

**WHAT ARE THE PSYCHOSOCIAL NEEDS
OF CANCER PATIENTS
AND THEIR MAIN CARERS?**

**A study of user experience of cancer services
with particular reference to psychosocial need**

June 2001

**The Institute for Health Research
Lancaster University**

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EXECUTIVE SUMMARY

Objectives

Focusing on service users' perspectives, this research project had the following objectives:

- To identify and document patient and main informal carer psychosocial needs, and to consider how patients and carers believe these could best be met.
- To explore patient and main informal carer experiences of specialist cancer services, with particular reference to psychosocial needs.
- To examine service providers' perspectives on the nature of current service provision and its adequacy in meeting the psychosocial needs of patients and their main carers.
- To identify examples of 'good practice' in meeting psychosocial need from the perspective of both patients/carers and service providers.

It is helpful to express these objectives as research questions:

- What are patient and carer psychosocial needs?
- Which needs are most prevalent?
- Who has what needs? How, if at all, do needs differ among patients and carers in relation to clinical and social characteristics?
- Are patients' and carers' needs being met?
- What can patients' and carers' experiences tell us about how needs could best be met?
- What are health professionals' perspectives on these needs and whether they are being met?

Study Setting and Methods

Study sites

The research took place in the north west of England. It involved the recruitment of cancer patients via out-patient clinics in four hospital and palliative care settings in three Health Authority areas:

- Lancaster, Morecambe, Kendal and the South Lakes
- Blackpool, Wyre and Fylde
- Blackburn, Hyndburn and Ribble Valley

Methods

We combined quantitative and qualitative methods as follows:

- A descriptive cross-sectional survey with two branches – a) patient survey, b) carer survey. This involved the postal distribution of a self-completion questionnaire pack to a consecutive sample of 1000 adult cancer patients (aged above 18 years) referred to the study with the assistance of 21 participating consultants and their staff in outpatient clinics and associated services in the three study sites, over a period of one year. Patients had one of four tumour types: lymphoma, breast, colorectal, lung, and were within one month from four 'critical moments' in their cancer journey: diagnosis; end of first treatment, first recurrence of cancer; the move from active treatment to palliative

care. Of the 1000 patient questionnaires distributed, 402 (40%) were returned. Response rates varied by tumour type and critical moment.

The main informal carers were recruited to the study via initial contact with patients; 262 completed carer questionnaires were returned. The patients and carers who participated represented a broad enough spectrum of experience and psychosocial need to enable us to generate meaningful results. The representativeness of the sample was adequate for the study's purposes.

- In depth guided interviews with a purposively selected sub-sample of surveyed patients (n=47) and carers (n=32). All tumour types and critical moments were represented in the patient and carer interview samples, and purposive selection ensured a broadly representative range of respondents by age and social circumstance.
- Short structured interviews with a purposively selected sample of health care professionals and managers (n=39) in the three study sites. The professionals were practising in hospital, palliative or primary care settings. The sample included: consultants (n=8), GPs (n=15), specialist nurses (n=9), dieticians (n=2), general managers (n=3) and support service co-ordinators (n=2).

Questionnaire psychosocial needs inventory (PNI)

A list of 48 psychosocial needs statements was developed in the project's six month pilot phase for use in the patient and carer self-completion questionnaires, referred to as our *psychosocial needs inventory* (PNI). Both patients and carers were instructed to complete the PNI with reference to *their own* needs. The PNI items were later grouped into seven needs categories: needs related to interaction with health professionals (nine items); information needs (five items); needs related to support networks (five items); identity needs (five items); emotional and spiritual needs (15 items); practical needs (eight items); childcare need (five items). The psychosocial needs inventory proved to be a relevant, discriminatory and sensitive survey instrument.

Principal findings

What are psychosocial needs?

- It is necessary to think broadly about what psychosocial needs consist of rather than narrowly equating them with psychological distress and anxiety. Needs are associated with:
 - interaction with health care professionals and the quality of professional practice (social and interpersonal skills, communication styles, demeanour);
 - the quality of care systems and procedures (accessibility, rapidity of treatment and other interventions);
 - involvement in treatment and health care decisions;
 - information requirements and opportunities;
 - social support networks – their range and quality, both lay and professional;
 - emotion, feeling states, worries and anxieties - about self and others;
 - spiritual concerns;
 - challenges to self-identity - body and self image;
 - practical needs - managing the demands of daily life and of treatment.

- In general, patients and carers *actively* shape their cancer experiences and psychosocial states. Their success in doing this positively is influenced by their access to resources, especially: information, prompt medical attention, ready access to health professionals, emotional support, and practical assistance.

Which psychosocial needs are most prevalent?

- The needs of importance to the great majority of cancer patients and carers related to:
 - finding valued qualities in health care professionals and systems, especially: - sensitivity, receptivity, honesty, respectfulness, speedy access, involvement in treatment decisions;
 - obtaining full information about what to expect from the disease and its treatment, about treatment timetables and schedules, services and additional sources of information;
 - securing good social support and assistance from family, friends and health care professionals;
 - locating sources of hope for the future and help in maintaining independence.
- Cancer specialists were a key source of information about the disease process and management plans. Their attitude and ability in imparting information had an important effect on the cancer experience at each stage of the cancer journey.
- Important minorities and sub-groups of patients and carers had additional psychosocial needs, especially in the ‘emotional and spiritual’, ‘identity’ and ‘practical’ needs categories. For example, patients and carers of lower socio-economic status had higher levels of practical need for help with financial matters and transport than the more affluent.

What needs are unmet, and who has unmet needs?

- Most needs rated by patients and carers as important were satisfied, reflecting well on services. However, using a stringent criterion for defining an unmet need we identified a range of unmet needs together with sub-groups of patients and carers who were at greatest risk of having unmet needs:
 - Unmet needs tended to be in the practical, self-identity, and emotional categories, for example: assistance with financial matters and welfare claims; advice about food and diet; help with housework; help in dealing with the unpredictability of the future and sad feelings; help with sexual needs.
 - Those with the following characteristics were at greatest risk of having unmet needs.
 - Patients:* younger; having a long-standing illness or disability; socio-economically disadvantaged; not having a faith; having difficulty in talking freely to a carer about the cancer; having social activities disrupted by the cancer; having financial difficulties.
 - Carers:* those who are *not* the partner or spouse of the patient; have existing caring responsibilities; have few people to call upon for help; are in poor health themselves; are caring for a patient who is in the palliative care only phase.
 - Carers had considerably more unmet psychosocial needs than patients. The problems for an important minority of carers were both serious and complex.
 - Lung cancer patients and their carers often felt abandoned by services and isolated because intervals between appointments could be long, and there was usually no clear-cut treatment plan.

The carer's role

- Carers played a crucial role, undertaking vital care work and emotion management.
- Carers' success in managing their own psychosocial needs had an important bearing on their ability to support the patient. The impact on the patient's well being was profound.
- Carers, especially spouse carers, often saw themselves as jointly 'fighting this illness' with the patient. It followed that they wanted, and needed, to share in all aspects of the cancer journey.
- Carers often wanted to be alongside the patient in medical settings, and to be party to the receipt of information about treatments and care. However, carers often experienced uncertainty about if, how and when they would be 'allowed' to participate in medical encounters, for example, being present during doctor-patient consultations, asking questions.

The perspectives of health professionals on psychosocial need

- Health professionals had varying degrees of appreciation of the range of psychosocial needs of patients, and especially of carers. Nurses had the greatest understanding of these needs, whilst consultants, in general, had the least (with the exception of consultants in palliative medicine).
- Consultants saw their role as treatment focused. They generally relied heavily of nursing staff to deal with the emotional and psychological needs of patients. They did have an awareness that their style of practice and manner of engagement with patients impacted significantly on patient psychological well being, and drew attention to the importance of 'good communication' with patients. Very few consultants mentioned carers, and patients were viewed as rather passive recipients of information.
- GPs were well placed to address psychosocial as well as clinical needs. However, they identified a number of changes in General Practice (especially on-call and out-of-hours arrangements) that undermined their ability to make the most of their position. Some GPs would welcome the opportunity to play a greater role in cancer care, noting their current marginal position. In general, they would like to be fully informed about their patients' treatments.
- Current and on-going changes in cancer services were largely welcomed and deemed to be bringing about service improvements.
- Some gaps and weaknesses were identified by a range of professionals: communication with patients (systems, styles and coverage of issues); communication with other health professionals; perceived difficulties in accessing specialist mental health professionals for patients in extreme distress; some consequences of changes in palliative care services (for example, pressure on beds and reducing opportunities for respite care); time and resource constraints; and excessive waiting times for some patients.

Recommendations

The recommendations arising from this study concern the professionals who deliver specialist cancer services, the structure of the services, and the information systems which link the various elements of the services together.

Understanding and identifying psychosocial needs

- There should be more widespread appreciation of patient and carer psychosocial needs among health professionals in cancer services. This would assist in improving the quality of care.
- Practitioners should have a full understanding of the ways in which both patients and carers can actively and positively shape their cancer experience. They should assist patients and carers in gaining access to the resources that enable them to manage their psychosocial states in positive ways, so minimising the danger of developing acute psychological distress. Resources include: information, prompt medical attention, ready access to health professionals, emotional support, and practical assistance.
- Cancer specialists should receive more training in communication skills.
- Patients and carers, either together or separately, should be encouraged to disclose concerns about the emotional, social and practical implications of their situation.
- Identifying psychosocial needs should be part of routine patient and carer assessment.
- Professionals should be alert to the sub-group variations in psychosocial need and unmet need so that support and assistance can be appropriately targeted. Our findings provide a useful guide.
- The multidimensional and socially situated perspective on psychosocial need developed in this study should be reflected in the education, training and current practice of health professionals in cancer services.

Responding to psychosocial need

- Patients should be allocated a 'key worker' – an appropriate professional to whom the patient and their carer can turn during their cancer journey, in the first instance, for information and advice.
- Sufficient time should be given in medical consultations to enable patients to be involved in treatment decisions, not only at diagnosis and relapse but also in palliative care.
- The cancer nurse specialist role is well established for breast cancer, and much valued by patients. Equivalent support should be made available to all cancer patients. This will require substantial investment by service providers.
- Information systems should enable rapid transmission of laboratory and radiological data to clinicians who should inform patients without delay of relevant results.
- Where social (emotional, identity, practical) needs arise, professionals can do much to assist in their alleviation either by offering support themselves or by directing the patient to other sources of support and assistance.
- Cancer services should facilitate easy access to counselling, relaxation, psychotherapy, dietetics, and practical advice for those who need it. These

interventions should be part of statutory service provision.

- **Gaps and weaknesses in services identified by the professionals in this study should be addressed.**
- **The sense of abandonment felt by many lung cancer patients and carers should be addressed.**
- **All professionals should share comprehensive clinical information rapidly between primary and secondary care so that there is a consistent approach.**
- **The role of GPs (and other primary care based professionals) in cancer care should be reviewed, with consideration given to the opportunities that are lost if they are relatively marginalised in cancer care.**
- **Current professional and service successes in meeting psychosocial needs should be acknowledged and built upon.**

Informal carers

- **Professionals should pay greater attention to the role played by, and the psychosocial needs of, informal carers. This would benefit both carers and patients.**
- **With due regard to ethical considerations and personal circumstances, carers should be given clear signals about the potential for their involvement in medical settings, with an emphasis on their being ‘invited in’ and included in discussions wherever possible.**
- **Designated support services for carers should be available. However, professionals should appreciate that carers ‘put the patient first’ and are sometimes reluctant to seek support for their own needs lest this diverts resources away from patients. Carers need reassurance that their needs are legitimate.**

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CHAPTER 1 Introduction

Study aim and objectives

This Report documents the methods and findings of a three year (1997-2000) multi-method observational study on the psychosocial needs of cancer patients and their main informal carers. The study's aim was to assist cancer services in a better understanding of the nature of the psychosocial needs of patients and informal carers. The project was set up in the wake of the Calman-Hine Report on cancer services (Department of Health 1995), which recommended that an ideal model of care should focus not only on clinical treatment, but relieve suffering by taking account of the practical, emotional, psychological and spiritual needs of patients, their families and carers. A sympathetic appreciation of the range of these psychosocial needs on the part of service providers can assist patients and carers in facing up to cancer, and in attending to its practical demands, whether or not service providers are able to directly meet these needs. While our research demonstrates that there are some needs that can only be fully addressed by individuals and agencies outside of the health services - for example, by family members, close friends and relatives, or by Social Services, employers or the Church - it is our view that an understanding of, and sensitivity to, these needs on the part of health service practitioners and those involved in running cancer support services can enable patients and informal carers to find pathways to the satisfaction of needs. For example, a cancer patient offered the opportunity to talk to a doctor or nurse about their fears for the well-being of their spouse or child, or about their anxieties concerning the loss of their job or the breakdown of relationships within their family, may not only help to relieve the patient's psychosocial stress but may facilitate some ameliorative action being taken by the patient or informal carer. Thus we have not confined our attention to those psychosocial needs that relate most closely to the patient/carer and health service interface, but to the full range of psychosocial needs bound up with living with cancer.

The research team set out with objectives that can be summarised as follows (see Appendix 1 for the research proposal): ¹

'User' focused research objectives:

- To identify and document patient and main informal carer psychosocial needs, and to consider how patients and carers believe these could best be met.
- To explore patient and main informal carer experiences of specialist cancer services, with particular reference to psychosocial needs.

'Provider' focused research objectives:

- To examine service providers' perspectives on the nature of current service provision and its adequacy in meeting the psychosocial needs of patients and their main carers.

¹ The research proposal contained a third 'user' focused objective: 'With particular reference to psychosocial needs, to compare patient and main carer experiences of cancer services within and between three Cancer Units'. As the fieldwork progressed it became apparent that there was uneven recruitment of patients in the study sites (see Chapter 3). This meant that it became untenable to compare services across sites and this objective had to be abandoned.

Policy and practice objective:

- To identify examples of ‘good practice’ in meeting psychosocial need from the perspective of both patients/carers and service providers.

In meeting these objectives we have used both quantitative (descriptive cross-sectional surveys of patients and main informal carers) and qualitative methods (in depth guided interviews with patients and carers; semi-structured and structured interviews with cancer service providers; focus group discussions with patients and informal carers). These methods are described in detail in Chapter 3.

Study location

This research took place in the northern part of the North West region of England. It involved the recruitment of cancer patients to the study who were attending out-patient clinics in four hospitals and other settings situated in three Health Authority areas, hereafter referred to as the three study sites:

Study sites

- (Site 1) **Lancaster, Morecambe, Kendal and the South Lakes**
Royal Lancaster Infirmary, Westmorland General Hospital, St John's Hospice
- (Site 2) **Blackpool, Wyre and Fylde**
Blackpool Victoria Hospital, Trinity Hospice in the Fylde
- (Site 3) **Blackburn, Hyndburn and Ribble Valley**
Blackburn Royal Infirmary, Park Lee Hospital

The study sites were selected principally because of their geographical proximity to each other and to the research team's academic base, and because they initially (at the project's planning stage) shared the use of a Cancer Centre, The Christie Hospital in Manchester. During the lifetime of the survey a new Cancer Centre based in Preston was being established as the Calman-Hine (Department of Health 1995) recommendations were implemented, serving the Cancer Units in the three study sites (although Blackburn services continued to make some use of the Christie Hospital). Thus there were a considerable number of service changes underway in the study period.

What are psychosocial needs?

In Chapter 2 we outline our understanding of what constitutes a psychosocial need, and describe how our approach contrasts with mainstream psycho-oncological research on cancer patients' psychosocial needs. Ours is a more sociological approach, giving more emphasis than is customary to the ‘social’ in the psychosocial. As we explain, it is the needs that underlie emotional and psychological distress, rather than this distress itself, which is of interest to us. That is, we do not equate psychosocial needs with clinical manifestations of psychological morbidity, and our study is not concerned with measuring such morbidity. In summary, our approach to psychosocial needs is as follows:

Psychosocial needs are embedded in features and qualities of life and social relationships that, from the viewpoint of patients and informal carers, are necessary, important, or critical to their psycho-emotional ability to live with the knowledge and social consequences of cancer, and thus to their ability to hold themselves and their social worlds together.

This conceptualisation of psychosocial needs set up a difficult challenge: we had to construct a 'list' of these needs before we could survey patients and informal carers to obtain a sense both of needs prevalence and their sub-group distribution. The list of needs had to be amenable to adaptation for use in a survey instrument. This work was undertaken in the pilot phase of the project, utilising qualitative research methods alongside a literature review on extant psychosocial needs research. The outcome was the production of a 48 item *psychosocial needs inventory* for use in patient and carer self-completion questionnaire instruments (see Appendix 2 for these questionnaires). It proved to be possible to use the same psychosocial needs inventory in both the patient and the main carer questionnaire. These items were later re-grouped into seven *patient psychosocial needs categories* using Cronbach's alpha test for internal reliability:

Patient psychosocial needs categories

- needs related to interaction with health professionals (9 items)
- information needs (5 items)
- needs related to support networks (5 items)
- identity needs (5 items)
- emotional and spiritual needs (15 items)
- practical needs (8 items).
- childcare needs (1 item)

Our purpose, however, was not simply to identify and 'count' psychosocial needs among patient and informal carers. We also wanted to obtain a richer understanding of what these needs are, the contexts in which they are generated, and how they are responded to and dealt with by patients and carers. That is, we sought an analytical and contextual understanding of psychosocial need. This demanded the use of qualitative research methodologies alongside quantitative ones. It is important to note, therefore, that the deployment of qualitative methods in this project was not merely to assist in the generation of a psychosocial needs inventory for use in the descriptive cross-sectional survey. Qualitative methods are not subsidiary to quantitative methods. Rather, the in-depth guided interviews which followed up the survey, involving a sub-sample of questionnaire respondents, were designed to generate data which could throw an explanatory light on the nature, prevalence and distribution of psychosocial needs. The benefits of drawing on both quantitative and qualitative approaches in researching psychosocial needs are demonstrated in our results.

Informal carers' psychosocial needs: companions through cancer

This research considers the psychosocial needs of the main informal carers of cancer patients *as well as* the needs of patients themselves. Paying attention to carers' needs alongside those of patients sets this research apart from most other research in the field of psycho-oncology. Whilst there is a body of work associated with the sociology of chronic illness and disability which examines the experiences of informal carers and family members connected with chronically ill people (Bury 1991; Kelly & Field 1996; Thomas 1999), this is an area that is under-explored in cancer studies. This minimal attention to the specificity of cancer issues is also true of the feminist and social policy literature on informal caring (Finch and Groves 1983; Thomas 1993, 1999). Informed by these 'carers' literatures, our research design was constructed with a particular supposition in mind: that the people who are the close companions of cancer patients and accompany them on their journey (the 'significant others') have psychosocial needs of their own that in many ways are just as pressing as are those of the patients. The project has generated questionnaire and interview data on the *independent*

experiences and needs of ‘carers’, and our findings are discussed at some length in Chapters 9-11.

In this study our operational definition of the main informal carer is as follows: the carer is that lay person whom a patient identifies as being in a close supportive role, and as ‘sharing most’ in their illness experience. Carers were recruited to the study via initial contact with patients, a process described in Chapter 3. This involved going to some lengths to explain our carer inclusion criteria to questionnaire pack recipients² because we recognised from the outset that the term ‘carer’, or ‘informal carer’, is conceptually and operationally problematic both in general (Thomas 1993; Heaton 1999) and in relation to cancer (Morris 1999). We made use of the term because it has wide currency in both health research and lay discourse, and is not easily substituted. Our pilot phase research suggested that the main difficulty in deploying the term in the field was that some patients, typically recently diagnosed patients, did not have the kinds of physical care needs that would lead them, their spouses, partners,³ other family members or close friends, to immediately define themselves as carers. However, sixty four per cent of returned patient questionnaires were accompanied by a completed carer questionnaire, indicating that the recipients of the questionnaire pack did understand our intentions and were able to identify a main carer.

Who has what psychosocial needs, and when?

In setting out to identify patient and carer psychosocial needs it was important to recognise that cancer patients do not constitute a homogenous group either clinically or socially. We wanted to find out something about the sub-group distribution of psychosocial needs: do they vary with tumour type and at different points in the cancer trajectory? Is there a social patterning of psychosocial need? Thus the study design and data collection methods had to facilitate sub-group analyses. To assist this, the design took account of the following variables.

Tumour type

To facilitate comparison between the psychosocial needs of patients with different types of cancer we elected to study a sub-group of the cancer population by focusing exclusively on patients with the following tumour types:

- breast
- colorectal
- lymphoma
- lung

These cancers were selected because: i) they are among the most common, ii) they make high demands on cancer services, and iii) they ensured that the study included a mix of cancers common in both men and women. These tumour types involve different treatment modalities and prognoses. We included lymphomas, which have a much lower incidence, in order to explore medical as opposed to surgical (breast and colorectal) treatment, and situations of good prognosis versus poor prognosis (lung). However, because our results show that there are both similarities and differences in psychosocial need in connection with tumour type, it is

² The questionnaire pack that was mailed to patients included information on who qualified as a ‘carer’ for this study (see Chapter 3 and Appendix 2).

³ It is important to note that this research did not build normative assumptions into its fieldwork materials concerning the sexuality and personal relationships of patients. That is, we avoided any suggestion that carers who were ‘partners’ would necessarily be heterosexual partners.

reasonable to suggest that we have identified some psychosocial needs that are of significance for all cancer patients and carers, irrespective of the tumour type involved.

The 'critical moment' in cancer trajectories

The research team wanted to capture a sense of psychosocial needs among patients and carers who were at different points in their cancer journeys. We hypothesised that psychosocial needs were likely to vary as the patient moved from diagnosis, through treatment and towards recovery or death. A longitudinal study design would have been ideal, but we were not in a position to mount a research project with the necessary longevity. Instead, a cross-sectional design was adopted such that patients with the requisite tumour types who were close to one of four 'critical moments' were recruited to the study. These four critical moments were defined as being within one month from the following event:

- diagnosis
- the end of first treatment
- first recurrence (notification that the cancer had returned)
- the move from active treatment to palliative care only.

These moments should not be understood to be synonymous with the way that cancer specialists routinely define the disease 'stage'. Rather, they are socio-medically defined markers of our own construction. The operationalisation of these moments for each tumour type proved to be quite difficult. For example, a lung cancer diagnosis often led directly to palliative care. For other reasons, too, we had to be content with the fact that not all patients were referred to the study strictly within one month of the critical moment trigger (see Chapter 3). Nevertheless, this element of the design has enabled us to gain some insight into the prevalence of, and variations in, psychosocial needs at different stages in the cancer trajectory.

The social patterning of psychosocial need

How do psychosocial needs vary among patients and carers who have different social characteristics, for example by gender, socio-economic status, household composition, and involvement in close and supportive relationships with others? Our findings throw some light on this. For example, whilst epidemiologists and sociologists have long reported that cancer mortality and morbidity trends display the familiar socio-economic gradients, and that there are serious health inequalities associated with cancer (Acheson Report 1998), our evidence suggests that psychosocial needs also vary by indicators of socio-economic status. In this Report, we pay some attention to these variations as well as to gender patterns. It should be noted that whilst it had been our intention to examine psychosocial needs in relation to ethnicity, and this was one of the reasons why Blackburn with its relatively large minority ethnic population was selected as a study site, we failed to make any headway in this area. This is mainly accounted for by the disappointingly low rate of referral of patients to the study from the Blackburn Royal Infirmary (see Chapter 3). Despite early attempts to find other ways to reach patients from minority ethnic groups with cancer, we soon came to the view that an investigation of ethnicity and psychosocial need would require an entirely different type of study design, informed by a community research expertise that we did not possess (Nazroo 1998). The result is that the patient sample is overwhelmingly white.

