

Identifying contributory factors leading to the suboptimal
management of constipation and the development of a nurse-led
clinic to improve constipation management in patients with cancer:
an action research study.

A Thesis submitted for the degree of Doctor of Philosophy

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Abstract

Constipation in cancer and palliative care is frequent, poorly managed and has a profound adverse effect on patients' lives. This qualitative study explores factors contributing to the suboptimal management of constipation and identifies strategies to alleviate it. In a three-staged action research study data were collected from 11 patient interviews, 26 health care professionals (HCPs) during six focus group meetings and a Constipation Management Clinic (CMC), comprising a cohort of 29 patients, which was developed as part of this study.

The findings from stage one, patient interviews, confirm that the management of constipation in patients with cancer and palliative care is suboptimal partly due to HCPs' poor knowledge and ambivalent attitudes, inadequate patient education and a lack of a concordant approach to management. Patients described feeling abandoned, their condition trivialised and many suffered considerable distress and embarrassment. In stage two, focus groups of HCPs were questioned on their understanding of the condition, its impact and their strategies for treatment. Findings from the patient interviews were fed back as a means of education and to facilitate discussion. The focus groups confirmed the findings from the patient interviews. It was therefore possible to postulate that constipation management would be improved by redressing the educational needs of HCPs, imparting knowledge to patients and working to develop a partnership approach.

To test this a CMC was developed during stage three. Patients with severe and intractable constipation were recruited to a nurse-led clinic that adopted a patient-focused, education-based management strategy which also encompassed a concordant approach to laxative recommendations. Following attendance there was an immediate improvement in bowel function in all patients who became more autonomous and concordant with their treatment regimens.

Aims of the study were to improve the research's skills and knowledge in research methodology in the cancer and palliative care setting, identify factors leading to the suboptimal management of constipation and to explore ways in which to alleviate the condition in patients with cancer. Throughout the project the action research methodology incorporated concurrent dissemination of findings to HCPs allowing them to discuss and assist with the evolution of the research and to modify their own practices to the benefit of patients generally.

This research demonstrates the advantages of adopting an action research approach when identifying strategies to reduce the incidence of constipation in patients with cancer and the importance of paying attention to detail when trying to manage this frequent and distressing problem.

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To maintain confidentiality pseudonyms have been used for patients and establishments where necessary throughout.

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Abbreviations

BNF	British National Formulary
CMC	Constipation Management Clinic
CNS	Clinical Nurse Specialist
DH	Department of Health
GP	General Practitioner
HCP	Health care professionals
LREC	Local Research Ethics Committee
MDT	Multidisciplinary team
NICE	National Institute for Clinical Excellence
NHS	National Health Service
RCT	Randomised Controlled Trials
SpR	Specialist Registrar
WHO	World Health Organization

Chapter 1

Introduction to the study

1.1 Introduction

In order to afford the reader with an appreciation of the conditions and setting in which this study was undertaken, this Chapter outlines the researcher's professional role and the Unit in which she practises. The Unit, as a cancer and palliative care service provision, is outlined followed by an exposure of the nature of the multi-professional team and the researcher's role and responsibilities therein. The researcher's clinical observations, that underpinned the research, are then presented along with their relevance to effective clinical practice. These observations are followed by a brief introduction to cancer, palliative care and constipation which is further developed in the literature review. Finally, to guide the reader through the three stages of this research a summary of the different chapters that comprise this thesis are offered.

This study adopted an action research methodology to explore the multifaceted problems identified in constipation in patients with cancer as there appeared to be disparity between patients' and HCPs' attitudes and management strategies.

1.2 The research setting

1.2.1 The Unit

This study was undertaken by a research nurse practising full-time in a 16-bedded inpatient unit for patients with advanced cancer. The Unit also comprises day care and outpatient services. The Unit works collaboratively with the adjacent cancer centre and is a key specialist palliative care provider within a cancer network serving a population of 1.3 million people. Additionally, the Unit serves its local geographical community and the health care professionals (HCPs) therein.

The Unit's service users comprise patients, their family/friends and HCPs, including those from other providers such as hospitals, hospices and the community (for example; General Practitioners (GPs), Macmillan and district nurses). Service users are afforded the expertise from the varying professionals practising in the Unit who form the multidisciplinary team (MDT).

1.2.2 The Multi-disciplinary team

The MDT includes doctors, nurses, health care assistants, complementary therapists, occupational therapist, physiotherapist, art therapist, social workers, counsellors and volunteer workers, and is headed by the clinical director who is also the cancer network lead specialist palliative care consultant. The status and skills mix of MDT members is wide ranging and includes junior doctors, specialist registrars (SpR) and pre-registration nurses who practise on the Unit as part of their rotational training. The MDT work collaboratively and uphold the philosophy of ‘the team’ approach. Most members participated in this study and many acted as core members.

In an attempt to explore HCP perceptions further the researcher instigated and worked collaboratively with a core team group which accommodated participation by transient MDT members. This study’s core MDT members consisted mainly of doctors and nurses (practising on the Unit) who shared responsibility for planning and implementing agreed goals of this research (Payne 2000). The study’s MDT welcomed all HCPs keen to participate in the group even if their involvement was limited or short-term due to rotation and work commitments. The advantages of this approach are that the varying team members afforded different personal and professional values, beliefs, skills and experiences (Reel and Hutchings 2007; Payne 2000; O’Neill and Squire 2001) many of whom were senior and had practiced in a variety of settings, for example community GPs and general ward nurses, thus affording the study guidance and validation of findings. The latter is an important consideration as Moss *et al* (1998) suggest that patients with cancer have contact with about 20 hospital professionals in addition to their primary HCPs. During MDT meeting members pooled their knowledge, expertise and experiences (Cook *et al* 2001; Barrett and Keeping 2005) and made joint decisions based upon shared professional view (Payne 2000; Handy 2001) thus bringing appropriate guidance and direction to the study.

In relation to this study, the researcher was facilitator and MDT team member (Meyer 2000) and adopted a lead role within the MDT as Reel and Hutchings (2007) note that in health and social care ineffective leadership may result in poor (or lack of) communication, mistrust, personal conflict and/or opposing views. The researcher ensured that members were kept informed of the study’s progress, held regular meetings and keep ultimate goals and objectives in mind and focus. Team members were encouraged and supported as the researcher was mindful of the view of Reel and Hutchings (2007) who note that members of the MDT who feel valued and trusted also engender a sense of pride and loyalty, thus enabling an MDT collaborative venture (McCray 2002) in which those involved share the common purpose of improving the management of constipation in patients with cancer.

Over the course of this study the core MDT members remained static. Additional members joined the team at key stages, for example community teams, who participated more directly in this study by affording ideas, making referrals and utilising the researcher as a source of support and advice when faced with problems managing constipation during their own practices.

1.2.3 The researcher's role and responsibilities

Part of the researcher's role within the MDT is to develop and embrace a philosophy of research and audit within the Unit. The researcher is responsible for the management of commercial randomised controlled trials (RCTs), the recruitment of patients to these studies and the initiation and administration of audits and surveys. The RCTs evaluate drugs for symptom management in patients with cancer whereas the scope of audits and surveys is wide-ranging. These projects are either qualitative, quantitative or both. The work varies from clinical to non-clinical, for example, auditing HCPs management of syringe drivers to surveying patients' satisfaction with their inpatient stay. Health care professionals take the lead on projects and receive support and training from the researcher. With the exception of RCTs, project findings are disseminated through an established programme of meetings including HCP journal clubs, training sessions, clinical governance meetings and network conferences. These setting were also utilised for the dissemination of findings from this study.

Research and audit aims to achieve and maintain high standards of care for patients with cancer, optimal symptom management and provide equitable service to users through a process comprising problem identification and resolution. However, the problems of constipation and its management appeared to be multifaceted as illustrated in the researcher's following observational findings and vignettes which also serve to illustrate the background to this study.

1.3 Observations in a clinical setting

The study had various triggers. During observational studies, led by the researcher, in an oncology and palliative care ward it was noted that constipation was poorly managed by HCPs. Most patients were predisposed to constipation but this was rarely recorded in the nursing or medical notes. Drugs known to cause or exacerbate constipation were prescribed but without prophylactic laxatives. The prescribing of laxatives was haphazard as was their administration.

Health care professionals appeared ambivalent and disinterested in constipation other than the opportunity to be rather flippant about it. It was noted that patients only reported being constipated once it had become problematic. When constipation was severe, HCPs attributed blame to the patient for being non-compliant with laxatives. It appeared that HCPs' patient

assessment was not conducive to identifying constipation as it inevitably relied on the individual reporting the condition.

The researcher observed that during drugs round nurses frequently asked patients if they wanted laxatives and over half the doses were omitted without further exploration with the patient. A bowel motion within the previous 24-hours was the most common reason patients declined laxatives, however, no consideration was given to stool size, consistency or ease of defecation. Issues of concern are that these practices negated the benefits of prophylactic laxative use, each dose omission could have constituted a drug error and HCPs failed to make appropriate patient assessment. It appeared that neither HCPs nor patients were aware of the importance of constipation management in patients with cancer and therefore the condition was inadequately managed.

1.3.1 Vignettes

The observational evidence was supported by the following vignettes which are presented as addition evidence of the poor management of constipation generally and locally within the Unit.

No. 1 – Mrs Morris (aged 56) chemotherapy patient

Over a period of 18 months Mrs Morris had not been appropriately assessed for constipation despite having several predisposing factors. Three weeks prior to the following incident Mrs Morris denied having constipation. On an emergency admission Mrs Morris was found to have a perforated bowel resulting from faecal impaction. Mrs Morris survived the surgery and asked to see the researcher. Mrs Morris reported that she had not admitted being constipated because it was so severe that she had to resort to the digital removal of her faeces. Mrs Morris said she felt embarrassed and ashamed. She had never used prophylactic laxatives because their use and role had never been explained to her.

No. 2 – Mrs Oliver (aged 83) palliative care patient

Mrs Oliver repeatedly told her General Practitioner (GP) and district nurse about feeling constipated and ‘leaking’ with diarrhoea. Mrs Oliver reported that the HCPs had not examined her abdomen or felt in her rectum to assess her symptoms. Despite her poor fluid intake Mrs Oliver was prescribed ispaghula husk which she found intolerable and made her retch, however, out of desperation she persevered. Mrs Oliver was referred to a continence nurse who she reported “...just turned up unexpectedly about 10 days later.” Mrs Oliver described her embarrassment and fear as the continence nurse spoke to her “... he was a very tall young man and he came into my

house, I didn't know who he was at first. He said he had heard that I was dirtying my knickers and wanted to know what size pads I wanted." Mrs Oliver never sought help again. She died a year later following unsuccessful surgery for a perforated bowel resulting from faecal impaction. The surgeon reported that Mrs Oliver had been constipated for so long that faeces had adhered to the bowel wall and, as result, tissue necrosis had occurred.

In summary, these observations indicate that constipation is inadequately managed in patients with advanced cancer and that patients fail to report its presence until it becomes severe. Constipation is a common problem the incidence of which increases in patients with cancer and further still for those in the palliative stage of their disease.

1.4 Background

1.4.1 Cancer

Cancer is predominantly a disease of the elderly affecting approximately 75% of those aged over 60 (Office of National Statistics 2007) the incidence of which is predicted to rise 30% by 2020 (Møller *et al* 2007). The most common cancers (breast, lung, colorectal and prostate) account for just over half the new cases of malignant cancer registered in 2004 (Office of National Statistics 2007). Cancer causes 25% of all deaths and one in three people will develop the disease (Office of National Statistics 2007; The NHS Cancer Plan (Department of Health (DH) 2000). A diagnosis of cancer does not always result in death but for those with advanced or non-curative disease oncology treatments may be limited. Patients with advanced cancer often endure complex physical symptoms and/or psychological burdens that require palliative care support.

1.4.2 Palliative care

Palliative care is available to all patients whose disease is not responding to active treatment. In the cancer setting palliative care is available at any stage during the course of the illness and in conjunction with anticancer treatment. The goal of palliative care is achievement of the best possible quality of life through palliation of physical and psychological symptoms especially when these needs have not been met in the non-specialist setting. The incidence of constipation is at its highest in the terminal phase but death often precedes its palliation. Constipation is a common insidious problem that often results from cancer, its treatments and/or prior to diagnosis.

1.4.3 Constipation

Constipation is more common in westernised societies than the Third World. Constipation affects between 2% and 27% of the Western population; the incidence of which rises to between 24% and 100% in patients with cancer. This vast discrepancy in epidemiological data is partially due to the problems of defining, identifying and reporting constipation. In research studies, constipation lacks objective definition and there is discordance between patients and HCPs on what constitutes constipation. Similarly, management strategies on constipation vary. It is noteworthy that there are a number of laxatives that can alleviate constipation but these are currently not used prophylactically or in optimal doses.

1.4.4 The problems

Constipation is frequently present in patients with advanced cancer but is rarely identified as being important. Prophylactic laxative prescribing is minimal, consistent laxative use by patients is rare and in many instances, HCPs fail to identify constipation as a problem. Patients and HCPs underestimate the consequences of constipation and lack any depth of knowledge in relation to its management. Constipation is inefficiently managed in patients with advanced cancer and the profound impact is detrimental to patients' quality of life. The existing body of evidence suggests that the management of constipation in advanced cancer is poorly managed among doctors, nurses and other healthcare professionals and it is rarely managed according to guidelines.

1.5 Study initiation

The catalysts for this study were the researcher's lack of research knowledge and her observations during nursing practice that constipation in patients with cancer was poorly managed. A year prior to undertaking this study the researcher commenced her role at the Unit as Research and Audit Sister. At this time she was aware of her limited knowledge on research methodology and methods. The Unit's Clinical Director, a representative from the university and the researcher met to identify an appropriate course to support her in her role. It was agreed that the researcher combine the academic element of this study (research methodology and methods) and the data collection element of her chosen topic (constipation in patients with cancer) to provide a framework for the researcher's Doctoral study.

1.6 Stages of the research

1.6.1 Identifying the problem – stage one

In an attempt to explore the problem further the observations outlined previously were debated with the MDT members. A consensus was reached that patient interviews should be conducted to identify the patients' experiences of constipation and thus provide appropriate baseline data on which to plan further interventions. The MDT considered that the successful management of constipation lay within the key elements of constipation assessment, appropriate laxative therapy and education. To confirm these theories and identify any further contributory factors, patient interviews were conducted to obtain patients' opinions, thus exploring their perceptions, experiences and management strategies of constipation.

This process was informed by a review of the literature which is presented in Chapter 2. It includes a more in-depth exploration of constipation and the effects on the individual. The range and use of laxatives are examined and the reasons why they are not taken consistently or at optimal doses are considered. This introduces and debates the concepts of compliance and concordance and how these apply to the adherence to laxative regimens.

Similarly, the methodological debates are presented in Chapter 3 and embody much of the groundwork that was undertaken to inform the study and provide the researcher with the appropriate levels of research understanding and skills to conduct it. Chapter 4 highlights the generic methods that were used throughout the study. These methods represent processes common to all stages whereas, to avoid confusion, the more specific methods are introduced as they were established at each stage of the study. Chapter 5 reports the findings of the patient interviews and forms the base qualitative information to inform this action research.

1.6.2 Exploring the scope of the problem – stage two

Stage two of the study consisted of focus groups that intended to establish HCPs' perceptions of constipation management, offer a method of dissemination and act as a member checking process to establish the trustworthiness of the data collected. The findings from stage one suggested that patients felt 'let down' by their HCPs as they perceived them as ambivalent and disinterested in managing constipation. Management strategies afforded to patients appeared ineffective and lacked coordination. Health care professional focus groups were conducted to provide feedback from stage one and to identify their perspectives and attitudes on constipation management strategies.

The rationale for the focus group, the specific methods used and the findings of the focus groups are presented in Chapter 6. The findings from stages one and two present conflicting management strategies between the two groups, often one blaming the other for any disparity.

1.6.3 The intervention – stage three

In light of the findings from stage one and two the MDT supported the researcher's proposal that a nurse-led clinic should be established. The development and implementation of the CMC was achieved as a direct result of the increased contributions of MDT members who worked collaboratively to reduce the incidents and severity of the condition in patients with cancer. From a patient perspective, the clinic provided a mechanism through which objectives identified during stages one and two were redressed. Details of the processes used are outlined in Chapter 7 whereas Chapter 8 presents the detailed analysis and overall evaluation of the nurse-led clinic outcomes and also includes the dissemination of information to the MDT, HCPs working on the Unit and to the wider HCP audience.

This action research is concluded in Chapter 9 which offers an overall discussion and draws together the main themes as they emerged from the three stages of the study. Here the researcher evaluates the effectiveness of the study and builds a rationale for the recommendations for practice that comprise Chapter 10.

Figure 1 shows the three stages of this researcher over the study's trajectory and the simultaneous nature of dissemination that occurred throughout.

Identifying the problem

Introduction to the study
(Chapter 1)

Concurrent processes

Observations, field notes and
experiences in practice.

Exploring the scope of the problem

Literature review
(Chapter 2)

Methodology and methods
(Chapters 3 and 4)

Dissemination to HCPs
Feedback and discussion

Interview process and
findings
(Chapter 5)

HCP focus groups: methods,
process and findings
(Chapter 6)

The intervention

The Constipation Management Clinic (CMC)
Development, methods, process and
evaluation
(Chapter 7)

Dissemination to HCPs
Feedback and discussions

The CMC findings
(Chapter 8)

Overall findings conclusions
(Chapter 9)

Recommendations
(Chapter 10)

Dissemination

Figure 1 – Core elements and simultaneous processes employed during this action research study exploring the management of constipation in patients with cancer.

1.7 Timelines

As inherent within an action research approach each stage of this study evolved over time and components were incorporated based on the findings at each stage and during developmental periods. For example, the need to review the contemporaneous literature on laxatives was not identified until following stage two and during development of the Constipation Management Clinic. Thus Chapter 2 and subsequent literature reviewed in this thesis reflects these study timelines. Figure 2 shows the periods of data collection only, however project planning mainly occurred between these episodes whereas data analysis took place simultaneously throughout.

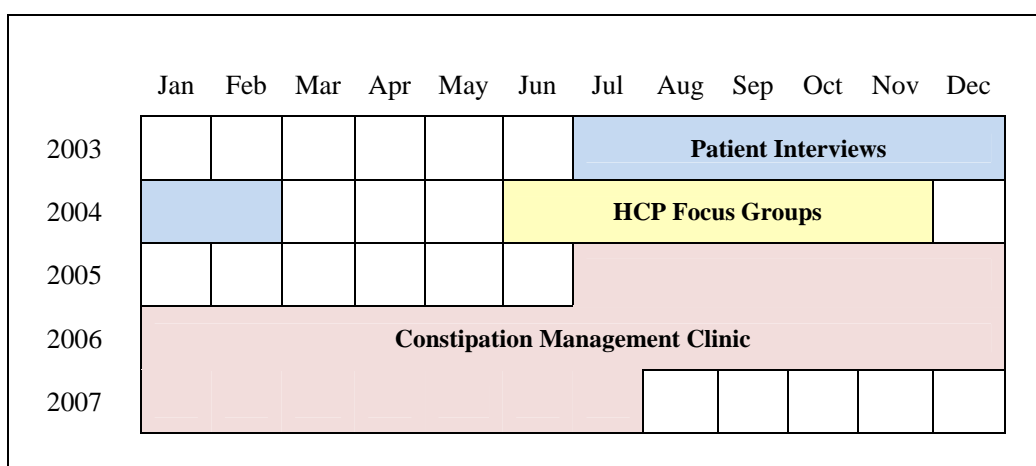


Figure 2 – Study timelines

1.8 Summary

Chapter 1 has introduced, set the context and outlined the rationale of the study as it is situated within cancer and palliative care and in context with the researcher's professional role and nursing experience. A brief insight has been given which exposes that constipation is poorly managed, patients' and HCPs' knowledge is inadequate, patients are not appropriately assessed, concordance has not been adopted and management of the condition in the community is fragmented. These issues are explored and debated further throughout in the following chapters.

For simplicity throughout this thesis:

- **Patients with cancer**

The term 'patients with cancer' comprise those with the diagnosis regardless of stage of disease, thus encompassing those with advanced cancer and/or receiving palliative care.

- **The 'Unit'**

The 'Unit' refers to the specialist palliative care unit in which the researcher practiced and coordinated this research.

- **Health care professional (HCP)**

The term 'health care professional' denotes a physician, nurse, therapist or other individual who is both trained in a particular discipline of health care and directly involved in the delivery of clinical care to patients.

- **The multidisciplinary team (MDT)**

The multidisciplinary team is a group of HCPs from different disciplines and/or settings who work collaboratively as a group with specific aims and objectives.

- **Defining the team for this research**

Due to the transient nature of many HCPs difficulties arose in identifying a static group for this research, therefore, throughout the remainder of this thesis the MDT refers to HCPs who contributed directly to this study in terms of working collaboratively by affording direction, opinions and guidance through periodical meetings and discussions as required.

Chapter 2

Constipation: literature expressing the scope of the problem

2.1 Introduction

This Chapter examines defecation as it presents in the general population and aligns this with the varying types of constipation and exacerbating factors in patients with advanced cancer. The incidence of constipation as it occurs in the general population is contrasted with the increasing prevalence at the end of life. Constipation presents several major problems in the clinical setting and these are discussed, including definition, subjectivity versus objectivity, reliability of data, disparity in perceptions, under reporting and suboptimal treatment. The causes of constipation in advanced cancer are also established together with some of the profound consequences patients often endure. The use, role, efficacy and side effects of laxatives are explored followed by the use of constipation identification and assessment tools. Finally, compliance and concordance is debated in order to provide a framework for improving the management of constipation in patients with advanced cancer.

2.2 Definitions

In order to appreciate the extent of the abnormality constipation represents it is necessary to define normal stool form and frequency in the general population and as perceived by individuals. In this thesis the term ‘bowel movement’ refers to stool defecation.

2.2.1 Normal bowel frequency and stool form

Most adults report at least one bowel movement in 24 hours (Connell *et al* 1965; Everhart *et al* 1989). Heaton *et al* (1992) report that this conventional norm of a regular 24 hour cycle is only seen in approximately 40% of men and 33% of women and over half the population had irregular bowel habits ranging from less than one to over 21 per week. Normal stools are usually considered to be types 3 and 4, based on the Bristol Stool Form Scale (Lewis and Heaton 1997) (Appendix 1), because they are the ones associated with least urgency, straining and feelings of incomplete evacuation, however, these were only present in 62% of men and 57% of women (Heaton *et al* 1992). Heaton *et al's* (1992) study excluded older people because of the likelihood that they would have problems with eyesight, hearing, mobility and/or transport to clinics. Therefore, the study is not representative of the general population as many will be aged 65 and over, a factor in itself that predisposes them to constipation and/or cancer and thus a group

particularly in need of constipation resolution (Long *et al* 1995; Petticrew *et al* 2001; Petticrew 1997).

Bassotti *et al* (2004) prospectively studied bowel frequency in the general population over a four week period using diaries to collect data based on the Rome II Criteria (Drossman *et al* 2000; Longstreth *et al* 2006). Patients reported on their bowel frequency and associated requirements including straining during defecation, incomplete emptying and/or difficult evacuation, manual manoeuvres to facilitate defecation, lumpy or hard stools and the use of laxatives. There was a large variation in bowel movement frequency ranging between one to three per day and one evacuation every four days. Less than 5% reported fewer than three evacuations each week.

Bassotti *et al* (2004) regarded the 61% response rate in their study as high and attributed this to its prospective nature and simplistic format of the diary, thus preserving reliability of bowel habit data, which may otherwise be considered as unreliable. One can postulate that some of the sample in Bassotti *et al*'s (2004) and Heaton *et al*'s (1992) studies would have a degree of constipation, however, as no data on the individual perceptions were collected any correlation of opinions is unknown.

Defecation patterns show that 90% of people in Western countries have between three bowel movements a day to three per week (Connell *et al* 1965; Everhart *et al* 1989; Heaton *et al* 1992; Bassotti *et al* 2004) and it is this definition of 'normal' frequency that continues to prevail in health care literature (Bandolier 1997). Johanson *et al* (1989) state that 62% of the general population believe that a bowel movement each day is essential. To be considered normal, a stool should be solid, moist and easy to pass. However, normal bowel frequency is subject to personal and cultural interpretation as well as emotional, psychological, environmental and dietary factors (Ross 1998).

2.2.2 Constipation

The word constipation is based on the Latin word *constipare* and means 'crowd together'. Historically, constipation was proffered as a basic explanation of disease, the notion being that poisonous material was released from decomposing waste in the intestines (Ebbell 1937 cited by Prather and Ortiz-Camacho 1998). Throughout human history constipation and bowel irregularity has been considered dangerous to health (Whorton 2000) and its aetiology and management has perplexed the medical profession (Prather and Ortiz-Camacho 1998; Heaton *et al* 1992). Sir Arthur Hurst laid the conventional foundations to the scientific approach to 'Constipation and Allied Disorders' over a century ago (Avery Jones 1972). However, constipation still presents

challenging problems in healthcare with painful and debilitating consequences to patients and is poorly managed by HCPs in multiple clinical settings (Heaton *et al* 1992; Bassotti *et al* 2004).

Constipation is commonly categorised into either primary or secondary. Primary constipation occurs where there is no underlying causative illness and is also called idiopathic (self originated, of unknown causation) or simple constipation (Hsieh 2005; Wright and Thomas 1995; Chey 2005; Stark 1999). Primary constipation is associated with lifestyle factors which include insufficient fibre in the diet, inadequate food and/or fluid intake, lack of exercise/mobility and environmental issues such as lack of privacy when toileting (Rao 2003; Koch *et al* 1997; Rao *et al* 1998; Fallon and O'Neill 1997; Nettina 1996; Long *et al* 1995; Winney 1998). When an endocrine, metabolic, neurological, psychiatric, structural or iatrogenic (inadvertently caused, for example as a result of drug use) explanation can be identified, constipation is said to be secondary (Prather and Ortiz-Camacho 1998; Schiller 2001).

In summary, bowel frequency is variable but it is generally accepted that the norm is between three bowel movements a day to three per week. Constipation can be either primary or secondary, the aetiology of which is not always evident. The nature and/or type of pre-existing bowel habit could serve to inform patients' history and management strategies, therefore was explored in this research. A substantial number of patients with cancer will experience primary and/or secondary constipation.

2.3 Epidemiology of constipation

There is wide variability in epidemiological studies due to the poor definition of 'constipation', different data ascertainment methods (Higgins and Johanson 2004) such as mailed questionnaires and telephone interviews and the unreliability of individuals' self-reported information. Thus, constipation is probably understated but affords an indication of the extent of its occurrence.

2.3.1 The general population

Constipation is a common problem affecting between 2% and 27% of the population in Western countries (Stewart *et al* 1999; Pare *et al* 2001; Higgins and Johnson 2004; Thompson and Heaton 1980; Talley *et al* 1993; Johanson *et al* 1989; Lemob and Camilleri 2003). Constipation is more prevalent in elderly people, in women and in Caucasians. Severe constipation is found almost exclusively in women (Preston and Lennard-Jones 1986; Sandier *et al* 1990; Pare *et al* 2001; Stewart *et al* 1999) the incidence of which increases with age (Johnason *et al* 1989; Read *et al* 1995). It is generally accepted that constipation is a complaint affecting around 10% of the adult population in general but approaching 20% of the elderly (Thompson and Heaton 1980).

2.3.2 Patients with advanced cancer

Studies indicate that 70% to 100% of patients with cancer have a problem with constipation (Potter and Higginson 2002; Walsh *et al* 2000; McMillan and Tittle 1995; Weitzner *et al* 1997; McMillan and Weitzner 1998; Tittle and McMillan 1994). In hospice settings the prevalence of constipation ranges from 24% to 84% (Walsh 1984; Donnelly and Walsh 1995; Addington-Hall *et al* 1991; Vainio and Auvinen 1996; Sykes 1998a). For example, in a prospective study using the self-reported Constipation Assessment Scale (McMillan and Williams 1989), 63% of patients had some degree of constipation on admission, of which 19% was rated as severe (McMillan 2002). By week two the presence of constipation had increased to 68% and those with severe constipation had risen to 22%. McMillan's (2002) study criteria excluded patients who did not have constipation documented as a problem on admission. It is unwise to assume that because constipation is not documented in records that patients are not experiencing it. It is well recorded that many patients fail to report their constipation unless specifically asked.

Constipation occurs in approximately 40% of patients referred to palliative care services (Curtis *et al* 1991) and up to 90% of patients treated with opioids (Twycross and Lack 1983; Walsh 1984; Sykes 1998a) and represents a significant problem in 40-50% of cases (Walsh 1984; Glare and Lickiss 1992). Constipation is more common in patients who are terminally ill with cancer than those dying from other causes (Sykes 1998b).

In summary, constipation appears to be a problem in the general population, the incidence and severity of which significantly increases in patients with advanced cancer. Prevention and alleviation of constipation in patients with advanced cancer was explored in this research as, according to Sykes (2004) it is preventable and treatable in this group but achievement of this is often impaired by clinical methodological considerations.

2.4 Causes of constipation

Constipation is often multi-factorial especially in patients with cancer and knowledge of the aetiology underpins management strategies. The main causes of constipation in patients with advanced cancer are shown in Table 1, some of which are discussed further in this Chapter.

<i>Structural abnormalities</i>
Obstruction
Pelvic tumour mass
Radiation fibrosis
Painful anorectal conditions (anal fissure, haemorrhoids, perianal abscess)
<i>Drugs</i>
Opioids
Anticholinergic (i.e. antispasmodics, antidepressants, haloperidol, antacids)
Antiemetics (especially ondansetron)
Diuretics
Anticonvulsants
Iron
Antihypertensive drugs
Anticancer agents (vinca alkaloids)
<i>Metabolic disturbances</i>
Dehydration (fever, vomiting, polyuria, poor fluid intake, diuretics)
Hypercalcaemia
Hypokalaemia
Uraemia
Hypothyroidism
<i>Neurological disorders</i>
Cerebral tumours
Spinal cord involvement
Sacral nerve infiltration
Autonomic failure
<i>General</i>
Advanced age
Inactivity
Depression
Sedation
Decreased intake
Low-fibre diet
Physical or social impediments

Table 1 – Causes of constipation in advanced cancer (Mancini and Bruera 1998).

Although constipation is not a physiological consequence of normal ageing, decreased mobility and other co-morbid medical conditions contribute to its increased prevalence in older adults (Hsieh 2005). The elderly and patients with advanced cancer are particularly prone to constipation resulting from dehydration. The recommended daily fluid intake is three litres each day (Otto 1997; Nettina 1996; Long *et al* 1995) however many patients will fail to achieve this. Likewise, the reduced mobility of many people suffering from cancer also predisposes them to constipation as reduced activity has been identified as a cause of constipation (Royle and Walsh 1992; Hill *et al* 1998; Winney 1998; Fallon and O'Neill 1997). Some cancer treatment drugs are well recognised as causing constipation and are key contributors to constipation in patients with cancer regardless of their age. Thus, the relatively advanced age of most cancer patients predisposes them to constipation (Sykes 1998a), probably from poor diet, insufficient fluid intake, limited mobility, co-

morbidity and use of constipating drug, especially opioids. However, Thorpe (2001) notes that dietary modifications, increasing fluids and exercise are important but are not usually sufficient to overcome opioid-induced constipation.

Drugs commonly used and known to cause and/or exacerbate constipation in patients with advanced cancer include chemotherapy agents, antiemetics and analgesics. Constipation may result in patients who have received neurotoxic chemotherapy agents, such as vinca alkaloids, epotostide and cisplatin, each of which may cause autonomic dysfunction (Tipton and Skeel 1999; Otto 1997) and reduce gastrointestinal transit time (Sharma 1998) leading to high faecal impaction (Long *et al* 1995). Up to 35% of patients receiving vinca alkaloids become constipated and 70% of those given carboplatin (Smith 2001).

Antiemetic drugs, especially those classed as 5-HT₃ antagonists¹ which slows intestinal transit time (Talley *et al* 1990) are frequently used for the prevention of chemotherapy induced nausea and vomiting (de Wit *et al* 2005) and for symptom palliation in advanced cancer. However, they often induce and/or exacerbate constipation (Ding *et al* 2007; Blackwell and Harding 1989; Bhatia *et al* 2003).

Opioids are the mainstay in the treatment of moderate to severe pain and are used extensively for the treatment of pain in patients with cancer (Quigley 2005; Portenoy 1994). Opioids decrease gastrointestinal motility and increase fluid absorption from the intestines. The increase in fluid absorption is further enhanced by the slowed gastrointestinal transit time (Fakata and Lipman 2005; Yuan *et al* 1997). The main issues of gastrointestinal aetiology that are directly associated with opioid induced constipation are reduced and or retarded peristalsis and the alteration in the production and resorption² of gut secretions (Long *et al* 1995; Nettina 1996; Otto 1997). The lack of peristalsis is exacerbated further by opioid induced increased bowel muscle tone which slows down transit time and facilitates absorption of fluid from the faeces, thus hard stools and peristaltic insufficiency (Hull 1988).

The extent of constipation and its tolerability is patient variable and may be affected by opioid dose (Fakata and Lipman 2005). Patients may require modification in strategies as constipation is more easily prevented than treated using appropriate laxative therapies (Sykes 2004; Tipton and Skeel 1999).

¹ The 5-HT₃ antagonists are a class of medications which act as receptor antagonists at the 5-hydroxytryptamine-3 receptor (5-HT₃ receptor), a subtype of serotonin receptor found in terminals of the vagus nerve and in certain areas of the brain (de Wit 2005).

² The loss of substance through physiologic or pathologic means (Mosby2001).

In summary, constipation in patients with advanced cancer is multi-factorial and includes primary and secondary aetiologies. Some drugs significantly compromise bowel function but their use is essential in an attempt to prolong life (chemotherapy agents) and in managing other symptoms for example pain, nausea and vomiting. Drugs are necessary for symptom alleviation and may prolong life. The routine prescribing and prophylactic use of laxatives is rarely adopted and consequently has a profound impact on patients.

2.5 Complications of constipation

There are several complications associated with constipation (Table 2). Two issues often presenting in patients with advanced cancer are establishing whether the individual is suffering with faecal impaction or tumour obstruction and differentiating between diarrhoea and overflow. The clinical management of these will differ depending on diagnosis but this is often problematic. Therefore the aforementioned complications are discussed in further detail.

Abdominal pain, cramps, bloating and/or distension, gastric fullness
 Increase of liver or retroperitoneal pain
 Nausea and/or vomiting
 Anorexia
 Halitosis
 Faecal impaction
 Bowel obstruction
 Intestinal perforation
 Overflow diarrhoea (which can lead to electrolyte disturbance)
 Fatigue, malaise, headaches
 Confusion, restlessness
 Rectal tearing, fissure, and haemorrhoids
 Straining to defecate in the constipated patient, which can lead to:

- Haemorrhoids
- Fainting
- Cardiac irregularities
- Movement of a deep vein thrombus to the pulmonary veins (pulmonary embolus)
- In severe cases, sudden cardiac death due to cardiac abnormalities

Campbell *et al* 1993; Glare and Lickiss 1992; Kollef and Neelon-Kollef 1991; Lamers 2000; McGuire *et al* 1950; Ross 1995; Trohman *et al* 1986; Winney 1998; Mancini and Bruera 1998; Pappagallo 2001; Maestri-Banks and Burns 1996; Norton 1996; Powell and Davies 1999; Ripamonti and Bruera 2002.

Table 2 – Potential complications of constipation

2.5.1 Faecal impaction versus obstruction

Failure to prevent constipation, together with its aetiology and other predisposing factors discussed, result in patients with cancer also being at risk of developing faecal impaction. Faecal impaction may develop as a result of severe constipation and is an accumulation of hardened or inspissated (thickened or hardened through absorption of the liquid portion) faeces in the large bowel and/or rectum that the individual is unable to move (Twycross and Wilcock 2001; Mosby 2001). Major factors that precipitate faecal impaction are opioid use, prolonged inactivity and reduced diet and fluids (Cefalu *et al* 1981). Faecal impaction can lead to bowel obstruction and consequently ischemia and may result in bowel perforation and even death (Drew and Herdson 1997; Shammi and Remington 1997; Freudenreich and Goff 2000).

Bowel obstruction can occur as a result of faecal impaction or be tumour related. Tumour obstruction occurs when the cancer mass enlarges and compresses intestines externally or blocks the intestines internally. Sykes (1998a) identified specific causes in the terminally-ill including local gastrointestinal obstruction due to tumour, partial and/or complete bowel obstruction, depression and neurological symptoms such as spinal cord compression. The incidence of obstruction was noted by Tsuneto *et al* (1998) who found that malignant intestinal obstruction was a frequent complication of abdominal and pelvic cancers and developed in 16% of patients who died in a hospice. Mercadante (1997) and Baines (1997) agreed and both authors state that colorectal, gastric, ovarian and uterine cancers are most commonly associated with malignant intestinal obstruction. Tsuneto *et al* (1998) found that malignant intestinal obstruction developed in 63% of patients with gastric cancer, 45% with ovarian cancer and 40% with colorectal cancer. Awareness of the presence of partial or complete malignant bowel obstruction is important as the management of the individual's constipation (which may or may not co-exist) may not be possible and pursuing its alleviation may result in more harm than good such as exacerbation of symptoms and increasing risk of bowel perforation (Tsuneto *et al* 1998).

Both faecal impaction and tumour obstruction may result in complete or partial blockage. Differentiating between the two can be problematic as patients with tumour related obstruction may exhibit symptoms similar to constipation, therefore any constipation management strategies in patients with advanced cancer should encompass a diagnostic element in order to identify and exclude those with malignant bowel obstruction as they will require alternative management. There is strong evidence that the oral treatment of faecal impaction is highly effective (Culbert *et al* 1998). When the diagnosis of constipation is unclear an abdominal x-ray may be required (Bruera *et al* 1994; Starreveld *et al* 1990; Smith and Lewis 1990; McKay *et al* 1983; Baines 1997). Faecal impaction or rectal obstruction causes increased production of mucus, which may present as a rectal discharge or diarrhoea (Goldfinger 1991).

2.5.2 Faecal incontinence: diarrhoea versus overflow

One of the side effects of constipation, especially when severe, is faecal incontinence. Faecal incontinence refers to the failure of the voluntary control of the anal sphincter, with involuntary passage of faeces, flatus and liquidity of faecal discharge. The constipated mass in the bowel becomes so hard and difficult to pass that any watery substance much higher up in the bowel passes round the blockage and leaks out of the rectum (Francombe *et al* 2001) this is often referred to as 'overflow'. In the clinical setting overflow is often reported as 'diarrhoea'. Faecal incontinence can be as a result of constipation but in clinical practice this association is rarely identified.

In a community based sample of 6,959 individuals Nelson *et al* (1995) conducted a telephone survey to determine the prevalence and characteristics associated with anal incontinence. Anal incontinence was defined as the involuntary passing of solid faeces, liquid faeces, or gas which were reported in 36% of the sample within the study. They found that sufferers of anal incontinence were predominantly those aged over 65 (30%) and female (63%). Overall 36% of the sample reported experiencing incontinence of solid faeces and 54% of liquid faeces. In a systematic review faecal incontinence was considered a major problem affecting between 11-15% of people in the community (Macmillan *et al* 2004). These figures need to be interpreted with caution because the relevant studies are hampered by possible under-reporting and by a lack of a consensus definition (Madoff *et al* 2004; Nelson *et al* 1995). Nelson *et al* (1995) found that the independent risk factors identified were female sex, advancing age, poor general health and physical limitations, all of which are also predisposing factors in cancer, palliative care and constipation. However, there appears to have been no attempt to establish whether or not any of these patients may have been experiencing simultaneous periods of constipation or any medical diagnosis that may have affected their bowel function.

Knowledge of constipation in this sample would have highlighted a group that potentially had been experiencing 'overflow' diarrhoea. Given the large sample size in Nelson *et al's* (1995) study and the high incidence of cancer and constipation in the general population, it is likely that the sample included patients with a diagnosis of cancer, constipation or both. In contrast Francombe *et al* (2001) reported the prevalence of faecal incontinence to be at least 2% of the general population, the incidence of which increased to 7% in those over 65 years of age. They further postulated that the true incidence was probably much higher but is often not reported because of the stigma associated with the problem. Johanson and Lafferty (1996) found that only one third of patients identified as having faecal incontinence had ever discussed the problem with a physician.

Diarrhoea and/or faecal incontinence care are common problems that may be secondary to constipation, thus when caring for patients with advanced cancer it is important to be aware of the potential for misdiagnosis. Patients may use descriptors such as diarrhoea, overflow or faecal incontinence as a rationale for why they believe they are not constipated. Patients may not volunteer information on faecal incontinence and eliciting such information may be facilitated by utilisation of a constipation assessment tool.

In summary, constipation often leads to multiple symptoms and complications in patients with advanced cancer. Bowel obstruction profoundly impacts on patients and presents clinical problems as its aetiologies cannot be established on subjective data alone and may be misdiagnosed as constipation despite the increased incidence of tumour related obstruction in some cancers. Similarly, a diagnosis of constipation may be rejected inadvertently when diarrhoea coexists in the belief that the two are mutually exclusive, possibly due to both being poorly defined and under-reported.

2.6 Laxative treatments

The role and use of laxatives in the management of constipation is well recognised and commonly accepted in both professional care and in the general population. Purgative use has been a mainstay of medical therapy for the last two millennia (Duncan 2000). Although the use of laxatives is commonplace most HCPs appear to lack an in-depth understanding of them. The following oral laxatives and their overall efficacy are discussed in the management of constipation generally and more specifically in patients with advanced cancer.

2.6.1 Types of laxatives

Laxatives are classified according to their mode of action and comprise various drugs and preparations including bulk-forming, stimulant laxatives, faecal softeners and osmotics (British National Formulary (BNF) 2005). Although other laxatives (such as bowel cleansing solutions) and novel treatments (for example some prokinetics, prosecretors and antibiotics) have been used to treat constipation they are not part of routine management and are excluded from the following.

Most laxatives are safe when used occasionally (Anton 2002) although all can have significant adverse effects, for example they may hinder the absorption of vitamins and may upset the electrolyte balance (Long *et al* 1995). The classical adverse effect of laxatives is diarrhoea and there are no features that absolutely differentiate this type of diarrhoea from any other (Anton

2002; Baker and Sandle 1996). Some of the adverse/unwanted effects of laxatives are shown in Table 3.

Laxative	Adverse effect	Reference
Danthron	Hepatotoxicity, contact dermatitis, may colour urine pink or red as well as staining the perianal skin pink or red.	Tolman <i>et al</i> (1976); Harland and Mortimer (1992); BNF (2005); BNF (2008)
Docusates (dioctyl sodium sulfosuccinate and related compounds)	Possible hepatotoxic effects Enhances uptake of drugs such as erythromycin.	Abramowicz (1997); Donowitz and Binder (1975); Dujovne <i>et al</i> (1972); BNF (2005); BNF (2008)
Ispaghula husk (psyllium)	Oesophageal obstruction in patients with dysphagia, gastrointestinal obstruction, anaphylaxis, asthma, shortness of breath, wheezing, urticaria.	Noble and Grannis (1984); BNF (2005); BNF (2008); Nelson (1987); Vaswani <i>et al</i> (1996); Jagjivan <i>et al</i> (1988)
Lactulose	Flatulence, abdominal: distension, rumbling pain, cramp.	Attar <i>et al</i> (1999); BNF (2005); BNF (2008)
Liquid paraffin	Associated with lipoid pneumonia as a result of aspiration of the oil, anal seepage of oily material, abdominal cramping, flatulence.	Fallon and O'Neill (1997); Xing and Soffer (2001); Bandla <i>et al</i> (1999); BNF (2005); BNF (2008)
Polyethylene glycol	Cramping, nausea, unpleasant taste, flatulence, loose stools, abdominal: pain, bloating, rumbling.	Andorsky and Goldner (1990); Attar <i>et al</i> (1999); BNF (2005); BNF (2008)
Senna	Hepatotoxicity, diarrhoea, flatulence, abdominal: distension, rumbling, pain, cramp.	Beuers <i>et al</i> (1991); BNF (2005); BNF (2008)
Senna plus lactulose	Diarrhoea, flatulence, abdominal: distension, rumbling, pain, cramp.	Agra <i>et al</i> (1998); Sykes (1991); BNF (2005); BNF (2008)

Table 3 – Adverse effects of laxatives

2.6.2 Efficacy of oral laxatives

Various reviews present conflicting evidence about the efficacy of laxatives. The reviews differ in their primary samples, which are chronic constipation in adults (Ramkumar and Rao 2005; Tramonte *et al* 1997), constipation in the elderly (Petticrew *et al* 1997), constipation in palliative care (Miles *et al* 2007) and opioid induced bowel dysfunction in cancer patients (Tamayo and Diaz-Zuluaga 2004).

These patient samples are diverse insomuch as chronic constipation reflects longevity of the condition regardless of cause, whereas opioid use, the elderly, cancer and/or palliative care allude to its possible aetiologies. It is explicit that elderly patients and opioid users were included in those studies assessing chronic constipation, therefore representative of patients in this study as many will be elderly, may have experienced chronic constipation during their lives and developed constipation as a result of cancer and/or its treatments and disease progression. Petticrew *et al* (1997) suggested that in the elderly any kind of laxative can increase stool frequency by about 1.4

bowel actions per week compared with a placebo. As the following two systematic reviews, Ramkumar and Rao (2005) and Miles *et al* (2007), present contemporary data they are discussed in more detail and comparisons made with other studies where appropriate.

Ramkumar and Rao (2005) examined randomised controlled trials (RCT) (period 1996 to 2006) that compared one agent with a placebo or compared two separate agents for efficacy and safety. The strength of evidence and grading of recommendations were determined using established methodological criteria by Schoenfeld *et al* (1998) and Jadad *et al* (1996). The results suggested there was good evidence to support the use and efficacy of polyethylene glycol in the treatment of constipation and lactulose and ispaghula husk were found to be efficacious and are moderately recommended in the treatment of constipation. There was poor evidence, to support the use of the other laxatives (considered for this study as outlined above) either due to poor study design, limited numbers and/or lack of efficacy.

The evidence to support laxative efficacy is impaired partially due to the varying study designs in which the intervention dose varied between studies. For example, psyllium doses ranged between 3.5g and 24g per day and in 2 studies the dose was not known. A further consideration is that Ramkumar and Rao (2005) identified their aim which ‘...was to undertake a systematic review of the efficacy and safety of traditional medical therapies for chronic constipation....’ However, given the studies’ designs, that of cross-over RCTs, it may be that some patients were not constipated at the point of cross-over as this may have been alleviated by the initial laxative used. Whilst it is acknowledged that a ‘washout’ period is explicit in some trials, the duration of this period varied and was only two days in some cases and needs to be considered given the ‘time to effect’ (Appendix 2) of some laxatives, which is further affected by gastrointestinal transit time.

2.6.3 Efficacy of laxatives in patients with advanced cancer

Miles *et al* (2007) state that the treatment of constipation in palliative care is based on inadequate experimental evidence as few RCTs make direct comparisons between different classes and/or combinations of laxatives. In their comprehensive literature search (period 1996 to 2005) and utilisation of two established methodological quality scales by Jadad *et al* (1996) and Rinck *et al* (1997) only four studies were identified. One of these studies compared a laxative not commonly available in England (Miles *et al* 2007) and is therefore excluded from the following discussion.

Agra *et al* (1998) compared senna with lactulose in a randomly assigned sample of 75 terminally ill patients. No significant difference was noted in efficacy between these two groups. These

findings were confirmed by Tamayo and Diaz-Zuluaga (2004) who further found that senna plus lactulose produced a superior effect, thus reinforcing the previous findings by Sykes (1991).

Sykes (1991) compared senna plus lactulose to co-danthramer which were randomly assigned in a crossover trial to 51 hospice patients with cancer. The dose was titrated according to response. Lactulose plus senna produced a superior effect in relation to bowel movement but caused more diarrhoea than co-danthramer. No significant differences were found between the opioid and non-opioid users, however, the latter group had a greater stool frequency (Sykes 1991). Furthermore, Sykes (1991) found senna plus lactulose equally as effective as magnesium hydroxide combined with liquid paraffin in 118 hospice patients with cancer.

Whilst the efficacy of laxatives are not contested it is important to be aware that they are the most common cause of diarrhoea in palliative care (Twycross and Lack 1986) thus warranting patient monitoring and dose titration.

In summary, by comparing and contrasting the aforementioned two contemporary and systematic reviews and other studies, it is possible to extrapolate the following valuable considerations which will be referred to in this study. These include laxative efficacy, side effects and formulation, outcome measures and rescue laxative use. Some oral laxatives are efficacious provided they are used consistently and in optimal doses. Laxative dose is variable in individuals and may require titration. Formulation, dose frequency and adverse effects impact on individuals consistent use and may need periodical modification. In the aforementioned studies, outcome measures on laxative efficacy, adverse effects, stool form and frequency were based on patient self-reports and supplementary data obtained using constipation risk and assessment tools.

2.7 Clinical methodological considerations

2.7.1 Defining constipation

Constipation is poorly defined (Harari *et al* 1993). There is no single definition of constipation and an attempt to collate published definitions of constipation provides a list of signs, symptoms, interpretations of beliefs and experiences as summarised below (Table 4).

<p>Frequency: the number of bowel motions per day/week, often described as ‘infrequent’</p> <p>Nature of stools/consistency: small hard rock, pellets, scybala (hardened masses of faeces), large bulky mass, watery/loose stools, diarrhoea, dry stools</p> <p>Ease of passage: pain on defecation, difficult evacuation, the amount of physical exertion to aid/facilitate defecation, dyschezia (excessive straining)</p> <p>Sensation of incomplete bowel evacuation: tensemum, ineffectual defecation/evacuation, anorectal obstruction or blockage</p> <p>Manual manoeuvres to facilitate defecation: digital removal of faeces, perineal support</p> <p>Duration of defecation: prolonged periods on the toilet, frequent visits to the toilet</p> <p>Laxatives: dependence on or intermittent use</p>
<hr/> <p>Norton 1996; McMillan and Williams 1989; Ross 1998; Tortora and Grabowski 2000; Mallett and Dougherty 2000; Woodruff 1993; Anton 2002; Nelson <i>et al</i> 1995; Drossman 1999; Maestri-Banks and Burns 1996; Winney 1998; Barloon and Lu 1997.</p>

Table 4 – Descriptors used to define constipation.

People most commonly define constipation by one or more descriptors. Constipation is often defined as fewer than three bowel movements a week though symptoms like straining, passing hard stools and inability to defecate when desired, together with abdominal pain also form part of the diagnosis (Bandolier 1997). The extent to which these symptoms coexist in individuals varies. Cimprach (1985) suggested that using a single parameter, such as frequency of stool, is too simplistic and that it is also important to assess consistency, size and ease of passage during defecation. Individuals vary in the importance they give to the different components of constipation when assessing their own bowel function and may introduce factors such as abdominal bloating (Sykes 1994). Defining constipation is also hindered by its overwhelming subjectivity.

2.7.2 Subjectivity versus objectivity

Clinical and epidemiological studies in constipation are largely based on subjective self-reporting (Potter and Higginson 2002; Everhart *et al* 1989; Drossman *et al* 1982; Sandler and Drossman 1987; Rendtorff and Kashgarian 1967). Constipation is seldom measured objectively due to the unpleasant nature of standard techniques (stool collection) or radiation exposure (x-rays), or both (Phillips 1991). Whilst 100-200g is regarded as an average daily defecation weight (Humes 2001) such measures are rarely alluded to in the literature. Similarly, transit time is rarely measured but

Sykes (1990) notes that food residual in the bowel is normally 1-2 days whereas in hospice patients with cancer this be between 4-12 days.

Individuals' expectations of 'normal' stool form and frequency vary. For example, a bowel motion every three days with minimal straining may be 'quite normal' to one person but another may regard this as being constipated because their bowel had not opened daily (Ashraf *et al* 1996; The Medicines Resource Centre (MeReC) 1994). A few hard pellets passed daily could be normal to one person whereas another may consider this as being constipated. Maestri-Banks and Burns (1996) and Potter and Higginson (2002) contend that as the individual is the only one to be fully aware of their bowel function the logical definition to use is theirs, thus self-reported constipation

Bassotti *et al* (2004) note that in their study on bowel habits, symptomatic individuals may have been more likely to participate than asymptomatic patients. This is an important consideration given the subjectivity of constipation as patients may not report and/or proactively manage the condition if they do not perceive themselves to be constipated. Ultimately this may affect their recruitment into research studies and lead to data bias.

In contemporary healthcare research studies, including those of Addison *et al* (2003), Stewart *et al* (1999) and Pare (2001), self-reported constipation is supplemented with data elicited using an assessment tool to afford an objective component and strengthen findings. Generally, HCPs are dependent on the patients' recollection of bowel history, which may be inaccurate particularly with regards to bowel frequency (Drossman *et al* 1982; Manning *et al* 1976).

2.7.3 Reliability and dependability of data

Self-reported constipation may describe real or imagined disturbance of bowel function and is considered unreliable. Manning *et al* (1976) collected bowel frequency data during the normal clinic interview in a randomly selected sample of 150 patients attending general medical outpatient clinics. Findings show that patients with six or less bowel actions per week tended to significantly underestimate bowel frequency whilst those with more frequent bowel actions tended to overestimate. The results suggest that retrospective bowel habit data are unlikely to elicit accurate information on bowel function and frequency. Heaton *et al* (1992) found moderately good agreement between reported and recorded information as 80% of people who claimed a once daily habit showed evidence on their recorded forms whereas claims of a twice daily habit were confirmed in 50% of cases (Heaton *et al* 1992).

Constipation cannot be defined or diagnosed by bowel frequency alone (Ashraf *et al* 1996; MeReC 1994; Drossman *et al* 1982; Manning *et al* 1976). The complexities of obtaining reliable data may

be partly due to the difference between patients' perceptions and clinical definitions as there is wide discrepancy in the criteria used by doctors and patients to diagnose constipation (Herz *et al* 1996).

