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Title: Exploring colorectal cancer patients' perceptions of the quality of their care

Date: May 2003

Originally published in:

Example citation: Thurston, M., Perry, C., & Kirby, K. (2003). *Exploring colorectal cancer patients' perceptions of the quality of their care*. Chester: Chester College of Higher Education

Version of item: Published version

Available at: <http://hdl.handle.net/10034/26035>

**Exploring colorectal cancer patients' perceptions
of the quality of their care**

A qualitative study in Halton

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May 2003

ISBN: 1-902275-29-2

Acknowledgements

We would like to thank all those people who participated in this study. In particular, we would like to thank:

- all those patients who gave their time to be interviewed;
- Alison Shead (Service Development Manager for Halton Primary Care Trust) for liaising with the Practices;
- all the Practice Managers and GPs in Halton who participated in recruiting patients to the study;
- members of the Project Steering Group who contributed to the study design.

This project was commissioned and funded by Widnes Primary Care Group.

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Summary

Background

The quality of cancer care has been the specific subject of attention in Government policy since the publication of the Calman-Hine Report (Department of Health, 1995). Subsequent publications, such as *The NHS Cancer Plan* for England and Wales (Department of Health, 200a), set out the Government's vision in terms of strategies designed 'to ensure that people with cancer get the right professional support and care' (p.5). However, evidence from patients and GPs suggests that good, supportive communication and patient involvement in treatment and care decisions are not typical of medical encounters in cancer care (Kavanagh and Broom, 1997; van der Molen, 200a; van der Molen, 2000b; Spellman et al, 1999; Bain and Campbell, 2000; Boman et al, 1999; the et al, 2000). This study set out to explore the local situation (Halton) with regard to colorectal cancer care by exploring how patients with a diagnosis of colorectal cancer perceived the quality of their care. Patients' perceptions of their interaction with primary care, the system of secondary care and discharge from hospital back into the community were all explored.

Study design and method

A qualitative approach, using semi-structured interviews, was used to explore perceptions of cancer care. Patients with a confirmed diagnosis of colorectal cancer were recruited via GP practices in Halton. Of the ten interviews carried out, all patients were over 40 years of age and 8 of the 10 had undergone surgery.

Findings and conclusion

A number of themes and sub-themes were identified from patients' narratives.

1. Accessing medical care.
 - Delays associated with seeking and obtaining help.
 - Practical problems with transport.
2. Communication with health professionals.
 - Breaking bad news.
 - Quality of explanations.
 - The quality of follow up care.
3. Support and care.
 - Care and concern.

-
- Sensitivity to patients' concerns.
 - Relationships with partners.

Patients' narratives showed commonality in relation to those aspects of care and patient-health professional interaction that mattered to them. However, it was evident that there were differences in respect of their views on the quality of their own care. There was also divergence in respect of how patients wanted to be treated and this was most evident in relation to the communication of information. The main conclusion was that accounting for differences in patients' experiences of cancer care can best be understood in terms of the quality of medical encounters between patients and health professionals at different points in the 'patient journey'.

Implications for service development

This was a small-scale qualitative study, which illuminated the local picture with regard to provision for patients with a diagnosis of colorectal cancer. On the basis of the findings, a number of implications for service development were identified.

- There is an identified need for clear, accurate and widely available information about the symptoms of colorectal cancer; the importance of early diagnosis; and all aspects of care and treatment.
- Innovative ways of providing information, such as utilising the knowledge and experiences of patients, as well as venues for the display and distribution of material, may be useful in reducing the stigma often associated with colorectal cancer, as well as improving access to information.
- Patients find it difficult to process large amounts of clinical information, particularly at critical times such as diagnosis. Thus, developing systems whereby patients are regularly supported, perhaps by specialist staff, could be beneficial to improving patients' understandings of their care and treatment.
- There is an identified need for health professionals to be sensitive to patients' anxieties, particularly at critical points in their care. For example, sensitivity towards the impact on patients of diagnostic uncertainty.
- Focusing on *caring* as an essential aspect of patient-health professional interaction is likely to improve the quality of patient experience.
- Opportunities for health professionals to reflect upon and develop their communication skills by exploiting local interest and expertise in areas such as neurolinguistic programming (NLP) may provide ways of improving the communication aspects of medical encounters.

-
- GPs might improve their appraisal of symptoms through enhancing the quality of their interactions with patients, through training in NLP.
 - Streamlining the interface between primary and secondary care, at diagnosis, throughout treatment and on discharge from hospital has the capacity to be beneficial to the quality of care. In particular, the exploration of health professional roles that traverse the boundaries of primary and secondary care may improve the *system* of care.

Chapter 1

Introduction

1.1 The quality of cancer care: national and local concerns

This study set out to explore how patients with colorectal cancer living in Halton perceived the quality of their care from first contact with their GP, through to diagnosis and treatment. The quality of cancer care has been the specific subject of attention in Government policy since the publication of the Calman-Hine Report (Department of Health, 1995), which made recommendations regarding the policy framework for commissioning cancer services, recommendations about professional practice and developed a set of principles for cancer services. There appears to be fairly widespread agreement that communication and patient involvement lie at the heart of good patient care (Department of Health, 1999; CRD, 2000; Borrás et al, 2001). For example, *The NHS Cancer Plan* for England and Wales (Department of Health, 2000) set out the Government's vision in terms of strategies designed 'to ensure that people with cancer get the right professional support and care' (p.5), with a specific focus on improving the 'patient experience' (p. 12) through the provision of good communication and involving patients in decisions about their own care. However, evidence from patients and GPs suggests that good, supportive communication and patient involvement in treatment and care decisions are not typical of medical encounters in cancer care (Kavanagh and Broom, 1997; van der Molen, 2000a; van der Molen, 2000b; Spellman et al, 1999; Bain and Campbell, 2000; Boman et al, 1999; The et al, 2000).

Cancer has been identified as a public health priority in Halton. Figures published in the Public Health Annual Report (North Cheshire Health, 2000) show high mortality rates from cancer for Halton residents compared with Warrington. Mortality rates reflect the combined impact of differential exposure to specific risk factors as well as various service-related factors, such as speed of referral to diagnostic tests. However, it is worth noting that the evidence base in respect of the relationship between services and outcomes for colorectal cancer is less well understood than, for example, that of lung or breast cancer. Furthermore, there is some, albeit anecdotal evidence, that primary care may not handle well the management of patients who present with potential cancer, particularly colorectal cancer. This study provides an opportunity for testing out some of these assumptions about the quality of local cancer care for patients with

colorectal cancer as well as considering how these might be implicated in improving outcomes for patients – in respect of care and survival.

1.2 Aims

The metaphor of the 'patient journey' is frequently used as a way of conceptualising the time period during which a patient experiences cancer. Thus, the study set out to understand the 'journey' from the point of view of the qualitative experience of the patient with a diagnosis of cancer, by exploring patients' perceptions of their interactions with the system of care. Patients' perceptions of their interaction with primary care, the system of secondary care and discharge from hospital back into the community, were all explored.

1.3 Qualitative research in studies of cancer care

Greenhalgh and Eversley (1999) argue that no single perspective can be used to describe the quality of care and the contribution of patients' views to the evaluation of health care is widely and increasingly acknowledged (Corney, 1999). Campbell et al (2000) point out that patients' perspectives can, potentially, be valuable indicators of the quality of care, particularly in relation to aspects of 'interpersonal care'. Whilst there has been an increase in the use of patient satisfaction surveys, it has been suggested more recently that qualitative research may be better able to shed insight into the complexity of the patient experience (Birchall et al, 2002). Qualitative research, which is exploratory, and sets out to describe, understand and explain phenomena, has considerable potential in this regard given that the open-ended nature of a qualitative approach allows the researcher to explore issues which have salience for those being studied (Thomas, 2000). It can document difficulties or obstacles involved and how these are perceived and dealt with (Barbour, 2000). This study uses semi-structured interviews to generate detailed, contextualised narratives, with the intention of exploring the management of patients with colorectal cancer in terms of their perceptions of the quality of their care.

In Chapter 2, aspects of colorectal cancer, Government policy in relation to cancer services and the territory of the quality of cancer care are explored in more detail, focusing specifically on care for patients with colorectal cancer where possible. Chapter 3 describes the study design and methods used and in Chapter 4 the findings of this study are presented. Finally, in Chapter 5, there is a discussion of the findings.

Chapter 2

Background and literature review

2.1 Introduction

In order to provide a broad context to the study, some aspects of the biology and epidemiology of colorectal cancer and the national policy context relating to cancer services in the United Kingdom are briefly examined. The Chapter then focuses on providing a detailed analysis of what is currently known about the quality of cancer care from empirical research. Specifically, consideration is given to patients' experiences during the initial stages of their cancer in respect of the recognition and reporting of symptoms and obtaining a diagnosis. Patients' information and communication needs, decision making about care and treatment, the need for psychosocial support and experiences of primary and secondary care are then examined in turn.

Much research has been carried out examining patients' experiences of living with cancer and the literature that has been reviewed concerns all types of the disease. Where work had been conducted with people with colorectal cancer specifically this has been highlighted. That there may be differences in peoples' experiences and views depending on the type of cancer may be important and should therefore be borne in mind.

2.2 Colorectal cancer

Colorectal cancer is the second most common malignancy in Britain (Department of Health, 2003; Hart et al, 1998) and the incidence of the disease is higher in the North West than in England and Wales as a whole (Bendel, 2002). The mortality rate is higher in the United Kingdom than in most other Western countries (Bain et al, 2002), which may partly be explained by British patients having more advanced disease at the time of diagnosis and treatment (Jones, 2001): the effectiveness of treatment and prospects for survival depend partly on the stage of disease at diagnosis (see for example Gatta et al, 2000; Major, 2003; Spurgeon et al, 2000). Colorectal cancer is classified using a system called 'Dukes' stages' as illustrated in the table overleaf (CRD, 1997). This is a classification system first published in 1932 that is accepted nationally and internationally (Colon Cancer Concern, 2003).

Table 2.2.1 Colorectal cancer classification

Dukes' Stage	Definition
A	Cancer localised within the bowel wall
B	Cancer which penetrates the bowel
C	Cancer spread to lymph nodes
D	Cancer with distant metastases (most often in the liver)

Since the year 2000 there has been a stable or slightly increasing incidence in colorectal cancer in the United Kingdom, but deaths have been falling (Major, 2003). Survival has in fact improved over the last ten years and there is now an overall survival rate of about 42% in men. For patients who receive an early diagnosis there has been a substantial improvement in survival, with a five year survival rate of 80%, although those diagnosed with advanced disease have shown no improvement in survival. The increase in survival rates for those with an early diagnosis has been because of improvements in surgery and better chemotherapy (Major, 2003). These findings concerning early diagnosis point up the importance of examining patients' understandings of colorectal cancer symptoms in the context of their decisions to seek an appointment with their GP.