The perspectives of health professionals on the psychosocial needs of patients and informal carers

Chapters 13 and 14 report the findings of our research with a range of health professionals in the three study sites. The Calman-Hine Report (Department of Health 1995) had signalled that patient and informal carers' perspectives might differ from those of the professionals who provide cancer services:

The development of cancer services should be patient centred and should take account of patients', families' and carers' views and preferences as well as those of professionals involved in cancer care. Individuals' perceptions of their needs may differ from those of the professional (Department of Health 1995:6).

With this in mind, one objective of the study was 'provider focused': to examine providers' perspectives on the nature of current service provision and its adequacy in meeting the psychosocial needs of patients and their main carers. Together with an understanding of patients' and informal carers' perspectives on psychosocial need, it was anticipated that these provider views could contribute to an understanding of the nature, prevalence and distribution of cancer-related psychosocial needs, and could indicate best practice.

With a few exceptions, the professionals who participated in the research were practising in hospital, palliative or primary care settings located in one of the three study sites. The research with health professionals took place in two phases. First, in the pilot phase a wide range of professionals (n=63) were interviewed about the services they provided, with particular reference to psychosocial need. The main purpose of these semi-structured interviews was to 'map out' the landscape of cancer services in the study sites and to gain a greater understanding of disease trajectories and their 'critical moments'. In this way, typical pathways through the services taken by patients with particular tumour types could be identified. This provided vital contextual information for understanding the psychosocial needs of patients and carers, as well as a baseline 'snap shot' of services soon to undergo significant change as the recommendations of the Calman-Hine Report (Department of Health 1995) were implemented as part of a national and regional programme. This round of interviews also enabled us to finalise plans for the recruitment of patients to the study (see Chapter 3). The pilot study reports are presented in Appendix 3. The research team published a paper on some of the issues raised in the pilot phase (Morris et al 1998).

The second stage in the research with health professionals occurred in the study's main fieldwork phase and involved structured interviews with professionals (n=39) in relevant primary, secondary and palliative care service settings in the three study sites. The interviews covered questions concerning services meeting needs, linking with other services, effectiveness, and change.

Ethical issues

Careful consideration was given to ethical considerations in the design of the research, and ethical matters were kept under review throughout. NHS Ethics Committee approval was obtained in the three Health Authority areas concerned, initially for the pilot phase of the project and then again for the main project phases. A key issue for Ethics Committees was the protection of patients and informal carers from potentially distressing information being revealed to them through the research process. For example, some patients may not know that they had a cancer diagnosis, and some may have been in denial. A condition for Ethics Committee approval was that the word 'cancer' should not be introduced in our study

documentation for patients and informal carers, and only used by us in discussion with patients and carers once it was clear that these respondents spoke of the illness in these terms. We instituted a number of other practices, in addition to those that inform the professional practices of university researchers in general, to avoid causing patients and informal carers any distress: abstaining from sending patients a questionnaire reminder letter if they were at the palliative care critical moment; accepting that clinicians involved in recruiting patients to the study would exercise their judgement and sometimes refrain from referring a particularly distressed patient to us if they thought that involvement in the study would cause additional problems; never placing patients and carers under any pressure to participate in the research (see Appendix 4 for the study consent form and other information for potential participants). We are confident in stating that the research was undertaken with extreme sensitivity and that patients, informal carers and health care professionals experienced it as such. We know that many patients and informal carers welcomed the opportunity to participate in the study, often motivated by the desire to 'help others' through their involvement. Some patients and carers told us that they had found participation personally beneficial, especially the opportunity to tell their story in interviews.

CHAPTER 2 Our approach to psychosocial needs

Identifying psychosocial needs

Identifying health needs is widely acknowledged to be fraught with difficulty, reflecting broader philosophical problems in understanding human ‘needs’ in general. There is no single ‘correct’ way to conceptualise, assess and measure health needs, they are context and purpose dependent. Clinicians, public health professionals, health service managers, economists, and sociologists define and measure ‘health needs’ differently (Bowling & Rees Jones 1997; Wright et al 1998). That cancer patients have health needs that encompass *psychosocial* as well as disease treatment needs has been officially acknowledged (Department of Health 1995; Royal College of Physicians & Royal College of Radiologists 1996). However, what these psychosocial needs actually are, and the prevalence and distribution of these needs among cancer patients with different clinical and social characteristics, is less well understood. Nor are the psychosocial needs of the main informal carers of cancer patients clearly understood, although they are now recognised to exist and require the attention of cancer services (Department of Health 1995).

The medical sub-discipline ‘psycho-oncology’ has played a critical role in raising awareness about patients’ psychosocial problems and has developed a particular approach to researching, clinically assessing, and responding to psychosocial needs. The hallmarks of this approach are: a focus on the emotional and psychological responses of patients to their disease and its treatment; the measurement of emotional distress (anxiety, depression, psychological and psychiatric morbidity, psychological pathology) and its treatment through psychotherapeutic or psychiatric interventions; the assessment of ‘quality of life’, operationalised in terms of measuring patients’ physical and emotional functioning; and a focus on the quality of clinicians’ communication with patients (Alderson et al 1994; Costain-Schou & Hewison 1999). Thus, psychosocial needs are equated with degrees of emotional and psychological distress or ‘inadequate’ (pathological) emotional functioning: the patient has a psychosocial need if s/he manifests a clinically defined problematic psychological response to cancer. If causes are attributed to these needs, these tend to be identified at the level of individual personality and other psychological characteristics. Psycho-oncology has played a key role in instigating a wide range of psychosocial interventions in clinical and support service contexts (Fallowfield 1995; Meyer & Mark 1995). A question now occupying psycho-oncologists, as yet unanswered, is whether psychosocial interventions (and which types) have a positive impact not just on the relief of emotional distress but on patient survival rates (Greer 1991; Fawzy et al 1995).

In this study, the approach to psychosocial needs differs from this mainstream psycho-oncological perspective in a number of important ways, particularly in relation to: how we define psychosocial needs; our emphasis on the social nature of these needs; and how we have researched these needs.

What we mean by psychosocial need

We are not equating psychosocial need with levels of emotional and psychological distress, nor are we concerned with measuring such distress (anxiety, depression and so on). Rather, we think of emotional and psychological states (‘good’ as well as ‘bad’) as being *manifestations* of the degree to which *underlying needs* have been addressed and met. Our interest is in identifying and understanding these underlying needs. The key questions for us are:

- What are these underlying needs?
- Which needs are most prevalent?
- How, if at all, do needs differ among patients and carers in relation to their clinical (tumour type, critical moment) and social characteristics (especially: gender, age, family and household circumstances, social support, and socio-economic status). In short, what is the distribution of needs: who has what needs?
- Are patients' and carers' needs being met?
- What can patients' and carers' experiences tell us about how needs could best be met?
- What are health professionals' perspectives on these needs and whether they are being met?

To illustrate what is meant by an underlying need, we can suggest that a patient who displays high levels of anxiety may have an unmet underlying psychosocial need to be treated with much more sensitivity by the doctors they encounter. Or they may need to be much better supported and understood by their spouse or wider family members. Our research is motivated by the conviction that if providers of cancer services could gain a greater understanding of what these underlying needs are, and of 'who has what needs', then healthcare professionals and others should be better able to address and meet these needs, and thus prevent and reduce the manifestations of unmet need in the form of acute individual emotional and psychological distress.

Having clarified that our concern is with the psychosocial needs that underlie the manifestations of patients' and carers' emotional and psychological states, the challenge is then to define what qualifies as a need. Here, our approach has been to generate an understanding of psychosocial need by posing the question *what, from the point of view of patients and carers, would make it easier to live with the knowledge and social consequences of having this illness?* It is the answers that patients and carers give to this question that is of greatest interest, but we have also researched health professionals' perceptions of what would make it easier for patients and carers to live with cancer. It seems reasonable to suggest that the answers given by patients and carers to this question provide a good indication of their cancer-related psychosocial needs. Our approach is thus a pragmatic one: *in this study, psychosocial needs are embedded in those features and qualities of life and social relationships that, from the viewpoint of patients and carers, are necessary, important or critical to their psycho-emotional ability to live with the knowledge and social consequences of the presence of cancer, and thus to their ability to hold themselves and their social worlds together.*²

As will become apparent, some of these features and qualities of life and social relationships pertain directly to health service provision and concern patients' and carers' relationships with cancer service personnel and structures. Other features are locked into the wider social lives of patients and carers, most notably their relationships with spouses, partners, family and friends, and their socio-economic circumstances.

This question, *what would make it easier to live with the knowledge and social consequences of having cancer?*, already rests upon two important assumptions that should be made explicit and kept under review. First, it is based on the premise that knowing that one has cancer, or

² In this Report we use the term 'cancer' in the 'What would make it easier...' question, and in related formulations. However, as noted in Chapter 1, it was a requirement of NHS Ethical Committee approval that the word cancer should not be used in survey documentation, nor in discussion with patients and carers until it was clear that this was how they talked about the illness concerned. Thus, in both the questionnaire and in interview discussion, the 'What would make it easier...' question was formulated with reference to 'this illness.'

that someone close to one has cancer, is something that most (but not necessarily all) people find psychologically and emotionally problematic. It follows that finding ways to make living with this knowledge easier is normatively considered to be 'a good thing'. These individual psycho-emotional sequelae of a cancer diagnosis reflect the wider public knowledge that cancer is a major cause of death in our society, and the pervasiveness of the 'death and suffering' meanings and imagery associated with cancer and its treatment in Western culture. Second, the question assumes that the knowledge that one has about cancer, and other people's knowledge about cancer, impacts upon social life and has real social consequences. These consequences are likely to include disrupted relationships, roles and routines, and may have significance for financial and material well being (for example, if there is the threat of loss of employment and income). From the start, we had to be open to the possibility that the empirical data might challenge both of these assumptions.

The social nature of psychosocial needs

Our approach pays much more attention than does the psycho-oncological to the *social* in the psychosocial. We see *both* the emotional and psychological distress that results when underlying psychosocial needs are unmet, *and* these needs themselves, as fundamentally social in character. Psycho-emotional states are social in that ontological states are formed in and through social relationships with other individuals and in specific socio-cultural and spatial contexts. Underlying psychosocial needs are social in that living with the knowledge and social consequences of a cancer diagnosis is profoundly shaped by the way individuals socially interact, and by the nature of their social settings. Thus our approach is sociological. This contrasts with psycho-oncology which is informed by the disciplines of psychology and medicine (psychiatry) wherein the causes of emotional and psychological distress are located primarily in individuals' personalities, cognitive functioning and other bounded psychological traits. In conceptual terms, psycho-oncologists effectively isolate the individual from their social context, something we see as problematic:

The main limitation [of psycho-oncology] is that the individual is considered separately from [his/her] social and material circumstances, such as: money or housing worries, ambitions at work, commitments at home, deadlines to meet, redundancy, transport problems, anxiety about what to tell the children, or being rejected by friends who will no longer offer much needed practical help (Alderson et al 1993: 69).

It is also important to note that we see cancer patients as active participants in their cancer dramas, not as passive victims of the disease, the social behaviours of others or of social circumstance. Rather, like any individual, the cancer patient has agency and volition - is a purposive social actor who is engaged in the creation of their own realities through interaction with others, albeit within constraints set by structures and material and other circumstance.

So, we see psychosocial needs as embedded in the social fabric, especially in the cancer patient's social relationships. We conceptualise patients' and informal carers' relationships with health professionals as particular types of social relationship. All of this means that in identifying psychosocial needs in the research we have to be finely attuned to the social dynamics involved in their formation (and thus, by implication, in their assuagement), and to think about these needs as changing and in flux, rather than as fixed and static. In this view, psychosocial needs are social products and social constructs: they emerge through social interactions (with health professionals, friends and family, employers and so forth) in particular social and material contexts.

How we have researched psychosocial needs

As stated above, our approach has been to identify psychosocial needs via eliciting patient and carers' answers to the question, *what would make it easier to live with the knowledge and social consequences of the presence of cancer?* We wanted to find out:

- what the needs are;
- the prevalence of needs;
- the distribution of needs among patients and informal carers in relation to their clinical (tumour type, critical moment) and social characteristics (especially: gender, age, family and household circumstances, social support, socio-economic status);
- whether needs are being met;
- what patients' and carers' experiences tell us about how needs could best be met;
- what health professionals' perspectives are on these needs and whether they are being met.

How have we operationalised this approach in the field? The first, and obvious, point is that this research is identifying psychosocial needs *from the patients' and informal carers' point of view*. However, it would have been unreasonable to expect patients and carers, in the midst of dealing with their own cancer, to think through and formulate their needs for us in a neatly packaged and finished fashion. Rather, guided by our *what would make it easier?* question, our initial task was twofold: (i) to explore patient and carer experiences of living with cancer and, through interpretation, to derive psychosocial needs from these experiences, and (ii) to draw on the (small) extant literature which has a comparable approach to cancer patients and carer needs. Nevertheless, it proved to be the case that some patients and carers were able to explicitly formulate their needs by giving direct answers to the question: *what would make it easier...?*

An early requirement was to generate a comprehensive listing of *potential* psychosocial needs and then to make this suitable for use in the patient and carer cross-sectional survey instruments. Only then could our *needs prevalence* and *distribution* questions be answered. The work of constructing this listing was undertaken in the pilot phase of the project, and is described in Chapter 3. The outcome was the production of a 48 item *psychosocial needs inventory* for use in patient and carer self-completion questionnaires (see Appendix 2 for these questionnaires). It proved to be possible to use the same psychosocial needs inventory in both the patient and the main carer questionnaire. As described in the previous chapter, these items were later re-grouped into seven psychosocial needs categories.

We wanted to go beyond listing and counting, however, to gain a deeper understanding and explanation of the nature, prevalence and distribution of these psychosocial needs. This was done through qualitative research in the form of loosely structured in depth interviews with a sub-sample of surveyed patients and carers. These methodological dimensions of the research, which constituted fieldwork stages, are discussed in Chapter 3, and the results are presented in subsequent chapters.

CHAPTER 3 Research Methods

Introduction

This study required a design that could bring quantitative and qualitative research methods into dialogue. From the outset, the research team recognised the value of complementing quantitative with qualitative approaches without making either subsidiary to the other. Throughout the life of the project we moved between these modes of data collection, using the insights from one to inform the other. For example, qualitative research in the pilot phase played a critical role in enabling us to identify 'needs statements' for use in the questionnaire's psychosocial needs inventory. However, we also recognised that there was a potential tension between these approaches given that they rest on different philosophical foundations and generate 'versions' of social reality that may be at variance with one another. The challenge was to harness this tension in the service of creative thinking about psychosocial need.

The data collection methods used to address each of our key research questions are presented in summary form in 1. What follows is an account of the research methods utilised in the project's three phases:

Pilot phase

(i) Generating a psychosocial needs inventory

An early study requirement was to generate a comprehensive listing of *potential* psychosocial needs with a view to constructing a psychosocial needs inventory for use in the patient and carer survey instruments. This involved a number of research tasks:

- Five focus group discussions were held with people who were or had been affected by cancer (involving 15 patients, 22 carers, 20 bereaved people; tumour types - breast, lung, colorectal). Participants were encouraged to talk about their cancer experiences and about what had made it more difficult or easier for them to live with cancer. We organised this through CancerCare, a voluntary support organisation operating in Lancaster and the South Lakes. We approached the five 'drop-in' centres in the area and, with the help of the facilitators, recruited volunteers who would feel comfortable talking about needs in the context of cancer. Individual interviews were arranged with the assistance of an Oncology Consultant. In both the focus groups and the individual interviews we adopted an open approach, asking for cancer narratives, and for respondents to reflect on what 'needs' they had or were having. Even with the small numbers involved we generated a wealth of data; people who volunteered to speak about the experience were able to do so with openness, and in detail. This encouraged us in our belief that qualitative interviews would be an appropriate method in the study, providing excellent data without causing additional distress to those who volunteered to take part. Dimensions and types of psychosocial need were identified through the thematic cross-sectional analysis of these data (transcribed tape recordings of the discussions).

Table 1: Summary of data collection methods with reference to the research questions

Research question	Project phase and data collection method
What are the underlying psychosocial needs of patients and carers?	<i>Pilot phase.</i> <ul style="list-style-type: none">• Individual in depth guided interviews with patients and carers.• Focus group discussions with patients and carers.• Semi-structured interviews with health care professionals.
Which needs are most prevalent?	<i>Main-stage phase.</i> <ul style="list-style-type: none">• Descriptive cross-sectional surveys. Instrument: self-completion questionnaire.• In depth guided interviews with a sub-sample of patients and carers.• Structured interviews with health care professionals.
How, if at all, do needs differ among patients and carers in relation to clinical (tumour type, critical moment) and social characteristics (especially: gender, age, family and household circumstances, social support, socio-economic status). In short, what is the sub-group distribution of needs. Who has what needs?	<i>Main-stage phase.</i> <ul style="list-style-type: none">• Descriptive cross-sectional surveys. Instrument: self-completion questionnaire• In depth guided interviews with a sub-sample of patients and carers.• Structured interviews with health care professionals.
Are patients and carers needs being met?	<i>Main-stage phase.</i> <ul style="list-style-type: none">• Descriptive cross-sectional surveys. Instrument: self-completion questionnaire.• In depth guided interviews with a sub-sample of patients and carers.• Structured interviews with health care professionals.
What can patients' and carers' experiences tell us about how needs could best be met?	<i>Main-stage phase.</i> <ul style="list-style-type: none">• In depth guided interviews with a sub-sample of patients and carers.

- Individual in depth guided interviews were conducted with 8 patients and 4 informal carers. Interviewees were encouraged to 'tell us their cancer story' and to reflect upon what had made it harder or easier for them to live with cancer. Dimensions and types of psychosocial need were identified through the thematic cross-sectional analysis of these interview transcript data.
- A literature review was undertaken to identify published studies where a comparable approach to psychosocial need had been adopted (that is, in contrast to the dominant psycho-oncological approach discussed in Chapter 2). These proved to be few in number,

but one set of studies were of direct relevance and use. These were a related series concerning the needs of cancer patients and their informal 'primary care givers' conducted by researchers in Nursing departments at the Universities of Kansas and Missouri, USA (Wingate & Lackey 1989; Hileman et al 1992; Harrington et al 1996) (see Appendix 5). The needs of informal primary care givers became the particular focus of the later studies in this series, resulting in the development of a 90 item *Home Caregiver Need Survey* (HCNS). We obtained permission to draw upon the HCNS, adapting elements of it to our research requirements in the British context.

- All members of the research team (none of whom had diagnosed cancer) were asked to engage their own imaginations by reflexively asking themselves the questions: if I had cancer, what would make it easier to live with the knowledge and social consequences of having this disease? How would I sustain my emotional and psychological well being? The needs listing which resulted was compared with those of patients and assisted in making us more sensitive to the subtleties and dimensions of need.

By these means we developed a list of 48 psychosocial needs statements, referred to overall as our psychosocial needs inventory (PNI), for use in the self-completion questionnaire surveys. The needs inventory was suitable for use in both the patient and informal carer questionnaires, with carers being instructed to think about each need item in relation to *their own needs* (not the needs of the patient). This facilitated comparison of patient and carer psychosocial needs.

(ii) Interviews with health professionals

With a few exceptions, the professionals who participated in the research were practising in hospital, palliative or primary care settings located in one of the three study sites. The research with health professionals took place in two phases. First, in the Pilot phase of the project, a wide range of professionals (n=63) were interviewed about the services they provided, with particular reference to psychosocial need. The main purpose of these semi-structured interviews was to 'map out' the landscape of cancer services in the study sites and to gain a greater understanding of disease trajectories and their 'critical moments'. In this way, typical pathways through the services taken by patients with particular tumour types could be identified. This provided vital contextual information for understanding the psychosocial needs of patients and carers, as well as a baseline 'snap shot' of services soon to undergo significant change as the recommendations of the Calman-Hine Report (Department of Health 1995) were implemented as part of a national and regional programme. This round of interviews also enabled us to finalise plans for the recruitment of patients to the study. The study Reports are presented in Appendix 3. The research team published a paper on some of the issues raised in this phase (Morris et al 1998).

The study sites were chosen for their adjacent borders and shared use of a Cancer Centre at the planning stage of the project (The Christie in Manchester). We did not approach the Preston site, because it was in the process of becoming the new Cancer Centre for the whole area, but each of the areas chosen was starting, or soon to start, using the Preston facilities. Many changes in response to the Calman-Hine report were being instigated during the project's lifetime, which added to the complexity of the project, but offered interesting avenues of enquiry. We aimed to gather information about the changes as background material for our research, particularly for our fieldwork discussions with health professionals.

The study main-stage

The key features of the main-stage study design are as follows:

- A descriptive cross-sectional survey with two branches – a) patient survey, b) carer survey - involving the postal distribution of a self-completion questionnaire pack to a consecutive sample of 1000 adult cancer patients (aged above 18 years) recruited to the study with the assistance of 21 participating consultants and their staff in outpatient clinics in the three study sites over a period of one year. As described in Chapter 2, patients had one of four tumour types - breast, colorectal, lymphoma and lung - and were within one month from four 'critical moments' in their cancer journey: diagnosis, end of first treatment, first recurrence, and the move from active treatment to palliative care.
- In depth guided interviews with a purposively selected sub-sample of surveyed patients (n=47) and carers (n=32) who had returned questionnaires and indicated their willingness to be contacted for a follow-up interview.
- Short structured interviews with a purposively selected sample of health professionals (n=39).

Each of these aspects of the design will be discussed in turn.

Cross-sectional surveys

Patient recruitment to the survey

Prior to commencing data collection we consulted widely with health professionals involved in delivering cancer services about possible patient recruitment mechanisms. With their help we decided that the most efficient route for gaining our sample was through outpatient clinics, as these provided a point through which the majority of cancer patients would pass at 'critical moments'. It was indicated that a small number of patients, mainly the very elderly, would not enter the hospital system, but be dealt with in the primary care sector. Access through GPs was considered, but rejected as possibly exacerbating distress among such patients. In addition the experiences of other researchers suggest this is an unwieldy method (Pooley & Gerrard, 1999). As most specialist cancer physicians and surgeons we contacted were willing to participate, it was decided that recruitment should take place through them. We hoped that this would allow us to access the bulk of cancer patients with particular tumours. However, we recognised that a few patients who were seen by consultants who were not designated cancer specialists would slip through the net, but we felt there would be sufficient numbers to represent the most usual patient journeys through cancer services.

Recruitment was therefore accomplished mainly through those outpatient clinics where willing designated consultants worked (see the last section of this chapter for a discussion of some of the difficulties). Our qualifying criteria were that patients be over 18 years of age, diagnosed with one of our four tumour types. In addition, we asked that patients be referred soon after (preferably within a month of) the four 'critical moments'.