2.7.4 Perceptions

Recognising constipation can be a challenge because of the lack of clear definition and because there is a disconnection between patients' definitions of constipation and those of clinicians (Boyle 1970; Herz *et al* 1996; Cash 2005). Clinicians need to understand not only the symptom-based criteria for constipation but also the other complaints and descriptors that patients may use to define their constipation (Cash 2005). Ambiguous and contrasting definitions add to the complexity of constipation and this is impeded further by the 'professional' versus 'patient' viewpoint.

Health care professionals and the body of scientific literature define constipation in terms of a 'gastrointestinal disorder' or as a 'common medical condition' (Anton 2002), the severity of which is most commonly associated with the frequency of defecation over a given time, for example Lembo and Camilleri (2003) classify severe constipation as only two bowel movements a month.

Using a questionnaire Boyle (1970) showed wide variation in doctors' and patients' definitions of constipation. Of the five statements used there was variation both between groups (patients and doctors) and within each group as to the definition of constipation (Table 5).

Definition	Patients	Doctors
Passing a lot of wind by the back passage	6 (5.6%)	-
Passing loose bowel motions	-	-
Passing dark-coloured motion	1 (0.9%)	-
Difficulty in opening one's bowels	64 (59.8%)	31 (88.6%)
Not opening one's bowels every day	36 (33.6%)	4 (11.4%)

Table 5 – Distribution of definitions of constipation, (Table VIII in Boyle 1970)

The problems with Boyle's (1970) study is that the descriptors were limited and respondents were only able to choose one item despite all criteria being associated with constipation. This study could be considered an outdated source but has face validity (Polit and Beck 2008) and supports the observations of the researcher and therefore underpins this study. More recently Herz *et al* (1996) studied 531 randomly selected patients (attending a clinic for complaints other than constipation) and 57 doctors. Patients' and physicians' concordance on several aspects of

constipation (including definitions, attitudes and management strategies) were compared. They found that severe constipation, whether secondary to a diagnosed disease or as a separate entity, was easily identified by patient and doctor alike but difficulty arose between normal defecations and non-severe constipation. This 'grey area' (Herz *et al* 1996) was considered to be of particular importance in this study as the suboptimal management of constipation *per se* often results in it becoming increasingly severe. Fifty percent of patients understood constipation differently from accepted medical definitions with 27% of patients considering it as defecation every two days or less and 25% as hard stools alone. In contrast all the doctors defined constipation as defecation less than every three days, sometimes in combination with hard stools.

Herz *et al* (1996) found it unsurprising that patients complaining of constipation often met with the scepticism of the doctor and left the consultation dissatisfied with the care that they received. As a result patients frequently treated their constipation themselves and interpreted the doctors' lack of action as an indication of the value they placed on their symptoms and by implication that the patients' concerns were unimportant and nothing of concern.

In the above studies it is important to consider how individuals' personal and subjective experience may have affected their responses. For example, doctors and nurses undertake several years of training underpinned by research and evidence-based practice which tends to be more quantitative and objectively focused. Thus it may be that HCPs are preoccupied with ascertaining factual and/or objective data rather than identifying and understanding patients' concerns. For example, a patient who reports opening their bowels every two days would not, in the studies by Boyle (1970) and Herz *et al* (1996) be regarded as constipated. However, if the patients' stools are small in size, hard, painful to pass and result in incomplete defecation arguably the patient is suffering with constipation.

In summary, there is no single or clear definition of constipation. People often use more than one descriptor that differ and coexist to varying degrees in individuals. The overriding subjectivity of constipation and unreliability of self-reported data impedes its definition and identification. Diagnosis of constipation should not be solely based on bowel frequency as this is more likely to indicate extreme severity. There is poor concordance on HCPs' and patients' classification of constipation but it is generally accepted that self-reported is the most appropriate definition to use however, it appears that HCPs fail to acknowledge the significance of patients' concerns. Constipation is insidious and needs preventing in preference to treating but this rarely occurs.

2.7.5 Reporting constipation

In a prospective study McMillan and Tittle (1995) found that 84% of hospice patients had some degree of constipation but it was only recorded as a problem in 29% of patients' charts. The study suggests that constipation is under-assessed and under-reported by both physicians and nurses, a finding which is further supported by Glare and Lickiss (1992) who state that when continually under-managed constipation contributes to unnecessary morbidity and mortality. The under-recording of constipation may be due to nurses' poor understanding of constipation. This is best illustrated in the study by Moore *et al* (1996) who used a constipation questionnaire that included questions on medication, medical diagnosis, signs, symptoms, pharmacological and non-pharmacological interventions. Only 43% of items were answered correctly thus illustrating a gap in nurses' knowledge (Moore *et al* 1996).

Doctors require a greater deviation from the norm than do their patients and in the clinical context. More than 50% of the patients presenting with constipation are referring to something other than the entity that the doctor recognises as constipation (Herz *et al* 1996). The result is that constipation may worsen insidiously and, if left untreated, may become severe and/or lead to faecal impaction (Nettina 1996), especially when exacerbated by illness and/or medications. As a result constipation is seldom resolved until it becomes a significant problem to the individual (Ross 1998) and may have been prevented in patients with advanced cancer by appropriate HCP patient assessment and clinical intervention.

2.7.6 Treatment

Constipation in patients with advanced cancer is foreseeable and preventable (Sykes 2004). Laxatives should be started concurrently with opioids (Palliative Care Formulary 2007; Bouvy *et al* 2002; West Midlands Palliative Care Physicians 2003; BNF 2005; BNF 2008; Sykes 1998b) as reflected in the following extract, but evidence suggests this occurs in less than half the cases.

“...constipation is a very common cause of distress and is almost invariable after administration of an opioid. It should be prevented, if possible, by regular administration of laxatives, a faecal softener with a peristaltic stimulant (e.g. Codanthramer) or lactulose solution with a senna preparation should be used...”
(BNF, 2006 p 16)

Over 90% of patients with cancer spend most of their last year of life at home (Addington-Hall and McCarthy 1995) and the co-prescribing of laxatives with opioids by community teams is paramount in order to prevent and/or alleviate constipation. However, Oxenham *et al* (2003) state that the co-prescribing of laxatives with opioids in patients with cancer remains suboptimal. Over

88% of GP practices in Lanarkshire (UK) and 541 of their patients were studied. The co-prescribing of laxatives with strong opioids occurred in less than 50% of cases. Given the recommendations advocating the co-prescribing of laxatives with strong and weak opioids Oxenham *et al*'s (2003) study appears to underestimate the extent of the problem. The provision of laxatives needs to be supported by knowledge of their efficacy, time to effect and consistent use. When medicines that doctors prescribe fail to produce the benefits they expect they often respond by varying the dose or selecting an alternative medicine (Marinker and Shaw 2003) without exploring the reasons for lack of efficacy. This may be partly due to HCPs' poor knowledge about the use and role of laxatives as Miles *et al* (2007) report that there are a limited number of eligible studies pertaining to laxative use in the management of constipation for palliative care patients, thus its' management is based on inadequate research evidence (Miles *et al* 2007). When laxatives are prescribed patients often fail to take them.

2.7.7 Laxative use

Approximately half of the drugs prescribed for patients with long-term conditions are not taken as prescribed (Haynes *et al* 1996; Cox *et al* 2002; Haynes *et al* 2005; Marinker and Shaw 2003). Laxatives are more often omitted than other drugs (Townsend *et al* 2003) partly due to a perceived lack of efficacy and over 21% of terminally ill patients either omitted and/or reduced their laxative dose (Zeppetella 1999).

Lack of laxative efficacy may partly be due to patients' failure to use them consistently, thus not taking a therapeutic and/or efficacious dose. Historically, patients use or non-use of medications was discussed in terms of 'compliance', however, more recently the term 'concordance' is used due to the benefits afforded by the patient-clinician shared decision making and choices based on individuals' understanding of the other persons preferences.

2.7.8 Constipation identification and assessment

Terminally ill cancer patients have many risk factors for constipation but its routine assessment in this population is insufficient (Bruera *et al* 1994). Specialised tools have been developed to facilitate an individualised approach to the assessment and prevention of constipation. A number of tools are specifically designed to measure constipation whereas others include constipation as a symptom within another assessment tool. It is widely accepted that patient assessment is an essential aspect of care planning (Hartweg 1990; Holt 1995; Hyde *et al* 1999; Ross 1998) yet lack of nursing literature surrounding assessment in relation to prevention of constipation suggests nurses seem reluctant to assess and identify those at risk of constipation (Richmond 2003).

The Rome Criteria were originally developed in 1987 by a group of gastroenterologists investigating the high prevalence of gastrointestinal functional disturbances. Consensus was reached on how to identify and define 'functional gastrointestinal disorders'. The criteria are summarised in Table 6. In an attempt to standardise the definition of constipation and impose some definitional uniformity for clinical research, the Rome II Criteria were further developed and set forth criteria for the diagnosis of chronic constipation in 1999 which include a description of chronicity, symptoms and the use of manual manoeuvres to assist defecation (Drossman *et al* 2000). The Rome II Criteria were utilised in this study due to its potential to obtain comprehensive data on patients' constipation and their management strategies, especially when certain aspects have been forgotten or not reported due to its embarrassing and sensitive nature.

Rome Diagnostic Criteria	
Constipation is defined by the occurrence of two or more of the following for at least 12 weeks in the last 12 months:	
<ul style="list-style-type: none"> • Straining in more than half of all defecations • Lumpy or hard stools in more than a quarter of all defecations • Sensations of incomplete evacuation in more than half of defecations • Sensation of anorectal obstruction or blockage in more than half of defecations • Manual manoeuvres to facilitate more than half of defecations (e.g. digital evacuation or perineal support) • Bowel frequency of less than three a week • Loose stools are not present and there are insufficient criteria for irritable bowel syndrome 	

Table 6 – Extract from the The Rome Diagnostic Criteria (Drossman *et al* 2000; Longstreth 2006).

Nurses use constipation assessment tools as a means of obtaining data about an individual's bowel function. For example, the Constipation Assessment Scale (McMillan and Williams 1989) comprises eight questions which are rated by the patient as either 'no problem', 'some problem' or 'severe problem'. Tools can be useful for establishing patients' 'normal' patterns of defecation, identifying those at risk of developing constipation, monitoring stool consistency, frequency of defecation and acting as an evaluation of interventions or therapies (Richmond and Wright 2004). There are two major issues of concern with constipation assessment tools, their lack of comprehensiveness (Richmond and Wright 2004) and poor utilisation by nurses (White 1995; Richmond 2003; Zernike and Henderson 1999). Tools alone will not assist the reduction of constipation but there is evidence that they may improve the identification and management of

constipation when utilised with a co-existing appropriate ethos of care (Zernike and Henderson 1999).

A prerequisite to the prevention of constipation is the assessment of the risk (Richmond and Wright 2004). A literature review of potential risk factors for constipation concluded that (despite the abundance of literature) there were no objective comprehensive risk assessment tools for constipation (Richmond and Wright 2004). The authors do not make it clear what is meant by 'objective comprehensive risk' or how often it would be used in light of evidence that suggests that nurses rarely utilise constipation assessment tools. Reasons for lack of use include the assumption that nurses should intuitively be able to identify patients at risk of constipation (White 1995). There also appears to be a gap in nurses' knowledge and understanding of constipation (George *et al* 1996; Moore *et al* 1996; Richmond and Devlin 2003) possibly due to nurses being reluctant to pursue expertise in bowel and related subjects, such as faeces, which is often regarded as an unclean or foul substance (Robinson-Wolf 1996).

The graphic representation afforded by the Bristol Stool Form Scale (Lewis and Heaton 1997) provides nurses with a tool for obtaining data about patients' stool form and consistency, whereas other nursing tools are based solely on subjective descriptions. The Bristol Stool Form Scale is a straightforward objective tool that measures 'transit time' (the time it takes for the food that is eaten to travel to the anus) and involves no exposure to radiation or stool handling (Lewis and Heaton 1997). Therefore the Bristol Stool Form Scale has the potential to guide nurses in their practice and assessment of constipation utilising a more contemporary and objective approach, in conjunction with patients' self-reported subjective reports.

The drawback with constipation assessment tools is that they are predominantly symptom-based and may not include other complaints and descriptors used by individuals to define their constipation (Cash 2005) and self-reported constipation is more common than in studies using Rome II criteria (Higgins and Johanson 2004; Pare *et al* 2001). Generally, patients do not volunteer information on bowel habit unless specifically asked (McMillan and Tittle 1995; McMillan 2002) and this omission by HCPs may be one of the exacerbating factors to the condition.

In summary, specialist tools have been developed in an attempt to diagnose constipation and identify those at risk. Tools lack comprehensiveness partly due to the problems of defining constipation. Elements of the Rome II criteria and use of the Bristol Stool Form Scale may assist the affirmation of confirmation by introducing an objective component to patients' self-reported constipation. The assumption that nurses should intuitively identify patients at risk is discounted

by the apparent knowledge gap in a condition regarded as unclear and unlikely to be reported by patients unless specifically asked.

When patient self-reported constipation is acknowledged by HCPs as a condition worthy of treating laxatives may be prescribed. However, when laxatives are prescribed patients appear reticent to take them.

2.7.9 Compliance versus concordance: the debate

Patients' non-compliance or non-concordance with prescribed medications presents a major health concern and represents a serious therapeutic deficit for patients (DH 2004). Marinker and Shaw (2003) describe compliance as the degree to which patients follow their prescribed drug regimen. Haynes *et al* (1996) expand further and describe non-compliance as being either intentional or involuntary depending on the quality of the information given, the impact of the regimen on daily life or their social isolation. Zeppetella (1999) adds that non-compliance takes several forms such as not collecting a prescription, not taking the medication, errors in dosage, timing and sequencing of administration and taking of additional non-prescribed medication.

Methods of measuring compliance vary from residual pill counting, measuring blood or urine levels for drug metabolites and interviewing. Most studies in respect to patient compliance with drug regimens rely on patient self-reporting (Zeppetella 1999). The value of such studies therefore could be considered limited as the accuracy of the self-reported data could be flawed through understatement or lacking truth.

The DH (2004) drew on various studies and noted that patients are more likely to benefit from their prescribed medication when they fully understand and accept their diagnosis, agree with the proposed treatments and therefore adhere to their prescribed drug regimen. To this end, concordance has been more recently used to define the process of successful prescribing and medicine taking, based on partnership, process and agreement between patient and a HCP about whether, when and how medicines are to be taken (Jones 2003; Marinker and Shaw 2003; Elwyn *et al* 2003). Key to this process is that the doctor identifies and understands the patient's views of taking the medication and explains the importance of the treatment. Based on shared decision making patients gain an understanding of the consequences of keeping (or not keeping) to the treatment (Jones 2003; Marinker 1997; Elwyn *et al* 1999). By respecting patients' beliefs and wishes and having an appreciation of each others' points of view leads to an agreement on prescribing and health outcomes improve (Jones 2003).

The DH (2004) endorsed and adopted the principles of concordance as being pivotal to the doctor patient relationship. The Medicines Partnership is an initiative supported by the DH (2004) and is aimed at enabling patients to obtain the optimum benefit from their medicines by fully involving them as partners in decisions about treatment and then supporting them through the process of medicine taking. The processes necessary to achieve this are described as concordance which is still considered a new approach to the prescribing and taking of medicines based on partnership (DH 2004) and is in contrast to compliance which is the following of instructions.

The beliefs and attitudes of HCPs play a central part in the achievement of concordance. The DH (2004) identifies the existence of compliance programmes focused on the practical difficulties of medicine taking. This document notes that the differences between the patient's beliefs and understanding of the diagnosis and proposed treatment and those of the HCP are crucially important and central to the patient's concordance. The HCP has a set of beliefs in relation to the appropriateness of particular medicines and how they should be used, which is based on a biomedical model. These beliefs are shaped by the content of professional training and on the evidence from a large body of scientific research.

Zeppetella (1999) states that a shift from the outdated notion of compliance and towards that of concordance appears a logical route forward. Prescribing should be perceived as an alliance in which the patient actively participates and medications are selected not only for the clinical indication but also as considered appropriate for the patients, their life style and preferences.

Weiss and Britten (2003) suggest that not all HCPs will embrace concordance as some will have concerns regarding affording the patients' views primacy. They go on to suggest that another concern for HCPs is time. The discussion of patients' views may lead to the requirement for longer consultations that would prove impracticable in many primary care settings. This resonates with findings of the DH (2007) that the average length of GP consultations increased from 8.4 minutes 1992/3 to 11.7 in 2006/7 and that the surgery practice nurse consultation increased to 15.5 minutes. Therefore increased time to achieve concordance was problematic (Weiss and Britten 2003).

Heath (2003) believes that until HCPs accept that the patient alone has the right to decide whether or not they will take a drug the move from the concept of compliance to that of concordance will continue to be cosmetic. It is debatable whether HCPs fully appreciate the meaning of concordance and therefore may not be equipped to promote it thus patients are failing to benefit from its theoretical advantages that advocate improved patient outcomes.

2.7.10 Medication adherence

Patients' failure to take their medications may be intentional or involuntary (Weiss and Britten 2003). Patients have different but equally cogent and coherent sets of ideas about their own illness, medicines in general and their medicines in particular (Beardon *et al* 1993; Marinker and Shaw 2003). These are based on their own preferences, priorities, beliefs, attitudes and life experience. There are many reasons why patients do not take their medicines and this may also include practical difficulties such as getting to a pharmacy, opening containers and remembering to take the medicines (Elwyn *et al* 2003).

Better informed patients may decline certain drugs if they remain unconvinced of their appropriateness or efficacy (Coulter 2002). The 'benefits versus harm' of a drug's use are central to the discussions on concordance (Jones 2003). In a study of 106 patients receiving palliative care Zeppetella (1999) found that 33% took less medication than prescribed. Although this was usually analgesia it covered the whole spectrum of medication. One of the reasons given for not taking medication was concerns about adverse effects. Seventeen percent of respondents took additional medication instead to compensate for any 'gaps' that they perceived in their drug regimens. Townsend *et al* (2003) support these findings for example, one patient in their study omitted her pain killers in preference to retiring to bed as a management strategy. This was in spite of her husband urging her to take the pain-killers as these would have enabled her to be up and 'normal' thus preventing their three small daughters returning from school and seeing their mother in bed. Additionally, drugs were frequently used to facilitate the ability to perform activities to fulfil social roles, for example, as grandparents and parents. The maintenance of social role and self-identity were perceived as important reasons for suppressing distressing symptoms by taking drugs (Townsend *et al* 2003). Conversely, Townsend *et al* (2003) express the psychosocial dilemma that often presents to patients that using drugs in this way may also symbolise 'ill health' and act as an indicator of dysfunction and overall affirmation of the severity and progress of a chronic illness and thereby presents a threat to, or loss of, identity. Townsend *et al* (2003) report that one of the key reasons for omitting drugs could lie in patients' desires to live life in the absence of illness and drugs, however, the study fails to acknowledge if, by omitting their medications, this desire is fulfilled to any degree.

The DH (2004) highlights the importance of patients having the opportunity to air their concern in regard to any medicines and have these addressed and states that the patient's beliefs about the medicine, or medicines in general, for example, that medicines are unnatural, harmful, addictive, or that they wear off over time and are therefore not worth taking, also contribute to non-adherence. In similar vein, Griffith (1990) notes that elderly patients are particularly at risk from the dangers of non-compliance as the illnesses and conditions that they suffer from often require

multiple and long-term therapy. In addition, poor memory, communication difficulties and deficient manipulative skills, as in rheumatoid arthritis, may complicate the situation. Drossman *et al* (2000) note that psychosocial factors are an important consideration in patient adherence because they are modulators of the patient's experience and behaviour thus affecting outcome.

Some patients expressed ambivalence to taking drugs in a number of ways. One tension was between the use of a regular drug regimen and a more flexible regimen as people self regulated their drug use in an attempt to gain equilibrium, relief from symptoms, or sense of a 'normal' life. Further ambivalence was shown in patients expressing reluctance to take drugs and their inability to be 'free' of them. Drugs both enabled respondents to continue to function in social roles and acted as a marker for their inability to perform such roles. Drug use was discussed in moral terms to show how people remained competent though seriously challenged by their illnesses, were stoical in their response to illness and were sensitive in their roles as family members.

Research has shown a widespread cultural belief that drugs should be as little used as possible (Britten 1996; Conrad 1985; Donovan and Blake 1992; Morgan 1996; Rogers *et al* 1998; Britten 1994). For example, in a sample of 544 people drawn from four general practices, 86% agreed with the statement "I would prefer not to take any medicine if I can avoid it," and 58% agreed with "I always take as small a dose as possible." Conversely, only 24% agreed with the statement "I would be happy to take a medicine over a long period of time," 26% agreed with "If I'm feeling ill I like to take medicine," and 15% agreed with "When you are ill you should always take a medicine" (Britten *et al* 2002).

Zeppetella (1999) identifies that many patients with advanced cancer do not take their medications even though they are in pain or some level of discomfort. Of particular interest to this study is that, second to opioids, over 21% of terminally ill patients either omitted and/or reduced their laxative dose. The overall aim of this study was to identify the drugs prescribed to terminally ill patients living at home and to assess their compliance with treatment. It was a small-scale study but illustrates several issues relating to compliance which are of specific interest to this study. The sample of 111 patients had been referred to the community palliative care team and mainly comprised of patients with malignant disease (92%). The sample had a mean age of 66.4 years (range 34-92 years). In addition to the main aim of assessing compliance, data were also collected on whether or not patients had any information about their medication, whether any additional non-prescribed medications were being used and if so, the underpinning reasons for doing so.

Using semi-structured interviews and 'pill counting' the study revealed that 106 patients were prescribed a total of 597 drugs. Sixty percent of patients were non-compliant with their

medications. Over 90% of patients had two or more prescribers. The mean number of prescribed drugs per patient was 5.6 (range 1-16) in which 20% of patients were prescribed eight or more drugs. Having an excessive number of drugs exacerbated non-adherence as regimens were complex, difficult to follow and interfered with the patients normal activities of living. The most common reason given for taking less medication than prescribed was offered by 34% of patients who felt the drug was ineffective and therefore not worth taking.

Twenty-four percent of patients experienced unfavourable events and 24% reported having anxieties about possible adverse events. A number of other factors that were important to patients and determined whether they took a particular drug or not, including disliking the taste, not having instructions, agreement on a particular regimen and consideration of such characteristics as the ability to take tablets or use inhalers. Once or twice daily preparations were preferred as they were less intrusive to the patients' lifestyles. Zeppetella (1999) concludes and stresses the importance of the prescribing process in the improvement of the levels of compliance, stating that patients were much more likely to take their medications if this did not interfere with their daily activities and if clear instructions for use were offered by the prescriber. Furthermore compliance was greatly enhanced if the patients were made aware of possible side effects, advised of means of minimising them and actions to be taken if they persisted. The study also identified that patients were more likely to take their drugs if the prescriber had taken time to explore possible fears, for example potential addiction and if instruction regarding what actions should be taken if the treatment was, or became, ineffective. Zeppetella (1999) suggests that countless terminally ill patients do not adhere to prescribed treatments and frequently search for their own remedies based on their life experiences (lay knowledge) or the experiences of those around them.

Townsend *et al* (2003) examined attitudes towards multiple drug use among patients with four or more chronic morbidities (patient with cancer often have multiple morbidity and polypharmacy). Twenty three people participated in this study by completing symptom diaries and participating in semi-structured interviews. All respondents expressed their dislike of drugs to some extent and drug use was often portrayed as the "last resort." Drugs occupied a central role in patients' lives and, despite acknowledging a dependence on drugs to live as 'normal' a life as possible respondents expressed an aversion to taking drugs for various reasons. Although some drug regimens were complex some respondents felt this was the means by which they could gain a degree of relief from distressing symptoms and only one respondent reported that his combined drug regimen was not a problem.

It is explicit from the aforementioned studies that patient education and information is lacking and this is likely to exacerbate their non-adherence with laxatives. Despite the suggestion by Beardon

et al (1993) that symptomatic patients with cancer prefer medications that alleviate their symptoms, in relation to constipation the emphasis is on its prevention rather than treatment, thus, individuals would be asymptomatic. In addition, the insidious nature of constipation may result in individuals being unaware that the condition is imminent, thus ultimately requiring treatment rather than prevention. These studies illustrate that patients do not like taking medicines if they can be avoided and may further explain some patients' reluctance to take prophylactic laxatives unless they fully understand the purpose and benefits.

2.7.11 Health care professionals' perceptions

Health care professionals acknowledge constipation as being the most common reason for non-compliance with opioids and as a result patients unnecessarily endure pain (Abbas and Abbas 2003). Findings indicate that 55% of HCPs believe that non-compliance with opioids was a problem for 15-50% of patients and 10% felt that non-compliance was a problem in over 50% of patients with cancer related pain. When invited to relate their thoughts regarding the reasons for non-compliance 75% of HCPs considered that patients failed to take their opioid therapy for fear of developing intractable constipation.

Doctors may initiate the discussion about treatment but then often dominate the discussion. When prescribed medicines fail to produce the expected benefit doctors vary the dose or select an alternate drug and focus almost exclusively on improving the quality of their own prescribing options rather than addressing the issue of patient compliance/concordance (Marinker and Shaw 2003).

Health care professionals do not always name the drug they prescribe and may not describe how new drugs differ in mechanism or purpose from those previously prescribed to a patient, thus failing to investigate the patients' understanding of a treatment or explore their concerns about drugs (Elwyn *et al* 2003). Marinker and Shaw (2003) state that concordance cannot be achieved by doctors acquiring new communication skills alone. Doctors and patients must learn how to "do concordance" not only on the basis of established evidence but also from their own reflective experiences.

In summary, the term compliance has been used to describe the level of patients' obedience with HCPs instructions and adhering to their prescribed medications. However, more recently the term concordance has been used to emphasise the patient-HCP partnership and agreement on drug regimen founded in respect of each other's opinions and in which the patient has been fully consulted and understands the implications especially in relation of omitting and/or ceasing the drug's use. It appears that the term 'concordance' has been introduced in an attempt to reduce the

incidence of non-compliance with prescribed medication (Elwyn *et al* 2003). For the evolving concept of concordance to succeed a change in practice is required. The emphasis should turn to patients' needs and wants and how these influence the way they take their medicines (Jones 2003). It is clear that the patients' beliefs, values and attitudes influence whether and the manner in which they take their prescribed drugs (Britten *et al* 2002; Elwyn *et al* 2003).

Concordance may not always be easy to achieve but without exploring and addressing these issues patients may not be able to obtain optimum benefit from the prescribed treatment. In reality however, few HCPs appear to know the meaning of concordance and it is often used as an alternative to compliance. Used interchangeably and without an appreciation of the concept of 'concordance' this approach fails to acknowledge the need to encompass patients' beliefs and wishes as part of the patient-healthcare agreement. Jones (2003) confirms this view stating that concordance has been hard to put into practice and one reason for this is that most health professionals either have not heard of the term or do not understand it.

Poor adherence with medications presents problems in health care and increases significantly in patients with advanced cancer who are more likely to omit laxatives than any other drug. Factors influencing patients' drug use include the provision of information about their illness and/or drug, impact on life, physical ability to collect and/or administer, lack of agreement on regimen (such as choice of laxative and timing), the perceived lack of efficacy and poor knowledge about the consequences of their non-use. Patients therefore may mistakenly believe that their reasons for omitting or ceasing laxative use are justifiable, for example that they lack efficacy, that taking a smaller than recommended dose is acceptable and a tendency to avoid their use unless symptomatic. It is well recognised by HCPs that in an attempt to avoid constipation patients omit their opioids and endure further unnecessary suffering.

Concordance is an approach that aims to redress and prevent problems through a collaborative working partnership between HCPs and patients. However, it appears that time constraints may suppress the process and contribute to its poor adoption by HCP who continue to dominate discussions around prescribing and are failing to explore patients' concerns, understandings and expectations from their laxative regimens.

2.8 Summary

This Chapter highlights the complexities arising when discussing bowel frequency, defining constipation and the incidence within the general population and in those with cancer. The prevalence of constipation is generally accepted to be 2% to 27% of the general population in the Western World and commonly presents in elderly people. Due to transitional aetiologies the

incidence of constipation increases from 51% to 100% in those with advanced cancer with a tendency to escalate over the disease progression.

Identification of constipation can be problematic due to its subjective nature and individuals varying components of what constitutes constipation. Often patients themselves are unaware that they are constipated and symptoms such as diarrhoea/overflow may mask an underlying problem of constipation.

Tools used to identify and measure constipation may be useful but they need to be used in conjunction with patients' self-reports which may be unreliable. The majority of nurses have an inadequate understanding of bowel function and there is a disparity between HCPs and patients in defining constipation. Health care professionals and patients are often talking about different entities when discussing constipation, each varying the components and attribution of severity. Patients are dissatisfied with care received and it is therefore understandable why patients fail to report constipation to HCPs until it becomes a profound problem.

The causes and specific problems that arise in the management of constipation in patients with cancer have been examined along with the need to retain the use of constipating drugs such as chemotherapy agents, antiemetics and opioids. Laxatives were discussed and their efficacy established in patients with advanced cancer, however, the prophylactic use is considered infrequent due to poor HCP prescribing and patient non-adherence with regimens.

The debates around the constructs of compliance and concordance have been discussed along with identification of the rationales as to why so many patients do not take their prescribed medications in general and their laxatives specifically. The elements required to achieve concordance and the nature of the necessary partnerships were examined.

The aforementioned literature and concepts influenced this research as prior knowledge of pertinent findings informed all stages of this action research study and the resultant patient interviews, HCP focus groups and the CMC. The clinic's interventions and outcomes measures utilised the contemporary findings in this Chapter. The role of the prescriber in the successful achievement of a partnership with patients and thereby their concordance with medications is highlighted as this also directly influenced the clinic and its processes.

Laxatives were presented as their efficacy and an in-depth knowledge of the individual functions and side effects proved to be essential in the successful planning, organisation and operation during the clinic stage of the research process. This information was central to the nurse/patient

dialogue in the clinic consultations and fundamental in achieving optimum outcomes for patients. This background expertise also became pivotal in the educational aspects that formed one of the key elements of this study through dissemination to HCPs in the local palliative care unit, regionally and nationally.

Overall, this Chapter serves several purposes. Initially, the identification and analysis of the existing body of knowledge equipped the researcher with the level of knowledge and understanding to enable appropriate and informative feedback to the MDT and gain support to progress the study to its next step, a process that is central to an action research philosophy. The review also presents a general backdrop to the study and affords the reader an insight into the extent and problem of constipation as it presents in patients with advanced cancer.

Although constipation is a common concern for both providers and consumers of health care in hospital and community settings, the associated problems appear to be continually underestimated by HCPs, to the point that unmanaged constipation contributes to unnecessary morbidity. The next stage of this study was to identify a methodology and methods that improve the management of constipation in patients with cancer and addressed the issues surrounding poor HCPs' knowledge and/or practice. Constipation in cancer can be anticipated and is largely preventable but insufficient attention is paid to a condition that is considered to be mundane and embarrassing (Sykes 2004). A great deal could be achieved immediately by improved patient information, the initiation of laxative therapy from the onset, (before constipation becomes problematic and/or intractable), identification of appropriate laxative regimens and titration and attention to the monitoring of outcomes.

Chapter 3

Methodology

3.1 Introduction

This Chapter offers an examination of the methodology selected as a framework for the study, that of action research. The researcher will examine the philosophical basis of action research and explain the rationale for the process of establishing the data as perceived by the individual suffering from constipation. The continuing debate concerning the scientific worth of quantitative and qualitative processes is outlined to strengthen the rationale for the selection of methodology. The Chapter will also include the essence of the quantitative versus qualitative debate and will identify some of the main or potential benefits and disadvantages of each approach. The discussion will include the identification of some key concepts to justify the use of action research as an appropriate methodology for the study.

To this end, May (2001) states that the methodology of the research process needs to be expounded to establish the philosophical stance adopted by the researcher and to guide and set the parameters of any study. Therefore, in this Chapter the interface and relationship between action research and other conceptions of research is considered. It is important to consider this carefully since the well debated proposition that professional practical decision-making must be rooted in 'research' or 'evidence' usually refers to notions of research and evidence that are in many ways not conducive to action research. Action research emphasises that practice should be based on research and evidence however it identifies and interprets key elements of the research in dissimilar ways, to other methodologies, with important practical consequences (Kemmis and McTaggart 2000; Hart and Bond 1995).

3.2 The philosophical debate

There is a significant interest and debate in the role of philosophical positions and paradigms in the process of conducting research. A paradigm can be described as a school of thought, a set of ideas or a world view (Polit and Beck 2008) however, in reality it is much more than this to the researcher (Parahoo 2006). A theoretical paradigm provides a structure for the research, influencing a number of factors, including the phenomena to be researched, the method and the means by which the data are analysed and interpreted. Paradigms for human inquiry are often characterised in terms of ways in which they respond to basic philosophical

questions: ontologic, epistemologic, axiologic and methodologic. These are examined in some depth in the following sections.

3.2.1 Quantitative versus qualitative debate

Polit and Beck (2004) believe that disciplined research inquiry in professional nursing is conducted and can be generally located within two broad paradigms and their associated methodologies. This section gives a brief outline of the key constructs and detail of the debate regarding the philosophy and the overall rigour and application of the research process to this study exploring the management of constipation in patients with cancer.

Winter and Munn-Giddins (2001) assert that there are two forms of social research that are commonly contrasted with each other; namely *quantitative* (based on numerical data) and *qualitative* (based on linguistic data). To position action research, and thereby this study within this debate, both philosophical approaches need to be examined. These theoretical approaches to research provide different, but in many ways, complementary forms of inquiry from the philosophical stances of ‘positivism’ and ‘humanism/interpretivism’. The following sections highlight and debate these polar philosophical positions within research, whilst acknowledging that the arguments presented represent extremes of a continuum, but are nonetheless adopted here to depict the fundamental differences of approach.

Despite the differences noted, quantitative and qualitative research methodologies have many similarities since both require researcher expertise, involve rigour in implementation and result in the generation of scientific knowledge (Parahoo 2006). However, researchers in all areas of study continue to debate the effectiveness and value of these polar positions in eliciting the truth. Although overall research design is inevitably defined as either quantitative or qualitative, a combination of approach is often preferred to enable a problem to be fully explored (Silverman 2001). Nonetheless, the researcher will outline the fundamental differences and expose the debate surrounding them, thereby establishing the philosophical basis of the chosen methodology, whilst acknowledging that such a wide difference in perspective seldom exists in reality (Silverman 2001).

Distinguishing between quantitative and qualitative approaches can be problematic as the commonly accepted idea that quantitative research is concerned with numbers, quantity and measurement, is overly simplistic (Polit and Beck 2008). Similarly over generalised is the use of sample; although quantitative researchers typically use large, probability samples and qualitative researchers use small, non-probability samples, this is not always the case. In

order to establish whether a study is quantitative or qualitative it is necessary to examine the three constituent parts of the conceptual paradigm described by Parahoo (2006). These components are the core philosophical assumptions underpinning the study (or ontology and epistemology), the methods of data collection and the techniques of data analysis (or methodology). Each element is considered in the following text.

3.3 Establishing the truth: Ontological perspective

3.3.1 Determinism versus meaning

The ontology of research pertains to the nature of reality (Polit and Beck 2008). Within a positivist paradigm there is an assumption that a reality exists and that there is a factual world which is determined by natural causes (Polit and Beck 2008). The polar position is adopted by humanism/interpretivism where reality is perceived to be multiple and subjective, constructed by and peculiar to individuals. The positivist paradigm underlines the scientific approach which assumes that there is a fixed, orderly reality that can be objectively studied, often associated with quantitative research (Polit and Beck 2004), whereas the 'interpretivist' researcher understands and appreciates the value of non-statistical data to create a reconstructed understanding of the social world.

Quantitative researchers generally advocate that the 'truth or fact' is total and that there is a single reality that can be defined and measured and assert that true objective accounts of the world can be given (Denzin and Lincoln 1994). To achieve this truth the researcher must remain totally objective to 'discover' truth and by so doing the values, feelings and personal perceptions cannot enter into the measurement of reality (Silverman 2001). Medical researchers usually adopt this totally objective stance as they strive towards precise scientific solutions to medical problems and this is often the preferred methodology in most research focused upon the care of people with cancer.

Conversely, qualitative research is thought to result in a softer or unscientific approach to the research process (Kamhawi and Weaver 2003). It has evolved from the behavioural and social sciences which promote the understanding of the uniqueness and holistic nature of people (Walliman 2006). Such research is often considered to lack the hard, scientific rigor of quantitative perspectives and is therefore considered to be less reliable (Polit and Beck 2008; Parahoo 2006; Burns and Grove 2003). The philosophical base of qualitative research is interpretive, humanistic or naturalistic and is concerned with appreciating the meaning of social interactions (Fielding 2001; Cuff *et al* 1992). Streubert and Carpenter 1995).

Generally, as illustrated above, qualitative researchers believe that truth is both complex and dynamic and can only be established by people in their natural environments (Streubert and Carpenter 1995; Hodder 2000). This is the most appropriate approach for this research, the management of constipation in patients with cancer, as the intention is to explore individuals within the context of their world, experiences and beliefs.

3.3.2 Objectivity versus subjectivity (epistemology/axiology)

The epistemology of any research relates to the relationship between the researcher and those being studied (Polit and Beck 2008). Polit and Beck (2008) note that within the positivist paradigm the researcher is independent from those being studied and thus the findings of the study are not influenced by them. In contrast, within a naturalistic/interpretivistic paradigm the researcher interacts with the respondents and therefore the findings are a creation of that interaction and are by nature subjective.

The axiologic differences between the paradigms are established through the management of biases and values (Polit and Beck 2008). Empirical scientists, researching within the positivist paradigm, argue that the study of any phenomena must be controlled and devoid of subjectivity (Streubert and Carpenter 1995). Polit and Hungler (1999) propound that empiricism is the most important characteristic of positivism and that only evidence that can be gathered, directly or indirectly, through the human senses can be called facts and used to underpin and generate knowledge. It is clear that this definition of empiricism implies that constructs such as anxiety, social support, satisfaction, well-being and so forth cannot be empirically investigated (Parahoo 2006). Nonetheless, such studies have been conducted and it has been possible to do so because although the word empiricism has come to be allied with the scientific approach, it is nevertheless the case that researchers in both traditions gather and analyse external evidence that is collected through their senses and therefore consider their research to be empirical (Parahoo 2006). However, in the main, empirical, quantitative research is considered to produce a hard or precise science that is based on rigor, objectivity and control (Parahoo 2006; Polit and Beck 2004).

An interpretivistic/humanistic research approach does not attempt to apply control to reduce biases to such a degree. Such researchers assume that knowledge is maximised when the distance between the inquirer and respondent is minimised. It is the voices and interpretations of those studied that are crucial to gaining knowledge of the area of study and subjective interactions are the primary way to access them. The findings from this form of inquiry are the product of the interaction between the inquirer and the respondents. In this

study a participatory approach to investigate current practice using research techniques and instigate change to enhance the quality of management constipation in a vulnerable client group was adopted. Participants' experiences and views are a valuable component of the process.

3.4 Reduction versus induction

The main intention of quantitative research is to be concise and reductionistic (Munhall 2007; Polit and Beck 2008; Parahoo 2006). Reductionism involves reducing the whole into parts so that those elements can be examined, usually individually. This is achieved by the quantitative researcher remaining detached from the study and taking care not to affect the outcome with their own values, thereby establishing objectivity (Cormack 2000; Streubert and Carpenter 1995; Polit and Beck 2008). On the other hand, qualitative research normally has a broad focus and aims to promote an understanding of the whole rather than the individual parts (Lofland 1971; Brockopp and Hastings-Tolsma 2003; Fielding 2001). This breadth of investigation is considered to be the cornerstone of the approach adopted for this study and has enabled the researcher to fully explore the research question from the respondents' perspectives. To achieve this, the use of observation, communication and interaction were essential for data collection.

The qualitative, action research process of this study required the researcher to play an active part in the process (LoBiondo and Haber 1994; Flick 2002). In qualitative research, the data gathered represent the shared interpretations of the researcher and respondents with no attempt made to control the interaction. Morse (1994a) states that in qualitative research, variables should not be controlled and that, by the nature of the process, the researcher may not be able to determine the variables until the final stages of the study. The data are therefore subjective and incorporate the perceptions of both the respondents and the researcher (Polit and Beck 2008; Burns and Grove 1997; Morse 1994b; Boswell and Cannon 2007). The researcher is mindful that data gathered in this way are inevitably influenced by the values and perceptions of the researcher and are therefore subjective. However, this subjectivity is considered to be essential to promote an in-depth understanding of the human experience of constipation as it appears to the individual affected by it (Burns and Grove 1997). The increased possibility of researcher bias (DePoy and Gitlin 2005) is acknowledged and the resultant importance of establishing a level of dependability to remove any extraneous material is discussed in Chapter 4 (Methods).

3.5 Challenges for evidence in palliative care

The most robust evidence is traditionally considered to come from randomised controlled trials (RCTs) because they are more likely to inform us than mislead us. Randomised controlled trials have become the gold standard for judging whether a treatment does more harm than good (Sackett *et al* 1996). However, what constitutes 'best evidence' has attracted criticism in some areas of medical and public health research (Williams and Garner 2002; Concato *et al* 2000) as there is controversy about the reliance on RCTs to evaluate health interventions and a tendency to downgrade the contribution of qualitative studies. Rychetnik *et al* (2002) argue against the current emphasis on RCTs for complex multi-faceted health interventions as difficulties arise in interpreting their results, particularly when there is a blurred distinction between failure to demonstrate effectiveness or good evidence of ineffectiveness. Thus recent debate has emerged about how to apply current accepted levels of evidence to emerging areas of health care research such as palliative care (Rychetnik *et al* 2002).

Randomised controlled trials have been found to be a useful and trustworthy methodology to investigate the efficacy of medication treatments (Grande and Todd 2000) however, they have inherent problems that limit their use in palliative care. For example, RCTs favour relatively simple, standardised and unvarying interventions that focus on highly selected populations and outcomes (Rochon *et al* 2005; Murray and Callahan 2003) which, according to Williams and Garner (2002) unfortunately implies that only factors that can be measured are recognised as important. Furthermore, this approach reinforces a dismissive attitude towards qualitative research by oversimplifying the complex nature of clinical care, and as a consequence, many groups are excluded from RCTs (Raphael 2000; Williams and Garner 2002; Rychetnik *et al* 2002).

One of the key principles of RCTs is a state of clinical equipoise, which means that no preference for any particular treatment can occur (King 2000) thus rendering them inappropriate to test complex interventions such as those encountered in qualitative studies which are not amenable to blinding. Furthermore, RCTs tend to de-contextualise individual risk factors and ignore significant societal changes and the diversity or cultural norms that influence outcomes. For example, patients with constipation have varying management strategies based on their experiences, beliefs, expectations and definitions of what constitutes constipation and/or normal bowel function.

In contrast to the homogenous population and simplicity of RCTs (as outlined above), palliative care patients are a diverse group with mixed morbidities, receive multiple treatments, are often elderly and have a limited prognosis. Thus, although RCTs are considered the gold standard in evidence based medicine they are too rigid and present a number of methodological difficulties in patients with cancer and palliative care who endure complex physical, psychological, existential and spiritual problems faced by patients, families and professionals (Bennett and Ahmedzai 2000; Hudson *et al* 2001; King 2000; Harding and Higginson 2003; Grande and Todd 2000). These difficulties include patient recruitment, gate-keeping by professionals (for example, reluctance to enrol their patients in research studies), small sample sizes, high attrition rates, rapidly changing clinical situations and limited survival times (King 2000; Harding and Higginson 2003; Grande and Todd 2000; Green and Thorogood 2004).

Bennett and Ahmedzai (2000) highlight that the focus of research in palliative care is often on the effectiveness of services on populations rather than the effect of treatments on patients. It is difficult to define the intervention precisely and uniformly, thus reflecting a more pragmatic approach, such as comparing a new service with best current practice (Grande and Todd 2000). However, as previously highlighted, the implementation of best practice in relation to constipation management is poorly adopted by HCPs, therefore this study considers ways in which patient outcomes can be optimised together with improving clinicians practices. To this end, this study harnesses the view of Raphael (2000) who argues that evidence-based practice is translated easily to the needs of the 'real' patients seen in practices and communities and thus outlines three forms of knowledge:

- Instrumental knowledge is developed through traditional scientific approaches. It is concerned with controlling physical and social environments as is attempted in RCTs. This pathway is reflected by dotted lines in Figure 3.
- Interactive knowledge is derived from sharing lived experiences and is concerned with understanding and the connections among human beings.
- Critical knowledge is derived from reflection and action on what is right and just. It is concerned with raising consciousness about the causes of problems and means of alleviating them. This model considers contextual factors such as physical, economical, social and environment levels and composition factors such as individual characteristics.

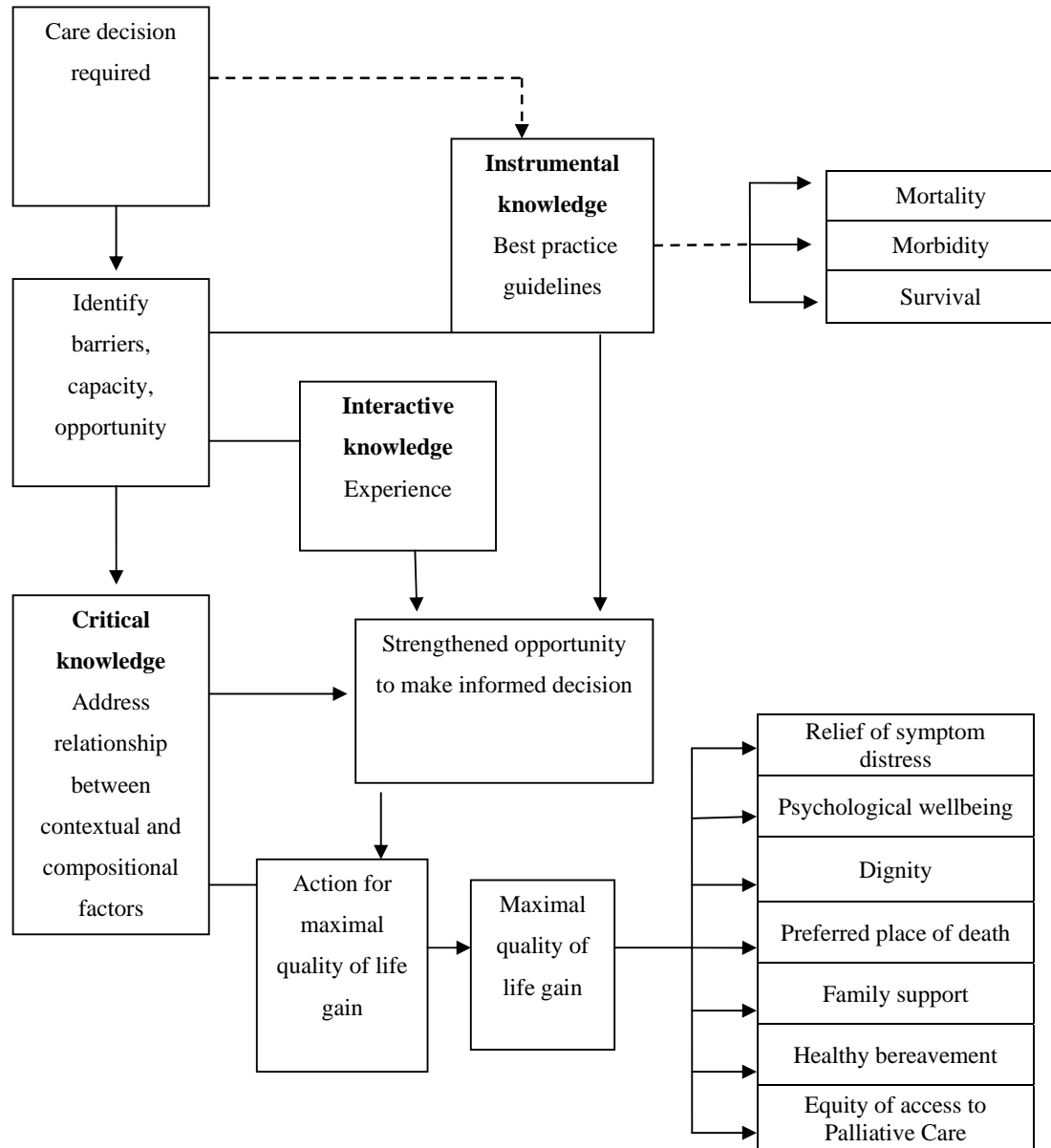


Figure 3 - A framework for equity-based evidence adapted to palliative care (dotted lines represent pathway for RCT-based evidence). Adapted from Kemp *et al.* (2002).

Of particular importance and relevance to this study is the view advocated by Kemp *et al* (2002) and reflected in Figure 3, that it is necessary to address confounding factors instead of controlling them, addressing the capacity to comply instead of compliance, consideration of health gains instead of outcome, and using multiple forms of knowledge instead of one form of knowledge.

Aoun and Kristjanson (2005) acknowledge the need for the gold standard of evidence in the mainstream medical model of RCTs and, even with the inherent difficulties, as outlined above, recognise their importance in palliative care. However, alternative designs may offer more feasible research that can be successfully implemented in palliative care, thus affording clinical evidence in situations where an RCT is not feasible (Aoun and Kristjanson 2005).

3.6 Action research

This section will give a brief outline of the foundations of action research and offer some definitions as they applied to this study. An overview of its processes and principles, stating when it is appropriate to use, and situating it within a practice research paradigm is included. The rationale for the choice of action research to direct this study is given. The role of the action research tools, the researcher and the ethical considerations are discussed. The application of action research within a social healthcare setting, nursing, is explored. An exposure of the key concepts as they informed this action research study will be highlighted.

3.6.1 Evolution of action research

One of the founders of the Gestalt school, Kurt Lewin (1890-1947) is universally recognised as the founder of modern social psychology and is also generally credited as the person who coined the term 'action research' (Lewin 1946). The term describes work that "*did not separate the investigation from the action needed to solve the problem*" (McFarland and Stansell 1993, p14).

Meyer (2000) notes that in general terms Lewin was concerned with social problems and specifically with intergroup relations and minority problems in the USA. Marrow (1969 p178) writes that Lewin focused on participative group processes for addressing conflict, crises, and change, generally within organisations and 'he wanted to reach beyond the mere description of group life and to investigate the conditions and forces which bring about change or resist it'. Greathouse (1997) adds that Lewin acknowledged that for change to

take place, the total situation has to be taken into account and warns that if isolated facts are used, a misrepresented picture could develop. Noffke and Stevenson (1995, p.2), describe the process described by Lewin as cyclical, involving a “*non-linear pattern of planning, acting, observing, and reflecting on the changes in the social situations*” in a continuum of a spiral of steps. Each step and spiral is compared and contrasted to the previous ones by reflecting on and analysing the outcomes and then modifying the actions as an ongoing process; also described as comparative research. McNiff and Whitehead (2006) write that Lewin emphasised direct professional/client collaboration and affirmed the role of group relations as a basis for problem-solving. He was an avid proponent of the principle that decisions are best implemented by those who contribute to the making of them (McNiff and Whitehead 2006). This concept is pivotal to action research and to this particular study.

In summary, the origins of action research may be varied but the overall philosophy remains similar in that the understanding that action research is participatory. There is collaboration between researchers and the study participants in the definition of the problem, the selection of an approach and research methods, the analysis of the data and the application to practice (Denzin and Lincoln 2005). Researchers specifically seek to empower people through the process of constructing and using knowledge, thus ultimately improving practice (Denzin and Lincoln 2000; Zuber-Skerritt 1991).

3.6.2 Definitions and key components of action research

Action research is known by many other names including, participatory research, collaborative inquiry, emancipatory research, action learning, and contextual action research, but all are variations of a similar process (Dick 1999; Green and Thorogood 2004; Kemmis and McTaggart 1992). Meyer (2000) suggests that action research is not easily defined and argues that it is a style rather than a specific methodology.

Action research is a form of social research that involves people in a process of change, including an understanding of how human beings interact with one another and how they respond to events and situations (Dick 1999; Meyer 2000; Winter and Munn-Giddings 2001; Green and Thorogood 2004; deVaus 2002). Action research is a multi dimensional process based on professional, organisational or community action and encompasses practical work that is also a form of learning for those involved (Winter and Munn-Giddings 2001; Smits 1997). By combining these processes, Winter and Munn-Giddings (2001) state that the ‘theory’ and ‘practice’ gap phenomenon is minimised and ‘action’ and ‘research’ are maximised. By acknowledging and understanding these elements it is possible to appreciate

the argument by Winter and Munn-Giddings (2001) that action research is concerned just as much with the process of inquiry as with its findings, and that by adopting them the impact on relationships should be both positive and illuminating. In addition the insights gained by the researcher from the practical involvement in the research process, is both a contrast and complement to objective data collected as part of the research.

Meyer (2002) opines that action research is identified with research in which the researcher/s works explicitly with and for people rather than undertaking research on them. Meyer (2002) continues and adds that its strength lies in its focus on generating solutions to practical problems and its ability to empower practitioners, encouraging them to engage with research and subsequent development, implementation or change activities (McNiff *et al* 1996).

McNiff and Whitehead (2006) enhance the definition of Meyer (2002) and purport that, action research can be described as a family of research methodologies, which pursue action (or change) and research (or understanding) at the same time. Essentially, McNiff and Whitehead (2006) also argue that action research is a form of inquiry that enables practitioners to investigate and evaluate their work. They describe action research as 'learning by doing' whereby a group of people identify a problem, employ research techniques to examine it, introduce a change or intervention to resolve the problem, evaluate their efforts, and if not satisfied, amend the action and try again (Kemmis and McTaggart 1992).

