorce. Finances. Concern about 17yr old daughter who won't accept support, feels a bit helpless.
P20	-	-	-	1: Not being able to do	Togetherness- acceptance, has had a good life spiritual strength. Good support Consultant, CNS	Concerned about son with mental health problems
C20	-	-	-		Togetherness- mutuality. Good support. CNS	
P21	-	-	-	1: How wife will cope?	Togetherness, mutuality good life, had my innings	Concerned about wife
C21	12	-	-		Togetherness- wants to carer for him in her way.” Just hope I can”.	Deferred support
P25	-	-	-	10: Current illness, how feeling physically, effects of treatment, not able to do, upset /distressed, money, feels about self support how daughter will cope, feels different	Togetherness	Needs more information, not sure about DHS & work. Who to ask?
C25	12	-	5		Togetherness	Carer excluded from diagnosis. Requires information, Has young family & working. Also sibling pressure for information and support
P30	11	-	-	3: Not being able to do, future, how feeling physically?	Togetherness- mutuality.	Poor disclosure. Patient told prognosis when not requested
C30	-	-	-		Togetherness, mutuality, has had stomach cancer herself. Spiritual strength	

P32	15 -	16 -		8: Current illness, not able to do, how feeling physically, effects of treatment, how feel about self, feel different, work, the future	Togetherness	Protracted diagnosis - told all in her mind. Hopeless. Helpless. Both angry.
BC3	20	15	11		Togetherness, we talked. He had really good care, extra time. CNS role, Surgeon	Grief. Wept throughout interview. How can I live without him? Miss him so much. Sister is support. Family good.
BC4	13	-	9		Togetherness, best friend. Hospice made a difference	Father. H/O depression. Now responsible for disabled mother. Work- stressful High BP.
BC5	11	-	-		Togetherness. Mutuality. CNP made a difference	H/O depression, concerned for teenage daughter
BC7	11	-	-		Togetherness, mutuality	Poor disclosure, poor co-ordination, poor death. Needed info and support for children
BC8	-	-	-		Togetherness, we talked. Care for her in my own way. Daughter & DN's helped.	
BC9	-	-	9		Togetherness, mutuality	Poor disclosure, poor co-ordination of care. CNP retrieved
BC11	-	-	-		Togetherness, good care Daughter & DN's made a difference. Died peacefully.	
BC12	10	-	7		Togetherness, mutuality. Hospice good	Poor disclosure and co-ordination. Now responsible for disabled mother.
BC15	-	11	9		Togetherness, mutuality	Protracted diagnosis. Hopeless from start. CNP retrieved.
BC16	-	-	-		Togetherness, talked, prior experience of collusion. Husband good support	Siblings no support
BC19	-	13	10		Togetherness, mutuality,	Poor disclosure, told prognosis, Hopeless. H/O depression. Unresolved issues
BC20	-	-	-		Togetherness, mutuality, acceptance, was able to be there. Satisfied.	
BC22	13	11	10		Togetherness, mutuality	Protracted diagnosis, told in his mind. 4Children, own needs wait. Finances
BC23	-	-	-		Togetherness, mutuality, acceptance, included, died at home. DN's. Spiritual, friends	
BC28	18	-	9		Togetherness	History of depression. Work stressful. Has other family responsibilities, sibling rivalry.

4.7.3.2 Carry on as normal

Examination of Tables 4.50, 4.51 and 4.52 shows that participants adopting 'carry on as normal' strategy resulted in normal scores for anxiety and depression on the HADS in 7 patients (P3, P4, P5, P7, P15, P29, P31), in 2 carers (C15, C29) and in 2 bereaved carers (BC1, BC6). On the GHQ12, normal scores were found in 2 carers (C15, C29), and 2 (7%) bereaved carers (BC1, BC6).

Examination of Table 4.50 shows that most patients adopting a 'Carry on as normal

strategy' had below threshold anxiety scores – 7 v.1 whereas it was the reverse for carers, but the numbers are small. For depression (Table 4.51) the picture seems clearer. All participants who had used 'carry on as normal' had below threshold scores, suggesting this strategy, like togetherness might help to reduce the risk of depression. Table 4.52 confirms the depression scores from the HADS in that more carers who adopted 'carry on as normal' strategy had above threshold distress scores.

Participants with at risk scores for anxiety, depression and psychological distress generally had negative appraisal of resources associated with the two previous major themes of sensitive communication and uncertainty. Patients had concerns about their current illness, not being able to do, the future, how their carer would cope, and had experienced poor disclosure. In carers negative appraisal and case score for anxiety was associated with 'the patient being the strong one in the relationship', exclusion from disclosure, a history of depression and a need for information.

Examination of Table 4.54 shows that responses from the at risk GHQ12 carers (C3, C4, C5, C7, C12) and the bereaved carer (BC27) demonstrate that in actual fact the situation was not normal, and that trying to maintain normality without appropriate resources actually increased their negative appraisal of the situation, and became an apparent source of stress.

Table 4.54 Case-ordered effects matrix showing comparing and contrasting of single units of analysis (at risk scores, concerns coping response and coping resources) in patient carers and bereaved carers adopting carry on as normal

Participant	Anxiety At risk >11	Depression At risk >11	GHQ12 At risk >4	Number and type of Patient Concerns	Positive appraisal, emotion focused, problem focused response/resources	Negative appraisal, emotion focused, problem focused response/resources
P3	-	-		4: Current illness, feeling physically, not able to do, feel about self	Togetherness, staying normal, talk about you in the future	
C3	12	7	7		Family, hospice	She's the strong one, own health, investigations for cancer
P4	-	-	-	3: Current illness, not being able to do, the future	Togetherness, wants to carry on as normal.	Poor co-ordination of care
C4	19	-	10		Togetherness, protective, have talked but now carry on as normal,	Excluded from disclosure, needs info. Sudden loss of mother, sorting out care for father with Alzheimers
P5	-	-	-	4: Current illness, feeling physically, not able to do, how husband will cope	Togetherness, acceptance	Disclosure when alone and told prognosis
C5	12		6			Togetherness, but excluded from disclosure. Needs information. History of depression. Pt is the strong one
P7	-	-	-	1: Current illness,	Togetherness, we talked, now carry on as normal	
C7	16	-	11			History of depression. Needs more information- who to ask? Sibling stress
P12	12	-	-	3: Current illness, not being able to do, the future.	We talked, carry on as normal, distraction. CNP role	Disclosure when alone, told prognosis,
C12	15	-	5			Excluded from disclosure, pt is the strong one, poor co-ordination, needs more access to information
P15	-	-		2:How feeling physically, effects of treatment.	Togetherness, we talked, now carry on as normal, wants to maintain independence.	Daughter is dying of breast cancer
C15	-	-	-		Togetherness, carry on as normal.	Info needs, shouldn't need to ask
P29	-	-	-	3: Current illness, how feeling physically, not being able to do	Togetherness, acceptance, carry on as normal. Spiritual strength	
C29	-	-	-		Togetherness, acceptance, carry on as normal. Calm, peaceful life	
P31 No Carer	-	-	-	6: Current illness, not able to do, alt med, feel physically effects of treatment, future,	Togetherness, we talk, but wife in hospital with depression. It's worse for family. Memory of collusion as a child with father dying with same cancer.	
BC1	-	-	-	-	Togetherness, we talked, carried on as normal.	Lived at a distance. Helpless at times. Thought of euthanasia
BC6	-	-	-	-	Togetherness, as normal, just wanted me to care for him.	Exhaustion. Went to work too.
BC27	12	-	5	-	Togetherness, good professional care. Extra time.	History of depression. On Prozac.

4.7.3.3 Avoidance

Table 4.55 shows that 15 of 17 patients who recalled using avoidance had normal HADS scores for anxiety and none were above threshold for depression. Whilst this might at first support its use as a coping response, 14 of these patients (P1,P2,P11,P14,P18,P19,P22,P23,P24,P26,P27,P28,P33,P34) expressed a variety of concerns including their current illness, fatigue and had concerns about how their carer would cope as their disease progressed, and they became more dependant (Table 4.55). These concerns were not, however, reflected in their HADS scores, which raises issues about using such scales alone with these patients

The number of bereaved carers using avoidance (6) is too small to interpret the differences, however 14 carers who used 'avoidance' had below threshold scores for depression- similar to patients. In contrast more (9 v. 6) had anxiety.

More carers who used 'avoidance' also had above threshold risk scores on the GHQ12 (11 v. 4). Thus, avoidance strategies appear to increase distress and anxiety in carers, although its use may mediate against depressive symptoms.

Examination of Table 4.55 indicates some of the associated factors

- 9 carers at risk scores for anxiety on the HADS also had above threshold scores on the GHQ12, again indicating validity between the scales. All nine plus the two at risk on the GHQ12 alone had been excluded from disclosure interview and had information needs. In contrast one carer, (C22) who had negative appraisal having been excluded from disclosure and who had information needs had no above threshold scores in HADS and GHQ12.
- 4 of the 6 bereaved carers who had at risk scores for anxiety on the HADS, and psychological distress on the GHQ12 had been excluded at disclosure and had

information needs. They also had post bereavement fatigue.

- 2 of the 4 bereaved carers had at risk scores for depression on the HADS, both admitted to unresolved issues, and one expressed feelings of suicide at times.
- The final 2 of the 6 bereaved carers had normal scores, but admitted to depression post bereavement. Both had commenced anti-depressants, and both had taken positive, problem focused action by addressing their concerns about their experiences at a meeting with healthcare professionals who had been involved.

This seems to have resulted in some resolution for them.

Table 4.55 Case-ordered effects matrix showing comparing and contrasting of single units of analysis (at risk scores, concerns coping response and coping resources) in patient carers and bereaved carers adopting an avoidance strategy

Participant	Anxiety At risk >11	Depression At risk >11	GHQ12 At risk >4	Number and type of Patient Concerns	Positive appraisal, emotion focused, problem focused response/resources	Negative appraisal emotion focused, problem focused response/resources
P1	-	-	-	4: Current illness, feeling physically, how will husband cope? Wants info on alternative medicine	Avoidance, distraction Pt avoids talking, to carer but talks to friends. Distraction. Deferred support	
C1	-	-	-		Carer r recognised his info needs - now having counseling.CNP access	
P2	-	-	-	4: Feeling physically, not able to do, will husband cope? Info alternative meds, diet	Avoidance talks to daughters, not carer, has DN's and hospice support	
C2	16		12			Excluded. History of depression. Hopeless and helpless
P6	-	-	-	No concerns.	Independent, one day at a time, deferred support	
C6					Long standing issues of patient independence. Excluded. Has accepted it Speaks to GP	
P8	-	-	-	2: Current illness. Not able to do.	Acceptance, but avoidance. Fatigue. Pt talks to friends not carer	
C8			8			Excluded. Would like more information, but we've always been different
P11	-	-	-	4: Current illness, the future, effects of treatment, how wife will cope?	Avoidance. Will be told when I have to know. Deferred access to support	
C11	16	-	9		Young family. Needs information for children and to plan future.	Blocked support. Pt will not talk to carer, avoidance
P14	-	-	-	1: Not being able to do.	Avoidance, talks to daughters and chemo nurse. Will talk when I have to.	
C14	15	-	11			Excluded from disclosure. Has info needs. Different as chalk

						and cheese.
P16	-	-	-	No concerns	Acceptance, avoidance independence, avoids talking to carer. Has arranged hospice.	
C16	-	-	-		Accepted fathers independence./ avoidance P revious counselling helped. Access to info at hospice	
P18	-	-	-	4: Current illness, not able to do, future-how will I die, how will wife cope?	Togetherness, avoidance /carry on as normal	Poor disclosure, told prognosis, deferred support. Has info needs
C18	11	-	5			Togetherness, avoidance. His agenda, no access to info. Talk /support only if he wants, Sacrifice own needs
P19	13	-	-	3: Current illness, the future, not able to do.		Avoidance. Diagnosis withheld from wife. Poor coordination hospital/GP
C19	12	-	5			Excluded at disclosure, needs info. Won't persue whilst patient defers support
P22	-	-	-	2: Current illness, support for wife and children	Togetherness, but don't really talk, avoidance, carry on as normal.	
C22	-	-	-			Togetherness, but excluded at disclosure, has info needs, wants counselling
P23				4: Current illness, feeling different, future, how will wife cope?		Avoidance I shove it out of my mind. Talks to nurses not carer
C23	15	14	12			CVA, lost independence, helpless, frustration, own needs secondary
P24	-	-	-	5: Current illness, effects of treatment, future- not able to do, feeling upset/ distressed	Avoidance..Try to be normal.Talks to sister, not carer. Goes to support group	
C24	13	-	4		Good GP	Avoidance, distraction, Info needs.. I love company, he doesn't
P26	12	-	-	6: Current illness, not able to do, work, future, how feeling physically, money		Avoidance, told diagnosis alone, poor co-ordination, MRSA. Defer support
C26	12		5			Excluded at disclosure, info needs, who to contact, what to anticipate.
P27	-	-	-	8. Current illness, not being able to do, future, effects of treatment, feeling different, feel about self, feel distressed, feeling physically	Togetherness, but avoidance	I'm not easy to live with, Deferred support
C27	-	-	4			I want support / info, he doesn't. Own needs secondary to pt. CNP support
P28	-	-	-	1: how wife & grandson will cope?	Togetherness, avoidance. Poor disclosure. Hospice support	
C28	19	-	6		Togetherness, accept avoidance	Poor disclosure, Patient was very depressed at first. Caring for deaf grandson too
P33 Carer unavailable	-	-	-	7: Current illness, not able to do, future, , feeling physically, feeling different from others, how son will cope?	Avoidance	
P34 C34 unavialable	-	-	-	No concerns	Acceptance, life achievements, spiritual strength. Divorced .Planned community care /hospice without bothering son at university. Also established care for daughter with anorexia.	

BC13	12	14	10			Pt had protracted diagnosis, poor disclosure, told prognosis, poor co-ordination .Unresolved.
BC14	-	-	-		Has resolved issues with hospice. Taking Prozac	Pt had poor disclosure, poor co-ordination, left him hopeless
BC18	14	-	10			Pt had poor disclosure. Colluded with father in not talking to disabled mother. Pain. Thought about euthanasia
BC24	17	18	12			Pt had protracted diagnosis, poor disclosure, died so quickly. H/O depression Son good, but feels suicidal at times
BC25	12	-	9			Pt had insidious onset, protracted diagnosis, poor disclosure. He didn't want to talk.
BC26	-	-	-		Retrieved at cancer centre. Taking Prozac.	Pt had repeated mistaken diagnosis, poor disclosure.

4.7.3.4 Inability to activate a coping response

Table 4.50 and 4.51 indicates that for patients, inability to activate a coping response was not highly associated with at risk for anxiety and depression, however there is a suggestion that the converse is true for carers and bereaved carers in terms of anxiety. Furthermore, Table 4.52 shows that three carers (C9, C13,C17) and four bereaved carers (BC2, BC10, BC17, BC21) who were unable to activate a coping response had at risk scores for psychological distress.

Examination of Table 4.56 shows that of the 10 participants who rated as unable to activate a coping response, all but 2 (P9, P17) had above threshold scores on all three scales. A number of issues seemed to contribute to an inability to activate a coping response, even where the patient appears to have some acceptance of their fate. The occurrence of multiple demands including recent loss, needs of other dependants, unresolved issues, lack of information and lack of professional support, all appear to reduce the capacity to cope in carers. Some appeared to be overwhelmed by previous experiences of loss, had unresolved issues and no resources to call on. Where coping resources were stretched to the limits it seemed to result in hopelessness. Psychological distress was apparent with consequences when bereaved. Not surprisingly the picture is that the participants most at

risk and in need of support have several sources of negative stress or stressful events and multiple needs with low resources. They also appear to actively appraise and seek solutions. This emphasizes the importance of healthcare professionals to assess wider social aspects of patient and carer's lives at an early stage of diagnosis. Health professionals need to anticipate and regularly reassess resource need in such individuals and adjust resources available to them to avoid crisis.

Table 4.56 Case-ordered effects matrix showing comparing and contrasting single units of analysis (at risk scores, concerns, coping response and coping resources) in patient carers and bereaved carers who appeared to have inability to activate a coping response

Participant	Anxiety At risk >11	Depression At risk >11	GHQ12 At risk >4	Number and type of Concerns	Patient emotion problem response/resources	Positive reappraisal, emotion focused, problem focused response/resources	Negative reappraisal, emotion problem response/resources
P9	-	-	-	3: Current illness, how feeling physically, not able to do			Wife died just before diagnosis. Grieving Step daughter now carer
C9	14	12	4	-			Multiple grief, guilt, recent death of estranged mother. Young family, work full time
P13	14	-	-	7: Current illness, how feeling physically, not able to do, effects of treatment, relationship with son, how feels about self – depressed, the future.			CVA before cancer, clawed hand, unable to do, How will son cope?
C13	14	14	8				History of depression. RTA, disability. Conflict with DHS. Who else will care? No support.
P17	-	-	-	3: How feeling physically, how mother will cope? future- how will I die?			Acceptance of own cancer, but brother died RTA recently. How will Mum cope
C17	11	-	8				Multiple loss. Other son died in RTA recently. Still grieving . Good husband,
BC2	17	10	8	-			H/O depression. Grief /conflict. Lost brother to HIV just before father. No support
BC10	16	16	12	-			H/O depression. Still grieving for son- HIV, cannot grieve for husband. Son in spirit.
BC17	17	-	7	-			H/O depression Multiple exposure to death. Conflict- step sister. Own health?cancer
BC21	13	-	11	-			H/O depression. Multiple loss, father soon after mother, regrets not talking to him.