The risk of colorectal cancer in young people is low (Hobbs, 2000) and incidence rises sharply with age (CRD, 1997). The majority of cases (99%) occur in those aged over 40 years and 85% of cases occur in those aged over 60 years (Hobbs, 2000). It is a disease mainly associated with developed countries and it is linked with diets high in fats and animal proteins and low in fruit, vegetables and fibre (Department of Health, 2003). There are two rare genetic syndromes which can lead to colorectal cancer: hereditary non-polyposis colorectal cancer and familial adenomatous polyposis. In addition, close relatives of people diagnosed with colorectal cancer are at increased risk, with about 25% of patients with colorectal cancer having a positive family history (CRD, 1997).

Primary symptoms of colorectal cancer are non-specific, occur relatively frequently in the population as a whole and can have a variety of causes, which may lead to difficulties with diagnosis (CRD, 1997). They include persistent rectal bleeding without anal symptoms (Wauters et al, 2000) and change in bowel habit (usually increased frequency, looser stools, or both) persistently over six weeks (Hobbs, 2000). Patients

may have iron deficiency anaemia, intestinal obstruction, a right sided abdominal mass or rectal mass (Hobbs, 2000).

Surgery is the only treatment that offers the prospect of cure from colorectal cancer (Spellman et al, 1999) and approximately 80% of patients with the disease undergo surgical treatment. Long-term survival is only likely if the tumour is completely removed and variability in outcomes achieved by different surgeons has been demonstrated (CRD, 1997). Radiotherapy is often used pre-operatively and chemotherapy can be beneficial in more advanced colorectal cancers.

Although the United Kingdom currently has no national screening programme for colorectal cancer (Hobbs, 2000), large randomised trials of screening with faecal occult blood tests in both the United States and Europe have shown a reduction in mortality of about 15% in those offered screening (Department of Health, 2003; Hart et al, 1998; Hobbs, 2000). Consequently, as part of the recent NHS Bowel Cancer Programme (Department of Health, 2003), a national screening programme for bowel cancer is to be instituted. The next stages of this development are to include:

- looking at the best available evidence on the benefits and costs of different approaches to screening;
- assessing the need for further pilots and implementing these;
- addressing workforce and training requirements and the need for new facilities;
- developing materials to educate specialists, healthcare workers and the public.

(Department of Health, 2003, p.47).

However, trials to date have revealed poor uptake of screening (Hart et al, 1998). The reasons for this are unknown but may, in part, be similar to those that result in a delay in presenting to the GP with first symptoms. Faecal occult blood screening is relatively cheap and easy, the main disadvantages are that the test has a low sensitivity with about 40% of cancers missed with a single screen and that faecal bleeding tends to occur late in the disease (Hobbs, 2000). Thus the best choice of screening methodology is not clear, specifically the choice between faecal occult bloods and flexible sigmoidoscopy (Department of Health, 2003). However, for people who are at substantial risk of colorectal cancer because of genetic syndromes, routine surveillance using colonoscopy can prevent death from colorectal cancer (CRD, 1997).

2.3 The national policy context

Kerr et al (2002, p.164) state that 'we have known for some time that cancer treatment in the United Kingdom needs to improve'. Traditionally, the United Kingdom has lagged behind many other countries in Europe and the United States in cancer control (Mayor, 2003) and the EURO CARE-2 study confirmed that survival rates for 18 out of the 25 cancers studied were poorer in Britain than in most other European countries (Gatta et al, 2000). This, and other concerns about cancer care and survival, has resulted in cancer having a high profile in Government health policy in recent years.

In 1995 the Calman-Hine Report (Department of Health, 1995) made recommendations regarding the policy framework for commissioning cancer services, recommendations about professional practice and developed a set of principles for cancer services. Attention was drawn to the central place of primary health care, as well as the dynamics at the interface of primary and secondary care, in the overall management of patients with suspected or actual cancer. This report has been described as 'an important first step in providing a vision for cancer services' (Commission for Health Improvement and Audit Commission, 2001a, p.3). However, it did not establish any central plan for implementing the proposals (Commission for Health Improvement and Audit Commission, 2001a).

Colorectal cancer specifically was also the subject of government scrutiny during the 1990s. In 1997 the Department of Health launched an initiative to improve NHS services for people with colorectal cancer with a document entitled 'Improving Outcomes in Colorectal Cancer' (Kmietowicz, 1997, p.1485). It was designed to help health authorities, GPs, hospitals and community health professionals to plan and provide the most effective services for people with the disease.

A few years later, cancer services were again the focus of the Government's attention. Cancer was reaffirmed as a 'top priority' (Commission for Health Improvement and Audit Commission, 2001a, p.5) and systems and resources for implementing the recommendations of the Calman-Hine Report were put in place. In addition, waiting times were assigned high importance. A target was set of a maximum two week wait between an urgent GP referral and a hospital clinic appointment. Initially this was only for patients with suspected breast cancer, but it has been extended to patients with any urgently suspected cancer (Commission for Health Improvement and Audit Commission, 2001a). A Cancer Action Team was also established in 1999 and a

National Cancer Director appointed, charged with developing a plan for cancer services.

The NHS Cancer Plan for England and Wales (Department of Health, 2000a) identified cancer services as a high priority for Government investment and reform across the NHS. The document highlighted the inequalities inherent in the provision of cancer care and set out the Government's vision in terms of strategies designed 'to ensure that people with cancer get the right professional support and care' (p.5). Whilst investment lay at the heart of the Government's plans, attention was also given to the role of the Cancer Services Collaborative and associated cancer networks in working together to 'redesign services, cut waits, and improve patient experience' (Department of Health, 2000a, p.12). Specific guidance was given in relation to local cancer services and their role in terms of 'pre-planning the different steps between referral and treatment' (Department of Health, 2000a, p.12). These guidelines also emphasised the need for good communication between health professionals and patients, both for delivering high quality care and for empowering people to be involved in decisions about their own care. Additionally, referral guidelines for GPs were published in 2000, and the National Institute for Clinical Excellence (NICE) issued guidance about the appropriate use of important cancer drugs (Commission for Health Improvement and Audit Commission, 2001a). The vision and strategies set out in The NHS Cancer Plan were underpinned by the 'modernisation agenda' (Department of Health, 1997; Secretary of State for Health, 2000) in that they committed the NHS to putting patients at the heart of services and to addressing many of the enduring problems with cancer care provision as revealed by empirical research.

In 2001 a review of cancer services in England and Wales was carried out (Commission for Health Improvement and Audit Commission, 2001a) to assess the state of cancer services and how far they had developed since the Calman-Hine report (Mayor, 2001). It was concluded that cancer services had improved, but that a lack of co-ordination meant that some patients continued to receive a poor standard of care (Mayor, 2001).

Very recently, in February 2003, a new NHS Bowel Cancer Programme was launched (Department of Health, 2003). The aims and objectives of this programme include:

- developing a national screening programme for bowel cancer;
- speeding up diagnosis for patients who present with symptoms associated with bowel cancer;

-
- improvements to bowel cancer treatment;
 - improved information on the causes and symptoms of bowel cancer;
 - development and expansion of the bowel cancer workforce.

(Department of Health, 2003, p.47).

Thus, it is clear that from a policy perspective, issues around cancer in general and colorectal cancer in particular are at the forefront of the Government's agenda.

2.4 Recognition and reporting of symptoms

For the majority of people who are diagnosed with cancer in the United Kingdom, the first step is their own recognition of a problem with which they consult their GP (Commission for Health Improvement and Audit Commission, 2001a; Farrell, 2001b). Just over 60% of those who ultimately receive a diagnosis of colorectal cancer are detected in this way (Commission for Health Improvement and Audit Commission, 2001a; Hobbs, 2000), with the remaining cases detected by a hospital specialist or an accident and emergency department attended by a person for an unrelated reason (Commission for Health Improvement and Audit Commission, 2001a). Thus, the importance of the recognition of possible symptoms of colorectal cancer by the general public is clear (Farrell, 2001b), especially given that, on initial presentation, one third of patients have locally advanced or metastatic disease (McArdle, 2000) and epidemiological evidence indicates that variations in survival from colorectal cancer can largely depend on differences in stage at diagnosis (see for example Gatta et al, 2000; Major, 2003; Spurgeon et al, 2000). However, studies in the United Kingdom have reported delays of around ten months between the onset of symptoms and the treatment of colorectal cancer (CRD, 1997).

Help seeking behaviour in respect of other diseases (for example, myocardial infarction) has been described as complex (Pattenden et al, 2002). In part, this is because appraisal of symptoms is often difficult for health professionals and particularly so for lay people. Research with cancer patients, including those with colorectal cancer, has shown that *no* delay in an initial consultation with a doctor is associated with clear knowledge, on the patient's part, of cancer symptoms (see for example de Nooijer et al, 2001; Farrell and Lewis, 2000, in Farrell, 2001b). There is also evidence that the extent of patients' knowledge about symptoms varies for different cancers. For example, Pullybank et al (2002) demonstrated that knowledge about breast cancer symptoms was much greater than knowledge of colorectal cancer symptoms: of women attending a breast clinic, 75% were able to name a breast cancer symptom,

whereas only 37% of patients attending a rectal bleeding clinic could name a symptom of colorectal cancer (Pullybank et al, 2002). Patients themselves, as well as health professionals, have identified a need for better information on how to recognise symptoms of all sorts of cancer (de Nooijer et al, 2001; Commission for Health Improvement and the Audit Commission, 2001a; Farrell and Lewis, 2000, in Farrell, 2001b; National Cancer Alliance 2000, cited in Farrell, 2001b), although evidence suggests that this is particularly the case for colorectal cancer.

Once a symptom has been recognised by an individual, there are various potential reasons for a delay in reporting that symptom to a GP. Some individuals may be reluctant because they simply believe that a symptom is not serious enough or is linked to a common ailment (de Nooijer et al, 2001; Commission for Health Improvement and Audit Commission, 2001a), an issue linked to the perceived need for more knowledge about cancer symptoms referred to above. Age may be important and there is evidence that the effect of age on symptom reporting may be different for different cancers or symptoms. For example, in a study of breast cancer patients Ramirez et al (1999) found an association between older age and longer delays in seeking medical advice. Conversely, Crosland and Rogers (1995) found that of people reporting rectal bleeding, a symptom of colorectal cancer, those aged 60 years and over were more likely to have consulted a doctor than younger people. Nosarti et al (2000) identified psychological factors (e.g. fear of cancer) rather than demographic characteristics to be associated with long patient delays before visiting a doctor. Some individuals suspect that something may be wrong but do not want this fear confirmed (Commission for Health Improvement and Audit Commission, 2001a).