We provided referral forms and patient introductory information sheets to each participating consultant, but we left it to the individual consultants to decide whether to ask patients if they would be willing to receive the questionnaire. Some consultants did find the time (not easy in a busy clinic) to introduce the project, but others were happy for us to send the questionnaire to the patient with a short standard covering letter signed by themselves. The letter was intended to assure patients of the legitimacy of the project, and the source through which we obtained their names. We also assured consultants that questionnaires would not be sent to newly diagnosed patients until at least a week after the date of the clinic, in order to avoid its arrival immediately after the diagnostic consultation.

Forms for recruitment required four pieces of information: name and address of patient for mailing purposes; tumour type and critical moment; date of referral to the project; name of referrer. It quickly became apparent that date of birth was also a useful piece of information, so that any missing information could be obtained from consultants' secretaries prior to mailing. In all, 21 consultants and their staff were involved, spread over the three study sites. They included ten designated cancer surgeons (breast and colorectal), eight specialist physicians (lung, haematology and palliative care), and three oncology specialists. In addition, two consultant pathologists helped us with recruitment. Some breast care nurse specialists were also involved to a large extent. Overall, recruitment was variable by source, with some specialists providing more names than others (average: 47 patients referred; range: 1-257; SD: 62). The main bulk of our referrals came from oncologists, palliative care consultants, breast and colorectal surgeons. Where recruitment levels were low it was generally the case that the consultant was too busy in clinic to perform the additional task of referring to the project. In those situations where a routine was put in place, usually involving delegation to other members of staff, a regular flow of referrals was forthcoming. Some consultants gave permission for specialist nurses or the pathology department to provide the referrals. From conversations we know that the professionals filtered out those patients who they felt were too unwell, too distressed or too confused to be contacted. However, we also know that where recruitment was intermittent, it was in a random, rather than systematic way; usually the consultant forgot to refer in the hectic pace of the clinic. In all, 1000 patients were sent questionnaire packs.

On receipt of referrals, questionnaires for patients and carers were coded for tumour type, critical moment, source of referral, and geographical area. An identification number was added to track response and to avoid duplicate mailings (as some patients were referred more than once from differing sources). The questionnaires were subsequently mailed out with a detailed introductory letter, the covering letter from the consultant, and a pre-paid reply envelope. Reminders were sent out after a month to non-responders, except for those patients who were referred as at the palliation only 'moment'. Returned questionnaires were recorded for date of return and offer of interview, and subsequently the data were entered into an SPSS file for analysis.

Carer recruitment to the survey

Carers were recruited to the study via initial contact with patients. Patients were requested to pass the carer questionnaire to the person they identified as their 'main carer'. Supporting information in the pack indicated that the carer need not be co-resident but was likely to be the person who 'shared most' in the illness experience. We went to some lengths to explain our carer inclusion criteria to questionnaire pack recipients because we recognised that the term 'carer' was problematic in some cancer contexts, as it can be in others (Heaton 1999). Our pilot study phase had confirmed that some people did not immediately associate a close companion through cancer with the term 'carer'. Recently diagnosed patients and their close companions were the ones most likely to express uncertainty about the carer label because patients did not usually have physical care needs. Despite this, we continued to use the term 'main carer' in fieldwork materials, with appropriate explanations, because the term has such wide cultural currency and is not easily substituted. Sixty-four per cent of returned patient questionnaires were accompanied by a completed carer questionnaire, indicating that the recipients of the questionnaire pack did understand our intentions and were able to identify a main carer.

Survey instruments

The patient questionnaire booklet was a self-completion instrument consisting of six sections: 'About your health now' (six main questions); 'About your daily life now' (the EORTC-C30 scale, Aaronson et al. 1993); 'What makes it easier to live with your current illness?' (the 48 item psychosocial needs inventory); 'About the services you have used' (three main questions); 'In what ways might services be improved?' (box for a free text answer); and 'About you' (14 questions on personal and relevant social characteristics).

The carer questionnaire booklet was a self-completion survey instrument also consisting of six sections: 'About your caring role' (five questions); 'About your health now' including the EORTC-C30 global health status indicator and the General Health Questionnaire (Goldberg et al. 1988); 'What makes it easier for you to live with this current illness?' (the 48 item psychosocial needs inventory); 'About the services you have used' (two main questions); 'In what ways might services be improved for you?' (box for a free text answer); and 'About you' (16 questions on personal and relevant social characteristics).

The questionnaires were entitled 'Your needs in illness' and no mention was made of the word 'cancer', as requested by the ethics committee. The questionnaires and introductory letter were piloted in outpatient oncology clinics with 30 people. Their comments were taken into account, and minor changes to wording were made. Questionnaire completion time was between 20 and 30 minutes. On the final page of both questionnaires, patients and carers were asked to indicate if they would be willing to be interviewed, and to supply contact details if they were.

The questionnaire psychosocial needs inventory

The centre pages of the patient and carer questionnaire booklets comprised of the same psychosocial needs inventory. The instructions to patients and carers for the completion of the psychosocial needs inventory were that, for each need statement, they should first indicate 'how important' it had been for them over the past few weeks on a scale from 1 to 5, and second, 'how satisfied' the need had been, again on a scale of 1 to 5 (the questionnaire packs are reproduced in Appendix 2).

In depth guided interviews with patients and carers

To gain a deeper understanding of the nature of psychosocial needs and cancer experiences among both patients and informal carers we conducted loosely structured, or 'guided' (Denzin & Lincoln 1994), interviews with a purposively selected sub-sample of surveyed patients (n=47) and carers (n=32). The purposive selection of cases for interview was informed by the need to include a range of men and women living with different tumour types, at different critical moments, and in different socio-economic and other social circumstances. Interviews were sensitively conducted by the project's researcher (SMM). They were arranged and conducted in the patient/carer's home, lasting about an hour per person, and all were tape recorded (with the respondent's permission) and later fully transcribed. Where possible, respondents were asked to sign a consent form prior to the interview taking place. The opportunity to ask questions was provided when arranging the time and date for interview and again at the start of each interview, when written information sheets with contact numbers were also provided. The interviews were loosely structured with the main request to participants being that they give an account of the cancer experience alongside reflections on what did or could make it easier to live with the cancer situation. Patient and carer interviews covered the same basic issues. There was: an invitation to 'tell your story' about the illness; the eliciting of reflections on what had made it easier or more difficult to live with the illness; a discussion of people, both professional and lay, who had been supportive/unsupportive (this was assisted by visually plotting these individuals on a 'map' comprised of concentric rings signifying different levels of support - see Appendix 6); an invitation to tell us what they

would say to someone else who was in a similar position; an invitation to add ‘any other comments’. At the end of each interview, the Hospital Anxiety and Depression Scale (Zigmond & Snaith 1983) was administered.

Where a patient and their carer had both completed questionnaires and were selected for interview, we had to decide whether to try to interview these individuals separately or jointly. Initially we decided that all interviews with patients and carers should be conducted separately, reflecting a sociological convention that research involving people in dyads (for example, married couples) should acknowledge potential power imbalances and conflicting interests in relationships by interviewing people separately (see discussions in Brannen 1988; Parker 1990; Gerhardt 1991; Twigg & Atkin 1994; Seymour et al. 1995). As our interviewing got underway, however, we revised our practice and decided, for a number of reasons, to be guided by whether the patient and carer preferred a separate or joint interview. A key consideration was our growing understanding that accounts of illness experiences, and the lived experiences themselves, are often constituted jointly rather than individually (especially in spouse and intimate couple relationships), through close social interaction and interlocution, and that this was better captured through joint interviewing (Gerhardt 1991). This interviewing practice and the ‘shared’ or ‘joint’ feature of cancer experiences, are discussed at length in one of our published papers (Morris 2001). Of the 32 informal carers interviewed, 19 were interviewed jointly with the patient they cared for. All of the interviews (with carers and/or patients) were conducted in people’s private homes and lasted for around one hour per person. All interviews were audio taped and fully transcribed, with respondents’ permission. (See Appendix 6 for the full interview schedule).

Structured interviews with health professionals

The second phase of interviews with 39 health professionals involved short structured interviews focusing on four topics: a) identifying patient and carer psychosocial needs; b) links with other services; c) service effectiveness in meeting needs; and d) service change. There was a final request for any other comments (see Appendix 7 for the interview schedule). The interview was deliberately kept short, as concern about time pressures was common among health professionals.

We wanted to interview health professionals who had regular experience of dealing with those cancer patients with one of the four tumour types of relevance to our study. We therefore purposively sampled a cross-section of professionals who were directly involved in cancer services: doctors, nurses, other therapists, and managers. In addition, we mailed all GP practices in one study site, and every other practice in the other two sites; we recruited a random selection of those who expressed an interest in being interviewed. The GP practices from which we obtained our GP sample ranged in list size from 1,400 to 11,000 (average: 6,500). The number of partners in the practice ranged from one to seven (average: 4). There were seven urban practices, six rural practices and two that had both urban and rural surgeries. Four practices were skewed toward an elderly population and six received social deprivation payments. Seven GPs described their practice as having a very mixed list. Interviews took place in the period February 1998 - August 1999.

Health professionals were given information about the project and its aims. The interviewer (SMM) discussed anonymity and confidentiality with each of them. Although we could not assure complete anonymity, the majority expressed a willingness to be quoted, with only five requiring the power of veto³. Several also expressed a particular interest in seeing the results.

³ These five professionals have not been quoted in this Report.

The health professional sample, shown in Table 2, consisted of 21 men and 18 women; the majority of doctors were male and all the nurses were female. The average age of the sample was 45 years (range: 28-59). GPs were slightly younger (average 44 years) than nurses (average 47 years) or consultants (average 49 years).

Table 2: Interviews with health professionals by professional group and study site, in Phase 2

Professional Group	Site 1	Site 2	Site 3	Total
GPs	9	3	3	15
Nurses	4	5	0	9
Consultants	3	2	3	8
Health Service Managers	2	1	0	3
Dieticians	1	1	0	2
Support Service Co-ordinators	2	0	0	2
Total	21	12	6	39

Data Analysis

Survey data

Frequency distributions and selected cross-tabulations for all single and composite variables were produced, and logistic regression analyses were undertaken for each of the 48 need items in the psychosocial needs inventory using a range of questionnaire response variables.

Patient and carer interview data

All patient and carer interviews were fully transcribed and entered into the NUD*IST4 qualitative analysis programme (QSR 1998). Each interview text (involving 79 respondents: carer alone (13), patient alone (28), carer and patient together (38 individuals)) was coded for study site, age, gender, respondent (patient and/or carer), patient tumour type and critical moment (at the time of patient referral to the study). Using NUD*IST4, a content analysis of each interview text was undertaken to identify topic categories, with new categories being added as they became apparent. In this way, 38 topic categories were generated, assisting in the manageability of this large data-set. For illustration, categories which featured in the majority of interview texts were (not in any order): carers, family, lay people other than family, time issues, transport, complaints about care, diagnosis, general practitioners, hospitals, identity, information, nurses, and medical treatments. Other more specific categories such as cancer recurrence, shock, support services, diet, and financial matters tended to feature in a sizeable minority of cases. Topics that were less frequently discussed, sometimes because they were sub-group specific, included children under school age, alternative health care, private health care, hospices, and stomas. The next stage in the analysis was the identification of analytical themes, although some of the topic themes became analytical themes.

This was undertaken initially through the close reading and re-reading of all transcripts by SMM, and of a selection of transcripts by CT, to support the validity of interpretation. This process was then developed through the examination of selected text at the intersection between topic categories and sample characteristics (for example, identity and gender, time issues and diagnosis, information needs and informal carers). Sub-group analyses across a range of themes were also undertaken, for example, for: carers' experiences; tumour type; critical moment; and gender. Attention was paid to both typical and less typical cases. The interview data analysis thus approximated a grounded theory approach (Bowling 1997)

wherein topic categories and analytical themes were derived from, and constructed through, a systematic engagement with the data. We also examined the ways in which theme convergences were presented at interview, particularly in joint patient/carer interviews. In this we used a dialogic analysis, related to both discourse and conversational analysis, but drawing its strength from its focus on relationality between the participants and the context of the speech act (Shotter 1995). In this part of the analysis we paid particular attention to the styles used and the interaction between speakers and addressees (Bakhtin 1986; Holquist 1990).

Health Professionals' interview data

All interviews were fully transcribed and entered into the NUD*IST4 qualitative analysis programme (QSR, 1998), and a thematic analysis undertaken.

Referral of patients to the study: a note on difficulties

Data on cancer incidence in the three study sites, for the relevant tumour types, was obtained from the Cancer Registry prior to the commencement of the study to confirm that we could obtain the numbers we needed for statistical analysis. During the course of the study we also sought local data on incidence for the four tumour types. This provided baseline data against which to check the referral of patients to the project. Two points are of note: a) we did not receive the number of referrals anticipated, and b) referral rates varied considerably, both between study sites and within study sites by tumour types and critical moments.

The fact that our total referral numbers were significantly lower than expected reflects our rather naïve expectations concerning the ease with which clinicians and clinic systems could support such a research project. In reality, despite the expressed willingness of consultants and other clinical staff to participate in and support the project by making referrals, the referral mechanisms proved to be difficult to operationalise in the context of busy clinics and some departmental reorganisation. We are extremely grateful to those health professionals who did find the time to refer patients to us. We do not think any systematic bias was built into the referral process, it was simply patchy because contingent on staff recall, time and priority issues.

Also problematic was the variation in referral patterns between the study sites. This compelled us to abandon one of our original objectives – to make some between-site comparisons. Thus the patient and carer data analyses presented are not disaggregated by study site. The highest referral rate was in study site 1 (Lancaster, Morecambe, Kendal and South Lakes), with all tumour types and critical moments represented, but not in the expected proportions (lung and colorectal referrals were lower than anticipated). We obtained reasonable numbers of referrals from study site 2 (Blackpool, Wyre & Fylde), but the majority of these came from the hospice and, while providing the range of tumour types, were at the 'palliative care only' critical moment. Colorectal and breast patients were referred from the hospital at earlier moments, but no lung patients were referred (due to restructuring and workload in the lung clinic). Likewise only a handful of lymphoma patients were referred. Referrals from the study site 3 (Blackburn, Hyndburn & Ribble Valley) were much fewer. Despite our best efforts and the averred willingness of consultants, referrals failed to materialise. It was eventually decided that little could be done to force referrals, although we sent a further encouraging letter, and made further contacts during the course of the study. Most of the referrals from this area were recently diagnosed patients with colorectal or breast tumours.

Other features of the referral pattern

By tumour type

Breast cancer and lymphoma referrals in study site 1 matched the expected 'pool' of new cases (as extracted from Cancer Registry and Pathology Department figures) reasonably well. However, in comparison, about a third of the potential lung patients and a quarter of the expected colorectal patients were referred. In study site 2, only about a fifth of the expected 'pool' of new breast cancer patients (at about 20 a month), and about a third of colorectal patients were referred.

By critical moment

It was difficult to establish what the expected numbers for the critical moments, apart from diagnosis, were likely to be, as figures record incidence. However, there were certain areas where numbers appeared low, especially for lung cancers at 'end of first treatment' and 'recurrence'. However, this is unsurprising given the clinical features of the disease in which diagnosis leads quickly to the palliative stage in the majority of cases. Few lymphomas were referred to us at the 'palliative only' moment. Again, this is linked to the clinical course of the disease, which may be chronic for years, so that it is often difficult to pinpoint the moment at which treatment becomes palliative only. For the cancers treated initially by surgery, breast and colorectal, there was some blurring of referrals around moment one and two. Diagnosis for these patients tended to lead on quickly to surgery (especially in the case of breast cancer, or emergency bowel surgery), which meant that there was only a small window of opportunity for the diagnosis moment. Questionnaires for people referred at diagnosis were often returned during convalescence after surgery, which should, strictly speaking, be considered 'end of first treatment' for those who were only having surgery. For those who had surgery followed by another treatment modality the 'end of first treatment' was difficult to access, due to the different medical disciplines involved – one Consultant's 'end' was another's beginning. Thus there are intrinsic problems in pinpointing these moments. In addition, from the patient perspective, diagnosis and treatment form part of the continuum of an initial experience of cancer since they are often swept from one appointment and/or procedure to another. It is also apparent from the questionnaires that very soon after diagnosis many patients feel unable to comment on their experience as they 'don't know yet'. While a case could be made for amalgamating these two categories, we have retained them in most of the analyses presented.

CHAPTER 4 Patient and Carer Sample Characteristics and Survey Response Rates

Introduction

This chapter describes the main characteristics of the patient and carer survey and interview samples. It also reports on survey response rates.

Variations in the referral rates of patients to the study across the study sites (discussed in Chapter 3), together with differential survey response rates by patients' residential location, tumour type, critical moment, gender and other variables, mean that we cannot claim to have obtained a fully representative survey sample of cancer patients with the tumour types and critical moments in question, in the study sites covered. For example, there is no doubt that patients in extreme distress, and thus with very high levels of psychosocial need, are missing from the sample. So too are minority ethnic patients, an issue discussed in Chapter 1. Nevertheless, we are confident that the patients (and carers) who did return completed questionnaires represented a broad enough spectrum of experience and psychosocial need to enable us to generate meaningful results of value and use to professionals involved in cancer services. The sample's representativeness is acceptable for our purposes, enabling us to explore most of our original project objectives. The numbers of patients and carers with particular tumour types, and at specific critical moments, the key variables that structured the sample, were sufficient to facilitate valid and robust statistical analyses.

Patient survey sample

Of the 1000 patient questionnaires distributed, 402 (or 40%) were returned. Response rates varied by tumour type (lymphoma, 58%; breast, 55%; colorectal, 33%; and lung, 26%) and by critical moment (diagnosis, 50%; end of first treatment, 47%; first recurrence 62%; and move from active treatment to palliative care, 19%). Whilst this might appear to be a low response rate for a social survey it has to be remembered that these patients were grappling with serious diseases and often unpleasant medical treatments. It is perhaps not surprising that the response rate for a self-completion questionnaire was low for patients in receipt of palliative care only, and we very much value the information we have obtained from those that took the trouble to participate in the study at such a stage in their lives. If patients at this critical moment were to be excluded from the sample then the overall response rate rises to 51%. Response rates are returned to later in this chapter.

Table 3 describes the achieved patient sample by key clinical, sociodemographic and socioeconomic variables. Tumour type and critical moment were based on the referring clinicians' categorisation; the others - gender, age, living situation, religious faith, housing tenure, use of car/van, 'global health' status (a combined morbidity and quality of life score from one section of the EORTC-C30 quality of life scale) were questionnaire variables. In this study, housing tenure and use of a car/van are used as markers of socioeconomic status. All but one of the patients who recorded their ethnicity described themselves as White.

Table 3. Patient sample by eight key variables, for tumour type.

	Breast	Lymphoma	Colorectal	Lung	Total
<u>Gender</u> n=402					
Female	183 (100%)	13 (36%)	46 (38%)	22 (36%)	264 (66%)
Male	-	23 (64%)	75 (62%)	40 (65%)	138 (34%)
<u>Age Group</u> n=400					
< 50	41 (22%)	9 (25%)	7 (6%)	3 (5%)	60 (15%)
50-59	68 (37%)	8 (22%)	21 (18%)	9 (15%)	106 (26%)
60-69	45 (25%)	10 (28%)	34 (28%)	22 (36%)	111 (28%)
70 and above	29 (16%)	9 (25%)	58 (48%)	27 (44%)	123 (31%)
<u>Living situation</u> n=381					
Lives with others	146 (83%)	28 (80%)	96 (84%)	46 (82%)	316 (83%)
Lives alone	30 (17%)	7 (20%)	18 (16%)	10 (18%)	65 (17%)
<u>Religious faith</u> n=363					
Has no faith	27 (16%)	5 (15%)	18 (17%)	11 (21%)	61 (17%)
Has a faith	143 (84%)	29 (85%)	89 (83%)	41 (79%)	302 (83%)
<u>Housing tenure</u> n=383					
Owner occupied	144 (81%)	29 (83%)	96 (84%)	44 (79%)	313 (82%)
Rented	25 (14%)	4 (11%)	15 (13%)	9 (16%)	53 (14%)
Other	8 (5%)	2 (6%)	4 (4%)	3 (5%)	17 (4%)
<u>Use of a car/van</u> n=383					
Yes	144 (81%)	29 (83%)	88 (78%)	46 (81%)	307 (80%)
No	34 (19%)	6 (17%)	25 (22%)	11 (19%)	76 (20%)
<u>Critical moment</u> n=402					
Diagnosis	109 (60%)	21 (58%)	67 (55%)	25 (40%)	222 (55%)
End of first treatment	35 (19%)	6 (17%)	33 (27%)	1 (2%)	75 (19%)
Recurrence	26 (14%)	6 (17%)	11 (9%)	1 (2%)	44 (11%)
Palliative only	13 (7%)	3 (8%)	10 (8%)	35 (57%)	61 (15%)
<u>Global health status</u> n=377					
0-25(%)	19 (11%)	6 (17%)	12 (10%)	19 (34%)	56 (15%)
26-50(%)	55 (32%)	12 (34%)	41 (36%)	15 (27%)	123 (33%)
51-75(%)	61 (36%)	10 (27%)	41 (36%)	17 (30%)	129 (34%)
76-100(%)	36 (21%)	7 (20%)	21 (18%)	5 (9%)	69 (18%)

Carer survey and interview samples

Completed questionnaires were returned by 262 informal carers. Sixty four per cent of returned patient questionnaires were accompanied by completed carer questionnaires. Only nine carer questionnaires were returned without a matching patient response. Because carers were effectively recruited by patients, we cannot give a meaningful carer response rate. One important feature of our achieved survey sample of carers is that there are almost equal numbers of male and female carers: women 131 (51%), men 129 (49%). The age range of carers is 16 to 88 years, with a mean age 58 years: 25% were aged under 50; 29% were aged 50-59; 26% were aged 60-69; and 20% were aged 70 or above. Ninety-nine per cent of carers who recorded their ethnicity described themselves as White.

Table 4 describes the achieved carer sample by the patients' clinical characteristics and by key carer sociodemographic and socioeconomic characteristics.

Table 5 describes the relationship between the carer and patient in both the survey and interview samples. It shows that the majority of carers in both the survey sample (75%, n=196) and the interview sample (78%, n=25) were spouses or partners; thus we are looking mainly at informal caring in intimate couple relationships. Most carers were co-resident. Non-couple carers were usually other kin carers or close friends.