4.7.3.5 Patient and carer coping response

The previous cross case analyses have indicated that when patients and carers share coping responses there seemed to be less risk of anxiety, depression or distress. It was decided to examine this statistically. Table 4.57 uses frequency of the key coping strategies to look

at the relationship between patients and carer coping. The result was significant (Kappa 0.895, $p=0.000$). This indicates that patient and carer coping response is strongly related. Hence, the healthcare professional should be sensitive to these situations when the strategies are not shared.

Table 4.57 Patient coping response and carer coping response

		Carer coping response				Total
		Togetherness	Carry on as normal	Avoidance	Inability to activate a coping response	
Pt coping response	Togetherness	4	0	0	0	4
	Carry on as normal	0	6	0	0	6
	Avoidance	1	1	15	0	17
	Inability to activate a coping response	0	0	0	3	3
Total		5	7	15	3	30
		Value	Asymp. Std. Error(a)	Approx. T(b)	Approx. Sig.	
Measure of Agreement	Kappa	.895	.072	7.764	.000	

a Not assuming the null hypothesis.

b Using the asymptotic standard error assuming the null hypothesis.

4.7.3.6 Carer and bereaved carer coping response

In contrast, the comparison of carers and bereaved cares resulted in a significant difference ($X^2 = 10.5$, $p= .014$). Inspection of Table 4.58 reveals that the bereaved carers were more likely to recall coping with 'togetherness' and less likely to 'carry on as normal' or 'avoidance'. Whilst this may indicate a difference in ongoing care and recall

of care, or that people use different strategies to respond as their situation changes.

Table 4.58 Carer and bereaved carer coping response

	Togetherness	Carry on as normal	Avoidance	Inability to activate a coping response
Carer	5	7	15	3
Bereaved carer	15	3	6	4
	Value	df	Asymp. Sig. (2-sided)	
Pearson Chi-Square	10.544(a)	3	.014	

3 cells (37.5%) have expected count less than 5. The minimum expected count is 3.38.

4.8 Summary

This study has set out to evaluate (describe, explore and explain), the perceptions and concerns and levels of psychological distress of patients, carers and bereaved carers affected by gastrointestinal cancer. The aim of the study was guided by two theoretical perspectives; firstly an adapted phenomenological perspective to capture the real world of the participants (using case study and contextual triangulation), and secondly by coping theory (Folkman, 1997).

The investigator's own clinical and research background and the review of the literature, had led to a theoretical framework which suggested that only through using a complex approach, would the real world of these people's 'cancer experience' be captured. As was anticipated, when exploring use of a case study approach using contextual triangulation, the present study entailed a lot of time consuming and rigorous data collection and three different stages of analysis.

The open interview technique allowed each person to construct with the interviewer an image of their experience, which was different for each because of variations for physical/organic reasons (e.g. other health problems, age, pain thresholds) psychological

reasons (e.g. beliefs, values, knowledge, personality, problem solving ability) and social reasons (e.g. access to services, emotional and social support, practical support).

However, whilst there were shared aspects of all these journeys as reflected through the interview themes (e.g. sensitive communication, living with uncertainty), what was repeatedly emerging from the data was that whilst these 92 participants had one thing in common; incurable gastrointestinal cancer, each of their journeys was both complex and interwoven. Each of the interviews, the measures of HADS and GHQ12 and the Concerns Checklist in patients contributed to unique variables and to what Holstein and Gubrium (1995) describe as a 'rich tapestry'. Stage Two of analysis confirmed this individuality. Stage Three of analysis identified that whilst it was impossible to draw neat conclusions, the rigour with which each source of data was analysed in Stage One and Two allowed induction and synthesis when compared and contrasted in Stage Three.

This then made it possible to compare findings with coping theory (Folkman, 1997), psychological theory of adaptation (Passik 2001) and identity threat (Coyle, 1999; Rogers et al., 2000). It was this application which suggested how the present study could help to improve our knowledge and understanding of ways in which patients, carers and bereaved carers appraised their experience, including what helped or hindered them to cope, and what may have affected their psychological well being.

CHAPTER FIVE

DISCUSSION, CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

5.1 Introduction

This chapter will discuss the important main aspects of the research study including the methodology and the effectiveness of the method selected, conclusions from the findings, reflexivity and the implications for clinical practice for a specialist gastrointestinal cancer centre.

5.2 Methodology and method

The primary aim of the current study, as reflected in the study aims and title, was to evaluate the needs of patients and their main carer affected by gastrointestinal cancer that is no longer curable and therefore requires palliative care. The close of Chapter One presented four clear areas for investigation. The first three of these had the intention of uncovering key, and new revelatory meanings regarding the under researched experience of incurable gastrointestinal cancer by seeking the perceptions, concerns and levels of psychological well being/distress of the experts in this area, namely, patients, carers and bereaved carers affected by this cancer. In light of the revelations and evidence from the above three questions the study aimed to explain how these findings could inform the providers of generic palliative care in a specialist gastrointestinal cancer centre.

5.2.1 External validity and theoretical framework

The development of a relevant theoretical framework and theoretical propositions evolved through the synthesis of background studies in order to identify gaps in the literature and appropriate methods of data collection and methods of analysis. A lack of

theory in relation to the needs of those affected by incurable gastrointestinal cancer (with no criteria for success or outcome indicators) became key to guiding both data collection and analysis. The literature had supported the proposition that use of both qualitative and quantitative data could be useful, and the established approach that emerged as having potential to answer the research questions was the single case study approach (Yin, 2003), set within the context of coping theory (Lazarus and Folkman, 1984; Folkman and Greer, 1997; Folkman, 2000).

Because of the use of mixed methods, triangulation of qualitative and quantitative data was possible, and this contributed to a wider explanation of the findings where analytical rather than statistical generalisation became the focus of the study. Using a purposive sample, incorporating between methods triangulation enabled recognition of each participant as a human and social being, coming from a meaningful world with their own background familiarity of incurable gastrointestinal cancer. It is this important pre-supposition that enabled the researcher to undertake this study where a mixed method approach of enquiry into the individual's experience supported use of the single case study design as a **revelatory case** (Yin, 2003) for achieving greater understanding and interpretation of the participants perceptions and concerns and measures of psychological well-being by allowing for individual differences to be acknowledged, highlighted and investigated (Hammersley, 1997).

Yin (2003) relates some of the strengths of using a case study approach to describe, explore or explain causal links in real life situations that are too complex for survey or experimental strategies, but may be generalised to theory in other similar situations. Such an approach was viewed as appropriate with the primary aims and title of the study which

had a process and outcome focus including an evaluation of need. It was the intention to identify the needs of this cancer group by exploring what each individual perceived as required to be met in order to maintain or improve their state of well-being or to anticipate and manage their deterioration. With no specific criteria for success or outcome indicators available the approach selected enabled evaluation of need through exploratory and explanatory components.

Yin (2003) describes a matrix of case study design that identifies the attributes of the case study in terms of embedded design. Whilst he suggests that this embedded design would normally benefit from data sourced from multiple cases, he also acknowledges and sanctions how multiple sources or subunits of data can be incorporated into an embedded single case study design. The criteria for a single case study would be in for example a critical case or as in this study, a revelatory case where in-depth study develops our knowledge in an area where so little is known (Yin, 2003, p.43-46).

5.2.2 Reliability and Construct validity of the study

Concern about precision and rigour for the reliability and construct validity of the study led to establishing a chain of evidence identifying the rationale for, and description of, clear focused research questions explicitly detailing why triangulation was selected as a method to meet the aims of the study (Morse 1991; Cutcliffe and McKenna, 1999). This use of both multiple sources of evidence for capturing complexity of the study participants and a chain of evidence including how all data was collected and analysed promoted construct validity such that the study could be repeated (Yin, 2003).

5.2.3 Internal validity of the study

Chapter Four of this study has demonstrated how each of the 92 participants (as the single units of analysis in the embedded single case study) provided a unique, experiential account in interview and measures of psychological well-being of what was real or meaningful to each of them. Internal validity was strengthened through the use of previously validated measures of HADS (Zigmond and Snaith, 1983) and GHQ12 (Goldberg, 1992) allowing statistical methods of analysis to be used. A further strength of the case study method was the explanation of these statistical findings through triangulation with data from the active interviews (Holstein and Gubrium, 1995), as well as the Concerns Checklist in patients (Harrison, 1994). An abundance of data of multiple realities was revealed and reported which in turn created significant opportunities for extensive analysis.

For example the use of the Concerns Checklist as well as HADS has shown that a more rigorous approach to identifying the relationship between unmet information needs and patients at risk of anxiety in the future may be helpful. Such a methodology that uses an additional measure when using the HADS has been encouraged in palliative care by Lloyd-Williams (1999), and in an oncology setting by Skarstein (2000). Furthermore, in its entirety, various stages of analysis have identified the unique responses of each individual (Parle et al., 1996) in varied and complex processes.

Internal validity was further secured by creating a structured technique for analysis and logical inference which, whilst adhering to the analysis for each source of data in Section One and Two of the analysis, then moved into comparison and contrasting of data in a reflexive, creative approach (Sandelowski, 1993) including a continuous reading

of, and reflections on the data in a process of interpretive reflexivity. This approach helped to improve the validity of the study and provided an audit trail. The importance of such an explicit approach to analysis in case study research to promote validity has been equally demonstrated in other studies adopting a multiple case design (e.g Kirshbaum, Booth and Luker, 2004).

The structured technique for analysis in this study also included the development and display of matrices of categories (e.g Table 4.5) and placing evidence within such categories, including frequency of different events (Miles and Huberman, 1994). From a methodological perspective it illustrated how adhering to a structured and systematic framework for recording, organizing, displaying and analyzing multiple sources of qualitative data in a series of matrices (Miles and Huberman, 1994) can promote more accurate analysis, interpretation and validity. This made both the method and the results accessible to the reader in a format that allowed a greater understanding of how aspects of the study methodology might be analytically generalized to other studies. Through triangulation of analysed data using for example pattern matching and rival explanations from deviant cases, synthesis has been possible to display and interpret the findings which, whilst refining the data, have not diluted the importance of each individual reality. As such, the research design was viewed as worthwhile and effective in contributing to knowledge and theory building and as a means of identifying future investigations in the entire field of caring for those affected by incurable gastrointestinal cancer.

Diversity of extremes have been noted in the results in for example those patients who demonstrated adjustment to their incurable diagnosis and revealed low levels of psychological distress in the ideal case to those carers affected by a number of complex

interrelated experiences and unable to activate a coping response when bereaved as a deviant case (Yin, 2003; Miles and Huberman, 1994). Whilst such facts might have been revealed from a variety of methodological approaches, the explanation building aspect of the case study approach through triangulation of numerical data and qualitative data has contributed to our knowledge about coping in the transition to palliative care in gastrointestinal cancer, and supports the in depth use of a case study approach.

This single case study approach in gastrointestinal cancer contrasted with a number of case studies identified in cancer and palliative care in single case (Lee, 2002) and in multiple case design (Bergen, 1992; Cowley et al., 2001; Skilbeck et al., 2002; Kirshbaum, Booth and Luker, 2004). This study has illustrated how the case study approach has been appropriate for a study in the context of transition to palliative care with a focus on the generic palliative care responsibilities in a specialist gastrointestinal cancer service.

More recent literature has emerged since the current study was designed and data collected supporting the advantages of case study design in palliative care (Walshe et al., 2005) including end-of-life care and bereavement (Payne et al., 2007). From a methodological perspective, Payne et al. 2007 illustrated the advantages of multiple embedded case design and cites 3 studies that demonstrate the effectiveness of this approach for examining processes and outcomes in dynamic healthcare organisations. Similar methodological issues have been explicitly described in Chapter Two of this study where methodological considerations for answering the research questions were examined. The limitations of the embedded single case study approach as compared to a multiple case design have been acknowledged, but the benefits of the approach are also

highlighted since the study has been able to meet the criteria for a revelatory case (Yin, 2003).

Whilst overall themes such as communication and information were found to be similar to other studies, this study has added to our knowledge in this area, and critically has informed gastrointestinal cancer service provision. The method selected revealed important subsidiary components in this population affected by incurable gastrointestinal cancer. Through comparing and contrasting units of analysis in the current study it has been possible to explore and attempt to explain the connections between subsets of data and to provide illustrative examples of the interplay between them. For example, from a cancer service perspective it suggests that the experience of disclosure may exert an influence over levels of coping and psychological well being. In some instances such as that of BC 25, the influence appears to be positive, whilst in other cases such as BC 19 recollection of poor disclosure appears to hamper adjustment to loss, and is reflected in levels of psychological distress when bereaved. Analysis of the triangulated data revealed that inclusion, access to information, and acknowledgement of their role as carer were highly valued by carers and we now know that carers' experiences of caring in incurable gastrointestinal cancer could be improved (to the extent of influencing their levels of psychological well-being) when their individual needs are assessed and met. This has serious implications for those providing a specialist cancer service to those affected.

Thus, the aim of combining methods in this study was not just to ensure validity. Rather, it contributed to interpreting the reality of the complex, inter-related aspects of individual perception and experience, service provision and care in what Silverman (2001) calls a true state of affairs.

Furthermore, the application of findings to theory suggest that in the case of carers, from a coping theory perspective, insights into the process of change and adaptation /maladaptation from the point of the patient being given an incurable diagnosis onwards have been identified. What has been revealed is that not only is it carer identity and autonomy which seem to be important but also how this can be promoted by the attitude and support of the gastrointestinal cancer service involved in the generic palliative care of the patient, primarily by supporting the carer through inclusion and providing access to information to enable them in their role as carer (Folkman, 2000).

It is thus argued that use of a single case study approach that used mixed methods in triangulation has captured multiple perspectives in multiple sub-units of analysis, to recognise and reveal more about the complex situations these people find themselves in when confronted by incurable gastrointestinal cancer. It has provided a means of exploring the breadth of process and outcome experienced in a flexible, but rigorous approach. The inclusion of a clear theoretical framework, the use of triangulation and reflexivity have together supported its use as reliable and valid for the purpose of this study.

5.3 Interpretation of the key issues arising from the case study

5.3.1 The need for an individualised approach with sensitive communication

Through exploring the perceptions and concerns of patients and carers who were living with, or who as a bereaved carer, had lived through the experience of incurable gastrointestinal cancer it was possible to confirm the considerable and well established literature on the importance of disclosing the diagnosis of cancer to

people in a sensitive way (e.g. Fallowfield et al., 1990; Butow, et al., 1996). Disclosure of bad news was a key issue for the majority of participants affected by the diagnosis of incurable gastrointestinal cancer, and contributed with other concerns to experiences of psychological distress.

- However, what is unique to this study is that whilst previous studies have predominantly investigated the effectiveness of the communication process between patients and healthcare professionals, and whilst such studies offer evidence to support use of communication that helps patients focus on positive aspects as this can help them cope with their illness, it is knowledge about the wider dimensions of the interaction between patients, their carers and healthcare professionals and how these may influence levels of psychological distress in a population specifically affected by incurable gastrointestinal cancer to which this study contributes a new and different perspective.

Perceived experiences and concerns revealed how the communication processes helped or hindered. This has developed earlier work and methodology in patients (e.g. Heaven and Maguire, 1998), and in carers (Pitceathly and Maguire, 2000).

- Importantly, this study identifies some of the key aspects of generic supportive and palliative care for this under researched cancer group, which was a principal aim of the study.

5.3.1.1 Sensitive communication and psychological distress in gastrointestinal cancer

As well as effective communication skills, the manner of the disclosure was perceived by participants as a measure of respect for their integrity and a measure of authentic caring (Macleod, 1997).

For patients, poor disclosure was significantly associated with at risk levels of anxiety. Distress and a reduction in coping response was associated with receiving bad news, or witnessing its disclosure in a blunt, insensitive manner often from a physician, who many participants never saw again. Conversely, and demonstrating the diversity of both individual participants and the methodology adopted, the experience of good communication in this study was also captured and perceived to be associated with timely, sensitive planning of disclosure (which included the presence of the patient's carer/friend if desired), assessment of what they did and did not want to know, and the healthcare professionals whole demeanour and relationship with the participant including an ability to express care and compassion and to assure ongoing access to support.

- Such revelatory data as this, and how for patients, poor disclosure was significantly associated with at risk levels of anxiety, served to contribute to answering the evaluation aspect of research question by identifying what communication strategies might positively influence or reduce coping and well-being in this cancer population.

Many years ago, Weaver (1972) argued that levels of sensitive, authentic communication affect the feelings of self-respect and esteem needs of the individuals

receiving information, and over three decades later, this study confirms this core value.

- Findings of this study therefore add to our knowledge in this cancer population and suggests that for patients poor disclosure in a generic palliative care setting adds to, or may trigger anxieties, by for example threatening identity and challenging self confidence to cope as noted in the literature (Macleod, 1997). Therefore, good disclosure practice may avoid such consequences or in fact strengthen patient coping strategies.

Healthcare practitioners skills for identifying information need and eliciting concerns are distinctly revealed by participants in this study and supported by a recent randomised controlled trial in communication skills training (Heaven and Maguire, 2006). They suggest that healthcare professionals should begin discussion of prognosis (or addressing questions about the future) by emphasising strengths, resources, support and probabilities and uncertainties. At the same time, they can sensitively probe to elicit concerns and information patients might want at various key points on the journey when transitions take place (e.g. when cancer recurs or at the transition to palliative care). Heaven et al. (2006) have identified an optimal multi-dimensional training method that incorporates this sensitive aspect of communication and supports many of the components identified by participants in the current study. The method stresses how it is not only skills of communication, but the interview structure, and professionals' attitudes and feelings which are important. It encourages facilitative behaviours which promote trust and effectively elicit information about emotions, worries, concerns and fear and includes open questions with an empathetic psychological focus, use of clarification and educated

guesses. In considering this style of communication and information exchange it can be seen that it has the potential to address physical, psychosocial, emotional and spiritual issues in an integrated holistic approach. As revealed in this study, it also affirms the importance of the wider aspects of effective communication such as planning, location and who to involve which are key components, and further suggests how the environmental aspects can influence appraisal and coping processes.