2.5 Obtaining a diagnosis

Colorectal cancer can be difficult to recognise as symptoms are the same as for other common, less serious conditions (Department of Health, 2003) and although many patients visit their GP with symptoms of possible cancer, few ultimately have the disease. For example, one case study found that for every one patient who had colorectal cancer (not including those who presented direct to hospital as emergencies), the GP had seen 300 with possible symptoms and referred 45 to hospital; and consultants had seen 28 people and ordered radiological and endoscopic testing on 17 people (George et al, 2000, cited in Commission for Health Improvement and the Audit Commission 2001b). This is a problem which has been widely recognised, for example Summerton (2000, p.1254) writes of the difficulty of

'separating the wheat from the chaff' when presented with symptoms of possible oncological significance.

If colorectal cancer is suspected, referral to secondary care is necessary as a definitive diagnosis can only be made using colonoscopy or sigmoidoscopy with double-contrast barium enema (CRD, 1997). As differences in survival rates between the United Kingdom and other European countries arise primarily in the first six months after diagnosis, as well as being linked to stage of disease at presentation, these differences may relate to delays in treatment (Spurgeon et al, 2000). As explained above, the NHS was asked to set a target of two weeks for referral from a GP to first hospital outpatient appointment for all suspected cases of cancer (Commission for Health Improvement and Audit Commission, 2001a). Farrell (2001b) states that there are continuing professional disagreements about the impact of delays on cancer outcomes, but she argues that studies of patient experience consistently support the importance of short waiting time from first seeking medical advice to being seen by specialists and treated.

Studies have revealed that some patients with cancer perceived their GP as a barrier to them being referred on to secondary care and receiving a definitive diagnosis for their disease (Bain and Campbell, 2000; Bain et al, 2002; Farrell, 2001a). Farrell (2001a) conducted fifteen focus groups with patients who had been diagnosed with either colorectal, lung or ovarian cancer and reported that some patients saw their GP as a barrier to specialist services because they took a long time to refer them on. Similar findings were revealed by Bain and colleagues (Bain and Campbell, 2000; Bain et al, 2002), who carried out focus groups with patients with colorectal cancer. Some of the patients in Farrell's study (2001a) felt that there had been a delay in their diagnosis because their GP had failed to listen properly to what they were saying. However, in both of these studies there were also those who did not see their GP as an obstacle, with some patients perceiving their GP as guide or advocate.

In a large nationwide survey of over 65,000 patients with cancer, Airey et al (2002) reported that 90% of patients were told of their diagnosis by a hospital doctor. Just over a quarter of individuals (28%) were on their own when told their diagnosis, but the preference of 54% of patients was that there was no-one else present at this time (Airey et al, 2002).

2.6 Information and communication

Addressing the information needs of patients has been seen as central to achieving the 'goals of current NHS policy' (CRD, 2000, p.6). The most common complaints made by cancer patients and their relatives are about inadequate information and poor communication (Department of Health, 2000b; Fallowfield, 1998; Meredith et al, 1996; National Cancer Alliance, 1996; van der Molen, 2000a). A considerable amount of research has been undertaken exploring the information and communication needs of patients with cancer (Farrell, 2001b) and the importance, for most people, of being given information at all stages of their experience, has been established (Farrell, 2001a). In their nationwide survey of over 65,000 patients with cancer Airey et al (2002) revealed that 13% of respondents felt that on at least one occasion during their first hospital treatment doctors or nurses had withheld information from them and evidence suggests that doctors often underestimate the amount and frankness of information that most patients need (White and Mcleod, 2002). van der Molen (2000b, p.48) states that 'adequate, appropriate and timely information can be a key element for many people in managing the experience of cancer'. For example, in a large scale United Kingdom study of cancer patients' needs and preferences for information, 98% of participants (2,203 people) preferred to know whether or not their illness was cancer and 87% (2,027 people) wanted all possible information (Jenkins et al, 2001). These findings reflect the results of many previous smaller scale studies (for example Jones et al 1999a; Meredith et al, 1996) and also studies which have linked patients' satisfaction with the information they have received to their psychological morbidity. For example, a significant correlation between those who scored highly on the Hospital Anxiety and Depression scale and dissatisfaction with information provided was found in patients about to start radiotherapy treatment (Montgomery et al, 1999 in Farrell, 2001b).

Farrell (2001b, p.9) concluded that although research has established that the majority of cancer patients do want to receive extensive information about their illness, 'there remains a dearth of good quality research about the different characteristics of active and non-active information seekers'. There can be many individual differences between patients regarding their information needs and preferences (CRD, 2000; Farrell, 2000a) and information giving requires sensitivity to each individual's needs (van der Molen, 2000b). Women have been the focus of most research regarding information needs (Leydon et al, 2000b), but some work has indicated that men may be less likely than women to seek out or to say that they want information (Farrell, 2001b). Other groups who have been described as being less likely to want, or to access,

information, are older people, people from ethnic groups and people from deprived areas (Farrell, 2001b). As indicated by Farrell (2001b), the evidence is not clear-cut however. For example, Ajaj et al (2001) surveyed 270 older people aged between 65 and 94 years and found that a large majority of respondents (88%) would want to be informed if their diagnosis was cancer.

For those people who do not want to receive information about their cancer, factors affecting uptake of information services are complex (Leydon et al, 2000a). In a qualitative study of 17 patients with cancer diagnosed within the previous six months Leydon et al (2000a) identified three themes to explain why patients may not want to seek or receive information. These were: faith in their doctor's medical expertise; hope, which could be maintained through silence and avoiding information; and charity to other patients in that explanations and information were perceived as scarce resources and participants in the research felt that others may be in more need than themselves. van der Molen (2000b) has concluded that further research is necessary to identify what factors determine when an individual with cancer reaches the stage where they wish to receive and can process information.

In addition to research exploring the information needs of different groups of people, there is also a need for further research investigating the changing information needs of cancer patients at different stages of their illness (Farrell, 2001b; Leydon et al, 2000a). It is not clear at what points in time cancer patients are ready to hear or understand information (Farrell, 2001a) and people with cancer can experience difficulty in retaining and processing information (van der Molen, 2000a). General studies of cancer services have indicated that the need for detailed information seems to start at the point of diagnostic testing (Farrell, 2001a), becomes more important at diagnosis (Farrell, 2001b) and continues through treatment and after-care (Farrell, 2001a). Thus research on cancer patients' preferences has shown that they wish to have information provided to them at many stages of their experience (Farrell, 2001b).

The family members of individuals who have cancer may also require information about the disease. In a review of the relevant literature, Rees et al (1998) concluded that the families of patients with cancer received little information from health care professionals, and they reported the results of their own focus group study of the spouses of women with breast cancer. They found that, as with patients, the information needs of spouses were highly individualistic, with some seeking and others avoiding information (Rees et al, 1998). The potentially problematic nature of providing

information to the family members of a cancer patient were highlighted by Ajaj et al (2001). These researchers reported that although the majority of their sample of 270 people aged between 65 and 94 years would want their family to know if they had a diagnosis of cancer, 28% would not wish their families to have this information. Although the authors comment that these findings may have been a reflection of their particular sample in which 45% of participants were widowed and 52% lived alone, it indicates that the diagnosis of cancer can cause conflict between health care professionals and family members. These results reflect some of the earlier findings of Benson and Britten (1996). In interviews with thirty patients with cancer, these researchers found that participants favoured openness with their family but most rejected unconditional disclosure of information without their consent or their family influencing what information they would be given (Benson and Britten, 1996).

Improving the quality of information available to all patients is a key component of UK health policy (CRD, 2000). Although the way in which cancer patients would like information provided may not be clear (Farrell, 2001a), the importance of tailoring information to meet individual patients' educational background, cultural orientation, and general level of understanding, to include life-management information around the repercussions a diagnosis of cancer can have on all areas of patients' lives, has been established (CRD, 2000; Leydon et al, 2000a). For example, Jones et al (1999b) demonstrated that people with cancer preferred information based on their own medical records rather than on general information. The repetition of oral messages and the provision of written information may be helpful too (White and Mcleod, 2002). Both the NHS Cancer Plan (Department of Health, 2000a) and the Cancer Information Strategy (NHS Executive, 2000) discuss information needs in terms of two factors: communication; and the provision of good quality information materials.

Research evidence has indicated that a 'willingness to listen and explain' is considered by patients to be one of the essential attributes of a health professional (Department of Health, 2000a, p. 63). The NHS Cancer Plan (Department of Health, 2000a) states that good face-to-face communication skills are vital in the care of patients with cancer. This reflects the findings of much research with individuals living with cancer that has highlighted the importance of 'people' (e.g. health professionals) as a source of information (James et al, 1999; Farrell 2000a). A focus group study of patients with colorectal cancer identified issues of verbal communication, particularly in relation to test results and delivering bad news, as very important to patients (Bain and Campbell, 2000).

In their previously mentioned nationwide survey of patients with cancer, Airey et al (2002) found that although very few patients (3%) thought that the explanations given by hospital doctors were hard to understand, 16% stated that they could not understand all or most of the doctors' answers to any questions that they asked and 18% that they could not understand all or most of the nurses' answers to questions. In addition, 12% of participants said that they had been given conflicting information at least once by doctors and nurses. Kearney et al (2003) suggest that negative attitudes to cancer persist among health care professionals and may create a barrier to communication between patients and health care professionals.

In a study of 131 patients with newly diagnosed melanoma, Schofield et al (2003) found that patients' satisfaction with communication, as well as their psychological morbidity, was associated with particular communication practices. Those practices linked to lower anxiety included preparing the patient for a possible diagnosis of cancer; having the people wanted by the patient present to hear the diagnosis; giving the patients as much information about the diagnosis as desired; providing written information; presenting the information clearly; discussing the patient's questions the same day; talking about the patient's feelings; and being reassuring. Those practices linked with lower levels of depression included using the word 'cancer'; discussing the severity of the situation, life expectancy and how the cancer might affect other aspects of life; and encouraging the patient to be involved in decisions about their care and treatment (Schofield et al, 2003).

Although research suggests that people with cancer want to have information given to them within the context of a professional consultation (Farrell, 2001b), and the NHS Cancer Plan emphasises that good face-to-face communication skills are vital for the care of patients with cancer (Department of Health, 2000a), there is also a need for access to 'high quality, accurate information that the patient can return to in their own time' (Department of Health, 2000a, p.64). For example, in focus groups carried out with a total of 85 people with cancer in England and Wales, Farrell (2000a) found that whilst the majority of participants agreed that they preferred information to be given verbally, some liked this to be backed up with written information.

Information technology has made it possible for patients to access a wide range of information on the internet (Farrell, 2001b). In a study of 205 patients attending either oncology or general practice outpatient appointments, James et al (1999) reported that patients were highly likely to indicate that they would use web-based resources, which

may become increasingly well used with the expansion of health information on the web. However, in her focus group study involving 85 cancer patients, Farrell (2001a) found that few people had actually used the internet. Individuals had accessed a wide range of other materials including leaflets, books, videos, NHS Direct, voluntary organisations and commercial organisations. She concluded, however, that those people who sought out information for themselves were less common than those who relied on health care professionals to provide them with all of their information (Farrell, 2001a).