As a problem-solving approach it could be argued that action research is undertaken on a daily basis to solve common problems, but this is often subconscious and no more than a passing action (Reason and Bradbury 2006). In contrast however, Carr and Kemmis (1986) define action research as a form of self-reflective inquiry undertaken by participants in social situations with the intention of improving, rationalising and justifying their practices, and in addition, improve their understanding of practices in the context where those practices are carried out. As Carr and Kemmis (1986, p.28) state, action researchers "*...see the development of theory or understanding as a by-product of the improvement of real situations, rather than application as a by-product of advances in 'pure' theory.*" This is a means to generate ideas (theory) that are relevant locally - to the people who are involved in the research, and to the environment in which it has taken place. However, action research is sometimes criticised for not generating theory that can be generalised globally, though this is a feature of any local intervention. In contrast, action research is "*the study of a social situation with a view to improving the quality of action within it*" (Elliott 1991, p.69).

Taylor and White (2000) and Zuber-Skerritt (1991) define some of the attributes that make action research uniquely different from simply just problem solving. For example, action research aims to contribute both to the practical concerns of people in a problematic situation whilst simultaneously furthering the social scientific knowledge base. This dual commitment in action research provides an opportunity for collaboration with members of the system, in changing practice, in what is agreed by participants as a desirable direction (Meyer 2000; Parahoo 2006). Accomplishing these goals requires the active collaboration of researcher and client, and thus stresses the importance of co-learning as a primary aspect of the research process (Meyer 2000; McNiff and Whitehead 2006; Polit and Beck 2008; Zuber-Skerritt 1991; Reason and Bradbury 2006).

What separates this type of research from general professional practices or daily problem-solving is the emphasis on scientific study, whereby the researcher examines the problem systematically and ensures that the intervention is informed by theoretical considerations (Waterman *et al* 1995; Williamson and Prosser 2002; Rolfe 1996; Glasson *et al* 2006). As a result, much of the researcher's time is spent on refining the methodological tools to suit the needs of the situation, whilst simultaneously collecting, analysing and presenting data on an ongoing, cyclical basis (Polit and Beck 2008; O'Brien 1998; Meyer 2000).

As indicated above most definitions of action research incorporate the following three elements; a participatory nature, a democratic drive and a concurrent contribution to change (Meyer 2002). Meyer (2002) argues that participation is essential to action research and it requires that participants recognise the need to change and are prepared to actively participate in the research and the change process. O'Brien (1998) agrees and states that people are more willing to apply what they have learned when they do it themselves. Meyer (2002) states that the separation or distance between the researcher and the researched that is observed in other research methodologies may not be so apparent in action research. The research design must be continually negotiated with participants and adopt a democratic stance.

In action research all participants should be regarded as being equal (Meyer 2002). Throughout any action research study findings should be reported and disseminated to participants for corroboration, validation and to inform the next stage of the study. This evolving style of research is therefore responsive to any arising situations and commonly involves collaborative spirals of planning, acting, observing, reflecting and re-planning. Meyer (2002) warns that this level of equality and collaboration can be difficult to achieve in

many health care settings and argues that an action researcher in nursing needs to be able to work across traditional professional boundaries and with various HCPs. To achieve this advanced interpersonal skills are required in addition to research ability.

Action research takes place in real world situations and aims to solve actual problems, it also acknowledges that the initiating researcher makes no attempt to remain objective, but openly acknowledges their bias to the other participants (Waterman *et al* 1995; Coghlan and Brannick 2001; Polit and Beck 2008).

3.6.3 Principles of action research

Winter (1989) highlights six key principles of action research; reflective critique, dialectical critique, collaborative resource, risk, plural structure, and theory, practice, transformation. The comprehensiveness of Winter's (1989) principles provides a framework around which action research can be practically applied, are cogent to and subsequently informed this study. Each are discussed as follows and supported by other authors:

- Reflexive critique provides an account of a situation. These may include notes, transcripts or official documents. The implication is that these are factually true accounts from the teller and are based on their personal interpretations, biases, assumptions and concerns upon which judgments are made. In this way, practical accounts can give rise to theoretical considerations (Williamson and Prosser 2002).
- Collaborative resource denotes that participants in an action research project are co-researchers (Meyer 2002). The principle of collaborative resource presupposes that each person's ideas are equally relevant and are potential resources for creating interpretive categories of analysis, negotiated among the participants (Meyer 2002). This approach also strives to avoid the skewing of credibility that may be held by the idea-holder, and provides insight by accepting the contradictions both between many viewpoints and within a single viewpoint (Winter 1989).
- Risk addresses the change process that can potentially threaten all previously established ways of doing things and may result in fears among the practitioners (Coghlan and Brannick 2001; Williamson and Prosser 2002). As individuals we are all uniquely different and as such, fears may arise as to how we are perceived by others during open discussion of our interpretations, ideas and judgments. This fear should be allayed by initiators of action research by pointing out that they too, will

be subject to the same fears and process and, regardless of outcome learning will take place for all those taking part (Winter 1989; Green and Thorogood 2004).

- The nature of this research approach embodies a multiplicity of views, commentaries and critiques, leading to multiple possible actions and interpretations. The process, by its nature results in many accounts being made explicit by those participating and a range of options for action can be presented. A report, therefore, acts as a support for ongoing discussion among collaborators, rather than a final conclusion of fact (Winter 1989).
- In action research, theory informs practice and practice refines theory in a continuous transformation (McNiff and Whitehead 2006; Polit and Beck 2008). Winter (1989) describes this as theory-practice transformation in his sixth and final principal of the action research process. In any setting, people's actions are based on implicitly (expressed indirectly) held assumptions, theories and hypotheses; and with every observed result, theoretical knowledge is improved. The two are intertwined aspects of a single change process (Dick 1999). It is the researcher's responsibility to make explicit (precisely and clearly expressed, leaving nothing to implication) the theoretical explanations for the actions; and to question the basis of those explanations. The ensuing practical applications that follow are subject to further analysis in a transforming cycle that continuously alternates the emphasis between theory and practice (Green and Thorogood 2004).

In summary, and of particular interest to this study, action research is a wide and diverse approach to research (Meyer 2002; McNiff and Whitehead 2006), therefore it is inevitable that what and how it is comprised is widely debated in the literature. However, in general terms action research involves practitioners establishing new ideas related to developments, changes or enhancements in practice and proffering these as their own theories of practice (Meyer 2000; Williamson and Prosser 2002; McNiff and Whitehead 2006). Action research is an emergent process, usually qualitative (Dick 1999), which develops and generally takes form as understanding of a phenomenon increases. It is also an interactive, step-by-step process that converges towards an enhanced understanding of what happens in a particular situation. Action research is also participative in as much that it is based on the premise that any changes in practice are most effectively achieved when those affected by that change are directly involved in its planning and implementation, thus participation in an action research is collaborative in nature. Each stage results from discussion and agreement amongst

participants, thus it is essentially democratic in nature, which is sometimes difficult to achieve within the delivery of health care.

3.6.4 Rationale for action research

There are a number of reasons why the researcher elected to use action research for this study. Williamson and Prosser (2002) argue that action research is emergent in nursing and health care as a means of changing practice and generating new knowledge. As noted in the introduction, the researcher is a practitioner, working as a research and audit sister in a palliative care setting. Part of this role is to examine current practices using research activities that may result in the initiation of change to enhance the quality of life of the patients, both in the hospital and follow-up community settings. Dick (1999) argues that when practitioners use action research they are offered the potential to increase the amount they learn consciously from their experience and has direct and obvious relevance to practice. It can also generate some worthwhile outcomes for the patients that feed directly into their care therefore the approach seemed the most appropriate (Meyer 2000; Glasson *et al* 2006).

Meyer (2002) argues that there is an increasing concern about the theory practice gap in clinical practice and argues that practitioners have to rely on their intuition and experience since traditional scientific knowledge often does not appear to correspond to the uniqueness of the situation. Meyer (2002) argues that action research can be considered as an approach that can address this in as much as it can draw on intuition and experience and can generate findings that are meaningful and useful to practitioners. This approach is also cogent with the current requirements of clinical governance and therefore an important component of this researcher's role.

3.7 The action research process used in this study

This section sets out to debate the framework for the emerging framework for this study. Mindful of the underpinning philosophy of action research the researcher examined various models. There are mostly similarities between models but also some slight differences, therefore the following paragraphs introduce the models that greatly influenced the study. As advocated by O'Brien (1998) these comprise firstly the model as described by Lewin and secondly include an outline of an action research model originating from Susman (1983).

3.7.1 Advantages of action research

The research action process alternates continuously between inquiry and action, between practice and innovative thinking based on practical decision-making and evaluative reflection (Dick 1999; Hart 2000). Dick (1999) highlights Lewin's four-stage spiral of steps that comprised his framework for action research as planning, acting, observing and reflecting. Lewin acknowledges that the planning stage usually starts with a general idea and a desire to reach a certain objective, although exactly how to achieve the objective is often not clear (Dick 1999). Therefore, the first step involves examining the idea carefully including any available evidence (Dick 1999; Williamson and Prosser 2002; Glasson *et al* 2006).

In the initial stage more fact-finding is often required and two main items emerge which are an overall plan of how to reach the objective and a decision in regard to the first step of action which are observing and reflecting (Dick 1999; Williamson and Prosser 2002; Glasson *et al* 2006). The first step calls for a broad fact-finding and may involve different groups, problems or communities. Lewin (1946) advocates that once the initial planning has taken place, the next stage, action, can be devoted to executing the first step towards the overall plan and progress to the observing and evaluation of the action. Lewin (1946) argues that this process shows whether what has been achieved is above or below expectation and secondly, it gives the planners an opportunity to learn (Glasson *et al* 2006; Meyer 2002). Furthermore, participants gather new general insight, including any strengths and weaknesses of certain actions. The fact-finding process should ultimately serve as a basis for modifying the next step and the 'overall plan' (Meyer 2002). Thus it would appear that as the steps progress and the research progresses, the components and direction of the research become more focused and specific to the problem being investigated and solutions presented to solve them (MacIsaac 1995; Dick 1999).

Lewin's 'steps' (Figure 4) are composed of planning, executing (acting), fact-finding (reconnaissance) and reflecting which are supported by Kemmis (cited in Hopkins 1985 and MacIsaac 1995) as the cyclical nature embraces the ethos of action research.

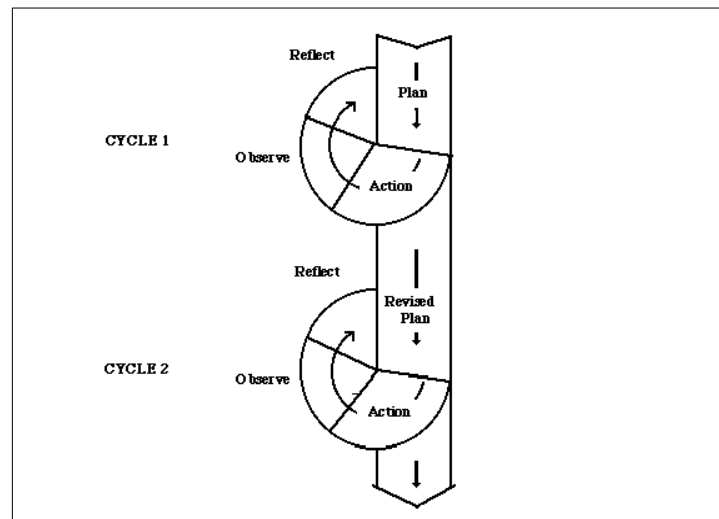


Figure 4 - Simple action research protocol after Kemmis (cited in Hopkins 1985 and MacIsaac 1995).

As noted earlier the model of Susman (1983) is similar but rather than four describes five phases to be conducted within each research cycle (Figure 5). Initially, a problem is identified and data is collected for a more detailed diagnosis. This is followed by a collective postulation of several possible solutions, from which a single plan of action emerges and is implemented. The results of the intervention are collected and analysed and the findings are interpreted in the light of how successful the action has been. At this point, the problem is reassessed and the process begins another cycle. This process continues until the problem is resolved.

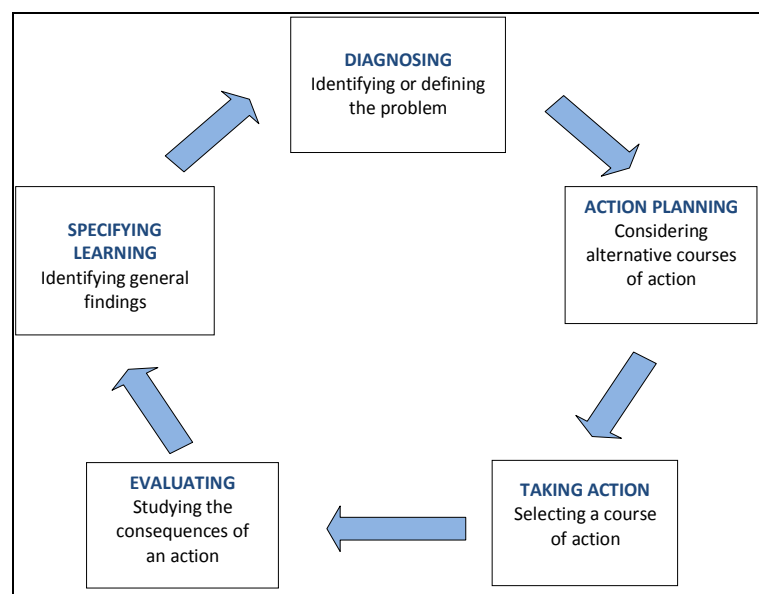


Figure 5 - Detailed action research model (adapted from Susman 1983).

Based on these two models the author elected to use the model as suggested by Susman (1983) but felt that a further step of dissemination should be added to ensure that any emerging change to practice was fed back to all participants not only locally throughout the Unit but also the a wider audience. The actual model used in this study is shown below (Figure 6).

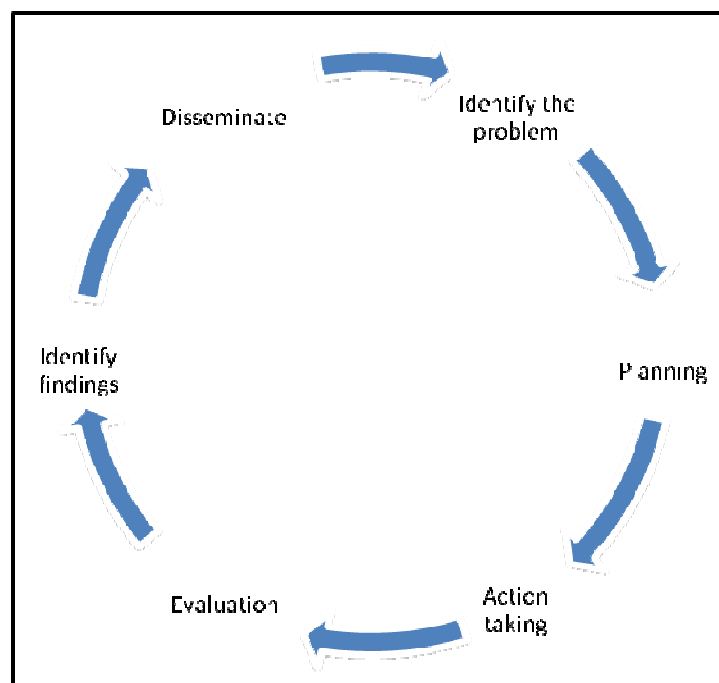


Figure 6 – Modified action research utilised for this study.

The primary focus of action research is the solving of real problems arising from genuine situations rather than contrived or experimental studies. When a situation is too ambiguous to frame a precise research question, action research can be used to pilot research, thus facilitating a more flexible approach than used by social scientists. Action research is often used by practitioners seeking to improve their own knowledge and practice. It is particularly appropriate to studies which may have more than one possible interpretation or require flexibility in order for change to take place quickly and holistically (O'Brien 1998). According to Winter and Munn-Giddings (2001) although we live in a culture where research is conventionally regarded as a specialised role, action research is a form of inquiry that can be undertaken by those who are not specialist researchers. Furthermore, the theory and application of action research also provides a framework for researchers who lack the methodological knowledge to deal with problems arising from practice, research and their practice, within any social context (O'Brien 1998).

3.7.2 Action research as reflective decision making

At the outset it is imperative to bear in mind that one of the most important characteristics of action research involves negotiating 'collaborative' methods and strategies of working, based on principles of partnership, mutual respect and equality, among people who usually interact within a set of hierarchical power relations (Glasson *et al* 2006; Meyer 2002). This may remain the case even if the aim of the action research is to develop and set up a joint project with a group of peers, professional colleagues, service users, or community members (Meyer 2002; Polit and Beck 2008). Another important concept of action research is that its value evolves as much from the quality of the reflection it stimulates as from the comprehensiveness of the data collected (McNiff and Whitehead 2006). In other words, as new and useful insights can be generated from critical reflection on a few carefully selected incidents or responses the researcher is not required to gather a considerable amount of data (Winter 1989). However, the process of 'critical reflection' can be problematic and difficult to achieve in reality. One of the main challenges may result from an inability to divorce current, ingrained modes of thought and routines from those being introduced as new and enhanced practices (Williamson and Prosser 2002; Glasson *et al* 2006). Many aspects of the situation will remain familiar and previously tried and trusted interpretations or practices will spring to mind and may be difficult to ignore and thus change. Therefore the group needs to work carefully and systematically to permit alternative perspectives to emerge (Dick 1999).

A useful indication of what might be involved is provided by the work of Hart (1995) relating to 'innovative thinking', who suggests that the ways in which professionals consider a practical situation frequently includes a number of 'questioning moves' in response to their first interpretation of an event, which are indicated as follows:

1. Making connections - what contextual influences are at work here?
2. Contradicting - is there a contrasting way in which this might be understood?
3. Taking the other's view - what might be the logic and purpose of the other person's response from within their own frame of reference?
4. Noting the impact of feeling - how do I feel about this, and what do these feelings tell me about what is going on here?
5. Suspending judgement - what else do I need to find out about before making a judgement about this?

(Points 1-5 summarised from Hart 1995, in Winter and Munn-Giddings 2001 p12).

The researcher found this particular approach to critical thinking useful at all stages of the action research process. Having examined the principles of action research and the component parts of the process this practical framework worked well as an adjunct to other more complex perspectives. It was made use of as a reference point during the planning stages, collaborating with peers and respondents, throughout data collection and the subsequent analysis of the data gathered.

3.7.3 Action research tools

Action research is a holistic approach to problem-solving rather than a single method for collecting and analysing data (Winter and Munn-Giddings 2001). As a result, it allows for several different research tools to be used, either simultaneously or alone, which may change as the project is conducted (McNiff and Whitehead 2006). These various methods, which are generally common to the qualitative research paradigm, include participant observation, keeping field notes, a research journal, document collection and analysis, recordings, questionnaire surveys, structured and unstructured interviews, and case studies (O'Brien, 1998). All these action research tools were used to a varying degree throughout the study to find and bring together the type and level of data to drive the research forward and to achieve the resultant change in practice. The use of interviews, focus groups and field notes are in Chapter 4, Methods. However, the use of observation is included here as it was one of the catalysts for the study and was used concurrently throughout.

3.7.4 Observation as a tool

Using an action research approach and pre-study the researcher/practitioner observes phenomena that influence and may even instigate the research. These observations can be either overt or covert (Polit and Beck 2008) and conducted consciously or subconsciously. Few scientists believe that their observations are non-reactive and that even observation alone in some way changes the object being observed or at least the context in which it is understood (Reynolds and Leininger 1995; Carr and Kemmis 1986). The impact of change on the 'observers' and those being 'observed' will vary depending on the circumstances under which observations take place but are none the less valuable in theory and practice (Carr and Kemmis 1986). It is important that the researcher is aware that there are differences in how the 'observer' and the 'observed' perceive themselves in relation to the research and the kind of acquired and resultant 'knowledge' (Carr and Kemmis 1986; Polit and Beck 2008). For example, professional development requires increasing and developing

existing skills and knowledge, therefore a subject who views himself or herself as a participant, co-operator or collaborator seeks to acquire knowledge and improve practice (Carr and Kemmis 1986) thus also harnessing the philosophy of action research and meeting one of this study's aims, the improvement of local HCP practice. In contrast, Green and Thorogood (2004) advocate that the key characteristic of observational design is that the researcher does not intervene (or at least deliberately) and seeks instead to document what happens in everyday natural occurring situations, the resultant data being talk and behaviour of those being studied. Although such an approach was used pre-study, during this research benefits were afforded to patients and HCPs following the researcher's concurrent observations thus requiring her to deliberately intervene when necessary in order to improve patient outcomes and HCPs practice.

3.8 Role of the action researcher

The role of the primary action researcher is to facilitate and implement the research in such a manner as to produce a mutually agreeable outcome for all participants, (Williamson and Prosser 2002; Glasson *et al* 2006) with the process being maintained by them. To accomplish this the primary researcher may have to adopt a variety of roles at different stages of the research process, for example, planner, facilitator, leader, observer, catalyser, designer, teacher, listener, synthesiser and reporter (O'Brien 1998; McNiff and Whitehead 2006). The ultimate aim however, is to nurture co-participants to the point where they understand the methods and are able to take responsibility for the process without the support of the primary researcher (O'Brien 1999). Central to the process is the primary researcher's role of facilitating dialogue and fostering a reflective analysis approach among participants and providing them with periodic reports and the final report when the research has concluded (Dick 1999; Meyer 2002).

3.9 The application of action research in healthcare

Action research lends itself to the needs of patients and the nursing process, within the social context of their constantly changing and turbulent environments. Nurses are encouraged to do and be involved in clinical research as it aims to promote and develop their nursing skills, ensures quality of patient services and nurtures innovation in practice (Manley 1997). However, Greenwood (1994) argues that traditional positivistic nursing research is failing to improve nursing practice, clinical nurses do not perceive research findings as important because they cannot see any relevance to the own practice. Thus, previous dissatisfaction with the knowledge generated by research has persuaded practitioners to turn to strategies

that aim to produce knowledge that is seen to be valid in helping people to improve a practical situation.

To improve practice Nolan (1993) argues that change in the current climate, the ‘top-down’ generation of knowledge so characteristic of traditional research, will need to be substituted with a more open and participative ‘bottom-up’ approach such as action research. The justification for using action research is that it provides a sense of ownership, while also focusing on values, beliefs and team-building among those involved (Squire 2001). It also ensures both the quality of patient services and the nurturing of innovation in practice (Winter and Munn-Giddings 2001). The theoretical framework by Lewin (1946) also provides nurses with the opportunity to analyse problems, devise programmes of action designed to solve problems and/or improve standards, carry out and evaluate these plans, and learn more about research in the process (Winter and Munn-Giddings 2001).

3.10 Summary

This Chapter has explored the various elements that have been put together to form the basis or philosophical underpinnings of the study. May (2001) contends that the conceptual framework influences all aspects of research and must be maintained throughout the process from the initial line of inquiry, the design of study and methods used for the interpretation of data.

The rationale for the researcher’s approach has been established and includes the most appropriate approach to elicit meaningful data to explain the research problem and implement resultant changes to practice. A debate locating the study within the wider research arena has been presented to offer the reader an opportunity to appreciate the philosophical stances adopted throughout. A sequential action research methodology was adopted as this was considered to be the most effective approach to gain a view of the world from the perspective of the individual experiencing constipation rather than a composite experience reported by the researcher.

The utility of action research to the advancement of professional practice has been explored. Since action research is a form of research closely linked to practice, practitioners and service users can readily undertake it, which makes it particularly useful for this study. Within the social dimension of healthcare, nurses are often faced with patients who have complex problems that are capricious in their presentation and diverse in management strategies, despite an abundance of theoretical literature supporting positive patient

outcomes. To improve nursing theory, practice and patient outcomes, nurses are increasingly being encouraged to undertake and be involved in research. To this end, action research provides an ideal framework whereby nurses can learn the research process experientially whilst practising in the nursing role with its inherent biases (which is explored in Chapter 4, Methods). The philosophy of action research is congruent with this study and it combines the production of knowledge with the process of changing practice (Hart and Bond 2005) and findings were shared with participants throughout the process of the study, so that discussion informed subsequent changes (Green and Thorogood 2004).

The principles and procedures of this type of research and epistemological underpinnings have been described, along with the evolution of the practice. An outline of the tools has been offered alongside the theory of critical reflection which underpinned the whole process from its inception through to the implementation of new practices.

Therefore, this research is essentially a medium scale action research study to which the researcher brings her nursing experience of working with cancer and palliative care patients who also have severe constipation. The general approach adopted in order to achieve this is directed by the basic tenets of interpretivism and this has been fully examined within the discussion. Having examined the underpinning philosophical basis of the research design, Chapter 4 (Methods), outlines and examines the processes used within the pre-established framework.

Chapter 4

Methods

4.1 Introduction

Within the philosophy of action research, where collaboration is central (McNiff and Whitehead 2006; Glasson *et al* 2006) key issues based on the previous Chapters were informally discussed with several HCPs practising within the Unit. These HCPs considered that the project was worth pursuing and subsequently formal discussions took place with the Unit's MDT and the adjacent cancer centre lead research nurse. The meetings commenced with the researcher presenting an outline of the findings from Chapters 1 and 2 followed by a discussion relating to the identification of appropriate research methods to take the study forward.

Feedback from this group generated support and interest in the research whilst also providing direction and focus to the study (Reason and Bradbury 2006). For example, the study originally intended to explore patients with advanced cancer whom were known to the Unit's MDT, however the lead research nurse suggested including all the patients with a malignancy as constipation management was often problematic. The latter provided equity of opportunity to patients and helped increase the sample size which is often difficult in this client group, especially when limited to those receiving palliative care (Addington-Hall 2002; Bennett and Ahmedzai 2000; Hudson *et al* 2001; King 2000; Harding and Higginson 2003; Grande and Todd 2000).

The MDT members agreed with a number of issues presented during the meetings and, on reflection, reported similarities in their own practices. For example, that patients were perceived as non-compliant and that laxatives were rarely administered as prescribed, therefore, establishing a need for the research and embracing the philosophy of action research in that it aimed to redress local HCP practices through the research process. The MDT suggested exploring the patients' perspectives as, in their experience, patients rarely articulated how bad their constipation had been and the reason for this reticence was unknown.

Three distinct stages developed subsequent to and as a result of each other. These are; 1) patient interviews to gather qualitative data, 2) HCP focus groups to afford the clinicians

perspectives, enable a degree of dissemination of the emergent findings and also to add credibility, dependability and conformability to same, and finally 3) the organisation and subsequent operation of a nurse-led clinic specialising in the management of constipation for patients with cancer. Methods were chosen and developed to best meet the needs of each sample, whilst also facilitating the gathering of appropriate data to inform the study and implement change.

This Chapter describes the methods applied by the researcher to the identified area of study. The aim of any methods section is to communicate what actions were undertaken to solve the research problem or to answer research questions (Polit and Beck 2008). Without discussion of the data collection methods the accuracy and validity of the conclusions may be subject to challenge which may negate the research itself (Parahoo 2006; DePoy and Gitlin 2005; Polit and Beck 2008).

Within the chosen methodological framework the methods evolved and varied over the course of this study, therefore, this Chapter mainly concentrates on the patient interviews stage, but also includes generic methods that are applicable to the whole study, for example Ethics and data analysis. Deviation from generic methods appear in the relevant Chapters, for example, it was necessary to amend the patient consent form and this modification is discussed in Chapter 7. Presenting the methods this way is considered to be the most appropriate approach otherwise the reader will be challenged to establish the order in which the study operated and/or their suitability, which varied depending on their application. Thus, some of the methods adopted for the HCP focus groups and the CMC will be presented in Chapters 6 and 7 respectively and are shown graphically (Figure 1) to illustrate the course of the research and simultaneousness of key elements and processes.

Initially it was not known what course this research would take nor all the methods that would ultimately be used, therefore, this section primarily focuses on patient interviews and associated methods including field notes and data management. As the research evolved, the following methods were adopted or modified to meet the needs of the focus groups and CMC and are therefore presented here as generic methods. Subsequent methods used appear in either Chapter 6 (HCP focus groups) or Chapter 7 (CMC processes and methods) as they are unique to these stages.

Methods are specific research techniques that fit with the theories, approaches and methodologies being used (Silverman 2001; Freshwater and Bishop 2004; Polit and Beck 2008). The evolving nature of this study using an action research approach led the

researcher to use a combination of methods which are outlined below. Action research promotes the use of methods deemed most appropriate to address the identified problem (Reason and Bradbury 2006), the initial method used was that of in-depth patient interviews. Following the patient interviews, as guided by the evolving action research methodology, focus groups emerged as the most effective method of obtaining the views of HCPs (Chapter 6), followed by a nurse-led clinic (Chapters 7 and 8) incorporating patient education as an intervention to facilitate change as an outcome of the CMC.

The following section presents the methods used during in-depth patient interviews to explore their perceptions, attitudes and management strategies

4.2 Obtaining Ethical approval

4.2.1 Nursing ethics

The proliferation of nursing research has led to ethical concerns and debates because the line of demarcation between what constitutes the expected practice of nursing and the collection of research information has become less distinct and ethical requirements sometimes conflict with methodological considerations (Polit and Beck 2008; Hawley 2007). To assist the researcher and to protect the interests of respondents various codes of ethics have been developed to guide the research process (Freshwater and Bishop 2004). The nursing profession operates within clear parameters of professional conduct and consequently, as a nurse, the researcher was conversant with the ethical requirements for this study.

In addition, the ethical principles of beneficence (the duty to do good; prevent harm and remove harm) and nonmaleficence (the obligation not to inflict harm intentionally) informed and guided the research (Beauchamp and Childress 2001; Wengraf 2001). For example, Hawley (2007) notes that all people are vulnerable at some time in their life and this usually occurs when a person is dependent on others and often this is as a result of serious illness. The sample in this study are both vulnerable and frequently experience transient symptoms such as pain. Therefore an attempt to alleviate any distress would take priority over the research proceedings (Beauchamp and Childress 2001; Wengraf 2001).

Due to cancer and/or its treatments, some patients may lack adequate decision-making capacity to give consent for research, for example due to cognitive impairment (Sandgren *et al* 2006). Cognitive impairment is a complication of advanced cancer that can occur several weeks before death (Bruera *et al* 1992). There is no consistency in defining cognitive

impairment and determining if a patient's function is impaired is a challenge, especially because impairment is usually subtle (Vardy *et al* 2007). There is poor correlation between the patients' perception of their cognitive impairment and the objective tests (Vardy *et al* 2006). Given the aforementioned evidence and the MDT members experiences with the client group a consensus was reached that any formal attempt at assessing cognitive function would be unreliable. Therefore, patients were only excluded if cognitive failure or confusion presented overtly.

Therefore, only patients who were able to give their informed consent were included. The study was conducted in accordance with the Declaration of Helsinki (World Medical Association 2000; Bassotti *et al* 2004) and Good Clinical Practice Guidelines and the Nursing and Midwifery Council (NMC 2004) throughout. Periodical 'Good Clinical Practice' training and update were maintained (Appendix 3 and 4) throughout this research.

4.2.2 Ethical Considerations of action research

In addition to the overarching ethical and moral requirements of nursing research, action research has its own specific implications and thus considerations. Action research is conducted in real-world circumstances and involves close and open communication among the participants therefore researchers must pay close attention to the specific ethical considerations that may present. To this end, the following principles, adapted from Winter (1996) and O'Brien (1999), were adhered to in this research:

- The researcher must ensure that the relevant persons, committees and authorities have been consulted and that the principles guiding the work are accepted in advance of the research process.
- All participants must be permitted to influence the process and outcomes.
- The development of the work must remain visible and open to suggestions from others.
- The wishes of those who do not wish to participate must be respected.
- Permission of the participants must be obtained before making examining documents produced for purposes other than the proposed action research.
- Descriptions of others' work and points of view must be negotiated with those concerned before being published.
- The researcher must accept responsibility for maintaining confidentiality.
- Decisions made about the direction of the research and the probable outcomes should be collective.

- Researchers are explicit about the nature of the research process from the beginning, including all personal biases and interests.

4.2.3 The process of gaining ethical approval

As a starting point and to obtain a more expert view and guidance on the proposed study a meeting was convened with members of the local Research and Development department. The research needed ethical approval for two reasons, firstly because the interviews were to be audio taped and secondly because of the study's academic component necessitating external review by the University. As the research was conducted within the palliative care unit and adjacent cancer centre it was only necessary to obtain approval from the Local Research Ethics Committee (LREC). Obtaining an ethical approval proved to be time consuming and spanned a period of several months due to delays in feedback from colleagues, postponed meetings and changes to the application process itself that was new to the local Research and Development personnel, thus causing further delays. The study proposal, flyer (Appendix 5), patient information sheet (Appendix 6), patient consent form (Appendix 7) and the completed 60 page Central Office for Research Ethics Committees (COREC) (DH 2005) application form were submitted to LREC in February 2003. Following minor changes (Appendix 8), ethical approval (Appendix 9) was received and data collection commenced in July 2003.

Due to the nature of the action research cycle, it was not always clear which direction and methods the study would take during its course, therefore, throughout the study any planned changes and developments were brought to the attention of the Research and Development department for advice on whether a referral for ethical revision/amendment was necessary. The sole amendment arising relates to the CMC and is therefore discussed during the planning of the CMC (Chapter 7).

4.2.4 Consent and confidentiality

Aveyard and Hawley (2005) describe the purpose of informed consent as an acknowledgment by individuals that they understand the patient information given, appreciate the nature and context in which the research is being undertaken and understand their commitment and obligations. Individuals must be given time to consider the implications of their participation and be provided with an opportunity to ask questions and have these answered appropriately and honestly (Faden and Beauchamp 1986). Coercion must not be used and individuals must be made aware that they can withdraw their consent at

any time (Aveyard and Hawley 2005). Once these criteria are met individuals are said to have been 'informed' and their subsequent signing of the consent is their agreement to participate within the boundaries of the information given. For example, if a patient were to consent but subsequently express a wish not to have the interview taped their data would be withdrawn from the study.

When the researcher met a potential participant for the first time the aims and objectives of the research were explained and a copy of the patient information sheet was given for them to review (Hawley 2007). A minimum of 24-hours elapsed before contact was made again, thus allowing patients time to read the document and consider any questions that they may have and whether or not they wished to proceed. A second meeting took place with those keen to proceed and at which time all questions answered. It was reiterated to patients that their consent and participation was purely voluntary and that they were free to discontinue at any time without explanation, that the interview would be audio taped, and that confidentiality would be maintained at all times and may be used in research publications and dissemination (Townsend *et al* 2003). Furthermore, in anticipation that some patients may subsequently want to withdraw from the study, the researcher inquired post interview if they were still in agreement that their data be used. This was to ensure that any sensitive data conveyed that may subsequently lead to distress or embarrassment could be discarded at the patient's request.

Following the interview the subject of patient anonymity arose. This relates to the process involved in ensuring that it was impossible for anyone other than the researcher being able to identify an individual by name (Hawley 2007). The researcher purchased three nine-sided dice containing the numbers 1 to 9. These were thrown twelve times to generate arbitrary three digit numbers. A book was used to list these unique numbers and subsequently each patient was allocated a code. All data pertaining to each respondent were only identifiable by the allocated code number. The book containing the codes and corresponding names was locked in a filing cabinet in the researcher's office.

4.3 Interviews

The following section examines the use of interviews as one of the main methods of data collection within the study. A rationale for the chosen approach is offered along with a discussion highlighting the strengths and weaknesses of the method. The actual process used within the research is explained including the use of probes and prompts used by the researcher to gather the optimum level of meaningful data from each respondent.

4.3.1 The nature of interviewing

By conducting patient interviews the researcher aimed to elicit respondents' perceptions about their constipation and its management, including attitudes and experiences. Morse *et al* (2001), Denzin and Lincoln (2003a) and Elliot (2005) believe that it is possible to explicitly obtain these perceptions from individuals and concur that such data are meaningful. One of the ways in which researchers endeavour to achieve this and understand the way in which people view their world, experiences and beliefs is through the interview process (DePoy and Gitlin 2005). Bowling (2002) describes the interviewer as an instrument through which the subject is allowed to present their truth from their perspective. Essentially, if the interview is flawed, the data are flawed (Morse *et al* 2001; Polit and Beck 2008; Parahoo 2006). Knowledge of the advantages and disadvantages of communication together with the interview process provides researchers with techniques to explore and elicit a deep understanding and appreciation of the interviewee's perspective and thereby optimise the value of the data to be analysed (Potter 1996).

The choice of an interviewing approach was not difficult to determine as the most appropriate for this stage of the study. Fielding (1993) identifies three main types of interviewing technique which vary in degree of structure from standardised or structured interviews through semi-standardised or semi-structured and finally to non-standardised or non-structured interviews. Polit and Beck (2008) note that structured interviews are suitable when the parameters of the sample are known or can be approximated in relation to the research topic and where there is no danger of loss of meaning as a result of imposing a standardised way of asking questions. A more unstructured technique is also considered by Potter (2002) to be valuable where the subject matter is sensitive or complicated. In these circumstances, researchers are able to customise and pinpoint their questions together with any further explanation and satisfy themselves that the individual respondent has sufficiently grasped the issues to reach a considered view (Wengraf 2001).

The researcher was confident that this more 'conversational' approach established rapport (Elliot 2005) with those respondents who otherwise might be hesitant to expand upon their personal experiences of constipation. Wengraf (2001) adds a slightly different perspective and includes a lightly structured interview. This option involves an interview that focuses on the process of recounting experiences of situations in a more narrative fashion. The latter option was instrumental in the chosen approach but included a minimal amount of direction or structure, where necessary, to elicit the required data and to generate themes. As the

objective of this research was to explore the patients' perspectives of their constipation and to identify appropriate treatments regimens this more flexible approach helped to facilitate the gathering of more detailed data for subsequent use in qualitative analysis.

The researcher was aware when planning and undertaking the interviews of the work of Fielding (2001), who notes that there are two principles that inform research interviews. Firstly, questions should be open-ended to capture spontaneous responses and secondly, respondents should be encouraged to identify their experiences and underlying attitudes, beliefs and values, which influence the management of their constipation. This approach was considered necessary in this particular research to elicit the depth of information required. The researcher was conscious of the inability of some respondents to fully articulate their experiences and requirements of treatment due to shyness, a lack of practise of being interviewed or embarrassment.

Silverman (2001) suggests that a common problem in non-structured interviews is that respondents give answers that they feel the interviewer wants to hear or that over-anxiety leads to a need to impress which can distort their responses (Lofland 1971; Fielding 2001). Polit and Beck (2004) and de Laine (2000) all propound that, ideally, an interviewer should be a neutral agent through whom questions and answers are passed. However, they note that this ideal is difficult to achieve in this instance as both respondents and interviewers interact as humans, which can affect the subjects' responses and introduce what is referred to as a bias or reactivity. Polit *et al* (2001) state that the problem of reactivity is merely one aspect of a more general phenomenon that cannot be eradicated; the general context of the interviewee experience affects what people say and do. However, all accounts must be interpreted in terms of the context in which they were produced. The researcher therefore adopted a loosely structured interview approach generally not guiding the responses of the respondents but ensuring that they maintained the parameters of the study throughout.

4.3.2 Location of interviews

One factor that puts subjects at ease and gives them more control is to have the interview in their own home (Zola 1986). Promoting control can also foster self-esteem and make the individual feel valued, useful and confident (Carpenter 2007). Whilst the respondents home might not always be the most convenient for the interviewer it would give some choice and control to the subject thereby emphasising the action research processes of working in partnership and sharing of the research process with the participants, in this instance the respondents (Whitehead and McNiff 2006).

In order to be as flexible as possible it was agreed by the MDT that respondents could choose to be interviewed either at their home or in a room within the Unit. The room identified in the Unit was quiet, had comfortable chairs, access to refreshments, support from other HCPs should they become unwell/distressed and other resources such as vomit bowls. However, the view offered by Zola (1986) is that in settings such as clinics, nursing homes or hospitals, subjects are likely to be less confident and able to offer frank response because they are less comfortable in the setting.

The flexibility afforded to patients ensured that they were able to choose where they would like to be interviewed, thus minimising the potential burden of travelling to the Unit and/or promoting control and optimising data outcomes. For those choosing to be interviewed in their own home the MDT raised the issue of potential harm to the researcher in terms of safety when practising in the community (Hitchcock *et al* 2003), therefore the researcher initiated a checking process whereby her whereabouts and contact telephone numbers were known by nominated colleagues when conducting domiciliary visits.

4.3.3 Duration of interviews

The duration of interviews is an important consideration in order to maintain focus. Fielding (2001) advocates 60 minutes as the maximum duration for interviews whereas Holloway and Wheeler (1996) suggest that the participants themselves should determine the length of time. Therefore, one hour per interview was allocated in the knowledge that this would vary depending on individuals' contributions, their wellbeing, ability to focus, until the topic had been exhausted and/or respondents wanted to stop.

It was also important to limit the number of interviews that were conducted each day to reduce resultant stresses on the interviewer, thereby setting aside an appropriate amount of time to focus on each respondent and the nature of their experiences. The rationale for this was twofold; firstly it reduced the strain of undertaking in-depth interviews for the researcher freeing her mind for each one to ensure that the process was optimised, and secondly to manage other work pressures by creating protected time away from other audit and research commitments. The protection of time also eliminated the possibility of interruption that might have been problematic for both respondent and interviewer.

4.3.4 Maintaining patients' comfort

Investigating peoples' personal habits and practices about their bowel management can be extremely intrusive. Therefore, in planning and during the interviews the researcher took into account the need not to guide the respondent into areas of discussion that might engender feelings of embarrassment or emotional discomfort. From an ethical and professional perspective it would be extremely unprofessional and inappropriate to engender informant distress regardless of the fact that psychological support was available. Gathering information in these conditions would comprise an unacceptable professional practice (NMC 2007) and any consequential loss of data is fully accepted and deemed to be outside the scope of this study and not necessary for its success. However, if respondents freely volunteered sensitive information, without evidence of distress, the data were included as the researcher considered that it must have been important to the respondent for them to have raised the point.

Due to the nature of cancer and/or its treatments, co-morbidities and prevailing symptoms (for example pain, fatigue, nausea and vomiting), were potential problems and therefore a major issue of concern to the researcher. Acutely aware of these problems and mindful of her professional nursing role and duty of care towards patients, the researcher ensured that their comfort was paramount (NMC 2004). For example, if a respondent became symptomatic the interview would be suspended, or discontinued if necessary, until the symptom had been alleviated.

For inpatients, interviews were not conducted during or around drug rounds or meal times. Outpatients were encouraged to take their medications as prescribed or as needed during the interview. All respondents were provided with refreshments and given a choice of seating. The room temperature and air flow was regulated using a fan. There was easy access to vomit bowls and tissues and any additional HCP support if needed. It was not possible influence the home environment, other than to encourage patients to take their medications as prescribed, and to report any discomfort to the researcher so that interview could be stopped.

4.3.5 Rapport

On meeting respondents for the interview the researcher introduced herself by giving her name, title and role within the Unit and this research. Respondents were greeted (shook their hand, smiled, enquired about their overall well-being and offered refreshments). The

researcher simultaneously made an objective assessment of the individuals' mobility and any obvious distress, such as breathlessness, to ensure any discomfort was addressed before the interview started. During this introductory stage time was afforded to respondents to relax and take any medications required and an informal chat often ensued in which patients appeared relaxed. Barr (2007) highlights the importance of the patient-clinician therapeutic relationship which is built on respect, trust and working collaboratively which is strengthened by accurate information and communication.

Immediately preceding the interview the researcher reiterated to respondents that their involvement was purely voluntary and that anonymity and confidentiality would be maintained at all times, and that they could discontinue the interview at any time without explanation. In addition, respondents were advised that, during the interview, there were no right or wrong answers and it was their experiences, beliefs and attitudes that were of interest as these potentially could help alleviate problems for patients in the future. In essence, patients were encouraged to engage in conversation and to freely express themselves and use any words they considered appropriate to describe their thoughts, experiences and concerns.

Following consent, which all patients gave, the interview commenced. The researcher considers that rapport was good and appropriate on the basis that patients appeared relaxed throughout and freely discussed their management strategies that may have otherwise been considered personal and intrusive, thus implying trust.

Respondents were invited to commence the interview by relating their current circumstances with regard to their constipation to afford them an entrée into the interview, and to make them feel more relaxed and build their confidence by encouraging the telling of their experiences. There were a number of advantages in applying this flexible approach, in particular participants could take more ownership of the interaction and an equal exchange of knowledge could be maintained throughout the process (Wengraf 2001).

4.3.6 Wording of questions

To encourage full and frank response to questions and enhance the overall flow of the interview the researcher adopted a non-judgemental and open stance. The questions were carefully crafted so that the respondents could not offer wide-ranging answers that they did not feel to be 'good' or 'bad' (Silverman 2001). Polit and Beck (2008) and Silverman (2001) note that respondents often give answers that they feel are either acceptable or desired by the researcher therefore, it was important to encourage candour of response to avoid such

bias or perceptual inaccuracy and thereby heighten the credibility, dependability, confirmability and transferability of the data. Aware of the sensitive nature of the discussion the researcher reiterated to respondents that there were no right or wrong answers. Respondents were encouraged to speak about their beliefs, expectations and experiences.

It became apparent during the pilot interviews that open questions were needed as a means of getting the interview underway and the following were identified to guide the process, for example;

- *What does constipation mean to you?*
- *How does constipation affect you?*
- *What bothers you most about being constipated?*
- *Who helps you manage your constipation?*

It was anticipated that these questions alone would not elicit the rich in-depth data required, however, their use was aimed at conveying a sense of the type of information required and, once asked, patients were given time to answer without interruption from the researcher. Salient points offered by respondents were noted by the researcher and explored further during the latter part of the interview.

4.3.7 Probes and prompts

The researcher used a series of prompts and probes to provide some direction to the interviews. These tools enabled the conversation to evolve in more depth and the emerging issues to be explored further. The use of cues and prompts were as neutral as possible as advocated by Fielding (1993) and de Laine (2000) who suggest that knowing when and how to probe is essential in order interview effectively and therefore provide meaningful data.

Denzin and Lincoln (2003b) suggest that researchers frequently neglect to give positive reinforcement to subjects for fear of biasing the response. However, in this study the researcher found that in encouraging a full response it was useful to reinforce the respondents' contributions without biasing the response by using comments such as; "That is the kind of information we need" or "Yes, that is really helpful for us to know", as prompts to promote responses, thus not indicative of bias or judgement. As the researcher did not intend to bias the findings in any way, caution was maintained by not showing agreement or disagreement with the content of response, therefore, the method of probing and prompting was considered at length before commencing the interview process (Fielding 1993). When

interviewees sought confirmation that their response was appropriate, the researcher responded by reminding them that there were no right or wrong answers. This resulted in the conversation being explored further and enabled the respondent to feel at ease. The advantages of using this flexible unstructured approach during the interviews had been established during the pilot interviews which are discussed later. Difficulties with probes and prompts had been overcome during this stage and the researcher established a firm process of extracting in-depth information by creating the conditions for the respondent to develop answers more fully (Fielding 1993; de Laine 2000; Holloway 2005).

Another technique suggested by the MDT and used by the researcher to elicit additional data was the use of the word 'else' in a question. Once the respondent has answered a question and was no longer speaking the researcher repeated the same question incorporating the word 'else'. For example "And how *else* do you feel your constipation may have been alleviated? The use of this approach commenced on the fourth interview and appeared to generate more data than on the previous three when used in conjunction with open questions. This technique may have helped patients identify all contributing factors rather than just articulating what they perceived to be the most obvious. It was usually only necessary to repeat the 'else' question once or twice before respondents appeared to impart all that they could or wanted to.

4.3.8 Allowing time

It was vital to allow an appropriate amount of time for each interview (Wengraf 2001) to ensure respondents had time to relax and were not rushed. For elderly and frail patients it was necessary to allow time for movement and general preparation for each interview to ensure that they were comfortable and 'put at ease'. Rapport may be destroyed if the interviewer becomes annoyed or impatient when the patient/respondent is slow to provide the necessary information (Haug and Ory 1987) and this ultimately negatively affects the quality of response and data. Preparing for the interview, for example ensuring patients were asymptomatic, medications were administered as prescribed and that refreshments were available, were time-consuming but necessary to optimise respondents comfort.

Slowness of response in elderly persons is often taken as lack of intellectual capacity, however, in their research Gress and Bhar (1984) show that the decrease in psychological function related to mental capacity among healthy adults is minimal and without the pressure of time older adults perform as well as younger subjects. Knowledge of this underscores the importance of allowing time and justified the maintenance of a less stereotypical stance.

Therefore, any slowness in response was managed in a constructive manner as any display of frustration would devalue the importance of the subjects' contribution and thus interfere with the credibility of the study (Domarad and Buschmann 1995).

The researcher was also mindful of possible sensory impairments which are common in the older person but which can also present in younger age groups. The National Institute of Ageing (1990) note that 50% of people aged over 65 can expect hearing problems and may mask or be aware of the deficit often resulting in inappropriate answers to questions, speaking too loudly, or too softly, frequently seeking clarification of questions and inappropriate interpretation of topic content. Domarad and Buschmann (1995) proffer interviewing techniques which can increase self-esteem in the older adult are: nonjudgmental wording of questions; providing positive reinforcement; giving the individual control; matching gender; allowing time; adapting to hearing and vision impairments; and adapting to reading deficits. Therefore great care was taken to accommodate for any hearing, vision and reading difficulties. This involved time issues but also the setting identified for each interview was required to maximise hearing potential e.g. free as possible from competing background noise.

4.3.9 Management of ambiguous responses

One of the advantages of using an unstructured interview approach to data collection is the ability to clarify ambiguous responses (Polit and Beck 2008). Vague responses such as being constipated for 'a while' or taking laxatives 'most of the time' needed to be made clear in order to identify possible contributory factors to constipation and thereby enable appropriate management strategies to be developed. In clarification the researcher asked closed-questions (based on information already ascertained) for example, "Within the last month or over a month?" or "Do you open your bowels less than three times a week or more than three times a week?"

The use of closed-questioning proved very useful and, as the interviews progressed, replaced open-ended questions when quantitative data were required to inform the research process, for example "Are you suffering with constipation at the moment?". In contrast, situations arose where the researcher deemed that clarification was not required, for example, when asked "How long have you been suffering with constipation?" the researcher was not sure which of the following applied: "four years" or "for years". In these instances, clarification was not sought as the patient's interpretation of the question indicated that constipation was not a new problem and identifying a more precise onset would not inform the study.

4.3.10 Managing deviation from the topic

During the pilot interviews, the researcher became aware that deviation from the topic occurred but this was often short-lived and returned to the topic of constipation resumed. In contrast, some deviations were time consuming and, in one case, the respondent became so immersed in her life history, spoke at length about why she had been in Uganda and the medical histories of all her family members. Such deviations were irrelevant and consumed valuable time. Keen not to offend the respondent and, potentially jeopardise the credibility of data, the researcher continued this particular interview and subsequently sought guidance on handling such deviation from two medical colleagues. The doctors reported that deviation is common in patient-doctor consultations and they suggested the following technique that reflects on what the respondent had said and then reply, “That is very interesting and I am interested to know more. Perhaps we can continue after the interview, is that OK?” This approach was used during subsequent interviews and positively received by respondents and the researcher continued with the interview by drawing on relevant data already discussed and asking a specific question, such as “How do you feel your constipation may have been alleviated?” thus bringing the discussion back to the topic of constipation.

4.3.11 Pilot interviews

Four pilot interviews were conducted to test the processes and resources. Two experts assisting in the development and preparation of the research participated and thereafter two further interviews were conducted with patients who understood and acknowledged that their participation was as a pilot to test the process. This included testing the equipment and facilities and assessing the acceptability and wording of interview contents.

Initiating the conversation about constipation was difficult as respondents reported that they did not know where to start or exactly what information was required. The researcher briefly explained a few details (Chapter 2) about constipation including the prevalence, causes and exacerbating factors. Thereafter respondents were asked open questions about their experiences and management strategies. Only a couple of questions were required before an open and frank conversation ensued. Once the respondent was speaking the researcher listened and made notes as necessary until the point being discussed had been exhausted and then more open and closed questions were used, as necessary, along with prompts and probes.

The process worked well as respondents spoke most of the time and raised key issues that informed the formal interviews. For example, one room was unsuitable as people often intruded despite an 'engaged' sign displayed on the door. The room was also noisy and had large windows that led to distraction when passers-by peered in. A pilot data sheet proved to be time consuming and distracted from the interview and was therefore discarded. A second room within the Unit was found to be suitable for the interviews and it had easy access to resources (for example, bowels and tissues) and was more secluded. Only a hand-held tape recorder, note pad and pen were used during the interview, thus full attention was given to the respondent and the interview process.

The two patients participating in the pilot stage reported that they had found the interview therapeutic and, having articulated their concerns in much more depth than they had been able to in the past, commented that they would like their data included in the research findings. As these patients had consented their data was included in the interview findings, Chapter 5.

4.4 Observation and field notes

The researcher used her observational skills and made a written note of what she perceived to be key issues throughout this research. These notes acted as evidence to remind the researcher what happened in the past and, cumulatively, used then to generate themes. For example, patients and HCPs' attitudes, unsubstantiated accounts of blame, suboptimal prescribing and/or laxative dispensing and peoples' interactions. As a starting point, observation proved to be an important data collection and experiential learning experience that informed the study within the action research framework (Reason and Bradbury 2006). Notes were taken on observations and were encompassed in the study's field notes.

Field notes were taken and maintained prior to and throughout this research. Polit and Beck (2008) and Richardson (2000) state that field notes are much broader, more analytic and more interpretive than a simple listing of occurrences as they require the observers participating to synthesise and understand the data. The researcher's field notes comprised observational notes, methodological notes (for example ideas on data collection methods), theoretical notes (such as connections and postulations) and personal notes (including frustrations, pleasure, anxieties and doubts) concurrently throughout this study (Richardson 2000). Field notes were usually lengthy and time-consuming to prepare and the researcher was disciplined to maintain consistency in order to provide a wealth of detail, the meaning and importance of which did not emerge for many months (Polit and Hungler 2008).

Prior to the initiation of this study the researcher's notes were predominantly reflective thus affording personal experiences, reflections and progress during nursing practice arising from methodological and theoretical concerns as highlighted in Chapter 1. In contrast, field notes taken throughout this research reflected and focused more on the encounters with respondents and HCPs. Notes were taken during interviews to supplement the spoken word and act as an *aide-mémoire* to add context to the data gathered. Additionally, rather than interrupting a respondent during the interview the researcher made salient notes that were reflected upon and discussed later during the conversation.