Furthermore, the importance of a supportive culture for effective communication has been identified by Booth et al. (1996), and explored in the review of the literature. Heaven et al. (2006) have confirmed that whilst training enhances skills, without support such as clinical supervision in the work environment it may have little effect on clinical practice. From a policy perspective (NICE, 2004) this study raises questions about the effectiveness of training programmes which do not incorporate a supervisory / transfer element, and supports the need for clinical supervision in clinical practice, since at the current time this is not a statutory aspect of the national communication skills training programme.

Whilst there has been a long established commitment to communication skills training in cancer (DoH, 2000), and a pre-condition of qualification to deliver patient care in the NHS that staff are able to demonstrate competence (DoH, 2000), findings from this study, support those of the NAO (2005) and Macmillan (2006) work that suggests there appears to have been little improvement in communication skills and management of disclosure in recent years. The problem is acute when considering the needs of carers. Because of the structure of cancer services in the U.K. the responsibility for assessing the eligibility of active, curative treatment for gastrointestinal cancers is likely to remain with

the specialist cancer centres. Significant to an incurable gastrointestinal cancer diagnosis when prognosis for the majority can be poor, The Supportive and Palliative Care Strategy (NICE, 2004), recommends that a cancer diagnosis should be communicated 'ideally in the company of a close relative or friend (if the patient wishes) and in the presence of a specialist nurse where possible'.

However, a recent survey by the National Audit Office (NAO, 2005) found that whilst less than 20% patients were on their own when told they had cancer, only 55% were with family or a friend as recommended by the guidance. Who they were accompanied by, when not with family or a friend is not clear. What this finding seems to call into question is the coordination and planning of the bad news disclosure, if such a high percentage of patients had no relative or friend present. The interviews used in the present study identified many such aspects, but the advantage of the method used was that it was possible to explore a range of issues, and the use of measures of psychological distress with all participants and the Concerns Checklist with patients added the benefit of a wider breadth of data from multiple sources.

In those patients in the NAO (2005) study who had nobody else present and who did not want anyone else present, it had to be questioned why? Were they simply trying to maintain their independence, as in 5 patients in the present study), but more importantly, (as the present study has illustrated), did they have any notion of the consequences of excluding their carer for their ongoing cancer experience? Surprisingly, little is commented upon about the consequences by the NAO - because such information has not been gathered in this very patient focused study. Because of its methodology incorporating the views of patients, carer and bereaved carers in the

present study the current author expresses concern at such a finding. Again a more proactive approach to educating both healthcare professionals and patients as to why it is important to include their carer at the outset appears crucial. However, it has to be acknowledged that patient confidentiality can be an ethical dilemma. In the five patients in the present study who were reluctant to involve their carer or where the carer lived apart from the patient there was evidence of carer frustration in relation to information need and access. It has been suggested that healthcare professionals might have to consider their role in mediating between patient and carer in order to meet carers needs (Wilson et al., 2002).

5.3.1.2 Sensitive communication, information and prognosis in patients

When considering the data sources in this triangulated study, 15 of the 24 patients who perceived sensitive communication as a key component of good care had unresolved concerns and information needs related to their current illness, the future, how their carer would cope, how they were feeling physically, and not being able to do the things they used to do. Similar patient concerns have been found in a mixed cancer group (Parle et al., 1996) and in patients dying of colorectal cancer (Maguire, 1999).

- In the present study, there were indications that patients did not seek information to address their concerns for fear of being told more than they wanted to know.

This finding emphasised the lack of an individualised approach and both poor disclosure and unmet information needs in patients. The finding was further strengthened by the findings that patient anxiety was significantly correlated with total concerns. The

study by Parle (1996) identified that an increasing number of concerns is associated with increased anxiety, which if applied to this study would result in 15 (44%) patients at risk of developing anxiety.

An awareness of prognosis has been identified as advantageous to cancer patients in order for them to put their affairs in order, to make plans and in some circumstances to choose their place of death, (Addington-Hall et al., 1997). However, there was considerable ambiguity amongst patients, and the present study suggests that this might be a simplistic point of view.

- What this study has shown is that for patients affected by incurable gastrointestinal cancer the issue is complicated and again, an individualised approach is required. Over half of patients (21) admitted to concerns about their illness, whilst nearly half (15) admitted to concerns about the future. Over two thirds (24) expressed concern about their main carer and how they would cope as their illness progressed. These were clearly information needs and with a diagnosis of incurable cancer, there are implications in these patient concerns about prognosis. Whilst it could be argued that such concerns might be addressed through appropriate information, (i.e. time left, levels of disability), the majority of patients stressed that they did not want a detailed time-table or 'countdown to death', and patient interviews revealed that it was fear of this which often curtailed their request for further information with a number of individuals stating they would have coped better if they had been told less.

In light of the importance of this aspect of communication that emerged as key to those patients affected by incurable gastrointestinal cancer, literature in relation to

prognosis was explored. In a study of a very large heterogenous sample of 2331 cancer patients, Jenkins (2001) used an adaptation of Cassileth's Information Needs Questionnaire to capture information preferences. Whilst Jenkin's study showed that 87% wanted all possible information, both good and bad news, 13% stated that in general they preferred to leave disclosure of details up to the physician. However, whilst this study provides evidence that the majority of patients appear to want to know, it is difficult to assess whether use of a questionnaire was able to capture their lived experience of disclosure and whether each of the 87%, whilst wanting all information, had actually been told their prognosis, and if so how did it affect them?

- What seems to be crucial is that whilst promoting disclosure of prognosis can be advantageous, the different sources of data in the present study, including data from carers and bereaved carers, identified how the importance of an individualized approach to disclosure and the amount and type of information in relation to prognosis was key in those confronting an incurable diagnosis of incurable gastrointestinal cancer.

Of importance to the present study where so many patients were at risk of increased anxiety, Parle et al. (1996) captures the essence of this individualised approach stressing that the first step in adaptive coping in cancer may be appraisal that minimises the perceived threat. Sensitive communication, eliciting concerns seem to be a key factor in contributing to coping at this stage of gastrointestinal cancer.

5.3.1.3 Sensitive communication, information and prognosis in carers and bereaved carers

Linked to the core component of sensitive communication in carers and bereaved carers were the interrelated themes of information and prognosis. As there was no significant agreement between patients and their carers in the experience of information need this appears to emphasize again the important aspect of an individualized approach to information and that patients and carers information needs are different, and should be assessed separately. This is not a new finding. Derdiarian (1989) and Keller (1996) found that partners had different information needs and that information should be individually tailored.

A substantial proportion of carers (13) and bereaved carers (10) who experienced poor disclosure had at risk scores for psychological distress, though this was not significant.

- However, what does seem to be important is intentionally or otherwise on the part of healthcare professionals, a third of both carers (11) and bereaved carers (9) recalled being excluded at the time of diagnosis or when bad news was told to the patient. This study has revealed that it is the impact of such experiences as exclusion as well as the interrelated themes (as in patients) of sensitive disclosure, access to information and prognosis which seems to be the crucial issue. Interviews with carers in the study identified that the main need in carers was for information that would help future planning and constructive action in supporting the patient, but the information needs of over half the sample of carers and bereaved carers had not been met.

Such carer data revealed how this was a problem focused strategy to cope with uncertainty and where information needs were not met, and access to information was limited, increased psychological distress appeared to restrict activating a coping response.

- Because the study included comparison of patient and carer single units of analysis, it was possible to demonstrate that when patients declined access to information it had detrimental consequences for access to information and support for their carers. In such circumstances it appeared to contribute to increased burden in carers, hence they experience higher levels of anxiety and distress with unmet information needs.

Whilst the importance of information to carers has been long established (Payne et al., 1999; Rose, 1999), and studies have included use of measures of psychological distress (Payne et al., 1999, Maguire, 1999), this study has further developed the importance of this in the under researched population of carers and bereaved carers in gastrointestinal cancer, including an explanation about how the consequences of poor disclosure and no access to information restricts a coping response.

It is suggested like Ellis-Hill et al. (2001), and Wilson et al. (2002), that healthcare professionals including nurses need to look at carers differently and develop different relationships to the traditional hierarchical model of the healthcare professional being the expert. This study has revealed that acknowledging the importance of including the carer at disclosure (because of their relationship with the patient, their contribution, expertise and need for information) might better support

them in both reducing their levels of psychological distress and equip them better to sustain and cope in their role (Nolan, 2001).

5.3.2 Living with uncertainty and fatigue

5.3.2.1. Fatigue and patients with incurable gastrointestinal cancer

Fatigue surfaced as a major issue for far more patients (22) than carers (6) or bereaved carers (8). The fact that it was recalled not just from interview data, but also as a major component of the most frequently identified patient concerns within the Concerns Checklist emphasized its importance for patients both immediately and in the context of their risk of developing anxiety in the future. These patient findings in relation to fatigue are supported by the National Audit Office (2005) study which showed that 59% of patients with cancer reported overwhelming tiredness, 60% patients experienced fatigue after leaving hospital and 20% thought they did not get sufficient help to cope with it. Together, such findings suggest that managing fatigue in patients with cancer is an under researched area of healthcare.

Fatigue as a symptom, whilst recognized in the generic cancer literature was not an area that emerged in the literature review and no studies were identified that specifically identified fatigue in gastrointestinal cancer. In response to the major importance attached to fatigue revealed by patients in this study, it was found when examining the generic cancer literature that the main issue when trying to define fatigue seems to be that there is no clear distinction between what is accepted as normal tiredness and what constitutes fatigue. In an attempt to capture the core components of cancer related fatigue Ream and

Richardson (1996) offer this definition which patients and carers in this study usually described:

‘Fatigue is a subjective, unpleasant symptom which incorporates total body feelings from tiredness to exhaustion creating an unrelenting overall condition which interferes with an individual’s ability to function to their normal capacity’

(Ream and Richardson, 1996; 527).

Furthermore, as was identified in the theme of sensitive communication in this study, related concepts in fatigue seem to be important. Glaus et al. (1996) in a study used a grounded theory approach to interview 20 cancer patients and 20 healthy individuals. Whilst different themes emerged between the two groups, both fitted a classification system that categorized expressions of fatigue as physical, affective or cognitive. The study by Glaus et al. (1996) is valuable as it helped to conceptualise cancer related fatigue, and also reflected the exploratory methodology used by many of the earlier studies in fatigue (Pearce and Richardson, 1996; Magnusson et al., 1999; Barsevick et al., 2001). However, a small sample size was common in these early studies which were often in specific cancers such as breast cancer, with the added risk of associated gender bias and where patients were receiving active treatment. Some of the more recent studies have emphasized the individual’s subjective point of view when assessing cancer related fatigue (e.g. Mock et al., 2003), but only one study was identified that captured the perceptions of both patients and their carer, as well as healthcare professionals in the advanced cancer stages (Krishnasamy, 2000).

An advantage of the present study, and because of the triangulated approach, interviews and concerns about fatigue in patients helped to identify wider dimensions including the effects associated with role and personal loss (Hinton, 1996). This has suggested that the effects of fatigue may be an important aspect of constructions of self

worth and self-esteem. The diversity of the data was further enriched by access to the responses of carers, and recall in bereaved carers of their complex experiences of caring for somebody with cancer related fatigue, as well as their personal experience of fatigue as a carer.

Although with a smaller sample size (15 patients and their carer or friend of choice), and healthcare professionals Krishnasamy's (2000) study does compare with the present study in that it used a mixed method approach of interview, including an interview and psychological measures with patients including the HADS. As in the present study Krishnasamy (2000) found that despite distress and sense of loss caused by limitations imposed by fatigue, there were limited cases of depression and only one patient at risk for anxiety. She therefore suggested that research that attempts to find out more about the meaning of fatigue with its many distressing facets of experience is more important than trying to measure it as current tools, such as the HADS, do not capture the experience. The fact that each participant identified the importance of addressing the struggle, of finding meaning in something as inherently disabling as the fatigue experience also has resonance with the present study. However, the benefits of over double the sample size of the present study, plus the multiple sources of data at an earlier stage of the cancer journey suggests that fatigue also has major implications for those who care for patients from the point of disclosure of incurable diagnosis.

Despite the fact patients identified fatigue as a source of psychological distress to themselves and to their carers, it was not an aspect of gastrointestinal cancer that any of the participants recalled being assessed by healthcare professionals. Knowles et al. (2000) found that whilst nurses were able to describe a number of the components of fatigue,

they did not necessarily acknowledge the intensity of the symptom or specifically assess fatigue. Sutcliffe et al. (1997) found that whilst patients in the terminal phase of their cancer rated it as the second most troublesome symptom, only 9% of nurses considered it to be a problem. Thus, there seems to be lack of knowledge and understanding in healthcare professionals about this symptom and its apparent importance both physically and mentally to patients and to their carers.

A large majority of patients in this study had metastatic disease, the presence of which has been associated with higher levels of fatigue and psychological distress (Glaus, 1998). Three bereaved carers recalled severe fatigue and increased psychological distress in patients they cared for with pancreatic cancer. Physiological studies have found a causal link between pancreatic cancer and depression (Kelsen, 1995; Massie, 2004), but the interpretation of findings for managing such patients appears limited. Fatigue is also a common symptom of depression, and has been associated with anxiety and depression (Smets et al., 1998), though the interdependence between fatigue and psychological distress does not seem to be well understood. These associated ideas are echoed by patients and carers in this study with, for example, role loss and association with other symptoms such as loss of appetite and weight loss, suggests that it may be more appropriate to consider fatigue in a symptom cluster rather than in isolation. Participant in this study appeared to acknowledge the complexity of fatigue rather than perceiving it as an individual symptom.

5.3.2.2 Fatigue, carers and bereaved carers

An almost significant association was found for fatigue and anxiety in carers. This, and the carers statements indicate that the impact of cancer related fatigue may not be mainly

related to the physical burden of care but to observing deterioration in the patient, and witnessing their fatigue. This study has revealed that this appeared to be one of the most difficult aspect of care giving in incurable gastrointestinal cancer. However, when comparing and contrasting data the association with anxiety suggested uncertainty over the future or having information needs also contributed to fatigue. Three carers who had at risk scores for anxiety also had a history of depression

Caring for an individual with high functional impairment as in advanced cancer has been shown to be positively correlated with depression and fatigue in the caregiver (Clarke, 2002) and has been shown to lead to strong feelings of isolation (Teel and Press, 1999), which may have been a contributing factor to a carry on as normal or avoidance strategy. However, the current data did not find a consistent association with fatigue and at risk scores for depression and psychological distress in the carers. Hence, the proposed association of a direct consequence, as suggested by Clarke (2002) cannot be confirmed. Many carers managed to mention social contacts and saw the isolation as temporary. There was no strong association with depressive symptoms. This again highlights the importance of avoiding making collective statements and categorizing these patients and carers. It emphasizes a need for an individualised approach when assessing and reassessing fatigue.

Fatigue does appear to reduce patients' quality of life, and seems to be associated with psychological distress in carers (Krishnasamy, 1997), confirmed by the present study. The situation seems to be exacerbated when carers describe themselves as needing information, excluded or overlooked by healthcare professionals or where symptoms of the patient's illness including fatigue, weight loss and poor appetite were ignored or

minimised by healthcare professionals. The situation appeared to be especially stressful and frustrating when carers felt they could not improve the fatigue situation in the patient through physical support, encouragement to rest and nourishing food, particularly if they were also attempting to take on the tasks and roles the patient could no longer deal with, or if the carer live apart from the patient.

- It would appear that because cancer related fatigue is so poorly defined or understood by even healthcare professionals, carers in this study appeared extremely challenged in trying to reduce its physical and emotional impact. Carers described how not being able to improve the patient's fatigue appeared to exacerbate their emotional feelings of failure, hopelessness and distress. For some it seemed to contribute to negative appraisal of their role as competent carer. The risk appears to be reduced self worth and self-esteem.

In the present study carers recalled how having to try and fathom out for themselves what the tiredness and exhaustion meant, whilst struggling with feelings of an inability to protect the patient from the impact of functional limitations, and the emotional distress associated with it were also additional source of stress.

However, despite the problem of a minority, the physical burden of caring did not seem to be an issue for the majority of carers in this study. Addington-Hall et al. (1995) found that only 7% of carers found caring for their dying relative burdensome, with 53% finding it rewarding, a finding reported in other studies (e.g. Grbich et al., 2001).

Fatigue in bereaved carers appears to occur between 4 to 9 months post bereavement. This might be interpreted as an accumulative, delayed response to loss, perhaps compounded by unresolved issues or experiences, on going demands of work, caring for

disabled parent left behind, needs of children. Once bereaved, carers acknowledge fatigue, but they do not associate this with physical toil, rather they appeared to identify their experiences as contributing to a positive or negative bereavement and in particular disclosure, information need, multiple additional stress sources, protracted diagnosis, and co-ordination of care. Five bereaved carers had at risk scores for anxiety and psychological distress. Three of these were female and under 55 years old. Two of these three had at risk scores for depression, were female and under 55 years old. There seems to be a requirement to monitor fatigue in carers when bereaved, even months later, as such symptoms may be masking increased psychological distress.

There was also an association with those bereaved carers who appeared to be accepting their loss and who showed signs of adjustment with satisfaction with support and care provided, both by health professionals and how they were assisted as carers to provide care. Screening instruments did not indicate a problem and despite admitting to sadness at the period 4 to 5 months post bereavement, their experiences appeared to be associated with low levels of psychological distress.

Even so, the present study indicates that the emotional burden of contributing factors such as protracted diagnosis, poor disclosure and poor coordination of care appeared to increase the likelihood of fatigue and psychological distress in both carers and the bereaved. What seems to be emerging is that carers appear to be psychologically burdened with the consequences of barely acknowledged and poorly managed fatigue in patients (Krishnasamy, 2000). Because fatigue is so rarely acknowledged, carers are not given any support to deal with it or where it cannot be improved, support to help the

patient adjust to its impact. In turn, neither do they receive any feedback to know whether they have made a difference and been effective in their role.