In a study of use of a national cancer information service, Boudioni (2001) compared the information requested by men with prostate or colorectal cancer with that requested by females with colorectal cancer. He reported complex patterns of information seeking behaviour with no pattern found either among men or in comparison to women, and concluded that there was a need for further research to enable the development of information services that are appropriate to individual needs and concerns.

New and different methods for providing patients with information have been utilised by some health care professionals. For example, in a randomised controlled trial of the possible benefits of preparatory information on video cassette for patients receiving chemotherapy or radiotherapy, Thomas et al (2000) found that 81% of patients found the video helpful. Scott et al (2001) conducted a systematic review of research that had investigated the effects of providing recordings of summaries of consultations to people with cancer and their families. They concluded that a wider use of consultation tapes and summary letters could benefit adults with cancer although consideration needed to be given to each individual's circumstances and preferences.

2.7 Decision making

There is widespread agreement that patients should not only be informed about health care and treatment options, but also be given the opportunity to be involved in decisions about their own care at all stages of the 'cancer journey' (Department of Health, 1999; CRD, 2000; Borrás et al, 2001). For example, in a study of decision making in cancer care Gattellari et al (2001) found that patients who reported a shared role in decision making were more satisfied with their care than those who reported that either themselves or the doctor exclusively made decisions. It is evident, however, that this shared decision making does not always happen (Kavanagh and Broom, 1997; van der Molen, 2000a; van der Molen, 2000b). Research has demonstrated that the majority of cancer patients fail to achieve their desired level of participation during

treatment decision-making (Gattellari et al, 2001). For example, in a study of 1,012 Canadian women with breast cancer, Degner et al (1997) found that two-thirds wanted to choose their treatment, or choose in collaboration with their doctor, and only 21% succeeded in this. In the national survey of cancer patients in the United Kingdom, 11% of patients said that they would have liked to have been more involved in decisions about their own care and 16% reported that on at least one occasion hospital doctors and nurses had talked about them as if they were not there (Airey et al, 2002).

One reason for this apparent lack of shared decision making may be that doctors generally have a poor ability to detect which patients want an active, shared, or passive role (Fallowfield, 2001). As an illustration of this, in a study conducted by Bruera et al (2001) to examine patient preferences for decision making and communication in palliative cancer care and doctors' perceptions of these preferences, the majority of patients preferred a shared approach, and doctors predicted that patients preferred a less shared approach than they in fact did.

People are likely to vary in the extent to which they want to participate in decision making, as well as in which decisions, (CRD, 2000; Farrell, 2001b) and, furthermore, for any one individual, this may not remain a constant over a time. Recent British qualitative studies have confirmed that some patients want to be involved in clinical decisions about their treatment (for example Farrell and Lewis, 2000, in Farrell 2001b). Degner et al (1997) found that 15% of the women with breast cancer in their study felt pushed to play more of an active role than they wanted and Fallowfield (2001) argues that a clear distinction needs to be made between a desire for information and a wish to assume responsibility for decision-making.

2.8 Psychosocial support

The guidance manuals produced by the NHS executive on commissioning cancer services suggest that people with cancer can benefit from psychosocial support and counselling (Farrell, 2001a). Cancer can cause considerable psychological distress in patients, families and carers and although only a minority of patients develop psychiatric illness, other psychologically and socially determined problems are common and people with cancer benefit from care in which psychological and medical care are co-ordinated (White and Mcleod, 2002). Various groups of cancer patients have been particularly identified as experiencing anxiety and depression and as needing psychological support such as those with lung cancer and women with gynaecological cancers and breast cancer (Farrell, 2001b). There is comparatively little research on

male patient views about the cancers that affect them specifically, prostate cancer and testicular cancer (Farrell, 2001b). More research is needed before the extent of the need for psychosocial support is firmly established (Farrell, 2001b).

There is also little research exploring what kinds of psychosocial support people with cancer, their families and carers want, or where they find the most effective forms of support (Farrell, 2001b). Farrell and Lewis (2000, in Farrell, 2001b) found that the majority of the people they interviewed stated that their greatest sources of emotional support were partners, relatives and friends. Other studies have revealed the importance of health professionals in terms of providing emotional support (for example Slevin et al, 1996). Slevin et al (1996) also found that cancer patients preferred doctor or nurse-led support groups rather than patient-led groups.

2.9 Primary care, secondary care and their interface

Patients with colorectal cancer are referred to secondary care for definitive diagnosis and treatment. Airey et al (2002) found relatively high levels of satisfaction with many aspects of this care. In their survey of over 65,000 patients with cancer they revealed that:

- 91% of patients had been given the name of the doctor in charge of their care, although a lower percentage (47%) had been given the name of the nurse in charge;
- 79% said that they were always treated with dignity and respect by their doctors and nurses;
- 86% of patients said that they had confidence and trust in the doctors responsible for their treatment;
- 79% said that they had confidence and trust in all of their nurses;
- 81% said that hospital staff did everything possible to help with their pain;
- 81% of patients felt that doctors spent enough time telling them what would happen when they left hospital;
- 56% were given written information to take home with them.

(Airey et al, 2002).

Follow up care for people who have been treated for cancer is managed by the consultants and hospitals where the patient has been treated (Farrell, 2001b). Airey et al (2002) reported that although 5% of patients who felt that they needed care when they left hospital did not think that the NHS met their needs, 57% said the NHS met

their needs very well. However, although there have been few studies exploring patient views of primary and community care services during outpatient treatment or after hospital discharge the evidence that there is suggests that care received from GP and community nursing services was at best 'patchy' (Farrell, 2001b, p.18). Thus, a need for development in the provision and delivery of primary and community services for cancer patients has been identified (Farrell, 2001b). There have been suggestions that follow up care could be provided by GPs, rather than being managed by secondary care (Farrell, 2001b). Most work in this area has been carried out with patients who have breast cancer and the findings are not clear-cut: there is evidence of greater satisfaction with follow-up care from a GP rather than a hospital as well as evidence of patients valuing hospital follow-up, particularly in the earlier stages of their disease (Farrell, 2001b).

Specifically in relation to colorectal cancer, however, home chemotherapy programmes have been suggested as an alternative to patients visiting the hospital. In a randomised controlled trial of home versus hospital outpatient chemotherapy for patients with colorectal cancer, Borrás et al (2001) found that home chemotherapy was not associated with an increased use of health services such as primary care or emergency departments, had no effect on patients' quality of life, but increased their compliance and satisfaction, particularly in relation to nursing care. They concluded that home chemotherapy was an acceptable and safe alternative to outpatient treatment that may improve treatment compliance (Borrás et al, 2001).

There is uncertainty about the most effective ways of providing care services in the community for patients with cancer (Farrell, 2001b). There is some evidence that, within the present system, the 'interface' between primary and secondary care is not always smoothly operated (Farrell, 2001b). For example, in a focus group study of patients with colorectal cancer, Bain and Campbell (2000) reported that tensions were perceived at the interface of primary and secondary care and that these were blamed for delays in referral and for communication breakdown. There was a perception by patients in this study that GPs and hospital doctors were not working together.

2.10 Conclusion

Both patients and GPs report that the experience of cancer care varies in terms of diagnosis and speed of access to appropriate services, as well as in the qualitative aspects of treatment and care (Spellman et al, 1999; Bain and Campbell, 2000; Boman et al, 1999; The et al, 2000). Some patients perceive their care to be excellent, yet

others report 'being given bad news in an insensitive way, being left in the dark about their condition and badly informed about their treatment and care' (Department of Health, 2000a, p.20). In a qualitative study of patients with colorectal cancer and their relatives, Bain et al (2002, p.369) concluded that 'from patients' perspectives, ideal cancer care cannot be achieved in a uniform way'. It is clear that care must be tailored to the individual patient's needs, as different patients can hold differing views on the nature of ideal care.

There are some areas, however, in which there is consensus among patients, health professionals and policy analysts about what constitutes good quality care. These include speedy referrals, the need for health professionals to have good communication skills and the need for patients to be able to access high quality information about their disease at a time when they are ready to do so.

Chapter 3

Methodology

3.1 Study design

Qualitative approaches are useful for conducting exploratory research into people's knowledge, beliefs and understandings of their world. They can provide rich data on the ways in which meaning is constructed and maintained by social actors. They also allow insight into the ways in which people interpret and contextualise knowledge, behaviour and meanings (Rice and Ezzy, 1999). The ability of qualitative research methodologies to generate analyses of the ways in which people interpret and attribute meaning to knowledge, behaviour, experiences and action makes them valuable for studying people's experiences of cancer care. Qualitative approaches are also valuable in situations where the 'social context of people's lives is of critical significance' (McDonald and Daly, in Rice and Ezzy, 1999, p.5). Cancer does not occur in a vacuum. Rather, it is embedded in complex, interrelated ways within the psychological, social, spiritual, economic and health dimensions of people's lives. For these reasons a qualitative approach, using semi-structured interviews, was used to explore perceptions of cancer care.

This study took place between January 2002 and December 2002.

3.2 Recruiting the sample

Given the qualitative and in-depth nature of this work a purposive (non-probability) approach to sampling was adopted in which individuals were identified by virtue of their status as a 'key informant' (Denscombe, 1998). Individuals were included in the sample because they were considered to be in the best position to reflect on their experiences of the care they had received. The potential sample was all patients in Halton (aged 18 and over) who had been diagnosed with colorectal cancer during 2001. It was anticipated that the majority of patients in this cohort would be sufficiently well to participate in the study and able to reflect on their experiences of care from first contact with primary care up to the point of their contact with a researcher. Individuals in this target population were identified at the level of the medical practice at which they were registered. Thus, a request to all Halton Practice Managers by the Halton Service Development Manager was made for them each to identify all those patients with a diagnosis of colorectal cancer in 2001. This process yielded a total number of 43

patients. However, three exclusion criteria were introduced in order to protect patient welfare:

- unconfirmed diagnosis;
- patient not fully informed of diagnosis;
- patient judged by GP to be too ill to be contacted.

Using these exclusion criteria reduced the number in the sample to 21. (It was the responsibility of the relevant GPs to operate the identified exclusion criteria during the scrutiny of their patient list).

Recruitment was on a voluntary basis and took place through general practice. All patients identified were sent a letter on practice headed note paper signed by the patient's GP. Included with the letter was a Patient Information Sheet and a Consent Form, which incorporated a tear-off slip to be returned to the Centre for Public Health Research. These 'consent to be contacted' slips allowed patients to give their consent for a researcher to contact them by telephone in order to arrange an interview, as well as answer any questions they might have had about the study. Before interviews took place, participants gave their consent in writing by signing the consent form. Before contact was made with those who had returned 'consent to be contacted' slips the researcher contacted the patient's Practice in order to confirm that s/he met the inclusion criteria for the study.

Eleven patients returned 'consent to be contacted' slips. One patient subsequently declined to participate due to deterioration in her health. Of the ten interviews carried out, all patients were over 40 years of age and 8 of the 10 had undergone surgery.