Field notes made during dissemination were in the form of delegates' feedback about the content of a presentation, reflections on practice, creative criticism, objections and issues of concern. Discussions often ensued between delegates and these were also noted. All delegates were advised that field notes were being taken and would be used in this study but the source of the narratives would remain confidential. Field notes were initially handwritten, as soon as possible, in order to retain as much contextual information as the researcher could remember, then subsequently analysed and themed. These data contained information regarding the environmental setting, the communication between groups of individuals and researcher, and the researcher's assessment of the interview experience, such as the quality of the interaction and any significant issues that arose.

The aforementioned utilisation of field notes continued throughout the research to capture contemporary data relating to the study, advantages and disadvantages of the process and data specifically pertinent to HCPs and their practices, beliefs and attitudes. Although the process of observation, participation and record keeping were exhausting and labour-intensive (Polit and Beck 2008) their significance to this study warrants their inclusion. To make the totality of field notes collected throughout this study manageable the data were transcribed verbatim into a computer (McCall 2000) and afford a thematic analysis (Emerson *et al* 1995). Field notes findings are presented and discussed in more details in Chapters 8 and 9 relating to the CMC and dissemination of study findings in general.

4.5 Data management

The following section gives an insight into how the data were collected, managed and analysed. Member checking of the resultant themes is included as this formed part of the validation process. In preparation for data analysis component the researcher attended a course entitled 'Qualitative Interview analysis' (Appendix 10).

4.5.1 Data transcription

An audio tape recorder was used to record the interviews and subsequently these were transcribed. An important consideration when analysing data is to determine whether to transcribe verbatim or selective transcription (Silverman 2001; Polit and Beck 2008). Verbatim transcription offers the advantage that all the information is available for subsequent analysis (Elliot 2005) whereas there is a danger that important data can be lost and the researcher may be unaware of significant points after the event if a more selective approach is adopted. In contrast, verbatim transcription can be extremely laborious and time consuming.

The researcher chose to transcribe the tapes verbatim often replaying sections to ensure accuracy. Tapes were transcribed into a Microsoft Word document within 48-hours of the interview to optimise the researcher's recall of non-verbal events such as respondents indicating parts of their body. This was a valuable process as it enabled a much greater level of understanding and the researcher was able to immerse herself in the data.

During computer transcription, the 'return' key (the significance of this will be discussed later) was used at the end of each question or statement so that data were in a simple format for data checking and subsequent analysis in Microsoft Excel. Each document was named respectively based on subject unique identifier, for example 'Interview 4351', Interview 7856' 'Interview 2462' and so on. All documents were proof read and offered to each participant to ensure the contents were both valid and reliable accounts of what had been discussed during the interview. Four interviewees read their transcripts and no errors or discrepancies were found. When asked, none of the interviewees wanted to change or withdraw any of their narrative in contrast they were keen that their data were used as part of this research. Each document was printed and read several times over the ensuing few days so that the researcher became familiar with the data and theorise on major themes and relationships between themes. Preliminary notes were made on the printed sheets.

4.5.2 Preparing interview data for analysis

Microsoft Excel was used for data storage and retrieval. The process of themeing was guided by a grounded theory approach and conducted manually by the researcher using Microsoft Word software instead of stationery consumables (for example paper, pen, scissors and highlighters). The term narrative denotes verbal extract (Elliot 2005). Essentially,

themes and sub-themes were created but instead of using highlighter pens and ‘cutting up’ sheets of paper (as if coding manually) Microsoft Excel software was used for speedy retrieval of data. This proved to be a flexible approach that permitted narratives to be reflected in more than one theme or sub-theme, ensured the researcher became immersed in the emergent themes and afforded the opportunity to theorise and make relationships contextual with the research setting as these components are often lost when using computer-assisted qualitative analysis computer programmes (Lee and Fielding 1991).

Following the aforementioned transcribing process each document was transferred to a Microsoft Excel worksheet in preparation for data analysis. This Excel file (which may contain several worksheets) was arbitrarily named ‘JACK’ for ease of identification. The Excel worksheet was an accumulative file, that is, by the end of the interviews all patient narratives were contained therein. Each document was transferred to Excel and analysed in chronological order following each interview.

Each interview transcript was opened in Microsoft Word. The ‘control’ key and letter ‘A’ were depressed simultaneously to select all the text contained in the Word document. This was then pasted into the Excel worksheet document using ‘control’ and ‘V’ simultaneously. As previously mentioned, because the ‘return’ key was used following each question and/or statement during transcribing, the narratives copied into Excel drop into individual cells (which will be discussed later), thus giving the flexibility of analysing each question, statement and response individually.

To ensure that data could be accurately identified to the interviewee, maintain its chronological order and facilitate the exclusion of non-relevant data, (such as duplication or confirmation), it was necessary to insert three additional data columns into the worksheet (Appendix 11). These columns are headed Col. A, Col. B, Col. C and Col. D. Col. A contained a consecutive line number starting from 1; Col. B the patient identifier number; Col. C all the narratives; and Col. D relevance of the narrative. Each line of data (which at this early stage consisted of only columns A-D), is referred to as a ‘record’. In total there were 2,400 records containing text that were subsequently reviewed manually by the researcher whom entered ‘Yes’ or ‘No’ in Col. D thus indicating whether or not the corresponding narratives were to be analysed.

The Excel ‘filter’ function was then used to exclude unwanted narratives and retain those for further analysis, for example only those with ‘Yes’ in Col. D were retained and subsequently

themed. In excel 'filtering' is enabled by choosing the following from the programme's menus and sub-menus: Data, Filter, Autofilter.

Using the filter process enabled the researcher a fast and reliable way of separating out those data that were relevant from the non-relevant narratives. For example, in 150 instances the narrative commenced with either 'Yes...' or 'OK...' as a reaffirmation or in acknowledgement of the previous narrative, therefore 'No' was entered in column D (adjacent to the corresponding narrative) to indicate the narrative was not required for analysis. In total 1,450 records were excluded and 950 narratives were ultimately retained and analysed.

Microsoft Excel facilitates the use of several workbooks within each file, therefore the master file, JACK, contained several worksheets. The first worksheet was named 'raw data' and 'read-only' which means no changes or deletions could be made in error – thus retaining all the original text in patient and chronological order for cross-checking and clarification. The 'raw data' worksheet was then copied into a second worksheet named 'main themes' and the process of filtering and 'theming' commenced.

4.5.3 Coding and theme allocation

The worksheet developed into a large table with successive narratives down the left and columns, containing named themes, across the top. As additional themes emerged these were subsequently added as new columns with corresponding names. By entering 'Yes' in the corresponding narrative and theme it became possible to utilise the filter function and extract all narratives pertinent to each main theme. For example, by the end of the 'theming' process 174 narratives contained references to how patients reported that their constipation had affected them. These 174 pieces of data were then sub-themed further, for example how it affects patients physically, psychologically, affects of quality of life (to name but a few) by utilising the aforementioned filtering process.

As previously stated, each patient's interview data were transcribed and themed on an individual basis and subsequently to each other. Therefore the process of content analysis was manageable and enabled the process of creating and adding additional themes for each interviewee in a controllable and methodological way. For example, for the first interviewee, Alice, had a total 142 narratives (records) that were then filtered to exclude non-relevant and erroneous data. The resultant relevant data were then given preliminary themes which are presented and shown in Chapter 5, interview findings.

The process of theming continued patient by patient and, simultaneously, main themes (level 1) emerged (which are presented and discussed in Chapter 5, interview findings) and were created to form a structure and theoretical hierarchy based on frequency of discussions and/or implied importance. For example, the main theme ‘drugs’ contained the most narratives whereas ‘benefits of constipation’ was only mentioned once. The resultant main themes concluded following the ninth interviewee as no new themes or sub-themes were emerging, however, three further interviews were conducted to ensure theme saturation had occurred (Gray 2004; Parahoo 2006; Polit and Beck 2008).

4.5.4 Member checking identified themes

A process of member checking had previously been undertaken with patients to summarise the main points that were highlighted in each interview. This second stage of member checking was conducted by two senior colleagues who agreed to read some transcripts in order to establish the credibility, dependability and confirmability of the themes and sub-themes identified by the researcher. Both checkers were conversant with qualitative research and proficient in analysing narrative data and, following their valuable contributions and comments, subsequently agreed with the themes and sub-themes identified. Thereafter, the overarching themes were also presented to HCPs during the focus groups; a process that provided another layer of member checking and validation which will be discussed in Chapter 6, HCPs Focus Groups. However, it is worth noting that no further clarification or rejection of the overarching themes were proffered by the latter group, thus agreement arising in contributory factors leading to the suboptimal management of constipation in patients with cancer, which will be identified in Chapter 5, Interview findings.

Throughout the process, the researcher was aware that sub-themes (level 2) were emerging and these too were processed. As a safety precaution, all data files were back-up (copied) periodically onto a separate computer and password protected so that only the researcher could access the data.

4.6 Trustworthiness and validation

The quality and robustness of the data are issues that all researchers struggle with. No matter the chosen methodology any research needs to be evaluated against certain criteria to ensure that it is worthy to be viewed as a worthwhile enterprise.

4.6.1 Terminology

Polit and Hungler (1999) describe trustworthiness as a term that is used in the evaluation of qualitative data. However, it is not universally used or indeed recognised within qualitative research but the general concept of validation of data is addressed in various ways by most authors (Morse *et al*; 2001; Angen 2000; Mishler 1991). By way of explanation, Morse *et al* (2001) identify current and past debates regarding the use of traditional techniques for establishing rigor in research, including reliability, validity and validation. Leininger (1994) contributes to the debate by arguing the importance of preserving and maintaining the purposes, goals and philosophical assumptions of the qualitative research paradigm and of using qualitative research methods and criteria appropriate to that paradigm. From this proposition Morse *et al* (2001) conclude that the use of quantitative criteria such as validity and reliability remains inappropriate for qualitative studies. However, May (2001) and Silverman (2001) amongst others have continued to use traditional terminology, including 'reliability' and 'validity'. Morse (1999) adds to this point of view by arguing that, by not using traditional quantitative evaluative criteria and terminology, qualitative researchers are losing ground in the world of evidence.

The reasons why such measures need to apply are straightforward and return to the central focus of qualitative research. Polit and Beck (2008) believe that making critical assessments of the reality of a situation places a heavy responsibility on all researchers. As the general orientation of this research is one of interpretivism it means that most observation is informed by a stance or 'appreciation' of trying to understand phenomena from the respondents' perspective. This approach identifies respondents, not the outsiders, or researchers, as experts regarding their situation, in this instance the management of their constipation. However, Fielding (2001) notes that researchers must interpret the data and in so doing inevitably use their own frame of reference to do so. He emphasises this point by arguing that researchers are never detached observers and their views are inescapably relative and directed by their own perspectives.

It is therefore difficult to establish a method by which an audience can have any direct way of validating claims made by the researcher. It can therefore be debated that objective observation is impossible to achieve in any research. Thus the evaluation and understanding of situations and phenomena generally is derived from experience and the researcher, by sharing the respondent's world, applies that ingrained personal and professional experience introspectively to the data. As a result although the researcher's description and conclusions may be exposed to audience scrutiny, the introspective knowledge embedded in those

findings by its very nature cannot be examined. Qualitative researchers therefore use tests of congruence or verifiability to assess the rigor of their processes.

Maxwell (1992) discusses five types of understanding or validity that may emerge from a qualitative study: descriptive, interpretive, theoretical, generalisable and evaluative. Polit *et al* (2001) address the trustworthiness of data from a slightly different perspective. They argue that the central question underlying the concepts of validity and reliability are whether the data reflects the truth. Polit and Beck (2004) and Polit *et al* (2001) note that many qualitative nurse researchers seek to evaluate the quality of their data and their findings through the procedures outlined by Lincoln and Guba (1985) who suggest four criteria for establishing the trustworthiness of qualitative data and the ensuing analysis; credibility, dependability, confirmability and transferability.

4.6.2 Issues of trustworthiness

Credibility is viewed as an overriding goal of qualitative research. It refers to the confidence in the truth of the data and the interpretations of them. Qualitative researchers must strive to establish confidence in the truth of the findings for the particular participants and the contexts in the research. Credibility involves two aspects, firstly that the research should be conducted in a way that enhances the believability of the findings and secondly that the researcher takes steps to demonstrate credibility to external readers (Polit and Beck 2008; Denzin and Lincoln 2003b, Green and Browne 2005).

The second criterion identified above is that of the dependability of the research. This essentially refers to the stability (reliability) of data over time and over conditions and whether the findings can be replicated or repeated. It is generally accepted that credibility cannot be attained in the absence of dependability (Polit and Beck 2008; Denzin and Lincoln 2003b; Green and Browne 2005). The interviewer who gathers credible data obtains believable data which accurately portrays the situation from the subject's point of view (Domarad and Buschmann 1995).

Confirmability refers to the objectivity or the potential for congruence between two or more independent people in regard to the accuracy, relevance or meaning of the data. The criteria are concerned with establishing that the data represent the information that the participants or respondents provided and that the interpretations represent the truth (Brewer 2000). To such an end the achievement of this criterion must reflect the participants' voice and the

conditions of the inquiry and not the biases, motivations or perspectives of the researcher (Green and Browne 2005).

The fourth criterion is that of transferability which essentially refers to the generalisability of the data, that is the extent to which the findings can be transferred to or have applicability in other settings or groups (Polit and Beck 2008; Parahoo 2006). The responsibility of the researcher is to provide sufficient descriptive data in the research to enable readers to evaluate the applicability of the findings to other contexts.

4.6.3 Rigour of the interview process

The researcher recognised fully that the dependability of the process was not particularly rigorous but was confident that the credibility and confirmability as suggested by Polit and Beck (2008) were robust. The rich and plentiful data obtained from each interview reflected the detailed experiences of the individual and was invaluable for this qualitative study and consistent with the philosophy of the process. The researcher is aware of the debates that continue concerning the use of this non-standardised approach to gathering information (Polit and Beck 2008; Polit and Hungler 1999; Morse 1994a; Burns and Grove 1997; Morse and Field 1995). Nonetheless, the lack of structure was viewed positively to gain a good breadth of response.

4.6.4 Interview bias

A well-established and longstanding body of opinion in the field of methodological research warns of the many effects the interviewer could have on the respondent's statements which could distort the results obtained. While advocates of non-standardised interviewing value and analyse the proactive part played in the discussion by the interviewer, proponents of standardised approaches regard these effects as undesirable. They seek to devise and maintain methods of quality control that could minimise the distorting impact of the interviewer on what the respondent feels able to say. Silverman (2001) identifies the Hawthorne or Halo effects that may influence the rigour of the interview and thereby lead to inaccuracies and misinterpretations. Polit and Hungler (1999) concur and describing the Hawthorne effect as the bias or change of behaviour introduced as a result of the respondents being aware that they are under study and the Halo effect as being when the researcher positively identifies with the respondent and as a result inadvertently distorts the data.

Polit and Beck (2008) acknowledge this possible researcher bias by noting that an active commitment to a particular perspective during the interview certainly affects results but argues that it is also easy to overstate the problem when, in fact, it may not be present. In a slightly different vein, Gilbert (2001) notes that much of what is considered interviewer bias is more correctly interviewer difference, which is inherent in the fact that interviewers are human actors in the same way as respondents. Whatever the approach, it is sensible to take into account some of the key debates regarding possible bias. The researcher was therefore conscious throughout all interviews of the potential for bias being introduced and consequently made every effort to reduce it by remaining as 'neutral' as possible throughout each encounter as previously highlighted.

On completion of each interview and by way of closure to the event, the researcher spent some time with the respondents summarising the key points raised. This process of data corroboration is described by Lincoln and Guba (1985) as member checking and can be considered an important technique for establishing the rigour of qualitative data. In a member check, the researcher provides feedback to study participants by describing the emerging data and the interpretations that might be placed upon it (Polit and Beck 2008). The processes of member checking was completed post each interview and will be revisited as a concept later in the research where focus groups were conducted to test the credibility and generally test the emerging data from the interview stage. Lincoln and Guba (1985) and Denzin and Lincoln (2003b) state that if researchers maintain that their interpretations of meanings are good representations of the realities expressed, respondents should be afforded an opportunity to react to them. By so doing, every effort was made to ensure that appropriate emphasis was attributed to each issue thereby accurately reflecting the depth of feeling and viewpoint. This proved to be a useful process and assisted greatly in the establishment of the overall findings of the research project.

To engender confidence and to augment the credibility (Polit and Beck 2008) of the findings, the process of analysis and the consequent emerging themes were debated with colleagues working within the specialist field of palliative care referred to above (focus groups). These specialists, from a variety of care professions, were able to confirm and generally verify the interpretation of the data and by so doing, enhanced the rigour of the process. This member checking and dissemination process referred to above is further discussed in stage two of the research process.

4.7 Sample identification

Sampling is the process of selecting a portion of the population to represent its total. The sample is therefore a subset of the total population (Polit *et al* 2001; Parahoo 2006). In nursing and social research the sample is usually people (Polit *et al* 2001; Fielding 2001) and is used rather than the total population because it is more cost-effective and efficient (Clough and Nutbrown 2002; Polit and Beck 2008). Reasonably accurate information can be obtained from a sample that can then be generalised to the total population (Polit and Beck 2004; Parahoo 2006), however Fielding (2001) states that the researcher must refrain from drawing conclusions about a particular problem based on faulty samples. The representation and transferability or generalisation to the total population is more suited to quantitative research whereas qualitative researchers are not preoccupied with issues of transferability of results (Denzin and Lincoln 2003b; Elliot 2005). As this study aimed to change local practice rather than be generalised to the total population the researcher considered that the sampling process used was appropriate.

4.7.1 Inclusion and exclusion criteria

Polit and Beck (2004) state that in identifying a sample the researcher should be specific about the criteria that define who are included in order to gather meaningful data. This identification of the parameters of the sample is essential to leave an audit trail thereby increasing the rigour of the study (Gray 2004).

A contentious point debated by the MDT related to the cause of constipation. Whilst some team members wanted to focus on opioid induced constipation, others regarded secondary constipation as being definitive enough. The researcher raised concerns with these issues including the difficulties of differentiating between aetiologies, all patients with cancer are predisposed to constipation, and a pre-cancer diagnosis of primary constipation may have been superseded by cancer related secondary constipation. The researcher proposed that all patients with cancer, regardless of cause, should be considered for inclusion as there was no evidence to suggest that beliefs, attitudes and management strategies varied between aetiological groups. The MDT concurred and agreed the following inclusion criteria: patients with a diagnosis of cancer aged 18 and over, able to give informed consent and have experienced constipation. Patients would, based on a medical opinion, be excluded if they were entering the terminal phase.

4.7.2 Sample size

The study aimed to interview between 10 and 15 patients. This number was considered to be adequate to achieve effective results as Polit and Beck (2004) propound that it is usually impractical for the researcher to use large samples for obtaining data in qualitative studies. This non-probability, convenience sampling method was considered to be the most effective to ensure that the issues involved in an in-depth qualitative study of this nature were fully addressed (deVaus 1991; Polit and Beck 2004; Arber 1993).

4.7.3 Sample bias

This mode of non-probability, convenience or volunteer sample identification is used widely where there may be difficulty in readily identifying a sufficient number of potential participants (Morse *et al* 2001; Polit and Beck 2004). In this qualitative study the researcher was less interested in obtaining a representative sample of people than achieving a broad and diverse group that represented various experiences of the effects of constipation and its management in cancer care. This sampling process is congruent with the overarching philosophy of the study whereby the purpose is to contribute to an understanding of the phenomena rather than to seek representation and generalisation of findings as commonly accepted (Parahoo 2006; Polit and Beck 2008). Having noted that generalisation is not vital to the results the researcher will draw on the opinions of Silverman (2004), Porter (1996) and Brewer (2000) and make some generalisations in the findings Chapters regarding the data gathered.

The researcher acknowledges that this form of non-probability, convenience or volunteer sampling (Parahoo 2006) has inherent biases in as much that the group is self-selecting and may represent those individuals that have their own agenda (Polit and Beck 2006, Burns and Grove 1997, Streubert and Carpenter 1995). Parahoo (2006) and Polit and Beck (2004) state that using volunteers is perhaps the least robust of sampling, as the researcher has little control over the selection of interviewees and is instead dependent upon people volunteering to take part. Although the weaknesses of the process are well documented in the research literature, this possible compromise in sample selection, according to Polit and Beck (2004), can be considered the norm within most disciplines. Nonetheless, this sampling strategy was considered efficacious, as it is often considered that the issues of bias and generalisation are of less importance within a qualitative study of this nature where small samples are the norm.

To support this from a qualitative perspective, Silverman (2001) states that the purpose of sampling is to study a representative subsection of a precisely defined population in order to make inferences about the whole population. However, he goes on to note that such sampling procedures are usually unavailable in qualitative research. Agar (1986) contributes to this discussion by concluding that when research assumes a 'learning role' it does not always make sense for the researcher to be concerned with a process that is scientific. Agar (1986) purports that the main thrust of the research often involves inquiry regarding 'what is going on here?' rather than a technical examination of cause and effect and thus does not depend upon the pretence of scientific control. Therefore, within the framework of this research, any bias in the sample was considered to be acceptable to ask the question 'what is going on here' in a general sense and make some kind of inference or generalisation to the total population.

4.7.4 Study promotion

Following Ethical approval raising awareness of the research took on a more formal approach and a letter (Appendix 12) was sent to named individuals in line with local practice and as required by the Trust's Research and Development department. It was impractical to directly inform all HCPs about the study however, some senior doctors and nurses had been made aware as they were also Ethics Committee members. The flyer was displayed in prominent areas and the senior pharmacist suggested holding a supply of referral cards at the pharmacy department for distribution to outpatients with their medications, which were dispensed at the hospital pharmacy.

Once the research was underway, the researcher took the opportunity to maintain and raise awareness of the study and its progress at clinical governance meetings, research and audit meetings and other meetings when the opportunity arose and as part of the Unit's educational programme. This process acted as a reminder to staff and encouraged new and enthusiastic staff to contribute to the research and/or make referrals.

4.8 Summary

This Chapter has introduced the methods used during the patient interviews, many of which were subsequently utilised during the latter two stages of the research. The study initiation process proved useful as it provided the opportunity for MDT members and other HCPs practising locally to become involved in the research, thus influencing outcomes and affording the study direction and embracing the philosophy of action research. Many HCPs

were unable to dedicate time to the study due to their own commitments and workload pressures but were otherwise in favour of the research. Meetings were often time-consuming and difficult to arrange due to HCPs other commitment but nonetheless ensured the MDT were kept informed and involved in the evolving research and its findings.

Ethics have been discussed in detail to convey the importance of the necessary components, including the researcher's obligations and maintaining patients' best interest. Confirmation that these had been met were confirmed by the The Ethics Committee Members who approved this study and stated that, in their opinions, there was insufficient research exploring constipation in patients with cancer, thus a worthwhile study.

The appropriateness of the methods used during the patient interviews has been discussed and their suitability confirmed. The transition from pre-study, non-reactive observation to research being more proactive with observational finding influence and guided the study in the form of field notes has been highlighted, along with the gathering of field notes which provided additional in-depth data that were subsequently themed and disseminated.

The researcher has examined and detailed the generic methods used throughout the study. These elements present the nature of methods in research to set the scene. Key ethical implications have been introduced and the processes of gaining the required approval outlined. The processes adopted by the researcher have been highlighted in some detail to underscore the importance of maintaining the physical and psychological comfort of the patients throughout the interviews. The methods of data collection have been explained and these include the use of observation as a method that was used throughout the study; from its inception to the CMC and the interview methods used in stage one of the study as they represent the initial stage in the action research process. The processes followed are explained in detail to afford a clear understanding of each step and the underpinning rationale for their adoption as being appropriate data collection approaches to capture the type of data required to inform this study. Sampling issues are highlighted as they applied to stage one of the study and include the inclusion and exclusion criteria. The issues of trustworthiness are discussed and the measures taken by the researcher to strengthen the rigour, through the use of member checking of data and the process of this action research are emphasised to reinforce the value and accuracy of the overall findings of the study. The system and actions involved in the analysis of the data are exposed to illustrate the process of content analysis and explain how the main themes emerged. Some of these issues are revisited in stage two and stage three of the action research process.

Chapter 5

Interview process and findings

5.1 Introduction

This Chapter reports the findings of the interviews. Initially an overview of interview process is presented including referrals, sample demographics, location and duration of interviews followed by data preparation and analysis. An outline of the interview findings is given followed by the emergent main themes and rationale why only some main themes are analysed and presented. Relevant themes are then presented along with the respondents' narratives as extracts to illustrate salient points and highlight contextual relationships where necessary. Included in the core themes are: benefits of talking about constipation, respondents' perceptions of HCPs' negativity, laxative use, misconceptions and fragmented and inappropriate after care. A brief summary is given at the end of each section and the main points will be drawn together to give an overall summary at the end of the Chapter and present the rationale for the next stage of this research.

5.2 The overall process

5.2.1 Referrals

Over a nine-month period, 17 patients expressed an interest in participating in the interviews. Eleven patients self-referred and six were received via a HCP. Six patients were excluded as they either did not have a cancer diagnosis or entered the terminal phase shortly after registering their interest. The remaining 11 patients who met the inclusion criteria were given the patient information sheet and subsequently consented and recruited into the interviewing stage of this research. Three copies of the consent form were signed (Polit and Beck 2008) of which one was filed in the patient's medical notes, one was retained by the researcher and one kept by the patient. None of the patients wished to withdraw completely or in part (any extracts) from the study.

5.2.2 Patient demographics

The interview sample comprised seven females and four males. Their average age was 66 (range 60-74 years) and the cancer diagnosis varied as shown in the following WHO International Classification of Diseases (1989) malignant categories: Respiratory (2), Breast

(2), Female genital organs (2), Male genital organs (1), Digestive organs (3), Head & Neck (1).

5.2.3 Location and duration of interviews

Ten respondents chose to be interviewed in the Unit and in seven cases this was because they were comfortable with the setting, regularly used its day care facilities and were familiar with the staff. In contrast to the view of Zola (1986) respondents did not appear to be lacking in confidence or frankness during the interviews. It may be that the ambiance and pre-established affinity most respondents had with the Unit and its staff resulted in individuals feeling confident and relaxed, thus affording candid and open discussion. Two interviews took place in the respondents' home due to their immobility and difficulties with transport. There was no difference in the quality of data obtained between locations.

Allowing time ensured data were obtained at a pace to suit respondent's needs, thus enabling the contemplation of facts and events which contributed to their story telling. Allowing time emerged as being one of the main advantages of the discussions around constipation as, in the past, being rushed was reported as one of the main barriers to articulating their concerns. Interviews lasted between 40-60 minutes and in all instances came to a natural end, that is, all issues considered by participants to be relevant and of concern had, in their opinions, been expressed.

5.2.4 The data

As discussed in Chapter 4 (Methods), 11 interview tapes were transcribed verbatim. Transcripts were offered back to respondents for checking but in most cases respondents declined to read them on the basis that the documents were lengthy. Five respondents preferred the researcher paraphrasing the transcripts and clarified points where necessary. Two respondents chose to read their transcripts in their entirety and reported that they were a true account of the interview.

The cycle of allocating themes continued until the ninth interview at which point saturation had occurred, that is, no new themes or sub-themes emerged. Table 7 shows an extract of the main themes (level 1) and the number of corresponding narratives. These narratives were then sub-themed (level 2) and when necessary into a third level. Table 8 shows the sub-themes (level 2) for 'drugs'. Some narratives were coded to more than one category to ensure representation in all relevant themes.

Drugs (all)	298
How constipation affects me	174
Assumptions / beliefs / attitudes / desires	97
Interactions with others	68
Information seeking / received	49
Methods to alleviate / pain endurance	46
Causes of constipation	40
Past medical history	38
Unresolved issues	38
Recollection	35
Frequency	35
BO if not eating / unwell	31
Anatomy and physiology	23
Definition / What constipation means to me	22
Difficulties talking with others	22
Descriptions of stool	22
How long have you been/suffered with constipation	21
Bowels at the moment	20
Descriptions of self	15

Table 7 – Extract of main themes (**level 1**)

Types, names and descriptions of drugs	89
Frequency of use	70
Effects of drugs	64
Interactions, help, information received	44
Source of drugs	24
Experimenting with laxatives	17
Unanswered questions / assumptions	11
Laxative use - prevent or treat constipation	8
Reasons laxatives not taken	2

Table 8 – Extract of sub-themes for ‘drugs’ (**level 2**)

5.3 Interview findings

Respondents engaged in in-depth discussions about their constipation and its management. Interviews were semi-structured as planned. Prompts and probes were used minimally as in all cases respondents dominated the conversation as they spoke intently about their beliefs, attitudes and experiences with constipation, including their definitions, management strategies, concerns and wishes. Respondents reported that, for the first time, a HCP had listened to their concerns, believed what they had said, provided reassurance and support.

The emergent themes were useful in establishing a wealth of data that informed various stages of this research. A comprehensive and variable representation of constipation management in patients with cancer developed and was subsequently presented and debated with the MDT. Due to the enormity of the data it was not possible to explore all the issues in detail and, in the MDT's opinion some themes were of minimal value due to their historical nature and were therefore excluded from further analysis. For example, 'past medical history' (level 1) contained narratives about previous illnesses, diagnostic tests and/or constipation as a child, and thus their relevance during the interview was often a mechanism through which respondents were able to formulate facts, timelines and events. In contrast, those reporting co-morbid conditions, such as a heart condition, were noted as such data informed the choice of the individuals' laxative regimen but is otherwise excluded from the remainder of this Chapter.

All respondents sought advice during the interviews. Although proffering support and advice was not anticipated during this stage of the study, the researcher was of the opinion that the advice was simple, straightforward and consisted basic nursing advice. Therefore, withholding such information from respondents would have been unethical. The remainder of this Chapter presents the main issues that were considered most relevant to this study followed by a discussion and recommendations for the next stage of this research.

5.3.1 A therapeutic discussion

Respondents reported that they found the interview itself beneficial as it had enabled them to 'off-load' as if voiding themselves of what had become their sole responsibility and distress as shown in the following extracts;

"...it's a lot less annoying when at least someone listens." (Carol)

"I don't feel so bad now ... " (Frank)

*“Just talking to you (the researcher) is good you know, it helps a lot.”
(Alice).*

“Thank heavens I’ve found someone who understands what I am going through. It’s a relief just to get it off your chest ...” (Kathy).

Some respondents were anxious and said that they had felt ‘stupid’ in the past when discussing constipation with HCPs but this had now been alleviated, possibly due to the researcher’s empathic approach and supporting comments. Positive reinforcement was used throughout as necessary, for example, respondents were advised that their experiences were common and that constipation in patients with cancer was an important symptom that warranted further exploration and this was being achieved through their valuable contributions during the interviews (Denzin and Lincoln 2003b).

“I feel better for knowing that other people have the same problems as me. I needed to know if what I was doing was wrong but I didn’t like to ask anyone else.” (Betty)

“I don’t feel so stupid now, I was beginning to feel like it was my imagination and nobody else really seemed to believe me.” (Linda)

“... then you feel stupid and wish you hadn’t mentioned it (being constipated).” (Matthew)

The interviewer was non-judgemental and avoided negativity and humour relating to constipation and it may be that this approach enabled respondents to feel more at ease and comfortable when exposing their experiences and concerns, thus they spoke more frankly and openly. Respondents reported that they had found the interview a positive experience and, when asked, none wanted to withdraw any of their narratives despite its sensitive nature and data and expressing criticisms of their HCPs.

Respondents expressed their sentiments of feeling ‘stupid’ and disbelieved by HCPs who they regarded as being more knowledgeable about health care issues than themselves. Explicit within respondents’ narratives was a perception that they were subservient in the HCP-patient relationship and thus failed to challenge negative behaviours. The negative sentiments appear to stem from respondents perceptions that HCPs are unhelpful and disbelieving of them. Health care professionals may not realise the impact their approach is having on patients. In light of this point, it is not difficult to see why there is a lack of concordance between these two groups when trying to manage constipation.

Evidence of frankness

In contrast to her previous nursing experience, the researcher found respondents to be more open and honest about their constipation and its management. For example, one practice deemed extremely personal and embarrassing by respondents was digital removal of faeces. In 10 years nursing experience only one patient (as presented in Chapter 1, vignettes) had ever reported adopting this practice whereas five respondents volunteered this information during the interviews:

“... and I had to pull it out with my finger in the end, I just didn’t know what else to do.” (Eric)

“Sometimes you know I have to, em sorry this sounds awful, but em, well I have to do it with my finger. I’ve never told anyone that.” (Alice)

“I don’t mind telling you (the researcher) about it (having to remove faeces digitally) because you understand.” (Betty)

It is possible that the rapport, environment, motivation and time afforded to patients during the interviews facilitated the openness and frankness explicit throughout the narratives (Barr 2007).

5.3.2 Patients’ perceptions

Respondents commented about their previous interactions with HCPs in which they were unlikely to have spoken so candidly as HCPs always seemed busy and rushed. Respondents identified several factors that make them reluctant to continue to seek assistance from their HCPs. One of the main barriers was that all respondents reported that their HCPs are repeatedly busy, as indicated by the embolded words in the following narratives:

*“She (the GP) gave me I think it was like Fybogel, but that seemed to make it worse. I can’t keep going back. She (the GP) **always** makes it obvious she is busy and you just feel like you shouldn’t be wasting their time with such silly things.” (David).*

*“You can’t **keep** pestering them (nurses), they are all so terribly busy ...” (Eric)*

*“There are so many sick people and it takes ages to get to see your GP. I know **they** are busy...” (Gillian)*

*“... all **they** want to do is scribble on the sheet (prescription form) and get you out as quick as **they** can.” (Betty)*

As a result of these interactions respondents came to conclusions that subsequently became more barriers to seeking help. For example, that they were wasting HCPs' time, that constipation was unimportant and that other sick people were more important than they were. All respondents had previously attempted to discuss their constipation with at least three other HCPs, however, this had always been received with what patients describe as negative responses, disinterest and/or ambivalence. Respondents were resigned to this negativity, apparently not knowing what else they could do, for example:

"Well what is there, you just tell the nurse and she comes and gives you a little more of the same and says "you'll be alright tomorrow" and tomorrow doesn't happen." (Frank).

"I did speak to a doctor about it, I told him I haven't been for seven weeks and he just made a joke of it." (Betty)

"I've told the district nurses but I don't know what they can do." (Gillian)

"You get the impression that these doctors and nurses see you as a pest keeping on about constipation. You just don't bother in the end." (Alice)

The doctor didn't seem interested. What else can I do?" (Carol).

Respondents appeared to believe that HCPs had no interest in helping to alleviate constipation nor were they concerned about the distress the condition caused to patients. As a result of this disinterest HCPs allegedly failed to proffer appropriate support or advice. Whilst the issues raised here are also alluded to in Chapters 1 and 2, there are no indications as to why HCP ambivalence appears to exist in constipation management, or why patients fail to challenge the *status quo* even when they are severely constipated. It may be that respondents lacked satisfaction with the attitude of their HCPs, were 'fed up' with trying to seek help, or were unable to convey their concerns and distress when disbelieved or not taken seriously.

Only Betty took the contrasting approach that appeared to be borne out of frustration and her desire to be less subservient to HCPs as, in her opinion, patients generally were, but without good reason. Betty describes her relationship with doctors as persistent in an attempt to get results as she describes;

"I don't take no being fobbed off from no doctor, I keep going back. Because I don't think people, to be truthful, all the patients are in awe of doctors and the medical profession, and I've discovered you don't have to be, if you stand up to them, you get some results." (Betty).

Perhaps because of her persistence, Betty felt she was regarded as a ‘pest’ but this did not bother her as she felt she benefited from timely appointments and referrals upon her demand. Despite Betty’s perseverance her constipation had not abated and she was still seeking treatment for this at the time of the interview,

“I’m gonna go back to my GP because I’m still having trouble with constipation.” (Betty)

For the 11 respondents in this study it appears that even when they made repeated efforts and were more demanding of their GP no improvement in their constipation was achieved, possibly because GPs may not have and/or employ the fundamental elements (knowledge, skills and resources) required by clinicians to deal with constipation in patients with cancer. Respondents rationalised why HCPs failed to optimise their constipation management, often accepting that nothing more could be done. However, this was based on the patient as a layperson and in the absence of more specialised skills, knowledge and resources which are available to HCPs. The implications are that HCPs may be failing to access supportive resources to help with constipation management, thus arguably failing in their duty of care towards patients.

Respondents appeared perplexed by the attitudes of HCPs who afforded them with disinterest or, at best, a ‘sympathetic ear’ as expressed below;

“I kept telling him (patient’s GP) but he said “with all the things wrong with you that (constipation) is the least of your problems. I suppose he’s right.” (Kathy)

“The doctor said “Don’t worry about that (constipation), the nurses will sort it out” but they don’t. The nurses say the doctors need to give me something. It’s a waste of time talking to them.” (Eric).

“My doctor just sort of said “oh dear, what can we do to help?” I don’t know why she’s asking me ‘cos I went to her for help.” (Alice).

“I have mentioned it so many times in the past that I don’t bother now because nobody ever did anything, it just gets ignored like nothing was said.” (Linda).

“Obviously I’m sure if they (hospital nurses and doctors) could have done something more to prevent it (constipation) they would have.” (Gillian).

By their omissions, (such as failing to use evidence based management strategies for constipation and for improving concordance), HCPs often reiterated, perhaps unknowingly,

respondents' fallacies that constipation was inevitable, difficult to manage and that little or nothing could be done to alleviate it. The reported sympathetic ear did nothing to abate patients' concerns as all respondents remained worried and distressed by the impact of their constipation.

Allowing time and encouraging patients to speak openly afforded respondents the opportunity to discuss their constipation thoroughly for the first time. The researcher's interest, time and support was commented upon by several respondents as being beneficial to the interview process and an approach that they had not previously encountered when attempting to discuss their constipation with other HCPs. Respondents considered the interviews as therapeutic.

5.3.3 Seeking help

Despite repeated and failed attempts to seek help from HCPs, respondents continued to be very anxious regarding their constipation, but considered that they had no one else to refer to for support and advice.

"I do tell them you know (doctors at the GP surgery) and they give me this stuff (laxatives) but really what else can they do?" (Linda)

"Who else is there to talk to?" (Kathy)

"I've told my GP but he just gives me more of the same (laxative). I don't think he really knows what to do with me." (Mathew)

"I've just moaned to my husband, it stresses him too." (Alice)

"My daughter tries to help, she goes to the health shop. She has spent a lot of money and I don't like that but she likes to feel she is helping." (Gillian)

"... it worries my wife too which makes me feel worse." (Frank)

"What's the point (talking with the GP). She's not really interested. She just says "Oh, well try this (another laxative)" and the same thing happens". (Carol)

"... I mean it's not as if there is somewhere you can go specifically for constipation is there? A bit like going to the dentist, you go there to get your teeth sorted or go over there (the oncology department) to get your chemo." (Betty).

"I don't think anything can be done. If it could they would be doing it already wouldn't they?" (David).

Despite its private and sensitive nature respondents felt that at times their constipation had become so bad that they would have spoken to anyone who would listen. Many respondents appeared reconciled to the fact that there was no one else to turn to for help and reported a desire to seek help, for example:

“Who could I talk to that I hadn’t already told?” (Betty)

“No one is really interested. It would be nice though if they were, then maybe they could help. It’s good to off-load and see what other people think.” (Alice)

“I would love to talk to someone who has had the same problems as me or someone who knows something about it (constipation).” (Eric)

“If there was someone out there who could help me then I want to talk to them. Do you know if there is somewhere, or er, or anyone who deals with constipation?” (Linda)

Although respondents appeared accepting of their plight with constipation, the opportunity to discuss it further with the researcher demonstrated a change from being ‘resigned’ to ‘optimism’ that additional help and information was available, which was in contrast to any discussions they had previously had with HCPs.

Respondents identified the researcher as a person who could potentially help them and opportunistically during the interviews asked questions about management strategies for constipation. Respondents keenly sought guidance and advice, especially reassurance relating to whether or not management strategies they had employed were acceptable and/or adopted by other patients, as expressed in the following examples;

“Well, you are doing this research so perhaps I should ask you. What else can I do?” (Eric)

“I thought I was going mad. These things are awful but it’s nice to know I’m not the only one who suffers and has to do it (remove faeces digitally). I thought I was the only person who had to do it. Cos you can’t really ask anyone else can you? ... What else can I do cos I don’t like having to take it out myself?” (Linda)

“I know you are doing this research and you must know something about it so is there anything I can do to get rid of it (constipation)?” (Alice)

“Have you come across any other people who have to take laxatives every day?” (Betty)

“I know it sounds bloody awful but I just had to do it (remove faeces digitally). Do other people have to do it?.” (Frank)

The researcher was able to answer many of respondents questions, thereafter, they generally became more talkative and started to assimilate the new information with their experiences, thus theorising on how their constipation may have been better managed.

Respondents implicitly portrayed HCPs’ negativity in regards to constipation management. HCPs support consisted of, at best, a sympathetic ear or an alternative laxative. It appears that respondents never received ongoing assessment of their constipation or laxative regimens, thus efficacy of the latter never appropriately established, as it cannot be assumed that a laxative lacks efficacy if the regimen is flawed, for example, suboptimal dose and/or inconsistent use.

Respondents were passive recipients of poor assessment and management of their constipation and felt that they had no one else to talk to leaving them helpless and troubled.

5.3.4 Improving management

Some respondents made suggestions based on their own experiences and thoughts based on their beliefs about what may have helped them overcome problems in the past. In particular was the suggestion that a clinic solely for constipation management could be developed that included support and advice as this was currently unavailable, for example;

“That’s what needs to be done, a clinic for constipation. It would be useful you know.” (Betty)

“There needs to be somewhere to go to and find out more about it (constipation). Somewhere for patients like me I mean.” (Eric)

“I know this is why you are doing this research and I think it needs to be done. You may not be able to help me but things need to improve.” (Kathy)

“Well, I wish someone had told me that before (following a brief explanation of how laxatives work) and I might not be in such a mess now. When we’ve finished here (the interview) can I come and see you to talk about my constipation?” (Linda)

It appeared that by talking about constipation with patients and identifying their issues of concern and perceived exacerbating factors enabled respondents to benefit from the

interaction itself. Furthermore, respondents freely made suggestions, based on their experiences, which ultimately contributed to the development of this research and fitting well with the action research methodology.

5.3.5 Laxative use

All respondents had used at least two types of laxatives (such as senna, lactulose, ispaghula husk, polyethylene glycol and co-danthrusate) and the majority of whom still had supplies at home. For example, respondents reported having between one to four bottles of lactulose, loads of senna, boxes of ispagula husk or polyethylene glycol.

Based on respondents verbal account of their regimens, it appears that that none of the respondents were taking laxatives on a daily basis nor were they on appropriate regimens as recommended in national recommendations and guidelines. These apparent suboptimal doses were further supported by evidence on the ‘current medications’ lists carried by half of the respondents. From these lists, the researcher noted that laxatives were prescribed at minimal doses and in some cases only entered on the ‘as required’ section of the sheet. Whilst further supplementary data were obtained from medical and/or nursing notes when available, these were often incomplete.

Identifying patients’ laxative use

Overall obtaining a laxative use history was problematic as all respondents had some difficulty in giving a comprehensive account of their medication use *per se*. For example, not being able to remember a drug’s name, dose used, what the medication was being used for or when they had last used it.

“There is a lot of stuff I have never heard of before ... they are all technical names, I don’t know the purpose of many of them” (Carol).

“I can’t remember what the fruity flavour medicine was for.” (Linda).

“But then the medication I was on after the operation... ... I can’t remember now but mainly painkillers, ... (steroids ... anti-nausea ... anti-diarrhoea) ... and other tablets. I think there was another tablet to stop constipation or something like that, I can’t remember what it was was.” (Eric).

“Oh, I don’t know, it was ages ago.” (Betty)

Eliciting information on drug name and their use was often aided by discussing related ailments, symptoms or anatomy, for example; painkillers, heart, bone, depression, bowels,

and constipation. Furthermore descriptors were generally given about the formulation type as reflected in the following narratives, which were used by respondents in an attempt to identify laxatives they had used.

“She gave me this white medicine...” (Alice).

“...a tiny chocolately sort of substance.” (Eric).

“It’s in a packet, you mix it with water...” (Linda)

“It looks like a bullet. Yellow”. (Gillian)

Respondents were unable to name these laxatives and appeared to look inquisitively at the researcher for assistance in identifying them. It may be that respondents were overwhelmed by the variety, quantity and role of their medications (as identified in the literature review, Chapter 2) and that this was compounded further by lack of familiarity with the drug’s name. There was an apparent lack of patients’ knowledge and understanding about laxatives throughout the data.

It was not possible to accurately identify patients’ laxative use based on their descriptions. For example, more than one laxative is in powder/granular form and needs to be mixed with water. The description of a ‘white’ laxative was perplexing and on further exploration (two days and three phone calls later), it transpired that the ‘white medicine’ described by Alice above was in fact not white but a transparent pale yellow liquid. Therefore, attempts to identify laxatives based solely on patients’ description may be unreliable and incomplete.

Frequency of laxative use

Although some patients were able to identify laxatives used in the past, it may be that additional ones had been used without respondents being aware that the medication was a laxative. Furthermore, when asked, respondents may have unknowingly omitted to provide a comprehensive account of their drug/medicine use because they did not consider them relevant or to be part of their drug regimen, for example;

“... a tablet from the chemist, it’s not a drug, it’s to do with constipation actually.” (Frank). (It transpired that this was senna.)

“Well, I didn’t get it from the doctor. I’ve got some other stuff but it’s not prescribed, em, vitamin tablets, senna,” (Gillian).

Out of all the medications laxatives were considered least important and overwhelmingly respondents reported that they only took them ‘as required’ and/or because ‘they didn’t work anyway’. In support of this respondents described how they had taken a laxative for a minimal period of time with little or no effect. Out of desperation, more or alternative laxatives would be tried, again for minimal periods of time, for example 2-3 days.

“Like, if I took it yesterday I should take another one this morning, but I think, ‘oh no, I’m going ‘here’ or ‘there’, and em, so I don’t take it, I don’t follow it through properly.” (Carol)

“At the moment, yeah, I went, to be truthful I tried four or five nights without taking the laxatives and I began to get more and more blocked and yesterday was so bad that I could not strain hard enough to push, it was really uncomfortable, I thought I was going to split my bottom it was so painful. So I had to take the laxatives.” (Betty)

“I keep it (senna) in the house in case we needed it, but as I say, we are not people who take laxatives regularly.” (Alice)

“I didn’t take my laxative, I thought I’d try a few days without first but then I had to take it for a couple of days. Maybe tonight I won’t take one because I want to get off of laxatives.” (Frank)

“Usually if I take Senokot or something like that just, but I mean I’m not a person who has to dose every week or anything like that.” (Eric)

“... by the third day then I am really beginning to panic a bit. I think I should and that’s when I usually take something on the second night, milpar or a senokot whatever’s handy, and it usually works over the third day.” (Linda)

The cycle would continue until defecation occurred then laxative use would cease. It appears that laxatives were only used to treat an episode of constipation but never used to prevent it, the assumption being that this management strategy was both correct; ‘take laxatives once you are constipated’, and appropriate; 2-3 days use of laxatives would, or at least should, have alleviated their constipation. Preventative use of laxatives was not a concept any of the respondents had considered, in contrast, weaning oneself off was considered a goal for fear of dependency on them. The side effects and dislike of some laxatives often deterred their use, for example; abdominal cramps, the size and quantity of some capsules, the taste of some liquid formulations.

“I used to take that (senna) but it gave me gripe pains.” (Linda)

“Lactulose is so sweet and makes me feel sick. I’m not taking that again.” (Frank)

“... it tastes awful.” (Alice)

“Have you seen the size of those tables? Sometimes I had to take four but I just can’t. It takes ages to get one down.” (Gillian)

“I can’t remember the name, that stuff in the packet, it made me wretch actually. I tried it for a few days but just couldn’t get on with it..” (David)

“With some of them I find I get gripe pains which sort of makes things worse really.” (Carol)

“... and he (the GP) already gave me this so I can’t just go back and say I don’t like it but I really don’t think it agrees with me, it makes me wretch.” (Betty)

Despite being daunted by these side effects, respondents felt that having overcome obstacles of obtaining laxatives all respondents expressed a reluctance to ask for alternatives because they had already tried various ones without success, and felt that their doctor would perceive them as being a nuisance.

None of the respondents gave a clear record of their laxative use but could readily describe the formulation (liquid, tablet, or capsule), colour and give an indication of dose (based on number of teaspoons or quantity of tablets/capsules). Approximate duration of laxative use was established along with any associated side effect of a particular laxative.

Regularity of use

The frequency of laxative use varied between respondents although they all expressed similar patterns, which was intermittent and infrequent use. From the respondents’ perspectives, however, laxative use was often described as being ‘regular’ and subsequently the use of this word, in relation to laxative use, was identified by the researcher as being ambiguous and a cause for concern.

Although most patients reported taking their laxatives ‘regularly’ this was negated by the additional instruction to take them ‘as required’ or ‘when you need them’. This apparent contradiction is highlighted in the following extracts, which are in response to the researcher asking: “Do you take laxatives regularly?”

“Yes, I do take them regularly but only when I need them.” (Kathy)

*“Yes, I take laxatives all the time and I don’t think I should have to so that’s why, as I say, I’m trying to wean myself off that’s why I experiment ...”
(patient stops taking laxatives for days at a time). (Betty)*

“Yes, I took them regularly for about four or it may have been five days but nothing happened so I thought what’s the point.” (Betty)

*“Yes, I do. Oh, well not when I’ve had my bowels open, obviously.”
(Mathew)*

It appears that the definition of the word ‘regular (-ly)’ may be leading to some ambiguity which is not surprising given its meaning: normal, customary, in conformity with a fixed procedure, occurring at fixed intervals, periodic, daily, everyday, and habitual (Collins Dictionary 2006). When considering the two key components ‘laxative prescribing’ (which includes frequency of use) and the definition of ‘regular’, it could be argued that patients who have been advised to take laxatives ‘as required’ are conforming with a fixed procedure, thus ‘regularly’.

Therefore, when assessing laxative use assumptions and interpretations cannot be made based on patients reports of regularity of use. In clinical practice experience has shown that clinicians often ask patients ‘Do you take your laxatives regularly?’ without further exploration or definition of what ‘regular’ means to the individual. Based on experience, the researcher postulates that in most cases HCPs assume ‘regular/ly’ to mean ‘daily’. Specific exploration on this point is outside the remit of this research but is alluded to in Chapter 6, HCPs Focus Groups.

Prophylaxis

It appears that patients only took laxatives on a daily basis for a few days to try and resolve an episode of constipation. Once stools became softer and/or bowel movements commenced then laxative use would cease. The cycle of stopping and starting laxatives subsequently ensued in often 3-4 day cycles, sometimes longer, until satisfactory defecation occurred, at which point, laxative use would stop completely until the respondent felt constipated again.

So whilst patients reported taking their laxatives ‘daily’ it appears, in fact, that none of the patients took their laxatives every single day without omission, nor with the concept of preventing constipation. Essentially, prophylactic use of laxatives was not a concept known to patients pre-interview. However, as each interview evolved it appeared that implicit information had been processed by respondents who suddenly became aware that if they had taken their laxatives more ‘regularly’ then perhaps their constipation would either have not

occurred or may have been less severe. As respondents had reported that they had taken their laxatives ‘when they needed them’ with varying success, the researcher posed the question either (as appropriate): “Did you ever consider taking laxatives every day?” or alternatively “What do you think would have happened if you had taken laxatives every day?” respondents replied;

“Well, maybe I wouldn’t be so constipated.” (Eric)

“I haven’t thought about it before now. But thinking about it – it is obvious really. I feel such a fool, why didn’t I work that out?” (Linda).

“Em, well, yes I suppose so. It does make sense...” (Gillian)

“Well if it’s OK to do that then I will. I’ve been trying to wean myself off you see. Nobody told me to do that before, do you think I should then?” (Betty)

The responses to the researcher’s latter question suggest that respondents react positively to the idea that they need to take laxatives ‘every day’ and that if they had done so then perhaps their constipation would not have become so severe. From the patients’ perspective, not having thought about the need to take laxatives ‘every day’ is an interesting thought because although most respondents report taking them every day it is evident from the narrative that respondents did not. On some occasions the latter became clear when respondents appended their narrative with “... obviously only when I need to...” or “When I’m constipated”

In all cases respondents reported taking their laxatives ‘every day’ but implicit within these narratives was their assumption that the researcher knew this was not the case, thus it was still not clear under which circumstances they would be taken. To overcome this ambiguity, the researcher was more precise during the discussion by asking “Do you take your laxatives every day whether you think you need them or not?” or “In the last two weeks have you taken a laxative every day without omission, that is at least on 14 consecutive days?” The response to both these questions was “No” despite all respondents stating that they took laxatives regularly.

Patients who become constipated due to insufficient laxative use are viewed by HCPs as non-compliant. Therefore, although HCPs are aware of the disparity between compliance and concordance it may be that with sufficient information, advice and encouragement patients would become more diligent with their laxative regimens because they understand and acknowledge the importance of their use.

As established in the literature review, laxatives need to be taken daily and at therapeutic doses in order to optimise efficacy, however, neither of these principles applied to the interviewees. It may be that patients expect laxatives to work within a short time period and resolve their constipation in the same way that taking, for example, a dose or two of paracetamol usually resolves a headache. It may also be that verbal instructions and the ‘directions for use’, (as written on laxative packaging), are too broad and vague to meet the needs of patients with cancer, especially those with disease related exacerbating factors as previously discussed.

Respondents reported having supplies of unused laxatives, which they had stopped using for a variety of reasons including dislike of taste and/lack of efficacy, that are known to be efficacious if use prophylactically and at optimal doses (Miles *et al* 2007). When laxatives were being taken they were used intermittently and at minimal doses. Side effects and dislike of formulation/taste often resulted in their disuse. In most cases respondents were unable to give a comprehensive account of their laxative use, partly due to problems of naming drugs *per se*. However, on further discussion with respondents it appears they are open to suggestion that laxatives do work if taken consistently, without omission and prophylactically.