Table 4: Carer sample by eight key variables, for patient's tumour type (N=262)

	Breast	Lymphoma	Colorectal	Lung	Total
<u>Gender</u> n=260					
Female	24 (21%)	19 (70%)	60 (77%)	28 (67%)	131 (50%)
Male	89 (79%)	8 (30%)	18 (23%)	14 (33%)	129 (50%)
<u>Age Group</u> n=248					
< 50	32 (29%)	11 (42%)	10 (14%)	8 (20%)	61 (25%)
50-59	37 (34%)	6 (23%)	16 (22%)	13 (32%)	72 (29%)
60-69	31 (28%)	6 (23%)	20 (28%)	8 (20%)	65 (26%)
70 and above	9 (8%)	3 (11%)	26 (36%)	12 (29%)	50 (20%)
<u>Living situation</u> n=262					
Lives with others	110 (97%)	27 (100%)	75 (96%)	40 (93%)	252 (96%)
Lives alone	4 (4%)	-	3 (4%)	3 (7%)	10 (4%)
<u>Religious faith</u> n=236					
Has no faith	30 (29%)	3 (12%)	17 (25%)	7 (18%)	57 (24%)
Has a faith	74 (71%)	23 (86%)	51 (75%)	31 (82%)	179 (76%)
<u>Tenure</u> n=255					
Owner occupied	94 (84%)	23 (88%)	67 (89%)	36 (86%)	220 (86%)
Rented	14 (13%)	3 (12%)	7 (9%)	5 (12%)	29 (11%)
Other	4 (4%)	-	1 (1%)	1 (2%)	6 (2%)
<u>Use of a car/van</u> n=255					
Yes	97 (87%)	24 (89%)	62 (83%)	34 (81%)	217 (85%)
No	14 (13%)	3 (11%)	13 (17%)	8 (19%)	38 (15%)
<u>Critical moment</u> n=262					
Diagnosis	67 (59%)	14 (52%)	46 (59%)	13 (30%)	140 (53%)
End of first treatment	18 (16%)	5 (19%)	15 (19%)	1 (2%)	39 (15%)
Recurrence	17 (15%)	6 (22%)	7 (9%)	-	30 (12%)
Palliative only	12 (11%)	2 (7%)	10 (13%)	29 (67%)	53 (20%)
<u>'Global health'</u> n=256					
0-25(%)	3 (3%)	3 (11%)	3 (4%)	3 (7%)	12 (5%)
26-50(%)	29 (26%)	5 (19%)	19 (25%)	15 (36%)	68 (27%)
51-75(%)	40 (36%)	10 (37%)	35 (47%)	14 (33%)	99 (39%)
76-100(%)	40 (36%)	9 (33%)	18 (24%)	10 (24%)	77 (30%)

Table 5: Relationship of carers to patients

Type of relationship	Questionnaire survey		Interviews
	<i>Number</i>	<i>% (rounded)</i>	<i>Number</i>
Husband	108	41	12
Wife	76	29	11
Partner	12	5	2
Daughter	23	9	2
Friend	10	4	1
Sister	7	3	1
Mother	4	1	3
Son	4	1	-
Brother	1	0	-
Other	5	2	-
Not known	12	5	-
Total	262	100	32

Table 6: Number of carer interviews by patient tumour type and critical moment.

Patient characteristics	Carer Interviews <i>Number</i>
<i>Tumour type</i>	
Breast	13
Colorectal	10
Lung	6
Lymphoma	3
Total	32
<i>Critical moment at referral to the study</i>	
Diagnosis	13
End of first treatment	6
Recurrence	6
Palliative only	7
Total	32

Patient and carer interview samples

As described in Chapter 3, the final section of the patient and carer questionnaires invited people to offer an interview; 51% of responding patients and 48% of carers did so. The gender of those offering an interview is shown in Table 7.

Table 7: Number of interview offers

<i>Patients:</i>		
	Male	73
	Female	<u>131</u>
Total:		204
<i>Carers:</i>		
	Male	68
	Female	<u>57</u>
Total:		125

The rationale for the purposive sample selection from among potential interviewees was discussed in Chapter 3. The gender and age characteristics of the final samples are shown in Table 8, with the study site locations of the respondents shown in Table 9.

Table 8: Gender and age of interviewee sample

	Male <i>Number</i>	Female <i>Number</i>	Average age	Age range
Patient sample	20	27	57 [S.D.: 12]	26-83
Carer sample	12	20	54 [S.D.: 16]	20-76
<i>Total</i>	32	47		

Table 9: Completed interviews by study site

Study Site	Patients <i>Number</i>	Carers <i>Number</i>	Total <i>Number</i>
Site 1	28	18	46
Site 2	15	12	27
Site 3	4	2	6
<i>Total</i>	47	32	79

Our practice of interviewing patients and carers either singly or jointly was discussed in Chapter 3 (see also Morris 2001). Tables 10 and 11 describe this interviewing pattern.

Table 10: Number of single and joint interviews

Interview arrangements	
Patient and carer interviewed together:	38
Patient and carer interviewed separately:	18
Patient interviewed singly	19
Carer interviewed singly:	4

Table 11: Relationship of interviewed carer to patient by whether interviewed singly or jointly

Carer's status	Joint interviews <i>Number</i>	Separate interviews <i>Number</i>	All interviews <i>Number</i>
Husband	6	6	12
Wife	7	4	11
Mother	1	2	3
Partner	2	0	2
Daughter	2	0	2
Sister	1	0	1
Friend	0	1	1
<i>Total</i>	19	13	32

Survey non-response

Ethical considerations demanded that we did not place pressure to respond on those who received our questionnaire pack. An examination of the limited data we have on non-respondents (age, gender, geographical location, tumour type and moment) suggests that those who *did* respond were more likely to be: younger, female, living in a semi-rural area, with breast cancer or a lymphoma, and not at a palliative care only phase of the cancer.

Table 12 shows that the patient response rates varied by the study site location of the patient, with the lowest rate in study site 2 (Blackpool, Wyre & Fylde). This reflects the relatively high proportion of patients at the palliative care only critical moment referred from that site (see Chapter 2 on referral patterns). The referral patterns by study site, discussed in Chapter 3, combined with the survey response patterns resulted in achieved patient and carer samples comprised disproportionately of residents in study site 1, shown in Table 13.

Table 12: Patient response rate by patient study site location

Study site	Number of questionnaires sent	Response rate (%)
1 (semi-rural)	517	52
2 (semi-rural)	392	27
3 (urban)	91	42
Overall	1000	41

Table 13: Survey sample respondents by study site

Location of respondents	Number	Percentage of all survey respondents
Site 1 (semi-rural)		%
Patients	269	40
Carers	177	26
Total	446	66
Site 2 (semi-rural)		
Patients	104	15
Carers	66	10
Total	170	25
Site 3 (urban)		
Patients	38	6
Carers	19	3
Total	57	9
Overall	673	100

Age

As expected from the subject of our research, we were dealing predominantly with people in the older age range. It has been estimated that 55% of all malignancies occur in people aged 65 years or over (McKenna 1994). The majority of our respondents were recently retired. Table 14 shows the average age of survey responders and non-responders.

Table 14: Average age of survey responders and non-responders

	Responders Years	Non-responders Years
Patients	63	68
Carers	58	no data

Gender

Women appear to be more willing to take part in research than men. And the apparently greater willingness of breast cancer patients to complete questionnaires and offer interviews is interesting - why should this be? Is it just a gender effect, or does age play a part (they are generally a younger group of patients)? Or is it to do with the media's wide coverage of breast cancer? Or, perhaps, these women have a special health care experience? Do they feel different from other types of cancer patient? These are important issues that will be examined in later project publications.

Table 15: Gender of survey responders and non-responders

		Questionnaires sent	Responders	Non-responders
<i>Patients</i>	<i>Male</i>	41% [n=412]	34% [n=138]	46% [n=276]
	<i>Female</i>	59% [n=588]	66% [n=264]	54% [n=322]
<i>Carers</i>	<i>Male</i>	No data	50% [n=129]	no data
	<i>Female</i>	No data	50% [n=131]	no data

Tumour type and critical moment

The higher response rate among breast cancer patients reflects a gender bias. The lymphoma sample was a small one, but this was expected due to the lower incidence of the disease. People at the palliation stage of the cancer were much less likely to return the questionnaires, probably due to poor health and their preoccupation with end of life matters.

CHAPTER 5 The psychosocial needs of cancer patients

Introduction

This chapter identifies the prevalence of psychosocial needs among cancer patients as captured by the *Psychosocial Needs Inventory (PNI)* in the patient questionnaire. It also considers the contributory factors to need and aspects of the sub-group distribution of such needs among patients.

As discussed in Chapter 3, the psychosocial needs inventory was developed from individual in-depth interviewing and focus group discussions with patients and informal carers who had experienced, or were currently living with, cancer. With permission, we also drew on comparable 'needs' research with cancer patients and informal carers reported by a team of North American researchers (Wingate & Lackey 1989; Harrington et al. 1996). The PNI comprises of 48 needs statements, making up the centre pages of the questionnaire (see Appendix 2). For each item listed, patients were instructed to indicate on a scale of one to five 'how important' it had been for them over the past few weeks and, secondly, 'how satisfied' they were that the need had been met. A box could be ticked if the patient wanted to indicate that the need did not apply to them.

The 48 needs items in the PNI were later grouped into seven needs categories - those related to health professionals (nine items); information needs (five items); needs related to support networks (five items); identity needs (five items); emotional and spiritual needs (15 items); practical needs (eight items); childcare need (one item). An internal reliability assessment was satisfied with Chronbach's alpha above 0.7 for each of the first six categories.

Results

Twenty-two respondents opted to leave the PNI section of the questionnaire entirely blank. Findings in this chapter are thus reported for 380 patients.

Needs prevalence

An important need was taken to be a need item scored by the respondent as either 'important' or 'very important'. Table 16 shows the seven psychosocial needs categories ranked by the mean percentage of importance. Within each category, needs items are ranked by importance.

Twenty-five of the 48 items were important for more than 50% of the patients. The mean scores were very high for 'health professionals', 'information' and 'support network' categories (85%, 80% and 75%) and comparatively low for 'identity', 'emotional and spiritual' and 'practical' categories (47%, 37% and 36% respectively). However, the number of respondents recording the items as 'not applicable' to them heavily influences the latter scores. In fact, if a need was identified, it tended to be strongly felt.

Every item in the 'health professional', 'information' and 'support network' categories was thought to be important by over half the respondents; 15 of the 19 items were thought to be important by over 70% of respondents. Within the other needs categories, some individual items scored highly - for example, having 'hope for the future' (70%) and receiving 'help in maintaining independence in the face of illness' (60%).

Table 16: The psychosocial needs inventory categories and items, ranked for importance

Needs items	Item important or very important %	Item not applicable %	Item not important %
<u>Health professional</u>			
Confidence in the health professionals I meet	93	2	3
Health professionals who have time to discuss issues with me	90	3	4
Easy and quick access to doctors	89	2	6
Honest information	89	5	4
Health professionals who treat me with respect	88	3	6
Information given sensitively	85	3	8
Health professionals who listen to me	85	3	8
Easy and quick access to health professionals other than doctors	83	8	6
Opportunities to participate in choices around treatment	63	19	11
<i>Category mean</i>	85	5	6
<u>Information</u>			
Information about treatment plans	86	7	5
Information about what to expect	86	6	6
Information about medication and side effects	82	10	5
Advice on what services and help are available	77	10	7
Access to other sources of information	67	12	10
<i>Category mean</i>	80	9	7
<u>Support network</u>			
Support from family	89	7	3
Support from friends	85	5	5
Support from care professionals	77	11	8
Someone to talk to	69	15	9
Support from neighbours	56	14	16
<i>Category mean</i>	75	10	8
<u>Identity</u>			
Help in maintaining independence in the face of illness	60	26	9
Help in maintaining a sense of control in my life	52	29	10
Support in dealing with changes in my body or the way I look	51	31	12
Support in dealing with any changes in the way others see me	37	33	19
Support in dealing with any changes in my sense of who I am	35	39	19
<i>Category mean</i>	47	32	14
<u>Emotional and Spiritual</u>			
Hope for the future	70	17	9
Help with any fears	52	29	11
Help in dealing with the unpredictability of the future	52	27	12
Time for myself	47	31	14
Help with finding a sense of purpose and meaning	44	30	18
Help with any sad feelings	41	38	13
Help in dealing with the feelings of others	39	39	14
Opportunities for personal prayer	35	34	23
Opportunities for meeting others who are in a similar situation	34	28	23
Help with any loneliness	33	49	12
Support from people of my faith	33	36	23
Help with any anger	27	47	17
Support from a spiritual advisor	19	43	30
Help with any feelings of guilt	17	58	18
Help in considering my sexual needs	14	59	18
<i>Category mean</i>	37	38	17
<u>Practical</u>			
Help with any distressing symptoms	49	38	9
Help with transport	47	39	11
Help in dealing with any tiredness	41	34	14
Advice about food and diet	39	38	13
Help with housework	35	44	13
Help with getting out and about socially	34	43	14
Help with financial matters	23	56	13
Help in filling out forms	21	55	16
<i>Category mean</i>	36	44	13
<u>Practical-child</u>			
Help with child care	7	81	11
<i>Category mean</i>	7	81	11

[n=380]

What factors are associated with need?

Table 17 shows the results of a logistic regression analysis in which the importance percentage for every need item is related to each of nine explanatory variables: clinical (tumour type, critical moment, global health status); sociodemographic (gender, age; living situation, religious faith); and socioeconomic (housing tenure, use of a car/van). These explanatory variables were shown in Table 3 in Chapter 4, for the whole patient sample. Logistic regression allows the needs effect of each variable to be assessed controlling for the effects of the other eight variables.

Importantly, there is at least one significant factor for all but one of the 48 need items, suggesting that need importance is differentially distributed by one or more clinical, sociodemographic or socioeconomic characteristic. Thus, for example, whilst the overall importance of need for the ‘health professional’ category items was high, for two of the nine items need importance was significantly *lower* for patients aged 70 or over than for younger patients, and importance of need decreased significantly for patients aged 50 or over for the item ‘opportunities to participate in choices around treatment’. Such significant age effects were found for 25 of the 48 needs items, suggesting that younger cancer patients often have a higher level of need than older patients for a range of psychosocial issues.

For the ‘health professional’ category of needs, there were no significant differences for gender, critical moment, housing tenure, and global health status. There were some significant differences for tumour type, with colorectal patients having a significantly lower level of need compared with patients with other tumour types for six of the nine items. Breast cancer patients had a significantly higher level of need for ‘opportunities to participate in choices around treatment’, even after controlling for age and gender. In one of the markers for socioeconomic status, ‘use of a car/van’, the more affluent patients had significantly higher needs levels for six of the items. Interestingly, for four and six of the health professional items respectively, levels of need were significantly lower for patients who were either living alone (compared with those living with others) or had a religious faith (compared with those without a faith).

The ‘information’ and ‘support network’ needs items were similar to the ‘health professional’ category in their associations with the nine explanatory variables. A gender effect was found for ‘access to other sources of information’ and ‘support from care professionals’ where women had significantly higher levels of need than men. Palliative care patients were more likely to require information about medication, ‘what to expect’ and treatment plans than patients at other critical moments.

The ‘identity’ category included items about bodily changes and perceptions concerning ‘the way others see me’; breast cancer patients had significantly higher levels of need than patients with other tumour types for these items. ‘Help in maintaining a sense of control in my life’ was a significantly higher level of need for patients at both first recurrence and palliative care than for patients at other critical moments. Other significant differences were found for socioeconomic status (housing tenure) and global health status.

‘Emotional and spiritual’ needs showed significant differences for age with higher levels of need among younger patients with the exception of ‘support from a spiritual advisor’ (higher among those aged 60 and above). Women had significantly higher levels of need than men in three items, and in two other items the level of need was significantly higher for breast cancer patients than for those with other tumour types. Lung cancer patients had a higher level of need than did those with other tumour types for ‘help in dealing with the feelings of others’. ‘Support from a spiritual advisor’ was a significantly higher level of need for patients at

recurrence and at the move to palliative care than for patients at other moments; those at the recurrence stage had a higher level of need for 'help in dealing with the unpredictability of the future'. Other significant differences among patients are shown in Table 17 for needs items in this category.

The most notable findings in the practical needs category relate to housing tenure and global health status. Patients not owning their accommodation, a marker of lower socioeconomic status, had significantly higher levels of need for all practical needs items than owner-occupiers, including: help with transport, advice about food and diet, dealing with tiredness, help with housework, help with financial matters, and help with filling out forms. The patients' global health status was linked closely to the 'practical' needs category, with levels of need rising with decreasing health status for six of the eight items. The only item where colorectal patients had a significantly higher level of need than patients with other tumour types was in this practical needs category: for 'advice about food and diet'.

For all needs categories, where there is a gender effect its direction is consistent: women have, or express, higher levels of need than men. Across all categories, needs tend to become significantly higher as health status declines with one important exception: 'help in considering my sexual needs' is a higher level need for those with better health than for those with poorest health.

Table 17: Psychosocial needs inventory categories and items by nine patient variables: logistic regression results [n=380]

	Age	Gender	Tumour type	Critical moment	Is living alone	Has a faith	Has use of car	Is an owner-occupier	Global health status
Health Professionals									
Confidence in the health professionals I meet			C ↓		↓	↓	↑		
Health professionals who have time to discuss issues with me			C ↓		↓	↓	↑		
Easy and quick access to doctors							↑		
Honest information			C ↓			↓	↑		
Health professionals who treat me with respect	70+ ↓					↓	↑		
Information given sensitively	70+ ↓								
Health professionals who listen to me			C ↓		↓	↓			
Easy and quick access to health professionals other than doctors			C ↓		↓	↓	↑		
Opportunities to participate in choices around treatment	< 50 ↑		B ↑ C ↓						
Information									
Information about treatment plans	70+ ↓			P ↑ E ↓			↑		
Information about what to expect	70+ ↓			P ↑ E ↓					
Information about medication and side effects	70+ ↓			P ↑					
Advice on what services and help are available			C ↓		↓	↓			↘ With code
Access to other sources of information	↘	F ↑				↓	↑		1 ↑
Support network									
Support from family							↑		
Support from friends	70+ ↓		(B,Lu) ↑						
Support from care professionals		F ↑				↓	↑		↘ With code
Someone to talk to	70+ ↓		B ↑						
Support from neighbours									
Identity									
Help in maintaining independence in the face of illness						↓		↓	
Help in maintaining a sense of control in my life	↘	F ↑		(R,P) ↑			↑	↓	
Support in dealing with changes in my body or the way I look			B ↑ C ↓					↓	4 ↓
Support in dealing with any changes in the way others see me			B ↑ C ↓						
Support in dealing with any changes in my sense of who I am		F ↑						↓	

Table 17: Cont.

	Age	Gender	Tumour type	Critical moment	Is living alone	Has a faith	Has use of car	Is an owner-occupier	Global health status
Emotional and Spiritual									
Hope for the future	70+ ↓								
Help with any fears	↘						↑	↓	
Help in dealing with the unpredictability of the future	↘			R ↑					4 ↓
Time for myself	70+ ↓	F ↑							
Help with finding a sense of purpose and meaning	70+ ↓								4 ↓
Help with any sad feelings	70+ ↓		B ↑ C ↓						
Help in dealing with the feelings of others	70+ ↓		Lu ↑						
Opportunities for personal prayer				D ↓		↑		↓	
Opportunities for meeting others who are in a similar situation	70+ ↓	F ↑						↓	
Help with any loneliness			B ↑						
Support from people of my faith						↑			
Help with any anger	70+ ↓								
Support from a spiritual advisor	60+ ↑		Lu ↓	(R,P) ↑		↑			
Help with any feelings of guilt		F ↑				↓			
Help in considering my sexual needs	60+ ↓					↓			3 ↑
Practical									
Help with any distressing symptoms	60+ ↓							↓	↘ With code
Help with transport					↓	↓	↓	↓	↘ With code
Help in dealing with any tiredness		F ↑			↓			↓	↘ With code
Advice about food and diet	60+ ↓		B ↓ C ↑					↓	
Help with housework		F ↑						↓	↘ With code
Help with getting out and about socially			B ↑ C ↓					↓	4 ↓
Help with financial matters	↘							↓	↘ With code
Help in filling out forms								↓	↘ With code
Practical –child									
Help with child care	<50 ↑	F ↑							

KEY:

Direction of need	Tumour type	Critical moment	Global Health Status Coding
↓ Decreased level of need	B Breast	D Diagnosis	On a scale from:
↑ Increased level of need	C Colorectal	E End of first treatment	1 (poorest health) → 4 (best health)
↘ Decreasing level of need	Ly Lymphoma	R Recurrence	
	Lu Lung	P Palliative only	

Discussion

This study differs from most research in mainstream psycho-oncology by focusing its attention not on psychological morbidity sequelae of cancer *per se* (van't Spijker et al. 1997; Greer 1994; McDaniel et al. 1995), but on the 'upstream' issues which are of concern to patients in their day-to-day struggle to live with the knowledge and social consequences of having cancer. Its starting point was to identify psychosocial needs as expressed by those living with cancer and to translate these into a survey instrument so that the prevalence and sub-group variations in psychosocial need among cancer patients could be identified. Our psychosocial needs inventory has proved to be a relevant, discriminatory and sensitive survey instrument. This work adds to those studies that have taken the patient experience as their point of departure, particularly the research of Slevin et al. (1996), Bliss & Johnson (1995), Veronesi et al. (1999), Leydon et al. (2000), among others.

In comparison with these studies, however, the research reported here is unique both in the breadth of psychosocial needs it has addressed in a single study and the consideration paid to a combination of patient social characteristics alongside more traditional clinical variables. As such, it offers a more comprehensive picture of patient psychosocial needs than has been achieved by important patient-centred studies focusing on particular dimensions of need: emotional needs (Slevin et al. 1996), needs at diagnosis (Bliss & Johnson 1995; Whelan et al., 1997), needs in terminal care (Mor et al. 1992), tumour type (Veronesi et al. 1999), information needs (Leydon et al. 2000), identity needs (Mathieson & Stam 1995; Morris 1998, 1999; Little et al. 1998). Through a unifying approach, this study is confirmatory of the existence of high levels of psychosocial need in a range of areas that have previously been identified in a rather fragmentary fashion.

Perhaps most importantly, the research has revealed interesting sub-group variations. The multivariate logistic regression demonstrates that levels of need vary by both clinical and social characteristics. These variations require interpretation. For example, the higher reported need of breast cancer patients to have the opportunity to participate in choices around treatment might reflect public awareness about different treatment options for breast cancer whereas there is less lay understanding of treatment options for other tumour types. The age effect seems to indicate the lower expectations of the health services and other domains of life held by older adults aged 70 and above (Walker et al 1998). The gender effect endorses the conventional wisdom about women being more likely to feel and/or express their psychosocial needs than men (Keller & Henrich 1999). That the level of need increases as health status declines is not a surprise (Mor et al. 1992). Other results are less explicable. Why is there, for instance, a significantly *lower* level of need among colorectal patients for the receipt of honest information from health professionals, or of having quick and easy access to health professionals other than doctors? There is some support for the finding that patients living alone have lower levels of need for some need items than those who live with others (Whelan et al. 1997; Liang et al.1990).

This study is unusual in examining socioeconomic variations in psychosocial need. Affluence does seem to make a difference. The apparently higher levels of need for some items among the more affluent probably reflects the tendency for more affluent patients to make greater demands on health professionals, information sources, and informal social support networks (Meredith et al. 1996; Elstad 1998). In contrast, for all items of practical need, patients of lower socioeconomic status had significantly higher levels of need. For such patients perhaps 'emotional and spiritual needs' as well as some others are a relative luxury that cannot be contemplated fully until practical issues are solved.