A copy of the letter to patients, the Consent Form and the Patient Information Sheet can be found in Appendix 1

3.3 Semi-structured interviews with key informants

Semi-structured interviews have a 'loose' structure consisting of a number of open-ended questions that define the area to be explored, but which allow the interviewer or interviewee to diverge in order to follow up particular areas in more detail (Britten, 1995). Thus, although the interview topics and questions were defined initially in relation to the purpose, aims and objectives of the study, the semi-structured format allowed participants to express ideas that were important to them. It also meant that answers could be clarified and more complex issues probed than would be possible

using a more structured approach. In-depth open-ended questions used within the framework of the semi-structured interview have been shown to reveal the complexities of 'satisfaction' and 'dissatisfaction' in patient-health professional encounters (Bowling, 2002) and for this reason were chosen as the method of data generation.

The interview schedule was developed in relation to three main areas that reflected different stages of the system of care: interaction with primary care; the system of secondary care; and, discharge from hospital back into the community. This, together with the emerging themes from the literature review, led to a series of open-ended questions being developed:

- To what extent are patients aware of the possible significance of symptoms?
- Do they perceive that they present 'late' and for what reasons?
- Do patients perceive that their signs and symptoms are 'optimally' dealt with?
- To what extent do patients feel that health service professionals were actively 'on their case'?
- Do patients perceive the referral process as a series of barriers to be overcome?
- Do patients 'see' and 'feel' the fragmentation in the system?
- What were they told, at what stage and by whom?
- How did they feel about what they were told?
- Were patients given timely, relevant and unambiguous information?
- Were patients treated ethically - with respect, dignity, actively involved in decision making relating to their care and treatment?
- Who are the people in the system they trust?

A copy of the interview schedule can be found in Appendix 2.

Interviews took place in participants' own homes and were audiotaped with their permission. Audiotapes were subsequently transcribed verbatim.

3.4 Ethical approval

Ethical approval for the study was sought from North Cheshire Local Research Ethics Committee and obtained in March 2002.

An amendment was put forward in August 2002. This amendment was for approval to extend the sample to include all those with a diagnosis of colorectal cancer in Halton in

2002. This request was made because of the relatively poor response rate from the 2001 cohort. Although ethical approval was obtained, it was not possible to organise the work with practices because of changes to personnel at the Primary Care Trust.

It was possible that taking part in the interview could cause some degree of distress. It was therefore agreed that interviewees were offered support, if necessary, through referral to a local support group (Widnes and Runcorn Cancer Support Group), through the Patients' Forum.

3.5 Data generation and analysis

There are many different theoretical approaches underlying qualitative research methods. One of the most established and influential of these is grounded theory (Glaser and Strauss, 1967). Grounded theory is essentially the development of theories and understandings through data. Grounded theory involves the systematic analysis of data to generate new hypotheses, explanations and interpretations (Glaser and Strauss, 1967). Unlike some other approaches, which involve logical deductions from existing theories, grounded theory is based *in* the data. This prevents data from being forced into rigid pre-established explanatory models which can 'contaminate' emerging categories and concepts (Glaser and Strauss 1967, p. 37). Furthermore, the use of data to form new hypotheses allows for the continual development and reformulation of theory. In this way grounded theory is a process rather than a static model.

Grounded theory was used as an approach to the analysis of the interview transcripts. By drawing hypotheses and explanations from patients' narratives, grounded theories have a greater potential to 'offer insight, enhance understanding and provide a meaningful guide to action' (Strauss and Corbin, 1998, p.12) in this case, in respect of cancer care for colorectal patients and perhaps more widely. Thus, interview transcripts were analysed thematically and coded in relation to key themes, sub-themes and dimensions. Such narrative analysis is well established as a vehicle for examining the subjective experience of those who experience cancer (Little et al, 1998).

Although qualitative findings are not statistically generalisable, they can be theoretically generalisable. This refers to the development of analytic frameworks or typologies developed from the data, or mechanisms identified which have applicability beyond the immediate context of the reported study (Thomas, 2000). Thus, the findings from this study have the potential not only to inform future service provision within the locality,

but might also be conceptually and theoretically generalisable beyond the local setting. This research project then, has relevance to the clinical governance agenda for PCTs locally, and perhaps generally, since it will generate findings that are of relevance to improving the quality of cancer care.

Chapter 4

Findings

4.1 Introduction

This chapter presents the findings in relation to patients' perceptions of their experiences of care. The analysis is based on the narratives generated by the semi-structured interviews. Three broad themes emerged from the transcripts: access to medical care; communication with health professionals; and support and care. Each of these themes is explored with reference to a number of sub-themes and dimensions in order to tease out the complexity of participants' narratives. The thematic analysis is supported by illustrative quotations from the interview transcripts. All quotations have been anonymised and are cited by code only.

Two points can be made about patients' narratives. Firstly, whilst it was possible to discern commonality in relation to those aspects of care and patient-health professional interaction that mattered to patients, it was evident that there were differences in respect of their views on the quality of their own care. Secondly, against a background of common views, within this relatively small sample there was divergence in respect of how patients wanted to be treated and this was most evident in relation to the communication of information. The implications of this for the provision of high quality care and how the patient experience might be improved locally are discussed in Chapter 5.

4.2 Accessing medical care

In seeking to make sense of patients' narratives in relation to accessing medical care two sub-themes were developed: firstly, delays associated with seeking and obtaining help and, secondly, the practical problems with transport. Each of these is explored more fully below.

4.2.1 Delays associated with seeking and obtaining help

The notion of delay in presentation and speed of subsequent referral and treatment was a major concern and was voiced by several patients. Three different dimensions to this notion were identified. Firstly, patients described delaying presenting to their GP for a number of reasons, including not wanting to bother the doctor, embarrassment and the attribution of other explanations for symptoms. Bothering the doctor

unnecessarily was a concern voiced by some participants, and was particularly implicated in the delayed presentation of patients with co-existing medical conditions. One patient commented:

“I took no notice. You get pain all the while and if you went along to your GP with every little pain you get...” (No.4/Male).

A few male patients voiced the view that their gender was a factor in delaying consulting a doctor. This was accounted for by their perception that they were more likely than women to feel uncomfortable discussing their symptoms. One male patient observed that:

“Men tend to clam up, keep it to themselves and hope it goes away.” (No.5/male).

The most frequently cited symptom reported by patients in the study was rectal bleeding and many respondents reported delaying presentation because they attributed alternative explanations for this symptom. A common belief was that the bleeding was caused by diet, particularly eating a lot of fruit and vegetables, or was due to less serious conditions. As a result, there was a tendency to ignore any bleeding or abdominal pain. Most patients attributed the rectal bleeding they were experiencing to haemorrhoids, perceiving these not to be a serious enough complaint to present to their GP. Therefore, many delayed consulting their doctor for varying periods of time from a few weeks, up to fifteen months. When concern had increased to a sufficiently high level to prompt a decision to present to a doctor, some patients reported problems getting an appointment, often because their preferred GP was difficult to see. The final trigger for patients to initiate a consultation with a GP tended to result from symptoms interfering with normal activities, and was often prompted by pressure from partners. One patient commented:

“It was my wife pushing me eventually.” (No.6/male).

The second way in which patients gave expression to the notion of delay could be understood in terms of the GP as gatekeeper. After presentation to a GP, care in general practice was evaluated by patients in terms of how quickly they were referred to secondary care. Some patients were satisfied with the response they received, reporting that their GP was receptive to their concerns when they presented with symptoms. However, although these patients praised the speed with which they were referred by their GP, many others reported experiencing a delay at this stage. A variety of reasons were given for this: a patient's co-morbidity; GPs attributing symptoms to other, less serious, conditions; GPs not taking patients' symptoms and

concerns seriously. A common perception among these patients was that the GP represented an obstacle to accessing medical care that they had to overcome. For some patients, co-morbidity was implicated in delayed referral by their GP. One patient reported:

“He told me to go home. He said it is only a bit of mucous, forget about it, you have enough wrong with you.” (No.2/male).

Conversely, hospital tests and treatment for other conditions could sometimes speed up a diagnosis even in cases where the GP was not receptive to patient concerns. For example, one patient described his experience when he consulted a doctor with symptoms:

“He just ignored it. Only for the hospital wanting to know why I was anaemic I would probably have been away now.” (No.4/male).

However, patients appeared to be perceptive and sympathetic to the difficulties facing GPs in being alert to the possibility of cancer in those patients with co-existing medical conditions. One respondent commented:

“I have that many things wrong with me... because you pass blood doesn't mean you have got bowel cancer. There could be a hundred things. You could have piles and God knows what and so I am not laying any blame on him.” (No.2/male).

Patients without co-existing medical conditions also reported delayed referral by their GPs. As well as displaying trust in their GP and an acceptance of the medical opinion given, many expressed their frustration at what was perceived as doctors ignoring or dismissing symptoms, particularly more vague symptoms such as pain, and not taking patients' concerns and worries seriously. Many patients felt that they were not taken seriously quickly enough and their symptoms often attributed to other less serious conditions, such as irritable bowel syndrome. One patient stated:

“He should have said, come tomorrow or next week and I'll examine you, but not, come back in three months. I think that is a big, big gap. All he said to me at the time is that it was nothing sinister, but it was sinister.” (No.8/male).

Although critical, patients appeared to offer explanations for why they thought the doctor had not taken their concerns seriously. This was usually perceived in terms of GPs' lacking time due to heavy workloads. Other respondents felt that the GP had difficulty determining which patients were not wasting his/her time. One patient explained:

"I think he has that many people seeing him with frivolous things, I think he thinks everybody is like that." (No.4/male).

A lack of continuity of GP was sometimes implicated in delayed referral or, conversely, as finally aiding referral in situations where a patients' own GP was perceived as not taking symptoms seriously. Clearly, in many cases, persistence by patients was necessary. One patient who experienced a delay in obtaining a referral reported:

"I shuffled around the practice, different doctors, and they won't listen to me...it was one of the new ones actually that got the first appointment at the hospital." (No.3/male).

Some patients reported that their GP did not ask them about any family history of bowel cancer. Although not always offering this information to the GP, unless asked, patients voiced their concern about relatives having had colorectal cancer, stating that this was often a major factor in their decision to consult a doctor. One patient commented:

"What concerned me was my mother died of it and her brother, my uncle, he died of it." (No.2/male).

The third way in which patients expressed the notion of delay was in respect of referral to secondary care. Once a referral to secondary care was deemed necessary by the GP, some patients were unhappy about the length of time they had to wait for an appointment to see a specialist. Other patients voiced their satisfaction at being "fast-tracked" through the system, commenting on the speed with which investigations were carried out, results obtained and treatment initiated. One patient described his experience:

"I thought the speed at which it was completed was...almost miraculous." (No.10/male).