5.3.6 Patients’ knowledge

Respondents were generally unaware of the cause of their constipation, often making reasonable assumptions and affording some suggestion, including, a poor diet, reduced mobility, drugs, cancer, ageing process and genetics. However, this array of responses was an accumulation from all 11 respondents and in five cases respondents did not know what may have contributed to their constipation, whilst others proffered more than one cause. Only three respondents clearly linked opioid use to their constipation.

In relation to causes of their constipation were the assumptions by respondents that they in some way may have been able to alleviate their constipation by increasing their diet as expressed in the following examples:

“I don’t think I eat enough. I just can’t eat like I used to. It would be nice if I could you know, go out and have a nice big meal.” (David)

“Em, I don’t know really. If I could go and eat a nice big curry, cos I like them, then I’m sure it will get me going. I don’t do that (eat big meals) these days so there is not much to come out is there?” (Linda)

“I eat lots of nuts and fruit. I just don’t understand why why I am so constipated.” (Betty)

“What you eat is important. If you eat rubbish then your bowels won’t work. What I don’t understand is I only eat good food, good quality food, I don’t eat rubbish, but I still have so much constipation.” (Eric)

“I should drink more. It’s not easy though when you don’t feel like it. I do try.” (Carol)

“I eat OK but not as much as I used to”. (Alice)

Reduced mobility was identified by most respondents as contributing to their constipation, but this was more in the form of a transition over many years as opposed to an acute change. For example, in the three following narratives respondents are aged 64, 68 and 79 respectively, all have advanced cancer and have reduced mobility.

“As you know I was a cricketer and very active but now, well, lucky if I get a round of golf in occasionally.” (David)

“I just don’t know. I shouldn’t be constipated. I used to be a gymnast and I was always busy and on the go, I did a lot of sport. I eat lots of nuts and fruit. I just don’t understand why, when I’m, as I say, I get a lot of exercise, why I am so constipated.” (Betty)

“Well you know, I can’t get around much these days. I sit in the chair most of the time, I can’t walk about much. So, I suppose that doesn’t help.” (Linda)

At the time of these interviews, David had last played golf three months earlier and it was unlikely that Betty “got a lot of exercise” as described as she became breathless with minimal exertion. Linda was virtually bed/chair bound and had been for two years. Thus whilst reduced mobility may have exacerbated their constipation it is unlikely to have been the sole cause, nor was there much likelihood that their mobility would improve as this generally deteriorates as patients become less well. The challenge is possibly in acknowledging respondents frustrations, answering their questions and identifying alternative constipation management strategies.

Some respondents appeared to have come to their own conclusions as to what had caused or exacerbated their constipation but this had rarely been confirmed, nor discussed, with them by a HCP, thus leaving respondents unsure and seeking confirmation, for example:

“The drugs don’t help, especially the painkillers.” (Eric)

“Someone said once that the morphine can make you constipated but I don’t know. Does it?” (Linda)

“All these tablets.” (Carol)

“Drugs, they make it worse.” (Kathy)

“Having these painkillers ... I’m almost convinced of it.” (Gillian)

“My mother used to suffer with it so maybe it’s genetic. Is it?” (Betty)

“I don’t know what causes constipation. What causes cancer? What causes anything? Who knows, nobody knows do they that’s why you’re doing this research.” (Frank)

Only one patient attributed some element of blame to the HCPs when he complained that, whilst an inpatient, the doctors should have been more diligent – not only in preventing his constipation but in at least listening to his concerns and responding appropriately rather than what appears to be in a dismissive way;

“And also they (the hospital doctors) did not compensate for my morphine. I kept telling them but they didn’t listen to me and I know that (morphine) caused it too. My other medications too, some of them say they can give you constipation. I read the leaflet in the packet.” (Eric).

Apart from Eric none of the remaining respondents attributed any degree of responsibility towards HCPs other than to comment on their attitudes and failure to provide information as previously identified.

Some respondents simply did not know why they had become constipated despite having several contributory risk factors. Respondents were perplexed when maintaining a healthy diet and fluids failed to alleviate their constipation. Drugs, especially analgesia, were identified as the main culprit in causing or exacerbating constipation and the simple solution was to stop taking opioids. As a result, pain increased, immobility worsened, and quality of life deteriorated.

5.3.7 Severe constipation

Emotionally, patients expressed feelings of sadness, crying, misery, isolation, irritation, and anger. Not feeling oneself and conscious of being constipated all the time was highlighted by several patients who were trying to live a normal life, but found being constipated compromised their quality of life. Respondents described a preference for being left alone,

not wanting to go out and withdrawing from others because their constipation had become so bad. One patient, Betty, described an experience when she was alone and very frightened because she was having to strain so much and for so long in order to try and pass a large hard stool that she thought she was going to induce a heart attack.

“... I was sweating, struggling and straining and I thought I was going to have a heart attack, I got all flashing lights in front of my eyes. I was frightened because there was no one there, I thought if I fall off the toilet or something goes wrong it was just so uncomfortable.” (Betty)

“Mainly it’s the embarrassment of it, I’ve said that a few times haven’t I. It’s the embarrassment of constipation, the discomfort you get with it I know sometimes I am quite uncomfortable with it and I know that a good clear out will relieve the discomfort. I just wish there was something I could do, I really am quite desperate.” (Gillian)

“Enduring the pain is better than being constipated but sometimes the pain is so bad. Maybe I just have to put up with it but I do sometimes think they wouldn’t let an animal suffer like this, they would put it down. Maybe that’s what should happen to me.” (Carol)

“... my family were coming over and I had all this stuff dripping out of me, it was on the carpet and kept running down my leg. It was so embarrassing. I had to tell my family because, well, I couldn’t hide it really ...” (Alice)

All respondents recounted how constipation affected them in terms of the physical sensation to defecate without actually being able to pass a motion. This resulted in several failed attempts and longer than normal durations sitting on the toilet often with little or no stools passed. Physically, patients endured pain during this process and the inability to push hard enough with their rectal muscles, extreme discomfort during defecation, expectations of having split their rectum and/or passing blood because their stools had become so hard, large and painful to pass.

Repeat episodes of these experiences had engendered negative feelings and a fearful anticipation and worry that things were not going to improve and that they would, at some point, reoccur. Patients also expressed a desperation and desire to be rid of the psychological and emotional affects of constipation, especially stress, anxiety and the embarrassment of faecal incontinence, so that they could maintain some normality and quality of life. All respondents had experienced desperation with their constipation and for many this still prevailed at the time of the interview.

5.3.8 Misconceptions

The following section highlights some of the common misconceptions respondents exposed during their interview. Respondents did not seek confirmation from the researcher about these issues but implicitly assumed their thoughts were sound, possibly because they were unable to assimilate an alternative point of view. These misconceptions appear never to have been challenged by HCPs possibly because respondents had not previously been afforded the opportunity to express them.

False hope

Descriptors used by respondents when discussing their constipation and associated symptoms were reflected in the literature review, however, knowledge of how the gastrointestinal system functions was lacking. For example, having a bowel motion (regardless of stool form or size) was always presented as being distressing but, in contrast, also used as a measure to support the assumption that their constipation had started to alleviate.

“Ah, it’s good when you do go, you feel much better for it and hope it doesn’t come back.” (Alice)

“Well I opened my bowels just two days ago, and em, it was sort of a bit too firm but lots of it. So I can’t be constipated at the moment” (Linda)

“I’ve had so much of this stuff (diarrhoea) coming out of me and I think there can’t be anymore but it keeps coming. One minute I’m constipated and the next this (diarrhoea). Quite the opposite really.” (Frank)

“I told my doctor I had diarrhoea and he gave me some Imodium (an anti-diarrhoea drug) so that will be sorted then.” (Alice)

*Sort of like constipation and diarrhoea at the same time if that is possible?”
“I don’t know where it keeps coming from. I haven’t eaten that much.” (Eric)*

“Being constipated is nice, at least you can go out and not worry about having to find a toilet like when you have that overflow diarrhoea.” (Linda)

“I think something gets stuck in the valve here (indicating right abdomen area), if the valves don’t work then it can’t get through.” (Mathew)

Respondents had assumed that if they were not eating sufficiently they were less likely to produce or pass a stool. In some respects this resulted in respondents being less concerned

with being constipated assuming that, eventually, enough faeces would be generated to produce a stool.

There were no narratives to suggest that the management strategies for these respondents had been improved in any way, nonetheless, the belief existed that their constipation was improving. This false sense of hope, albeit temporary, may in itself be exacerbating constipation itself as the urgency to resolve an episode of constipation had subsided.

Pain endurance as a compromise

Pain endurance in preference to constipation was seen as a compromise that sometimes had to be made. This ultimately resulted in patients unnecessarily suffering with pain but also may have done very little to ease their constipation, however, none of the patients were aware of this as expressed in the following:

“It’s a balance one has to make. Take the morphine or be in pain. I think I would sooner be in pain than be constipated.” (Eric)

“Well, that’s why I kept doing this experiment, to see if when I didn’t take the painkillers, would my constipation go (rhetorically speaking), because they told me it (the analgesia) would make me constipated”. (Betty).

“When I haven’t been for four days then I stop the painkillers for a while. Then I think oh now my leg hurts and I take it (painkillers) again, and well, I think what should I do for the best. I still haven’t been (had bowels open).” (Linda).

Implicit within these extracts is the belief that something constructive and positive has taken place that, to varying extents, is indicative of constipation relief. In contrast however, it is more likely such actions will exacerbate constipation and result in further symptoms and additional unnecessary suffering. For example, anti-diarrhoeal drugs will exacerbate constipation and the patients’ assumptions that diarrhoea was only ever the opposite of constipation may result in the latter being neglected and thus becoming severe, the impact of which has been established in Chapter 2.

Liquid morphine is less constipating

The misconception that liquid morphine is less constipating than the tablet formulation resulted in one respondent taking much higher doses than may have been necessary, and still without prophylactic laxatives, as Eric describes;

“Well I take the liquid morphine now so I know that’s OK ... (on further exploration) but I thought because it was liquid then it wouldn’t make me constipated.” (Eric)

Similarly, the use of anti-diarrhoea drugs were seen as a way of stopping overflow/diarrhoea but without any thought as to the consequences of their actions, which is exacerbation of constipation.

Assumptions about patients’ knowledge on bowel function

Whilst the following extract may be regarded as uncommon, it does highlight the importance of not making assumption about patients’ knowledge. One 56 year old gentleman reported that only two years ago he learnt that having ones bowels opened did not mean passing urine, the latter which he referred as having a ‘whiz’.

*“The nurse asked me if I’d opened my bowels and I replied to the nurse “Yes, no problem, I’ve been.” And it wasn’t until the gentleman in the bed next door to me turned round and said “They don’t mean going a whiz³” and I said “Well I thought that what’s what opening your bowels meant wasn’t it?” He said “No, the other one, you know as is passing the waste matter. You know, being blunt having a, having a s***⁴.” Oh, oh, so when the nurse came back I called the nurse over and I said “Ah there’s a slight misunderstanding.” em, and when I explained to her then she said how long have you been in bed since you haven’t been to the toilet and I said “seven days”, which it was, I hadn’t actually gone to the toilet. She said “I suggest you go”. Anyway, they gave me some ... (laxatives).” (Frank)*

The above example raises the awareness of the importance of not making assumptions when assessing patients’ bowel function with them, as this often leads to confusion and misunderstanding. In the event that the HCP conducted a proper bowel assessment, including stool form and frequency, both he/she and the patient would have realised they were discussing different things.

Loose stools caused confusion

The onset of loose stools was thought by some respondents to be partial alleviation of their constipation and a hope that things were resolving. However, when the sensations of constipation remained, for example feeling bloated and/or a full rectum, respondents became perplexed.

³ This respondent used the word ‘whiz’ to report ‘passing urine’

⁴ Word concealed to minimise risk of offence.

Respondents described being confused by the fact that they had experienced diarrhoea at some point during an episode of constipation. Feeling bloated and having the sensation of a full rectum were presented as being still very evident even though they were passing loose watery stools. Eric's account typifies that of other respondents' experiences, for example;

"I might not go (have bowels open) for two days and when I did go it would be solid then loose at the same time. And the end yeah, it was just sort of like, it would be solid and then it would come out watery, followed up by watery. You could say a bit of constipation and diarrhoea at the same time if that's possible?" (David)

None of the respondents had heard of 'overflow diarrhoea' and expressed surprise when the researcher explained that it is not an uncommon side effect of constipation. Furthermore, all reported that they had experienced overflow diarrhoea and were confused as, in their understanding diarrhoea was the opposite of constipation and could not occur simultaneously. Respondents expressed relief that what they had experienced was not altogether uncommon and appeared optimistic that the researcher may be able to help them overcome this problem, which in some respects was worse than being constipated itself and possibly more embarrassing as it was harder to conceal from other people.

Digital removal of faeces was necessary

In contrast, some respondents reported being extremely embarrassed by another technique they found necessary to perform, which was to digitally remove hard faeces from their rectum. For those who discussed removing their faeces digitally they did so in order to express to the researcher just how desperate they had become to alleviate their constipation. In all cases respondents deemed the practice necessary and some reported feeling ashamed and embarrassed, however, the latter was somewhat abated when the researcher conveyed that she was aware of their dilemma and acknowledged that the practice was not uncommon under such circumstances. Performing digital removal of faeces always appeared to be conducted out of sheer desperation when stools had become so hard and stuck in the anal canal. It is possible that as this research progressed the cessation of having to remove faeces digitally may be regarded as an outcome measure.

When is constipation alleviated

For the purpose of simplicity and to avoid ambiguity the researcher has themed reports of defecation as either 'incomplete' or 'complete'. 'Incomplete' relates to a bowel motion that

gives little or no relief. ‘Complete’ refers to defecation which, when reported by patients implies that their rectal contents have been dispelled and that they ‘feel better’ as a result. It cannot be assumed by the researcher that the rectum has been emptied or that the constipation has subsided. In contrast however, it appears that patients believe this to be the case. Relief following defecation was expressed as pleasurable and how, overall, the patient subsequently felt, for example;

“...it’s good when I do go, it’s nice, you know, you feel better for it obviously.” (Alice)

“When I do go I feel a lot better for it.” (Frank)

“It is just such a relief.” (Betty)

“I start to look forward to things again, especially having my family around and knowing I’m not going to be preoccupied with going to the toilet ...” (Carol)

One of the main outcomes for those who were able to open their bowels and pass what they considered a ‘good amount’ was a sense of being relieved. This relief also engendered a hope that their constipation would not occur again. Respondents made the assumption that by passing a ‘good motion’ their constipation had resolved, thus not attempting to alleviate it further or prevent any subsequent onset. Given respondents assumption that constipation had been relieved they made, what they felt was, a logical decision to stop taking their laxatives on the basis that these were longer needed. Given respondents lack of understanding about the causes, consequences and nature of constipation it is understandable why they assume that laxatives were no longer required, which was also a practice that aligned itself with a previously identified desire, which is to wean off laxatives (Chapter 2) and not be dependent on their use.

Weaning off laxatives

Fear of dependence and the weaning off laxatives was considered by respondents to be a good reason not to take them. However, none of the respondents were able to expand further on their concerns relating to dependence other than an assumption than ‘one should not need to be reliant on them’. The assumptions made were that faeces would eventually be passed for example;

“Well, it has to come out eventually doesn’t it?” (Eric)

“I’ll just have to put up with it (the constipation) then until I manage to go (to the toilet).” (Mathew)

Maybe I’ll try some prune juice. That may help push it through. There’s only one way out isn’t there (laughing).” (Alice)

The interview data was void of any implicit or explicit references to the potential impact and acute complications, including death, which can result from constipation (as previously discussed: faecal impaction, bowel perforation, and complete intestinal obstruction). It appears that patients also fail to recognise the importance and significance of therapeutic constipation management.

Respondents’ misconceptions impaired any potential management of constipation not least of all because overwhelmingly they had accepted that nothing further could be done. When motions were passed, regardless of stool form and concerted efforts to expedite the process, respondents believed that their constipation had resolved or abated. Similar, loose stools signified constipation abatement. Management strategies deemed necessary by respondents included omitting opioids (thus enduring pain), removing faeces digitally and weaning off of laxatives. Overall, respondents had a poor knowledge about constipation and its management exacerbated further by their misconceptions.

5.3.9 Support mechanisms

Support afforded to respondents varied from family/friend, GP, Macmillan, district nurse, hospital clinical nurse specialist, oncologist and/or the palliative care team. Input from these varied and although in some cases an HCP had been assigned respondents reported that they had either not met the individual or that their contact was minimal.

Respondents described how HCPs would only temporarily deal with their constipation and ‘try something different’ before suggesting that they (the respondent as patient) speak with someone else if things do not improve. For example, hospital doctors said the nurses would deal with constipation whereas GPs said the district nurse could provide help. According to respondents the problem with the district nurses is that the practitioner would vary on each visit and they rarely agreed on management strategies. Furthermore, district nurses were perceived as always being too busy and not really interested in discussing problems with constipation other than offering to administer suppositories to promote defecation. Whilst all respondents had resorted to using suppositories at some point they all commented that they would prefer not to use them because it was embarrassing and an invasive procedure. In

most cases, the district nurse was much younger than the respondent and in some cases the opposite sex. Both these factors further contributed to respondent embarrassment.

“The district nurse told me to take this medicine (a laxative) and said to try it which I did but nothing happened. When they came the next time, em, I think that was about a week later, it was a different nurse and she said “Oh, I’ll ask the doctor to give you something else” but nobody mentioned it again. The nurse did say that I need to keep an eye on it (constipation) but em, well, I never heard anymore.” (Gillian).

“A young man came and said I needed suppositories but I wouldn’t let him do it. Maybe I should have but, well, I was a bit frightened to tell you the truth. I’d never met him before and, well, I’m 87. I just said “what’s the point of doing that?” and he muttered something I didn’t quite understand, but I didn’t want him to do it anyway.” (Alice)

“Yes, I would have told my doctor but when I went back there was someone else and she said “Oh, well, just try this and she gave me a piece of paper and said “take some of this...” (Patient was given a prescription for lactulose) which I had already tried and didn’t work before so I didn’t bother. I can’t go back again.” (Carol)

“The district nurse is very helpful you know, she does try but I don’t always see her, sometimes someone else comes and I don’t think they know what to do. The Macmillan nurse sometimes comes but she just said that the district nurses will sort it”. (Linda)

“I kept telling the doctors and he said “Oh, don’t worry about that, the nurses will sort it” (Kathy)

“I told the district nurse and she said “well, what do you expect me to do, you need to tell your GP”. So I called him he said he would visit the next day but he didn’t turn up and someone else from the surgery phoned that night and I told the whole story again. She said she would come the next day and guess what... nobody turned up. Well, I ask you, what else can I do.” (Mathew)

“I have mentioned it, to a few people actually. I have told my GP, and, em, all these people come and go (to patient’s home) and I don’t know who half of them are or what they come for. It’s confusing. In hospital I had things put in my, you know, bottom (suppositories) and, em, yes that’s it, the doctor said he didn’t know why they had done that. My Macmillan nurse said she can’t do them (suppositories).” (Eric)

Respondents implied that on occasions suppositories were administered in the absence of a clear explanation of what was being administered or why. One respondent recalls his experience with the medical team during an inpatient episode;

“... every time I said to them about constipation “Oh, don’t worry we will take care of that” and they used to inject something behind, kind of cream that would loosen my bowels. It was kind of an artificial inducement of

getting your bowels cleaned out. I was thinking this should not be happening because at one stage I was on nearly 100mg of morphine per day, you see, but they did not compensate for that, my constipation.” (David)

All respondents reported that they disliked having suppositories and had felt that the decision to administer them had been done in the patients’ absence of clear understanding of why they were necessary and/or what the procedure involved. Furthermore, suppositories failed to alleviate their constipation and provided no more than short term relief in some cases.

It is possible that patients are sometimes reticent when discussing constipation management with other HCPs and this may result in patients not wholly articulating their knowledge about constipation, its management, and their strategies because they had tried to on many occasions in the past and had ultimately become ‘fed-up’ with asking. When asked by the researcher if they had ever specifically initiated a consultation with an HCP about constipation all respondents implied that this would have been a waste of time based on their previous interactions. In contrast however, patients appeared to allude to their problems with constipation in the hope that HCPs would pick-up the cues and show interest and provide appropriate support.

“I did mention it (to GP) but he didn’t say anything. I suppose it’s not really that important is it?” (Alice)

“You get fed up with asking really, telling them and just nothing happens, maybe they just think I’m making a fuss but it really does bother me and I don’t know what to do. It is nice though, talking to you (the researcher), at least you are interested...” (Eric)

“Believe me I have tried. Waste of time.” (Betty)

It appears that very few patients persevere with seeking advice and support from their HCPs as, in the past, this has proved ineffective and generated at best a sympathetic ear. Respondents felt that HCPs do not take constipation seriously and are ambivalent towards its management, GPs reportedly just gave out more prescriptions for alternative laxatives, doctors generally put the onus on nurses to ‘deal with things’, and the circle of blaming someone else often ensued.

5.4 Discussion

This patient interview stage of the research worked well and the methods used were helpful in eliciting in-depth meaningful data. The collaborative MDT approach enabled a working partnership that afforded members an element of ownership of the project and thus their

valuable contributions and support such as making referrals, data analysis, identification and prioritising of themes and planning the next stage of the research. Clinical participants (doctors and nurses) reflected upon their own practice and reported modifying these based on the findings of this Chapter.

The sample identified met the inclusion criteria and all respondents made valuable contributions to this study as several major themes emerged that reflected their beliefs, attitudes and perceptions about their constipation and its management, thus meeting the overall aim of the patient interviews. Respondents considered that they had benefitted from the interviews because someone was at last interested in their plight, believed them and provided support and advice, albeit minimal and informal. There was no evidence that interview location, duration and/or content caused any distress to respondents.

Although constipation is highlighted in the literature review as a very personal subject that patients may be reluctant to discuss in-depth, it appears that an environment based on patient-clinician discussion can be created that is conducive to supporting patients' needs and wishes. All respondents reported that they had found the interview itself a positive experience and, when asked, none wanted to withdraw any of their comments. Allowing time and encouraging patients to speak openly afforded respondents the opportunity to discuss their constipation thoroughly for the first time. Eight respondents voluntarily reported that they found the interview itself therapeutic and attributed this to the time and support afforded, and the researcher's interest in their difficulties with constipation. Until the interviews, respondents believed that no further help could be afforded to them to alleviate their constipation. HCPs were reactive and respondents passive.

It appears from the main themes identified that it may be possible to improve the management of constipation in patients with cancer by redressing some of the issues presented. For example, respondents felt that HCPs were too busy, disinterested and/or unresponsive, therefore leaving patients feeling that their constipation was unimportant and not worth pursuing. A reticence to challenge such attitudes appears to stem from respondents' assumption that HCPs were more knowledgeable than they were and that clinicians had tried all possible management strategies.

Explicit within the data is that HCPs' negatively influence constipation management. Respondents had many unanswered questions, made ill-informed decisions and made inaccurate assumptions. For example, that constipation was inevitable and that laxatives do

not work. Laxatives remained in respondents' home for use as last resort, their use always intermittent and avoided if possible.

Through the interview process respondents became optimistic that help could be afforded and took the opportunity to ask questions, seek clarification on their management strategies and make suggestions about how improvements could be made. Towards the latter part of each interview respondents were able to identify contributory factors to their own constipation and by reflecting identify how, if managed differently, their constipation could have been alleviated/prevented. By exploring these issues with respondents further emergent ideas evolved on how constipation may be better managed in the future. These included affording time and having in-depth discussions with patients, providing appropriate advice, education and support, especially in the form of continuity of care and follow-up, a component clearly absent for all respondents.

Although all respondents had used laxatives and/or had supplies at home, there were consistent difficulties in naming these. It may be possible to elicit a more comprehensive account of laxative use by utilising sample laxatives, a theory presented to the MDT examined as a method in Chapter 7. There was no evidence in respondents' narratives that proactive laxative strategies (as discussed in Chapter 2) had ever been explored with them by any of their HCPs. Doses of laxatives were suboptimal in all cases, partly because their use was intermittent. None of the respondents used laxatives prophylactically because they were unaware of the need to do so.

Patient knowledge and education is an important consideration if constipation management strategies are to improve as without this component respondents make their own ill-informed assumptions and resultant misconceptions as highlighted throughout this Chapter.

It is unlikely that dietary methods and/or increasing mobility will alleviate constipation to a significant degree especially when drug induced and/or in those with advanced disease, therefore laxatives need to be used consistently, in optimal doses and prophylactically depending on stool form and ease of defecation. When adopting this regimen it may be possible to prevent the onset of severe constipation and the resultant stresses and burdens respondents reported enduring.

Fear of repeated episodes of constipation prevailed and unnecessary suffering ensued due to inappropriate strategies such as omitting opioids. Respondents' misconceptions engendered false hope in those wrongly believed any motion passed was a degree of alleviation of their

constipation. Overall, respondents had a poor knowledge about constipation and its management and respondents were reluctant to persevere with seeking advice from their HCPs due to the inconsistent and fragmented care and attention given to this distressing symptom.

The process of improving the management of constipation in patients with cancer is likely to be a lengthy process as there are many contributory factors, as highlighted throughout this Chapter, many of which it may be possible to redress using a more concordant and consistent approach encompassing continuity of care and follow-up. It may be that by being better informed and supported patients' constipation can be alleviated and/or prevented.

Before the interview respondents appeared to have given up seeking support and were enduring constipation in the belief that it was an inevitable consequence of their cancer. As a result of their interview however, respondents were afforded some advice and support but in most cases their disease was advanced and life limiting and it was not possible to assess the impact of the information given.

5.5 Summary

As an initial stage in identifying some of the contributory factors to constipation in this client group the interviews proved very useful and informed the latter two stages of this research. Respondents' data implicitly and explicitly identify many factors that clearly contributed to their constipation. It may be possible to redress some of these issues using a more patient-focused and individualised plan of care, encompassing patient education and continuity of care. In order to advance this research the collaborative HCP approach was maintained and partnership broadened to include the community teams as respondents identified them as negatively influencing constipation. To this end, the second stage of this research was initiated.

5.5.1 The next step: Rationale for HCP focus groups

It was evident within the data that patients' perceive HCPs as being negative, (encompassing disinterest, ambivalence and failing in their duty of care). It was decided by the MDT that the data should be confirmed and validated by HCPs from both the local primary care settings and a wider representation from the Unit. To achieve this and within the action research methodology adopted for this research it was proposed by the MDT that HCP focus groups should be conducted in order to provide contrasting perspectives. Furthermore, the

opportunity to draw the attention of HCPs to some of the issues raised by patients may act as a catalyst for improving constipation management, or at least, provide a medium for airing contrasting views. Within this research context, HCPs were given the opportunity to hear and comment on the aforementioned patient issues of concern and alleged suboptimal practices. These, together with overall focus groups findings are presented in Chapter 6 whereby the proposal for a nurse-led clinic specialising in constipation management for patient with cancer was well supported.

Chapter 6

Focus groups: methods, process and findings

6.1 Introduction

This Chapter presents the methods and findings from the focus groups that were conducted as a result of the interviews. The key overarching issues of methods such as sampling, audio taping, issues of rigour and the process of data collection and analysis are outlined in Chapter 4. The use of focus groups as an additional method used during this stage of the research is debated in this Chapter along with its effectiveness, and the actual steps taken are described to maintain an audit trail throughout the study. Having gathered the views of patients it was decided by the MDT that the perceptions of HCPs should be captured to provide a more inclusive representation of the management of constipation. The interviews had revealed that the patients generally were receiving suboptimal laxative regimens and clearly indicated that they considered that the poor communication and/or attitudes of HCPs exacerbated management of their constipation.

The use of focus groups greatly enhanced the rigour of the research by introducing an element of member checking (Polit and Beck 2008) and presented a forum for the dissemination of findings from stage one. It was anticipated that the focus group data would support the interview findings, thus validating the patients' perceptions or alternatively highlight contrasting points of view that may need to be taken into consideration when planning the next stage of the research. Mindful of these requirements the focus groups were planned to comprise two elements. Firstly discussions to determine HCPs' management strategies and to identify their beliefs regarding the contributing factors to constipation in patients with cancer and secondly, to provide an opportunity for HCPs to respond to the thematic findings from the patient interviews and ascertain the areas of agreement and disparity between the two groups. Overall, by conducting focus groups an element of dissemination would be introduced and provide an opportunity to introduce new participants to the study, (for example community GPs, Macmillan and district nurses), and work more collaboratively with them in reducing constipation in patients with cancer. Working more collaboratively with community HCPs was essential preventing problems of gate-keeping which leads to denied access to study participants (Green and Thorogood 2004; Polit and Hungler 1999; Krueger and Casey 2000).

6.2 Rationale for focus groups

Focus groups are an important data collection method frequently used in qualitative research (Polit and Beck 2008). A major advantage of a group format is that it is efficient (Parahoo 2006). According to Côté-Arsenault and Morrison-Breedy (2005) the purpose of the focus group is to explore and understand the context in which perceptions, beliefs and attitudes develop. To achieve this, focus groups should be small enough for everyone to participate, but large enough to elicit a range of responses (Clark 1999; Morrison-Breedy *et al* 2001; Polit and Beck 2008; Krueger 1988). Focus groups also capitalise on the interaction within a group to extract rich experiential data (Asbury 1995) and facilitate the exploration of attitudes and perceptions relating to concepts or services that are developed in part by interaction with others (Krueger 1993). Developing the emphasis on interaction, Kitzinger (1995) states that group processes can assist people to explore and clarify their views in ways that would be less easily accessible in a one to one interview. Kitzinger (1995) adds that when group dynamics work well the participants work alongside the researcher, taking the research in new and often unexplored directions. Polit and Beck (2008) maintain that the interviewer (or moderator) plays a critical role in the success of focus group interviews. It is their role to facilitate a dynamic, controlled process that yields meaningful data.

In contrast to the researcher's informal discussion with HCPs, (which occurred prior to and concurrently throughout this research), the focus group discussions facilitated peer reviewing, thus affording credibility of the findings and an opportunity to expose any diversity of practice between sub-groups. Participants were encouraged to speak to one another, ask questions, exchange anecdotes, and comment on each others' experiences and point of view (Kitzinger 1994) and to encourage a sense of 'group' participation when exploring and questioning their own practices. Due to the contentious issues raised so far the researcher carefully managed the focus groups to ensure that all the emerging issues were explored. These included inappropriate laxative prescribing, inadequate patient education, ambivalence and joviality.

An advantage of focus groups is that they allow the collection of data from several people throughout the duration of the meeting, provided each participant has the opportunity to speak (Bader and Rossi 2002; Polit and Beck 2008). A disadvantage of focus groups is that dominant participants may over-speak (Krueger and Casey 2000) and/or disregard other group members and it is possible that interruptions will occur resulting in more than one person speaking at a time (Bader and Rossi 2002; Polit and Beck 2008). In this study, when

dominance and interruptions occurred the researcher struggled to decipher exactly what was being said and by whom. To overcome this, the researcher adopted a strategy of acknowledging and expressing her appreciation for the contribution, followed by a reaffirmation of the essence of what was being expressed by the speaker, thus clarifying detail that might otherwise be lost (Bader and Rossi 2002). Thereafter, the question or statement was purposefully redirected to the remaining participants to gain their opinions. This approach proved to be successful throughout the focus group meetings when supremacy issues emerged, which was most commonly instigated by senior GPs, who posed a threat of overwhelming other participants.

6.3 The sample

Four focus groups were conducted over a six month period. A convenience sample was used for the focus groups (as in stage one). Twenty six HCPs from the community teams and the palliative care unit participated. Health care professionals were represented by GPs (4), GP Registrars (4), Specialist Palliative Registrars (3), Consultants (2), GP practice nurses (1), Macmillan nurses (4), district nurses (5), and ward nurses (3). A brief overview of the study was presented during the introduction to each of the focus group meetings along with assurance of the respondents' confidentiality and anonymity. The focus group meetings were audio taped and lasted no more than an hour. Polit and Beck (2008) suggest that the optimum group size for a focus group is 6-12 people however, Côté-Arsenault and Morrison-Breedy (2005) and Bader and Rossi (2002) consider that group of five can also be effective. In this study the largest focus group comprised of nine participants (GPs, GP Registrars and a GP practice nurses) and the smallest group contained five (district nurses and ward nurses). District nurses were less able to attend planned focus group meetings due to staff shortages, therefore, these were conducted as and when opportunities arose.

6.4 Data analysis

The focus groups were audio taped and subsequently transcribed verbatim (as discussed in Chapter 4). The coding, analysis of data and theorising occurred simultaneously throughout the process to guide thought and to record analytical insights and interpretation. For the purpose of describing and presenting substantiation for the conclusions drawn, steps of reduction and selective sampling of the data were used. To lend a context to the analysis of the data a note of the nature of the group dynamics was maintained (Carey 1995). A record was maintained of specific comments, jokes, anecdotes, questions, censorship, changes of mind or deferring to the opinion of others (Macleod *et al* 1996). Macleod *et al* (1996) state

that a sense of the whole group should be reflected in the data analysis by using quotations from more than one participant rather than presenting isolated examples from one individual. To achieve a member checking of this stage of data collection (Polit and Beck 2008) a copy of each transcript was forwarded to a nominated member of each focus group and subsequently returned as being a true reflection of the discussion.

6.5 Key findings

6.5.1 Constipation and humour

It was evident from the commencement of each focus group that constipation was perceived as a 'humorous' subject. Prior to the audio tapes being activated delegates spoke informally about their 'surprise' that an hour had been allocated to discuss constipation which, in their opinion, would take no more than 20 minutes. There was an air of jocularity which became the medium through which the researcher relaxed the group, however, once the audio tapes were activated and the introduction given, a more formal, less-jovial discussion followed. Through this approach a wealth of information was gathered and the researcher was able to expose various personal and professional perspectives relating to the management of constipation in palliative care.

6.5.2 Sub groups within focus group participants

Interestingly, but perhaps predictably, four sub groups emerged within the focus group participants. For the purpose of simplicity these are referred to, and represent, the following:

- GP group (GPs and GP Registrars)
- Community group (Macmillan and district nurses)
- Specialist palliative care group (specialist palliative registrars and palliative care consultants)
- Ward nurses and GP practice nurses group.

The community and specialist palliative groups adhered more succinctly to issues presented for discussion than did the GP group who were inclined to deviate to constipation in the general population and in the elderly. Additionally, the GP group appeared less concerned about the impact and management of constipation than the community or specialist palliative groups and despite being acutely conscious of the majority of the issues raised during the discussions, the GP group tended to put the onus of patient assessment and management on

to others, for example to the patient and/or district nurses. In contrast, the specialist palliative group not only acknowledged the prevalence, impact and significance of constipation in patients with cancer, they also appeared to assume responsibility for seeking to improve the situation by challenging current practices and engaging more fully in this research.

6.5.3 Defining and identifying constipation

Descriptors used to define constipation reflected those identified in the literature review (Chapter 2). However, in contrast to the literature, the absence of a clear definition did not indicate a lack of HCPs' acknowledgement of constipation as a problem in terms of its prevalence and management. Nevertheless, the GP group appeared less conscious of the significant impact of constipation on patients with cancer. Consequently, unless patients volunteered the information, it was unlikely to be identified by GPs. GPs were less proactive in identifying constipation in the erroneous belief that it was being managed by district nurses. To support this, GPs made unsubstantiated assumptions, demonstrated in the following narratives, that identification and management of constipation in patients with cancer falls within the role of the district nurse:

GP 1: "I think a lot of the problems go to the district nurses anyway, a lot more than come to us anyway."

GP 2 and GP 3: "Yes, yes."

GP 1: "...because they are often going in and seeing the patient. And they go in (to see the patient) often and more regularly than we do."

GP 3: "Oh, yes, I agree"

GP 1: "And they are trained to deal with it (constipation) which we're not particularly."

GP 2: "Yes but they can prescribe as well now so they can really manage the whole of the problem and, as you say, I don't think they discuss it so much even with us now because they can, (hesitating) eh, I think they can prescribe suppositories can't they?"

GP 1: "I don't know what they can prescribe."

GP 2: "They are a bit slow about doing rectals. I have a feeling, you know I would have done a rectal and they haven't, I'm not quite clear what the situation is."

GP 3: "Em... I don't know either."

GP 2: "I don't know if they (DN's) do rectals. They may do."

GP1: "Certainly some district nurses do. I had a discussion with a district nurse in the past saying... .. If you don't find anything in the rectum ..."

The lack of GPs involvement was perceived by the district nurses as being unsupportive of their practice, thus left to 'get on with it' without medical support, even when the need arose. The community group expected GPs to conduct physical examinations on patients to assist the safe and accurate assessment of constipation in patients with cancer. Only the specialist palliative group and Macmillan nurses highlighted the dangers of misdiagnosing bowel obstruction which raised issues of responsibility. There was concern as to who is and should be responsible to; a) conduct rectal examinations and b) prescribe rectal enemas. Disagreement between the GP group and the community group developed, one placing the onus on the other.

The specialist palliative group were not particularly concerned in this GP versus community group debate being more interested in the manner in which this discrepancy impacted on the patient. The debates led to the agreed conclusion that patients must be as, if not more, confused than they regarding the most appropriate HCP with whom to discuss and receive treatment for their constipation. One area of total agreement was that all participants agreed that that by the time patients reported being constipated it had already become a distressing symptom and problematic to manage.

6.5.4 Constipation - causes and contributing factors

There was also overall agreement that patients' medications, especially opioids, were the most likely cause of constipation in patients with cancer, followed by the failure of doctors (in primary and secondary care settings) to take preventative measures by prescribing laxatives. Referring to themselves, the GP group reflected on their own practices and what they 'should' be doing as opposed to what they actually did. For example:

GP3: "When we prescribe opioids we should always also educate the patient at the same time that this (the opioids) may cause constipation, if you are not having regular bowel movements then take the laxatives which should be prescribed at the same time."

GP1: "Education is the problem, we don't have time for it. How long would it take for me to explain it all to the patient, where do you start?"

The failure of GPs to instigate education was perceived as an oversight on their part. The most common rationale offered was that most patients in primary care were non-cancer patients and therefore, according to the GPs, prescribed analgesia for short-term use when laxatives were not required. Consequently the need to ensure that laxatives were included was not foremost in their minds and could therefore be disregarded when prescribing opioids for patients with cancer.

GP 1: “I don’t always remember to co-prescribe laxatives. Usually I wait, well, find out when the patient comes back but em, they don’t usually do they?”

GP 3: “Yes, it is easy to forget isn’t it. I’m probably guilty of that too.”

GPs described themselves as being ‘historically poor’ at providing patient education in relation to taking laxatives, or “if truth be told”, other medications. They also perceived that time taken in education was too time consuming and therefore prohibitive. They founded this comment in the context of the current health care climate of limited resources, including an average of just 8 minutes per patient consultation. In contrast the specialist palliative group argued that patient education was a major element of their consultations. However, the nature of the education that HCPs offered was unclear and appeared to consist mainly of verbal advice. The HCPs were unable to afford any indication of how, or indeed whether, the information had been interpreted or understood by the patient. Vague and often ambiguous instructions, such as ‘take the laxatives as required’ were discussed as constituting ‘patient education’. The consensus gained in all focus groups was that patient education was generally both minimal and inappropriate. Participants advising patients to take laxatives ‘as required’ or ‘as needed’ was identified as a common instruction given to patients. However, once debated within the focus group discussions, participants became aware of how inappropriate these instructions were. To support this, HCPs questioned their own practice, for example:

GP 2: “This assumes patients know as much as the doctor Doctors should give more explicit instructions to patients we are making assumptions about patients’ knowledge”.

GP 1 and 3: (in agreement)

In the absence of appropriate patient education it is not difficult to understand why patients become confused by the information offered by HCPs. Given that all HCPs in the focus groups identified causes of constipation and the necessity to take preventative measures in this client group, the following example is contrary to these beliefs:

GP3: “Usually, if you are prescribing opioids, what I usually say to the patients is one of the common side effects of these drugs is constipation, so if you are aware that you are not going as often or the consistency is harder then you need to introduce a laxative...”

This statement generally would not have made it clear exactly who would be introducing the laxative. The patient would probably consider that it would be their responsibility rather than the HCP. Other vague statements such as the next quote were commonplace.

GP2: “I think I usually do tell patients that they need to vary and step up their dose of laxatives, increase roughage and fluids....”

These comments not only suggest that HCPs are uncertain of the exact nature of the information that they provide, but also demonstrates a lack of insight as regards other symptoms to which patients are prone as a result of constipation and/or cancer and its treatments. These symptoms would include nausea/vomiting and the risk of faecal impaction which rather than being resolved may be exacerbated by roughage especially when patients are unable to tolerate sufficient fluids. Although the patients interviewed considered that HCPs (especially GPs) were reluctant to treat their constipation because they lacked knowledge, the HCPs in the focus groups supposed that patients were unwilling to discuss constipation, probably for the reason that it was ‘very private’ or because they did not deem it important enough to reveal to their GP.

Although patients were described by some HCPs as being non-compliant with laxative therapy, it appeared that HCPs acknowledge that they may be partly responsible by not providing appropriate information and education. This may result in patients omitting laxatives in the belief that they were no longer required as their constipation had alleviated. There was no suggestion that the GP group were keen to address these issues as in their opinion this was a role for the district nurses.

GP 3: “The District nurses sort it though ... well, I thought they did anyway.”

GP 1: “Well if they don’t they should do.”

GP 2: “Yes I agree. Has anyone asked them?”

District nurses and Macmillan nurses were critical of GPs for their inadequate and inappropriate prescribing patterns of laxatives, especially the choice of laxatives which was sometime based on cost rather than efficacy. The laxative most commonly prescribed,

lactulose, was the thought to be the cheapest but evidence suggest this is not the case (Christie *et al* 2002; Guest and Varney 2004). Furthermore, community nurses found GPs reluctant to undertake domiciliary visits to physically assess cancer patients with constipation and opted to prescribe suppositories or enemas that the district nurses were then required to administer. GPs supported this claim and reported that they considered it to be the community team's responsibility to undertake rectal examinations. District nurses commented that generally few DNs possessed the skills and knowledge to conduct physical examinations. Given the risk of bowel obstruction and difficulties differentiating between diarrhoea and overflow, the district nurses and Macmillan nurses were eager that the GPs be more involved. Focus group participants reflected the findings of the literature review in that differentiating between diarrhoea and overflow is problematic (Anton 2002). This was compounded further by some doctors who prescribed anti-diarrhoea drugs without examining patients. The specialist palliative group had become frustrated by this practice but felt powerless to change GP practices.

SpR 2: "Is often difficult explaining to patients why they shouldn't be taking anti-diarrhoea drug when their GP has told them to take it."

SpR 1: "Most of the time you find out the GP hasn't done a PR (rectal examination) ...before prescribing these (anti-diarrhoea drugs) which you would expect them to."

SpR 3: "I phoned a GP once to put him in the picture (having prescribed anti-diarrhoea drugs to a severely constipated patient) and he thanked me for letting him know. It seemed to go over his head that what I was actually doing was trying very discretely to let him know that he had actually made things worse for the patient"

DN 1: "... yes, yes. We've told them too but, ah, they don't seem to listen to us."

DN 2 and Macmillan 1: (Concur with DN 1 above).

6.5.5 HPCs views on patient interview findings

None of the HCPs were surprised by the findings that emerged from the patients' interview data. In response, HCPs reiterated the importance of alleviating constipation in patients with cancer and raised salient points that needed to be addressed in order to alleviate the problems encountered. When invited to make suggestions several ideas were offered and debated.

Patient education was identified as being essential as this could lead to patients being competent to titrate their laxative dose depending on stool frequency and consistency. Due

to the complexities arising in patients with cancer, patient education and self-management of laxatives would need to be assessed and monitored on an on-going basis. However, to support this, HCPs recognised that their own prescribing practices needed to be improved in order to optimise the benefits of patient education. Improving their own practices was voiced as something participants, especially the GPs, would endeavour to address immediately. In addition, it was acknowledged that, in light of the focus groups and patient interview findings, constipation was a more serious problem than they had previously thought. The focus groups appeared to have impacted on HCPs who subsequently reported their intention to be more diligent in their practices, especially with prescribing. It appeared to be the HCPs means of ‘doing their bit’ however, they were clear in that more importantly;

GP2: “Somebody needs to take responsibly for this problem and these patients ...” .

From the focus group discussions, the researcher felt that a degree of peer reflection and enhanced understanding had taken place that would lead to participants improving their management of constipation in patients with cancer. Focus group participants concurred that the researcher should explore the feasibility of a nurse-led clinic specialising in constipation management for patients with cancer as the next stage of this action research. The basis of the clinic would establish whether the management of constipation in patients with cancer could be improved by focusing on some of the issues raised so far.

Comparing and contrasting patients’ views with HCPs

It is evident from this study thus far that there is disparity between patients’ and HCPs’ perceptions, understandings and expectations of how constipation should be managed in patients with cancer. These inconsistencies are evident between patients and their HCPs and within HCPs groups; one often blaming the other. HCPs appear to acknowledge their responsibilities, but fail to be proactive with their management strategies. Overall, patients report that nobody bothers with constipation and HCPs acknowledge this.

6.6 Summary

In summary of this section, the opinions offered were various but generally similar in each of the four broad groupings of HCPs represented. The initial joviality expressed by some HCPs abated during the course of the meeting as their attitudes transformed, in the realisation that perhaps their practice relating to the management of constipation in this group was insufficient and needs further exploration. The consensus was that information offered to

patients was generally inadequate, often ambiguous and negatively impacted on individuals. It became apparent that the responsibility for constipation management in primary care was controversial and perhaps outside the scope of this study. However, those present had highlighted a problem that until this meeting had not been debated. The forum had offered the opportunity to share opinion and experience and would therefore go some way to disseminate the existence and ethos of this study.

6.6.1 Informing and directing the research

One of the main purposes of the focus groups was to validate the findings of the interviews and in so doing act as a form of member checking. Therefore, the researcher moved the focus groups on to discussion relating to the interview findings and ways in which the study could progress. This engendered a collaborative approach to constipation and its management in patients with cancer as focus group delegates afforded the study direction. The focus group process also prompted an element of participant self-reflection on his or her own practices, thus the first step in improving constipation management in patients with cancer. The utilisation of focus groups as a method widened the spectrum of HCPs as it incorporated the community teams and further provided the opportunity for collaboration with a group who are more likely to be patients' primary contact.

The MDT considered that focus group were the most robust action to take for validation of interview findings, member checking, dissemination, improving HCP practice and informing the next stage of this research, all of which are evident in this Chapter.

6.6.2 Rationale for constipation management clinic

In relation to HCPs there are several factors contributing to suboptimal constipation management in patients with cancer, for example a lack of; knowledge, confidence, insight and time. Furthermore, in cancer care the demands for being knowledgeable and focused on a particular client group necessitates that skills and knowledge are refined, rather than broad. For example, within the adjacent cancer centre the HCPs tend to be more knowledgeable relating to cancer and its treatments; epidemiology, aetiology, survival rates, drug treatments and their administration, (for example chemotherapy, Hickman lines), and usually with a particular anatomical region such as breast, head and neck, bowel, or ovary. As a result the academic and clinical demands imposed upon such clinicians and the resulting knowledge tends to focus more within their chosen speciality, which may be rendering them less knowledgeable of their patients' other needs and problems.

Thus, unfamiliarity and limited knowledge of the needs of cancer patients with constipation results in a lack of confidence when applying management strategies and poor insights into the complexities and burdens of this distressing symptom, as reflected in Chapter 2. This strongly indicates that the previous samples in this research, (interviewees and HCPs), have the same issues of concern with regards to constipation management and are reflective of the current patients and HCPs needs, thus validating the previous findings and confirming the need for the clinic and related research.

In light of the evidence thus far (Chapters 2, 5 and 6), constipation constitutes a frequent problem in cancer patients and when uncontrolled can lead to severe complications ranging from abdominal bloating to bowel perforation. It appears that constipation is both a distressing and underestimated complication in patients with cancer, which is preventable and treatable with appropriate laxative use.

After discussion and debate with the MDT it was decided that rather than concentrate on the education of HCPs the needs of existing patients with constipation were paramount, especially those with a limited prognosis. Furthermore, as previously highlighted, HCPs were not a static group and were often disinterested in constipation and its management and thus unlikely to attend educational meetings on the subject. The aim of the CMC was purposefully designed to focus on patients needs in the knowledge that HCPs would be encompassed in the process of improving constipation management by way of the post-consultation communication.

Chapter 7

The CMC - planning, methods and process evaluation

7.1 Introduction

This Chapter presents the processes and methods used during the Constipation Management Clinic (CMC), which was developed as a result of the findings thus far (Chapters 5 and 6). The CMC originated from the evaluation and dissemination of the patient interviews and HCPs focus groups, thereby harnessing the ethos of action research. The collaborative approach with the Unit's MDT and associated HCPs was integral throughout the CMC thus providing guidance and support. In addition to direction and assistance the MDT acted as a member checking group to ensure that the emerging data were credible and generally trustworthy. They also reported gaining a huge insight and deeper understanding of constipation management which they were able to directly utilise to change and underpin clinical practice.

Chapter 7 includes the rationale, planning and methods utilised during this interventional stage of the research whereas Chapter 8 concentrates on the findings that emerged from the CMC data. The development and implementation processes of a clinic specialising in the management of constipation in patients with cancer are presented in this Chapter as is an explanation of how findings were used to collect supplementary data to triangulate and strengthen the emerging issues. An evaluation of the referral process, sample identification and recruitment is offered to enable the reader an appreciation of the nature of the methods used. The sample demographics are presented followed by the rationale for why this group is appropriate for inclusion into this stage of the study. As in previous stages throughout the CMC the researcher maintained field notes to record salient comments, observations, actions and outcomes. These notes were accumulated and themed (as reflected in Chapter 4) thus affording an overall representation of findings. Extracts illustrate points and highlight contextual relationships where necessary throughout this Chapter.

The scope of the CMC preparation is exposed including the personal development of the researcher and the CMC framework that was devised in light of the findings of stages one and two of the study. The rationale for the development of specific elements of the CMC framework is examined followed by detailed components of the clinic including the duration

of consultations, the physical examination and medical support. The overarching aims of this research, reducing constipation in patients with cancer and improving HCPs' management of the condition, were explored concurrently during the CMC. Within the philosophy of action research this Chapter includes an explanation of the methods of dissemination of findings to HCPs, thereby affording the opportunity to improve practice and facilitating a collaborative approach to improving patient outcomes.

7.2 The objectives of the CMC

A constipation management clinic was initiated following and consequential of the findings of patient interviews and HCP focus groups. The scope of the clinic was discussed within the local MDT within the Unit. A dedicated patient-focused approach to constipation management was subsequently adopted that aimed to decrease the incidence and/or severity in patients with cancer. The objectives are summarised as follows:

- To facilitate an environment in which patients were able to speak at length and candidly about their bowel habits and related concerns.
- To identify individuals' understandings and management strategies.
- To examine initiatives to assist the identification of laxatives previously tried.
- To initiate a comprehensive patient assessment including a physical examination.
- To improve patient education.
- To provide support and advice.
- To develop a concordant approach to constipation management.
- To provide continuity of care.

7.3 Extended Ethical Approval

Ethical advice was sought for the final stage of the study in relation to patient consent which resulted in minor amendments.

- The CMC consultation was not being tape-recorded therefore all reference to this was removed from the patient information sheet and consent form.
- Patients needed to consent to the use of their data for academic purposes. This usage was indicated on the patient information sheet and consent forms which were submitted to Ethics (Appendix 13) and subsequently approved (Appendix 14).

It was agreed that patients declining the use of their data would not be recruited into this study but would have precisely the same access to the CMC. It was proposed that the CMC was an adjunct to the Unit's existing services and the researcher's clinical practice was within the scope of the extended nurse role. These were established by the Ethics Committee, the specialist palliative care clinical director and the MDT and full Ethics approval for the next step in the action research was gained.

7.4 Preparing for the CMC

Initially, the researcher embarked on a further literature search and examined the current databases but was unable to locate any substantive studies relating to the use of nurse-led clinics specifically for the management of constipation in adult patients with cancer. In contrast, there is an abundance of literature providing support and guidance on nurse-led clinics (Hatchett 2003) that were reviewed and informed the preparation of the CMC. Perhaps the most useful at this stage of the action research was that of Briggs (1997) who argues that the most valuable features of nurse-led clinics include direct referral mechanisms, assessment and technical skills, freedom to initiate diagnostic tests, prescription of medications, increased autonomy and scope for decision making and discharge. These features were used throughout the CMC and are expanded upon in this Chapter. Additionally, the researcher attended a conference on nurse-led clinics (Appendix 15) and a symposium on coordinating constipation management (Appendix 16). These afforded insightful information that were utilised within the CMC.

The growth of nurse-led clinics since the 1980s has enabled nurses to manage their own case load of patients with increasing autonomy. Hatchett (2003) describes nurse-led clinics as an educative role in which patients are afforded insights into the significance of their symptoms, differentiating between those of concern that require further treatment or adjustment of medication and those that may be from alternative causes. Furthermore, the nurse's role involves the skills of history taking and physical assessment, considering the significance of assessment, ordering further investigations as necessary and referring on to colleagues and other disciplines as appropriate (Baraniak and Gardner 2001; Hatchett 2003) and encompass a patient follow-up element which may be face-to-face or by telephone (Cox and Wilson 2003).

The government's nursing strategy supports nurse-led clinics as a way of making a more efficient use of health care resources and provide greater access to healthcare for patients (DH 1999). However, Bliss and Cohen (1977) note that the clinicians increased autonomy

when undertaking initiatives such as nurse-led clinics must be supported by the collaboration with other healthcare providers to ensure a coordinated approach to services and patient management.