Summary

A greater understanding of the issues which contribute to psychological morbidity in cancer patients and their carers will help to ensure that psychosocial support services are both fully comprehensive and targeted at those patients and carers who really need them. This is especially important in the current context of the implementation of the Calman-Hine patient-centred recommendations, and at a time when, as Meyer and Mark's (1995) meta-analysis demonstrated, the evidence base for the benefits of psychosocial intervention is in the process of construction (Fallowfield 1995; Fawzy et al. 1995). Our findings confirm that cancer service providers should ensure that:

- health professionals understand the expectations of their patients and appreciate that psychosocial needs vary among patient groups;
- information needs should include advice on services as well as treatment plans and medication;
- health professionals are aware that they are as important as family and friends in providing support;
- support services include help in maintaining a patient's independence and sense of control over events;
- services are provided to help patients deal with a range of emotional and spiritual issues, or if these services exist elsewhere, health professionals can access them on behalf of their patients;
- health professionals are aware of the practical needs (including child care) which concern patients, and elicit these needs as part of routine medical assessment.

CHAPTER 6 The significant unmet needs of cancer patients: probing psychosocial concerns

Introduction

This chapter examines the ‘significant unmet needs’ of cancer patients. A significant unmet need is defined as a need that patients identify as both important *and* unsatisfied. We ask what kind of psychosocial needs may remain unmet amongst cancer patients, and whether there are particular groups within the population of cancer patients who are more likely to experience unmet need. As in the preceding chapter, the main data source is the patient questionnaire, particularly the psychosocial needs inventory (PNI) section. A supplementary data source is the follow-up in depth guided interviews with patients. Our aim is to identify particular needs that may be under-addressed in health services.

We also consider whether multidisciplinary cancer teams can be expected to deal with all aspects of the cancer experience. The task of doing something about the shortfall in meeting psychosocial needs may be a little more complicated than most have appreciated. Recommendations in the literature are commonly limited to the requirement that health care professionals have good communication skills, and that patients have easy access to relevant information. It is difficult to develop appropriate psychosocial support services without understanding much more about what might make it easier to live with the knowledge and social consequences of having this illness.

Unmet need was addressed specifically by Houts et al. (1988) who found more unmet practical needs in the terminal phase, and more emotional and spiritual needs around the time of diagnosis. Guadagnoli and Mor (1991) studied patients who were undergoing chemotherapy and found unmet need in 27% of their sample. Poorer health status was linked with higher levels of need in a study of patients with advanced cancer, whilst unmet need was primarily associated with the social support network (Mor et al 1992). More recently, a large study in Australia found that patients' perceived needs were highest in the psychological, health system and information, physical, and daily living domains, lowest in the domains of patient care and support and sexuality, and that subgroups of patients had differing needs (Sanson-Fisher et al 2000).

Unmet need

Defining unmet need is crucial, for different definitions may produce different results. Our definition is a fairly stringent one. A ‘significant need’ is here defined as a need that is deemed to be important or very important by the patient; it becomes a ‘significant unmet need’ if it is also perceived as not satisfied. Hence, the focus on ‘significant unmet need’ helps to exclude minor concerns that are not satisfied. While ideally one would like patients to be totally satisfied, the focus on those needs deemed important by the patient seems appropriate.

Analysis and explanatory variables.

The technique of logistic regression was used to analyse the relationship between unmet need and a range of sociodemographic, socioeconomic and illness variables. A number of variables were used to identify patients likely to have significant unmet needs. We distinguish between two types of variable: those with which patients enter the cancer journey (people variables) and those that relate more specifically to their ‘cancer journey’ (patient variables).

The ‘people’ variables used are patients’ age, gender, whether they are owner-occupiers of their dwelling (housing tenure) and whether they own or have use of a car/van (established indicators of socio-economic status), whether they live alone, whether they have a religious faith, whether they have caring responsibilities and whether they have a long standing illness or disability. The variables which more closely relate to respondents’ roles as ‘patients’ are: the nature of the tumour; the critical moment in the disease trajectory; their global health status; whether they can

talk freely to the main carer about the illness; whether they have been offered support services; and whether their physical condition interferes with their social, or family, or financial circumstances. As the global health variable gives a measure of overall health, this variable subsumes long-standing illness and disability, which is therefore omitted from any analysis that includes global health.

Results

As reported in the previous chapter, of the 402 returned questionnaires, 22 had entirely blank responses to the 48 need items and these patients are excluded from the analysis. Subsequently, any patients with missing values for the explanatory variables used in the analysis were also excluded. Thus, the final dataset used in this paper involved 295 cases, of whom: 34% were male; 44% were under 60 years of age; 14% lived alone; 82% stated they had a religious faith; 82% were owner-occupiers; and 84% owned/had the use of a car/van. Only 9% had caring responsibilities for others, while 38% had an existing long standing illness or disability.

How many significant unmet needs?

Table 18 shows that approaching two-thirds (62%) of cancer patients surveyed indicated that they had no significant unmet needs. It is heartening to find that in the majority of cases important needs were being appropriately recognised and satisfied, although this outcome partly reflects the stringency of the criterion following our operational definition of significant unmet need. In contrast, approaching one in five patients (18%) identified either one or two significant unmet needs; a further 15% identified between three and nine unmet needs, while a residual 4% indicated ten or more unmet needs (in fact, four patients identified over twenty unmet needs). Clearly there is a considerable range in terms of patients experiencing significant unmet need.

Table 18: Number of significant unmet needs

Number of significant unmet needs	Number of Patients	Percentage of total patient sample
Nil	183	62.0
1	37	12.5
2	17	5.8
3-9	45	15.3
10+	13	4.4
Total	295	100.0

What are the significant needs and the significant unmet needs?

Not unexpectedly there was a considerable range in terms of which needs items listed on the psychosocial needs inventory were regarded as important or very important. As Table 19 shows, the top ranked item – ‘Confidence in the health professionals I meet’ – was so categorised by 94% of the patients – while the lowest ranked item – ‘Help with child care’ – was identified as important by just 7% of patients. This difference highlights an important point. As patients, almost all people want the best from the health professionals (for example, ‘Confidence in the health professionals I meet’; ‘Health professionals who have time to discuss issues with me’; ‘Health professionals who treat me with respect’) but many of the other needs will reflect patients’ current social circumstances. For example, given the age distribution in this sample of cancer patients, relatively few will have caring responsibilities for a child. In brief, while there may be personality differences between patients (that is, some people may be more easily dissatisfied than others), this chapter largely focuses on the relevance of *social* context (that is, some social contexts produce a wider range of needs than others).

Table 19: Significant need and unmet need

(ranked by percentage rating item as important or very important) [n=295 cases]

Need item	Those rating item as important or very important		Those with significant unmet need for item	
	Number	%	Number	% ^a
Confidence in health professionals I meet	277	94	6	2
Health Professionals who have time to discuss issues with me	272	92	9	3
Health Professionals who treat me with respect	269	91	3	1
Easy and quick access to doctors	269	91	16	6
Support from family	268	91	3	1
Honest information	267	91	11	4
Information given sensitively	263	89	11	4
Information about treatment plans	262	89	13	5
Information about what to expect	261	88	18	7
Health professionals who listen to me	261	88	6	2
Support from friends	258	87	3	1
Easy and quick access to Health Professionals other than doctors	254	86	9	4
Information about medication and side effects	248	84	11	4
Advice on what services and help are available	239	81	13	5
Support from care professionals	233	79	10	4
Hope for the future	214	73	19	9
Someone to talk to	210	71	10	5
Access to other sources of information	209	71	13	6
Opportunities to participate in choices around treatment	198	67	21	11
Help in maintaining independence in the face of illness	179	61	15	8
Support from neighbours	169	57	2	1
Help with any fears	166	56	16	10
Help in dealing with the unpredictability of the future	160	54	20	13
Help in maintaining a sense of control in my life	160	54	18	11
Support in dealing with changes in my body or the way I look	154	52	15	10
Help with any distressing symptoms	149	51	11	7
Time for myself	143	48	7	5
Help with finding a sense of purpose and meaning	140	47	10	7
Help with transport	135	46	12	9
Help with any sad feelings	130	44	18	14
Help in dealing with any tiredness	122	41	14	11
Help in dealing with feelings of others	119	40	15	13
Advice about food and diet	112	38	21	19
Support in dealing with any changes in the way other see me	110	37	11	10
Opportunities for personal prayer	107	36	4	4
Help with any loneliness	105	36	12	11
Support in dealing with any changes in my sense of who I am	104	35	9	9
Support from people of my faith	102	35	4	4
Opportunities for meeting others who are in a similar situation	100	34	15	15
Help with housework	93	32	10	11
Help with getting out and about socially	93	32	6	6
Help with any anger	85	29	16	19
Help with financial matters	63	21	22	35
Help in filling out forms	58	20	14	24
Support from a spiritual advisor	54	18	1	2
Help with any feelings of guilt	53	18	5	9
Help in considering my sexual needs	41	14	5	12
Help with child care	21	7	2	10

^a Percentage of those who rated the item as important or very important

The next question to consider is whether these important needs are met satisfactorily. The last two columns of Table 19 highlight two complementary points. The more ‘universal’ needs are being generally met, while there tends to be a much higher proportion of significant unmet need in relation to some important needs identified by a minority of patients. In broad terms, therefore, it would seem that most of the ‘health care’ needs are being met, while some needs that might be termed ‘social and emotional’ are much more likely to be unsatisfied.

This outcome becomes clearer in Table 20 where significant unmet need is ranked. It focuses on all the items where at least one in ten of those reporting a need for the item rated it as a significant unmet need. So, for example, while only 63 patients regarded ‘Help with financial matters’ as important or very important, over one-third (35%) felt that their need in this area had not been met satisfactorily. In fact, it is notable that when ordered by percentage of significant unmet need, the items emerging with the highest rankings are very different from those in Table 16, where the ranked order related to the proportions rating the item as important or very important.

We suggest that the need items that represent real difficulty for some patients, identified in Table 20, can be broadly divided into three main themes - managing daily life, managing emotions, and dealing with changes in social identity. The exception is the item, ‘Opportunities to participate in choices around treatment’, where two-thirds (67%) of the sample identified this item as important, and over one in ten of these patients felt that this was a significant unmet need. This item goes against the broad trend of satisfaction of need items that directly involve health care personnel in the conventional sense. We consider the implications of this outcome in the ‘Discussion’ section.

Table 20: Significant need and unmet need: the top 18 items

(ranked by percentage with significant unmet need) [n=295 cases]

Need item	Those rating item as important or very important		Those with significant unmet need for item	
	<i>Number</i>	<i>%</i>	<i>Number</i>	<i>%^a</i>
Help with financial matters	63	21	22	35
Help in filling out forms	58	20	14	24
Help with any anger	85	29	16	19
Advice about food and diet	112	38	21	19
Opportunities for meeting others who are in a similar situation	100	34	15	15
Help with any sad feelings	130	44	18	14
Help in dealing with feelings of others	119	40	15	13
Help in dealing with the unpredictability of the future	160	54	20	13
Help in considering my sexual needs	41	14	5	12
Help in dealing with any tiredness	122	41	14	11
Help with any loneliness	105	36	12	11
Help in maintaining a sense of control in my life	160	54	18	11
Help with housework	93	32	10	11
Opportunities to participate in choices around treatment	198	67	21	11
Support in dealing with any changes in the way other see me	110	37	11	10
Support in dealing with changes in my body or the way I look	154	52	15	10
Help with any fears	166	56	16	10
Help with child care	21	7	2	10

^a Percentage of those who rated the item as important or very important

Managing daily life

Everybody has a daily life to manage but for some – even without the impact of the cancer experience – this is more difficult than for others. For cancer patients, financial matters come top of the list in Table 20; it is the item with the highest proportion of unmet need (35%) among those who identify the item as important. Other matters to do with managing daily life, such as filling in

forms, managing diet, tiredness, housework and child care, also rate highly as significant unmet needs.

The interview data suggested that the item on 'filling in forms' was mostly associated with claims for social security payments:

Patient: And the financial side of it, I am getting stressed out every day because they have pushed me around from pillar to post - "fill a form in here", "fill that form in", another set of forms came with the answer, asking me these questions. That has been my biggest problem. [Man (age 50) recently diagnosed with lung cancer.]

This man goes on to say that he could not afford repairs on his car. The lack of finance had a knock-on effect, making him a 'prisoner' in his home and undermining his will to live:

When the car was up and running I just got in and went, and did it myself, and that is the biggest problem I have at the moment. I've sort of become a prisoner and it's getting to me. I'm thinking, well, if I can't go out and do this, and do some of the things I used to be able to... I sit many a time in the evening and think why the hell should I bother? I might as well just sit here and let it happen.

It was notable that many interviewed patients had received help with applying for financial support from health care professionals, usually specialist nurses or GPs, but the process was often complicated and slow:

Patient: But 12 weeks! Surely it doesn't take 12 weeks. Even the [consultant radiologist] wrote a letter to them. [The specialist nurse] wrote from the hospice. So they've had the information from the experts, so there's no reason for them to be holding back really. [Woman (age 49) at the end of first treatment for breast cancer.]

This extract shows how the ultimate meeting of a social need is often out of the hands of health professionals. Interestingly, a few of the interviewees who were experiencing financial hardship expressed the opinion that this aspect of living with cancer was almost worse than the disease itself:

Patient: I'm very happy with the medical side of it. I'm quite happy with the treatment, well more than happy with the treatment. I'm happy that I'm going to be OK, and I shall be carrying on, apart from having the bag on beside me for the rest of me life. But the main worries I've had have purely and simply been the financial help that I need to get me through until I'm on my feet again and I can get back to work. [Man (age 54) at the end of first treatment for colorectal cancer.]

Managing emotions and self identity

Becoming a cancer patient heralds emotional upheaval and the need to re-negotiate identity (Mathieson & Stam 1995). Need items to do with emotional response and changes to self-identity constituted significant unmet needs for a small but important proportion of patients. For example, almost one in five (19%) of those who rated 'help with any anger' as important perceived little support. The interview data suggested that anger was mostly associated with instances of perceived poor clinical care, especially late diagnosis, and with loss of independence and control. It was notable that when strong emotion was discussed it was often hedged around with observations about normative expectations (Radley & Billig 1996), and the desire to be positive and protect the feelings of others:

Patient: It's difficult, but you've got to look on the bright side of things. I mean if you let yourself get down, you're only making yourself miserable, which makes everybody round

you miserable, and nobody has a life at all. [Woman (age 61) with recurrence of breast cancer.]

Strong feelings were described in interviews as intermittent, or occurring at particular points, and/or in relation to other life circumstances. If emotions require more managing at some times than at others, and if people are wary of expressing their emotions too forcefully for the sake of others, it is likely that levels of unmet emotional need may be higher than reported.

One woman who was having emotional difficulties associated with the responses of her family described how help from health care professionals had played a crucial supportive role:

Patient: Through [the time I was in hospital] I had a lot of counselling from some of the nurses. I really had gone down to the lowest level I think I'd been. I was physically and mentally exhausted, apart from having everything else happen, and it was the support that I got from the nurses there, they were great and they listened. [Woman (age 50) with recurrent breast cancer]

Some patients found talking to other cancer patients of assistance in meeting emotional and identity-sustaining needs. For example:

Patient: She was so full of life and energy and fun, and this was somebody who'd been through this and survived. That was really, really sustaining, to know that you can come out of this with a sense of humour and you can actually still be there so many months later, so that helped tremendously. [Woman (age 49) at the end of first treatment for breast cancer.]

'Opportunities for meeting others in a similar situation' was a significant unmet need for 15% of those who rated this as important. While many interviewees were wary of formal support groups there was much talk of contact with other cancer patients. This was reported as helpful for various reasons, such as modelling new identity through meeting 'survivors', for picking up information and 'tips', for feeling less 'different', or it just being good to talk to someone who'd gone through the same experience.

Which patients are likely to have significant unmet needs?

Is there scope for identifying groups of patients who are likely to have difficulties that will not be met? More pertinently, which types of variables seem to be particularly helpful in this quest? Can we tell which types of person are more likely to have significant unmet need by focusing on 'people' variables (that is, those attributes held by people entering the 'cancer journey') or 'illness' variables (that is, those variables aggravated by, or which come into play as a result of, the illness). If the differences are 'people' variables, then there is scope for recognising from the outset those persons who are likely to be candidates for having significant unmet needs unless something is done. In contrast, if the differences are identified by the 'illness' variables, then one must await the outcome of the illness before beginning to recognise the candidates who are more likely to have significant unmet needs in the course of their cancer journey. The analysis suggests that both sets of variables are relevant.

Logistic analysis was used to test the relationship between patients with and without significant unmet needs and a range of explanatory variables: firstly using the eight 'people' variables, and then adding the eight 'illness' variables (and replacing 'long-standing illness/disability' with 'global health'). As backward elimination and forward selection procedures yielded different results, the best model was found by using the Akaike information criterion (Lindsay & Jones 1998). Of the eight 'people' variables, those entering the cancer journey with any of the following characteristics were statistically more likely to have at least one significant unmet need: being younger; having a long-standing illness or disability; not owning/having use of a car; not having a faith. In other words, patients with these pre-illness characteristics were at greater risk of experiencing significant unmet need.

Entering the eight variables representing the ‘illness’ into the model, in addition to the ‘people’ variables retains the four previously significant variables (apart from long standing illness/disability, which is now replaced by global health status), but adds a further three: not being able to talk freely to the main carer about the cancer; having social activities interfered with by the illness; and having financial difficulties.

Interest usually centres on *significant* variables, but importance should also be attached to the finding that certain variables are *not* significant. Of the ‘people’ variables, their gender, whether or not they are owner-occupiers, live alone, or have caring responsibilities were all *not* significant, while this was the case among the ‘illness’ variables for tumour type, cancer interfering with family life, and whether support services have been offered by health professionals. The possibilities for an explanation for a lack of significance will be at least two-fold – either the non-significant variables are correlated and thus subsumed under significant variable(s) or, alternatively, that they are not indicators for distinguishing those with significant unmet needs. Some variables, for example health status, which is significant, is associated with critical moment, which was found not to be significant. Although patients in poorer health are more likely to have unmet needs, there seems little doubt that for patients who are socially or economically disadvantaged in some way, there is a much greater likelihood of there being significant unmet need during their cancer journey.

Discussion and summary

Focusing on the significant unmet needs of cancer patients in relation to their psychosocial concerns fits in with recent policy initiatives to streamline cancer services ‘around the needs of the patient’ (Department of Health 2000 (Cancer Plan)). This chapter contributes to the assessment of how far this occurs. We also want to consider how feasible it is to achieve a completely favourable outcome in satisfying needs given that so many significant unmet needs are ‘social’ in character.

Using a fairly stringent criterion to determine a significant unmet need, it was quite remarkable that nearly two-thirds (62%) of patients had no such needs in terms of the 48 needs items presented, a proportion that mirrors that of ‘satisfied patients’ found in most traditional patient satisfaction surveys (Sitzia & Wood 1997). Between 71% and 94% of surveyed patients expressed the importance of good relationships with health care professionals and obtaining information, but few expressed dissatisfaction with these aspects of need. Apart from one item (opportunities to participate in choices around treatment) levels of significant unmet need in these areas were low (2-6%). This reflects well on health care professionals who, in the great majority in this study, were treating patients with the respect, courtesy and concern that they expected. The exception – where 11% of patients who wanted opportunities to participate in choices around treatment felt that this need had not been satisfied – probably illustrates where there is still some range of opinion and practice within the medical profession (Charles et al, 2000). Similarly, items about support from family and friends produced rates of high importance (87-91%) and low unmet need (1%). Whatever the personal cost to family and friends in responding to need, the questionnaire data suggests that there rarely seems a significant shortfall on their part from the patients’ perspective.

As revealed in Table 20, the items of significant unmet need cluster around aspects of the management of daily life, emotions, and social identity, rather than around more clinical experiences and needs. This suggests that cancer services are less responsive to non-clinical aspects of the cancer experience that cause significant difficulty for patients in particular circumstances.

Importantly, our analysis did not identify tumour type or critical moment as markers for significant unmet need. This suggests that help from health care professionals is not located unevenly as far as

clinical characteristics are concerned. We did find, however, that some of the significant unmet needs are associated with patients' socio-economic circumstances (car/van ownership/use, financial status) and other features of their social lives: age; ability to talk freely to a main carer; the presence or absence of a faith; and whether the illness interferes with social activities. These findings suggest three things. First, another dimension of documented cancer health inequality (Wilkinson 1996; Acheson Report 1998; Graham 2000a) is that there are higher levels of significant unmet need amongst those who are relatively socially and economically disadvantaged. Second, those with higher levels of social support and social capital (Cohen & Syme 1985; Graham 2000b; Krishnasamy 1996; Wingate & Lackey 1989), through participation in Church activities for example, are less likely to have significant unmet needs. Third, our findings may also reflect differential levels of expectation among patients, although disentangling patient expectations is complex (Sitzia & Wood 1997; Thompson & Sunol 1995). For example, younger patients, more used to a 'therapy culture' (James 1998), may have higher expectations of services and of lay people around them, and thus be more likely to be disappointed, than older people. Whatever the full explanation for the differential distribution of significant unmet needs, is it helpful to cancer service providers to know which specific groups of patients have higher levels of such needs?

This question relates to how much cancer services, primarily designed to treat disease, should be involved in addressing the kinds of unmet social, emotional and identity needs highlighted in this study. There are certainly examples of good practice in attending to some of these needs in our study sites. For example, help with financial need (and concomitant form-filling) is often given by specialist palliative services, specialist nurses, attached social workers and GPs; emotional help is being given through NHS linked counselling and charitable support organisations. We know that nation-wide coverage in the latter is variable (Sibbald et al. 1993). While befriending schemes and support groups have become more widespread in cancer care over recent years (Fawzy et al. 1995), our findings suggest that there is still scope for doing more in this area. Other studies have shown that the presence of, and confidence in, a support network are related to lower expressed need (Guadagnoli & Mor 1991; Mor et al 1992). The importance of managing emotion so as not to alienate others may be particularly important, and sources of help outside the lay circle may be especially helpful. Of course, some aspects of significant unmet need relate to problems that arise in the interstices of various care systems, and it is currently not the responsibility of health care professionals to become directly involved in arranging home care assistance or child-care, for example. Should things be otherwise?

We would suggest that cancer services could go further than they currently do. It is increasingly recognised that the management of cancer should be provided by multidisciplinary teams (MDTs) and that the constitution of these teams should reflect the full range of needs experienced by cancer patients from diagnosis to cure or terminal care (Department of Health 1995; Department of Health 2000). Based on the findings in this study, we would argue that MDTs should include social workers, counsellors and spiritual advisors as well as the current standard of relevant medical and nursing specialities and the palliative care team. At the very least, health care professionals should network with these other care providers, and the needs of each new patient with cancer should be assessed with such a network in mind. The specialist medical and nursing teams are uniquely placed to identify the full range of psychosocial needs of their patients and, in doing so, to access appropriate support that could have an important effect on the cancer experience. Meeting the full range of psychosocial need is likely to contribute significantly to the well being of cancer patients and thus to reduce rates of cancer-related psychological morbidity.

CHAPTER 7 Tumour type: patients and carers

Introduction

We chose to study the experiences of people with four particular tumour types - breast, lung, colorectal and lymphoma – to see if psychosocial needs varied with the nature of the cancer involved. Our assumption was that while there would be overall similarities in the experience of 'cancer', different types of tumour would have different implications, treatment trajectories and services associated with them. The statistical analyses of the survey data found some correlations between the 'tumour type' variable and specific needs, whether met or unmet, but the variations were not as extensive as expected. However, the qualitative interview data provide indications that there may be issues surrounding the particular tumour type and the experience of cancer that are not picked up through survey research. In addition, these data offer a detailed picture of the different configurations of treatment trajectories and supportive services for people with tumours in different bodily sites. People's perceptions of cancer also appear to be influenced by tumour type. This chapter reports our key patient and carer interview findings on the relevance of tumour type.