5.3.3 Living with uncertainty and Coordination of care

There was a strong statistical agreement between patients and their carers in their experience of poor coordination of care. Of those describing poor coordination of care 4 patients, 9 carers and 4 bereaved carers had at risk scores for anxiety. Nine carers and 8 bereaved carers had at risk scores for psychological distress. Poor coordination of care was seen in several aspects of the cancer trajectory. The key points are now discussed:

5.3.3.1 Protracted diagnosis

It is well established in the literature that the majority of patients are aware that they have cancer at the time of their investigations (Holland, 1990), and that patients associate delayed diagnosis with less successful treatment (Barracough, 1994). An increase in psychological distress associated with delayed diagnosis and advanced disease has been long established as demonstrated by Maguire (1978) and Barracough (1994) who suggest that it is the threat to survival, well-being and uncertainty about the future that induces this. In the present study 5 patients, 7 carers and 10 bereaved carers recalled the pre-diagnosis period of investigations and issues about protracted diagnosis and delay. The majority of these participants experienced disclosure of diagnosis prior to referral to the specialist gastrointestinal cancer centre.

The manner in which they were treated before their diagnosis remained an important and often unresolved concern to patients and carers in this study who experienced delay.

There is some indication in participants that such aspects of care as protracted diagnosis and delayed treatment seem to take on a new or renewed significance for individuals confronted by incurable disease.

Protracted diagnosis was strongly evident in the recall of bereaved carers, 7 of whom had at risk scores for anxiety, 5 of whom had at risk scores for depression, and 8 of whom had at risk scores for psychological distress. Although the association could not be demonstrated statistically, primarily because of small numbers, three bereaved carers who had witnessed and experienced protracted diagnosis in their partner or friend, stated they had had post bereavement depression. They had normal scores for psychological distress, but all three were taking antidepressants.

- It is apparent that protracted diagnosis may be a source of unresolved concerns, psychological distress, anxiety and depression in some bereaved carers, and should be assessed as a risk factor by healthcare professionals.
- The implications for a specialist gastrointestinal cancer centre receiving patients following a protracted diagnosis is an area that has not been explored in the literature. This study has revealed that it creates vulnerability in those affected and appears to have consequences and that a proactive approach to exploring the consequences for patients and carers is an area that requires further study.
- Likewise, from a cancer service perspective, how patient and carer feedback is offered to referring units in order for them to learn from patient and carer experience of delayed diagnosis in gastrointestinal cancer through a constructive educational approach also requires further exploration. Whilst outcome guidance has now been released in the gastrointestinal cancers of oesophagus, stomach,

bowel and pancreas, including guidance to GP's over symptom presentation, the "specialist" nature of these cancers means that the average GP or district general hospital may only be exposed to such patients on a very rare basis in their professional working life.

5.3.4 Coping strategies and levels of psychological distress

5.3.4.1 Personal identity threat, emotional loss and coping response

In discussing the emotional work of terminally ill people Exley (1999), defines 'emotional work' as:

'the skill and effort required to deal with peoples' feelings (both the individual's own and those of others) within the private sphere' Exley 1999 Pg 152

In response to this threat to personal identity and loss, Exley (1999) suggests that people who are dying regulate their own and others emotions by hiding their feelings for the sake of others and to make their demise easier upon their families.

Statistical analysis found that patient and carer coping response were strongly related, indicating most dyads shared the same approach. In contrast carers and bereaved carer coping response were significantly different, but this might just reflect different samples.

The stages of analysis in this study identified that for the majority of participants the adoption of avoidance or carry on as normal strategies appeared to restrict access to information and professional support to help adjustment and activate other strategies to plan and make best use of the time available as indicated by the coping work of Fallowfield (2002b), Folkman (1997) and Folkman and Greer (2000).

This was very apparent in this study in those who adopted a carry on as normal or avoidance strategy. Whilst the use of such strategies can be useful, and have been

acknowledged as potentially beneficial in the short term (Rose, 1997) it appeared in the majority of cases, that they had negative impact in the context in which they were adopted. The use of such coping strategies was invariably associated with negative appraisal of the resources that would activate a positive coping response. These findings are congruent with a recent study examining the emotional impact of cancer on patients and carers (Macmillan, 2006), where 58% of patients felt their emotional needs were not looked after as well as their physical needs.

5.3.4.2 Togetherness

Despite adopting togetherness as a strategy, carers and bereaved carers under 55 years of age, and female carers and bereaved carers under 55 years of age who continued to have multiple demands on their coping resources (such as a dependant relative, young children, or/and recent other loss) had at risk scores for anxiety, depression, and psychological distress. Whilst Payne (1999) also identified young carers and young female carers as a vulnerable group, the findings in the current study appear to contribute an explanation as to why this group of carers can be particularly vulnerable.

5.3.4.3 Carry on as normal

Responses from participants adopting this strategy demonstrated that in actual fact the situation was far from normal, and trying to maintain normality without appropriate resources actually increased their negative appraisal of the situation, and became an apparent source of stress. At risk scores occurred predominantly in carers and tended be related to negative appraisal of such issues as the impact of fatigue on the patient, as well as their experience of poor communication, uncertainty, poor coordination of care, and in particular high information needs.

- Carrying on as normal appeared to restrict access to resources and reduced capacity in the individual to activate an appropriate coping response.

Rose (1997) suggested that normalizing is adopted in an attempt to make the situation more bearable and manageable. She suggested it could be helpful if it was located at the togetherness end of the spectrum, and this appeared so for a small number of participants in this study. Their aim seemed to be an attempt to create a sense of ordinariness, maintaining a relatively normal lifestyle as a means of lessening the threat posed by the disease, making this a time for living rather than a preamble to death. Rose suggested that the thought that the patient and carer were still ordinary members of society seemed to be both a goal and a comfort. In the present study the participants were confronted by incurable upper gastrointestinal cancer. The situation cannot be resolved and the disease is progressing, compounded by such dire symptoms as intractable fatigue.

Hence, adopting a carry on as normal strategy actually appeared to reduce the capacity to relinquish untenable goals, and set new realistic goals that might promote a more positive affect (Folkman 2000). Hence, for most it appeared to be associated with risk for affect disorder. Furthermore, there were consequences for carers in this study simply ignoring what was happening, with attempts at combining normal life and caring duties seemed to be associated with increased stress in carers, a finding previously identified by Corbin and Strauss (1988).

5.3.4.4 Avoidance

This strategy was not beneficial. In fact many carers and bereaved carers describing it indicated that they were colluding with the patient. Thus, adopting avoidance and not talking as a strategy resulted in psychological distress for some participants, particularly

carers and bereaved carers. Carers found the strain of pretending difficult and were excluded from discussion of their feelings, and in some cases, information. Bereaved carers who recalled avoidance and trying to cope on their own appeared to have more unresolved emotional issues.

Many of the contributing factors appeared to be related to a negative appraisal of healthcare issues such as exclusion at disclosure, witnessing poor disclosure, uncertainty related to information needs and poor coordination of care, which prevented or restricted activating a positive emotion focused and problem solving response to the incurable cancer diagnosis. This coping response demonstrates how appraisal of a situation and coping processes are influenced both by the characteristics of the individual and their whole environment (Folkman, 1997).

Of special importance is the finding of adoption of avoidance as a strategy in carers (and as recalled by bereaved carers). It was often done in collusion with the patient and appeared to develop frustration especially in relation to information needs. Whilst most carers wanted to support the patient in their coping strategy, it clearly increased their levels of psychological distress. In Rose's (1997) study, people who were attempting to deny or avoid the reality of what was happening were also described as more unhappy and less able to make the most of the time remaining than those who were more accepting.

- This strategy appeared to distance carers and bereaved carers from access to support to share their worries or concerns. It clearly needs to be addressed by healthcare professionals. An important indication of potential problems was from

the bereaved carers who had experienced avoidance and protracted diagnosis and poor disclosure.

Two of the 6, had at risk scores for depression and 2 others admitted to post bereavement depression and had commenced anti-depressants. Again, this finding needs further investigation with larger numbers, and has importance for training healthcare professionals in proactive techniques.

5.3.4.5 Inability to activate a coping response

A number of issues seemed to contribute to this inability to activate a coping response. (Parle et al., 1996; Folkman and Greer, 1984).

- The occurrence of multiple demands including recent loss, needs of other dependants, unresolved issues, lack of information and lack of professional support appear to reduce the capacity to cope in carers. Where coping resources were stretched to the limits it seemed to result in hopelessness). Psychological distress was apparent with consequences when bereaved.

This stressed the requirement for healthcare professionals to assess wider social aspects of patient and carers lives at an early stage of diagnosis. Health professionals need to anticipate and regularly reassess resources needed for the sanity of carers and recovery of the bereaved.

5.4 Case study data, existing theoretical models and new theoretical developments

5.4.1 Sensitive communication, coping and psychological theory

The cancer literature concentrating on the importance of communication skills (Faulkner and Maguire, 1994; Booth, 1996; Heaven and Maguire, 1996; Wilkinson et al., 1998; Audit Commission, 1992; National Cancer Alliance, 1996; Beaver et al., 1999) has been

acknowledged in Chapter One. Findings of this study support such skills as a prerequisite for those working in a specialist cancer centre with those affected by incurable gastrointestinal cancer.

The crucial issue seems to be about an individualized proactive approach to assessing patient and carer needs through sensitive communication and ongoing support (Fallowfield et al., 2002; Jenkins, 2001). However, this was not the experience of many patients, carers and bereaved carers in this study. There appear to be only a very limited number of studies which identify the long term effects of the nature of the disclosure (e.g. Butow et al., 1996). In the present study poor disclosure, (actual or witnessed) and information needs appeared to be associated with negative appraisal of their situation and an apparent restricted ability to activate a positive coping response. In such circumstances adopting an 'avoidance' or 'carry on as normal' strategy, appeared to be an emotion focused response and a means of regaining power and trying to maintain control.

- Whilst Rose (1997) had identified these coping strategies through use of unstructured interviews with a sample of 21 carers of terminally ill patients, indications from the present triangulated study of 92 participants, (34 patients, 30 carers and 28 bereaved carers), has effectively widened the application of these coping strategies and revealed its effectiveness for use in an in an under researched cancer population. The classification model she describes has been found to be useful with patients and their carers at an earlier stage of the cancer trajectory, as well as at later stage in bereavement, and as such has contributed a new perspective on coping in generic palliative care in gastrointestinal cancer.

5.4.2 Personal identity threat and sensitive communication

In a study using grounded theory Coyle (1999) identified 'personal identity threat' as the key variable for understanding dissatisfaction with healthcare. Perceived or experienced threats to personal identity led participants to a negative appraisal of themselves, to feel dehumanized, objectified, stereotyped, disempowered or devalued and were found to be the major aspects of negative experience of healthcare. These aspects seem relevant to the findings of the present study and will be explored further.

Despite its historical association with audit, the satisfaction with hospital care literature (e.g. Rogers, 2000; Coyle, 1999) where personal identity threat is identified, was one of the useful theories in trying to explain the conceptual importance of authenticity and sensitivity in communication and why it mattered and appeared to be such a crucial component of care to participants in this study. Of significance to this study, where sensitive communication in physician and patient communication has been identified as key, Annadale and Hunt (1998) argued that it is the dissatisfaction with healthcare which is the important issue because of the consequences for the relationship between patient and healthcare professional and furthermore, as a measure of the healthcare professionals behaviour.

5.4.3 Carers, bereaved carers and sensitive communication: application to theory.

It might be considered that with the passing of time bereaved carers recalled less need for information, but there were other associated factors which carers and bereaved carers recalled which appeared to be associated with negative appraisal of their situation. In addition to its utility in patients, Coyle's (1999) model of threat to

personal identity and Hinton's (1996) theory of threat of loss were also very helpful in considering carers and bereaved carers. In this study dissatisfaction or disappointment in healthcare was reflected in two principal areas for carers and the bereaved:

- Firstly, when witnessing or feeling a negative emotional response to the patient's experience of cancer and healthcare, such as the patients presenting symptoms not being taken seriously and resulting in delayed diagnosis, or witnessing blunt disclosure of diagnosis or at the stopping of chemotherapy.
- Secondly, as a threat to their own personal moral identity in their social role as a competent carer, involved in such issues as maintaining the patient's and their own physical and mental health, bodily awareness of the patient in such areas as fatigue, and the ability to use health services appropriately (Coyle, 1999).

5.4.4 Carers and emotional work

Another aspect of the carer role that emerged in the study was in relation to the concept of emotional work as described by carers and bereaved carers. Keeping their own emotions under control and not showing their distress to the patient was recalled with a sense of satisfaction by an important minority of carers and bereaved carers. There were other recollections of carers attempts at maintaining the patient's emotional health, or avoiding further exposure to distress. Whilst a simple example of this was restricting the number of visitors to ensure the patient had an afternoon rest, carers also admitted to more subtle strategies, the outcome of which appeared to put them at risk of increased psychological distress.

As well as with genuine love and affection, carers seemed to look upon this with a moral sense of responsibility, protecting and nurturing within their role. This study seemed to complement the suggestion that emotional support, as a component of social support in coping, helps to fulfill several functions such as intimacy, social integration, nurturing others, reassurance of worth, assistance, guidance and advice. This use of emotional support has been acknowledged in the literature of women's accounts of caring and in the coping literature (Simmons, 1994; Lazarus and Folkman, 1984). However, only a limited amount of literature that discusses emotional work as a therapeutic aspect of care was found, and this tended to be in the context of healthcare professionals as opposed to lay carers.

In their study of patient satisfaction with nurses' caring during hospitalization, Larson and Ferkeitch's (1993) describe emotional intelligence and emotional labour as 'intentional actions that convey physical care and emotional concern and promote a sense of security in another'. Despite its focus on professional carers, this description could equally be applied to the recalled perceptions of many expert carers and bereaved carers in the present study, and highlights their desire to promote and maintain psychological well being in their relative or friend. However, there were also other examples such as deferring involvement of the Macmillan nurse or supporting the patient's decision not to go to the hospice, which, whilst intended to protect the patient actually had repercussions for the carer in that it restricted their own access to support and information.

- Dissatisfaction in carers seemed to be exacerbated by a failure by healthcare professionals to identify their role as carer involved in trying to maintain emotional well being in the patient. Failure to anticipate carers information

and support needs, to sensitively acknowledge the carers own personal loss, their own healthcare needs, (which in participants with a history of depression or the extra burden of other recent loss, children or dependants) resulted in high levels of psychological distress, and a restricted ability to activate a coping response.

These findings emphasize the requirement by healthcare professionals to acknowledge the emotional work of carers rather than presuming that they have the resources to meet both their own and the patient's needs.

- What does not seem to be acknowledged in the literature is how carers are consequential victims of the poor management of the patient. As in other studies with carers (e.g. Rose, 1997; Payne et al., 1999) this study has shown that information at the time of diagnosis of incurable disease and subsequently was a key issue for the majority of carers and the bereaved. The information needs of over half the sample were not met. Carer burden and psychological distress was not related to physical burden, but to the emotional burden of frustrations and concerns at the lack of healthcare professional acknowledgement of their role and access to the resources (including information), which they required to care.

This has been highlighted by many authors (Grande, 1997; Davis, 1996; Payne, 1999; Payne, 2001; Nolan, 1986). It is apparent that their negative appraisal and restricted access to coping resources appears to restrict a positive coping response in themselves (Folkman, 1997), and as the patient's carer, may also restrict supporting adaptation and coping in the patient. The aspects of better communication between healthcare

professionals, patient and carer, to supply information and coordinate care in order to anticipate and meet needs is echoed by Davis et al. (1996), who explored the experiences of patients suffering from a terminal illness and their carers. Using a semi-structured interview in a survey method, their results suggest that it was usually a spouse or the daughter who was the main carer, and that most patients preferred to retain their independence of the support services as long as possible. Davis concluded that a number of these limitations could have been reduced if earlier diagnosis had been made or if support services had been called in earlier. Burden of care in this context appears to be related to lack of support and information, despite a willingness to care.

5.4.5 Coordination of care: Protracted diagnosis, delay and coping response

The aspects of protracted diagnosis cannot be viewed in isolation and was frequently compounded by such factors as poor disclosure, limited support, lack of information, and the increased stress of children or other dependants. Many of the participants who explored their experienced of prolonged investigations and delay in diagnosis had been referred to the specialist cancer centre from a non- cancer general hospital. The delay in referring them to the specialist centre appeared to contribute to both patient and carer distress associated with lost opportunities for treatment because of the delay in diagnosis, and was evident as an unresolved concern in a number of the bereaved. Thus, for individuals it is difficult to predict if or when they might resolve the concerns protracted diagnosis was associated with.

- However, participants associated some or all of these contributory factors with negative appraisal of their situation and a break in the anticipated trusting relationship with healthcare professionals. In turn, this might exclude some

carers from getting help to resolve feelings. Those with low resources or self-doubt/ worth may be inclined to interpret these mixed feelings negatively and restrict their positive emotional coping response (Folkman, 1997; Folkman and Greer, 2000). The effect on participants appears to be an emotional response which seems in keeping with the 'personal identity threat' identified by (Coyle, 1999), and the emotional threat of loss 'where death threatens to take away everything a person has valued' (Chochinov et al., 2002).

5.4.6 Adjustment disorder and coping response

The adoption of 'carry on as normal' or 'avoidance' strategy suggests that some of the participants may have been experiencing adjustment disorder. Passik (2003) describes how the literature on child abuse and that on mental health (e.g. Carson et al., 1989) highlights many overlaps between anxiety, depression and adjustment disorder. Passik suggests that coping inflexibility in response to illness may be an indicator for risk of adjustment disorder and that adjustment disorder may be a more useful concept in these cases than depression. In the present study anxiety, depression and psychological distress were used.