To widen the basis of support a personalised letter (Appendix 17) and executive copy of the study's aims and objectives (Appendix 18) was forward to all the oncology consultants and the senior pharmacist in the adjacent cancer centre as some of their patients would be eligible for inclusion in the study. In the letter, the researcher also sought permission to display flyers (Appendix 19) and referral cards in prominent areas within the cancer centre to encourage referrals. Consultants were asked to feedback any objections, concerns or suggestions about the study and/or its development to the researcher.

Four oncologists responded to the letter stating that they had no objections and were content for the CMC to proceed. This was considered a general support for the study and an implicit reaffirmation of the importance of the management of their patients' constipation. In addition and in accordance with local practice, notification of the extended Ethical approval for this study was conveyed to all the oncologists at one of their clinical governance meetings. A colleague, who was central to the MDT and therefore the study reported that a brief outline of the study was given, discussions followed and that no objections were received. Once again this general agreement was viewed as an endorsement of the topic area and the proposed CMC.

7.5 Researcher's skills and experience

During the CMC it was anticipated that the researcher would practise in an extended role that focused on the assessment and treatment recommendations for patients with constipation. The researcher was aware of her professional responsibilities stipulated by the Nursing & Midwifery Council (2004) and that any decisions and actions taken must serve in the patients' best interests and within her level of professional training and experience. The researcher was cognisant of the requirement that nurses must only undertake activities for which they have been trained and are competent to perform (UKCC 1996) therefore, in order to provide the planned holistic service, for example encompassing a physical examination, further training was clearly required. These are explained in the following paragraphs.

Findings from Chapters 2, 5 and 6 strongly suggested that many patients presenting with constipation had not had a physical examination to confirm its presence and/or severity. This was confirmed as being likely by the Unit's MDT. The MDT considered that the

provision of a physical examination would be an important element to include in the CMC as it would facilitate a more comprehensive patient assessment and highlight potential problems such as bowel obstruction which would require urgent medical assessment. Furthermore, a physical assessment might reveal the need for an x-ray and also influence laxative choice and dose. Therefore the medical team suggested that the researcher undertook further training to improve her skills and knowledge relating to physical examinations as these would afford patients with a more holistic assessment and greater understanding of the nature and extent of the problem.

7.5.1 Physical examination

Although the researcher was proficient at, and had previously performed, digital rectal examinations as part of her clinical practice she undertook training by the specialist palliative care consultant and his team to learn how to perform an abdominal examination. Following several observed patient physical examinations (by a senior medical team member) the researcher was assessed as being competent to conduct simple abdominal and rectal examinations. The researcher's physical assessment was not intended to be as comprehensive as the medical model but to act as a mechanism for raising the alarm should something more sinister than constipation present, such as bowel obstruction. The researcher remained accountable for her actions (NMC 2008) with overall clinical responsibility maintained by the specialist palliative care consultant.

Objective data were collected during the physical examination. As advised during tutorials by the medical team, the researcher checked for abdominal swelling and/or distension, sensitivity/tenderness when the abdomen was gently pressed, the inability to digitally circumvent a rectal mass and any other abnormalities such as rectal bleeding and/or inflammation. Any of these signs/symptoms may be as a result of, amongst other things, bowel obstruction, ascities or bowel perforation. It was therefore agreed that the Unit's medical team would be informed immediately should any of these symptoms be present.

7.5.2 Laxative prescribing: developing a system

A great deal of groundwork was necessary in preparation for making recommendations and prescribing laxatives as the reasons why patients omit their medication are multiple and need to be examined on an individual basis (Zeppetalla 1999; Elwyn *et al* 2003) and as highlighted in Chapters 2 and 5. Patients' lack of information regarding their condition and the importance of treatment significantly contributes to poor compliance or concordance

(Kennedy 2003), therefore, the CMC aimed to redress any shortfall through patient education and information giving based on the individuals' needs.

The MDT debated the most effective system of prescribing within the CMC and reached the conclusion that it might be necessary for the researcher to prescribe laxatives to patients not currently taking appropriate regimens. The MDT decided that without this the patient would be obliged to return to their GP, or other medical prescriber which would result in further delays and negate the ethos of the clinic: holistic constipation management. The patients would be revisiting a situation which had essentially not been successful in resolving their constipation in the past.

The MDT debated the requirement for the researcher to undertake supplementary skills updating, such as a nurse-prescribing course and guidance on the processes of requesting diagnostic tests. A general consensus was reached that further training would be inappropriate given the complexity, time and academic requirements afforded to this study and her other work related research and audit commitments. It was therefore agreed that, in partnership with the researcher, the Unit's medical doctors would endorse/sign prescriptions and order any diagnostic tests deemed necessary. Therefore the ultimate responsibility remained with the medical team and the CMC could progress in the immediate future. In the event, this system worked effectively as the partnership discussion between the researcher and doctors ensured that collaboration and the team approach were maintained within the ethos of action research. Some junior doctors required justification from the researcher regarding choice of laxatives which in itself introduced an educational element to the encounter. All prescriptions were ultimately endorsed. The team approach ensured that patients were afforded a timely and comprehensive CMC service. Prescriptions were subsequently dispensed from the hospital pharmacy and therefore could be taken by patients within hours of prescribing rather than being delayed by days whilst awaiting further appointment with their prescribing GP or oncologist.

7.5.3 Laxative prescribing: establishing the appropriate drug regimen

To widen her knowledge and understanding of laxatives and their use the researcher revisited the literature that had been reviewed at the outset of the study and re-examined it. It is evident in the literature that not all laxatives are appropriate to use in patients with cancer. For example, despite the evidence to support the efficacy of psyllium in the treatment of chronic constipation, (Ramkumar and Rao 2005), bulk-forming laxatives should not be used by individuals who are debilitated, have advanced disease and/or who are unable to drink the

required amount of water with the administered dose (Tamayo and Diaz-Zuluaga 2004). This frequently includes the elderly and those who are dehydrated (Bossard *et al* 2004; Ginsberg *et al* 2007). In the absence of sufficient fluids the osmotic nature of psyllium exacerbates dehydration and constipation. Therefore the use of laxatives containing psyllium was avoided.

The drug information afforded to patients during the CMC was subsequently obtained from a variety of sources. These included extrapolation during the literature review, the most recent versions of the BNF (2008) and PCF (2007), directly from the drug's manufacture and during discussions with the MDT. Laxative regimen recommendations included the use of senna, lactulose, co-danthrusate and polyethylene glycol. This list is not an exhaustive but affords guidance on those known to be efficacious (Miles *et al* 2007) to optimise constipation management should the need arise. The safety and efficacy of these recommendations were underpinned by the literature review, BNF (2008) and PCF (2007).

Having completed extensive inquiry as to the efficacy of various laxatives the researcher considered the existing availability of laxatives to the patients. As the interview data had revealed that most patients had supplies of laxatives in their home and that these had rarely been taken appropriately it seemed an appropriate starting point. It is well recorded that laxatives work but they are the very ones that are often omitted and or reduced (Townsend *et al* 2003; Zeppetella 1999). The researcher raised this point at the next the MDT meeting where it was agreed that these existing supplies could be re-commenced if they formed part of the planned regimen provided expiry dates had not been exceeded. Therefore, recommendations for laxative use were initially based on the individual's existing regimen, whereby prescribed laxative medication was adjusted as advocated by the Crown Committee (DH 1998), provided its cessation had been due to the individual's perceived lack of efficacy as opposed to difficulties with the formulation.

Thereafter, patients were encouraged to select their laxatives. Laxative regimens were identified using a concordant approach, thus agreement based on the individuals' informed decision and preferences of formulation and frequency of use (Zeppetella 1999; Kennedy 2003). Patients' perseverance with agreed regimens may falter (Heath 2003) if they remain unconvinced of laxative efficacy or have negative experiences (Marinker and Shaw 2004) therefore, patient information and education was the instrument through which adherence was optimised as there is strong evidence that certain laxatives are efficacious provided they are taken consistently and at therapeutic doses. Regimens were not rigid: laxative choice, dose and efficacy fluctuated in individuals depending on other factors such as escalating

opioid dose. Self-titration formed part of the regimen in order to empower patients to make timely modifications to their dose depending on stool form and ease of defecation. Drug information and support was available 24-hours and reviewed during follow-up CMC consultations. There is evidence to support the benefits of this approach as it ensures consistent laxative use, thus its efficacy, and improves patients' concordance through the provision of contemporary drug information.

Benefits of giving information

Although some information is offered by HCPs most of the information on contraindications, side effects, interactions and dose is provided on written patient inserts provided within the drug's packet. This information is usually produced in minute typeface, unfamiliar wording and/or perplexing to individuals. Patients often consider such information discouraging and not beneficial in determining the balance between risks and benefits (Kennedy 2003). Therefore during the CMC patients were offered clear verbal and written instructions relating to their laxative regimens (Zeppetella 1999). Pertinent information was given to patients in a concerted effort to minimise ambiguity. For example, the researcher's advice relating to directions for laxative did not include 'regular' as individuals interpret this differently (Chapter 5). Similarly, 'as needed' was not used as constipation is insidious and patients may not be aware that they were becoming constipated. Patients were advised take their laxatives on a daily basis, whether they felt they need them or not and to regulate the dose based on stool form and ease of defecation. To ensure the timely identification of subsequent problems (for example bowel obstruction) patients were advised to report any changes to their bowel function and/or related symptoms (other than improvements in constipation) to the researcher or their primary HCP as soon as possible.

The accuracy of the information given is paramount. Dickinson and Raynor (2003) agree and propose that the ideal source of drug information is accurate, up-to-date and practically useful. In the CMC, for example, patients who found liquid formulation unpalatable were informed about the various ways of improving the flavour and/or consistency, similarly, alternative formulations (liquid to/from tablet) were offered where available. Kennedy (2003) and Dickinson and Raynor (2003) support the customisation and personalisation of information as there is a need to ensure patients are able to strike a balance between a treatment's beneficial and adverse effects, thus making an informed decision based on reliable, consistent and understandable information. To this end, those patients who expressed a desire to be 'weaned off' laxatives because they thought that they would become addicted or adversely affected were advised to the contrary. Furthermore it was explained to

patients that the use of laxatives was to counterbalance the effects of opioids and redress the imbalance caused by other drugs for example, analgesia. Such an approach is more likely to underpin the patient-clinician partnership and improve patient concordance (Kennedy 2003). Information about the side effects of laxatives was used to inform patients of actual and potential problems as this often reduces anxiety and/or misconceptions (Woolf *et al* 2005). For example, some patients may tolerate flatus whereas others may find it unacceptable, therefore, methods to alleviate flatus were explored and/or an alternative laxative identified. The patients were therefore forewarned of such possibilities and management advice proffered. Patients' fears and/or concerns were explored and advice on 'what to do' if the treatment was, or became, ineffective. In so doing the researcher fostered a concordant relationship between herself and the patients.

Reiterating in context: the 'explosive episode'

In preparation and anticipation of the effects of laxative regimens aimed at managing 'troublesome constipation' patients were advised that they might experience an 'explosive episode' of faeces which could induce, amongst other things, a degree of lethargy. The researcher used the term 'explosive episode' as this was how patients had described the event in the past. Patients were advised that such a motion was not uncommon but if it caused concern or anxiety, they should telephone the researcher or any member of the nursing/medical team using the 24-hour support telephone number. This offer of access and reassurance offered the patient a line of communication (Zeppetella 1999) and the researcher an opportunity to reinforce the process of continuing to take medications as prescribed.

In summary, drug information was available and imparted at the time of a consultation. The researcher ensured that it was accessible and consistent, high quality and contemporaneous (Elwyn *et al* 2003; Dickinson and Raynor 2003; Kennedy 2003) thus optimising the opportunity to improve patient concordance and create a therapeutic regimen to alleviate the individual's constipation. Information given was straightforward and uncomplicated using educational techniques and tools discussed later in this Chapter. Ultimately, patients were informed about the use and role of laxatives which enabled them to adopt a regimen that encompassed their prophylactic use of laxatives and the ability to titrate laxatives based on their stool form and frequency.

7.6 Sample identification and referrals

To attract potential participants, flyers and referral cards were placed on display boards and stands in strategically positioned areas. Two flyers were placed within the Unit inpatient ward and outpatients day centre, three in the adjacent cancer centre (clinic patients waiting areas), one in the outpatients department of a local hospital, one in an adjoining cancer resource and information centre and one at the hospital pharmacy. A letter outlining the CMC was sent to clinical nurse specialist and local community Macmillan nurses raising awareness of the CMC and affording them the opportunity to identify patients they deemed appropriate.

Over a 24-month period 44 patients were referred to the CMC. Thirty patients self-referred and 14 were referred by a HCP. Twenty-nine patients were recruited into this study and of the remaining 15, two developed tumour related bowel obstruction and five died prior to their initial appointment or were entering the terminal phase of their illness and therefore too unwell to attend. Three patients did not have a diagnosis of cancer and therefore did not meet the inclusion criteria and five were unable make the necessary travel arrangements. The following patient demographics and subsequent Chapter report on the CMC findings for the 29 patients included in this stage of the study.

7.6.1 Self-referral

Twenty-two patients self-referred, which supports the interview findings where respondents highlighted their perceived need for a dedicated CMC from which they would seek support. Whilst it is acknowledged that symptomatic patients are more likely to have responded than asymptomatic (Bassotti *et al* 2004) their eagerness reflects their desperation to be free from constipation.

“... I did mention it to (another day-care patient) that I was having trouble going and she said you helped her and that I should ask to see you.” (KV)

“.....actually I was eavesdropping onwho were talking about it. I get it (constipation) a lot and well, I knew they wouldn't mind so I laughed and said “can I join the club”.... Harry said you helped him and I thought well...” (RB)

Self-referral occurred in response to the flyers and as a result of word-of-mouth recommendation of HCPs, family members and other patients. Some patients advised others attending day clinics in the Unit of the existence and benefits that the CMC offered. This

initiated several more enquiries and self-referrals and introduced a form of snowballing of sample (Polit and Beck 2008) where one patient identified others to participate in the CMC.

7.6.2 Referral by an HCP

Seven patients were referred to the CMC by a HCP and of these four were from colleagues practising within the Unit. These HCPs acknowledged that the management of the patients' constipation had 'defeated them'. As previously highlighted, concerns have been identified with regard to nursing and medical teams' knowledge and suboptimal management of constipation, therefore, within the action research paradigm it was encouraging that the practitioners became ready participants in the research, made appropriate referrals to the CMC and participated in constipation management in order to optimise patient outcomes and their own learning. In addition to these referrals from the Unit three referrals were received from the community teams (GP, MacMillan and district nurses). The HCPs making these referrals had in most cases been those who had contributed to the focus groups or who had a colleague who had done so.

7.6.3 Endorsement from doctors

In the instance when referrals were not received from a doctor (for example self-referral or nurse), a courtesy telephone call was made to obtain the doctor's/consultant's support and ensure there were no known contra indication to the individual's recruitment, such as known or suspected bowel obstruction. For those without an oncologist and/or whose care had been superseded by another specialty, such as palliative care services, the patient's GP was contacted in order to:

- Open up lines of communication and rapport building (especially to GPs who may not have known the researcher or her role)
- Raise awareness of the aims and objectives of the CMC.
- Inform of the planned interventions, thus preventing any diversity in practice between doctor and researcher with regards to the patient's constipation management.
- Establish patient's cancer diagnosis and stage, thus giving insight into those with or predisposed to tumour related bowel obstruction.
- Identify any objections doctors may have to the research, especially the planned interventions and/or patient's involvement.
- Discuss any other issues/concerns the doctor may have.

None of the oncologists or GPs objected to their patients being recruited into the study. Following medical approval, patients received a copy of the patient information sheet. In the event no information was received from medical members that resulted in any patient being ineligible to attend the CMC. In contrast, doctors welcomed the fact that the researcher was prepared to manage the patients' constipation and in some cases referrals were accompanied by wishes of 'good luck'. The intonation in these comments, usually from oncologists, was rather jovial in manner and from this the researcher deduced that they deemed the intervention either not of importance and/or not likely to succeed. The rationales offered were usually based in the problematic nature of the patient and/or that they were unlikely to comply with their laxatives or medications generally. These comments were generally related directly to the patient being discussed at the time. To give a flavour of the comments made some were jotted down in the filed notes and are presented below:

"She's not very compliant with her medications." (Oncologist 1)

*"He is under the psychologist and may be a very difficult patient."
(Oncologist 2)*

"She is very difficult. She has seen everyone and plays one off against the other, she won't take her laxatives." "Happy for you to have a go ...if you think you can help." (Oncologist 3)

"I'd be delighted if you could help." (GP 1)

These comments appear to indicate that the oncologists and the GP considered that the patients were in some way deviant as they were non-compliant with their laxative regimen. Although the non-compliance labeling is evident in the literature review (Heath 2003; Elwyn *et al* 2003; Weiss and Britten 2003; Marinker and Shaw 2004) and focus groups (Chapter 6) the researcher draws attention to the fact that oncologists were not specifically asked about their patients' behaviours nor what may have contributed to their constipation. The narratives were proffered voluntarily and in a defensive manner, perhaps because they had knowingly failed in their duty of care. Evidentially both constipation and non-compliance had been identified but not action taken, possibly due to limited resources or a lack of knowledge, skills and/or poor attitudes to constipation and its management (Zernike and Henderson 1999; White 1995; Richmond 2003; Richmond and Wright, 2004; Moore *et al* 1996).

7.7 Recruitment

The clinic was successful in attracting an appropriate sample. All patients recruited had a cancer diagnosis and had experienced constipation during their disease progression. All presented with varying degrees of constipation which they had previously reported to one or more of their HCPs and in some cases this consisted of their GP, Macmillan nurse, district nurse and oncologist. Three patients had a recent admission via their local Accident and Emergency department for treatment of constipation and, following discharge, one man was enduring breakthrough pain in preference to risking another episode of constipation (example Appendix 20) however, this strategy proved unsuccessful. In all three cases constipation represented and patients self-referred to the CMC.

It was not always possible to offer consultations to patients within 48-hours of their request. Some patients sought interim advice from the researcher, however, it was reiterated that the advice given should not replace their CMC attendance and in support of this need the clinic's aims and objectives were conveyed. The resultant conversations established that none of the patients were taking laxatives on a daily basis, therefore provisional recommendations were made on an individual basis, for example on stool form, frequency, diagnosis and current laxative regimen. The interim advice and the clinic's aims and objectives were welcomed by patients who reported being optimistic their constipation may be relieved. All 29 patients met the inclusion criteria of the study.

7.7.1 Sample demographics

The sample that was recruited to the CMC comprised 20 females and 9 males were with an average age 66 years (range 29-84 years). Cancer diagnosis, disease stage, co-morbidities and type of constipation varied. Data in some cases were incomplete and overall the MDT considered that other than primary cancer diagnosis, based on the WHO International Classification of Diseases (1989) malignant categories, further analysis was not required as these would not inform the study's findings further, therefore, primary diagnoses are: Respiratory (7), Breast (6), Female genital organs (5), Male genital organs (4), Digestive organs (4), Central nervous system (1), Urinary tract (1) and Head & Neck (1).

7.7.2 Initial contact

The researcher considered it important to develop rapport with the patients prior to attending the CMC and used the same approach that had proved successful during the interview stage of the study. Establishing a good rapport has several potential advantages including making

patients feel comfortable about their frankness during the consultation and the belief that the discussion itself was therapeutic, all of which are highlighted and debated in Chapters 4 and 5. Therefore, on initial contact (telephone or in person) the researcher introduced herself and gave a brief overview of the study's aims and objectives and outlined the CMC's main components. Patients were welcomed to the clinic and advised that if they did not wish to consent to take part in the study would not disadvantage their consultation in any way and that they could continue to attend the CMC. Patients were informed that results could not be guaranteed but based on a patient-researcher partnership and collaborative working it may be possible to modify existing strategies and empower them to become more proactive in managing their constipation, the end result aiming to be alleviation of their constipation.

7.8 Data collection

The main data collection methods, expounded in the generic methods Chapter, were also employed during the data collection process of the CMC. Observation and interviewing skills and the recording of field notes honed during the interview and focus group stages of the study formed the cornerstone of the CMC data collection. The rationales for interviewing, observation and the maintenance of field notes to achieve effective data collection have been presented in Chapter 4 so are not revisited here. However, variants of these or new strategies that were used are presented in the following sections. One of these new strategies was the reviewing of medical notes and development of a framework to form the basis of and guide the consultative interviews that comprised the interface with the patients. Similarly, central to data collection in the CMC, was an understanding of the complex and individual nature of constipation and its management in patients with cancer which was previously highlighted in Chapters 2, 4, 5 and 6. Therefore to generate meaningful data in the CMC it was decided that individual outcome measures needed to be established to establish improvement of bowel function. The methods of achieving these are also included in this section.

7.8.1 Medical notes

As a starting point and a method peculiar to this stage, the researcher decided to review any existing medical notes. In the event it was not possible to access GP or medical notes from other hospitals but those that were available locally (the Unit and the adjacent cancer centre) were scanned. The medical notes proved to be useful in providing initial and then supplementary data regarding the individual's social and medical history which otherwise may have been time consuming to elicit from patients and, in most cases, captured events

spanning several years, the contents of which may have not been recalled by the patients or could have caused great distress.

It was noted that, in cases where constipation had been recorded in the medical notes, the information was generally inadequate, vague and void of assessment data or treatment plans, thus reflecting under identification and/or under-reporting. From this evidence it appeared that local practice reflected the findings of previous studies in relation to the poor identification, assessment and reporting of constipation (Moore *et al* 1996; Glare and Lickiss 1992; McMillan 2002; McMillan and Tittle 1995).

7.8.2 The consultative-interview

Due to patients' frankness and openness during the interviews (Chapter 5), the researcher adopted an approach that was influenced by the semi-structured interview methods (Chapter 4), thus resulting in a consultative-interview. The aim of this process was to capture as much salient information as possible which was subsequently used to inform constipation management strategies and in an attempt to optimise concordance (Usherwood 1999; Collins *et al* 2006). Patients were advised to allow approximately one hour for the initial consultation.

7.8.3 Allowing time to elicit the patients' perspectives

Initial consultation

Each patient's initial consultation lasted approximately one hour and was sufficient in order to cover all the planned aspects/components. Allowing an appropriate time to listen to and for patients to respond was an important factor as it ensured that those with impaired hearing, sight and/or cognitive function were not rushed or disadvantaged in any way. This proved successful for patients as they considered they had been given a full opportunity to expose their concerns and, additionally, the researcher had the opportunity to collect full and rich data on which to base the findings of the study.

Follow-up consultations

Follow-up appointments kept to a similar format but excluded basic demographic data collection and previous medical history. Follow-up appointments lasted between 10-35 minutes, the focus predominantly that of re-assessment, laxative regimens and their titration,

patient education and concordance. The scheduling of the follow-up appointments was kept deliberately flexible as it was common for patients to be late for their appointments due other confounding factors such as feeling unwell, underestimating their immobility, being reliant on others for transport and when other inpatients' medical treatments took priority. Thus, appointments were often rescheduled for later in the day of kept by telephone consultation to evaluate patient outcomes and suggest alternative actions.

When constipation had been alleviated and the patients were content to maintain their regimen, the follow-up appointment lasted no more than 20 minutes. For patients attending the Unit's day centre appointments were made at their request. In the interim period informal monitoring was assessed by day centre nursing staff who periodically asked patients if they required a CMC follow-up. For other patients the CMC contact number and Unit's 24-hours support line telephone numbers were given and patients advised that they could make contact whenever necessary. Once severe constipation had been resolved and self-titration established few patients required ongoing CMC appointments.

7.9 The CMC framework

Although the study is essentially qualitative in nature, viewing constipation from the individual's perspective, the researcher considered it necessary to impose some structure on the consultations to ensure that all the planned components were included. It was also imperative that a starting point was established against which any improvement, or otherwise could be assessed. Therefore central to the planning stage of the CMC the researcher set about developing a framework as a guide. In operation it proved to be invaluable to the researcher, during CMC consultations also as a point of reference to HCP colleagues who generally operated within a different research paradigm. The framework also provided, to HCPs, a source of transparency of the CMC process and consultations.

In the clinic setting the researcher considered it necessary to be as succinct and comprehensive as possible in capturing base data especially those to be used as the particular and personal outcome measures for each patient. To facilitate this, a draft data form was created. However, during the form's creation and piloting it became evident that the resultant seven page document was too lengthy and complex which distracted from one of the key components of the CMC, that of patient communication. Therefore, significant points were extrapolated from the form, categorised into five key components to produce the resultant CMC's framework (Figure 7). Note taking was utilised (as an alternative to the proposed

data pro forma) and recorded in the field notes to detail salient points throughout the appointment.

The CMC comprised five major components: history taking, physical examination, assessment, patient education and concordance. These components were loosely structured, that is, all stages other than physical examination were included but not necessarily in a rigid format in order to encourage patients to articulate their account of events, experiences, beliefs and concerns. A physical examination was performed only when necessary and its need based on a joint decision between patient and researcher. The rationale for the choice of the five components is explored in further detail in the following paragraphs.

7.9.1 History taking

The researcher considered that history taking was crucial in order to identify patients' misconceptions, educational needs and to inform management strategies. Without this data the researcher would not have had sufficient information to inform any educational needs or identify appropriate plans and/or management strategies, and thus unable to improve concordance and/or alleviate constipation. For example, given the likelihood that over-flow diarrhoea might co-present with constipation was important to inform patients about the detrimental use of anti-diarrhoea drugs in these circumstances. The history taking primarily involved a conversation with the aim of both rapport building and eliciting information. Open and closed questions were asked along with prompts and probes where necessary as reflected in Methods, Chapter 4.

As *aide-mémoire* the researcher made brief notes on significant points arising. For example, not being able to tolerate fluids and the practice of taking laxatives 'as needed'. Patients were asked to expand on key points such as using laxatives 'as needed' in order to explore exactly when and under what circumstances they identified a 'need'. Similarly, a report implying that laxatives were being 'taken all the time' needed clarification as the statement is ambiguous. Even if the point raised by patients seemed irrelevant to the researcher, exploring these was important in order to overcome any reticence derived from previous HCPs' negativity. For example, feeling that they were making a fuss and perhaps constipation was not 'that important'.

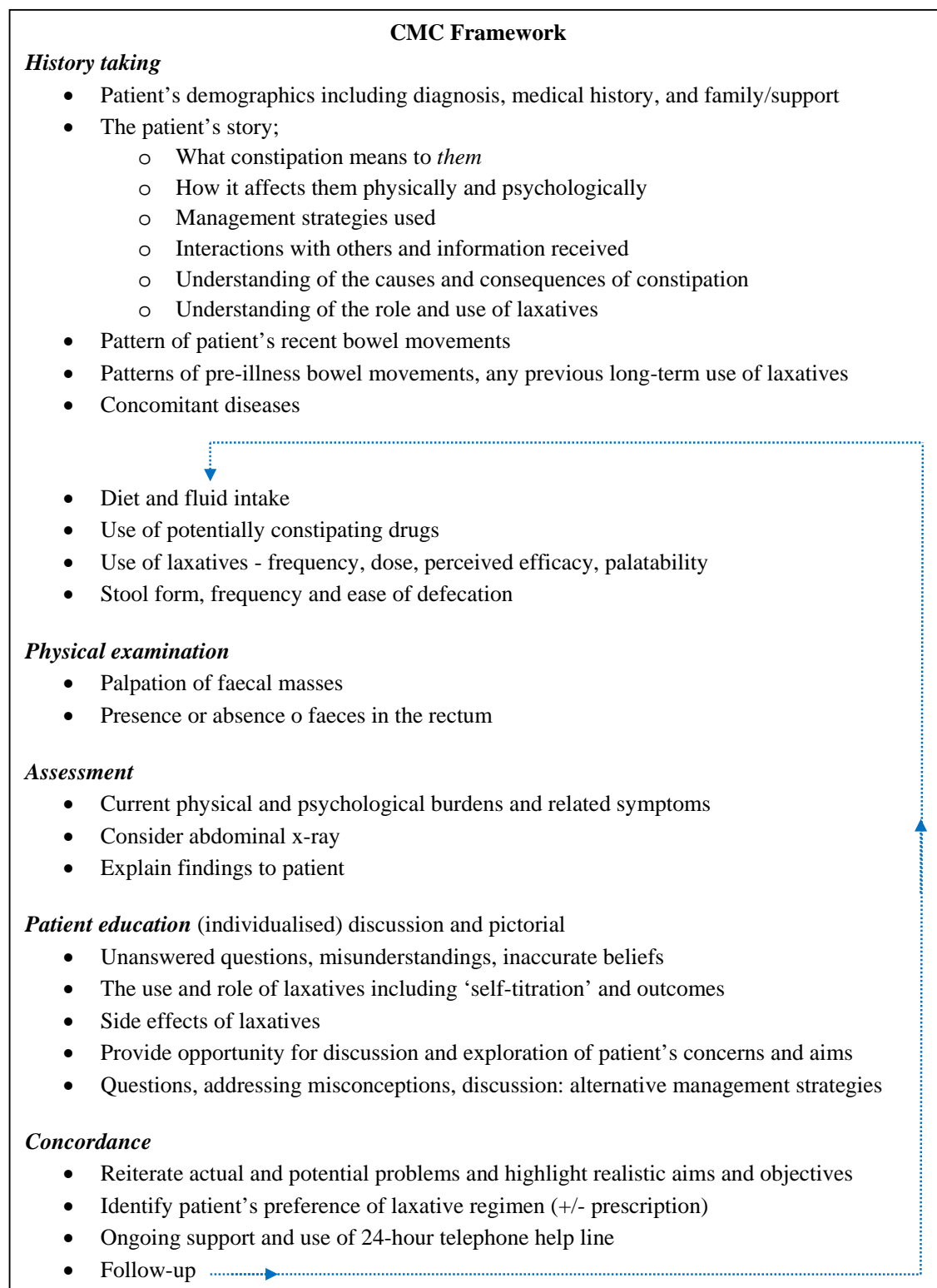


Figure 7 – The Constipation Management Clinic framework

As highlighted in the interviews (Chapter 5) history taking was viewed by the researcher as an important element of the interaction as it implicitly proffered support, reassurance and displayed interest in the patients' constipation and related problems. In some cases when patients asked direct questions requiring a succinct response these were answered immediately, however, when a more detailed explanation was required, this was noted and ensured that all points were covered. Specific CMC notes were recorded as the personal outcome measures for each patient.

7.9.2 Defining constipation - the individual's interpretation

It is noted in the literature reviewed for the study that frequency of defecation does not necessarily correlate with a diagnosis of constipation or indicate its severity (Ashraf *et al* 1996; MeReC 1994; Daisy *et al* 2002; Drossman *et al* 1982; Manning *et al* 1976). Therefore, the consultative-interview encompassed a fact-finding element to elicit the patient's experiences, perceptions and definitions of what constipation means to them. Patients were advised that there is no single definition of constipation and that it was their beliefs, perceptions and experiences that were of relevance during the initial part of the consultation. Thereafter, patients were encouraged to state the signs and symptoms which they contributed to their constipation. Following this the researcher asked specific questions based on the literature review (Table 2) to ensure any signs/symptoms were collected that may have otherwise been forgotten by the patient. The Bristol Stool Form Scale (Appendix 1) was used to obtain objective data thus giving an indication of its form at varying stages. The process worked well and often signs and symptoms identified were used and encompassed in the individuals' outcome measures. The researcher made notes and referred to these later during the CMC and/or in the post-CMC letter to HCPs.

7.9.3 Patients' drug use

During each patient's first CMC consultation the researcher made a record of all the drugs individuals reported using including any that they had taken in the past. These data were supplemented with information from the medical notes. Whilst the researcher was aware that these data sources, verbal and medical notes, were unlikely to yield a comprehensive record (Chapters 2 and 5), it was imperative to identify any issues of concern that needed redressing for example, difficulty taking formulations, intolerable side effects of laxatives and omitting analgesia to prevent constipation.

As highlighted in Chapter 5, Interview findings, all patients had some difficulty providing laxative information. The researcher proposed that laxative examples could be obtained for the sole purpose of aiding patients' recall of those used and reasons why they were discontinued. The MDT concurred and thereafter samples were requested (Appendix 21) and obtained with the agreement of and from the senior pharmacist in the Unit. The researcher purchased supplementary laxatives from a local chemist as often the packaging differs from hospital supplies. In some cases it was the packaging that patients recognised rather than the product itself. To supplement the laxative data a selection of examples were subsequently retrieved from a box conveniently situated in the consulting room. In the event these proved to be greatly successful for patients and the researcher and led to the gathering of useful data.

7.9.4 Assessment of present bowel status

Identifying patients' current bowel status and management strategies provided base data that informed outcome measures and acted as a check to ensure that there was not an advancement of their cancer or any other condition that required urgent medical intervention: for example, in patients presenting with severe constipation the medical team needed to eliminate the possibility of bowel obstruction. In such circumstances the patients would be discharged from the clinic if found to be tumour related which further tests were completed. In addition the physical examination provided objective data to accompany subjective reports of severe constipation and in so doing; outcome measures.

Therefore in the event specific information about current bowel function were not forthcoming from patients, perhaps because they had forgotten, open and closed questions would be asked based on the Bristol Stool Form Scale and the Rome II Criteria. For example, pain during defecation, faecal incontinence and unpleasant taste in the mouth. Information that may be deemed personal and/or intrusive was dealt with sensitively to avoid patient embarrassment. In such cases the researcher proffered information in the context as management strategies and experiences of other patients, thus providing the opportunity for patients to simply listen and form their own conclusions as to whether the information was useful or not. For example, patients who suffered with faecal incontinence and endured anal soreness due to frequent toileting find that moist sensitive wipes alleviate this discomfort. Thus, in the knowledge that anal incontinence is not uncommon, (as highlighted in Chapters 2 and 5), patients can discretely choose whether or not to articulate their concerns and/or related experiences.

7.9.5 Patient education and concordance with regimens

Patient education is an effective method of improving individuals' understanding and ultimately concordance with medication and improving outcomes (Légaré *et al* 2008; Elwyn *et al* 1999; Towle and Godolphin 1999). Elwyn *et al* (2003) contend that doctors do not commonly investigate patients' understanding of a proposed treatment or deal with any concerns in relation to a drug and when they do encourage patients to ask questions, patients rarely do. Doctors rarely assess the patient's ability to understand and follow a treatment plan, even though they report to do this in approximately 50% of their consultations (Cox *et al* 2002). Therefore to optimise the process, information was customised to the needs of individuals (Cox *et al* 2002; Kennedy 2003) based on their history and assessment. Access to further information was provided and patients were helped to interpret the data (Kennedy 2003) through discussion, explanation and the use of tools.

Lack of patient information and a poor understanding of the causes, consequences and management of constipation contribute to its development (Chapters 2, 5 and 6). Emergent themes from the former informed the patient education component in establishing some of the elements requiring further exploration on an individualised basis. For example, it was not necessary to categorically define constipation other than to say that such a definition does not exist, as in contrast, the individual's characterisation of the condition was more important. The researcher proposed that, for example, an enhanced understanding of the workings of a normal bowel, the transition to dysfunction, the detrimental effects of opioids and the role and use of laxatives may improve patients' understanding about the causes and consequences of *their* constipation and empower them to make informed decisions on management strategies. Therefore, these elements were included in the educational component of the CMC.

Patient education focused on individuals needs. All explanations avoided the use of medical/nursing terminology as this is generally not used in day-to-day conversation by laypeople and may lead to confusion. For example, 'transit time', 'peristalsis', 'prophylactic/ally' and 'gastrointestinal tract' are not commonly used outside the health care environment. Patients with poor knowledge about the cause of their constipation were advised about the contributory factors that may have predisposed them to constipation. In most cases this included opioid use, other drugs, poor mobility and reduced fluid intake. Supporting explanations were given using commonly used words and phrases in a step-by step approach. For example, 'transit time' was covered when describing the time it take for food to be digested once eaten and subsequently passed as faecal matter and 'prophylactic'

was described as the need to 'take laxatives everyday to counteract the effects of...' for example, opioids.

7.9.6 Educational tools

As identified in Chapter 2 and postulated in Chapters 5 and 6, education was considered to be crucial in optimising concordance. To assist the process three documents were obtained (Appendices 1, 22 and 23) and one created by the researcher, the body chart, (Appendix 24) and used as educational tools. These proved useful as they simplified information that may otherwise have been incomprehensible to patients. For example, the Bristol Stool Form Scale has been validated as an objective tool for assessing stool form rather than relying on individuals' subjective descriptors as these may vary (Lewis and Heaton 1997). The body chart was useful in aiding the researcher's explanation of the journey and transit time of food, faeces and laxatives was aided by the use of the body chart as graphically it was possible to demonstrate why the latter often takes longer than expected before results are evident. The 'correct positioning' tool provided practical help on easing defecation and the 'Human body and constipation' chart visually shows how faecal soiling occurs.

Within the philosophy of action research and its cycle, it was envisaged that if further educational tools and aids were required then these could be developed or obtained and used as required for all patients.

7.9.7 Specific information to impart

Based on the finding thus far (Chapters 2, 5 and 6), it is likely that patients' clarification, education and/or further information on the following:

1. Defining constipation
2. The insidious nature of constipation
3. Normal bowel function
4. Factors impeding normal function
5. Causes of constipation
6. Consequences of constipation
7. The detrimental effects of drugs
8. Frequency of defecation – daily is not necessary
9. Stool form – soft and easy to pass is more important than frequency
10. Defining 'regularly'
11. What does 'as required' relate to
12. The concept of prophylactic
13. The use and role of laxatives

14. Side effects of laxatives
15. Titrating laxatives
16. Making laxatives more palatable
17. The use of moist wipes
18. What to expect when treating an episode of constipation, especially severe
19. Over-flow diarrhoea
20. Who to contact for further advice and support
21. Alleviating constipation may take several days to achieve
22. Preparing for the 'explosive episode'

This list is not exhaustive but gives an indication of the extent of the information gathered in preparation for the CMC. Information was proffered to patients on individualised need and to varying degrees. For example, making laxatives more tolerable only applied to those taking liquid formulations whereas all patients were given a 24-hour contact number.

The majority of the information given was evidence based and is reflected in the literature review (Chapter 2). For example, the adverse effect of laxatives and guidance on commonly used doses, time to effect and additional comments and recommendations for use (Appendix 2) specifically for patients with cancer. In contrast, some information was based on the researcher's nursing experience and/or reports from patients about what they found useful and effective strategies, such as the use of moist sensitive wipes. The following examples show the depth of planning and information acquired by the researcher and MDT in preparation for the CMC.

Side effects of laxatives

Knowledge to the potential adverse events and side effects of laxatives was important in limiting the number of their occurrence and in optimising concordance. The side effects of laxatives occur to varying degrees in individuals. In relation to laxatives recommended during the CMC, this section outlines the most common side effects and, for reasons that will be established, alludes to those seen infrequently. Information about the side effects of laxatives was used to inform patients of actual and potential problems as this often reduces anxiety and/or misconceptions (Woolf *et al* 2005). For example, some patients may tolerate flatus whereas others may find it unacceptable, therefore, methods to alleviate flatus were explored and/or an alternative laxative offered. Patients who disliked the liquid formulations were given advice on how to make the product more palatable.

It was planned that directions for laxative use would not include ‘regular’ as individuals, (as highlighted in Chapter 5), interpret this differently. Similarly, ‘as needed’ would not be used as constipation is insidious and patients may not have been aware that they were becoming constipated. Patients were advised to take their laxatives on a daily basis, whether they thought them necessary or not, and to regulate the dose based on stool form and ease of defecation. In the event of any adverse or unforeseen effects and as a precaution, patients were asked to report any subsequent changes to their bowel function, other than improvements in constipation, to the researcher or their primary HCP (i.e. GP, Macmillan Nurse) as soon as possible.

Patients will be informed about the use and role of laxatives to enable them to adopt a regimen that encompasses both the prophylactic use of laxatives and the ability to titrate laxatives based on their stool form and frequency. Although some information is offered by HCPs most of the information on contraindications, side effects, interactions and dose is provided on written patient inserts provided within the drug’s packet and is usually produced in minute typeface and what could for some be incomprehensible wording. Patients often consider such information discouraging and not beneficial in determining the balance between risks and benefits (Kennedy 2003). The CMC aimed to redress these through patient education and information giving based on the individuals needs. Patients lack of information regarding their condition and the importance of treatment greatly contributes to poor compliance or concordance. Kennedy (2003) purports that informed partnership decision making by patients and doctors to achieve concordance concerning treatment, requires the timely availability of reliable and understandable information.

7.10 Outcome measures

As indicated above the framework created used outcomes measures to establish improvements in bowel function. During the interviews (Chapter 5) respondents reported randomly on their bowel function, constipation, definition and accompanying symptoms over the course of the interview. In the CMC this information was needed as baseline data for setting realistic patient-focused goals and as outcome measures for subsequent interventions. These data were obtained during the initial history taking component of the CMC. Patients were asked open and closed questions (Chapter 4) in relation to stool form and frequency and what was normal for them prior to their cancer diagnosis and/or development of constipation. This gave the researcher insight into what the individuals’ exceptions (Bassotti *et al* 2004) may be and gave an account of the individuals’ normal pattern. Given the questionable reliability or dependability of self-reported historical

(Møller *et al* 1997; Manning *et al* 1976; Heaton *et al* 1992) which in all cases related to events at least three months earlier, the MDT were of the opinion that this snap-shot would suffice as the most pressing issues related to individuals' current episode of constipation. Therefore, patients were asked how constipation currently affected them and notes were taken, for example, hard stools, bowels not opened for four days and the degree of straining. These descriptors became the individuals' measures that were compared at subsequent appointments. Therefore, primary outcome measures use were identified by and individualised to patients based on self-reports (Maestri-Banks and Burns 1996).

Few prompts were used at this stage in order to allow patients time to think and contemplate their responses, thereafter prompts (as discussed in Chapter 4) and questions were asked to obtain supplementary data using the Bristol Stool Form Scale (Lewis and Heaton 1997) and based on the Rome II Criteria (Drossman *et al* 2000) (Chapter 2).

Another outcome measure was the cessation of digital removal of faeces in patients who volunteered the information. Secondary outcome measures also related to laxative regimen by comparing and contrasting this as a baseline with that identified during and after constipation had been alleviated. Patients' ability to self-titrate their laxatives was identified as a secondary outcome measure in those attempting to achieve this.

7.11 Laxative regimen recommendations

Laxative regimens were identified using a concordant approach, thus agreement based on the individuals' informed decision and preference of formulation and frequency of use (Zeppetella 1999; Kennedy 2003). Patients' perseverance with agreed regimens might have faltered (Heath 2003) if they remained unconvinced of laxative efficacy or continued to have negative experiences (Marinker and Shaw 2004) thus, patient education was used as the instrument through which adherence was optimised as there strong evidence exists that certain laxatives are efficacious. Laxative recommendations included the use of laculose, senna, lactulose, co-danthrusate and polyethylene glycol. This list is not exhaustive but affords guidance on efficacious laxatives (Miles *et al* 2007) to optimise constipation management should the need arise.

From reviewing the literature, the researcher discovered that the prevention of constipation requires consistent and prophylactic treatment and that not all laxatives are appropriate to use in patients with cancer. For example, despite the evidence to support the efficacy of psyllium in the treatment of chronic constipation, (Ramkumar and Rao 2005) bulk-forming

laxatives should not be used in patients who are: debilitated, have advanced disease and/or who are unable to drink the required amount of water with the administered dose (Tamayo 2004). This frequently includes the elderly and those who are dehydrated (Bosshard *et al* 2004; Ginsberg *et al* 2007). In the absence of sufficient fluids the osmotic nature of psyllium exacerbates dehydration and constipation. Therefore the use of laxatives containing psyllium was avoided in the CMC.

Patients presenting with troublesome/severe constipation were commenced on an appropriate laxative regimen. Regimens were selected based on patients' preferences (laxative, dose, and formulation), guided by the researcher as necessary. In most cases increasing current laxative dose (and/or those most recently prescribed) was encouraged as their lack of efficacy was alleged by patients but not proven. Additional guidance on how to make these regimens more palatable was offered when dislike deterred their use. In contrast however, alternative laxatives were prescribed when side effects were deemed unacceptable.

7.11.1 Drug information

Dickinson and Raynor (2003) propose that the ideal source of drug information is accurate, up-to-date and practically useful. Kennedy (2003) and Dickinson and Raynor (2003) support the customisation and personalisation of information and argue that there is a need to ensure patients are able to strike a balance between a treatment's beneficial and adverse effects, together with associated reliable and consistent sources of advice and information. In the CMC drug information was made available and offered at the time of a consultation, thus accessible and consistent high quality information (Elwyn *et al* 2003; Dickinson and Raynor 2003). Ultimately, concordance was optimised, drug efficacy established and constipation alleviated.

Drug information afforded to patients was obtained from a variety of sources. These included; extrapolation during the literature review (Chapter 2), the most recent versions of the BNF (2008) and FCP (2007), directly from the drug's manufacture and during discussions with the medical team. Information given to patients was up-to-date and conveyed to patients in a simple and uncomplicated manner using the aforementioned educational techniques and tools.

7.11.2 Titration and escalating dose

During the CMC the need to titrate, use rescue laxatives and/or use higher than normal doses was supported by the research evidence presented in Chapter 2 (Ramkumar and Rao 2005; Tramonte *et al* 1997; Petticrew *et al* 1997; Miles *et al* 2007; Tamayo 2004) and is supported by the periodical BNF (2008) and Palliative Care Formulary (2007). However, given that most patients' preferences to take as 'little as possible' if at all (Britten *et al* 2002; Britten 1996; Conrad 1985; Donovan and Blake 1992; Morgan 1996; Rogers *et al* 1998; Britten 1994) the researcher postulated that increasing and escalating laxative dose may have resulted in patients being reluctant to adhere to the recommendations. The latter did not happen as in most cases successful prophylactic regimens were within normal ranges (BNF 2008) and when treating severe constipation, the recommendations to use a high laxative dose was proffered to patients with information, education, support and advice.

Regimens were not rigid. Laxative choice, dose and efficacy fluctuated in individuals depending on other factors such as escalating opioid dose. Self-titration formed part of the regimen in order to empower patients to make timely modifications to their dose depending on stool form and frequency. Drug information and support was made available to patients and consistently reviewed during follow-up CMC consultations. There is evidence to support the use of this approach as it ensures consistent laxative use, thus its efficacy, and patient concordance, both of which can be optimised through the provision of contemporary drug information.

7.11.3 Reiterating in context: preparing for an 'explosive episode'

In preparation and anticipation of the outcomes of the laxative regimens aimed at managing 'troublesome constipation' patients were advised that they might experience an 'explosive episode' of faeces which could induce, amongst other things, a degree of lethargy. The researcher used the term 'explosive episode' as this was how patients had described the event in the past. Patients were advised that such an event was not uncommon but if it caused concern or anxiety, they could telephone the researcher or any member of the nursing/medical team using the 24-hour support telephone number.

7.12 Continuity of care post CMC consultation

In line with normal clinical practice a letter outlining each patient's CMC appointment would be sent to HCPs involved in their care. This channel of communication ensured continuity of care thus preventing diversity of practice (National Institute of Clinical Excellence 2004),

provided a point of contact for HCPs requiring further information and raised their awareness of the clinic and profound impact constipation has on patients. Patients would be followed-up 7-10 days after their initial clinic appointment in the knowledge that, should they require any further information and/or support in the interim period they could telephone the Unit's well established 24-hour telephone advice line number, which encompasses out-of-hours⁵ should the need arise.

The sharing of these experiences and feedback to HCPs was a central component of this action research study and considered a method of dissemination both within the Unit and externally to the GPs and community teams supporting the patients in the locality. To facilitate this process the researcher forwarded a letter not only to the GP but also to the patient's consultant and other known HCPs such as Macmillan and district nurse and other agencies involved in the individual's care. The letter aimed to give an overview of the individual and their presenting problems and afford the reader an insight into the patient's causes and consequences of their constipation and the plans underway to alleviate the condition. The aim was to ensure continuity of care and afford the reader further support with managing the individuals constipation if required.

Patients were advised that follow-up should occur within 7-10 days, or sooner should they have any concerns or worsening symptoms. Patients' preferences prevailed in follow-up format, which was either to return to the Unit for another appointment or be follow-up by telephone either at their initiation or by the researcher. The latter option was facilitated as, in the researcher's experience, would lessen the burden on this vulnerable group, thus preventing further distress. For patients attending the day care unit, follow-up coincided with these attendance dates.

7.13 Evaluation of the CMC framework

The CMC framework worked well as it afforded a structure within which comprehensive and timely data were obtained, assessments carried out and in which patient education prevailed. The cyclical nature ensured that subsequent consultations were also comprehensive, that information was re-evaluated and that the educational element could be refined or reiterated as necessary. The CMC afforded patients with an individualised assessment, advice and information together with continuity of care to optimise outcomes. The consultative-interview proved effective in providing rich data on constipation management strategies,

⁵ Monday-Friday 17:00-08:00 hrs, all day weekends and Bank holidays.

related concerns and misconceptions which were then compared and contrasted with contemporary evidence-based best practices, especially the efficacy of laxatives and improved patient outcomes through concordance.

The consultation was a consultative-interview in which patients articulated their experiences and concerns relating to their constipation history. In contrast to the findings in Chapters 2, 5 and 6, patients responded positively to the opportunity to explore their multifaceted problems with constipation and keenly engaged in all components of the framework. Foremost to their keenness was an acknowledgment that their plight had been acknowledged, they were being 'listened to' and thus appeared open and honest regarding their management strategies, an outcome attributed to the interview process and its techniques. None of the patients reported, or appeared, distressed by the disclosure of sensitive information which was possibly due to the nature and context in which the consultation occurred and the fact that there were no time constraints. All patients described the physical and psychological burdens that they believed were the result of their constipation.

7.14 Summary

This Chapter has presented the methods, preparation processes, the development and implementation of the CMC. The collaborative MDT involvement was apparent throughout and afforded the CMC and its patients a more holistic and comprehensive approach to their constipation management than previously encountered. The rationale for the CMC as a natural progression of the study was based on the evidence presented in Chapters 2, 5 and 6. Plans, aims and objectives were formalised and establishment and the implementation of the CMC ensued, including the extensive planning which was undertaken and included the widening of peer support and encouraging HCPs be involved in the study.

Data collection that were planned and conducted proved to be useful in establishing the individual's current medical status, their support mechanisms, the identification of actual and/or potential problems, such as poor dexterity, anxieties and practical difficulties with clinic attendance all of which required addressing. In addition, bowel habit data were collected despite the reported difficulties in assessment (Chapter 2) and the questionable validity and reliability of self-reported bowel function (Manning *et al* 1976), as the MDT considered these to be appropriate outcome measures.

The rationale for the identified outcome measures is established along with justification of their use in light of the questionable validity of self-reported constipation. These data were

supplemented by objective data thus confirming patients' subjective reports, the ultimate aim of which was to apply a sense of validation to the data and outcomes.

The preparation of the researcher to lead the CMC as an effective and safe practitioner has also been highlighted. This facilitated the development of enhanced knowledge and skills to ensure that patients' needs could be met, problems identified and prompt action taken. The parameters of sample identification and referral have been exposed along with data collection and outcome measures. Some of the problems relating to constipation, such as its lack of definition, have been discussed in order to explain why it is not always possible, nor necessary, to have these precisely identified. Being a qualitative study, the patients' points of view are of more relevance to this research and are presented in detail in Chapter 8.

The CMC framework has been presented as its development culminated from the research findings thus far and contributions from the MDT. The application of the framework was underpinned by previously used methods (Chapter 4) that proved effective in obtaining in-depth meaningful data. These included the 'consultative-interview' based on interviewing skills and techniques and the recording of field notes which facilitated a comprehensive account of the individuals' history and current bowel status. The importance of patient education and information has been discussed along with the need for these to be appropriate and contemporary in order to take full advantage of their potential benefits. Additional methods used specifically for the CMC included the use of charts and laxative examples as part of the diagnostic and educational processes have also been explained. Visual tools were used to aid and simplify the educational component as some of the information may otherwise be new and or cause confusion as for example, it could not be assumed that patients had an accurate mental image of the anatomy and physiology of the body. The planning processes, informed by the interview stage, pertaining to possible problems that might arise due to ambiguity, subjectivity, lack of definition and/or patients' poor understanding and knowledge are discussed to illustrate some of the detail of preparation prior to the CMC.

In the event, laxative regimens were derived using a concordant approach and based on the individual being fully informed about the actual and potential consequences of their use and non-use, along with up-to-date drug information such as potential side effects. This concordant approach enabled patients to make informed decisions about laxative use and self-titrating regimens. The ability to self-titrate laxatives was underpinned by the information given to patients relating to stool form and frequency and planning for outcomes, thus reiterating in context. The latter was important in order to prevent patients

from making inaccurate assumptions and subsequently taking inappropriate actions such as ceasing laxatives based on their misdiagnosis of diarrhoea. Follow-up consultations provided continuity of care and ensured that patients' constipation and its management were maintained. As death approaches the causes and consequences of constipation might change and management strategies will likely need modifying. For example, although constipation may have been resolved and prevented for a period of time as a result of their CMC attendance, the subsequent development of tumor related bowel obstruction is likely to occur in some patients.

The findings of the CMC are presented in Chapter 8. The process of dissemination appears at the latter part of Chapter 8 as this occurred concurrently throughout this research and became more prolific, meaningful and relevant as the CMC became more established.

Chapter 8

The Constipation Management Clinic findings

8.1 Introduction

This Chapter presents the findings from the CMC and represents the cornerstone of this action research study. The main aim of this stage was to reduce the incidence and/or severity of constipation in patients with cancer. The aims and objectives were informed by the literature review, the patient interviews and HCP focus groups. Through the use of a qualitative approach, the researcher utilised the individuals' (HCPs and patients) perceptions, beliefs and attitudes which were considered to be inherently meaningful (Denzin and Lincoln 2003a) and are therefore reflected in the main themes and outcomes emerging from the CMC. This CMC stage of the study also set out to improve local HCPs' practices through the ongoing dissemination which included contemporary study findings, thus bringing together the collaborative multiprofessional approach and the multidimensional components that are explored and presented. The means of dissemination of all the findings are included in this Chapter.