In the questionnaires we asked both patients and carers to write down the 'name of the illness' they were currently experiencing. 79% of patients [n=317] and 81% [n=212] of carers identified the cancer by type, with a further 3% of patients 2% and of carers specifying a secondary cancer. 5% [n=18] of patients and 7% [n=17] of carers just wrote 'cancer' in the space provided. Among patients 10% [n=40] did not complete this box, and 4% [n=14] completed but without mentioning cancer at all; for carers these figures were 8% [n=21] and 2% [n=5] respectively. These figures suggest that the large majority of people are able to 'name' their cancer type in specific terms.

In the interviews we administered the Hospital Anxiety and Depression Scale (HADS) to all participants. Although no categorical conclusions can be drawn from the data thus generated, due to small sample size, there were some interesting features. See Table 21.

Table 21: Tumour type of those patients and carers who scored as cases or borderline cases on the HAD anxiety scale

	Lung	Breast	Colorectal	Lymphoma	Total
Patients	5 [n=10]	5 [n=19]	3 [n=11]	2 [n=7]	15 [n=47]
Carers	5 [n=6]	4 [n=13]	6 [n=10]	2 [n=3]	17 [n=32]
Total	10 [n=16]	9 [n=32]	9 [n=21]	4 [n=10]	32 [n=79]

Overall the interview respondents showed high anxiety scores on the HAD scale, with 32% of patients and 59% of carers scoring as cases or borderline cases. Although the numbers are small there is some indication that lung cancer patients and carers were more anxious than those with other types of cancer, with half of the patients and 5 out of the 6 carers scoring as cases or borderline cases for anxiety. These high proportions were not matched by any of the other tumour types. Female carers [70%] in general scored higher on the HAD anxiety score than male carers [25%], male patients [35%] or female patients [30%] (see Gender chapter). Patients [44%] and carers [86%] dealing with the 'palliative only' critical moment also scored higher on anxiety than people at other moments, although more than half the carers [54%] at the time around diagnosis scored high (see Chapter 8).

Table 22: Tumour type of those patients and carers who scored as cases or borderline cases on the HAD depression scale

	Lung	Breast	Colorectal	Lymphoma	Total
Patients	4 [n=10]	3 [n=19]	2 [n=11]	3 [n=7]	12 [n=47]
Carers	3 [n=6]	2 [n=13]	0 [n=10]	1 [n=3]	6 [n=32]
Total	7 [n=16]	5 [n=32]	2 [n=21]	4 [n=10]	18 [n=79]

Respondents did not score so high for the depression part of the HAD scale, with 25% of patients and 19% of carers reaching 'borderline' or 'case' scores (see Table 22). However, again lung cancer patients and carers were more likely to score highly on the HAD depression scale. Male patients [30%] were more likely to be high scorers for depression than female patients [22%], female carers [20%] or male carers [17%]. Again patients [33%] and carers [29%] dealing with the palliative care only critical moment scored higher on depression than people at other moments [7% of patient and carers at moments 2 and 3 combined], and patients [33%] and carers [31%] at the moment around diagnosis were also likely to score high (see the following chapter).

Implications of tumour type

Different tumours have different prognoses. This is true even within subdivisions of the four tumour types we have chosen (for example, in breast cancer the prognosis is likely to be better with mucinosis and tubular cancers than with ductal or lobular cancers (Working Group on Living with Breast Cancer 2001)). However, between our four tumour types there are marked differences in five year survival statistics (Coleman 1999). For example, fewer than half of all lung cancer patients will survive five years. Lung cancer is the commonest cancer in the UK and the commonest cause of death from cancer (ONS 1997). Hence we speculated that there would be differences in people's reactions and psychosocial needs instigated by the prognosis.

In the interviews we found that respondents with all types of cancer often spoke of their initial experience in ways which evoked the cultural spectre of 'cancer = death'. Their perception of cancer was changed by the diagnosis and information they acquired from the health professionals they met. This more precise reference to the type of cancer was drawn on as a means of differentiating and constructing 'hope'. It was notable that those with poorer prognoses, especially lung cancer patients, managed knowledge of their tumour type in similar ways to patients with more chance of remission. The following explores some of the ways in which patients and carers use the specificity of their cancer, new knowledge and information, as well as comparisons with others, to manage the cultural implications of 'cancer=death'. It is suggested that this is a process which patients and carers 'need' to undergo in order to live with the cancer. In this process the information given to them by health professionals and the way it is given have an important part to play.

With a diagnosis of cancer a person's world changes. The 'need' to accommodate these changes arises. This is more than just 'coping' in an individualist sense, rather the person draws on their history, their environment and the words and actions of other people to manage the changes. This happens both in the personal sphere, and also in the new world they encounter when entering the medical system. Often an initial period of shock is described, a twilight zone, which is a prelude to getting on with it, being able to go on living with the knowledge of a cancer diagnosis, minimising risk and expanding hope. At later stages there may be a need to readjust in the reverse direction, to 'modify expectations' and return to the cultural expectation that 'cancer = death'. However, even at this stage, attempts to present cancer as still manageable are evident. Finding ways of constructing it as 'liveable with' become important, and various strategies were employed in interviewees' talk. Some of these ways were directly linked to learning about their own specific tumour type and through redefining 'cancer'.

Many studies have indicated the importance of good quality information in helping people deal with a cancer diagnosis. In our questionnaire items about information and the way it was given were rated very highly. In Bliss & Johnson's (1995) study stories about 'communication and information systems' accounted for 27% of the total narratives. However, there were many indications in our study that it is not merely the provision of good information that eases patients' and carers' passage, but the way they use it (such as in constructing hope for the future) to manage the difficult feelings which cancer rouses.

Prior to diagnosis most of the respondents presented a picture of themselves as generally ignorant about the specifics of cancer, and equating it with an early death:

Patient: Nobody would mention the dreaded word, you know, and even I have this, did have at the time, this fear of the word cancer and suddenly it dawned on me that this was what I'd got. [L150 man (49) with a recurrence of lymphoma]

Talking from the new position as cancer patient or carer they acknowledge a general view of cancer, but become more specific about their own cancer, and their new-found knowledge. This may be linked to modern treatments, as in the following examples from a male lymphoma patient:

Patient: Cancer is always thought of as a dreadful thing still, and yet really there are 200 types of cancer and they are all treatable, whether they are curable or not, I don't know. So there was this response [from other people], 'oh, my goodness, T 's got cancer and that's the end' which thankfully it hasn't been for me, you know ... so I had quite a fear of it myself of it up till then, you know. I now realise that there are other forms of cancer anyway, and it's more curable, treatable than it was before ... suddenly there was a whole new chapter of health care, I'd never really known about cancer, as 99% of the people don't know about it. [L150 man (49) with a recurrence of lymphoma]

The presentation of cancer as differentiated, with a numerical range, and a percentage to describe the magnitude of people who 'don't know', invokes the reassurance of scientific knowledge, where measurements can be made and odds assessed, and where 'progress' has produced more treatment. As another male lymphoma patient expressed it:

Patient: The sophistication of the chemotherapy treatment ... is now from my understanding, so refined as to much better be able to target the type of problem you have, be it lymphoma or any other sort of cancer ... And I think the other thing that is pointed out to you is that no two cases are even similar, never mind alike. [K236 man (69) with recently diagnosed lymphoma]

The cancer can now be targeted, it has become a specific, rather than a generalised threat. This particular patient cited his own knowledge as limited, and went on to cite the source of his information:

Patient: And the way [the Consultant] explained it to us was that there were only about 50 cases of this particular type and they were all in the North of England. This is what he had found out through his research. [K236 man (69) with recently diagnosed lymphoma]

The differentiation of cancer can be very precise, reinforcing an individualised view. Information received from the health services plays a large part in the presentation of the cancer experience. Here the quoting of the doctor, a number, a specific location, and research emphasises the location of cancer in a scientific discourse.

Entering the cancer arena makes the illness specific, not only in general terms, as in learning that it takes many forms, but in very personalised ways to do with 'my' cancer. In this way cancer is

individualised, circumscribed, and becomes potentially more manageable. However, it should be noted that in these quotes, as in much of the data, the issue of knowledge is punctuated with uncertainties, such as whether the cancer is curable or not, and acknowledgements of the limits of one's own understanding and experience. An undercurrent of not knowing much about other people's cancers, and the uncertainty of how one's own cancer may respond to treatment, was frequently constituted through 'asides' and qualifiers.

As well as displaying a more discriminating knowledge of cancer, the particular type of cancer encountered may also be cited as a reason to be hopeful, and several interviewees sought to compare the particular tumour type favourably with that of those with a 'worse' type of cancer:

Carer: It's probably one of the better cancers - if you have to have cancer it's one of the least life threatening ones going, as long as it's caught in time. I might be totally wrong, but that's what my feeling is. It must be one of the better cancers to cure, it can be removed.
[L99 husband (50) of woman (46) at the end of first treatment for breast cancer]

Knowledge is here linked to feeling, as the carer presents the cancer episode in a hopeful light. He later goes on to say that because the breast can be removed and is 'external' it stands to reason that it must be less threatening than an internal cancer. However, perception of 'worse' types of cancers were clearly influenced by the speaker's own cancer situation:

Patient: It was serious, but maybe not life threatening ... whereas breast cancer and that sort of thing, cancer of the colon and what have you, it is. [K256 man (64) with lymphoma at the end of first treatment]

Patient: [My friend has leukaemia] It's a nasty cancer. He is talking about giving things up, but I want to join things, I am looking ahead to new things to do. [L125 man (55) with recently diagnosed lung cancer]

In the following sections we explore the four specific cancers we studied in more depth.

Lung cancer patients and carers - poor prognosis

The statistical analyses of the questionnaire data suggested that lung cancer patients had significantly higher needs in two items – 'Help in dealing with the feelings of others' and 'Support from friends' - but a significantly lowered need for 'Support from a spiritual advisor'.

In all ten lung cancer patients (six men and four women) and six carers (two men and four women) were interviewed. The average age of patients was 61 (range: 41-83) and of carers was 60 (range: 51-67), which meant this subsample was slightly older than the whole sample.

While it was clear from their explicit talk of impending death that many of those with a lung cancer diagnosis understood that their cancer was terminal, there were a few interviews where initially it seemed questionable whether they understood the full implications of their diagnosis. This might suggest difficulties in the communication of prognosis (either in the giving or receiving), and in two cases (a female carer of an elderly husband, and a male carer of a wife who was disabled by a stroke) the prognosis was being deliberately 'played down' by carers. However, a close examination of all the interviews with lung cancer patients and carers suggests another possible explanation: that it may be an artefact of the way people talk about such matters. The respondents' discourse on the terminal prognosis was shifting, containing reference to the outcome (i.e. death) as well as passages which constructed hope and maintained references to the here and now (e.g. to treatment, to their present feelings of wellness). Thus their talk was sometimes contradictory and sometimes involved a 'debate' about possible readings of the situation they found themselves in. Uncertainty becomes something of an ally, because then there are still possibilities.

Faller, Lang & Schilling (1995) suggest that patients try to control or underplay their negative feelings to avoid giving their carers any reason for emotional withdrawal. Our data suggest that while this is part of the picture, the managing of a lung cancer diagnosis involves seeking ways of carrying on and maintaining identity for both patients and carers. These examples may help to illustrate these observations.

Patient: I said “How long have I got?” And [my GP] said “12 to 18 months.” I said “You must be bloody joking.” And he said, “What do you mean?” I said “Just what I said.” He said, “Well, two years at the most.” I asked [the consultant] about that and he said, “No, nobody can guarantee you the time, how long you've got.” And I said [to my GP], “Well, I'm going to tell you something - I'm going to bloody torture you when I'm 75”. He said, “Do you think so?” I said, “I damn well know so, and that's it. I'm not giving in to you”. ... [I say] forget it and carry on life as you have done. Don't worry about it, because you can last for years with it. ... Because, as I told [the consultant], I said, “Look, are you sure I have cancer?” He says “Why?” I said, “Well, I don't feel any different to what I did before you lot ever told me”. ... as we were going up into the cafe, there was a lady she was in a wheelchair, she'd no arms and she'd no legs and it just hit me. I said to [my daughter] “I have something to be thankful for, I can walk around and I can use me hands, that lady can't” ... I just think many a time to myself, well, there's people worse off than you. But how long I have to live, I don't know. [K327 woman (68) with lung cancer, palliative care only]

Patient: [The consultant] had also told me that there was absolutely no sign of the cancer having spread to anywhere else apart from the gland here. But in some ways I say, well thank God it did spread there, because had it not it could have gone undetected for a long time, and it might have been too late to do anything when it was detected. However, my husband did ask the question “Having caught it fairly early, and it being a small tumour, it must be pretty good?” And [the consultant] said, “Well yes. Had it not spread it would have been better.” There would have been perhaps more chance of surviving for that bit longer. But at the moment it doesn't seem to have spread anywhere else. So I continue to be very hopeful. ... In some ways it's been a wonderful experience. I know this is going to sound a bit strange, but it's like an adventure. You're going into something totally blind because you don't know what's going to happen at the end. I still don't know what the end of it's going to be and it's still like an adventure, and every day is a bonus day almost. ... I am exactly the same person as I was in June, it just so happens that I've got a tumour on my lung which is cancer. It is the word 'cancer' that does it with people really, I'm quite sure that's what it is, just the thought of cancer. And I don't know what can be done to get over that. ... Hopefully the treatment will be successful but if you're frightened, you stop enjoying your life, you just become very fearful about everything and you wouldn't do anything then. I made myself walk up steps instead of taking a lift or an escalator, because until I start wheezing or whatever, I will. If I can get up a flight of stairs and I don't wheeze that means that it's not spreading. That's very simplistic probably. But if you don't exert your lungs you're never going to know whether it's getting worse. [L227 woman (55) with recently diagnosed lung cancer]

Patient: I've got to make [the garden] more labour saving, but that's something constructive. I feel, for me to do and it is a project of mine. I look at it as something going on, you see. So there is that aspect of it, I think it changes me from that point of view. But I think in an odd sort of way, the experience has been a stimulus, it has wakened me up, given me a kick up the backside, and said “Life's more than just enjoying yourself, you've now got something to get your teeth into, do and get rid of, and all that.” So there is an enthusiasm there that wasn't there before. ... in a rather curious way, having accepted the fact that I've got it, a few weeks later, I began in a rather odd way to enjoy the experience in the stimulus that it is causing and possibly the reactions of other people, you become in a

sense more important to them because you are doing something different. It's rather difficult for you to understand, it's in my head, I know what I want to say, but it's rather difficult to express it really. I suppose it gives you a certain uniqueness, something to aim for, and go in for. It's like getting a really good part in a play and you put it on and it's tremendous, the adrenaline surge. [L125 man (55) with recently diagnosed lung cancer]

Patient: I'm responsible for putting it there [because I smoked] so I've got to do everything I can possibly do to get rid of it, or to put it in remission, so that I can maybe get another 20 years. ... try and live as normal life as you possibly can, don't sit and think I've got this alien inside me that's going to kick over because there's no way, it won't take over me. ... End of the day it probably will, but at the moment it won't. One thing I didn't want to know was how long I had, I don't want to know that yet, I'll ask that when I'm ready to ask it. When I start feeling it and feeling ill and not able to do what I normally do, then I'll turn round to the specialist and say, "What's the situation now, how long have I got, have I got six months, six years or what?" If he says, "Well, you've got six months" - fair enough. I'll enjoy myself for that six months and put my house in order, but at the moment I don't want to know, because I don't feel ill in any way at all. [L394 man (50) with recently diagnosed lung cancer]

While the future was discussed in the interviews, there was a stronger focus on the present, particularly among patients. In the present, hope for carrying on and for living with a fairly good quality of life, for some time at least, was constructed around several themes: personal determination; state of present health; comparisons with others who are worse off; information about 'spread' and treatment possibilities; framing it as an 'adventure/stimulus' and a chance for positive action. Conversations with health personnel about 'how long?' were described as being avoided, or challenged, or left open. When they did occur they were presented as difficult to handle

Patient: It could be as little as three months. I mean, he didn't say you have got three months, I must stress that, but we came home and then of course the three months preys on your mind and we just seemed to go further down really, didn't we? [K473 woman (41) with recently diagnosed lung cancer]

Carer: [The consultant] was doing a bit of talking and then suddenly eight months came up in this conversation and he flustered rather and shuffled his papers about and I thought then, "Are you saying that J. has eight months to live?" ... If somebody would be truthful. As I say, J. doesn't want to know, and if I was in his shoes I wouldn't want to know, at least I don't think I would. [K198 carer of man (61) with recently diagnosed lung cancer]

In these ways the patients quoted here seem to manage to 'keep going'. However, it seemed that those who were being given some treatment [n=3] found this easier. There were several references to being 'in limbo' from those who were not being given or awaiting treatment.

Patient: We really want to get on with the chemotherapy now... at least we think we would feel we were doing something else. We just feel as if nothing...

Carer: It just feels as though the cancer's growing.

Researcher: Nothing's happening.

Carer: And no one is doing anything for us now, we're up against a stone wall. ... You went for a scan and sat around waiting all day, and you get results, and you'd eventually get an appointment, and they'd do something about it. But weeks just roll into months.

Patient: It's three weeks since they said, "Would you like the chemotherapy?" We discussed it over night, and I said the day after that I would. So it's three weeks, and I've had my scan and I've had my blood tests and everything, so I'm just waiting to go ahead with it. [K473 woman (41) with recently diagnosed lung cancer]

Carer: [The consultant] said, "We'll get a CT scan done". And so that was the next thing we would have to wait to hear to go to [hospital x] for this scan. And we waited and waited and didn't hear anything. So we got the appointment for the scan, and then we were to see the consultant again. Well we didn't hear anything for about a fortnight, so I rang up and got a very helpful young lady [consultant's secretary]. [K198 carer of man (59) with recently diagnosed lung cancer]

Carer: [We chose to go to a hospital further from our home because we would be seen more quickly]. Because in those two weeks you think, "Oh it's going to spread", and you're so worried. I used to lie awake at night thinking it's going somewhere else, and I was really pleased to go in and have it done that quickly. [P295 carer of man (63) with lung cancer, palliative care only]

Carer: We have had these hold-ups in the middle where we have had to ask people. If he hadn't been bad that day, I don't know when we would have got the appointment with [the oncologist] because we didn't have one. When we saw [the consultant], he just said that it was lung cancer and they'd found these cancer spots on the liver and we did ask what the prognosis was, because I'm afraid I quite like to know things. I still feel that we are in limbo. ... He just said, "Well, we don't like to do that because nobody knows," and you accept that nobody knows the time and the place, but he said, "We would rather deal in three months at a time." So we have an appointment to see him in September. ... [If he hadn't been] ill, we wouldn't have seen anybody for three months, which seems a long time. ... I just feel that it is a little bit glib to say, "Oh, we'll just take it three months at a time," because some things you need more than three months at a time to sort out or arrange or whatever. [P53 wife (64) of man (72) with lung cancer at the palliative only phase]

Patient: I'm very disappointed. And up to now, I don't have to go and see them till the eighteenth of this month, which is a long time again. [P71 man (83) with lung cancer, palliative care only]

Lung cancer patients occasionally made a reference to their carers' future. For the carers their own lives after the death of the patient were more frequently discussed. In this way the carers were more oriented toward the future, as their concerns about 'what to expect' also suggest.

Carer: I can think about it and I think, "Hell, have I got 20 years after [my husband] on my own?" ... You've got to try and think positive and you've got to try and think strongly, I could say that to somebody. But what else can you say really? I mean you are going to be in a fine old state. Having been with him 42 years gone June, that is a hell of a long time. [K198 wife of man (61) with recently diagnosed lung cancer]

Carer: Some people enjoy being on their own. But I think that when you've been married unless you are in a very poor marriage then you are obviously, male or female, going to suffer when the other one goes, because you are losing all the companionship and everything. [P53 wife of man (72) with lung cancer, palliative care only]

Carer: But I think all sorts of crazy things. For instance, I wouldn't want to take a box [coffin] down these stairs. I know it's silly. [P250 husband (63) of woman (65) with lung cancer, palliative care only]

A few carers presented the cancer as a situation which had made them reconsider their perspective on life

Carer: I visualised on two years retiring and having twenty years' retirement but this has put it all in perspective that you don't know what's around the corner. [K473 husband (57) of woman (41) with recently diagnosed lung cancer]

Carer: I think it affects people in different ways, but at the end of the day it comes down to the same thing. I think it's just a matter of exchanging ideas, because it's the unknown quantity. The only thing you can do is take each day as it comes, unless you are so organised that you can say "Right, in three weeks time I'm going to get this," but you can't. You don't know what's going to happen next day. [P250 husband (63) of woman (65) with lung cancer, palliative care only]

Other carers spoke about the need to scale their lives down, to learn to 'remember' the increasing limitations of their patients, and to consider the illness when making plans for future activities.

Carer: He's adjusting down. We've been used to going out every day, and we do quite a bit of voluntary work for the [Salvation] Army and it's all had to be scaled down. You find, you think, "Oh we'll go such and such a place," and then you think, just a minute, [my husband] can't walk that far. There's all sorts of little things that happen and you just have to scale your life down. ... the Macmillan nurse said to me "Keep him going." Well, I don't need to keep him going, he keeps himself going, but between us, it's just so easy to give up, and sit down, and think we cannot do this. And then perhaps with a few adjustments you can, and you have just got to think less actively. We have to do things more slowly, we still do them, but you have to do them more slowly. [P53 wife (64) of man (72) with lung cancer at the palliative only phase]

All the carers expressed the distress of the situation in their own ways at interview:

Carer: I find that if I keep myself busy then I don't think about things. It's times like when you're just like getting into bed, and you've got your thoughts to yourself. Little things that might happen throughout the day and you think, is it getting any worse? [P250 husband (63) of woman (65) with lung cancer at the palliative only phase]

Carer: The hardest thing for me is to see him suffer, because he's such an active man [crying]. [P295 wife (51) of man (63) with lung cancer at the palliative only phase]

Carer: I'm not in the main a bawly sort of person but there have been times lately when I've sneaked off on my own. [K198 wife (58) of man (61) with recently diagnosed lung cancer]

Carer: Because we have our faith and we don't think it's the end, that makes a big difference to us. It's very hard to put that across to somebody else who really can only think that they don't want to leave this life. I think people have the fear that the end is near, and the other fear is the pain and the suffering. And I will admit that we've got lots of people who are praying for F. to be healed. I don't actually pray for him to be healed, but I do pray that he won't suffer. [P53 wife (64) of man (72) with lung cancer at the palliative only phase]

Breast cancer patients and carers - treatments and services

The statistical analyses of the questionnaire data suggested that breast cancer patients had significantly higher needs in seven items – 'Opportunities to participate in choices around treatment', 'Support in dealing with changes in my body or the way I look', 'Support in dealing with any changes in the way others see me', 'Help with any sad feelings', 'Someone to talk to', 'Support from friends', 'Help with getting out and about socially' - but a significantly lowered need for 'Advice about food and diet'.