However, many patients in their progress through secondary care experienced delays. In particular, respondents perceived that conducting investigations could be a lengthy process, with many patients reporting that they waited months for tests. Additionally, the length of time they actually waited for some tests did not match that which health professionals had told them to expect. One respondent commented:

"Everything took so long to go through. Six months to wait for a scan. I was told I would wait two months." (No.9/female).

Another patient spoke of a delay between having one test and undergoing a further investigation:

"I think it was about six months before I got seen to, from February when I had the camera to September when I had the barium." (No.3/male).

Delays in undergoing investigations and in receiving the results of tests were a source of heightened anxiety for patients. Many patients described themselves as "worried" at these stages, although recognition of limited resources was apparent. For example, one patient stated:

"I know they only have so many scan machines." (No.9/female).

Systems for the reporting of results also appeared to contribute to the anxiety experienced by respondents. This includes the practice of reporting the results of some tests back to patients only if a problem is identified. Patients expressed the opinion that they would appreciate the reassurance that the reporting of all good results would provide. A lack of flexibility in the existing NHS systems for processing results was also cited as a reason for some delays. Patients appeared keen to be involved in the process, with a view to speeding up the system. One respondent expressed frustration with being unable to contribute in this way:

"With the X-ray, it's there. I say why can't I take it and they say, oh no we can't do that and then you are waiting seven or eight days. You know if there is something wrong with you, you are thinking they could come quicker." (No.3/male).

4.2.2 Practical problems with transport

Access to medical care was also described as a practical problem by many patients, particularly in relation to hospital care. These difficulties often related to transport or parking and were sometimes exacerbated by co-existing morbidity. Transport to and from hospitals was reported as being particularly difficult for those without their own transport, who lived in areas lacking an adequate bus service. Problems could be compounded by problems accessing provision of transport by ambulance. One patient remarked:

"They assume, I think, to a certain extent, that everyone has access to a car...the ambulance service...I rang them on the Friday, I wanted to visit on the Wednesday, and they said it was too late." (No.7/male).

For other respondents, in terms of convenience when attending for treatment, appreciation was expressed with regard to the rota system whereby staff from Clatterbridge Hospital travel to Warrington and Halton hospitals. One respondent commented:

“They just have a tour around, which is excellent, and it takes the pressure off the people parking.” (No.6/male).

4.3 Communication with health professionals

Interactions with a number of health professionals were described by patients in a variety of ways and there were three different dimensions to this. Patients talked of the way in which their diagnosis was given to them and the breaking of bad news generally. Secondly, the quality of explanations at different stages of the process of care was a subject of discussion. Finally, the quality of follow up care was a dimension of patients’ narratives that reflected salient issues in respect of access to information once a patient was discharged and felt more “on their own”.

4.3.1 Breaking bad news

Variation among patients was apparent with regard to their experience of being told that they had cancer. Some spoke of specialists spending time with them when breaking the news and of being treated in a sensitive manner. These patients reported being satisfied with the way their diagnosis was communicated to them, the perception being that they were addressed respectfully with the assumption that they would be able to understand what they were being told. Patients reported reacting to what was described by one respondent as, *“the ordeal of being given the news”*, by feeling worried and fearful about what lay ahead of them. Many described their feelings of disorientation on being given the diagnosis. Patients commonly described feeling *“shocked”*, *“dumbstruck”*, *“dazed”* and unable to understand how cancer had happened to them, particularly if they considered themselves to be healthy individuals who had never been ill very much previously. The difficulties inherent in processing information given at this stage were also apparent, with many patients reporting that they could not recall what was said once the consultation was over. Some described how the shock at being diagnosed with cancer prevented them from asking questions. For example, one patient commented:

“I felt like my mind became blocked. I couldn’t have asked questions, lots of things I would have liked to have asked, later on, but at the spur of the moment, I couldn’t think of anything.” (No.8/male).

Although some patients reported feeling very anxious, most particularly appreciated the straightforward language that was used by some specialists. One patient commented:

“Well they explained it to me and I liked the way, no messing around, straight to the word, no messing. I was made up with him.” (No.4/male).

However, although some were told their diagnosis directly by a specialist, many respondents reported that bad news was communicated to them indirectly, often through the use of euphemisms, such as “a blockage” or “a growth”. There was a perception that some specialists tried to gauge patients’ level of understanding by asking them what they thought the diagnosis was. Patients felt that staff do not mention the word ‘cancer’ unless the patient does, because of a fear that using the word may cause some to panic. One patient expressed it thus:

“Nobody mentions the word cancer – you have got something nasty, you have got something here.... unless you mention it, they won’t mention it...I would sooner them said to me you’ve got cancer and we’re going to cut it out.” (No.6/male).

Patients commonly reported that euphemisms were used, not only by some specialists when delivering a diagnosis, but also more casually by other hospital staff that they came into contact with, particularly during tests. Patients reported that, both during and after investigations, nurses often referred to “something nasty” or “a lesion”. Patients varied in their understandings of this terminology, with some saying that it prepared them for bad news. One patient commented:

“Having been told that I had a lesion by the nurse who had seen to me when I came round after the colonoscopy....in a sense I was partially prepared for the results that came... whilst nobody said it was a cancerous growth, a lesion sounded important enough to possibly be that.” (No.5/male).

For other patients, the use of euphemisms appeared to be responsible for their being uncertain about their diagnosis. This appeared to be partly due to a lack of communication between specialists and nursing staff both concerning what individual patients had been told. This lack of consistency in the use of the language used to discuss cancer could be the cause of some distress. The partner of one patient described how they were shocked on hearing the news in this way:

“We didn’t realise. He (specialist) never mentioned cancer at all.....it was this sister that did his premed that said cancer because then we were taken aback a bit. She said, he did tell you? So we said no, he never mentioned.” (No.3/wife).

4.3.2 Quality of explanations

Notwithstanding the above comments, many patients praised the quality of explanations about their illness and treatment from specialists and other hospital staff. Some reported that specialists tried to involve them by showing them “photographs” of their tumours. Explanations about treatment, including what would happen during surgery, were perceived as being particularly comprehensive, and delivered simply and

clearly. Respondents valued honesty in these explanations, expressing the view that this led to them being clear as to what to expect both before and after their operations. Some patients appreciated the literature they were given, finding it easy to understand. One patient remarked:

“I thought it was good, very good. It wasn’t technical. They simplified it for us.” (No.1/male).

However, not all respondents were satisfied with the explanations they received whilst undergoing hospital treatment. A few patients felt that they had not been warned about possible side effects, particularly nightmares, from the morphine administered post-operatively for pain relief. Others perceived that they were not given adequate explanations for certain procedures. One patient commented:

“I was discharged with a catheter and I don’t know why I had a catheter, I didn’t need one. I didn’t want it in the first place.” (No.4/male).

Some patients reported that they would have liked the chance to speak to other people who had been through the same treatment so that they could learn more about what was involved. Those patients who had gained information in this way appeared to value what they had learnt from this source. For example, one patient expressed the view that he had learnt more about the possible side effects of chemotherapy, from other patients who he had encountered when attending for treatment, than from staff:

“One guy told me everything, I thought he was the consultant at first.” (No.6/male).

Others expressed the view that it was difficult to process the large amount of information being offered and as a result many found it difficult to recall what had been said during consultations with medical staff. Many patients relied on their partners to accompany them in order to assist them in clarification and recall of conversations once the consultation was over. The use of technical language could also lead to confusion, as one patient remarked:

“There is that much information coming at you and they are using certain types of words and you look it up after, what does that mean you know.” (No.3/male).

Patients displayed variation in their behaviour and attitudes with regard to seeking information about their illness and treatment. Some stated that they were keen to be given as much information as possible, feeling that this made the process of treatment easier for them. In contrast, other respondents described fear as preventing them from seeking explanations, in particular demonstrating reluctance to listen. For example,

one patient expressed his reaction to efforts by hospital staff to explain what his surgery would involve:

“They were trying to give me information....I said, just do it, you know, before I change my mind....you can tell me all about it after.... I was too bloody frightened, I didn’t want to know.” (No.2/male).

4.3.3 The quality of follow up care

Many patients were satisfied with the follow up care they received after they were discharged from hospital, having undergone surgery. Respondents reported that staff enquired about arrangements at home and commented on how smoothly they perceived their journey to be through the system of care. Confidence was expressed in being able to communicate at any time with someone who was able to give advice, as one patient remarked:

“The follow up care was absolutely tremendous...if I have any problems at all I only have to pick up the phone and get an answer to my question, with the colostomy nurse, with the cancer specialist, anybody.” (No.10/male).

In particular, patients appreciated the role of the colorectal nurse as an easy to access and reliable source of information, as one patient commented:

“Her function is being there from day to day for anything that occurs that you are unhappy about, and so you can get on the phone and give her a ring, and that is a really good, positive position for her to be in. She can feed me with information, put my mind at rest, I don’t have to wait for the next appointment with the surgeon to get information.” (No.5/male).

However, some patients reported experiencing difficulties as a result of breakdowns in communication when seeking appropriate follow up care. Respondents accounted for this in terms of a perceived fragmentation in the system, which was viewed as an obstacle that they had to overcome. There was a perception that, having been discharged from hospital, they were “on their own” and confusion was apparent as to who were the appropriate health professionals to approach if they experienced problems post-operatively. One patient described experiencing difficulty identifying whom to approach for assistance:

“Nobody wanted to know...I rang the hospital and asked them if they would sort it out and they said that I was discharged and no longer anything to do with them. I rang again and they said tell him to get it (a catheter) out himself.” (No.4/male).

Other patients expressed reluctance to seek advice when experiencing problems after discharge from hospital, but reflected that they would have appreciated unsolicited attention. One patient expressed the view that they felt uncomfortable seeking help:

“Nobody at all came out...I don’t like to keep ringing up. It would have been nice if someone had come for a chat and to give advice.” (No.3/male).

It was apparent that patients did not always receive the information that they needed once they had been discharged from hospital. It was reported that there was a lack of dietary advice in the post-operative period, particularly for patients whose diabetes was a complication in terms of recovery. Other patients reported problems gaining information as to suitable exercises to try to build up strength. One patient commented:

“I asked for any exercises because I was that weak. I did think I needed help but nobody seemed to want to know. You are wondering how much to exercise.” (No.3/male).

Lack of continuity was a concern for some patients who reported that when they attended for check-ups, after being discharged from hospital, they would have preferred to see the same doctor. In practice, this was rarely the case and it was reported that patients see many different doctors. As a result, follow up care could sometimes be perceived as impersonal, as described by one patient who reported that seeing many doctors meant they felt unable to seek answers to questions:

“You always expect the same doctor is going to see you but it isn’t. It is someone different all the time. You could get used to the one doctor, and sort of relate to him...you would be able to ask him questions more.” (No.8/male).

4.4 Support and care

Many patients spoke about the support that they had received during the course of their illness. This took the form of both psychological and practical support from a variety of people with whom patients came into contact. In particular, patients identified a number of medical staff and also partners as being central to the provision of support. Many patients were very satisfied with the level of support that they felt they had received, a common perception being that the medical team were *“all part of a huge support group”* helping both patients and their families cope with the challenges that cancer presents. More specifically, three different dimensions to the notion of support could be identified: the importance of care and concern; sensitivity to the patients’ concerns; and, relationships with partners.