The first section reports the overall findings from the patients perspective and the remainder of the Chapter expands on these main themes and introduces the researcher's findings that were gleaned from medical notes, where available and perhaps more importantly, from the field notes. Where the data originate from patient report excerpts from the transcripts are used as evidence to support the arguments made. However, in instances where data have been gathered from either the medical or field notes the findings are presented as a general discussion. The sections are presented on a time line as far as possible to allow the reader an easier understanding of the findings.

The CMC laxative regimen identification, prescribing and patient self-titration are presented followed by the benefits adopting a concordant approach to constipation management and providing continuity of care. The evidence illustrating how and to what extent the CMC achieved its aims and objectives are presented. These are offered as themes along with respondents' narratives in order to present the data in context thus affording verification to the reader as to the appropriateness of the overall evaluation of the CMC presented in Chapter 9. The advantages of using example laxatives, as discussed in Chapter 7, are

presented followed by patient education and information giving which formed a major component of the CMC.

The remainder of the Chapter highlights the value of working collaboratively with the MDT when trying to resolve problems and improve constipation management in patients with cancer. To this end, the role and impact of dissemination is followed by the informal evaluation of the CMC which is offered as this emerged from the data, along with patients unmet needs.

8.2 The effectiveness of the CMC

In order to maintain the central importance of the patients' perspectives to this qualitative study this section presents findings that represent the data as reported by them. Some of the points made are purely introduced without great discussion at this point but are returned to in other guises and places throughout the Chapter.

8.2.1 Welcomed by patients

Perhaps the main finding of the CMC was that the patients were generally excited and welcomed it as being innovative and from their perspective, much needed. Patients appeared relieved that a clinic which focused on constipation had been initiated, not least of all because of its uniqueness but also because they became optimistic about finding a solution to their constipation. Patients seemed relieved that there was 'somewhere to go' where they could discuss their constipation and resulting problems in private and consequently they were eager to attend their first appointment as soon as possible despite previously being advised that positive outcomes could not be guaranteed.

"... (constipation) It's awful, you just can't imagine..... Takes over your life..... If only I could get rid of it I'm sure I'd feel so much better. My doctor says I'm bound to feel rough but I'm sure if I could get rid of this constipation and feeling bloated all the time it would help." (MH)

"I get so embarrassed all this leaking and down my legs. You sit down and sometimes I think Oh, I better not get up in case I've made a mess on the settee or something." (JT)

"... It really hurts when it gets stuck half in and half out. Then my head pounds and my heart starts to thump and I begin to panic. When it's out I just want to cry, it hurts so much." (CT)

Patients were advised that outcomes might be variable and, although evidence based interventions were utilised, success was also dependent on patient-clinician (researcher) concordance. This patient enthusiasm in regard to the CMC reflected the desires of some of the patients interviewed in stage one of the study.

8.2.2 Alleviating constipation

The second overarching finding was that the patients perceived the CMC to be successful. The data revealed that of the 29 patient recruited, 21 reported ‘an alleviation’ (to varying degrees) of their constipation and therefore the focus of the consultations was able to progress to that of laxative titration and prophylactic use rather than initial resolution. It was found that the remaining eight patients required further increases in their dose, or, due to an agreed lack of efficacy and/or dislike of their current regimen, justified the use of an alternative laxative, therefore a prescription was raised by the researcher.

The measure of success of the CMC was achieved through patients’ self-reports of constipation in line with the tenets of qualitative research from the individual’s perspective (Polit and Beck 2008) and set against the personal outcomes measures that were established on initial consultation. Within 10 days of their first CMC appointment several patients reported ‘complete alleviation’ of their constipation whilst others describe improvements in stool form, frequency and/or ease of defecation. Patients recognised that their constipation had been eased because they took their laxatives regularly and consistently. Furthermore patients understood the need for prophylactic use of laxatives and the consequences of none adherence to their regimen.

Sadly, not all patients accomplished an ideal laxative regimen based on self-titration as death preceded this. Nonetheless, identification and concordance was achieved in all cases, as patients reported having ‘taken daily without exception’. However, not all patients achieved alleviation of constipation as quickly as they would have liked but expressed a willingness to persevere on the basis that ‘things had already improved’.

“.....I did pass a lot but it was quite lumpy and hard but not as bad as it use to be ... (EB)

“.....I thought it was a bit softer but I still have to strain quite a bit” (DP)

“My back pain isn’t so bad now and....., I’m sure it gets worse when I’m constipated” (JL)

“I’m getting my life back. I’m tempted not to wear pads but I’ll wait a bit longer.” (EE) (Appendix 25)

Five patients who reported the need to remove faeces digitally stated that this was no longer necessary and expressed a desire to avoid recommencing the practice.

“No, I don’t do that (digital removal of faeces) anymore.... it’s nice and soft” (JS)

“... and I don’t have to take it out myself now.” (EE)

Patients identified their personal outcome measures explaining specifically what constituted an improvement in their constipation. As these outcomes were subjective and varied between individuals it was not possible to compare, contrast and/or assimilate various components. However, given the qualitative nature of this study these data are evidence that patients believed they benefited from the CMC.

8.2.3 Patients’ subjective outcome measures

To enable success to be claimed and congruent with an essentially qualitative approach subjective personal outcome measures were established to provide base line information against which any achievement of the CMC could be assessed. The outcome measure of self-reported constipation worked effectively as all patients had at least three descriptors that they considered problematic. Descriptors used by patients to define constipation are as reflected in Chapter 2. These were recorded as base line information. Most common were hardness of stools and difficult defecation.

“The best outcome to me.... to be able to pass a soft motion rather than having to struggle to pass anything at all.....that would be great!” (EE)

“....it is so difficult and painful to have my bowels open... it would be much easier if my motions were softer..... I would do anything that you think I should to achieve it!” (AB)

In all instances patients were desperate to be relieved their constipation. In describing the severity of their constipation patients often used words such as ‘not too bad’, ‘quite bad’, ‘awful’, ‘troublesome’ or ‘very bad’.

“It’s been really bad for weeks.....” (JL)

“Yes it’s very troublesome.... Awful in fact...” (BW)

*“Not so bad this week... but I suppose that it quite bad if that makes sense?”
(JL)*

The term ‘severe’ was a descriptor predominantly favoured by HCPs, whereas, patients used words such as ‘bad’ or ‘troublesome’ to indicate severity. HCPs use of the word ‘severe’ may be influenced by their predominantly medical and quantitative backgrounds which could be further compounded by the problems of identifying and defining constipation as previously discussed (Herz *et al* 1996; Anton 2002; Lembo and Camilleri 2003; Boyle 1970; Cash 2005). Due to the subjective nature of these descriptors it could be that patients and HCPs interpret these words with varying degrees of emphasis, thus, HCPs only identify ‘severe’ and a significant problem whereas the patient describes the experience as ‘quite bad’.

Nonetheless, patients’ descriptors were used and when co-presented with a degree of severity, these became the initial outcome measures by which subsequent consultations were compared. As indicated as evidence of CMC success, seven patients reported using digital removal of faeces and their cessation of this in all cases were considered an outcome measure.

8.2.4 Reducing stress

As previously discussed in Chapter 7, patients were given the Unit’s 24-hour telephone support and advice number to use in the event they had further questions and/or concerns about their constipation or its management. Patients reported that being aware of these resources was extremely useful as it dispelled their fears and anxieties, especially out-of-hours when patients felt unsupported and vulnerable and community teams were unlikely to be accessible for example;

*“I didn’t have to use the number but knowing I could was useful. I think I was less worried because when you live alone there is no one else to ask.”
(LL)*

“I didn’t worry so much cos when I phoned before they told me what to do and things got sorted.” (SS)

*“It is really helpful knowing there is someone to talk to even at night.”
(KW)*

Patients stated that they were less stressed and able to enjoy life more. Maintaining normality and interacting with others, especially loved ones, was perceived as more

pleasurable as soon as their constipation had been relieved. Furthermore, both hospital appointments and social engagements became not only possible but pleasant. Fears, that the signs and symptoms of constipation were in fact not constipation but something more sinister such as disease progression, predictably resulted in patients' being anxious.

"I thought the cancer was just getting bigger." (TM)

(Crying) "... this is the first time I have admitted that (fears of disease progression) I just couldn't tell my wife...." (JM) (Appendix 26)

"You just think well, this is as good as it gets and carry on." (BF)

These conversations were initiated by patients during the CMC consultation and it appeared that they had been reticent about raising such issues with HCPs, including their GP and cancer specialist, mainly because they had ignored the patients' plea for help in the past.

8.3 The physical examination

It was possible to correlate some elements of self-reported constipation in seven patients who underwent a physical examination thus providing objective data to supplement patients' subjective accounts. These included patients' reports of bowel not opened for several days, frequent and ongoing loose stools, distended abdomen and the individual's sensation that their rectum was 'blocked'. Patients' verbal consent was obtained prior to the procedure.

The researcher found that seven patients had a palpable mass in their colon and of these five had evidence of firm-hard stools in the anal canal. The physical examination confirmed the severity of the individual's constipation and offered reassurance to patients that their concerns were justified and important. The information pertaining to the location of their faeces was used during the patient education element of the clinic. The location and confirmation of their constipation was also of benefit to patients in as much that they described being 'pleased' that the researcher had been so thorough and 'taken them seriously'.

8.3.1 Benefits of a physical examination: reducing anxiety, stress and fear

The benefits of undertaking a physical examination were various and although the process was viewed as being necessary as a safety intervention it proved to hold more, perhaps unforeseen, outcomes. The most commonly reported positive outcome was that it allayed mounting fears of advancement of the existing cancer to the bowel. Some patients indicated

that although they had not raised these anxieties with their cancer specialist they had been concerned that their constipation was something ‘more sinister’. Therefore, such a systematic and comprehensive assessment of constipation was met with relief. This sentiment is indicated in the excerpt below which was gained from a patient who reported that the physical examination not only diminished their fears that their cancer had progressed, but gave them more confidence that the researcher ‘as clinician’ was competent to deal with their constipation, for example;

“I must say, you obviously know what you are doing which is more than I can say for my GP. He never once examined me.” (EE)

“The doctor said the district nurse would do it (PR examination) but she didn’t.” (AB)

“My wife tried to put those things in (suppositories) but she couldn’t do it. I said something felt like it was stuck there (in the anal canal) but she didn’t want to force it because I wasn’t sure what it was.” (JL)

“My husband said “Oh dear you look 8-months pregnant (laughing). I made a joke of it but really I didn’t want to worry him in case it was the cancer. But I did feel constipated too, so you don’t know do you? It’s a relief to know it is constipation.....” (BW)

The physical examination not only reduced the patients’ anxiety levels but also ensured that the researcher subsequently provided appropriate information and advice based on the individuals’ needs, namely, treating troublesome constipation. Treating troublesome (severe) constipation was achieved with optimal doses of oral laxatives, the identification of which derived through patient education and concordance.

8.3.2 Haemorrhoids: treatment and reassurance

It is not surprising that approximately a third of patients presented with painful and itchy haemorrhoids which were subsequently addressed at the clinic with simple and effective practical advice. This comprised the suggestion to use sensitive wipes instead of toilet paper and haemorrhoid cream to relieve the itching. In some instances rectal bleeding had created additional pressure and anxiety. Whilst referral back to the GP may have been appropriate, some patients declined as they reported being faced with a similar ambivalence to their constipation. For example, when the following patient mentioned her haemorrhoids (which had become troublesome and bleeding) to her GP he responded by saying;

“Oh that is the least of your problems...” “I was surprised when he said that because it really bothers me but there’s obviously nothing he can give me for it. I thought he would but he didn’t.” (EE)

The GP failed to give any support or advice. EE suffered unnecessary discomfort and distress. Patients were advised by the researcher that haemorrhoids may subside as a result of constipation alleviation (softer stools). The presence of haemorrhoids and advice given to patients was conveyed to HCPs in the post-CMC letter. It is not known why the GP failed to provide this simple and straightforward advice that took only a few minutes to impart, however, exploration of issues pertaining to GPs attitudes is outside the remit of this research.

8.4 Researcher’s skills and medical support

The CMC process worked well as in most cases constipation was confirmed. Medical support was sought for three patients in who concerns were raised during the physical examination. Two patients presented with a distended abdomen that was sensitive to gentle touch. A third patient presented with ‘*something stuck*’ in his rectum and reported that he had not had his bowel open for seven days. On examination, a palpable mass was felt in his transverse and distending colon. A very hard mass was also evident in his rectum. The medical team concurred with the researcher’s suspicion that all three referrals to them were appropriate and the patients’ subsequent x-ray confirmed tumour bowel obstruction in one case, ascities in the second and severe faecal impaction in the third. Suspecting only constipation none of these patients were being monitored by their HCPs. The patient with faecal impaction was admitted to the inpatient Unit and maintained contact with the CMC whereas those with tumour obstruction were discharged from the CMC.

Three further patients were referred for abdominal x-rays the findings of which all confirmed constipation. Furthermore, as the results of x-rays were usually sent for the doctor’s attention it was quite reassuring that the investigation results were promptly conveyed to the researcher so that patient management could proceed without delay. The timely reporting of patients x-ray results to the researcher was in an acknowledgement by the reviewing doctor that the individual was severely constipated (as opposed to suffering with tumour obstruction) and therefore needed appropriate judicious interventions as soon as possible to alleviate symptom distress, (such as pain and/or nausea) or other complications such as bowel perforation.

It was reassuring for the researcher to discover that, based on her abdominal examination of six patients and speculation that severe constipation was likely. If the x-ray had revealed a tumour mass the patient would have been referred back to the medical team, however, in these six cases severe constipation was confirmed as a result of the abdominal x-rays, thus reaffirming the newly acquired skills, knowledge and confidence acquired by the researcher. By way of ongoing researcher education, doctors were keen to show the researcher the x-ray and identify areas of interest including evidence of faeces and/or air in the colon and how to differentiate between the two. The researcher did not adopt a diagnostic role but did find such information beneficial in informing and underpinning her own knowledge and practice. This subsequently was used to impart a more simplistic explanation of constipation and its management to patients, carers and colleagues.

At their first CMC appointment over half the patients had ‘troublesome’ constipation and in the remainder it was less severe. Following assessment by the researcher some patients were identified as being ‘severely’ constipated despite their reports that it was “*not too bad at the moment*”. It appears from the narratives that the former comment occasionally related to the patient’s attempts to manage their constipation rather than the actual condition itself. For example, when asked to report on how bad their constipation was currently (at the time of the consultation) the reply was often ambiguous, for example:

“Quite bad but it has been worse.” (JM)

“Well it’s not too bad at the moment because.....I’ll take some laxatives tonight and perhaps they will work.” (EM)

“... I’ve had all this diarrhoea so I can’t be constipated but it keeps coming back.” (PP)

“I don’t know. I feel so awful, perhaps it’s the cancer and well.....” (JA)

“My doctors don’t seem bothered so I suppose it’s not that bad... (EY)

Following the physical assessment the researcher considered three of the above patients (PP, JA and EY) to be severely constipated. All patients reported being worried by their constipation, not least of all, because their attempts to ease it had failed and HCP support was absent. For the researcher, what had once been perceived as the domain of the ‘doctor’ it had become evident that working more collaboratively and challenging the status quo can improve patient outcomes. The researcher was surprised how keen colleagues were to accept advice and guidance on constipation management and laxative regimens. Similarly, when requesting assistance of physical examinations, ordering x-rays, and signing laxative

prescription, the researcher found it useful and productive that doctors either accepted the researcher's decision and/or, following usually minimal clarification, agreed with the researcher's findings and recommendations.

8.5 Patient education

The flexibility of the CMC framework ensured that an ongoing assessment of the individuals' needs was maintained and appended to the researcher's clinic notes as necessary. Education was interactive and became a focal point during the appointment and one in which patients came to recognise the actual and potential causes of their constipation and the use and role of laxatives. In many cases patients arrived at their own conclusions as to why they had become constipated and how this could be alleviated, however, these conjectures were now evidence based and supported with confirmation from the researcher, thus validating that patients' education had improved and thus concordance more likely to be attained. The CMC framework was also informed by patient reporting which enhanced the process inasmuch as when new problems arose they were explored and resolved, and thus afforded an ongoing evidence base on which to make suggestion to other patients and HCPs during dissemination. For example, 'specific information to impart' (Chapter 7) was appended to include the use of sensitive wipes which was proffered by the third clinic attendees who advocated their use.

Overall, the framework embraced the philosophy of action research as it was cyclical in nature and facilitated problem identification, planning, action taking, resolution, evaluation and assessment at each stage. Furthermore, the framework was created collaborative by the MDT and encapsulated contributions from patients. The framework was practical, easy to understand and comprehensive.

8.5.1 The use of visual aids

The educational element was led by the researcher whom identified key issues of concern that appeared to have been exacerbating constipation, such as opioid use and/or the suboptimal use of laxatives. This process facilitated the provision of individualised information to patients at a pace to suit them. The evaluation of the patients' understanding was informally undertaken during the subsequent discussion and/or as expressed in patients' narratives.

For those patients who had a limited understanding of the workings of the bowel the researcher utilised the pre designed visual learning materials. In reality this group comprised nearly all the patients attending the CMC. A verbal dialogue by the researcher accompanied the use of visual aids. A two-way discussion always ensued as patients asked questions and summarized their thoughts as reflected in the narratives presented in this section. These tools were welcomed by patients and proved effective in explaining salient points in simple terms accompanied by graphical representations, thus facilitating patients understanding. The latter was tested by the researcher asking salient questions, such as “how do you think your constipation could have been prevented?” which was reported upon by some patients as “taking laxatives every day without exception”.

The body chart

To demonstrate how the bowel worked the researcher used a diagrammatic body chart. This proved to be of practical use as patients reported that it was straightforward and easy to understand. Using different coloured pens the researcher drew on the chart using a systematic approach. Firstly, the path of a meal from mouth, stomach, small intestines, large bowel then rectum/defecation. A brief explanation about transit time and peristalsis followed. The transition to bowel dysfunction was then explained and an impression of hard faeces drawn on the body chart. The problems of using laxatives after the onset of constipation were then explained. These were depicted on the body chart as laxatives in the stomach and hard faeces. A verbal explanation highlighted the distance between the two and the duration of time before the laxative is able to take effect.

“...it makes sense once it’s explained.” (TJ)

“... getting rid of all the waste in your body would be good otherwise it will be sort of rotting inside, stagnant like.” (JM)

“... people (HCPs) just assume we (patients) know all this but we’re not doctors so why should we but ... I know now and it’s not difficult when you think about it.” (CH)

“It is clear. I explained it to my wife and even she said it made sense ...” (EM)

“Well you see, I thought I had a valve here and it was blocked ... I didn’t know the bowel was that long ... I didn’t really know how it worked I suppose but I thought I did.” (EE)

The researcher also proffered an analogy which was that unlike many medicines that patients take ‘as required’, such as paracetamol for a headache (for which all patients confirmed they had done), laxatives do not work immediately nor are they just *treatment* for constipation, thus the importance of preventing the condition.

The use of pictorial representations was well received and identified by patients as being an excellent medium for improving their understanding. Patients often commented that the visual aids were uncomplicated and improved their comprehension and reinforced the verbal information given. All patients reported that this use and role of laxatives had never been explained to them and that the causes and consequences of constipation had only been alluded to briefly by HCPs, if at all. Patients had only used laxatives ‘as required’, which was interpreted by them to mean once they felt constipated.

The body chart not only proved to be a useful teaching aid but also as a document to record patients’ progress and facilitate explanations of change by comparing and contrasting their previous consultations. Seven patients requested a photocopy of their completed body-chart to take home to aid explanation to another family member or as an *aide-mémoire* to assist their constipation management.

The Bristol Stool Form Chart

In similar fashion to the body chart the researcher utilised the Bristol Stool Form Chart to assist the educational component of the consultation. It again proved to be successful in establishing semi-objective data on current stool form but the conversations invariably proceeded to elicit data pertaining to individuals’ varying and past stool forms. None of the patients had seen the Bristol Stool Form Chart prior to the CMC and found that by pointing at a particular form they could accurately indicate the nature of their stool. The following narratives referred to usefulness of the Bristol Stool Form Chart.

“Ah, this is good... saves you having to describe it which doesn’t always sound very nice does it.” (EM)

“...(laughing) ... this is clever actually.” (JE)

“Yes, it’s like that one but sometimes a bit of that. This is good, makes it easy for me to explain.” (DW)

In many cases patients were unable to distinguish between symptoms presenting as a result of constipation and those endured due to their disease and/or its treatments. In subsequent

CMC appointments however, patients were able to correlate improvements of other symptoms as their constipation abated, for example back pain, lethargy and nausea. When asked how the association had been made patients attributed it to a better understanding of how their bowels worked and the use and role of laxatives.

Health care professionals response to visual aids

Interestingly, several HCPs, particularly nurses, requested copies of the charts and commented on their potential value for use in their own practice, especially patient education and assessment. This not only indicated the nurses' recognition that the management of constipation might be improved but also their receptiveness to respond to such needs. This interest is in contrast to the literature whereby the apparent gap in nurses' knowledge and understanding of constipation (George *et al* 1996; Moore *et al* 1996) which is further compounded by a reluctance to under-report bowel habits and related subjects (Robinson-Wolf 1996).

The positive approach by HCPs provided further validation of the success of the clinic and the benefits of using an action theory methodological approach in this research which set out to incorporate a multidimensional and MDT approach to alleviate constipation in patients with cancer. It was also considered to represent a form of dissemination of findings and practice and therefore a robust conduit for a change in knowledge, and thus practice, which in itself should enhance patient outcome.

In summary, it appears that the aforementioned charts and explanations were effective in improving patients understanding of bowel function and the use and role of laxatives. It is likely that the patient-focused approach lends itself to identifying individuals' needs and was proffered at a pace to suit the patients and without time constraints. Checking the patients understanding was achieved through direct questioning and prompts, for example when asked how their constipation might have been prevented all patients reported daily use of laxatives.

8.5.2 The use of example laxatives

As indicated previously the researcher found that the problems of identifying patients' previous or current laxative use resolved with the aid of the laxatives examples. The examples proved effective as all patients identified additional laxatives that they had not mentioned earlier, including perceived efficacy and reasons for cessation. This may be

merely as result of the patients' forgetfulness, or perhaps they had been considered unimportant, or deemed ineffective and/or intolerable. For example;

"Oh yes, I've had that (indicating senna) but it gave me cramps." (DC)

"I've tried that (indicating ispaghula husk) but I can't take that again. I only used one but just couldn't swallow it, made me feel sick." (VE)

"I'd forgotten about that one (lactulose). It worked okay, made it (stools) soft like but it's so sticky and sweet." (EE)

"... yes.... ages ago. Seemed to work.... Can't remember why I stopped taking it now." (ML)

Throughout the example laxative stage the drug most frequently identified as having been used was senna. In most cases senna had not been highlighted because its use had originated from an over-the-counter purchase rather than from the patients' GP. Ispaghula husk and lactulose were also recognised but these had more often than not been discarded due to a perceived lack of efficacy. They were remembered as a result of packaging/item recognition during the CMC.

To achieve optimum effect the example medications were positioned within reach of patients who were encouraged to handle and examine them. The underpinning rationale for this was identified following the patient interviews (stage one) and proved to be valuable for several reasons. Firstly and previously acknowledged, patients identified additional laxatives that they had used in the past but had failed to recall usually because they had forgotten the name of the laxatives or simply that they had used them until they recognised either the laxative box/container or the tablet/capsule. Secondly and as it transpired the, patients became aware that there were additional laxatives that could be tried therefore appeared to be more optimistic that 'something' may be available that *would* alleviate their constipation. To this end, the example laxatives facilitated a more comprehensive account of laxative and it was also possible to ascertain remaining supplies that patient had which could potentially be recommended without incurring further burdens such as financial costs and pharmacy visits.

On reviewing the examples patients expressed a 'wish' to find a laxative that worked but this was in the absence of the knowledge that they needed to be taken consistently and prophylactically, therefore, alternatives were not always necessary. Again the lack of understanding of the need to take laxatives regularly and at an appropriate dosage emerged as a finding as it had done throughout the data gathering processes of the study. However, alternatives were sometimes necessary or expedited at the patients' requested based on

personal preference, especially in relation to formulation: tablet, capsule or liquid and thus harnessing the ethos of a concordant approach (Dickinson and Raynor 2003; Jones 2003; Britten *et al* 2002).

In summary, the use of laxative examples proved extremely useful in facilitating a more comprehensive account of laxative use than identified during the patient interviews. Furthermore, it enabled the researcher to encourage patients to try alternatives if necessary when side effects and/or lack of efficacy had deterred their use. The researcher raised prescriptions for six patients who required alternative laxatives. As reflected in the literature review this concordant approach is more likely to facilitate compliance with laxative regimens and empower patients to take more control over their use (Dickinson and Raynor 2003; Jones 2003; Britten *et al* 2002). This was achieved as patients began to successfully self-tritrate their laxatives to attain maximum effect and control.

“Oh, I didn’t realise I could take a tablet. I would prefer that really.” (LC)

“I can’t manage those tablets, they are like bullets. My’ GP didn’t say I could have it like this (liquid). (TM)

“He (GP) just told me to take this (ispaghula husk) but I can’t. It goes all thick and blobby, makes me wretch. Can I have something else, perhaps something easier to swallow?” (SS)

“I will try what you asked me to do (optimising current regimen) but if it doesn’t work,.....I did have it before (in hospital) but they didn’t give me it when I went home..... I didn’t mind that.” (PJ)

The use of examples also raised patient’s awareness that, in contrast to the interview findings more could be done to ameliorate their constipation. In addition the patients’ newly acquired knowledge of different laxatives led to some degree of incredulity as they challenged the fact that alternative laxatives had not been introduced in the past, especially when unacceptable side effects had resulted in poor levels of laxative adherence.

“Why didn’t my doctor give me this then?” (MV)

“I don’t understand why....my doctor is good he didn’t tell me I could try these.” (EE)

“... no he didn’t say a thing my doctor..... either he doesn’t know about these or he can’t be bothered.” (KW)

“..... I took it and it does seem better but I still would like to try that one (pointing to an alternative) because taking mine is not very nice when you need so much (20mls of lactulose three times a day).” (EE)

The educational element became more interactive at this stage as patients asked direct questions relating to how their bowels worked and the use and role of laxatives. Most patients were unaware of the duration of transit through the gastrointestinal tract so the use of pictorial tools facilitated a clearer understanding of why laxatives often take longer than expected to work.

“It does make sense you know. It seems obvious now but..... I’m I wish someone had explained that earlier.” (JL)

“I feel such a fool. I could have worked that out for myself if you think about it.” (SS)

“You should be told about these things when they give you these drugs. I understand why now, it is easy to see what is happening to me.” (CY)

Furthermore, education reinforced the importance of taking laxatives every day, without omission, as the dose taken on day 1 may not take effect and/or be passed rectally until day 3 or longer. As the process of bowel function had been clearly explained during the CMC, incorporating bowel stasis and peristalsis insufficiency, patients reported a better understanding of how constipation manifested and the use and role of laxatives. Some patients explicitly stated that it would have been useful if someone had explained such things in this way before as it had now become clear and obvious to them.

The importance of patient information and education was viewed as being central to achieving an optimum level of concordance and through this, constipation could be reduced (Dickinson and Raynor 2003, Jones 2003; Britten *et al* 2002; Zeppetella 1999). The researcher made full use of the information sheets and charts as discussed in Chapter 7. It was apparent that the patients generally had little or no knowledge of how their bowels worked and therefore did not fully understand their constipation. This is unsurprising given the seriousness of their conditions and the resultant vital treatments and adjustments to diagnosis.

Patients were also afforded information on how to make some laxatives more tolerable rather than discontinuing them completely, as found in Chapters 2 and 5. For example, fruit squash can be added to polyethylene glycol (minimum 125 mls of water per sachet plus fruit juice or squash). The researcher contacted the manufacturing pharmaceutical company who

confirmed this to be safe practice as it would not impair the drug's efficacy, however, they do not advocate the use of carbonated/fizzy drinks as the latter not evidence based.

Generally, patients had inadequate knowledge about the causes and consequences of their constipation. The data revealed that the onset of the patients' constipation varied from those who had suffered with chronic pre existing constipation which had greatly worsened since their cancer diagnosis and those with secondary constipation as a result of their morbidities. The use of opioids was considered, by the researcher, to be the most likely cause in most cases.

"You know, these doctors..... should have known this (pointing to body chart) if this had been explained to me before... I spoke to so many of them (HCPs) and they didn't show me anything like this. It makes it so easy to understand." (TM)

"I like your pictures. I used to be a teacher but I'd forgotten how simple things are to understand with them.... It does make sense what you say." (MH)

The relief that the patients felt was almost palpable. There was a certain reflective accusation that, from the patients' perspective, they considered that they had not been given enough information relating to constipation thus far during their treatment. Of course, this may have been offered by HCPs but at a stressful time in the patients' lives had not been fully understood. On the other hand it has to be considered that they may have not been offered any meaningful information. In contrast it may be that patients failed to articulate their problems with constipation because they had not been specifically asked (McMillan and Tittle 1995; McMillan 2002). By eliciting patients' perceptions, experiences and understandings it was possible to individualise educational needs. This represents a new approach and was considered pivotal to the success of the CMC.

8.6 Laxative regimens

This section brings together patients' laxative use insofar as their use in the past, their current use (at the point of first consultation) followed by regimen recommendations during the CMC and titration thereafter.

8.6.1 Establishing the current situation

The medical records and patient's self report, in several instances obtained with the prompting of the example laxatives indicated that only six patients had been co-prescribed senna and lactulose but had not taken them prophylactically or consistently. The remaining 15 patients had used senna and lactulose but contrary to recommendations, these had been prescribed as a sole agent and often one subsequently to the other when the first product appeared to lack efficacy. In most cases, lactulose 5-10 mls once or twice a day, and/or 1-2 senna at night had been prescribed accompanied by the advice to take 'as required' and in some cases patients had up to five different laxatives at home.

It would appear that, prior to their attendance at the CMC none of the patients were currently undertaking appropriate laxative therapy nor, as it became apparent later, were they aware of the proper use and role of laxatives and the HCPs and patient disparity on assessment, identification and under reporting was also evident (Herz *et al* 1996; Boyle 1970; Cash 2005; McMillan and Tittle 1995; Moore *et al* 1996; Oxenham *et al* 2003; Walsh 1984; Donnelly *et al* 1994; Addington-Hall *et al* 1991; Vainio and Auvinen 1996; Sykes 1998). It was possible to redress these issues, along with others that are outlined below, by utilising the specifically developed CMC framework to provide a comprehensive and individualised approach to constipation management.

As indicated previously, none of these patients were using their laxatives prophylactically or consistently. In most cases, lactulose 5-10 mls once or twice a day, and/or 1-2 senna at night had been prescribed accompanied by the advice to take 'as required'.

"Those (liquid paraffin and senna) he (the GP) gave me ages ago but they didn't work then the Mac nurse.... said to take this (lactulose) and well, have you tasted it?,...awful, made me feel sick. I had senna in the house so I tried that, then someone else gave me this (psyllium based product) and it made me worse. About four or five weeks ago..... the Mac nurse said try this (polyethylene glycol) and I suppose it helped a bit." (DR)

"I've got so much stuff at home. I don't use it though which makes me think why am I keeping it. It seems such a waste." (GG)

"... I could open a shop" If I bring it in here you could add it to your collection (laughing) .. some I bought in the shops and I don't think you have them in there (pointing to the examples)..." (NJ)

All patients had adopted an 'as required' regimen, in the belief that this was appropriate, together with a desire to take as little as possible. All patients had been prescribed various

laxatives in the past and in some cases reported having up to five different types which they had discarded due to a perceived lack of efficacy or dislike of formulation.

8.6.2 Researcher's recommendations

In most cases the researcher's recommendations amounted to an increase in individuals' current laxative/s to a therapeutic dose. The therapeutic dose included taking laxatives every day without omission whether patients considered that they needed them or not. That is, regardless of whether they deemed themselves to be constipated. This was important as all patients had at least three predisposing factors to their constipation most commonly that of opioid use. The aforementioned therapeutic dose subsequently became the regimen that patients used for self-titration purposes and in the knowledge that, if these laxatives remained ineffective, they could obtain alternatives at the CMC. In most cases increasing current laxative dose, together with consistent and prophylactic use, was successful in alleviating constipation.

Patients presenting with troublesome/severe constipation were commenced regimens at higher doses than would be used for prophylactic use. Regimens were selected based on patient's preferences (laxative, dose and formulation), guided by the researcher as necessary. Eight patients required further increases in dose or an alternative laxative. A concordant approach was used to identify an appropriate laxative regimen for each patient, that is, patients acknowledged that they had failed to use the drug appropriately and were therefore willing to try it again in the knowledge that it was much more likely to be efficacious when used consistently and prophylactically. Patients, in partnership and guided by the researcher, were pivotal in the decision making process regarding the identification of their laxative regimen coupled with an agreement to test its efficacy. Regimens recommended to patients were mainly those known to be efficacious when taken in optimal doses, as reflected in Chapter 2: lactulose, senna, lactulose plus senna, co-danthrusate and polyethylene glycol. Laxative efficacy was subsequently experienced by patients in most cases.

Alternative laxatives were prescribed when patients found their existing regimen either unpalatable or not as efficacious as anticipated. In some cases patients taking 10mls of lactulose once or twice a week was tolerable whereas taking 20mls three times a day became unacceptable and often caused excessive wind. Whilst some patients were not disturbed by such regimens and/or side effects some preferred to try an alternative laxative. In most cases, patients using methods to make laxatives more tolerable found the intervention useful, thus enabling them to persevere with their regimen as shown in the following excerpts;

“I was really surprised, my wife got some of the grape juice and I added some of that. It’s OK you know, taste just fine.” (JL)

“Yes, that worked, I was really surprised. I couldn’t taste it at all after that.” (MF)

“I found the orange juice worked well because generally I found that a bit sharp so the sweetness of the lactulose sort of counterbalanced that. I don’t mind taking it now.” (RP)

Several other patients using techniques to camouflage liquid formulations also reported that this process was successful and had enabled them to tolerate the laxative and thus adhere to their regimens.

The prescribing of laxatives was generally uncomplicated however the researcher raised a concern about the use of polyethylene glycol in one patient prone to electrolyte imbalance. The Unit’s doctors were also unsure about the safety of polyethylene glycol under such circumstances. As a result it was decided that the researcher liaised with the drug’s manufacturing company. This scenario is discussed later under ‘Problem resolution - the MDT approach’. The patient was subsequently prescribed polyethylene glycol with excellent results despite previously discarding the product for lack of efficacy some months earlier.

As predicted, most patients held supplies of unused laxatives that were subsequently utilised. When prescriptions were raised by the researcher they were countersigned by one of the doctors as planned. Some doctors embarked on discussions with the researcher about her choice of laxatives to ensure choices made were evidence based and appropriate to the individual. Comments made at the time generally indicated that the doctor considered the researcher’s choice of regimen appropriate and probably more evidenced based than their own laxative prescribing patterns.

Patients were pleased that they were able to obtain laxative directly from the pharmacy following their CMC appointment thus timely commencement of regimens. Similar to the findings in Chapter 5, patients reported that they lacked confidence in the community teams in affording appropriate support and advice on constipation management. However, patients did not raise any concerns about the need to contact their GP for repeat prescriptions despite describing events which implied this support mechanism had failed in the past. It may be that patients were happy to obtain repeat prescriptions as obtaining these did not require contact with the GP but rather a request via the surgery receptionist.

8.6.3 Laxative titration

During the CMC the need to titrate, use rescue laxatives and/or use higher than normal doses was supported by the research evidence (Ramkumar and Rao 2005; Tramonte *et al* 1997; Petticrew *et al* 1997; Miles *et al* 2007; Tamayo and Diaz-Zuluga 2004) and is supported by the periodical BNF (2008) and PCF (2007). However, given that most patients' preferences to take as 'little as possible' if at all (Britten *et al* 2002; Britten 1996; Conrad 1985; Donovan and Blake 1992; Morgan 1996; Rogers *et al* 1998; Britten 1994) the researcher postulated that increasing and escalating laxative dose may result in patients' reluctance to adhere to the recommendations. The latter did not occur as in most cases successful prophylactic regimens were within normal ranges (BNF 2008) and when treating severe constipation, the recommendation to use a high laxative dose was proffered to patients with information, education, support and advice. As reflected in the literature review (Chapter 2) this concordant approach to prescribing is more likely to facilitate compliance with laxative regimens and empower patients to take control over their use, which also appeared to be evident in patients attending the CMC.

Whilst the choice of laxatives and doses varied between patients, the important outcome reported by all patients was that they took laxatives consistently, and in most cases daily without omission, because they understood the importance of doing so. Laxatives were only omitted as part of the titration process and/or to facilitate social events thereafter resuming the regimen became 'the norm' as prophylactic use. Two patients reported running out of supplies of their laxatives and attributed responsibility for this to themselves in terms of they should have 'known better'.

One of the aims of the CMC was to enable patients to titrate their laxatives to self manage their constipation. Overall, patients reported that they deemed themselves confident in their ability to titrate laxatives based on stool form, frequency and ease of defecation. When familiarising themselves with laxative choice and/or dose, patients tended to raise questions that merely required reassurance from the researcher. This input mainly concerned confirmation that adjustments made to laxative regimens were appropriate and would probably maintain therapeutic benefit. For example,

"My bowels are much better now with the 20mls (of lactulose) twice a day but they (the stools) are still a bit firm..... It is OK to take a bit more, maybe another spoonful (5mls)?" (SS)

"I don't think I need three (polyethylene glycol) now, it (stool) is quite soft. I was thinking maybe if I took just two, a day that is, is that OK?" (MV)

“I took two senna at night and then one spoonful (5mls) of lactulose in the morning, it’s OK but I thought I’d try a bit more lactulose and only one senna because I sometimes I get a bit of gripe.” (TS)

“...so just sticking with 1-2 senna at night and lactulose in the morning and in the evening works. I don’t change it....., I know I can but really I think I’ll just make sure I take it every day. I do take it every day. I never used to but then.... I didn’t know ...” (GT)

Some patients developed regimens that were unusual however if they were considered successful by the patients they were deemed appropriate. These had all been reviewed by the researcher and regarded as safe doses and/or combinations of laxatives. For example, one patient reported being relieved of her constipation and satisfied with her bowel function when using one polyethylene glycol on alternate days. This would normally be regarded as a suboptimal dose especially in light of the patient’s opioid dose which would have exacerbated her constipation. However, this particular patient had a history of irritable bowel syndrome and laxative abuse which may have impacted on her constipation and/or laxative regimen. The important outcome was that the patient reported that she had, for the first time in her life, identified a regimen that alleviated her troublesome constipation and therefore success was achieved.

Whilst some of the regimens may be considered unusual, it is important to note that they were resultant of the patients’ titrating their laxatives themselves and finding a level that worked effectively in alleviating their constipation. The most common confirmation sought by patients was to establish that their regimen was safe and might prove efficacious. For example 20-30mls of lactulose twice a day +/- 2-4 senna at night which was a higher dose than previously prescribed.

Another patient’s regimen consisted of one polyethylene glycol in the morning, one senna tablet at lunch time and two co-danthrusate tablets at night. It is possible that co-danthrusate or polyethylene glycol used as a sole agent may have been of equal efficacy, however, the patient’s development and acceptance of this regimen was of more importance since he had assumed control and was confident in his ability to manage his current, acceptable, bowel function. On discussion with the medical team and further investigation, the researcher could not locate any evidence to indicate that this combination of laxatives could be detrimental to the patient’s health so once more the regimen was considered a success.

As time elapsed, patients reported varying their doses of laxatives based on their stool form and frequency. This was supported by comments including;

“I would be eating my toast and all of a sudden I have to go. I rush to the loo, we’ve got one downstairs which is good because I wouldn’t get to the one upstairs in time. I’ve been caught short a couple of times, but I usually make it.” (SS)

“I felt it was a bit too soft so I missed the evening dose for a couple of days.” (JH) However patient continued with the morning dose.

“It was becoming a bit, I wouldn’t say hard not like before, but a bit firmer so I took another one (polyethylene glycol) that night. I will take an extra one tonight too I think... it will help.” (MH)

The ability to titrate and predict stool frequency and/or consistency was reported as being of central significance as it was employed to maximise opportunities and arrangements for outings and social events. One patient reported experiencing extremely soft motions daily between 08:00 - 09:00 hrs and was therefore aware of the urgency urgent access to a lavatory to open his bowels. Although this was not particularly troublesome to him in his own home there were occasions when the fear of faecal incontinence caused him extreme distress. For example, once a month he was required to leave home before 07:30 hrs to undertake a lengthy car journey to a hospital in central London. The journey could take 1.5 hours and toileting facilities were unavailable until reaching his destination. Following three clinic appointments this patient considered that he had ‘become empowered’ as he had established a laxative regimen that included omitting his laxatives two days before the hospital visits; which had resolved the problem. He subsequently resumed his laxative regimen recognising that his stools would become somewhat harder in the short term. Thus illustrating that patients can successfully titrate their laxative to reduce embarrassment and accommodate activity.

8.7 Communication to HCPs

To ensure that HCPs were appraised of any changes to their patients’ regimens a comprehensive letter (examples Appendix 26 and 27) outlining the current situation was sent after each CMC appointment. The letter contained an overview of the individual’s presenting problems with constipation and highlighting possible causes and outlining the CMC plan to alleviate the condition. The proposed laxative regimen was identified so that GPs could source repeat prescriptions as necessary, which is normal practice when prescribing from the hospital outpatient setting. The post-CMC letter reflected the practice of patient self-titration

(Appendix 28 and 29) and consistent use of laxatives (Appendix 30 and 31) to ensure that all HCPs involved in the individuals care were kept informed and were also proffered the researcher's contact number should any issues of concern arise. It is noteworthy that none of the patients' GPs raised questions or concerns in relation to their patients' constipation management based on the researcher's recommendations and in all cases continued to prescribe the proposed laxative and dosage. Due the constraints of this study it was not possible to explore GPs views on the researcher's recommendation.

It is perhaps outside of the parameters of this study to make any inference or draw conclusions as to the reasons why HCPs had failed to use alternative laxatives. However, as a result of the post-CMC letter it may be that these 'prescribers' adopt a more proactive approach to their patients' constipation management rather than merely, due to an inadequate understanding or choice of preparation, provide repeat prescriptions of a laxative that had minimal effect. Within the philosophy of action research this process of follow-up information to HCPs was considered to be an additional opportunity to disseminate the CMC findings.

8.8 Patient empowerment: taking control

As alluded to in several previous sections, one of the finding of the CMC patients became more confident and empowered. This was apparent as patients grew to understand their constipation more fully and were able to titrate their laxatives to achieve the best personal outcome. The researcher drew the conclusion that patients became empowered because they understood how constipation manifested and the use and role of laxatives. Patients assumed control of their constipation management by liaising with other HCPs and being more proactive in identifying appropriate management strategies. This was evidenced by the fact that some patients reported that they had requested further supplies of laxatives to accommodate an increase in dose to achieve titration. These requests had been made to the researcher, to the patients prescribing doctor or pharmacist (in the form of repeat prescription) as appropriate to the individual and their circumstances.

"...I just asked my GP for more..... because I need them to be of any use... to make me go as you said..."(GT)

".... I think that I need more can you sort it out for me?.... (TM)

".... I just made sure that I kept ordering them when I got all the other tablets..... I used not to do that." (TS)

Some patients recounted how during periods of admission patients they had ensured that their titrated laxative regimens were reflected on their drug charts, which was also considered to demonstrate empowerment.

“I told them when I went in what I wanted as it works.....and makes me feel much better” (SS)

Patients declared that they had reported to HCPs, with whom they subsequently came into contact, how much better they felt as a result of their improved bowel movements. They also considered that their new appreciation of the manifestation of constipation and the role and actions of laxatives had greatly assisted in the success of laxative titration. This anecdotal evidence was supported by several HCPs who made contact with the researcher to confirm and/or clarify laxative regimens. For example, HCPs frequently sought confirmation of laxative regimens and advice for constipation management *per se*, thus developing their own knowledge to the benefit of patients in the future.

Similarly, patients recounted that they been empowered to manage their own constipation. For example, following seven years of struggling with constipation, one patient emotionally reported how pleased she was that finally her constipation was being resolved. The knowledge she had acquired during the consultation had promoted an understanding of “what was going wrong” and “what she could do” to compensate for the adverse affects of her illnesses and medications. Being capable of assuming control and make positive changes, without relying on HCPs who had been either uninterested or indifferent to her plight, became so empowering that she described how she felt;

“I’ve got my life back.....and I know how to prevent it (constipation) happening again. And if I can’t sort it I’ll contact you if that’s OK because I know my GP won’t be interested.” (EE)

“Yes, it’s (constipation) much better, I’ve passed a lot of stuff but.... I still feel like its stuck, you know.... in my bottom (anal canal).” (JM)

“... and I don’t get so much back pain now which used to bother me a lot.” (CW)

It is noteworthy that generally patients preferred a softer stool. Three patients reported that their stools had become a softer than anticipated but preferred this to being constipated. Fear of being constipated reoccurring was perceived as reason not to reduce laxative dose and it

appears that, for some patients, once bowel function had resumed to their acceptable norm (soft, frequent and easy to pass) patients refrained from jeopardising this delicate balance (Appendix 28). Living with stools ‘a little too soft’ was acceptable to them as this was manageable, less painful and a lot less distressing.

“I never want that (constipation) to happen again, I’d rather go to the toilet four or five times a day than risk that again.” (PJ)

“No, that’s OK. I’m happy with this (slightly too soft stool) can’t risk that again. Give me a week or two and then maybe I’ll cut down a smidge, but let me enjoy getting it out for now.” (BM)

Any misconceptions relating to their drug regimens were also discussed. For example, patients were advised that opioid use would induce or exacerbate constipation but it was not necessary to reduce their use in order to minimise constipation, on the contrary, preventing constipation could be achieved by optimal laxative use. The difference between diarrhoea and overflow was explained using the body chart and a rationale given as to why laxatives would be needed to remove the offending faecal blockage causing the 'overflow'. Patients accepted that indefinite prophylactic and consistent use of laxatives would be necessary in order to lessen/prevent constipation since they understood the rationale for this need and that partial alleviation of their constipation might be the best outcome.

“If I go out I sometimes use a pad just in case but I would rather do that than become constipated again. When I was constipated I couldn’t even go out you see, so (laughing) let’s just keep it like this (soft).” (TM)

This example and the previous ones highlight that patients’ preferences vary inasmuch as some prefer being a bit ‘too soft’ whilst others are not disturbed by the occasional ‘firmer’ stool. The ability to self-titrate laxatives ensured that individual preference could be achieved and maintained, and in most cases, until the terminal phase of their illness. However, it is worth noting that patients could still choose how they prefer their bowels to be managed, even when they experienced a degree of faecal incontinence which is not uncommon in this client group.

The realisation that their laxatives may not be taken for a couple of days resulted in a concerted effort to obtain more supplies as soon as possible to prevent another episode of constipation. Responsibility for bowel management had shifted from the HCPs to the patients themselves and it became apparent that the latter were no longer reliant on others to help manage their constipation.

“I should have known, I usually ring the GP but I forgot.” (SS)

“... my husband is going today, I said to him “don’t you dare come home without it (laughing)”. I don’t want that (constipation) happening again.” (BW)

It is worth noting that in these instances the community teams (GP, Macmillan nurse and district nurse) also failed to notice the patients need for repeat laxative prescriptions. This depletion of medication not only applied to the patient’s laxatives; other drugs were in short supply as well. To this end one housebound man who lived alone reported waiting 10 days before getting more supplies of his antiemetics and laxatives. Conversely, one patient had three bottles of lactulose each labeled with differing instructions for use. The failure of some HCPs to be more diligent with this vulnerable group may be due to the reported indifference to constipation and its management.

8.8.1 Moving from describing constipation to prediction and prevention

Over the following weeks and in some cases months, none of the patients reported experiencing an episode of constipation similar to, or as severe as, that which had prompted their initial referral to the clinic. Whereas previously, stool form and frequency had been used solely as descriptors to report constipation, now, in contrast patients monitored these as indicators that laxative doses might have needed adjusting. This step forward indicated that patients had become empowered and had taken control since the emphasis had altered from ‘describing constipation’ to ‘predicting constipation’. Ultimately, this reinforced the act of self-management including titration of laxatives. The management of the patient’s constipation shifted from the referring doctor, to whom patients were dependent, to the researcher (as clinician), thus facilitating the interventions that potentially empowered the patients to take control themselves, which was one of the clinics objectives.

8.8.2 The ‘explosive episode’ experience

As part of the initial consultation the researcher had cautioned patients that they might experience ‘an explosive episode’. Two days following her first consultation one patient eagerly telephoned the researcher to report that she had experienced a ‘massive’ bowel evacuation and now felt “so much better”. She further recounted that she was “delighted” with the outcome and described the information received during the consultation as of “immeasurable” use as she considered herself more involved and therefore less anxious about the consequences, particularly because she appreciated exactly what was happening.

The feedback and general liaison with the researcher following an ‘explosive episode’ was considered vitally important in order to assess the efficacy of the laxative and bowel function and facilitated the titration of laxatives as necessary. Following the explosive episode adjustments to laxative doses were made using a concordant approach between clinician and patient, based on the patient’s preference together with descriptions of their stool form and frequency. Thereafter, patients acquired further control of their laxatives and became more independent with regards to titration and without exception reported improvements in their bowel function.

“... I’m glad you told what could happen because I think I would have panicked..... what a relief though..... I just can’t explain it... how much better I felt.” (BW)

“... what a relief... what a relief... I felt so much better in all ways...” (FJ)

Those who experienced a predicted ‘explosive’ episode described how physically and psychologically relieved they were immediately post defecation, especially in the hope that the buildup of constipation over the preceding days or weeks had been resolved. Patients reported that being forewarned of what to expect during an ‘explosive episode’ made it a less stressful (Appendix 30) experience as they felt reassured and optimistic that the situation would subsequently improve. When asked if the episode had distressed them, patients reported that it had not because they had known what to expect and, in the knowledge of the 24-hours telephone support line, knew what to do if they had any concerns.

8.8.3 Loss of rectal sensation

As the CMC progressed two patients reported that they were concerned that they had been soiling their undergarments and leaking soft stools without realising that, faeces was being passed at the time. As a result they were using incontinence pads continuously. In both cases this occurred approximately 3 months following clinic attendance and initial alleviation of their constipation. On further medical exploration both patients had developed spinal cord compression which had resulted in loss of rectal sensation and faecal incontinence.

Faecal incontinence is extremely distressing however one patient chose to manage this by continuing with his laxative regimen and thus prevent constipation even though this meant he continually wore an incontinence pad. The remaining patient became bed-bound and opted to reduce laxatives to a minimal dose and supplemented this with enemas twice a week

to remove the resultant firmer/solid faeces. The recognition by patients that they could influence their stool form and frequency was underpinned by their confidence in titrating their laxative regimens.

8.9 Positive comments received from patients

All patients reported some alleviation of their constipation and were therefore very positive. Defecation was generally reported as being easier and less problematic to manage. In some cases other symptoms identified (by individuals) as being related to their constipation had eased, especially back pain. All patients reported, to varying degrees, improvements in their constipation. This was expressed during follow-up consultations where patients appeared surprised and delighted by the improvement in their bowel function. The ‘surprise’ may be because the intervention, taking laxatives daily without omission was, as reported by several patients, ‘simple’ and ‘obvious’. However, this ‘simple’ approach only became ‘obvious’ to patients following the initial consultation which included a clear explanation about the role of laxatives and the exact nature of how they worked. Therefore the implications gleaned by the researcher are that patient’s knowledge had been generally improved and that they considered themselves ‘delighted’ with the outcomes, which were alleviation of constipation and its symptoms.

All patients reported that their constipation has been completely, or partly, relieved which was the main aim of the CMC, thus demonstrating its effectiveness. Descriptions of ‘having a good clear out’, ‘feeling much better’, ‘frequent stools that were easier to pass’, and not having to remove faeces digitally were all attributed to the relief of constipation.

“I couldn’t believe it. It was so nice to have a good clear out and I thought at one point this is never going to stop but it did. I just couldn’t believe there was so much there..... I do feel so much better.” (JE)

“I go every day now and..... it’s really soft. I used to have to.... put my finger in a help it out but I don’t have to now.” (JH)

“I may not go every day but when I do its soft and easy to pass” (TM)

“I just can’t believe how use this has been... I thought well there’s nothing to lose by coming (to the CMC) but I really didn’t expect it would be so simple.” (KK)

In contrast to the interview findings (Chapter 5) patients no longer described, or discussed, how difficult defecation was but rather, how easy it had become. Related narratives imply that these positive outcomes came as some surprise to patients possibly because the

intervention was obvious and easy to adhere to. Interactions with patients changed from them reactively conveying the symptoms and burdens of constipation to an acknowledgement of how that they could overcome and/or prevent the problem by utilising simple methods. In most cases patients now considered themselves capable of managing their constipation and only liaised with the researcher as required, usually seeking confirmation that their self-titrated laxative regimens were appropriate and/or safe to use.

Patients were less concerned that HCPs displayed ambivalence or disinterest to their predicament other than a reflective sadness and realisation that they had probably suffered unnecessarily for so long. If constipation had been prevented sooner it is likely that related signs and symptoms would also have been abated during their advancing disease.

8.10 Achieving concordance

Concordance was based on identifying what patients felt was important and agreeing how they feel their constipation would be better managed in a 'shared decision making' which leads to 'shared understanding' (Jones 2003; Dickinson and Raynor 2003). The process worked well and was supported by the education component in which provided contemporary information of constipation and its management, especially in relation to laxatives and their use which is in contrast to the finding of Elwyn *et al* (2003) who note that patients often leave consultations with questions unasked or unanswered. In the CMC the researcher ensured that questions were encouraged and answered. In the absence of the aforementioned, Dickinson and Raynor (2003) state that television and the internet may be used as an alternative source for information but Jones (2003) points out that such information is often untailored, incomplete, irrelevant or wrong and therefore can add to the patients' feelings of anxiety, uncertainty and confusion.