In all 19 female breast cancer patients and 13 carers (nine men and four women) were interviewed. The average age of patients was 52 (range: 26-76) and of carers was 50 (range: 30-67), which meant this subsample was slightly younger than the whole sample whose average age was 57 (range 26-83) for patients and 55 (range: 20-76) for carers.

Breast cancer patients at diagnosis and end of first treatment had different issues to deal with than those of lung cancer patients, although there were many comments on the initial fear that the diagnosis meant they would die soon. However, this seemed to be centred on the initial diagnosis, although a residual sense of threat was also expressed:

Patient: I left there realising that maybe I wasn't as immortal as I thought and that life is very precious. I remember noticing the clouds in the sky, and I realised that I take that for granted. I don't look at the clouds, and I don't see how beautiful they are. I realise that that's because I assumed that I was going to live to be a 100 and maybe I'm not. So there was certainly that awareness that day. [K239 woman (49) at the end of first treatment for breast cancer]

Patient: Odd days when you feel a bit down and you think, "Oh, I hope it has gone and it's not going to come back." But then that's life, isn't it? [L99 woman (46) at the end of first treatment for breast cancer]

Reassurance about limited spread of the disease early in the process of treatment was presented as very reassuring and releasing, allowing them to get on with life. Like patients in a study by Bliss and Johnson (1995) they were concerned to put cancer 'behind' them.

Carer: After the operation the results came back as being as good or better than we had hoped. A lot of the apprehension disappeared, but it's at the back of your mind even now that she's had cancer and there's a possibility of reoccurring at a later stage. But who's to say that I'm not carrying cancer about with me now and I don't know that I've got it. ... Once the operation was done you felt like you were on the road to recovery. [L99 husband (50) of woman (46) at the end of first treatment for breast cancer]

Patient: So when the consultant came there this morning I did say that I was a bit worried about it. He said, "The results are fine." And I just needed to hear that and I was off again. [K239 woman (49) at the end of first treatment for breast cancer]

Patient: But you've just got to be positive and [the oncologist]'s told me that they've got everything, so they don't see why I shouldn't be all right after this treatment, so that's a big help. [K202 woman (40) with recently diagnosed breast cancer]

Unlike lung cancer patients, those with breast cancer were actively treated from the point of diagnosis. All had surgery, and many had chemotherapy or radiotherapy as well. They were swept into a whirl of activity and very few comments were made about having to wait, rather the speed of attention was frequently mentioned:

Patient: I was diagnosed on the Friday and I started my first chemotherapy on the Wednesday. [L140 woman (26) with recently diagnosed breast cancer. Joint with mother (51)]

Patient: I'm sure they didn't waste any time. I felt very cared for, yes that's the word. [L185 woman (66) with recently diagnosed breast cancer]

Only very few felt they had to wait any length of time once diagnosis was made. Although waiting time was short even in these cases, the time was filled with anxiety and seemed long:

Patient: After that I had another wait of about another ten days and then they removed the tissue surrounding where the lump had been and took out 11 lymph nodes as well. Then you have to wait again for another week after that to get those results through, so it's quite long winded. I think that's quite stressful actually. [L490 woman (43) with recently diagnosed breast cancer]

Patient: We were thinking ten days is a long time to wait. But when we were told that there are people on the NHS waiting three months, I was really quite horrified. Because that was actually the worse time from initially seeing [surgeon] to getting the initial results through. Before I went in for the needle biopsy, they were probably my worst times for anxiety. Because we really were treading water and we'd no idea. Even though there's been times since where we've been very down and it's been quite terrible, at least you know what you're down about and what you're worried about. ... [The surgeon] said to us that had I not picked reconstruction at the same time, he would have had me in within a fortnight to do the operation, so I wouldn't have had to wait. [P184 woman (32) with recently diagnosed breast cancer]

Patient: I'm supposed to have [checks] on a regular basis because it may flare up somewhere else. So, a delayed appointment could mean the difference between life and death to me. ... what can a cancer do in three months? It can kill you in three months. [P2 woman (49) with breast cancer at the end of first treatment]

Getting on with the treatment was presented as useful in combating the feelings the cancer has aroused as well as the disease itself. Being diagnosed was a moment of stasis, of liminality (Little et al 1998), which was eased by the activity of treatment, which represented moving forward, continuing life:

Patient: I knew I had to have chemo, and I think that I was feeling better after the operation and I just wanted to get on, and get the chemo done, you know, let's get going. [L99 woman (46) at the end of first treatment for breast cancer]

Breast cancer is different from other tumour types, because it is very rare for patients to feel ill with it prior to diagnosis. The other three tumour types generally involve some uncomfortable symptoms which sends the patient to the doctor. Thus there may be some lingering disbelief:

Patient: The cancer thing didn't put me into feelings of panic or anything, just a bit disbelief, saying, "Come on, pull the other leg, it's got bells on. I haven't got cancer, I'm all right". Because I didn't feel ill with it. If you had a form of cancer where you were feeling really ill, well that would be awful. The only thing that has made me feel ill, is people trying to cure me. [K153 woman (69) with breast cancer at end of first treatment]

Patient: I assumed that it was going to be fairly routine and that the consultant would say, "No problem", because I still felt I was a sort of non-cancer person. [K239 woman (49) at the end of first treatment for breast cancer]

Patient: I still don't believe I've got it, even after all this time, it still hasn't really sunk in, if I did let it sink it, I think I'd just break down, so I just keep it to one side. [P164 woman (55) with breast cancer at the palliative only phase]

The difficulties caused by treatment had to be dealt with. A few respondents seemed to use this part of the experience as a focus, which helped the 'cancer' to recede in their consciousness, as other problems were more pressing:

Patient: But I think this has stressed me more than anything, you know, not being able to work my arm [because of lymphoedema], more than the actual - I think really, I shut it out of my mind. [P87 woman (64) at the end of first treatment for breast cancer]

Any outer signs of the disease and treatment were a reminder to the patient and the world at large of the cancer, and could be a challenge to the patient's identity. The questionnaire data suggested that significantly more breast cancer patients, as compared to colorectal patients, rated 'support in dealing with changes in my body' and 'support in dealing with any changes in the way others see me' as important.

Patient: But that was the hardest thing, going that first morning [to take my daughter to school], especially with a wig on. [K202 woman (40) with recently diagnosed breast cancer]

Patient: And it's not very nice to look at. They made a nice operation, but it - my body's exactly the same except there's no breast there. ... It's very nice, how it's been cut and that, but it is emotional. You look at yourself - you're lopsided, and it's not very nice. ...

Researcher: You've talked a bit about the changes in your appearance and needing to feel comfortable. So have you found that difficult?

Patient: Now you're asking me. I start to feel I want to cry. I'm not sorry for myself. I just think, what a shame. You know, there's nothing - you put on a good act because you don't want people to think that it matters. [L185 woman (66) with recently diagnosed breast cancer]

Patient: I've lost my self image in a lot of ways. I've lost my shape and what have you and that's important to me actually, my appearance. I've tried to keep up appearances all the time and that is important and losing my hair upset me, but a wig's better than my own hair ever was anyway [laugh] but it's not much fun when you take it off. [K153 woman (69) with breast cancer at end of first treatment]

Breast cancer patients had a different experience from people with other tumour types in the provision of breast nurse specialists. While those colorectal patients who were given stomas did see the stoma nurse, and people at the palliative care only critical moment were mostly referred to Macmillan nurses, there was no equivalent universal service for other tumour types. All the breast cancer patients [n=19] (bar one who had a complicated diagnosis and was being treated in Manchester) and many of their carers had seen the breast nurse specialist in their area, and most had quite extensive dealings with her. This was a service that was highly valued by the vast majority of patients.

Patient: What was particularly helpful from my point of view was that when I was so shocked on the Tuesday and I couldn't think straight [the breast nurse] actually phoned my work because she recognised that there was no way that I could be at work the following day. She asked my permission to do that and that was really a helpful thing for me because it was something that I wasn't capable of doing at that point in time. [L140 Woman (26) with recently diagnosed breast cancer]

Patient: [The breast nurse] has been out to see me here two or three times, she saw me once in the hospital, and she's phoned most weeks to say, "How are you?" And she actually spent most of the beginning half of last week badgering [hospital x] for the oestrogen receptor test, because when I'd seen her I was saying, "We're just really waiting for that and

it is a bit like treading water.” [L490 woman (43) with recently diagnosed breast cancer]

Patient: After the operation they came round to you, and I wasn't very well and while [the breast nurse] was just talking to me she stayed with me and got me drinks of water and they really are brilliant. [P87 woman (64) at the end of first treatment for breast cancer]

There were a few who had some criticism of this service, however, which mostly centred around accessibility. The questionnaire data revealed that a significant number of female patients as compared to male patients rated 'easy and quick access to health professionals other than doctors' and 'support from care professionals' as important. Breast cancer patients were significantly more likely to rate 'easy and quick access to health professionals other than doctors' as important in comparison to colorectal patients.

Patient: I phoned [the breast nurse] up and I told her about it, and I said, “Look we do need some back-up and all that”, but she's never got back to us. [P2 woman (49) with breast cancer at the end of first treatment]

A few expressed a desire for more monitoring:

Patient: I think they think that because you're all right - there are people who have got it more seriously than I have - or had it - I understand that. They have to deal with the ones that are really ill. But you do feel a little bit out on a limb. You don't want somebody on the door every ten minutes, you want to get on with getting better, but at the same time it would be lovely to think that they are keeping an eye on you. [L185 woman (66) with recently diagnosed breast cancer]

Often behind problems of physical accessibility were questions of legitimacy and identity. Patients weighed their own concerns and needs for independence against breast nurses' limited time

Patient: I would have been able to ring the breast cancer nurses, but it's that having to go and do it, you know, it's hard and then you feel you're being a nuisance, just asking a silly little question [about attending a wedding]. [L99 woman (46) at the end of first treatment for breast cancer]

Patient: I do talk to [the breast] nurse. She's very nice. But it's only a matter of 'passing the time' I'd say. She always says you can give me a ring, but you know how busy they are. [P61 woman (65) with recurrence of breast cancer]

Breast nurses were more available around the time of diagnosis and surgery and many women mentioned seeing them frequently at this time. However, when other services, such as chemotherapy and radiotherapy units or Macmillan and hospice services, were accessed, contact with the breast nurses lessened, for example:

Patient: There was the Breast Counsellor Nurse, but I haven't seen her very much. Though she would've come if I'd asked her to, she was very nice. But it's a while since all this happened after the surgery and before the chemo. So I get pushed into a different group of people with the chemo than I was. [K153 woman (69) with breast cancer at end of first treatment]

Breast cancer patients at diagnosis and first treatment had a different experience from people with other tumour types. They experience few symptoms prior to diagnosis, they were given quick and active treatment aimed at cure, and they had a designated nurse specialist.

Colorectal patients and carers - major surgery and stomas

The statistical analyses of the questionnaire data suggested that colorectal cancer patients had significantly higher need in only one item – ‘Advice about food and diet’ - but significantly lowered needs for eleven items: ‘Confidence in the health professionals I meet’, ‘Health professionals who have time to discuss issues with me’, ‘Honest information’, ‘Health professionals who listen to me’, ‘Easy and quick access to health professionals other than doctors’, ‘Opportunities to participate in choices around treatment’, ‘Advice on what services and help are available’, ‘Support in dealing with changes in my body or the way I look’, ‘Support in dealing with any changes in the way others see me’, ‘Help with any sad feelings’, ‘Help with getting out and about socially’.

We interviewed 11 patients and ten carers who were dealing with colorectal cancer. Two interviews were with carers only, who talked about their patients, bringing the number of patients we had data on up to 13. There were nine male and two female patients, and nine female and one male carer. The average age of patients was 63 (range: 38-81) and for carers was 61 (range: 20-76), which made them slightly older on average than the sample as a whole. Colorectal patients, unlike the other tumour types, were always given major surgery, often with the formation of a stoma. Some had adjunctive chemotherapy [n=3], radiotherapy [n=3] or both [n=3]. Three had only surgery and one was awaiting surgery.

Treatment time scale

The abdominal surgery required in colorectal cancer is major, and a few patients mentioned being surprised at its extent:

Patient: Mr [surgeon] told me I was going in and that I would have no bottom left when I saw him and that I was going to have a colostomy, a bag. But as far as I was concerned that was it, it was just an operation, but as soon as she [the nurse] said it was major operation, I mean to me major operation is heart you know, a really big operation. [P46 man (72) recently diagnosed with colorectal cancer]

Carer: I knew it was going to be a major operation, but somehow or other I hadn't quite realised how big, because of course I didn't know how much they were taking out. I suppose if you thought about it logically and properly all the way through, you would realise that it had to be quite an opening. [K167 wife (70) of man (69) with recently diagnosed colorectal cancer]

The time for recuperation was also described as longer than expected by a few:

Patient: People don't realise how much it knocks it out of you when you're weak anyway and you're just recovering or recouping. And even though I'm eating well and sleeping well, I'm still very, very, quite weak. [P254 man (54) with recently diagnosed colorectal cancer]

Carer: I think probably the most difficult part that I observed is that he expected by now to be doing a huge walk down town and back again. And I think he is disappointed, he'd been told, we'd both been told, that it could take two or three months before he was really feeling fit. [K167 wife (70) of man (69) with recently diagnosed colorectal cancer]

For those who had chemotherapy and/or radiotherapy as well treatment could be quite protracted, as recovery from surgery had to be well under way before further treatment could take place.

Carer: By the weekend he was feeling quite chipper and perky, he was even feeling chipper on Monday after it, but by Tuesday you could see that [the chemotherapy] already

it was taking its toll. So now I think he realises that it is going to be like this and we'll just have to realise that it is going to take a lot longer, whereas if it's just a normal, say appendectomy or something like that, well after six weeks you're back to normal and that's it, you've forgotten about it. [K167 wife (70) of man (69) with recently diagnosed colorectal cancer]

Stomas

Bliss & Johnson (1995) describe colorectal patients in their study being concerned with the incapacitating effects of surgery and adjunctive treatment. They also suggest that the social consequences, particularly of stoma formation, could make the process of recovery more protracted. In our study we found that those who had stomas and their carers talked a great deal about 'managing the stoma'. In our interviews nine patients and seven carers spoke about stomas, with eight patients (six men and two women) presently having stomas. Of the remaining (four male patients and one female) two had not needed a stoma, one had not yet had an operation, one had had her stoma reversed, and the other, having had the initial diagnosis several years before, did not indicate whether he had a stoma or not.

The creation of a colostomy or ileostomy is major surgery and the initial need is to recover from surgery. At the same time the patient (and often the carer) have to get used to managing the stoma, which takes time. This was a prime need, and issues such as changing the bags, odour, getting into a routine, embarrassment, and then thinking about how to manage excursions away from the home were often spoken of at length (see MacDonald 1988). Adjusting to the stoma was a major task, made better by the feeling that it was better to have a stoma than the cancer, or by other more pressing problems, such as handling diabetes, financial problems, or hospital acquired infection. Two were keen to have their stomas reversed

Patient: I'm not looking forward to [the reversal operation] but it has to be. It will be well worth it to get rid of the bag actually. [B29 man (71) with colorectal cancer at the end of first treatment]

Patient: I'd argued and argued to have it taken away.[L348 woman (63) with recurrence of colorectal cancer]

and one gave thanks that her husband did not need a colostomy, because he was a "fastidious sort of chap" [L303 wife (67) of man with recently diagnosed colorectal cancer].

Adjusting to the stoma required managing the equipment:

Patient: This has been the problem, the bag. The thing is, it bulges off the skin, breaking away and all this. And I found out what was wrong, it was an outer ring involved and also the inner one which wouldn't seal it. [B29 man (71) with colorectal cancer at the end of first treatment]

Patient: I had this conception of this hot water bottle type thing hanging down from your side, and I thought, no way will I ever get to grips with that. But it's all water under the bridge now. [P234 man (58) with colorectal cancer at the palliative only phase]

Patient: When [the stoma nurse] first came, I wouldn't look at it, I would not look at it. Then as days went on I thought, I'd knew I'd have to, and my daughter said, "Well, think about it, when you changed the children, mum, and it's yourself." ... I thought I'd never do it. I'd tell anybody that's listening you think I will never do it. [The stoma nurse] said, "You will, you will, I can tell that you've got it in you, you'll do it." So that was the first time ... the second time I tried it and then I said, "Well, it wasn't too bad." [B18 woman (67) with colorectal cancer at the end of first treatment]

Managing diet was an additional concern:

Patient: I've just had a couple of bad days, like one Sunday, four times after I came home, but I'd had some cauliflower, I haven't had any since. [B18 woman (67) with colorectal cancer at the end of first treatment]

As the patient recovers and gets used to handling the bag, issues around being in public arise, which involve worries and the need to plan excursions:

Patient: It's just a funny feeling, because a friend came the other day and you've to get used to that as well, because it's like a bubbling sensation, and it is funny just getting used to it. But I said to [my husband] "I mean you couldn't really change in town because you need water. You couldn't go in a toilet, could you? ... You couldn't wash yourself or anything, so what could you do?" [B18 woman (67) with colorectal cancer at the end of first treatment]

Patient: It is limiting because you have always got to think that it might need emptying. And it's all right, but the best place is at home where you can do it. If you are outside, it might not be very convenient. [K167 man (69) with recently diagnosed colorectal cancer]

Patient: I took me swimming cossie, because you have all these little caps things that fit over the stoma, but I just didn't feel confident. I still really don't now.

Carer: I think at the back of your mind you still feel [odd], because you still use the word 'freak'.

Patient: I think it is at the back of my mind. It's not natural, there's no control over any of the movements at all. I could be sitting here and there'd be a loud noise come. In hospital when it was starting working, it was so embarrassing, I used to lay a pillow across my middle [laugh]. [P234 man (58) with colorectal cancer at the palliative only phase. Carer: wife (50)]

However, the difficulties of the stoma could be put in a positive light, especially in reference to the cancer:

Patient: Then you were dealing with a colostomy, which took your mind off the cancer anyway, because that was a pain in the neck [laugh]. [L348 woman (63) with a recurrence of colorectal cancer]

Patient: The cancer can spread, but the stoma can't. [P46 wife (71) of man (72) recently diagnosed with colorectal cancer]

Although underlying concerns about identity and altered body image were frequently mentioned and constructed as unlikely to change, there was also an expression of belief that they could adjust to the stoma given time, and regain some sense of normality within the new parameters:

Patient: I can't see it changing, I think I will get used to it. I don't think it will change too much, it's a question of familiarisation, of doing it and finding that you can do it. You do this and you think, oh I can do that. And it just stretches out a little bit all the time. And then eventually you are as normal as you can get, I suppose really. So it is a question of slowly building, putting some foundations and slowly building away. [L98 man (53) with colorectal cancer at the end of first treatment]

Patient: I think it will always be different. For a start the one thing I don't like really, you just can't have the same control because when it comes, it comes. ... but I suppose it can be

managed. I think you will be able to enjoy a lot of things. It's not as though at my age that I'm going to take up sports or anything like that. We used to travel a lot, it shouldn't hinder it too much. But it will take time I suppose to get used to it. [K167 man (69) with recently diagnosed colorectal cancer]

As with breast cancer, there were specialist nurses to provide support. However, they were designated 'stoma' nurses, rather than colorectal cancer nurses, and only came into contact with those patients who had formation of a stoma. They were always well regarded and had often regularly visited the patient at home and in hospital. Information and help from this source seemed readily available. However, it seemed that more emphasis was placed on patient education and managing the equipment than on the 'counselling', which breast patients described as part of the breast nurse specialist role. Stoma nurses did provide intensive contact, both pre- and post-operatively for all the patients with a stoma in our interview sample. The delivery services for equipment, accessed through the stoma nurses, were also highly praised.

Carer: They just say to us, "If there's any problems, ring," and they are there at the end of the phone. It's the same with all his equipment he has to have, you just ring up and it's there the following day. [P234 wife (50) of man (58) with colorectal cancer at the palliative only phase]

Preparation for the operation in the form of explanations and the viewing of equipment and leaflets was said to be useful, but it was hard to imagine the outcome for those who had no prior experience of stomas. One patient felt he would have liked more 'tuition', but also felt that help was easily available.

Carers were often involved and educated alongside the patient

Carer: The stoma nurse came and showed us both, actually they showed him how to do it several times. She explained it all again. And that if there was ever any trouble we must call. So I met the stoma nurse there and since then I've met three of them and they did come to the house, they always included the two of us. So, and I think that's very good. [K167 wife (70) of man (69) with recently diagnosed colorectal cancer]

The carers we spoke with seemed to get involved in managing the stoma, in terms of support more usually than in physical assistance. However, one woman mentioned never having even seen her late husband's stoma and the fact that her son was unwilling to address the subject of her colostomy. Of the eight patients with stomas who were interviewed two were women. One of the women mentioned her husband and daughter as seeing the stoma and talking about it (the other woman had had her stoma reversed two years previously). Two of the wives of men with stomas talked about helping with it at times (usually initially). There was the general impression that all the pairs interviewed shared information and discussed the stoma between them, even if they did not mention actual physical contact with it.

Lymphoma - getting involved with the chemotherapy unit and curability

In all seven lymphoma cancer patients (five men and two women) and three carers (all women) were interviewed. The average age of patients was 55 (range: 49-69) and of carers was 50 (range: 46-57), which meant this sub-sample was similar to the survey sample.

Lymphoma patients were different from the other tumour types in the fact that they had no surgery greater than a biopsy. Their treatment experiences centred around chemotherapy and the hospital unit which delivered this. Lymphoma patients often reported feeling quite ill prior to diagnosis [four of the seven] and diagnosis was often a lengthy process. Hence, for lymphoma patients it was often a relief to be diagnosed, to finally know what was wrong.