4.4.1 Care and concern

It was evident that demonstrations of care and concern by staff were an important dimension of patient-health professional interaction, particularly for those undergoing treatment. Respondents reported that they valued the attention they received with regard to their comfort. Many praised various hospital staff, often for what might be thought of as quite trivial matters. For example, one patient commented:

“One of the carers came in and plumped your pillow up and checked you were OK. They were really great. Even to the girl bringing the water in, she emptied my thing about three times a day.” (No.1/male).

In contrast, one patient reported experiencing difficulties with regard to care:

“Some of the nurses...when you called them they pretend they can't hear you...the nurse would not raise the end of the bed so I had to sit on a chair all night because she couldn't be bothered and I ended up with sores sitting on a chair all day and night. They would come around, have you been in the bed, no, they were made up they didn't have to make the bed.” (No.4/male).

Many respondents singled out the colorectal cancer nurse as being an important source of support, a common perception being that the role of a nurse designated solely to colorectal cancer care contributed to the provision of a high level of individual attention. After discharge from hospital, patients continued to value the support the colorectal cancer nurse provided, reporting that this made adjusting after surgery more straightforward, particularly for those who had colostomies. Others felt that the colorectal nurse had been a key supportive figure who dispelled their fears and dealt with any concerns, as one commented:

“I would class the help that was given from the colorectal nurse as being psychologically supportive.....she would always put my mind at res.” (No.5/male).

Other hospital staff were also specified with regard to the provision of emotional support, often by simple acts such as enquiring how patients were feeling or taking the time to chat. Appreciation was also expressed by patients with regard to the daily visits by the surgeon who had carried out their operation. Highlighting the theme of communication, discussed earlier, it was clear that surgeons taking time to talk was especially welcome. One patient valued the presence of the surgeon straight after surgery and found this particularly reassuring:

“When I was coming round, you know when you have had the operation and you are not awake, I heard a voice saying we have done the operation and it is a success and I was made up

even though I couldn't speak. I felt great when he told me that."
(No.4/male).

4.4.2 Sensitivity to patients' concerns

It was important to patients that staff were sensitive to their fears, particularly when facing surgery. One patient clearly valued the sensitivity shown by a member of staff in an individual attempt at reassurance just before his operation commenced:

"The anaesthetist said I don't know whether you are scared or anything like that but between you and me I know what I am doing." (No.1/male).

Sensitivity by health professionals was important to respondents at all stages of their treatment of care. For example, patients spoke of their embarrassment when undergoing investigations, but expressed their appreciation of the way staff approached physical examinations, as one patient commented:

"The staff, you know it is nothing to them, and they make you feel as though it is nothing." (No.6/male).

4.4.3 Relationships with partners

Some patients spoke of what they felt were positive things that had resulted from their having had cancer. This was expressed in terms of the effect on relationships, for example some spoke of their illness bringing them closer to their partners. The role of partners in the provision of both emotional and practical support was highlighted in this study, there being a sense that patients and partners perceived themselves to be experiencing cancer together. However having cancer was reported as having impacted negatively on some relationships, for example one patient remarked:

"A lot of people are frightened of you when you have it you know...they think it's catching." (No.3/male).

In contrast, family, friends and neighbours were generally perceived to be supportive, particularly as a source of practical assistance, as one patient remarked:

"There are really a lot of good, positive outcomes from cancer, not from the disease itself, but from all the contact and the good things that people do for you. We have met so many good people ...who have gone out of their way to help, especially with transport...that is a really positive thing." (No.5/male).

Chapter 5

Discussion

5.1 Introduction

This was a small-scale qualitative study that set out to explore the quality of local cancer care from the perspectives of those patients with a diagnosis of colorectal cancer. The findings presented in chapter 4 shed some light on the dynamics of the local situation. At a general level, it is evident that there is a large degree of consistency with the findings from other work, particularly the findings from large-scale quantitative (survey) studies as detailed in Chapter 2. It is also evident that, locally, patients can receive both the best of care and the worst of care. If services are to improve in line with Government commitments for cancer care, then understanding the processes that lead to this variation in patient experience, and, in particular, the role of staff in this, is important. Following discussion of these points, this chapter will conclude with a consideration of the implications of the findings for local service provision.

5.2 Obtaining a diagnosis

Understanding the process by which a diagnosis is reached may well be important in reducing colorectal cancer mortality given that early diagnosis has been found to have an important impact on survival (Gatta et al, 2000; Major, 2003; Spurgeon et al, 2000). There are three aspects to this process: the help seeking behaviour of the patient; the interaction between patient and GP in which symptoms are described (by the patient) and appraised (by the doctor); and the referral pathway as an outcome of this process. The findings from this study reflect those of the literature in the main and suggest that each of these dimensions may be experienced by the patient as problematic. Firstly, it is evident that patients, for a variety of reasons, often delay in visiting their GP to discuss symptoms. This may be because of fear about the possibility of a serious diagnosis or a genuine belief in the lack of seriousness of symptoms but the consequence is the same: delay in accessing medical care. A lack of awareness about the possible significance of symptoms, combined with a set of beliefs about the under-resourcing of the NHS can lead to a decision of *“not wanting to bother busy staff”* as one patient put it. Whilst there is a realism to patients’ expressed views about the resourcing of the health care system that would be difficult to change, accurate and widely available information about symptomology, the importance of early contact with

the GP and the significance of an early diagnosis in terms of survival might encourage patients to be more proactive in seeking help. It might also enable patients to more effectively and accurately describe their symptoms and help to combat some of the fear often associated with a possible diagnosis of cancer.

The second aspect of the diagnostic process, namely effective symptom appraisal, is partly dependent on the clinical skills of the GP. Critically, it is also dependent on a quality interaction with the patient, in which the GP is predisposed to listening and probing replies actively. This is particularly the case for colorectal cancer symptomology, described as ambiguous, and often associated with co-morbidity because of the age group of the patients concerned. The findings from this study suggest that some patients perceived this interaction as a gatekeeping exercise, in which they did not feel listened to. In part, these findings reflect the problems of decision making in such circumstances (Summerton, 2000). However, ensuring that GPs and other health professionals are aware of colorectal cancer risk factors (such as family history), of the importance of early diagnosis in respect of survival and of the likelihood of delay in patients presenting to their GP, may be beneficial. Perhaps as important are those aspects of the clinical encounter that are concerned with communication, discussed in more detail below. Green and Holden (2003) point out that whilst GPs may be used to living with diagnostic uncertainty, patients are not. They argue for the importance of GPs communicating accurately with patients about the difficulties of diagnosis and the length of time it might take in order to avoid unrealistic expectations.

The third dimension of obtaining a diagnosis relates to the interface between primary and secondary care. Patients articulated concerns about delays in receiving hospital appointments, test results, and so a definitive diagnosis, this period of uncertainty generating much anxiety. The issue of waiting times is central to an appreciation of the quality of cancer care because of the way in which they impact on the patient experience. Waiting times have been assigned high importance in Government policy, as evidenced by the target set of a maximum two week wait between an urgent GP referral and a hospital clinic appointment (Commission for Health Improvement and Audit Commission, 2001a) and the aim of the new NHS Bowel Cancer Programme to speed up diagnosis for patients presenting with symptoms associated with bowel cancer (Department of Health, 2003). This highlights the importance of the capacity of the system to respond effectively and efficiently to referrals so that care for symptomatic patients is streamlined. In part this is about resources, but it is also about

the interface between primary and secondary care and the way in which there can be a lack of transparency concerning responsibility for individual patient care at this juncture. This can be important in cases where action may need to be taken to follow up referrals. In this study, the interface between primary and secondary care was also identified as being important when patients were discharged from hospital, an issue that will be discussed later.

5.3 The meaning of individualised care

It was evident from this relatively small sample of patients that there was diversity in relation to their needs, for example, in relation to information, and moreover, that this sometimes varied for the same individual over the course of their care and treatment. Against this background of individual diversity, it was also evident that there was some commonality in respect of those aspects of care that contributed positively to the patient experience, explored in more detail below. In these circumstances, the challenge for those charged with improving the quality of cancer care is to ensure consistency of standards but remove uniformity of response. In other words, quality of care, to some degree, is about a flexible and individual response to each patient. However, this raises the question of the extent to which it is possible for a large bureaucratic system such as the NHS to deliver individualised care. Whilst certain contexts may constrain a tendency towards flexible professional practice, the findings from this study suggest that practitioners may not in fact be predisposed towards this model of practice. For example, some patients perceived a lack of willingness to be flexible about their care and treatment arrangements.

Evidence from this and other studies suggests that health professionals may, in some circumstances, seek to 'manage' their encounters with patients. In order to deliver individualised care in which patients' needs can be met, health professionals must be receptive to 'hearing' and appraising patient views and concerns, and acting upon this information (Kennedy, 2003). Tarrant et al (2003) argue that this kind of quality interaction with each and every patient can be important in making care personal whatever the context, and is not dependent on a continuing relationship between health professional and patient. It is within this kind of context that patients are likely to be actively involved in decisions about their care and treatment.

There are two aspects of individualised care that were particularly highlighted in this study: communication and information and the importance to patients of feeling cared for. These are explored in more detail below.

5.3.1 Communication and information

Although transparent and effective *systems* are fundamental to the quality of cancer care, the quality of health professional-patient interactions are as important, as indicated earlier. The findings from this study illustrate that patients experienced both good and bad interactions with staff in primary, secondary and community settings. Examples of positive interactions often revolved around the effective communication of, *clinical* explanations and information. Consistent with other findings (for example, Department of Health, 2000b; Fallowfield, 1998; Meredith et al, 1996; National Cancer Alliance, 1996; van der Molen, 2000a), poor interactions with staff often reflected problems with communication, such as a lack of sensitivity to concerns and anxieties; a tendency towards making assumptions about how much information and honesty patients and family members wanted; and a confusing and inconsistent use of terminology.

This analysis of health professional-patient interaction points up the importance of offering staff opportunities to reflect on practice and engage in further education and training to enhance these aspects of their practice. However, rather than viewing communication as a set of skills and techniques in which to be trained, the focus here is on viewing communication as an active process in which the dynamics of the relationship between participants is paramount. Thus, patients are not viewed as passive recipients but active partnerships in the management of their care (Kennedy, 2003). Neurolinguistic programming (NLP¹) has been applied to the field of health care with some beneficial outcomes and its use in respect of cancer care specifically has been highlighted (Rushworth, 1994). Because of its focus on developing rapport and communication, NLP has the potential to improve the quality of health professional-patient relationships such that patients feel supported and relaxed and therefore receptive to the interaction. Exploiting local interest and expertise in NLP (at Halton PCT, for example) may be productive in developing staff education and training for those professionals with direct responsibility for the treatment and care of cancer patients.