Whilst the HADS had been useful with the patient sample, the researcher was concerned that both the evidence from the patient interviews and the Concerns Checklist identified crucial areas of patient need, including concerns about the future, not being able to do the things they used to and unmet needs in their carers that appeared important but were not 'captured' in the HADS scores. These were expressed in terms the researcher associated with an inability to adapt to their cancer diagnosis. As has been

discussed, other concerns such as fatigue which if not acknowledged and professional support given to cope with it, may have contributed to their sense of loss of role and dignity (Chochinov, 2002; Krishnasamy, 2000). As a consequence they were not be able to 'adjust' to their cancer, which may further explain why so many adopted avoidance and carry on as normal and why togetherness did not always help.

In a study with ambulatory oncology patients Passik et al. (2001), found that a validated measure for depression did not help in identifying adjustment disorder in patients. Similarly, the HADS may not ideally help in the present study. As noted in the Review of the Literature (Chapter One, Section 1.5.9.1), Lloyd- Williams et al. (2001) found that items on the HADS were poor discriminators for depression in patients with advanced metastatic disease. Similarly the HADS depression appeared to fail to detect depression in some bereaved carers.

Thus, the present data does raise doubts about the sensitivity of the HADS with these participants and concepts such as depression. It may be more appropriate to the cancer trajectory as one of adjustment and adaptation, which is a need of all participants rather than categorizing some as depressed or anxious, with the risk of ignoring adjustment in the rest. Absence of problems is not the same as providing a support system that strengthens and adds to the quality of life.

When considering participants in this study who adopted carry on as normal or avoidance, their behaviour reflected rigid thinking and they appeared to address their new problem with strategies they would have used before, which Passik (2003) suggests are traits of adjustment disorder.

The present study suggests that early assessment and a proactive approach may well be key contributing factors to adjustment in gastrointestinal cancer. Making sense of what is happening, anticipating future needs with appraisal of resources and activating coping strategies might promote positive psychological well being. The patients in this study had low levels of depression, but many did not have the information and support needed to adjust (i.e. to understand and make plans) and therefore fell into the carry on as normal or avoidance strategy.

- The focus seems to be on addressing concerns, facilitating communication between the patient and others, establishing and supporting social support networks and reshaping negative or self-defeating thoughts (Passik et al., 2003).

The importance of psychological and educational support has been identified in the literature and is a strong theme in the Supportive and Palliative Care Strategy (NICE, 2004). However, the present study would appear to identify patients and carers want support and care that can help to prevent anxiety, depression and psychological distress (i.e. helps adjustment and adaptation). Thus, in a specialist gastrointestinal cancer centre facilitating adjustment to the diagnosis and establishing support to meet individual needs in patients and carers might be more beneficial than concentrating on diagnosing and treating anxiety and depression.

5.4.7 Fatigue and personal identity threat

It was apparent from this study that fatigue was often seen as something almost abstract, out of the control of both patients and carers, and overlooked by healthcare professionals.

- However, both the revelations of the in-depth interviews and the Concerns Checklist in 22 patients in the present study indicated that fatigue affected them in more than just a physical way, and appeared to be a stigma associated with concepts of loss, self-worth, self-esteem and dignity, all of which appeared to be related to a threat to their personal identity (Coyle, 1999).

In an attempt to better understand cancer related fatigue, its association with personal loss and how it might be better managed in generic palliative care in a specialist gastrointestinal cancer centre the literature was further explored. Whilst acknowledged as an important principle, studies with a patient perspective were limited, particularly in examining the broader theoretical impact of fatigue (including its relationship with dignity, psychological distress and coping). One recent Swedish study by Johannsson et al. (2006) describe how in their small study, patients with incurable cancer emphasised the need to be free from physical symptoms such as pain, fatigue and shortness of breath in order to feel functional. Being functional meant that the patients were able to carry out the ordinary tasks of everyday life, which in turn contributed to their psychological well-being. This Swedish study used focus groups with five participants with incurable cancer, including a patient with cholangiocarcinoma.

In order to explore and explain the implications and debilitating distress of fatigue in incurable gastrointestinal cancer, other theoretical perspectives were also examined. In a palliative care study with terminally ill people (Chochinov et al., 2002) participants described events in their cancer experience when dignity had been upheld or threatened.

Three major dignitary themes were identified; (i) illness related concerns, (ii) dignity conserving perspectives and practices and (iii) social dignity inventory. On reflection and when contrasting and comparing data in analysis these themes appeared to have accord in helping to explain the theory underpinning findings from the data in relation to fatigue and loss in incurable gastrointestinal cancer, and further developed the concepts in the theory of threat to personal identity by Coyle (1999).

Illness related concerns: reflected loss of independence in not being able to do the things they used to do, loss of health through their current illness (progressive, incurable cancer), loss of physical strength, cognitive impairment exacerbated by uncertainty about the future, and concerns about how their carer would cope with them when dying and when bereaved.

Dignity conserving perspectives and practices such as the continuity of self and role were threatened by fatigue, with reduced capacity to achieve and feel pride. In many patients their experience of disclosure and blunt prognosis and lack of support following disclosure, appeared to reduce their hopefulness and resilience. To try to maintain dignity, autonomy and control, many adopted an avoidance and/or carry on as normal strategy. Acceptance and adjustment to fatigue seemed to be difficult because it did not appear to have been acknowledged sufficiently by healthcare professionals to explain, manage or adapt to it. Of concern dignity conserving practices such as a carry on as normal strategy was for many an unrealistic strategy as it appeared to only remind them of their loss of function and dignity when they were unable to achieve and maintain their normal activity and role.

Social dignity inventory. Fatigue increased privacy boundaries. Patients recalled how they withdrew from normal social and working roles and interaction with others.

Social support of friends and family was a physical and psychological resource utilised by patients, but fatigue and its associated symptoms often appeared to threaten this.

The concept of being a burden to their carer was a major concern to the majority of patients, as well as concerns about dying, the aftermath of dying and how their carer would cope. The attitudes of those around them appeared important to patients in the context of the role of their carer and their support needs and the authentic caring attitude of healthcare professionals.

- Thus, loss and dignity (Chochinov et al., 2002) contributing to personal identity threat (Coyle, 1999) seem to have a key role in those dealing with incurable gastrointestinal cancer, as they appear to restrict adaptation, adjustment and the ability to appraise and activate positive coping processes (Parle et al., 1996; Folkman, 1997). Chochinov (2002) found that loss of dignity was generally associated with psychological distress, hopelessness, depression and, and even a desire for hastened death.

The accounts of threat to dignity to some extent helps to define what dignity is for those affected, and seems to be related to the inner or core self of the individual. From a healthcare service perspective and since it has been identified as a key concept in exploring and explaining the perceptions and experiences and levels of psychological distress in those affected by incurable gastrointestinal cancer there may be scope to examine how dignity might be adopted as the key ethical foundation on which to base generic supportive and palliative care in a specialist gastrointestinal cancer centre. Whilst

the intention of this study was to identify participants perceptions and concerns and to identify what might help, it is apparent from applying the findings to theory of dignity, coping, personal identity threat and self worth that there are specific proposals for improvement in clinical practice that can be made and would benefit from further research. This therapeutic potential of issues identified from the study is explored in Section 5.8.

5.5 Implications of the study findings for patients carers and bereaved carers affected by incurable gastrointestinal cancer

From what participants in this study perceived, increased fortitude reflected the readiness, strength and stamina to face the illness (Radwin, 2000), and appeared to have parallel components of dignity identified by Chochinov (2002), and psychosocial and spiritual aspects of meaning based coping (Folkman and Greer, 2000). This is contrary to feeling dehumanised, disempowered and devalued, associated with loss of identity and dissatisfaction identified in dissatisfaction by Coyle (1999), as discussed earlier. This approach appears to have the potential to promote positive appraisal and problem focused coping by supporting individuals in adjustment whilst helping them keep a sense of personal control and a sense of personal accomplishment (Folkman, 1997).

From participants' experiences, a strong component contributing to psychological well-being was related to the assessment and provision of their psychosocial care which in this study appeared to be inextricably linked to an individualized approach to assessment of need and authentic communication skills. In the present study aspects recalled by participants that they experienced or assessed would have helped them adjust to the incurable cancer experience in their role as patient or carer included:

- being treated as an individual,
- anticipating that they might have fears and concerns,
- tailoring information,
- answering questions about the illness and its treatment,
- addressing their concerns about the future,
- correcting misunderstandings,
- acknowledging and alleviating symptoms effectively,
- anticipating future needs by involving other healthcare professionals to plan and implement care for the future.
- helping the patient talk to their carer,
- valuing the presence of their carer in the context of the patient carer relationship

The adjustment to the incurable cancer diagnosis seemed to be associated with appraisal of resources and meaning based coping (Folkman, 1997; Folkman and Greer, 2000) where through sensitive communication, managing uncertainty (including coordinating of care and fatigue, and inclusion of carers) individuals are assisted to come to terms with the incurable diagnosis, and are supported in making new realistic achievable plans from which they can gain satisfaction, and which carers can support them in.

Reflecting on patients, carers and bereaved carers in this study it is apparent that the issues of communication, information and psychological need are inextricably linked within an holistic framework of physical, psychological, social and spiritual components. An example of this might be the ability to acknowledge, and explore when desired, loss of role, loss of good health, loss of body integrity, loss of self esteem, (Hinton, 1996), along with losses secondary to cancer (financial, social and occupational) which appear

to be important. Promoting adjustment by encouraging people to discuss how they feel about their lifestyle changes, their family role change and their fears of dependency, seem to be related to not only loss but also to preparing them through anticipatory grief. Just discussing the issues may improve a sense of autonomy, control and morale associated with dignity, self worth and self-esteem (Chochinov, 2002).

- Taking into account that so many patients and carers adopted carry on as normal or avoidance as a means of maintaining control, exploring these adaptive changes appear to be key.

With an emphasis on the uniqueness of each individual's experience of cancer, which this study has confirmed, it may be possible to help patients and carers allay exaggerated fears by encouraging them to consider different possible outcomes for their situation. It is suggested that helping patients focus on what aspects of the disease and its treatment they have control over and encouraging behaviour modification that will keep them involved and positive could provide a better quality of life. These appear to be related to adjustment and modification of goals to achieve a realistic outcome as found in meaning based coping (Folkman and Greer, 2000).

5.5.1 Policy implications

Application to the CNS role illustrates how it could be potentially utilised in a specialist gastrointestinal cancer centre.

Lloyd-Williams (2003) has suggested that for many the presence of a knowledgeable, caring professional (such as a Clinical Nurse Specialist) within the cancer multidisciplinary team, who is able to assess their needs and disclose truthful information sensitively should suffice to meet psychosocial needs. However, a key aspect of the role

identified in this study was the addressing of uncertainty through effective sensitive communication and coordination of care, to the benefit of patients and carers. Findings from this study suggest that the CNS role working in a generic palliative care setting requires further investigation, but this aspect of sensitive communication and coordination of care appear key to improve the cancer experience for both patient and those important to them. In relation to assessment of psychosocial needs, the issue seems to be about identifying between those who need “companioning” (Thompson et al., 2001) and those who have more complex psychosocial and psychiatric needs, either as secondary to mental health problems aggravated by the challenge incurable cancer presents, or simply as an acute response to the incurable cancer diagnosis.

Lloyd-Williams and Payne (2003) looked at how clinical nurse specialists working in palliative care assess and manage depression in patients. 79% believed their skills were poor in assessment of depression, 92% perceived that they required further training. Whilst there seems to be a skills deficit which may not be met through traditional approaches to advanced communication skills training, this current study has identified that it is not necessarily skills in assessing depression by the CNS which are required in the generic palliative care of those affected by incurable gastrointestinal cancer, though these might be advantageous, but the ability to identify those at risk of psychological distress.

5.5.2 Carers, bereaved carers and cancer policy

Until recently in cancer and palliative care, (DoH, 2004), there was little or no evidence of attempts at reconfiguration of services to meet the needs of this large and important body of people (Krishnasamy, 2001; Thomas et al., 2002). Many of the issues identified

by participants in this study (e.g sensitive communication and coordination of care), are apparently being addressed in The Gold Standards Framework (GSF) (DoH, 2003), as a means of implementing the Supportive and Palliative Care Strategy (NICE, 2004) in primary care.

The 'seven gold standards' of the GSF, which encourage optimal community palliative care for patients in the last year of their life, were developed by a multidisciplinary reference group supported by Macmillan Cancer Care. Support to carers is one of the seven gold standards with an emphasis on regarding carers as an integral part of the care episode. The results of this study from both interviews, HADS and GHQ12 confirm the importance of taking the carers' healthcare into account.

In the GSF it is proposed that emotional support should be offered through listening, keeping the carer fully informed and encouraged and supported to play as active a role in patients care as they and the patient desire. Practical hands on support such as respite care, equipment and access to a night sitter is also offered. Bereavement support is being developed with each GP practice encouraged to develop a practice bereavement protocol where visits are planned, notes tagged and others informed. The GSF is being disseminated nationally. It is currently used in 40% of GP practices across the UK, and from 2005 has been funded by the NHS End of Life Care Programme (DoH, 2005). Clearly its effect is going to take time to implement and there appear to be immense training and human resource implications, but the inclusion of carers needs appears very timely.

Many carers also experienced fatigue, but mainly related to unresolved issues and dealing with fatigue in patients. Hence, there is an urgent requirement to develop and

evaluate supportive care strategies targeted at meeting the explicit needs of carers of patients with gastrointestinal cancer

- Cancer related fatigue is a complex and unpredictable symptom that may give rise to feelings of frustration and resentment in patients. Healthcare professionals should proactively anticipate this symptom and facilitate carer and family communication around this challenging problem.
- Fatigue affects people differently. The importance of including carers in key consultations, and an awareness of tailoring individual information needs is vital to promote self-efficacy in the management and prevention of fatigue for patients and carers.
- Carers with multiple demands or with poor health, and young carers are at greater risk of developing depression when bereaved, and this is an area that requires further investigation.
- Fatigue seems to require multi-dimensional input if it is to be effectively managed. The high probability of its occurrence in incurable gastrointestinal cancer should be anticipated, and both patients and carers equipped and supported to adapt to its limitations.

5.5.3 Implications for practice and carers

Findings from this study seem to indicate that we need to look at carers differently both in primary and secondary care. A recent review of 606 people with cancer and 550 people affected by cancer (carers and family/ friends) examining the emotional impact of cancer (Macmillan, 2006) also appears to support this. Ellis-Hill and Payne (2001) propose that it is the power differential between health care provider and family carer that

needs addressing. Current policy (NICE, 2004) suggests that carers needs should be managed in primary care. However, this study has identified that what is important in such roles as the CNS in gastrointestinal cancer is an understanding and ability to anticipate the cancer trajectory for those affected. From the first symptoms and concerns during the acute phases of investigation, diagnosis, or at recurrence and transition to incurable disease, carers have specific needs which need to be addressed in conjunction with the needs of the patient and as part of the specialist gastrointestinal cancer service. Through exploring patient, carer and bereaved carer experiences and levels of psychological distress it has been possible to identify how there are many key transition points with potential challenges which can become barriers if not appropriately managed in an individualized and sensitive way.

Time is limited in incurable gastrointestinal cancer. Delay in including carers until planning discharge or when in the community misses the opportunity to identify the context of their personal and individual relationship with the patient, their ability or desire to care, and the resources they have (or not) for managing the situation emotionally and practically and initiating appropriate interventions.

The majority of carers in this study saw themselves in terms of their relationship with the patient rather than in a separate role. Their caring role seemed to be based on a desire to show love and concern rather than an additional burden they had taken on. However, as has been discussed, when they witnessed personal identity threat to the patient (Coyle, 1999; Rogers, 2000) or moral identity threat to themselves as a competent carer (Coyle, 1999), and had no acknowledgement or support about the consequences of this, their established relationship with the patient was threatened, and led to negative

appraisal of the situation often resulting in avoidance or carry on as normal by the patient or an inability to activate a coping response.

5.5.4 Promoting autonomy in carers

Nolan (2001) suggested we move towards more innovative programmes of support for family members that promote satisfaction with care giving. Ellis Hill (2001) supported this and suggested we focus on both carer and cared for, so that the quality and meaning of life for both is enhanced. In response to this and taking into account the results of this study it is proposed that the gastrointestinal CNS role has the potential for focusing on a strategy of inclusion and partnership with the patient and carer from the point of referral with a suspected cancer diagnosis. The aim would be to encourage a strategy of togetherness, avoiding collusion and promoting adjustment and meaning based coping.

The role also has the potential to plan, initiate and coordinate access to the healthcare professionals involved in supportive and palliative care in the in the community (DoH, 2004; Grande, 1997; Davis, 1996). This study identified that carers did not expect professionals to ask about their concerns, and carers were often reluctant to approach professionals, as the patient was viewed as the priority, a similar finding to that of Rogers (2000), and Smith (2000). In response to this it is suggested that the ideal model for the CNS role should be one that establishes a working relationship with the patient and carer at the outset of the cancer journey. This would enable assessment and would anticipate need for intervention in the immediate time and the future. It is considered that involving carers from the outset would then more likely encourage them to ask for help before a crisis occurs.

Importantly, the recognition of the carer through assessment of their needs and acknowledging their expertise in their relationship with the patient may promote their self esteem and self-worth and validates their experience as carer (Langer, 1993; Coyle, 1999; Finlay, 1999). Professional interventions that support or develop the role as competent carer may then be viewed as collaborative rather than superior. The model proposed would include a proactive approach where the CNS initiates meetings between themselves and carers to encourage carers to become involved. As well as assessing patient psychosocial needs the CNS would also assess the wider psychosocial needs of carers, including their relationship with family and friends, any other dependants, their own health needs, social and spiritual aspects and their work situation. The importance of this was clearly demonstrated in the present study. The younger carers (under 55yrs old), and young female carers who had other responsibilities (e.g. young children, other dependants) had increased psychological distress, which confirms the findings of Payne et al. (1999) for this vulnerable group, and for some there was also indications that this restricted their ability to activate coping mechanisms when bereaved.