An appreciation of the philosophy of concordance appeared to be underpinned by the patient education inasmuch as patients reported having a better understanding of how constipation develops and the use and role of laxatives. By combining the CMC framework elements most patients adopted responsibility for laxative titration based on their efficacy. The researcher is of the opinion that the time afforded to these patients during the CMC enabled them to relax and embrace the ethos of concordance through discussion and information sharing.

To achieve the most favourable outcomes for the patient the ideal should be that he or she would be concordant with taking their prescribed drugs. For success in this action research,

the issue of patient concordance with their laxatives was of great importance not only in order to optimise laxative efficacy and patient outcomes, but also in terms of data collection and ultimately in addressing the research aim and objectives.

8.11 Follow-up appointments

Each patient had a planned follow-up appointment that occurred within 10 days of their initial clinic attendance. The average number of CMC appointments was 3 (range 1 – 9) and follow-up telephone calls 2.5 (range 0 – 13). In most cases patients reported adherence to their new daily regimen. Follow-up appointments were also guided by the CMC framework other than the initial history taking which was omitted. A CMC follow-up consultation letter was sent to HCPs and filled in the medical notes along with a record of patient's telephone calls (Appendices 32 and 33).

Once the patients had achieved self titration there was minimal need for them to return for monitoring or any ongoing intervention. Some patients telephoned the researcher to report their current situation but this was more to maintain general support rather than any specific reason associated with the study.

8.12 Patients' evaluation of CMC

The patients appeared relaxed throughout the CMC consultations and freely discussed their management strategies that may have otherwise been considered personal and intrusive, thus implying trust.

8.12.1 Informal evaluation

During the CMCs conception there were no plans to formally evaluate the patients' satisfaction with the service and/or interventions as this process would have introduced a fourth stage to the research. However, in order to obtain an insight into patients' satisfaction a convenience sample of five patients who were no longer attending the CMC was informally asked, by the Day Care Sister, about their constipation and its management. All patients reported an easing of their constipation and that they found the CMC to be extremely beneficial. It was reassuring to note that patients had not sought further support from the CMC as they no longer experienced problems with constipation, and that self-titration and prophylactic use of laxatives had continued.

Other patients voluntarily proffered evaluative feedback of their satisfaction with the CMC. Most commonly patients reported relief that, finally, someone had been of assistance in the resolution of their constipation. The three patients who had reported that their stools were softer than they would have preferred and/or were experiencing faecal incontinence subsequent to the alleviation of their initial constipation, reported that this outcome was more acceptable than being constipated. In the latter instance the cause of incontinence was identified as being related to disease progression and a lack of rectal sensation as a result of the development of a degree of spinal cord compression (within the last few weeks of life).

“Fantastic, explained everything, don’t know why this helps but it does, I really don’t know what I would have done if you hadn’t been able to help, the education was really useful, I’m so delighted..... I can’t tell you how much better my life is now.” (EE)

Even in the absence of a formal assessment, some CMC patients identified their symptom mitigation due to the Clinic. For example, during the Unit’s day centre periodical assessment of patients’ symptoms and severity it was noted that patients attributed alleviation of their constipation and other symptoms to the CMC (Appendix 34).

Similarly, nurses in the adjacent cancer centre received positive feedback from their patients and subsequently the nurses became more proactive in referring patients to the clinic. In addition, a number of nurses became more diligent when they encountered patients with constipation and sought advice from the researcher regarding constipation management and identifying appropriate regimens.

A community specialist palliative care consultant relayed with excitement the positive feedback she had received from one of her patients. Seemingly, the consultant had struggled for several months to resolve the patient’s constipation, however, to no avail. However, within two weeks of attending the clinic the patient reported to her consultant that her constipation had resolved and that she knew exactly what to do to prevent it reoccurring. The consultant was so delighted that she made a point of contacting the researcher to convey the feedback. The following comments were recorded in the field notes:

“I reviewed Mrs. Jones last week and she just told me how you had helped her with constipation. She was so pleased, I’ve never seen her so happy. She says it (her constipation) has completely resolved..... I wanted to make sure you knew what affect you were having on people....” (Specialist Palliative Care Consultant 1)

This sentiment was also reported by the sister of another patient.

“Oh, I saw EE’s sister today and she told me that EE is so much better now (that her constipation has been alleviated). She asked me to thank you for your help.” (Specialist Palliative Care Consultant 2)

Overall, feedback indicated positive outcomes, both in the amelioration of the patients’ constipation and their general well being.

8.13 Problem resolution - the MDT approach

On the whole the CMC ran smoothly and successfully but there were occasions when the researcher sought additional support and guidance from members of the MDT to assist in the resolution of emerging issues. These were generally debated amongst the team members and resulting action plans were pursued by the researcher. Examples of such situations are presented in the following sections.

8.13.1 The ghost matrix

Two patients reported passing what they considered to be undigested food in their stools. One person described passing ‘peas’ whilst the other reported ‘corn’. The researcher discussed these scenarios with medical colleagues and a suggestion that these patients were taking excessive amounts of laxatives was ruled out as their stools were otherwise firm, frequent and easy to pass. Another theory proposed by one doctor was that, in his experience, some patients taking the opioid analgesia oxycodone hydrochloride have been known to pass the capsule of the drug in their stools. This discussion and a subsequent telephone call to the drug manufacturer confirmed that the patient’s analgesia, oxycodone hydrochloride, was impregnated into a ‘ghost matrix’ capsule which or that could be passed undigested. Furthermore, provided the drug was maintained in the gastrointestinal tract for a minimum six hours all the analgesia would have been absorbed thus optimising the efficacy of the analgesia. As neither patient reported experiencing recent escalating pain it was commented upon, by the medical team, that what had been expelled via the gastrointestinal tract was the ‘ghost matrix’ capsule which was evident on defecation and thus incorrectly assumed, by patients, to have been undigested food. The difference in colour (green peas and yellow corn) related to the different strengths of oxycodone hydrochloride. This information proved not only to be reassuring to patients that this was not necessarily as a result of disease progression, but also a learning curve for HCPs who may have arrived at a

similar conclusion, that of undigested food. This information was disseminated to HCPs within the Unit and via patients' post-CMC letter (Appendix 35).

It was important to disseminate this information given that this drug is commonly used in this client group and it was therefore important that HCPs were cognisant of these potential occurrences so that appropriate advice could be offered to patients. Failure to do so might result in patients being unnecessarily concerned in relation to their disease and its progression. Furthermore, without this knowledge HCPs could embark upon unnecessary time consuming and expensive tests and investigations. These would burden patients with the unpleasant task of stool sample collection, storage and delivery to the hospital or pathology laboratory.

It is acknowledged that the passing of undigested food may occur as a result of the cancer disease progression or patient's co-morbidities, for example malabsorption syndrome resulting in steatorrhoea (faecal matter that is frothy, foul-smelling and floats because of a high fat content), however, in the aforementioned case the medical team agreed that no further investigations were necessary unless further problems or symptoms arose which may be indicative of disease progression.

8.13.2 The use of polyethylene glycol

A situation arose whereby the researcher sought advice from medical colleague regarding a 34-year patient predisposed to an electrolyte imbalance as a result of one of her chronic co-morbidities. The question posed related to the safe use of polyethylene glycol, which contains electrolytes as a potential laxative for this patient. None of the medical team could afford advice, nor was it clear from drug information sheet or available literature (BNF 2008; PCF 2007).

A telephone call to the drug's manufacturing company assured the researcher that electrolytes in the product remain within the compound and are not absorbed systemically. When asked specifically if the drug could safely be used by a patient with renal acidosis the answer was in the affirmative. The aforementioned information relating to polyethylene glycol use was disseminated to all relevant HCPs (Appendix 36). The Unit's nursing and medical teams were also advised of the safety of polyethylene glycol for patients with renal acidosis thus contributing to their knowledge. The patient was advised and she subsequently used the laxative with good results and no adverse effects identified (Appendix 25).

Concerns were raised, by HCPs, about the use of polyethylene glycol. Often patients reported not liking the taste, therefore discarding it after a few sips. As a result, nurses were asking doctors for an alternative laxative before its efficacy was established. Due to the products known efficacy in patients with cancer the medical team were keen to continue the therapy at least until those with severe constipation had been resolved. When the researcher spoke with the nurses and observed their practices it became clear that the product was not being used appropriately for the client group or to its best advantages to make it more palatable to patients. In some cases the product, one sachet of polyethylene glycol, was being mixed in a tumbler of water (200-250 mls) as opposed to the recommended 125 mls. Nurses acknowledged that they simply 'guessed' the volume on the basis that 'a little extra fluid' would not do the patient any harm but in on reflection their actions were counterproductive as patients could not tolerate the volume. In order to ensure that future doses were mixed in 125 mls of water, a plastic cup was marked to indicate the volume and then pinned to the wall in the treatment room as a guide. Other questions were also raised about the use of polyethylene glycol therefore the researcher contacted the drug manufacturing company and disseminated the information to the Unit's staff (Appendix 37), during formal presentations and to patients using the product.

8.14 Unmet needs

The researcher found that not all consultations dealt solely with the management of constipation. Several patients presented with other issues. Although not by any means exhaustive, one or two of these instances are described here by way of examples.

In one instance, the CMC appointment was delayed as the patient was showing signs of discomfort in sitting. On further exploration it became evident that he had developed bilateral thigh and scrotal oedema within the last few days and had been unsuccessful in getting an appointment to see his GP and therefore not received any treatment. This gentleman's distress was so palpable that on enquiry the researcher was able to secure an appointment with a member of the Unit's medical team who agreed to review the oedema as a matter of urgency. The patient was offered the option to reschedule the CMC appointment but chose to continue, evidently reassured by the fact that he would be seen by a specialist that day. In similar vein, one patient became breathless so the consultation was suspended whilst she recovered but was recommenced at the patient's request following a 20-minute break.

Whilst it is acknowledged that some of the actions taken fell outside the remit of this research, the researcher within her professional nursing role and duty of care was concerned

for the well being of these patients and considered that failure to take appropriate action would have been unprofessional and unethical.

The researcher acknowledges that disease progression was probably present in all patients but it was not expressed explicitly as this might have caused a great deal of distress and/or distracted from the consultation in hand. When disease progression was alluded to by patients the researcher suggested that individuals contact their oncologist who could advise them as necessary. This was supported with the explanation that the researcher was not a doctor and that contemporary information in relation to their disease was not within the scope of the CMC. In the event that patients became disturbed about their disease/prognosis the Unit's social team members were available to provide psychological support, however, none of the patients required such input.

8.15 Dissemination of findings to HCPs

The dissemination of findings and advancement of practice is one of the central tenets of action research. Therefore, the local MDT and the wider community of GPs and community nurses were involved in as many elements of the study as possible. These opportunities were both informal and formal. Some of these are indicated in this section.

8.15.1 Informal: through communication

In some cases, the community teams sought advice from the researcher relating to management strategies. In these instances community HCPs predominately sought confirmation that their patients' self-titrated laxative regimen was acceptable. Thus evidence that community HCPs were taking more interest in their patients' constipation management, which is in contrast to the findings of the patient interviews and focus groups (Chapters 5 and 6).

In addition, several telephone calls were received from HCPs as a direct result from the sending of the aforementioned letters and through word-of-mouth as regards this research study. Of the 12 telephone calls received from HCPs eight originated from community nurses (Macmillan or district nurses) and four from ward nurses (generally or from the Unit). The nature of guidance sought related to cancer patients with constipation and specifically advice relating to choice of laxative, reassurance regarding optimum dose, or in one instance, encouragement to expedite a patient physical assessment by their GP.

In the above scenario it was reported to the researcher that the patient had an advanced ovarian cancer and had not opened her bowels for nine days. The GP, allegedly, had refused to see the patient and requested that an inexperienced nurse to perform a digital rectal evacuation and then administer an enema. In this instance, the researcher briefly discussed important issues pertaining to patients with ovarian cancer and or those who may have obstructed. Thereafter, the nurse reported feeling better informed and more confident in taking the researcher's advice which was to seek further medical support from the GP and encourage a medical assessment. Furthermore, the researcher recommended that, given the probability of encountering similar situations in the future, it might be useful to develop advanced skills of performing digital rectal examinations. The nurse valued the advice and was given of a contact telephone number to explore options of digital rectal examination training. In addition the nurse was provided with copies of relevant literature to inform not only her practice but also other members of her team thus perpetuating the cycle of this action research which aims to improve skills, knowledge and communication to alleviate constipation in patients with cancer.

8.15.2 Formal: presentations by the researcher

Dissemination of research findings and educational presentations were conducted concurrently throughout the five-year course of this research (Appendix 38). Furthermore, these meetings provided a platform for HCPs with varying status (Appendix 39) and from diverse settings to compare and contrast their practices: this also supported the rationale for this research and identify training needs. For example, during a symposium on constipation management and the preliminary findings of this research, one palliative care consultant objected to the practice of prescribing in the CMC stating that;

“ to teach GPs you need to send the patient back to them to get their prescription.” (Consultant)

The ensuing discussion at the symposium identified several issues about health care profession education *per se* however the majority of the delegates argued that it would be both unethical and inappropriate to use patients as the medium for HCP education as palliative care patients comprise a vulnerable group. Failure to provide prescriptions in the CMC would result in unnecessary time delays therefore subjecting patients to prolonged suffering and an increased risk of further complications such as bowel obstruction or perforation. The discussion at the symposia concluded in favour of providing prescriptions at the CMC for two main reasons: Firstly, it was deemed to be in the patient's best interest

to endeavour to alleviate their constipation as soon as possible, thus preventing further distress and/or complications. In addition, the symposia delegates postulated that as a result of the CMC's education element, especially the role and use of laxatives, patients would be more empowered in their constipation management and would therefore want to expedite new laxative regimens without delay.

During discussions post presentation delegates expressed an enhanced understanding of the actual and potential problems of constipation and its management, including the need for patient education. Some subsequently liaised with the researcher for advice on a named-patient basis and appropriate prescribing. This type of dissemination became a normal practice for those who joined the Unit's medical team as part of their rotational placement. The researcher became a source of support to HCPs, especially those practising on the Unit when faced with complex problems.

8.15.3 Promotion and dissemination by groups

Community teams also became more aware and supportive of the CMC. This was as a direct result of the patients reporting a successful outcome to their constipation management and their newly acquired ability to titrate their laxatives. Following an explanation, supporting evidence and reassurance from the researcher the nurses seemed more comfortable with the patient's regimen. It also appears that the community teams were keen to maintain contact with the researcher as a support mechanism for help and advice when managing their patients' constipation.

Similarly, over a period of time, the existence of the clinic, this research, dissemination and the researcher and her work *per se* filtered to the community teams and other HCPs. As this research progressed the researcher became aware that her knowledge base and skills pertinent to research methodology and methods in cancer and palliative care had increased along with her confidence. As a result of this study and her increased skills and knowledge, the researcher was identified by other HCPs as reference point for advice and support on constipation management *per se*. This role further extended to advising and supporting colleagues (HCPs and professionals allied to health) on other issues relating to cancer patients and palliative care, for example; research, audit, patient assessment, symptom management, service improvement and development. As this research concludes, the nursing and medical team is considering a permanent provision of the CMC within the Unit and the resulting implications on limited resources; especially in terms of time and the financial burden. In contrast however, some HCPs are currently in favour of not only

keeping the clinic but further developing it to encompass the management of other distressing symptoms.

One of the Unit's consultants and two specialist registrars reported to that this research was alluded to by a palliative care doctor exploring the use of new drugs for constipation management in patients with cancer. The palliative care doctor was aware of this study as she had been an attendee at one of the formal presentations made by the researcher. It appears that during her presentation at a prestigious annual opioid conference in November 2007 she made positive reference to the nature of this research and how it complemented her own work. This further supports the evidence that dissemination has occurred by HCPs.

8.16 Evaluation of dissemination (HCPs)

Some attendees to these presentations subsequently worked alongside the researcher at the Unit and conveyed how informative the presentations had been and reported a positive impact on their practices, especially in relation to constipation management. Doctors reported how the results of this research raised their awareness of the importance of appropriate constipation management. The following examples were recorded in the field notes also reflect the comments from other doctors who joined the Unit as part of their training rotation:

"I attended your talk at the Drugs and therapeutic day recently and found your talk really interesting. It really opened my eyes to the problems. I hadn't realised how bad things were. What you said really made sense, it was so useful." (GP trainee)

"... I'm a lot more diligent now when talking with patients and think more about what I prescribe and what I say to them." (SpR)

"Your talk was excellent. So interesting.... we need to get this message across to our doctors..... When you have finished your research would you consider working with us to develop an education programme for doctors looking at these issues? (Consultant and SpR from a hospital in London specialising in oncology and palliative care)

"I think some of it was basic stuff but overall there was a lot of it I didn't know. I would have liked more information on how to do digital rectal examinations." (SpR)

On three separate occasions HCPs working in the day centre unit reported overhearing patients (study recruits) advocating the CMC to other patients and describing how valuable they had found it in resolving their constipation. This type of discussion is commonplace in

the Unit day centre where patients frequently discuss and compare their illnesses, prognosis and treatments. Thus, clinic recruits encouraged other patients with constipation to seek referral because the CMC had worked.

Although HCPs were not formally asked to comment on their perceptions of the CMC (advantages and disadvantages) it appeared that as the CMC evolved and became more established HCPs were more in favour and accepting of the service as patients and HCPs appeared to benefit. During the early implementation of the CMC two consultants regarded the CMC as labour intensive and of benefit to only a limited number of patients, thus not cost effective. Over the ensuing years both consultants made CMC referrals and received thanks from their patients for doing so as in all cases constipation had been alleviated. It is reassuring that this positive feed-back was conveyed to the researcher and is thus evidence of dissemination and CMC evaluation, albeit informal.

8.17 Summary

This Chapter has presented the finding of the CMC. Overall, the planning, initiation and implementation of the CMC has been established and the advantages of collaborative approach outlined. The referral process and recruitment of an appropriate sample serve to confirm the suitability of the methods and process utilised and the need for the CMC. Patient self-referral ensures patients timely attendance and renders them less reliant on an unsound mechanism for constipation management. Doctors appear to endorse the process as no issues of complaints or concern were received.

The 29 patients recruited into the CMC were identified over a two year period, thus affording what would be considered a robust sample size for a piece of qualitative research, especially as approximately half had advanced disease. Data were collected from a variety of sources and, although complex and time-consuming, the resultant in-depth data is presented in this Chapter, along with patient narrative, as evidence of the holistic approach to constipation and its management afforded during the CMC.

The main outcome measures relied on patients' reports of to what extent that they considered that their constipation has been ameliorated and the mechanism by which this was achieved, such as patient education and/or ongoing support. Support and continuity of care was proffered and in most cases, maintained until death. The average number of CMC attendances was three as in most cases telephone consultation was reported as being as

effective and more convenient to patients, especially those who had limited life expectancy and/or who had difficulties with transport.

Patients had learnt that laxatives are effective provided they are used consistently and prophylactically. The learnt experience was underpinned with the new knowledge patients had acquired as part of the clinics interventions including the acknowledgment that self-titration was both possible and safe, and the desires of patients to wean themselves off laxatives would be unrealistic, especially in light of why they had developed constipation in the first place. Patients reported that their increased knowledge and understanding of this had enabled them to be more accepting of laxative use and the clear explanation proffered by the researcher had made understanding the problems easier.

There is strong evidence that concordance was improved, that patients took laxatives prophylactically and that self-titration with laxatives is both possible and effective. Evidence of this was apparent when patients sought clarification and/or identified regimens that they planned to commence. Following reassurance the cycle continued along with general information exchange that were simplified due to the patient-defined dialogue, that is patient's descriptors were used by the researcher thus reinforcing their appropriateness.

The collaborative MDT approach was paramount as without this support, advice and guidance it is unlikely that the CMC would have achieved its aims and objectives. A sense of ownership prevailed and was maintained as the CMC became more established and assumed to be one of the Unit's services rather than a research project. The researcher disseminated extensively which not only promoted and raised awareness of the CMC but provided a medium for raising the profile of constipation and its management in patients with cancer. Delegates and formal presentations reported improving their own practices as a result of these disseminations. Whilst it was not possible to formally evaluate the CMC there is evidence to suggest that patients and HCPs benefited from its existence and the process of its development and application.

This stage represented an innovative change to current practice within the Unit and emerged from the first two stages of the study. The perceived benefits of adopting an action research methodology became evident as, intrinsically throughout the CMC, its cyclical nature afforded the study with evolving refinements in patients' best interests. In addition, the dissemination (amalgamated and abridged version of slides used during presentation: Appendix 40) of constipation management strategies by both patients and the researcher to

affiliated HCPs, further encompassed the philosophy of action research. This dissemination and cyclical process adopted are evident in the findings presented in this Chapter.

Chapter 9

Overall findings and conclusions

9.1 Introduction

This Chapter brings together the overall findings of the study and presents them as a discussion chapter that addresses the main findings of this action research study. It is presented in five sections the first of which introduces the conclusions from the research process and the effectiveness of the action research process and the team working of the HCPs. Although the study was primarily centred on the experiences of patients, the action research process that guided it was found to be greatly successful in the achievement of improving patient outcomes. The second section examines the change that was made, namely the CMC and this quite naturally leads into the third section that concludes the patient's perspectives that emerged from the data. The perspectives of HCPs are presented in the fourth section which then introduces the researcher's personal reflection of the whole process.

The review of the literature that comprised of the steps of this research evidenced an abundance of literature relating to the causes of constipation, management strategies and evidence of non-compliance with laxative regimens. However, as the researcher's initial observations indicated laxatives were poorly prescribed by HCPs and used suboptimally by patients. The research has therefore concentrated on the improvement of these practices and in so doing how to enhance patients' outcomes. In contrast however, there was no evidence suggestive that working more collaboratively with patients utilising concordance and a patient focused approach, such as those used and developed in the CMC, had ever been previously explored to improve constipation management in patients with cancer.

9.2 The Research Process

The nature of the process proved to be most successful in achieving the aims of the research. The process of examining various methodologies and methods afforded the researcher a deeper understanding of the nature and scope of the research processes and ensured that appropriate methods were used throughout. The in-depth examination of research methodology provided a launch pad for this study. In addition, the researcher was able to develop appropriate research skills thereby one of the main aims of the study was achieved;

developing research knowledge and skills to underpin her role of research and audit sister as outlined in the introduction to this study. The researcher was able to work collaboratively with patients and HCPs to capture data from both groups to advance the management of constipation in cancer and palliative care.

9.2.1 Appropriateness of design

The overall design and methods used during this study proved to be appropriate in ensuring that data obtained were both meaningful and constructive in informing the various stages of the research, thus harnessing the advantages of an action research methodology. Due to the study's nature and the methodology used it was possible to raise awareness to HCPs of the need for further research utilising a qualitative paradigm, as the emphasis of research inquiry within cancer and palliative care is located within.

Thus, not only were the totality of the primary and subsequent problems explored overtly within the local health care profession but also the process incorporated the philosophy of user involvement (NICE 2004) for service planning with the resultant outcome, that of a patient-focused clinic that aimed to reduce the incidence and/or severity of constipation in patients with cancer. In so doing, the researcher considers that the central principles of action research: participation, democracy with concurrent contribution to change (Meyer 2002; Thomas O'Brien 2006) were accomplished.

The flexible cyclical nature of action research, where one stage emerged from and was resultant of another, proved to be successful. The modified action cycle (Figure 6) that emerged as the most effective to guide the process worked well for both groups of respondents, HCPs and patients with cancer and in palliative care. This also encouraged a collaborative approach in decision making and planning with both groups and presents a model that will inform future like research and audit on the Unit. The action research cycle proved to be efficient in gaining ongoing and meaningful data. Formal data emerged from meetings, such as stage initiating, whilst individual encounters (interviews and clinic consultations) generated more flexible data based on individuals' needs. The cycle adopted an evolving, dynamic structure that established an effective and innovative change in practice.

9.2.2 The nature of the team

One of the main tenets of this action research was to directly disseminate research findings into practice thus ensuring informed and evidence based care. The central importance of the MDT as the vehicle for support, collaboration and dissemination in achieving and maintaining this has been debated at the outset and highlighted throughout the study. As initially outlined in Chapter 1, identifying the primary problem of constipation management was based on researcher experience. However, through the medium of the MDT forum it was recognised that it was a worthwhile area of practice to examine; one that could lead to a change in practice that would greatly benefit patients. Therefore, the action research enabled an inclusive, democratic planning process where the MDT, of which the researcher was an equal partner, embraced the study and worked collaboratively to reach agreement regarding planning and ultimately change of current practice. In the event, the MDT proved invaluable in the resolution of any emerging problems offering advice as appropriate. This in itself reaffirmed a team ownership of the study and acted as a covert form of dissemination of findings. Importantly, the patients were able to adopt an equal and central role in the resolution of their constipation. They were able to offer their experiences and work with the researcher towards achieving titration of their laxative regimens. The action research approach proved to be most effective in the breaking down of professional barriers and promoting true team working within the Unit and in the local community. This in itself was instrumental in initiating an effective change to practice, that of the CMC.

The medical team offered teaching and on-going medical support as and when required. Although evidence has been presented that illustrates the nature of this continual support it is worth emphasising the value of their input in achieving the successful outcomes of the CMC. Again this exemplifies the team approach that was fostered and central to the success of the CMC. For example, the practice of physical examinations was demonstrated, explained and observed by senior clinicians to ensure that the researcher's knowledge and skills were appropriate. In the few instances when advice was sought the medical team were on hand and willing to provide it. Therefore, it is concluded that the availability of medical support and advice further enhanced the CMC's aims and objectives thus affording patients with the advanced expertise afforded by the specialist palliative care medical team.

9.2.3 New MDT members

The nature of the MDT introduced a different and evolving feel to the study. In most action research studies the group of people central to the research remains constant throughout the

process (McNiff and Whitehead 2006). In this instance, the transient nature of medical trainees and nursing staff had to be accommodated. As new members joined the MDT it was often necessary to have impromptu conversations with the replacement staff members to apprise them of the study and gain their support as required (Meyer 2002). For example, core medical staff members were not always available to authorise patient prescriptions generated by the researcher. When prescriptions were proffered to junior doctors for authorisation a brief summary of the study was often necessary followed by an in-depth discussion about choice of laxative regimen. This justification of regimen was always appropriate and beneficial for various reasons. Firstly, the researcher was obliged to present a synopsis of the patient and their respective presenting problems pertaining to constipation. The benefits being that the researcher was challenged to ensure that her judgement was evidence based and sound. However, in relation to laxative regimens it transpired that junior doctors often lacked knowledge regarding constipation management and therefore the researcher's recommendation met with the doctor's acceptance of the rationale afforded and thus authorisation of the prescription. Therefore, at a local level the action research cycle was influential in as much as when a problem was identified action was planned, taken and evaluated. Once again the researcher was able to disseminate findings and the trainee doctor was better informed about constipation management in patients with advanced cancer.

One of the unexpected outcomes of the study emerged from the aforementioned transient group. As the main group of HCPs moving in and then out of the MDT consisted of specialist registrars and trainee GPs on rotation, they took their newly acquired knowledge with them to other clinical areas; some of these were in local to the Unit whilst others were scattered nationwide. The results being that an understanding of constipation management, even if incomplete was thus disseminated to other services to the benefit of patients.

9.2.4 Dissemination of knowledge and understanding to MDT and HCPs

The dissemination of findings became a natural process and occurred at all stages of the research, from the initial and extensive review of the literature to the CMC and its findings. This was achieved at formal presentations to HCPs and informally during MDT meetings, patient encounters and *ad hoc* conversations. Overall, the promotion and dissemination of the CMC and its findings were positively received and no challenges or concerns arose. This section concentrates and concludes the processes of dissemination to HCPs.

At the outset only a handful of referrals were received from GPs. However, further referrals were made as the study developed and GPs became more aware of positive outcomes.

Whereas some HCPs referred patients to the CMC it became evident that others merely required a resource to gain information. A number of HCPs requested advice regarding constipation management in order to expand their own knowledge and maintain optimum patient care. The MDT agreed that this would be yet another opportunity to effect change to current practice and would provide an unplanned means of enhancing practice through dissemination. In the event it proved to be simple to facilitate and the researcher, as part of her role, accepted the responsibility of support for HCPs. Given the success of this resource, and the varying efficacy of some HCPs practices, it is concluded that a comprehensive constipation management support and advice help line should be maintained to benefit both patients and HCPs.

9.2.5 Collaborative working with the MDT and other HCPs

The researcher worked collaboratively with all the other members of the MDT and staff practising on the Unit throughout the action research process. Working in partnership with the medical team ensured the acquisition of shared knowledge relating to the management of constipation and promoted implicit dissemination of findings. Discussing specific management strategies created debates pertaining to the advantages and disadvantages of various approaches thus maintaining the best interest of each patient. In the event of complex presenting symptoms and/or concerns with proposed regimens, informal meetings promoted the distribution of new information (such as obtained from pharmacological companies) and the sharing of experiences.

This method of dissemination improved the researcher's knowledge and skills of constipation management in patients with advanced cancer. It also served to raise awareness of what was perceived, by patients, to be a lack of doctors' interest and time in address constipation. All patients were receiving care from their GP and in some cases several doctors and HCPs were actively involved in the individuals' care and support. In spite of this medical support, in many instances constipation identification and/or assessment had not occurred. Frequently offered reasons for this shortfall were that the patient had not highlighted constipation as a problem. The subsequent post-clinic discharge letter revealing the severity of patients' constipation, discussions and management strategies proved effective in highlighting this lack of diligence of medical assessment. Without this action research the opportunity to draw doctors' attention to the impact of their suboptimal management of constipation in patients would not have presented.

9.2.6 Rigour: Issues of trustworthiness

Through the processes adopted and previously debated, the researcher believes that the study has demonstrated a high level of credibility, dependability and confirmability which are viewed as the overriding goal of qualitative research (Polit and Beck 2008). The emerging data and findings were tested by the MDT throughout the process and have been presented with positive response to various groups and external professionals on several occasions. The feedback gleaned from the dissemination of the findings leads the researcher to consider that they could be transferred to other similar specialist settings.

9.2.7 Success of an action research approach

Proactive measures enabled change, enquiry and service development. In contrast to pre-study experiences (such as those outlined in Chapter 1) the researcher found that initiating changes and challenging the *status quo* in the guise of ‘doing research’ was more acceptable to clinicians. HCPs appeared less defensive and more co-operative, often volunteering to participate in the study, or at least, provide guidance and advice when necessary. Thus, evaluating proactive measures and assessing their value became issues of debate in which HCPs were keen to be involved, provide theories and suggest further solutions. In many ways dissemination became a natural phenomenon that occurred during day-to-day discussions and by request at formal meetings and presentations at a local and national level.

9.3 The change: CMC

The change of practice, namely the introduction of the CMC, proved to be most successful in the amelioration of constipation in patients with cancer and in palliative care. The CMC represents an innovative addition to the provision of care in the Unit and the local community and, as far as can be established, is the first to be developed nationally. It arose out of the findings of the patient interviews and the HCP focus groups. The MDT members embraced the process and worked collaboratively with the researcher throughout.

9.3.1 Benefits of the CMC

By listening and encouraging patients to articulate their experiences, concerns and understanding of the reasons why their constipation had become problematic provided a structure on which to plan individualised patient-focused care. Thus, misunderstandings, poor management strategies and non-compliance were addressed during the remaining three elements of assessment, education and concordance. Encompassing the practical element of

conducting a physical examination was perceived by patients as being thorough and comprehensive. The physical examination proved to be a useful way of affording patients and the researcher with an objective evaluation of the individuals' constipation, often confirming patients' subjective accounts and dispelling fears and/or anxieties that their cancer had progressed. Whilst it is acknowledged that, in many cases, disease progression is also likely to have taken place, patients were reassured that endeavours to alleviate constipation and its related symptoms would be made on the basis that they were also suffering with a degree of constipation.

Not only did the physical examination serve to identify and subsequently monitor the extent of patients' constipation but also appeared to convey to them that the clinician was both knowledgeable and interested in alleviating constipation, which was in contrast to their experiences in the past with HCPs who rarely conducted physical examinations in relation to constipation management. This enhanced perceived credibility became central to the success of the CMC as it encouraged the patient to adhere to any subsequent advice and constipation management strategies. It is concluded that all HCPs should ensure that patients, when necessary, have access to timely physical examinations (abdominal and/or rectal) as part of the constipation assessment process. Initially it will be necessary for each clinician to establish who is responsible for conducting physical examinations, especially between GPs and district nurses, as this is unclear locally.

9.3.2 Identifying appropriate laxative regimens

It is concluded that by utilising the abundance of reliable knowledge available in relation to laxative pharmacology, HCPs can offer safe and effective laxative advice to their patients, which is in contrast to current practices where under-prescribing prevails.

The efficacy of laxatives is generally recognised and has been highlighted in the literature review. However, it became apparent during the research that patients for reasons that have been previously highlighted failed to take them appropriately. The success of the CMC was achieved quite simply through the process of partnership that included an explanation of the causes of constipation, the nature of laxatives and the manner in which laxatives work. This educational process was enabled by the preparation of the researcher who informally studied the pharmacology of laxatives in preparation for the CMC including regimens and combinations, dose ranges and side effects thus, ensuring any advice given was evidence based, safe and likely to be efficacious. Whilst this knowledge is considered invaluable, the findings from this research suggest that the majority of patients required only standard doses

of laxatives (as opposed to escalating and higher doses than considered the norm) the benefits being acquired through consistent and prophylactic use. For those experiencing unacceptable side effects from previous regimens, alternatives were prescribed with good effects and to patients' satisfaction. In instances when concomitant illness and potentially distressing side effects of laxatives caused concern, the researcher's knowledge informed the process and prevented unnecessary problems. In addition, the raising of prescriptions for laxatives by the researcher, that were signed for by medical colleagues, worked effectively and demonstrates a process that was both timely and beneficial to the patients.

9.3.3 Patient self-titration of laxatives

Through partnership working with the patients, all patients (other than those who died shortly after recruitment) demonstrated the ability to self-titrate laxatives which they reported to be efficacious. Self-titration was always based on stool form and ease of defecation and subsequently monitored for changes; all of which were identified by patients themselves. The researcher considered all patient self-titrated regimens to be safe and appropriate. Therefore, it is concluded that patients are able to safely titrate their own laxatives, however, this needs to be underpinned by appropriate education and ongoing advice and support, either by telephone or follow-up appointments.

9.3.4 Education: causes and consequences of constipation

The findings of the research indicate the centrality of education to achieve optimum management of constipation in patients with cancer and in palliative care. The dissemination of findings to HCPs has been highlighted in the previous section and here this is extended perhaps equally importantly to the patients themselves. Through the medium of interview the researcher was able to proffer advice and support to those suffering with severe constipation and redress misconceptions. Generally, patients were ill informed about the causes and consequences of constipation *per se* and overall were unaware of the contributory factors and profound effects resulting from cancer and its treatments. Without such knowledge is it understandable that patients assumed that nothing could be done as, for many, living with a degree of constipation had become the norm. However, it is concluded that reversing the causative factors in patients with advanced cancer in itself may be problematic and/or ineffective, therefore, education needs to focus on the use and role of laxatives.

In order to facilitate a concordant approach to laxative use it is important to address patients' misconceptions that may otherwise deter their use. Being aware of the 'explosive episode' and often accompanied overflow diarrhoea was identified as a positive step toward alleviating constipation which was in contrast to patients previous beliefs whereby they had assumed that they had taken too much laxative and therefore subsequently stopped taking them. Similarly, to dispel the belief that 'nothing else can be done' it is important to make patients aware that alternative laxatives are available should their current regimen be unacceptable, thus ensuring alternatives can be tried as and when appropriate.

By affording patients with such information it is concluded that adherence to laxative regimens are optimised and subsequently titrated based on stool form and ease of defecation, thus harnessing the benefits of prophylactic use.

9.3.5 CMC: resources

This section has discussed the overall success of the CMC which generally ran smoothly. However, one problem was not foreseen at the planning stage and essentially arose out of the success of the CMC. Despite the overall achievements relating to the establishment of HCP and patient support for the CMC one shortfall was quickly identified. Whilst the need for resources during the development and setting-up of the clinic was viewed as inevitable, once established, additional administrative support became necessary and this had not been predicted. Few additional resources had been anticipated or were readily available as referrals increased. This situation was eventually resolved through negotiation within the MDT where secretarial support was identified. Although problematic at the time it is worth noting that without the study the demand, nature and extent of resources needed would not have been identified.

9.4 Patients' perspectives

The study set out to explore the patients' perspective and these were initially explored in stage one interviews and thereafter in the CMC. The patients provided insightful information that was vital to the study and the advancement of patient care. It is apparent in the data that the patients and HCPs had very different perceptions and priorities relating to the management of constipation. The HCPs pursued the medical imperatives of saving life and therefore concentrated their input and interest to this end. Whereas the patients were obviously anxious to be cured of their cancer they were also concerned with the management of their constipation and general quality of their daily lives. In both stages of the research,

where patients were central to data collection, it was evident that they considered that their reports of constipation had more or less been ignored, treated as something that was of little consequence or as a result of non-compliance with their medication.

The fact that the researcher had dedicated time for patients to talk about their constipation in itself worked extremely well. The four key areas identified in the CMC framework (history taking, assessment of current constipation status, education and concordance) were covered at a pace to suit each patient and to meet their individual needs. The patients reported the extent to which they appreciated the opportunity to discuss their constipation with an HCP who was actually not only willing to listen to their concerns but also make a concerted effort to work towards a resolution. By listening to and working in partnership with patients they became empowered which was instrumental in achieving the self titration of their laxative regimen. The interviews highlighted that patients often found HCPs to be 'too busy' in general, thus both parties appeared reticent when discussing constipation. Given the current climate of limited health care resources it is unlikely that patients will be afforded more time to manage their constipation, especially from GPs whose average consultation time is only 11.7 minutes (DH 2007).

The ability to manage their constipation emerged from a rigorous effort to provide patients with the knowledge and understanding of the condition and the purpose and role of their laxatives. This in itself was viewed as a relief by some and a regaining 'a life' by others. The educational tools that were used in the clinic but arose out of the interview data were most effective as illustration and explanation of the workings of the bowel and possible causes of their constipation. These were readily assimilated into current practice both on the Unit and by other HCPs as tools to aid future practice.

9.4.1 The impact of constipation

The added burden that constipation placed on patients at an extremely distressing time of their lives was a constant theme that ran through all the data and patient encounters. Being diagnosed with cancer immensely impacted on patients physically and psychologically and engendered fears about treatments, prognosis, death and dying. Although patients regarded their constipation as troublesome the fact that HCPs disregarded it conveyed to the patient the sense that it was unimportant. The level of disinterest afforded to patients engendered feelings of helplessness and one of being relegated to suffer in silence because no one really wanted to listen, the effects of which had a detrimental impact on their quality of life. Therefore HCPs need to be aware of such feelings which are paramount and therefore should

be addressed accordingly. The most effective method of achieving this is to initiate appropriate and timely interventions to alleviate unnecessary suffering in a vulnerable group with limited life expectancy.

9.4.2 Psychological affects: reducing anxiety, stress and fear

The introduction of the CMC enabled patients to articulate their fears and anxieties in a way that they had not been able to do in the past. Such expressions in themselves enabled patients to unload and feel less stressed and anxious in the knowledge that assistance and resolution of their constipation may be forthcoming. An alleviation of constipation reduced patients' anxiety, stress and fears which further impacted on their relationships with family and friends, whereby enjoyment in their company returned. Constipation was one less thing to worry about and it actually became manageable to facilitate social engagements thus eliminating anxiety and stress. Outings and engagements were more manageable and pleasurable. Misconceptions about disease progression meant that fears had, albeit temporarily, subsided as had associated physical and psychological symptoms. Fears of imminent death, resulting from incorrect physiological assumptions, were allayed thus reflecting a more realistic prognosis, thus further reducing anxieties around death and dying.

Suffering in silence was no long necessary as concerns were believed and action taken that reflected an appreciation of the reality of the profound impact constipation had had on their lives. Stress and anxiety changed to optimism and hope and subsequently jubilation when constipation had been relieved. Patients were psychologically less concerned that HCPs were ambivalent or disinterested in their constipation management as support from the CMC was always available.

It is concluded that patients report a reduction in their stress, anxiety and fear as a result of the CMC, even prior to alleviation of their constipation, thus having a positive impact on their quality of life.

9.4.3 Empowerment: shifting the focus

Empowering patients allowed them to take control at a time when facing impending death often renders individuals as powerless and without hope. Making choices and influencing their management strategies demonstrated to individuals that their ability to alleviate their constipation resulted in reduced physical and psychological burdens thus improving their quality of life. Given the poor prognosis of many cancer patients with advancing disease it is

reassuring that improvements in quality of life can be achieved by focusing on alleviating the physical and psychological impact of constipation.

Patients' misconceptions that constipation was inevitable and untreatable changed to reflect a more positive approach encompassing possible methods of preventing recurrence based on their new knowledge base. Patients no longer used negative descriptors to explain their experiences of constipation but rather as a measurement to predict a degree of constipation for which they would titrate their laxatives. Patients were less reliant on HCPs and more in control and empowered to take appropriate action to prevent and/or alleviate constipation as necessary. It is concluded that the negative beliefs of patients and their dependence on HCPs can be modified to empower patients to take more control with their constipation management.

9.5 HCPs perspectives

The findings of the study indicate that HCPs perceptions of constipation management varied from those of the patients. The researcher considered that the HCPs that comprised the focus groups were taken aback by the comments made by some of the patients that were interviewed. The GPs in the groups had not previously viewed constipation management as being of particular importance to them: often considering management to fall within the scope of district and Macmillan nurses. Conversely the district and Macmillan nurses judged it to be within the role of the GP. Of particular importance was a lack of insight about the complexities surrounding identification of constipation, reliability of patient report and HCP data, patient assessment and responsibilities, concordance and the additional challenges presenting in patients with advanced cancer. The only consensus reached related to the prevalence of constipation and the fact that no one accepted responsibility for its management.

The GPs initial reactions to the invitation to participate in the study were interesting in as much as they were surprised that such research was being undertaken. On the other hand the nursing members of groups appeared to recognise the importance of constipation management to their patients. There are many reasons why this should be the case. The medical HCPs quite naturally were more concerned with initiating and monitoring life saving interventions. This is also the expectation of the patients, some of whom were reticent in raising the issue of their constipation in what was a limited time opportunity. The nurses in contrast usually spent more time with the patients and were perceived perhaps

differently by them culminating in the situation where the patients were more likely to raise their concerns.

The researcher considered that the HCPs, especially the doctors were sometimes locked into their pre-conceived ideas of what constituted scientific evidence and sometimes struggled to fully appreciate a qualitative research study. As the study progressed they became more accustomed to the processes and ultimately they embraced the process in its entirety.

9.5.1 Dissemination

Following dissemination, HCPs reported having an enhanced understanding of the totality of the problem and in most cases stated being, or at least aiming to be, more diligent in their practice. The latter intention was more evident in focus group participants, probably due to the small number of HCPs being provided with contemporary findings relating to their patients.

The process of dissemination occurred concurrently throughout this research and afforded contemporary research finding to HCP who will care for patients with advanced cancer. Although each HCP would be involved with such patients to varying degrees, it is concluded that through dissemination the profile of constipation and its management have been raised. All HCPs were afforded the message that patients with advanced cancer are suffering unnecessarily with constipation because doctors and nurses are remiss in their identification and treatment of the condition. The contemporary findings of this study were afforded during dissemination as they demonstrate that constipation in patients with advanced cancer can be alleviated by adopting a patient-focused holistic approach that encompasses patient education in order to facilitate joint decision making with patients and improve concordance. Many HCPs reported being more diligent in their practice and all were afforded the researcher's contact number should they require further advice or support on constipation managements and/or to request further dissemination. It is reassuring that a snowballing effect occurred in which HCPs disseminated knowledge of this researcher to their peers and that, following her agreement, the researcher has been included in HCPs educational programmes.

Dissemination, presentations and teaching continued throughout this research (Appendix 37) including a poster at an annual nursing conference (Appendix 41). Evidence suggests that delegates found these clear and easy to understand and that they learnt something valuable (Appendix 42). Further dissemination is underway at the request of colleagues and

professional bodies (Appendix 43, 44 and 45) and as initiated by the researcher to a wider audience via a second proposed national poster (Appendix 46).

9.6 Researcher learning: reflection

On reflection the researcher considers that the action research study was most successful. The involvement of both HCPs and patients as respondents and referring to the MDT for guidance and support proved to be quite challenging at the outset. However, as the research process unfolded and the researcher became more confident in her research knowledge and skills these interactions became more manageable. The researcher, although part of the MDT from the outset in her role as research and audit sister developed in professional stature and credibility not only in her clinical expertise but also her research knowledge and skills. This element was important as during the span of this study the researcher was also responsible for the conduction of other various research studies and drug trials. It also constituted one of the main triggers for undertaking the study.

On reflection, the researcher considers that the action research approach that was adopted after reviewing several alternative qualitative research paradigms was most valuable in harnessing the MDT and Unit staff in the development of nurse-led services within the local area. The methodology provided the researcher with knowledge and commitment to advance collaborative partnership working with HCPs and patients. The researcher agrees with the advocates of action research such as Glasson *et al* (2006) and Meyer (2002) that consider action research promotes learning throughout the process and therefore has an appeal to practitioners. It is able to focus on the resolution of real problems arising from genuine situations from practice. Therefore it will form the basis of further studies aimed at the symptom management of patients in the future.

The researcher has learned that the cyclical nature of the process afforded time for patients, HCPs, the MDT and herself to develop their expertise, commitment, partnership and ownership of a person centred service that in the event was enthusiastically welcomed by patients. On reflection the ethos of clinical research in a local setting working through partnership, ownership and evaluation and enabled the researcher to achieve one of her professional goal that of developing a research and audit culture within the Units MDT. The skills and knowledge acquired during this study have informed the researcher's professional role and resulted in the production of the Unit's comprehensive portfolio of research and audit which was acknowledged as such during peer review (Appendix 47).

Chapter 10

Recommendations

10.1 Introduction

This study demonstrates the importance and benefits of adopting an action research approach into clinical practice in cancer and palliative care. The advantages of this approach are evident throughout this study and benefits are afforded to both HCPs and patients. In relation to constipation and its management, the resultant three stages of this research have improved patient outcomes and increased HCPs' knowledge and awareness about the condition's profound impact. In addition, the researcher gained experience and improved her own knowledge in several key areas, these are outlined in the following.

10.2 Patient interviews focussing on constipation

Sufferers of constipation in patients with cancer should be afforded assessment utilising a 'consultative-interview' approach to establish the totality of the condition and their management strategies as the latter are not identified during the routine HCP assessment. All those participating in this stage of the study reported that, in contrast to previous experiences, just talking about their constipation and its related problems helps either physically and/or psychologically. Interview respondents were central contributors to this study providing data that supported the rationale for the CMC. All the patients were keen and enthusiastic to participate thus confirming the value of user involvement in research and service development. Therefore, their participation should be further encouraged and maintained in future nursing research.

10.3 HCP focus groups

The use of HCP focus groups should be encouraged by nurses as they constitute a mechanism for raising awareness of areas of practice that might be explored in future study. Focus groups have the potential to expose contrasting practices, beliefs and attitudes which in themselves can be harnessed to optimise and facilitate best practice. Furthermore, focus groups provide specialists the opportunity to impart contemporaneous research findings to clinicians who often lack the time, motivation, skills or knowledge to support the needs of a

vulnerable group who represent a minority of their workload. Conducting focus groups during this study had a positive impact on participants who subsequently reported being more diligent in their practices, especially with prescribing. The HCP focus groups encouraged collaboration and promoted ownership of the study and minimised the risk of professional gate-keeping, therefore, affording better patient outcomes. The use of HCP focus groups should be encouraged as the data afforded can improve symptom management in patients with advanced cancer.

10.4 Availability of a CMC

Patients with advanced cancer should be afforded the benefits of a CMC as their needs are not currently being met. All patients have the potential to benefit from attendance at a CMC even in the event that their constipation transpires to be obstruction, thus affording timely and alternative management strategies to be put in place. Patients recruited in this study appeared to freely seek support at the CMC and embraced the advice and on-going support afforded. The CMC's philosophy and emergent findings confirmed patients' preference for empowerment over their constipation and their ability to self-titrate laxatives to prevent the condition or manage stool form. It may be that all patients with cancer, regardless of stage/advancement, benefit from attending a CMC as its components embrace patient education and concordance, thus preventing the onset of constipation during the advancing stages of their disease.

10.5 Laxative examples should be encompassed in routine practice

It is recommended that laxative examples should be made available for use in routine practice. It may be that each patient's laxative history use can be improved by utilisation of example laxatives. This does not necessarily need to be in a clinic environment, but rather routinely during constipation assessment. Given the problems of identifying drugs *per se*, it may be worthwhile exploring the use of other example drugs, such as analgesics, as this may alleviate the problems associated with patients who are unable to remember the names of their medications. All patients with advanced cancer should be afforded example laxatives in order to identify their use and reasons for non-use. This method proved extremely valuable during the CMC when obtaining data on laxatives used.

10.6 Patient education needs to be improved

It is recommended that patient education should be meaningfully included in practice. This study demonstrates that improved patient education in patients with advanced cancer increases their compliance with laxative regimens. Furthermore, patients' appreciations of the actual and potential problems of constipation and its management, including the pros and cons of laxative use, should be encompassed during patient education along with the supporting educational literature used in this study. It is likely that the totality of the information is too extensive for individuals to accept and comprehend during each appointment. To overcome this, patient education and information giving needs to be patient-focused and proffered using aids and a systematic approach where necessary. Salient points need reiterating during subsequent discussions and new information or educational needs identified and offered.

10.7 Encourage patient self-titration of laxatives

HCPs need to make a more concerted effort to facilitate patients' ability self-titrate their laxatives based on stool form and ease of defecation. This study demonstrates that patients with advanced cancer are receptive to the notion and are able to establish a fluctuating laxative regimen that is efficacious. Underpinned with appropriate patient education and follow-up, self-titration of laxatives leads to patient empowerment and a degree of independence to manage bowel function based on individuals' preferences and commitments. Consistent advice and support from HCPs must accompany the process of patient's self-titration of laxatives until accomplished to the individuals satisfaction.

10.8 Evaluating the CMC

As part of the on-going audit of the cancer services it is recommended that the CMC should be formally evaluated. This study was not able to undertake this element due to study limitations. Comments appraising the CMC were collected informally when proffered by patients and HCPs and these preliminary data suggest that patients considered that they benefited and were satisfied with the service. A formal assessment and evaluation of the CMC from patients and HCPs may highlight strengths and weakness of the CMC thus affording ideas for further development.

10.9 The CMC as a resource

The CMC became a resource to which a variety of HCPs referred to in order to improve their practice and knowledge. Thus, contemporaneous data pertinent to constipation management in patients with advanced cancer should be established and maintained in the varying local service settings. Given the literature base generated, which often focused on specific issues and/or problems, it is postulated that other symptoms may be better managed using a similar focused approach, thus exploring contemporary symptom management strategies.

10.10 Changing HCPs' attitudes

The ongoing dissemination of the findings of this study should continue locally and nationally. By concomitantly disseminating the results of this study there is strong evidence to suggest some HCPs become more diligent about constipation and its management. Raising the profile and engendering the ethos of the CMC has resulted in HCPs adopting a positive attitude and proactive approach to constipation management. Therefore further dissemination of this study and its findings has been requested and will be maintained in association with the researcher's role.

10.11 HCP education – a more holistic focus

It is recommended a survey is undertaken to identify educational and training needs of local HCPs. The majority of literature captures, for example, the causes and consequences of constipation, the use and efficacy of laxatives, and constipation assessment tools, however, this is rarely compared and contrasted with reliability or dependability of patient-reported data or the under-reporting of constipation by HCPs. It may be worthwhile exploring the latter at a local level thus raising awareness of contributory factors less commonly highlighted in the literature which predominantly influence practice. If found to be suboptimal at a local level the resultant findings may engender a more positive approach to constipation management whilst encapsulating the philosophy of action research and experiential learning, of which the latter two were found by the author to be invaluable during this study and her role.

10.12 Affording patients time

Patients should be afforded more time to discuss their constipation. The allocation of time manifests in multiple forms ranging from GP patient consultation time to setting-up and

running a CMC. Whilst it is challenging to envisage how, within the current NHS climate and limited resources, HCPs can afford patients more time, this may in itself alleviate constipation. Further research needs to explore precisely what factors result in disinterest and ambivalence to constipation as redressing these attitudes may motivate HCPs to proactively change their priorities and thereby effectively manage the patients' constipation. Ultimately such measures may lead to better use of limited resources as patients become less constipated and require fewer HCP consultations following appropriate management and self-titration of laxative regimens.

10.13 Laxatives should not be taken 'as required'

It is clear from the evidence in this study that the taking of laxatives 'as required' is inappropriate for in this client group. Therefore, patients should be advised to 'take their laxatives whether they feel they need them or not'. However, these instructions must be underpinned with the patients' understanding of prophylactic use together with a physical and verbal assessment to confirm the presence and/or risk of constipation in this vulnerable and predisposed group.

10.14 Final conclusion to the study

It is concluded that the approach employed in this research could be taken forward as a useful design template when assessing and aiming to improve the management of other distressing symptoms in patients with cancer.

For the researcher, the experience, knowledge and accomplishments afforded by this study are numerous and include,

- A raised awareness of varying methodologies and the benefits of their application.
- The practical application of action research and the use of varying methods when exploring complex problems in patients with advanced cancer.
- The opportunity to develop and work collaboratively with patients and HCPs
- Participating in the development and implementation of a service provision which improves patient outcomes and HCP practice.
- A deeper understanding of the complexities and needs of patients with advanced cancer.
- Growth in her professional role, that of providing appropriate support, advice and guidance to colleagues when undertaking research and audit.

This study has demonstrated the effectiveness of an action research approach to facilitate a holistic approach to constipation management in patients with cancer in palliative care. Furthermore, this study highlights the value of a nurse-led clinic and the importance of attention to detail when trying to manage this frequent and distressing problem in patients with cancer.

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Appendices