Improving the quality of information available to all patients is a key component of UK health policy (CRD, 2000) and patients in this study highlighted the type and amount of information that they received, as distinct from the way in which information was communicated, as another pertinent issue in the quality of their care. Consistent with

¹ Neurolinguistic programming is concerned with learning about how people communicate.

the findings from the literature, as a group they displayed variation in their information seeking behaviour and their perception of how satisfactory the information that they gathered was. This underlines the importance of tailoring information to meet individual patients' educational background, cultural orientation and general level of understanding (CRD, 2000; Leydon et al, 2000a). However, there were two points made that are particularly relevant to this debate. Firstly, the view that it was difficult to process large amounts of information at one time, particularly at diagnosis, was expressed frequently. This indicates that a system whereby the patient is seen by a health professional soon after critical points in their care to discuss their understandings and care and treatment options may improve the quality of patients' experiences. Secondly, patients who had gained information by talking to other patients about their experiences appeared to greatly value what they had learnt from this source. This is relevant to the concept of the 'expert patient', which gives primacy to the idea of the patient as 'expert in his or her experience, feelings, fears, hopes and desires' (Kennedy, 2003. p.1276). This suggests that medical encounters which seek to integrate clinical information with patients' understandings (including beliefs and feelings) may be a valuable model for enabling professionals to think through how they might improve the communication dimensions of their practice.

5.3.2 Feeling cared for

The second dimension of individualised care that was raised by this study was the importance to patients of feeling cared for. Besides partners, health professionals were identified as the most important group in terms of giving psychological support, a finding similar to that reported in the literature (Farrell, 2001b; Slevin et al, 1996). A number of examples were cited by patients of ways in which health professionals demonstrated their concern for, and sensitivity towards, patients' anxieties and feelings. These examples were less to do with direct clinical care and more to do with the often taken for granted aspects of care. Patients described actions by health professionals that were carried out "*without having to say anything*", a sign that was often taken to mean that they were, literally, being taken care of. Quality of care in this sense seems, on the face of it, cheap and easy to deliver, given that concern and sensitivity is conveyed through everyday actions and activities. However, the contexts within which care is frequently mediated are characterised by under-resourcing, particularly in terms of staffing. The specialist nurse post (colostomy care) was also perceived by patients as being someone who was specifically there to meet their care needs and made them feel supported after discharge from hospital, a time many found

disorienting. These findings place centre stage the notion of 'caring' in professional practice.

5.4 Co-ordination of the cancer care system

Perhaps not surprisingly, patients in this study did not directly allude to matters of service co-ordination. However, it was evident that a lack of co-ordinated, coherent and well-resourced local care provision impacted to some degree on their experiences as patients. For example, patients talked about delays in referrals from primary to secondary care and the extent to which they felt isolated on discharge from hospital. This highlights the importance of identifying critical points of the care pathway where different parts of the system may not interface effectively in terms of sustaining patient support. Thinking in terms of different forms of support at these critical points may be beneficial. For example, patients identified patient groups as an important source of support, as well as family members and friends. Finding ways of developing a network of support, particularly in community settings may be one way of sustaining patients, particularly after discharge. In addition, the appreciation of the service given by the specialist nurse (colostomy care) suggests that these specialist roles which, in effect, traverse the primary-secondary care boundary, may be an effective way of co-ordinating patient care.

5.5 Conclusion

It is important not to overstate the findings from this small-scale qualitative study. However, given that many of the findings are consistent with those from other studies, including large scale survey findings such as the National Survey of NHS patients with Cancer (Airey et al, 2002), this gives a fairly sound basis for drawing conclusions. The findings illuminate the local picture with regard to provision for patients with a diagnosis of colorectal cancer. The situation may be different for other types of cancer, although it is likely, given the generic nature of many of the issues uncovered, that there will be some degree of convergence.

The findings have been used as a basis for identifying a number of implications for local service providers, identified below, and, to this extent can contribute to the evidence base surrounding patients' evaluations of their care. Thus, the findings can be used as an agenda to inform future service development in a manner that is consistent with the aspiration of improving the quality of the patient experience, including outcomes, as specified within current Government policy.

5.6 Implications for local service provision

Whilst the resourcing of the system of cancer care locally has been discussed above, accounting for differences in patients' experiences of cancer care can perhaps best be understood in terms of the quality of medical encounters between patients and health professionals at different points in the 'patient journey'. There are a number of implications that can be identified based on this analysis, which are summarised below.

- Some local patients receive the best of care: that is, there is much that patients appreciate about the care they receive. This provides a sound basis for service improvement.
- There is an identified need for clear, accurate and widely available information about the symptoms of colorectal cancer; the importance of early diagnosis; and all aspects of care and treatment. Innovative ways of providing some of this information, such as utilising the knowledge and experiences of patients, as well as venues for the display and distribution of material, may be useful in reducing the stigma often associated with colorectal cancer as well as improving access to information.
- Patients find it difficult to process large amounts of clinical information, particularly at critical times such as diagnosis. Thus developing systems whereby patients are regularly supported, perhaps by specialist staff, could be beneficial to improving patients' understandings of their care and treatment.
- There is an identified need for health professionals to be sensitive to patients' anxieties, particularly at critical points in their care. For example, sensitivity towards the effects on patients of diagnostic uncertainty.
- Focusing on *caring* as an essential aspect of patient-health professional interaction is likely to improve the quality of patient experience.
- Opportunities for health professionals to reflect upon and develop their communication skills by exploiting local interest and expertise in areas such as NLP may provide ways of improving the communication aspects of medical encounters, such as that identified in the two bullet points above.

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- In addition, GPs might improve their appraisal of symptoms through enhancing the quality of their interactions with patients, through training in NLP.
 - Streamlining the interface between primary and secondary care, at diagnosis, throughout treatment and on discharge from hospital has the capacity to be beneficial to quality of care. In particular, the exploration of health professional roles that traverse the boundaries of primary and secondary care may improve the *system* of care.

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Appendix 1

Letter to patients
Patient Consent Form
Patient Information Sheet

To be sent on Practice Notepaper

Date

Dear Patient,

"Consulting patients on their views about the quality of their care"

I am writing to you to ask if you would be willing to take part in a research study being organised and carried out by the Centre for Public Health Research at Chester College of Higher Education.

The focus of the study is to explore the views and experiences of patients in relation to the quality of their overall care so that cancer services may be improved. You are being invited because you are a patient who has had contact with your GP and hospital services during the last year due to your condition, and you are therefore in a position to comment in this respect.

I enclose an information sheet for you to keep, with a tear-off slip at the base. If you are willing to take part, please complete the tear-off slip and return it in the prepaid envelope provided. A researcher will then contact you in a few days to arrange an interview at a time and in a place convenient to you.

If you require any further information about this study, please do not hesitate to contact Karen Kirby at the Centre for Public Health Research (01244 380926).

Yours faithfully,

GP/Practice Manager



PATIENT CONSENT FORM

Title of Project: "Consulting patients on their views about the quality of their care"

Name of Researcher: Karen Kirby

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I agree to take part in the above study.

_____ Name of Subject	_____ Date	_____ Signature
_____ Name of Person taking consent (if different from researcher)	_____ Date	_____ Signature
_____ Researcher	_____ Date	_____ Signature

Patient Information Sheet

Consulting patients on their views about the quality of their care

You are being invited to take part in a research study by participating in an informal interview about your experiences and views on the quality of your care. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The aim of the study is to explore the experiences of patients with colorectal cancer in Halton. The focus will be on finding out patients' views on their experiences of care from first contact with their GP, through to diagnosis and treatment. The findings from the study will be incorporated into improving the quality of care for cancer patients in Halton.

Why have I been chosen?

You, and other patients with colorectal cancer in Halton, have been approached because your views and experiences would be valuable in terms of contributing to the development of cancer care services.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?

If you decide to take part, you should keep this information sheet, but sign and return the tear-off slip at the base, in the prepaid envelope provided. This will give your consent for a researcher from the Centre for Public Health Research at Chester College to contact you to invite you to attend an informal interview at a time and place convenient to you. At this interview, you will have the opportunity to raise and discuss your views and experiences relating to your care. With your

permission, the interview will be audio taped. However, participants will not be identifiable in the final written report.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks foreseen in taking part in the study. However, if talking about your experiences causes you any distress you will, if you wish, be given assistance to access appropriate support groups.

What are the possible benefits of taking part?

As a patient it is possible that you may welcome the opportunity to share and discuss your views and experiences.

What will happen to the results of the research study?

It is hoped that the findings may be used to improve cancer care services in Halton. Individuals who participate will not be identified in any subsequent report or publication.

Who is organising and funding the research?

The research is funded by Halton Primary Care Groups. The Centre for Public Health Research at Chester College is carrying out the study.

Who may I contact for further information?

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact Karen Kirby on 01244 380926.

Thank you for your interest and co-operation in this research.

✂.....

please tear off here and return this slip in the prepaid envelope.

I agree to a researcher contacting me to arrange for me to attend an interview in due course.

Name: _____ Phone Number: _____

Address: _____

Date: _____ Signature: _____

Appendix 2

Interview schedule

Consulting patients on their views about the quality of their care

Interview schedule

Presenting to GP with symptoms

What was it that first led to you consulting your GP?

Probe:

- To what extent were they aware of the possible significance of signs and symptoms?

What was your experience like when you went to your GP with symptoms?

Probe:

- Did they feel their concerns were dealt with appropriately by the GP?
- Did they feel they understood everything they were told?
- Were they able to recall everything they were told by the GP after they had left the surgery?
- Explore experience of access to other forms of information other than face-to-face from doctor
- Explore perceptions of the quality of information provided? Was information timely, relevant and unambiguous?
- Did they feel able to voice all their questions/concerns?

The process of referral

What was your experience like (of the process of referral)?

Probe:

- How did they feel about the process of referral?
- Explore perceptions about communication between GP and secondary care?
- Explore perceptions of speed of referral, speed of results of tests?
- To what extent did patients feel that health service professionals were actively 'on their case'?
- What were patients told, at what stage and by whom?
- How did they feel about what they were told?
- Did they understand everything they were told?
- Explore perceptions of how they were given their diagnosis?
- Did they feel it was difficult/easy to ask questions/voice concerns with secondary care health professionals?
- Explore extent of involvement in treatment options.

Quality of care

How do you feel about the quality of care you receive?

Probe:

- Explore perceptions of the quality of care received?
- Do patients perceive that their signs and symptoms are 'optimally' dealt with?
- Do patients 'see' and 'feel' the fragmentation in the system?
- Explore perceptions relating to access to psychological support (support groups, counselling etc.)
- Explore perceptions of support for practical aspects of their lives impacted by a diagnosis of cancer
- Did patients feel they were treated ethically - with respect and dignity?
- Who are the people in the system they trust?

Concluding comments

Do they have any further comments about any aspect of their experiences of care?