The mutuality, caring and partnership in this model appears to promote acknowledgement of the reality of their situation (Rose, 1997). Coming to terms with progressive incurable disease appears to be necessary for acceptance and adaptation to such symptoms as fatigue. Rose (2001) noted the importance to carers following the death of a loved one that they had discussed the future and could carry on in the future in a way that their loved one would have approved.

This type of intimate conversation would be impossible without mutuality and partnership. This appears to be associated with anticipatory grief and equipping the carer

for their loss which was evident in the recollection of a small number of bereaved carers who, although expressing sadness, considered that because their experience had been favourable, their experiences were positively associated with adjustment in bereavement, a finding supported by (Folkman and Greer, 2000).

Acknowledging the importance of competence, members of the specialist gastrointestinal cancer multidisciplinary team should also be able to assess whether the patient might benefit from referral on to specialist palliative care, psychological or psychiatric assessment. Also other resources such as self-help groups and access to national information services may be useful resources, as well as access to hospice day care as a means of providing access to educational, supportive and cognitive-behavioural methods in those patients requiring more in depth psychological assessment and support. The key issue seems to be assessment at an early stage.

5.5.5 Future therapeutic potential of issues identified from the study

It is viewed as an essential requisite of a specialist cancer centre to explore the views of its client group, in order to improve practice and meet their needs. This study meets the criteria recommended for Cancer services identified by the Department of Health (2000a), and The Supportive and Palliative Care Strategy (NICE, 2004). In looking to the future of services in a specialist gastrointestinal cancer centre, it seems imperative to indicate how the results may be utilized, and how healthcare outcomes based on the implementation of these findings might be developed and implemented.

The impact of receiving a cancer diagnosis of incurable disease is a key point along the cancer trajectory and requires a proactive approach to those affected. There is evidence from this study that this transition may be helped by supporting those involved through

such aspects as planned disclosure, which includes the patient's carer if desired and proactive approach to eliciting concerns about the future, providing tailored information, acknowledging fatigue and accessing supportive and palliative care. Converting knowledge into practice necessitates effective tools or application models to direct this process. With this in mind, it is possible to predict further use for the case study's findings, and to discuss how they may be developed into practical application for assessing and meeting the needs of those affected by incurable gastrointestinal cancer.

A patient centred approach to meeting need appears to be key. As each of the main themes of the research has described there are factors that contribute towards either negative or positive well-being in those affected by gastrointestinal cancer, and a key contribution to this is the relationship of healthcare professionals to promote or reduce capacity to cope through aspects such as the theory explored of caring and respect. This foundation of care has the potential to promote self-worth, dignity and integrity in those affected (Chochinov, 2002). This study demonstrates the importance of advanced communication skills with an emphasis on assessment of concerns by all healthcare professionals involved with such patients and their carers, and an environment that supports those healthcare professionals working in such a culture, such as that revealed by Heaven et al. (2006).

5.5.5.1 Application of a dignity promoting model in generic palliative care in gastrointestinal cancer

This study has shown that not being treated with dignity and respect can undermine a sense of value or worth. The three major dignitary themes identified by Chochinov (2002) have been shown to be potentially useful in how we might characterize and

address the concerns and psycho-social needs of this cancer population. Illness related concerns, dignity conserving perspectives and practices and social dignity inventory appear to be key for what matters and for improving the outcome for those affected. More recently, Chochinov (2007) has reaffirmed the need for healthcare providers to affirm the patient's value, seeing the patient as they really are, rather than how their illness has debilitated them in order to preserve a sense of dignity. He suggests that this approach and the intimate connection between care provider's affirmation and patient's self perception, underscores the basis of dignity conserving care which is applicable across all aspects of care and not just palliative care. In considering a dignity preserving model he suggests that Attitude, Behaviour, Compassion and Dialogue can be the core framework (Chochinov 2007). He also encourages a culture which could be integrated into the cancer multi-disciplinary team that would support a questioning, but supportive philosophy and culture of applying the core framework to each patient discussion and consultation.

- In examining attitudes and assumptions he encourages a reflective process of how would I feel in this patient's situation?
- Professional behaviours including communication towards patients must always include respect and kindness and show the patient that they have your full attention.
- Compassion like empathy acknowledges the person beyond their illness, and can be shown in communication, spoken or unspoken.
- Dialogue is a critical element of dignity conserving care, and must acknowledge the person beyond the illness itself.

Whilst the model is applicable to all members of the cancer multi-disciplinary team through development of a dignity preserving culture, this is a future development, but one which can now be clearly based on the evidence from the expert users of the service.

5.6 Limitations to the study

Whilst this study has revealed new findings in the generic palliative care aspects of gastrointestinal cancer, and has challenged some earlier findings it is also necessary to address the limitations of this exploratory evaluation case study, with the potential for rectifying such limitations through future studies.

Limitations to this study are predominantly due to the constraints of a single site case study and the limited resources of a single part-time researcher. More resources might have allowed the researcher to consider a multi-centre study, sourcing data from multiple cases, and even a longitudinal study which may have given a wider perspective of the experience of those affected by incurable gastro-intestinal cancer, including post bereavement adjustment.

A small number of studies in the literature demonstrated the benefits of study over time, and the initial proposition was to interview carers when in their caring role and subsequently when bereaved. However, as was discussed in the methodological considerations, because a number of carers required healthcare intervention (identified in the preliminary and pilot interviews), to have then interviewed these carers when bereaved would have risked introducing bias to the study. To not have intervened and would have been unethical.

It would have been of interest to assess the influences of time through repeat interview and measures of psychological well being at perhaps 3 and 6 month intervals with

participants. This might have highlighted those individuals who appeared to be adjusting or not to their experience of living with or caring for someone with incurable gastrointestinal cancer, or adjustment over a period of time when bereaved.

Findings do not claim to be generalisable as they are from a single case in a single location. However, participants were sourced from 100 mile radius from multiple other non specialist hospitals and this along with the individual unique response of each participant served to emphasise the need for an individualised approach to those affected by this cancer. In considering generalising to theory, this study substantiates much of the literature relating to coping theory and theory of personal identity threat and loss, and these are areas that would benefit from further in depth study in this cancer population.

Important themes such as sensitive communication and fatigue in gastrointestinal cancer have been revealed and described in this study. Their relevance and the consequences for those affected by gastrointestinal cancer is an area that would benefit from future exploration and enquiry

However, in summary this study has more clearly identified the needs of patients, carers and bereaved carers in an under researched area of cancer care, and how their experiences may affect them psychologically. The implications for a specialist cancer centre in light of these findings have been explored.

5.6.1 Future Research

This is a preliminary study and it has served to identify the emphasis for future research into the needs of this group of patients and their carers. Further research might illuminate this situation more, and substantiate the key adaptation and psychological support aspects in this cancer population. The HADS and assessment of coping response has revealed

that patients are likely to be experiencing anxiety and adjustment disorder rather than depression.

- When considering the results of this study compared to studies in palliative care settings (many of which are hospice based), indications are that the findings of studies of levels of psychological well-being/distress in palliative care may not be accurately compared with a specialist gastrointestinal centre providing generic palliative care. This single case study has revealed that during the transition to palliative care in gastrointestinal cancer increased levels of adjustment and anxiety in patients predominate as opposed to the increased levels of depression found in many specialist palliative care studies.

Perhaps this is where the focus for psychological support in the transition to generic palliative care (NICE, 2004) in a Specialist Gastrointestinal Cancer Unit should concentrate its efforts, where the use of other measures alongside the Concerns Checklist might be both a means of constructing a more person centred consultation such as that utilized by Rogers et al. (2008).

The current study had the advantage of comparing and contrasting multiple sources of data. The aim was not to specifically identify cause and effect, but rather explanation and association. The clusters of physical and psychological revelations such as those found in the analysis of fatigue could to some extent be explained by the detrimental organic effect of progressive cancer. However, from 3 sources of data (interviews, Concerns Checklist and HADS) a more holistic interpretation of the psychological effects of fatigue in those affected has been revealed. The application to theory of loss, dignity, and self worth offer greater understanding to inform clinical practice

However, the clusters of analysed data emerging from analysis supply a more ontological perspective and a greater understanding of the nature of the transition and what variables appear to promote adjustment at this stage have been revealed including what processes might reduce incidence of anxiety in patients and psychological distress, (including depression), in carers and the bereaved. However, because the process at this stage of the cancer trajectory in gastrointestinal cancer is not clear-cut and with a focus on service provision and clinical practice perhaps this study is revealing that the important issue is interventions/ strategies for managing clusters of e.g. concerns rather than just measuring depression. The Concerns checklist with the HADS has revealed itself as a prognostic indicator for anxiety in the future. Perhaps this is an area that could be further investigated in gastrointestinal cancer with a longitudinal approach identified as beneficial in case study research.

5.7 Summary of major findings from the study

1. Ultimately, this study has entered new territory by exploring an earlier stage of the cancer trajectory where to date little research examining psychological issues in gastrointestinal cancer has been undertaken.
2. Patients' carers and bereaved carers affected by incurable gastrointestinal cancer have varying, individual needs. The importance of assessing and meeting these needs for adjustment and coping is reflected in their perception and concerns and their measures of psychological well-being/distress.
3. The link between witnessing effective care to the patient and psychological well-being/distress in carers both when in their caring role and as recalled when bereaved is supported in this study.

4. The consequences for carers for access to information, access to support in their role as carer and ultimately as the key carer for the patient if excluded from disclosure has consequences not previously explored in the cancer or gastrointestinal literature.
5. Insight into the coping strategies previously recognized in carers (Rose1997) and the association and influence/ consequences of experience of healthcare in cancer is revealed to an extent not previously explored in the cancer or supportive and palliative care literature.
6. The physical health deterioration as reflected in fatigue had a strong influence over psychological health, and all patients expressed difficulty over the personal loss that fatigue inflicted upon them. Loss of role, loss of self esteem are issues that requires further investigation in those affected by fatigue in gastrointestinal cancer
7. The issues that support improved psychological well-being in patients and their carers include service strategies that incorporate i) an individualised approach with sensitive communication, (ii) addressing issues in relation to living with uncertainty (iii) promoting individual coping strategies
8. There seem to be key healthcare responsibilities that need to be proactively addressed in order to assist patients and their carers come to terms with their incurable diagnosis.
9. There are indications from the literature that creating a culture of support to healthcare professionals in a specialist cancer centre may positively impact on

assessing and addressing sensitive issues with patients and carers. This requires further investigation.

10. In view of the issues of for example, delayed diagnosis, poor disclosure there are wide ranging implications that are outside of the direct responsibility of a specialist cancer centre. However, this study has demonstrated the importance of these aspects of cancer care, and this is clearly an area that requires further exploration in relation to cancer policy.
11. The experience of those affected by incurable gastrointestinal cancer has been illuminated. 92 individuals have told their personal stories and in doing so they have given many examples of what has contribute to their psychological well-being/distress It appears that assessing and meeting individual needs accompanied by an emphasis on dignity conserving practice which incorporates sensitive communication, backed by information and support that reduces uncertainty, constitute the key factors in the construct of what helps those affected by incurable gastrointestinal cancer.

5.8 Summary

Through the findings in the study it has been possible to identify implications for specialist gastrointestinal cancer services, which strongly reflect meeting the needs of patients and carers affected by gastrointestinal cancer, and how these might improve the outcome for those left behind.

Emphasis is given to the psychological components of communication skills and adaptation. This application of participant findings illustrates how the important issues to both patients and cares such as loss, addressing self worth and dignity can be addressed

which may have positive affect to those adapting to bereavement. It also identifies a model that could be achieved, maintained and evaluated by those affected by this cancer.

However, in acknowledging the complexity of the data, and despite the attempts at rigour and quality control, others who read this story may interpret the findings differently. It is argued that this is good science, and reinforces the aim of analytical induction. With such a complex phenomena it is more likely that opinions would vary than for there to be a strong and resolved model, but not only does the approach used reveal ideas for future research, it also emphasizes the need for dignity as well as flexibility in clinical practice.

Fowlie (1989) captures the essence of both the flexibility, individuality and adjustment components of such practice.

Quality of Life is a construct of individual design for each patient, which change with time and circumstances. It may not be readily or usefully measured. It may be amenable to improvements only for individuals in individual ways and that therefore is not useful for policy making other than a policy which allows for greater flexibility in patient care. In advanced cancer when the patient's life is limited and he has some awareness of this, his needs and concerns are highly individualistic, not readily amenable to measurement or estimate by observers. Ultimately, his quality of life is determined by the extent to which he has come to terms with his condition and is at peace with himself.

Fowlie 1989

It is argued that the findings of this study have the potential to improve the service to those affected by incurable gastrointestinal cancer. However, the impact of such changes remains to be evaluated in further investigation.

5.9 Reflexivity

This section explores the important issues experienced by the researcher during the study in relation to the concept of reflexivity. Yin (2003) emphasises the importance of reflecting on the research experience in relation to the impact of the researcher upon the conduct and outcomes of the study, including the research design, data collection and analysis. Reflexivity assumes that the researcher should engage in continuous self-critique and self-appraisal and explain how the experience has or has not influenced the research process (Koch and Harrington, 2004). The account will be given in the first person and will focus on some of the issues that emerged during the course of undertaking this research through an ongoing reflective conversation (Mulhall et al., 1999).

As a senior clinical nurse I was aware at the outset that I both influenced and was influenced by the process of engaging in this work (Horsburgh, 2003). A previous research study (Byrne, 1997) had firmly established my interest in research in cancer care, and in particular the psychological needs of those affected. I therefore came to this study with some esoteric knowledge and with an empathetic approach to these people. I was aware that the research outcomes plus any ensuing therapeutic impact in the care of those affected by gastrointestinal cancer would be influenced by my stance as the researcher.

Before the study commenced I was a senior nurse working with a multidisciplinary team caring for patients with a range of gastro-intestinal cancers. With the centralisation of cancer services (Department of Health, 2000b), cancer teams became more specialised and during the research process, (but after data collection was completed) the liver cancer

team with whom I elected to work was transferred to another Hospital Trust 6 miles away from where the study took place. However, close links are still maintained through regular meetings both at Cancer Network level and through clinical audit.

At the outset, when considering the potential research design I was conscious that my characteristics as a cancer nurse probably helped me gain acceptance in the field by healthcare colleagues and therefore assisted access to potential participants. However, having made my motives clear to other healthcare professionals and participants, because of the case study approach I had elected to use, the insight I already had into those affected by gastrointestinal cancer was viewed as a benefit, rather than a risk.

This was particularly in relation to use of an active interview approach (Holstein and Gubrium, 1995) using interview guidelines, where because I could understand a great deal of what I was hearing, I was able to interact in the interview, and check out my interpretation with the participant there and then. Thus, I found myself using reflexivity with participants in the interview process in a reciprocal way. Yin (2003) emphasises the benefit of an open interview technique in case study research, suggesting like Holstein and Gubrium (1995) that such an approach enables the participant to become an informant in the research process rather than just a mere respondent or vessel of answers.

Whilst my background including my beliefs and interests and value judgements might have influenced why the research was proposed and undertaken (Mulhall, 1999), the method I selected was also influenced by my desire to let participants tell it as it was. I wanted to hear about their experiences to know about their concerns and levels of psychological well being/distress and to better understand how they considered the specialist gastrointestinal healthcare team could improve things for them.

A major dilemma explored during the preliminary and pilot stages of the study design was whether to involve patients and carers with whom I as the researcher had been professionally involved. The process of whether I would be able to completely avoid any bias in the study by such approaches as bracketing my own views was extensively debated with academic experts, and patients and carers themselves. More importantly I wanted to avoid undermining patient and carer autonomy, but also to elicit concern about bias in influencing the interview or restricting the participant's true opinion of their experience. However, contrary to the traditional research assumption the risk of my influencing bias, field notes taken during this early phase of the study revealed how each participant considered that my prior knowledge contributed to their experience in the research interview and they all stated that they felt they were encouraged and supported to give opinion freely and did not in any way feel obliged or restricted, and able to tell it how it was "spots and all".

Thus the study evolved as reciprocal in nature because of the nurse researcher relationship I developed with all the participants and not just the twelve known to me professionally. Personally I reflected on how my interview approach moved along a continuum that wavered between neutrality when broaching a new area of discussion as guided by the interview guidelines to one of reciprocity when the patient revealed an area familiar to me as the researcher, and how an interactive process ensued. However, I considered that I was using reflexivity with all participants in a similar fashion from a feminist experiential standpoint (Mauthner et al., 2003), which rather than biasing the study, actually promoted understanding of the experience of participants involved, a view

supported in qualitative approaches (such as the interview approach) by Sandelowski (1986).

Whilst I had set out with the aim of professional non-involvement with the data, during the interview process I actually found the reflexive approach enabled a more complete picture to be revealed of the issues important to the expert participants. After each interview whilst I reflected on the content of the interview, as the study progressed I felt more comfortable with my position as nurse-researcher and felt less need to continually justify my interview approach.

Throughout the study I was aware of the dichotomy of my need as a researcher to achieve full and accurate data gathering set against my therapeutic role of cancer nurse and a need to do no harm. Kleinman (1991) suggests that field researchers' feelings not only affect the research but also become part of the process itself. Having identified in the pilot study that it might be difficult to separate out the roles of nurse and researcher as well as my interpretation of what was being told to me about their experiences of care, I was glad that I had established a set of safety rule (Section 2.10) to adhere to when participants became distressed.

Over 35 % of the sample demonstrated a need for professional intervention. Where this was identified I acknowledged the need expressed by the participant during the interview, explored it with them, and then suggested that it might be useful to come back to this once the interview was completed. In this way the researcher was able to maintain her research role, but when the interview was completed was able to revert to clinical role, and when necessary and with the participant approval, was able to involve other healthcare professionals in order to address the patient or carer need or concern.

Whilst other studies have shown how participants appear to welcome the opportunity to share experiences and discuss the care they have received (Rose and Webb, 1997; Payne et al., 1999, 2002; Luker et al., 2003; Woods et al., 2003), this study has shown how a reciprocal approach can develop an insight into participant experience which they consider does not cause undue distress.

Despite listening to patients every day in my clinical work, and whilst I felt prepared for the emotional impact of listening to participants experiences, I was sometimes surprised how affronted I felt for them because of the strength of the expression of their feelings and frustrations. However, it was this response which prompted me to then explore the literature looking at the concepts of dignity (Chochinov, 2002), self-worth (Rogers, 2000), personal identity threat (Coyle, 1999) and adaptation, (Passik, 2002).

In the early part of data collection I decided that I should only undertake a maximum of two interviews per day. My experience of undertaking four interviews on one day, having travelled ninety miles to the location, to meet two patients and their carers, left me feeling physically and emotionally drained and there was concern that this might have affected my interaction with participants and the quality of the interview.

It has been suggested that fieldwork is about emotions (Coffey, 1999) and that we have feelings about our research setting, people and experiences. It is suggested that this can show itself in feelings of pain, joy, hurt, excitement, anger, love, confusion, satisfaction, loss happiness and sadness – and certainly this was my experience. I have felt sad when a patient recalled to me how much he missed fell walking and playing cricket, only to find in the next moment, laughing with him as he said ‘I don’t play cricket anymore - but then neither do the England Team!’

I felt concern and intervened at the end of the interview when a patient told me he experienced a lot of pain at night, or when carers told me they had no access to support and did not know what to expect next. I felt sadness and concern when a bereaved carer told me this was the first time they had spoken about their experience to anyone and that life really was not worth living anymore. To have not reverted to clinical role and intervened would have been both unethical and neglectful on my part having recognised this need in participants.

In the early part of data collection I became aware of the number of issues revealed by participants that led to personal reflection on both my skills as a researcher and as a cancer nurse. Whilst I was already receiving clinical supervision in my role as a cancer nurse, I also decided to seek clinical/ academic support on a consistently regular basis from one of my academic supervisors, to explore the implications of the study findings. Coffey (1999) described the experience of fieldwork as a personal journey of self-discovery. Bolton (2000) suggested that an important aspect of the caring role in nursing is emotional labour. Whilst encouraged to offer empathy (Reynolds et al., 2000), empathy being the ability to feel in oneself the feelings being experienced by someone else, I have been surprised at the strength of my emotions. Despite stirring these emotions in participants, and despite a need to intervene at the end of a number of interviews, every participant thanked me at the end of the interview and many stated what a positive experience it had been for them and how they hoped it would help others.

The requirement for support to researchers working in sensitive areas of cancer and palliative care has recently been highlighted by Payne et al. (2007). On reflection I find that this ethos of support appears to have some comparison with the study by Booth et al.

(1996), and Heaven et al. (2007) where the environmental and clinical support to those working in sensitive areas of cancer was found to promote improved communication and information exchange with cancer patients. Furthermore, it also had the effect of sustaining and nurturing skills in the healthcare professional involved.

- Such findings and my own personal experience of clinical and research supervision throughout this study suggest that the benefits for developing such a culture within a specialist gastrointestinal cancer service may have the potential for improving the generic palliative care aspect of the service

Having access to this clinical research supervision also assisted my reflections and professional concerns I had in that I might find myself judging other healthcare professionals with whom I worked. However, I had discussed this with many of them when I went to talk to them about recruiting patients to the study and each said they would welcome feedback as to how they could improve practice. What I did find was that I tended to identify with what was happening or question whether my practice was similar or how it could be improved.

Ultimately, reflexivity, as a key part of the theoretical framework for this study has allowed me to establish a collaborative, non-hierarchical relationship between myself as a nurse researcher and participants. Adhering to a framework for analysis (Yin, 2003), and displaying such data in a process of transparency in matrices (Miles and Huberman, 1984) has fostered interpretation through pattern matching and explanation building. Through reflexivity, participants have played a key active role in the construction and validation of knowledge about incurable gastrointestinal cancer. With this in mind it has

been possible to bridge the nurse researcher role in a professional manner and to the benefit of all involved.

5.10 Conclusions

This study has illustrated the wide diversity amongst those affected by incurable gastrointestinal cancer. The perceptions and concerns of 92 people have been listened to, and their levels of psychological well-being measured. It offers new insight in a number of areas and in particular the association of health service care and how this increases or decreases access to coping/ improving levels of psychological well being. New insight is offered in areas such as those advocated in appraisal of coping resources by Parle in 1996, what influences positive psychological well-being in coping theory by Folkman in 1997, and what can contribute to personal identity threat (Coyle, 1999), dignity and self worth (Chochinov, 2002).

A single case study approach has enabled an in-depth study of the meaning of lived experience of incurable gastrointestinal cancer. The use of multiple data collection methods has enabled valid comparison and highlighted strong links between levels of psychological distress and the individual perception of poor experience of disclosure, exclusion if a carer, limited access to information. Links between the physical incapacity experienced by fatigue were also compounded by additional factors that centred on the personal psychological attributes of fatigue and how they affected patients and their carers psychologically.

The current case study using triangulation was able to reveal individual meaning as well as collaborative interpretation of the constituents and processes of living, dying, or caring for someone with incurable gastrointestinal cancer. The breadth of such an approach has

not been found previously in a British study in gastrointestinal cancer, and this exploratory and explanatory approach provides evidence and a strong new insight into the effects of incurable gastrointestinal cancer upon those affected. Fisher's exact test was highly significant ($p= 0.002$) for anxiety and poor disclosure in patients. Contributing factors to this are explored. Patient anxiety was significantly correlated with total concerns ($r=0.419$ $p=.017$). In carers Fisher's exact test was significant for psychological distress and information ($p = .029$) with a trend for younger female carers and bereaved carers to be more anxious than older carers. There was a clear association between insensitive disclosure, unmet information needs, poor coordination of care and increased psychological distress in carers, with unresolved consequences when bereaved. Such results hold potential for practical application and key quality issues which address how a specialist gastrointestinal cancer service should develop its standards of care and audit practice.

By entering the participant's world, although very briefly, this study has explored the perceptions and concerns of those affected by incurable gastrointestinal cancer, and links with coping and psychological well-being. The closing section of this chapter has reiterated justification for study into this area. There is a need to pursue this work with ongoing study, whilst publishing and promoting evidence of the positive outcomes for all parties involved.

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Your Ref:

LIVERPOOL RESEARCH ETHICS COMMITTEE



Dear Mrs Byrne

AN EVALUATION OF THE NEEDS OF PATIENTS RECEIVING PALLIATIVE CARE FOR UPPER GASTRO-INTESTINAL CANCER (AND THEIR MAIN CARER)

The above study was discussed at a meeting of the Liverpool Research Ethics Committee on 7 April 1999 and I am pleased to inform you that no ethical objection was found.

The Trust or appropriate Health Service Authority must be asked for permission for the study to proceed. Please contact

Any proposed amendments to the protocols must be notified to the Liverpool Research Ethics Committee for approval before implementation.

Yours sincerely

Dr E J Tunn
Chairman
Liverpool Research Ethics Committee



Direct Line:
Fax:
Your ref:
Our ref:
Please ask for:

30 June, 1999

Dear Ms Byrne,

Re: Project ID: 1456 - An evaluation of the needs of patients receiving palliative care for upper gastro-intestinal Cancer and their main carer.

Thank you for letting me have the completed registration form and the completed costing form for the above trial. I am please to confirm that the Trust will be happy for you to conduct this work on its premises. I understand that the project has received Ethical approval and the appropriate Indemnities have been agreed.

Please contact me if you require any further advice or assistance.

Yours sincerely,

Professor A Shenkin
Director of Research & Development

APPENDIX THREE

PATIENT INFORMATION SHEET

An evaluation of the needs of patients receiving palliative care for upper gastrointestinal cancer and their main carer

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully and ask others if you wish. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study is using two questionnaires and an interview to explore the experiences of patients and carers affected by incurable upper gastrointestinal cancer. Your Medical Consultant has agreed to us approaching you about this study.

If you agree to participate, we will also ask you if we can invite your main carer/ friend to be involved and to complete similar questionnaires and an interview. The information you (and your carer) give us will help us to improve our understanding of how upper gastrointestinal cancer affects both patients and their carers. The interview with you and your carer will take place separately and not together.

Why have I been chosen?

Patients and carers affected by incurable upper gastrointestinal cancer are able to take part in this study.

We will be studying about 30 patients and 30 carers during the next 12-18 months.

Do I have to take part?

Your participation in the study is voluntary and it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and this will not affect your future care.

What will happen to me if I take part?

If you agree to participate I will contact you and make an appointment either to meet in your own home, or in an appropriate clinic setting at the hospital. You will be asked to fill in two questionnaires. The questionnaires enquire about how you have been feeling recently, and take between 5-10 minutes to complete.

We will also ask you to take part in an interview which asks you questions about your experience of incurable upper gastrointestinal cancer. With your permission the interview will be recorded.

What are the possible benefits of taking part?

Taking part in this study will not benefit you. However, the information will be used to evaluate the current service supplied to patients and their carers affected by upper gastrointestinal cancer, and this should benefit patients and carers in the future.

Will my taking part in this study be confidential?

All information which is collected about you during the course of the research will be strictly confidential. The questionnaire will not contain your name but only a code and your birth date. Likewise, the tape recording of your interview will be transcribed and coded and will not contain your name. Once transcribed, the tape recording will be destroyed.

The information from this study about you will be held in a computer (in a coded way) and will be used for this research. The computer records about you will be held in a computer in The School of Health Research at Liverpool John Moores University (in a coded way).

Your G.P. will be informed that you are taking part in the research.

What will happen to the results of the research study?

Once the study has finished the results will be presented to the healthcare team at the hospital involved and published in a scientific journal. Patients and carers will not be identified.

Contact for further information

If you require any further information about the study please contact:

Clare Byrne,
Advanced Nurse Practitioner /Research Fellow
Liverpool John Moores University

Dated 11/01 2001.

APPENDIX FOUR

CARER INFORMATION SHEET

An evaluation of the needs of patients receiving palliative care for upper gastrointestinal cancer and their main carer

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully and ask others if you wish. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study is using two questionnaires and an interview to explore the experiences of patients and carers affected by incurable upper gastrointestinal cancer. The medical Consultant caring for your relative/friend has agreed to us approaching you about this study.

If you agree to participate, the information you (and your relative/friend) give us will help us to improve our understanding of how upper gastrointestinal cancer affects both patients and their carers. The interview with you and your relative/friend will take place separately and not together.

Why have I been chosen?

Patients and carers affected by incurable upper gastrointestinal cancer are able to take part in this study.

We will be studying about 30 patients and 30 carers during the next 12-18 months.

Do I have to take part?

Your participation in the study is voluntary and it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and this will not affect your future care.

What will happen to me if I take part?

If you agree to participate I will contact you and make an appointment either to meet in your own home, or in an appropriate clinic setting at the hospital. You will be asked to fill in two questionnaires. The questionnaires enquire about how you have been feeling recently, and take between 5-10 minutes to complete.

We will also ask you to take part in an interview which asks you questions about your experience of caring for someone with upper gastrointestinal cancer. With your permission the interview will be recorded.

What are the possible benefits of taking part?

Taking part in this study will not benefit you. However, the information will be used to evaluate the current service supplied to patients and their carers affected by upper gastrointestinal cancer, and this should benefit other patients and carers in the future.

Will my taking part in this study be confidential?

All information which is collected about you during the course of the research will be strictly confidential. The questionnaire will not contain your name but only a code and your birth date. Likewise, the tape recording of your interview will be transcribed and coded and will not contain your name. Once transcribed, the tape recording will be destroyed.

The information from this study about you will be held in a computer (in a coded way) and will be used for this research. The computer records about you will be held in a computer in The School of Healthcare Research at Liverpool John Moores University (in a coded way).

Your G.P. will be informed that you are taking part in the research.

What will happen to the results of the research study?

Once the study has finished the results will be presented to the healthcare team at the hospital involved and published in a scientific journal. Patients and carers will not be identified.

Contact for further information

If you require any further information about the study please contact:

Clare Byrne,
Advanced Nurse Practitioner /Research Fellow
Liverpool John Moores University

Dated 11/01 2001.

APPENDIX FIVE

BEREAVED CARER INFORMATION SHEET

An evaluation of the needs of patients receiving palliative care for upper gastrointestinal cancer and their main carer

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully and ask others if you wish. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study is using two questionnaires and an interview to explore the experiences of patients and carers affected by incurable upper gastrointestinal cancer. The medical Consultant who cared for your deceased relative/friend has agreed to us approaching you about this study. If you agree to participate, the information you give us will help us to improve our understanding of how upper gastrointestinal cancer affects both patients and their carers. The interview with you and your relative/friend will take place separately and not together.

Why have I been chosen?

Patients and carers affected by incurable upper gastrointestinal cancer are able to take part in this study. We will be studying about 30 patients, 30 carers and 30 bereaved carers during the next 12-18 months.

Do I have to take part?

Your participation in the study is voluntary and it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and this will not affect your future care.

What will happen to me if I take part?

If you agree to participate I will contact you and make an appointment either to meet in your own home, or in an appropriate clinic setting at the hospital. You will be asked to fill in two questionnaires. The questionnaires enquire about how you have been feeling recently, and take between 5-10 minutes to complete.

We will also ask you to take part in an interview which asks you questions about your experience of caring for someone with upper gastrointestinal cancer. With your permission the interview will be recorded.

What are the possible benefits of taking part?

Taking part in this study will not benefit you. However, the information will be used to evaluate the current service supplied to patients and their carers affected by upper gastrointestinal cancer, and this should benefit other patients and carers in the future.

Will my taking part in this study be confidential?

All information which is collected about you during the course of the research will be strictly confidential. The questionnaire will not contain your name but only a code and your birth date. Likewise, the tape recording of your interview will be transcribed and coded and will not contain your name. Once transcribed, the tape recording will be destroyed.

The information from this study about you will be held in a computer (in a coded way) and will be used for this research. The computer records about you will be held in a computer in The School of Healthcare Research at Liverpool John Moores University (in a coded way).

Your G.P. will be informed that you are taking part in the research.

What will happen to the results of the research study?

Once the study has finished the results will be presented to the healthcare team at the hospital involved and published in a scientific journal. Patients and carers will not be identified.

Contact for further information

If you require any further information about the study please contact:

Clare Byrne,
Advanced Nurse Practitioner /Research Fellow
Liverpool John Moores University

Dated 11/01 2001.

APPENDIX SIX
CONSENT FORM

Identification Number for this study:.....Initials.....

An evaluation of the needs of patients receiving palliative care for upper gastrointestinal cancer and their main carer

Please initial box

1) I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.

3) (Patient only) I understand that sections of any of my medical notes may be looked at by responsible individuals or regulatory authorities and I give permission to this.

4) I give permission for the information to be held in a computer (in a coded way) .

5) I agree to take part in the study.

Name of Patient

Date

Signature

Name of Person taking consent

Date

Signature

Date

Signature

Researcher

If you have any further questions, please contact

Clare Byrne,
Advanced Nurse Practitioner /Research Fellow
Liverpool John Moores University

Dated 11/01 2001. Version 1

APPENDIX SEVEN**GP letter**

Date

Dear Dr,

Re Name and address of patient/carer

Project: An evaluation of the needs of patients receiving palliative care for upper gastrointestinal cancer and their main carer

I am writing to inform you that the above patient has agreed to take part in a study which investigates their quality of life.

This will involve asking them to complete 2 quality of life questionnaires, and to take part in an interview.

Your patient has been given written information about this project and they have given consent to complete the questionnaires and to take part in the interview. Ethical committee permission has been obtained to undertake this project.

We will assume you agree for your patient to take part in this study. Please will you let us know if you would rather they did not.

Yours sincerely

Clare Byrne
Advanced Nurse Practitioner /Research Fellow
Liverpool John Moores University

Dated 11/01/2001

APPENDIX EIGHT

Hospital Anxiety and Depression Scale (HADS) Zigmond and Snaith 1983)

I feel tense or wound up	Most of the time	
	A lot of the time	
	From time to time , occasionally	
	Not at all	
I still enjoy the things I used to	Definitely as much	
	Not quite so much	
	Only a little	
	Hardly at all	
I get a sort of frightened feeling as if something awful is about to happen	Very definitely and quite badly	
	Yes, but not too badly	
	A little but it doesn't worry me	
	Not at all	
I can laugh and see the funny side of things	As much as I ever could	
	Not quite so much	
	Definitely not so much now	
	Not at all	
Worrying thoughts go through my mind	A great deal of the time	
	A lot of the time	
	From time to time but not too often	
	Only occasionally	
I feel cheerful	Not at all	
	Not often	
	Sometimes	
	Most of the time	
I can sit at ease and feel relaxed	Definitely	
	Usually	
	Not often	
	Not at all	

I feel as if I've slowed down	Nearly all the time	
	Very often	
	Sometimes	
	Not at all	
I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all	
	Occasionally	
	Quite often	
	Very often	
I have lost interest in my appearance	Definitely	
	I don't take as much care as I should	
	I may not take quite as much care	
	I take just as much care as ever	
I feel restless as if I have to be on the move	Very much indeed	
	Quite a lot	
	Not very much	
	Not at all	
I look forward with enjoyment to things	As much as I ever did	
	Rather less than I used to	
	Definitely less than I used to	
	Hardly at all	
I get a sudden feeling of panic	Very often	
	Quite often	
	Not very often	
	Not at all	
I can enjoy a good book or radio or TV programme	Often	
	Sometimes	
	Not often	
	Very seldom	

APPENDIX NINE

GHQ12: GENERAL HEALTH OVER THE PAST FEW WEEKS

Code number Initials Date **Please read this carefully:**

We should like to know how your health has been in general **over the past few weeks**. Please answer ALL the questions by ticking the box below the answer which you think most applies to you.

HAVE YOU RECENTLY: (tick one box)

1. been able to concentrate on whatever you're doing?

Better than usual

Same as usual

Less than usual

Much less than usual

2. lost much sleep over worry?

Not at all

No more than usual

Rather more than usual

Much more than usual

3. felt you were playing a useful part in things?

More so than usual

Same as usual

Less useful than usual

Much less useful

4. felt capable of making decisions about things?

More so than usual

Same as usual

Less so usual

Much less capable

5. felt constantly under strain?

Not at all

No more than usual

Rather more than usual

Much more than usual

6. felt you couldn't overcome your difficulties?

Not at all

No more than usual

Rather more than usual

Much more than usual

HAVE YOU RECENTLY: (tick one box)

7. been able to enjoy your normal day-to-day activities?

More so than usual

Same as usual

Less so usual

Much less than usual

8. been able to face up to your problems?

More so than usual

Same as usual

Less able than usual

Much less able

9. been feeling unhappy and depressed?

Not at all

No more than usual

Rather more than usual

Much more than usual

10. been losing confidence in yourself?

Not at all

No more than usual

Rather more than usual

Much more than usual

11. been thinking of yourself as a worthless person?

Not at all

No more than usual

Rather more than usual

Much more than usual

12. been feeling reasonably happy all things considered?

More so than usual

About the same as
usual

Less so than usual

Much less than usual

APPENDIX TEN

The Concerns Checklist.

Please answer the following questions. If you answer 'Yes' to any question, please comment in the space provided.

Do you have any concerns about	Yes	No	If yes, comment please
Your current illness?			
How you are feeling physically?			
The effects of any treatment on your body?			
Feeling different from other people?			
Feeling upset or distressed?			
Not being able to do the things you used to?			
The future?			
Money worries?			
Your relationship with your partner?			
How you feel about yourself?			
The support you are getting?			
Any other concerns?			

APPENDIX ELEVEN

Summary of the Results of the Concerns Checklist

Concern	Yes / patient code / explore	No / patient code / explore
<p>Your current illness</p> <p>21 (61%)</p>	<p>P1 why the CEA level wasn't checked more frequently after my first cancer was removed</p> <p>P3 Yes, but I know the best is being done</p> <p>P4 Yes</p> <p>P5 Yes I put on a brave face</p> <p>P7 only when I'm on my own, but it soon passes</p> <p>P9 I got to know about it just after my wife died. I get the odd twinge and I think oh blimey, now behave yourself you know. It's just one of those things you have to accept</p> <p>P11 Concern that it will grow out of control, and will not be treatable with chemo, that's my main worry.</p> <p>P12 Sometimes, what to anticipate next, because I want to maintain my independence as long as possible, be in control.</p> <p>P13 Yes, but I've also had a stroke and I've been left with diarrhea from radiotherapy</p> <p>P18 Yes, keeping it under control</p> <p>P19 Yes, it seems to be racing ahead, taking over, but I know everything has been done.</p> <p>P22 Yes, but I've accepted it, I'm just carrying on.</p> <p>P23 Yes, to a degree, but twenty three hours of the day I block it out.</p> <p>P24 Yes, how will I finish up? With severe pain? That's the vision I've got, I don't want to know.</p> <p>P25 Yes, now it's in the liver, are the tumours going to shrink with chemo?</p> <p>P26 Yes, is it going to take off again and when?</p> <p>P27 What's next, how long? Shots in the locker.</p> <p>P29 Yes, has it spread</p> <p>P31 Yes, it's a killer illness, I'd rather live 20 or 30 years more.</p> <p>P32 Yes, the tiredness</p> <p>P33 Yes, what's going to happen, will it come back? Uncertain about the future.</p>	<p>No, but.....</p> <p>P8 <i>No, but I sometimes wish I was back to normal</i></p> <p>P10 No, I know everything possible and beyond has been done</p> <p>P12 <i>No, but it's always there in my subconscious, it never leaves you</i></p> <p>P14 No, I just get on with it</p> <p>P17 <i>No, but has the chemo' worked and kept it under control</i></p> <p>P19 <i>No, But he did tell my son there are still a couple of growths there, there is nothing to stop them spreading.</i></p> <p>P21 No I've accepted it.</p> <p>P28 No, everything's being done.</p> <p>P34 No, as long as it is as well managed as it is at the moment. I know it is happening and it is unavoidable, it is not a concern.</p>
<p>How you are feeling physically</p> <p>20 (58.8%)</p>	<p>Fatigue P1, P2, P3, P9, P10, P17, P21, P26, P27, P29, P30</p> <p>P5 but I'm starting to accept it, take it as it comes, go along with it</p> <p>P7 Sometimes a sickly feeling, but it wears off</p> <p>P8 I just wish I could walk a bit further</p> <p>P13 I'm 18 up here and 80 odd down here. I can't use this hand; they call it a claw.</p> <p>P15 Nausea sometimes and no energy- pep pill.</p> <p>P25 Yes, I am tired I can't standup for long, I get uncomfortable and start to leak, then I have to sit down. I wonder how I would manage at work?</p> <p>P31 Everyday you have different feelings. Indigestion feeling tired. I'm in a stressful situation with my wife in hospital with depression. I've had 4 operations</p> <p>P32 Yes, the tiredness and losing so much weight</p> <p>P33 Not too bad, but I'm so frightened you know to do damage. I used to do a lot before going to hospital,</p>	<p>No, but.....</p> <p>P18 No, because I know why</p> <p>P19 No, I am feeling better physically</p> <p>P34 <i>Irritated, yes, it is a master irritation, when on Saturday I couldn't get to the library because I was just too ill, and had to go back to bed, that was an irritation. But again, as long as I can operate even at a much reduced level, then no it's not really a concern.</i></p>

	decorating you know	
The effects of any aspect of the treatment on your body 10 (29 %)	Tired P2, P26 P11 Nausea P13 The uncontrollable diarrhea. P15 Yes, more information about why I wasn't offered treatment. P24 Yes, diarrhea, watery eyes, watery nose, feet and hands go sore as if they've been burnt P25 Yes, I've had two lots of chemo, surgery and I've got a colostomy. P27 The treatment, the stent, having these fevers on and off all the time P31 Chemotherapy , becoming impotent P32 Yes, the chemotherapy – is it worth my while?	P1 No, other than fatigue P14 No, if I've got to do it I'll do it. P20 No, if anything it's given me strength. P34 <i>No, we are in a desperate situation I suppose as far as the cancer is concerned, and therefore desperate remedies one expects</i>
Feeling different from other people 5 (14.7%)	P23 In a minor way I feel embarrassed about wearing a colostomy bag. P27 Yes, particularly in hospital, not everyday life P30 Yes, when I was first diagnosed I felt I'm not as good as they are now P32 Yes, everyone knows and they are looking at me P33 Yes, I can't run about, you know, breathing, going up the stairs.	No, but..... P3 <i>No, but I do have a concern that I look like me, being in a wheelchair, becoming invisible</i> P8 No, it never occurs to me. P12 No, despite the colostomy P24 No I still go out for a pint P25 No, it doesn't really bother me. I feel different, and I'm sure I'd feel different if my husband was still around. P28 No, not at all. P34 No, but you are aware of it. You know when you are sitting holding a conversation, you're aware that the gut you are arguing with is likely to see the result of the next general election and you are not... that sets things in context.
Feeling upset or distressed 5 (14.7%)	P9 Yes, but I think that's because of my wife dying so suddenly. P19 Yes, the way I was told my diagnosis, my God life wasn't worth living P21 Sometimes I worry about my wife, how will she cope? P25 Not too much, but when I do it's with family. P27 Yes, at times, there was so much more I wanted to do.	P1 –rarely P3- no, it's a natural thing P8 No, but I regret I can't put a pair of shorts on and take my shirt off, because my body is so thin, but that doesn't worry me, as long as I can sit out when the sun comes out, and I don't like wearing braces. P11 No, just occasionally. I have thought less and less about it. I'm trying to get back to normal. P15 No, only about my daughter having breast cancer and not being able to care for her. Some days I will get up and I will just lash out at him (husbands photograph), then I say I'm sorry, I have a little weep and then I'm all right. P20 No, it's in God's hands P28, After the initial shock I'm getting on with it. P30 At the beginning, but not now. P32 No, it's my husband, he's too angry even to talk to you today.
Not being able to do the things you used to 22 (64.7%)	Tiredness P2, P3, P8, P20, P26, P27, P4 to a degree I'm carrying on as normal for as long as possible P5 only because I want to. I haven't as much strength to do things like painting the yard walls P10 Yes, frustrating P12 Yes, I've lost confidence, I couldn't go anywhere	P6 No, I've adapted to this P7 No, I still go out to the darts and the bingo P34 Just irritated. Most of them I can do, it is just that I take longer.

	<p>on my own.</p> <p>P13 I used to be a dressmaker, but since the stroke....</p> <p>P14 Yes, sometimes housework</p> <p>P18 Yes, I used to do a lot, walking, mountaineering.</p> <p>P21 Yes, I was so active mentally and physically.</p> <p>I was an accountant. I worked at home after I retired. I played a lot of bowls, secretary of the club.</p> <p>P24 Tired, yes. I used to attack things. My wife says I do too much. Maybe that's why I feel a bit depressed and narky</p> <p>P25 Yes, a bit I can't be quite the person I was. I can't lift my granddaughters.</p> <p>P29 Yes, but you accept it. It's in my upbringing, my culture. I came to this country age 12 from Italy</p> <p>P30 Yes, I was involved on so many committees.</p> <p>P31 Yes, well I was a self-employed builder, I've just finished building this house.</p> <p>P32 Yes, very frustrating. I take it out on everyone</p> <p>P33 Yes, the sons have to do everything.</p>	
<p>The future</p> <p>14 (41%)</p>	<p>P4 Yes, but faith can move mountains.</p> <p>P12 Yes, but I think I'm better off not knowing, take what it throws at me, each day at a time.</p> <p>P17 I'm a bit frightened of dying. How I'm going to die .</p> <p>P18 Yes, how will it be dying?</p> <p>P19 Yes, well I want to be to give my daughter away.</p> <p>P23 Yes, because it's terminal, how long have I got? When the cancer kicks in again... in my mind it's going to be in remission for years.</p> <p>P24 Yes, am I going to be in pain, I keep it at the back of my mind?</p> <p>P25 Yes, I would like to be able to make plans – fluid plans, rather than being completely in the dark.</p> <p>P27 Yes, how will I die?</p> <p>P26 When will I be able to return to work, I can't afford to stop?</p> <p>P30 Yes how things will affect me, leave me inactive make me an invalid</p> <p>P31 Yes, but I don't look too far ahead. I would like to think it could be cured.</p> <p>P32 I don't think I have one. We had such plans, what's the use of him retiring on his own?</p> <p>P33 Yes, we can't plan ahead now, you never know what's going to happen.</p>	<p>No, but.....</p> <p>P6 No I don't look too far ahead</p> <p>P8 No, not really. It's all so uncertain. I would have taken a bet I was the next to go in this road, but two have gone this week alone - so you just don't know.</p> <p>P10 No, I know what to expect</p> <p>P11 <i>Not knowing how long.</i> <i>I could get knocked down by a bus. I think about the kids and what's going to happen. Carry on and forget about it, and when I need to know I will get told.</i></p> <p>P13 No, I just live every day as it comes, you don't know what can happen, look at the night I had the stroke.</p> <p>P14 No, I don't think about it.</p> <p>P20 Not really, I'm dying, I don't want to but....</p> <p>P22 Not really, I've lived my three score years and ten, now everything is a bonus.</p> <p>P29 No, day by day. I know I only have months to live.</p> <p>P34 <i>It's very short term. No, I have concerns about my children's future, yes I have that.</i></p>
<p>Your work</p> <p>5 (14.7%)</p>	<p>P25 Yes, I feel it would be nice to sort out, can I go back part-time?</p> <p>P26 It would be good to know when</p> <p>P27 Yes, I mean I can no longer get to London, and I'd been planning an art exhibition. My wife is going to carry on with it, we've chosen the exhibits and frames.</p> <p>P29 Yes, the housework, my husband's very good.</p> <p>P32 Yes, they're going to finish me up, that makes you feel worse.</p>	<p>P14 No, but I do miss my work</p> <p>P23 I'd have stayed on working, but the company closed down.</p> <p>P33 I've been retired about 8years, I've been healthy all my life.</p> <p>P34 No, I have done a good job for 20 odd years, and I'm sad to lose that. I am sad to lose the students. Yes, that bit hurts. I have put a lot into the work over a number of years, but no, I have brought it nicely to an end.</p>
	P25 My mortgage - if I die it's paid off. If I live that's	P24 <i>No, I get a good pension. I was made</i>

<p>Money worries</p> <p>3 (9%)</p>	<p>the problem!</p> <p>P26 We've just been saving for a trip to Australia, but what if I have to stop work?</p> <p>P33 I'd like to know more about what I might be entitled to after paying my taxes all these years.</p>	<p><i>redundant, got my pension at 52, and put money in investments. 10 years later I retired from my part time job in the post-room 1-6. Two weeks later, what do they tell me- I've got cancer.</i></p> <p>P29 No we've been careful all our lives.</p> <p>P34 No, not any longer.</p>
<p>Your relationship with partner / main carer (if applicable)</p> <p>4 (11.7%)</p> <p>see no, but...</p>	<p>P1,</p> <p>P5 worried about how he will cope without me. Yes, maybe I should talk to somebody because I'm stronger, my husband weak, perhaps we need help as a couple. He feels inadequate.</p> <p>P10 My Mum, I'm trying to get everything sorted out for her, her divorce and so on.</p> <p>P13 Yes, with my son, I get fretful. We get a bit niggly you know. I do like to know what's going on.</p>	<p>No, but....</p> <p>P2, <i>No-but how will he cope?</i></p> <p>P 3 – No if anything it's stronger</p> <p>P 4 No, stronger if anything</p> <p>P7 No, my daughter's been great really</p> <p>P8 No, we have our usual tantrums with one another. You know it's only natural. I will tell her to get a hearing aid and she will tell me to put my teeth in.</p> <p>P11 <i>No, we are getting back to normal. We don't actually talk about the disease and what's going to happen. The Health Visitor tried to get us to talk to each other.</i></p> <p>P14 <i>No, he's alright if he keeps himself down. He can be a pain, hasty tempered if you say the wrong word.</i></p> <p>P15 No, my family are wonderful</p> <p>P17 <i>No, but I am concerned how my Mum will cope</i></p> <p>P20 No, my son & sister have looked after me so well</p> <p>P21 <i>No, Only how she will manage.</i></p> <p>P22 <i>No, only my wife and children might like to talk to somebody.</i></p> <p>P23 No, but, well if the abscess clears up, the district nurses will stop coming. If I pop off how my wife will cope, she's had a stroke but gets no help.,</p> <p>P24 <i>No, she says I do too much</i></p> <p>P25 I'm not sure how my husband would have coped worrying about me.</p> <p>P28 Not at all, only I worry how she will cope, but she may go before me.</p> <p>P30 Not really, only my sexual relationship because of this treatment, but my wife's not bothered.</p> <p>P32 No can't do enough for me, he's worse than ever now.</p> <p>P33 No, we understand one another.</p> <p>P34 Well I haven't got a partner or a main carer. I have such good friends and colleagues, who come.</p>
<p>How you feel about yourself</p> <p>5 (14.7%)</p>	<p>P3 – I want to be the person everybody knows, normal as possible</p> <p>P13 Just that I get a bit depressed.</p> <p>P25 Physically I'm not quite the same person I was - though I'm the same person inside. My Christian faith helps.</p> <p>P27 Yes and No. There are certain aspects to my character I really don't like, but that's me.</p> <p>P32 Yes, I feel an utter mess.</p>	<p>P15 No, only tired</p> <p>P19 No, I am feeling positive</p> <p>P20 No, I have a strong faith, God's good.</p> <p>P34 <i>No, it has not focussed on me. I keep saying it is focussed on other people. My concerns are much more how it is going to hurt some other people, but no, I don't have any personal concerns about it, no.</i></p>
<p>The support you are getting</p>	<p>P22 support for my wife and children</p> <p>P25 Yes, doing the chemo myself at home, and looking after the line.</p> <p>The responsibility was awful and the hospital was so</p>	<p>No.....</p> <p>P3, No it's been marvellous</p> <p>P6 No, it's there but not intrusive</p> <p>P7 No, it's been wonderful</p>

<p>2 (6 %)</p>	<p>far away.</p>	<p>P8 No, family support is good, medical support has been good, hospital support has been good, I have no complaints at all P10 No, it's been brilliant, the last 12 months has been an extra. P12 No, it's only a phone call away, very reassuring P15 <i>No, but if I need more, where is it going to come from?</i> P20 No, not at all, it's been brilliant, couldn't have been more. P21 No, only I do wish the nurse would listen rather than talk all the time. P24 No, if we need it it's there P28 No, there's plenty of it. P34 Absolutely not, no. It has been very good and if it carries on at this level, then the NHS has every reason to be proud of yourselves. It shouldn't be on the back foot of the defensive as it is at the moment. I can understand why people are placed in that position and I can understand the stress under which they are working, but certainly my experience has been that they are making it work and I have nothing to complain about, nothing at all.</p>
<p>Any other concerns 4 (11.7%)</p>	<p>P1- access to information about alternative medicine P2- alternative medicine, diet, vitamins – no harm P3 Talking to another cancer victim, to compare experiences, my cancer is very rare. P31 Alternative medicine</p>	