Patient: I think I kept so calm because I felt so ill. ... I had this inner calm. I don't know where it came from, but it was there because I felt so rough. And in my mind, it was kill or cure me. I didn't tell [the consultant] that, can't go round saying that to people, but that's the way I felt. It was just awful. I think you reach a point of no return, you're that ill, you don't really care, you just want an end. [P280 woman (49) with recently diagnosed lymphoma]

Patient: I don't think they expected me to live on reflection because they didn't know what the hell was wrong with me and I just played it very low key. I just did what the hell they told me to do, and really I was so weak I couldn't do anything ... I never asked too many questions because I think a little knowledge is quite a dangerous thing, but once they got me into that [oncology] Unit and they started with the treatment, then things got better, well not better, but started to improve more, no end. [L224 man (50) with recently diagnosed lymphoma]

Information about treatability and a hopeful prognosis (in six of the seven cases) was presented as very reassuring, moving patients from 'cancer=death' to a position where the illness was manageable

Patient: So I consider myself very lucky. That's about the end of the story. ... Once I heard that that was clear I relaxed and I was quite happy to face any routine that was required. ... I mean you just have to live through it until you came out the other end. ... People say, "Oh, I know somebody who had lymphoma 15 years ago and they are still around". I'm always glad to hear stories like that. ... you just celebrate that it's apparently minimal. I say apparently because one will always live, I suppose, with the thought that it might recur, it is perfectly possible. I'm not daft enough to think that it won't, but the professor did say that he treated somebody else with similar symptoms and it had completely gone, so one lives in hope, I mean that's all you can do, isn't it? [K236 Man (69) with recently diagnosed lymphoma]

Patient: You obviously hear the word cancer and think that's it terminal, finished. And of course, since we've been through it we realise that it isn't and that there are so many different kinds of it. ... But if it happened again, I certainly wouldn't be as worried, knowing that there are treatments for this sort of thing. And that a lot of the cancers are curable today, or at least, you can be held in remission, whereas you think of cancer 15 - 20 years ago, it was final. [K256 man (64) with lymphoma at the end of first treatment]

Patient: I consider [my wife's] incidence [of breast cancer] was major and hopefully mine is extremely minor. Hopefully. ... I just put it out of my mind. I can't sit and think about it full stop. The worst was before I'd seen [the consultant]- You'd wake up in the morning - what day is it? - Oh I'm working today - Oh, by the way, I've got cancer - it used to hit you in the morning. And when I saw [the consultant] that was erased. So he must have had a major part to play. [L124 man (55) with recently diagnosed lymphoma]

Patient: [the consultant] said he gets one a week with non-Hodgkin's lymphoma, and he's had good results from the chemotherapy, and he said "I haven't lost a patient yet!" So that filled me [laugh] that made me feel you know, so [he] did help in that way. [P74 woman (50) with recently diagnosed lymphoma]

Improvement after treatment was reported by all the lymphoma patients, although one had relapsed quicker than he expected

Patient: But had it been really painful or anything like that then it would have felt it. But it's just been sort of one of those things like toothache, like it appeared and then it's gone again. And so that's it. [K256 man (64) with lymphoma at the end of first treatment]

Patient: I was eating a lot and it was just so good to feel human, to be able to eat food and enjoy it, to pass it, to pass it the natural way, and just to feel human, I cried with sheer relief. I didn't cry when I was ill those three weeks, I didn't cry when I was getting all the needles and everything stuck inside me, I didn't cry when I had the operation, but I cried because I could eat and feel normal. [P280 woman (49) with recently diagnosed lymphoma]

The services at the hospital oncology unit in one area were particularly praised for making the experience easier

Carer: When they came in to see you in the ward, they obviously had been discussing you before you came in. They all knew about your blood sugar, about everything ... one day they said "Well, we can sense that you are not so confused today, how do you feel about it?" You felt that they had actually taken you in, similarly with everybody there.

Patient: It makes you feel as though you count. [L224 man (50) with recently diagnosed lymphoma. Carer: female partner (46)]

While one location had extensive support services and an oncology unit, the other location from which our lymphoma patients came had a haematology unit, which was also praised. However, in the community help with psychosocial problems was less easily available than with the other cancers, as one woman who had an episode of mental dis-balance (probably due to sudden steroid withdrawal) reported:

Patient: Counselling was the main thing. I asked [the doctor] at [hospital x], if there was any form of counselling or anyone I could go to. She said that they didn't have anything at [hospital x], which she said she was disappointed about, but she said, "If you want someone to talk to, I'll talk to you". ... At [hospital y] they have counselling and there's so many people you could see. At [hospital x] there's no one. It was my own GP that got me a Macmillan Nurse, but it's just a shame, because I think you need support at this time, and there was just nothing. But like I say, [the hospital doctor] was wonderful, she made an appointment and spoke to me and tried to help me out, but of course she's busy, it's not fair, taking her time. It's proper counsellors you need, and to be with other people that are going through the same thing. [P74 woman (50) with recently diagnosed lymphoma]

Having lymphoma diagnosed differed from the other cancers as it was presented as more curable to the patient, and because the services were more hospital-centred. The specialism involved was medical rather than surgical, and the specialist oncology nurses involved were ward-based, rather than breast, stoma or Macmillan nurses, who were more usually based in the community.

Summary

The four tumour types we chose had different treatments and survival trajectories. This affected the experience of patients in terms of services, treatments and life expectations. However, among surveyed patients there were fewer indications of variations in psychosocial need by the different bodily sites of the disease than expected. In the statistical analyses, a colorectal diagnosis had more significance for needs than the other tumour types, but in a positive direction (this group expressed fewer needs than the others). There was no variation in unmet need that could be accounted for by this tumour type. In the interviews, a more differentiated story emerges. Whilst respondents with all types of cancer often spoke of their initial experience in ways which evoked the cultural spectre of 'cancer = death', their initial perception of cancer was changed by the diagnosis and information they acquired from the health professionals they met. The differentiation of the amorphous 'cancer' into particular cancers was a process which occurred early on, but was ongoing and re-appraised at different stages, such as at recurrence. The manner and quality of information and its specificity to their own personal situation seemed very important in the processes that patients and carers underwent in order to manage the cancer and continue with life.

For those with lung cancer there were different questions than for those with more 'curable' cancers, such as whether to obtain more detail regarding what to expect. This need appeared to be more pressing for carers than patients, as patients tended to focus on the present as a means to 'carry on'. The carers of lung cancer patients, in particular, suffered from high levels of anxiety. There were also some expressions of feeling abandoned and isolated, as intervals between appointments could be long and there was usually no clear cut treatment plan. Referral to hospice and palliative services tended to help with these feelings.

Breast cancer patients had designated nurses, who were an important point of contact and information, although there were a few people who experienced access problems with these services. Breast cancer patients were swept into a whirl of treatment activity, which was presented as reassuring. The desire to be monitored after treatment was also frequently mentioned. Breast cancer is different from other tumour types in that it is very rare for patients to feel ill prior to diagnosis. The other three tumour types generally involve some uncomfortable symptoms that send the patient to the doctor. This absence of symptoms in breast cancer sometimes resulted in a lingering disbelief in the cancer. The issue of image was raised, as treatment tended to disfigure - especially loss of hair through chemotherapy.

Colorectal patients also had image and identity issues to deal with when there was stoma formation and this was often presented as limiting social activity. Surgery was often major and the time taken to recover from it, and any chemotherapy regimens, was mentioned as difficult to come to terms with. While stoma nurses and the ease of obtaining supplies of necessary appliances was praised by several, lack of advice about food and diet was mentioned as a main problem by a few.

Lymphoma patients were different from those with other tumour types in that they had no surgery more major than a biopsy. Their treatment experiences centred around chemotherapy and the hospital unit which delivered this. Lymphoma patients often reported feeling quite ill prior to diagnosis, and diagnosis was often a lengthy process. Hence, for lymphoma patients it was often a relief to be diagnosed, to finally know what was wrong. They differed from those with other tumour types in having the hospital unit as their main source of both treatment and support.

CHAPTER 8 Critical moments: patients and carers

Introduction

This chapter draws on the qualitative interview data with patients and carers to explore the ways in which the cancer experience changes as patients differentially pass through the critical moments we identified. Once again, the qualitative data highlights issues not captured in the survey data, providing a more nuanced account of the impact of the phase of the cancer on psychosocial needs.

As the previous chapter suggests, the particular nature of the tumour type affects the initial experience of cancer, although for almost all patients and carers there is a time of acute fear around diagnosis in which the 'cancer=death' scenario is evoked. Weisman (1977) suggests that existential problems occur mainly at this time. As patients and carers are informed about the specifics of their cancer and enter treatment, the fear begins to recede for most. The variable prognoses of the tumour types, however, means that different 'journeys' are embarked upon. For lung cancer patients and carers there is often little distinction between moment 1 (being diagnosed) and moment 4 (being given palliative treatment only), while for people with the other tumour types being diagnosed and given primary treatment may be the only experience of the disease. However, recurrence (moment 3) is always a possibility for cancer patients and fourteen of our interviewees were at this moment. There were indications in our study that recurrence re-arouses existential fears and people respond with distress, followed by 'getting on with it' again, as active or palliative treatment is pursued.

The HADS scores of patients and carers suggested that the moment around diagnosis and that around palliative care only were most likely to involve anxiety, and to a lesser extent depression (see Tables 23 & 24). This may be explicable in terms of change. The initiation into the illness is a new experience and thus likely to raise anxiety until some clarity about the illness and its treatment are reached. Recurrence is distressing, but the process embarked upon is similar to that begun at diagnosis, and the systems are familiar. The move into 'palliative care only' is another change, although not always clearly marked, which often brings with it some shift in services and the knowledge that existential hopes will not be fulfilled in the long run. Even at this 'moment' our respondents presented themselves as making efforts to maintain something of their normal life and social identity. While our respondents, being volunteers, were more likely to be those who were 'coping', and thus a particular subsample of all patients and carers, the ongoing thread through the 'journey' seemed to be a presentation of cancer as a situation which had to be 'got on with', if meaningful existence were to continue.

Table 23: Critical moment of those patients and carers who scored as cases or borderline cases on the HAD anxiety scale

	Diagnosis	End of first treatment	Recurrence	Palliative	Total
Patients	8 [n=21]	2 [n=9]	1 [n=8]	4 [n=9]	15 [n=47]
Carers	7 [n=13]	3 [n=6]	1 [n=6]	6 [n=7]	17 [n=32]
Total	15 [n=34]	5 [n=15]	2 [n=14]	10 [n=16]	32 [n=79]

Table 24: Critical moment of those patients and carers who scored as cases or borderline cases on the HAD depression scale

	Diagnosis		End of first treatment	Recurrence	Palliative	Total
Patients	7	[n=21]	2 [n=9]	0 [n=8]	3 [n=9]	10 [n=47]
Carers	4	[n=13]	0 [n=6]	0 [n=6]	2 [n=7]	6[n=32]
Total	11	[n=34]	2 [n=15]	0 [n=14]	5 [n=16]	32 [n=79]

Our interview sample contained more respondents at moment 1 (diagnosis) than at other times, but was fairly evenly spread over the other three moments. Gender representation was also fairly evenly spread, but with more women carers [n=9] than men [n=4] at moment 1 and moment 4 [5 women carers and 2 male carers]. There were also more women patients [n=12] at moment 1 than men [n=9] and at moment 3 [women = 6, men =2]. Apart from patients at moment 4, whose average age was 65, the average age of patients and carers was between 54 and 59 years.

Moment One - around diagnosis

The statistical analyses only showed one need item as statistically significant at this moment. 'Opportunities for personal prayer' was significantly lower than for the other three moments. This can be compared with the fact that another item in the 'spiritual' category, 'Support from a spiritual advisor', was significantly raised at the recurrence and palliative only moments, suggesting that spiritual matters become more prominent further on in the cancer journey.

In the interviews we asked patients and carers to 'tell the story of their illness from the 'beginning''. Some respondents asked what we meant by 'beginning' and the researcher would reply that it was whenever they considered it to be. Most began with a history of first indications, such as symptoms, or a routine check-up or screening. The events around diagnosis were described by virtually all the respondents, even those presently at a later stage. It was clearly a memorable time and was often described in detail, and with the words of the 'bad news' consultation recounted. Diagnosis could be somewhat expected [15 descriptions], where symptoms, or personal feelings of 'just knowing' gave forewarning, or a complete shock [17 descriptions]. Others described the diagnosis moment in more matter-of-fact terms. Some patients had moved from being 'unworried' to being 'prepared' through hints from health personnel prior to confirmation. For a few finally being diagnosed was expressed as a relief, especially where the time from first symptoms to diagnosis was prolonged. Additionally, the diagnosis was a legitimisation for a few people who felt that their symptoms were not taken seriously enough. Delays in diagnosis were common, sometimes caused by the patient's late consultation over symptoms [12 reported], but often through GP or hospital failure to diagnose quickly [16 reported]. In two of these cases patients were considering formal complaints (backed by the GP) against hospital services. Six [out of 10] lung patients reported a slowness in the services in providing diagnosis, usually because the GP tried to treat them initially. [cf. colorectal - two out of 11; breast two out of 19; lymphoma one out of seven]. No lung cancer patients reported that they had delayed consultation once they developed symptoms [cf. colorectal two out of 11; breast four out of 19; lymphoma two out of seven]. Delays ranged from a few weeks to a few months in both scenarios.

Speed in referral, diagnosis and treatment was a comfort to many, and one couple even considered it fortuitous that a mistake had been made which led to a quicker diagnosis. Being told clearly, with the carer included was also important, as was the manner of the telling. Being left in 'limbo' after the diagnosis was hard (Preston et al 1999), as was difficult information about prognosis being given too quickly, but staff support and clear information and plans of action seemed to ameliorate the worst of the shock. Many respondents used the word 'shock', but usually described it as passing as treatment got under way and they got to know things about their cancer. The word cancer aroused fears, both through cultural connotations and through previous personal experience

of other peoples' cancer. Fears were often allayed through information and medical action, and by good prognosis and encouraging test results. Acceptance (because there was no alternative) was described by several, as something almost instantaneous, or coming with time.

Being prepared

Having an inkling that there would be a cancer diagnosis through symptoms, personal feelings or early hints from health professionals was presented as useful in lessening the shock, as it thus became a gradual process of awareness.

Patient: I knew there was something, I'd been passing a lot of blood and this, and I thought there's something bad here and I accepted it. [B29 man (71) with colorectal cancer at end of first treatment]

Carer: I think that they actually prepared us very well for bad news on Friday.

Patient: They did. Although they couldn't actually tell us anything definitely ... but from the clinical examination they could tell that it was suspicious. ... So, they had prepared us. ... If anything on the Friday it was a relief to be given the diagnosis because then at least you know what it is, what you're dealing with, and you can get on with treating it. ... So to be given the diagnosis was actually more of a relief than upsetting. It was more upsetting on the Tuesday going through all the tests and being told that it was suspicious and knowing yourself really that it was anyway. [L140 woman (26) with recently diagnosed breast cancer. Carer: mother (51)]

Being surprised by the diagnosis was presented as very difficult, and could be exacerbated by concurrent personal circumstances:

Patient: A fortnight later I went back and had to queue up for about three hours and finally got to see the doctor again and he sprung the information that this was a lymphoma. I was somewhat startled by this. ... The difficulty was on a personal level, because a matter of days before I lost a very good friend after several years of illness with [lymphoma]. And we had to go to his funeral, and this was very, very, stressful indeed. ... However, I slowly came to terms with it. It was a very, very, stressful period until I had been through the scan [and been given a good prognosis]. [K236 man (69) with recently diagnosed lymphoma]

Patient: And I assumed that it was going to be fairly routine and that the consultant would say "no problem" because I still felt I was a sort of non-cancer person. He took a biopsy and I actually knew from his manner, I think, that this was something a little more serious. [K239 woman (49) at the end of first treatment for breast cancer]

Patient: Presumably it must have gone through the doctor's mind and through everyone else that came into contact with me, and yet nobody dared mention this taboo word. Presumably, the medical profession have their reservations about mentioning it to patients. Lack of honesty, that's not true, but I don't know, perhaps they didn't want to upset me. [L150 man (49) with a recurrence of lymphoma]

Being believed

Where the patient was experiencing symptoms, but there was a delay in diagnosis, it was difficult for both patients and carers

Carer: Yes, well he started being ill two Christmases ago actually ... and he's been backwards and forwards to hospital with no great result really. In fact I think he and we all got to feeling that it was in his mind and there was nothing, because they kept sending him home and saying there's nothing wrong. [B33 mother (76) of a man (49) at the end of first treatment for colorectal cancer]

Some expressed anger about not having their presentation of symptoms taken seriously enough:

Patient: And [the GP practice] missed all that. I was suffering and suffering. I'm not bitter, but one thing's always stuck in my mind, one sister [in the GP practice] said to me, "I really think you want them to find something wrong with you," and there I was going to hospital to be pumped out. [P295 man (63) with lung cancer at the palliative only phase]

Speedy referral and diagnosis

A speedy referral to specialist services from the GP or within the hospital setting was noted by many [n=20]. For most it was a comfort, but for a few it felt too quick.

Patient: I went down to see Dr [GP] and he said he didn't like the feel of it. And he actually rang then to get me an appointment with Mr [surgeon] and I think I probably saw him within the week. It was very, very quick. [K133 woman (60) with a recurrence of breast cancer]

Patient: It was so quick that they diagnosed it that I didn't have time to think about it really.

Carer: I thought a little bit about it and I consoled myself with the fact that everything was happening so quickly and that and a good job the mistake was made for it to be found when it was. Otherwise it could have - [P46 man (72) with recently diagnosed colorectal cancer. Carer: wife (71)]

Patient: So I went to see [the consultant] and he had the x-ray results but he wasn't really sure. So he took me to see Mr [surgeon], that was all in the same ten minutes. He jumped the queue actually because there were other people waiting to see Mr [surgeon]. [He] had a look at the lump and asked me if I could go back at one o'clock the same day and have a biopsy. Which was excellent. [K234 woman (54) with recently diagnosed lung cancer]

Patient: My Macmillan Nurse, when she came out with us she said, "Do you think we're going too quick for you?" And I just said, "Well no, not really. If it's serious the quicker, the better." I felt a bit numb all through it really, you think it's a dreaded word, cancer for everybody. I think the waiting was the worst, waiting to find out the things. [P87 woman (64) at the end of first treatment for breast cancer]

Patient: [Talking about wife's cancer] The surgeon came across and spoke to us the same day. ... That hit me more than anything. It was very, very traumatic to be told all this in one day. [P295 man (63) with lung cancer at the palliative only phase]

Time taken over the process of diagnosis and starting treatment [n= 28] was generally presented as lost and potentially threatening. It was evaluated with different degrees of anger

Carer: We knew there were only two things it could be: TB or cancer. ... But it was June before we found out for sure, and then it was July before he had the treatment. When we first went, I'm not blaming the doctor, but he said, "Oh, maybe it's some inflammation, we'll put him on antibiotics for ten days." So that was another three weeks wasted while he had the antibiotics, and of course he was no better after the antibiotics. [P71 wife (67) of man (83) with lung cancer at the palliative only phase]

Patient: So I had antibiotics, painkillers, and it didn't get any better after about five days, so I went back and saw another GP and she said that that was a swollen lymph gland and that I seemed to have a disc problem in the back of my neck, which was causing pain in the face. So to carry on taking antibiotics till the course finished and then if I didn't improve to

go back again. Which I did. I saw my own GP eventually and he didn't like the lump. He didn't like the other two diagnoses, so he sent me, the following morning, for an x-ray, and he said the x-ray result would take about a week. But he phoned me the same night. The radiographer had phoned him, and they said that I seemed to have some kind of swelling in the chest. They thought it was lymph glands, ... [I saw several consultants and had several tests]. [The oncologist] said "I can't promise a cure but it is very treatable," on the Thursday, and on Tuesday I was having my first chemo. But I had quite a long waiting period in between being diagnosed as having cancer and finding out what type and if it was treatable. [K234 woman (54) with recently diagnosed lung cancer]

Patient: I don't know whether it was funny at the time or whether I saw the funny side of it afterwards, [the consultant] just hadn't got a clue, he just didn't know what to do, he tried all these different treatments which were just not working at all. He came one day, brought with him all the heavy team, his right hand man, and his right hand woman [laugh], stood at the end of the bed and said "I'm going to have to mention this, we're going to have to do an AIDS test." [L224 man (50) with recently diagnosed lymphoma]

Carer: They did have the tests. ... How they missed it, I don't know. ... For six weeks I was so stressed out and so worked up, I thought, "I've had enough of this." So I rang the surgery and said, "Please can a doctor come and visit him," and then he came with all his notes told him that he should go to the hospital. [P295 wife (51) of man (63) with lung cancer at the palliative only phase]

Being given a clear diagnosis sensitively

The way the diagnosis was given was often recounted. The manner of communicating this news came in different forms, some better than others. 'Bluntness' was appreciated by some as clear information, but criticised by others as leaving them 'stunned', especially where the diagnosis was unexpected or had taken a long time to process

Patient: Just that blunt statement from the specialist. Mind you, possibly it was better that way, I don't know. [L139 man (81) with colorectal cancer at the palliative only phase]

Patient: [My GP] said, "Sit down." I said, "Why?" He said, "You've cancer of lung. You might as well know straight out." I said, "If I have I have and that's all there is to it." So, we had a talk. [K327 woman (68) with lung cancer at the palliative only phase]

Patient: I was totally on my own. [The consultant told me] then walked out of the room and I was there for 20 minutes on my own in the room and completely stunned and dry mouthed ... [Then] the nurse came in and said, "Oh, you can go now, [the surgeon]'s secretary will be in touch with you in about seven days. If they're not, give them a ring and hurry them up. And if you see a bit of bleeding at all, don't worry about it it's quite normal." And off she went. And so I was left to get dressed and come out and get the public transport and come home on my own. [P254 man (54) with recently diagnosed colorectal cancer]

Carer: In the middle of the ward, he just came out with all this, "It's cancer." I thought that was bad, he should have said, "Can you come into the room?" or something, I didn't think that was very nice in front of everyone. [L98 wife (50) of man (53) with colorectal cancer at the end of first treatment]

For a woman who was 'prepared' for bad news it was not the diagnosis that distressed her so much as an immediate delivery of her poor prognosis, and the manner of its delivery:

Patient: When I went back I thought I was prepared for bad news, and I was to a certain

extent. He told me that the lump had proved to be malignant obviously. ... But the thing that really knocked me for six - not only did he tell me that I had cancer -[cries] I'm sorry this upsets me every time I think about it - He also said it was incurable. Which I wasn't too happy about it, as you can imagine. I think it might have been kinder had he just told me I had cancer, I was prepared for it. I knew it wasn't going to be good news, I'm not stupid. But I just wish he hadn't said that, because I found that was the one thing in my mind all the time. He was very kind in his own way I suppose, and he perhaps thinks he's doing the right thing, but I don't think that you need to know that straight away. I think, just to be told that you've got cancer is earth shattering anyway, ... but it was the incurable bit, that was the thing that really got me. [L227 woman (55) with recently diagnosed lung cancer]

Likewise for a carer who had just heard the diagnosis:

Carer: [The surgeon] said, "My gut feeling is that, we shouldn't go ahead with [further investigations] at all." I said, "Fine. As it's inoperative what time scale are we looking at?", and he said, "Four months." Just like that. And well, you were just gob smacked, didn't know what to say. [P250 husband (63) of woman (65) with lung cancer at the palliative only phase]

While the shock of being told in straightforward terms was distressing for some, all who reported lack of clarity in information giving found this difficult:

Carer: The doctor was a bit - he wasn't too keen on telling us I think. ... He seemed to skirt round it and finally he said 'I'm sorry Mr. [C.] I can't do anything for you it's not worth taking [her] lung out because spreading to [her] oesophagus and that was more or less it at [hospital x]. They said you could go home that night.

Patient: They let me go on that night, so we felt a bit isolated. [K473 woman (41) with recently diagnosed lung cancer. Carer: husband (57)]

Patient: Well he told me I'd got to have a test, he didn't really say it was cancer.

Researcher: Right, but did you assume that or?

Patient: More or less, having your breast off, there's only one reason for it, really? But it was really a shock. I ended up on tranquillisers. ... Went to pieces, for want of a better word. [P2 woman (49) with breast cancer at the end of first treatment]

Carer: I ended up feeling more sorry for him [the junior doctor] than I did for ourselves. Because he really beat about the bush ... He went round and round the maple so many times, I was getting to the point when I wanted to say, "Well come on spit it out, we were already suspecting that." [K198 lung 1 male age 61 separate interviews [carer -wife age 58]

Patient: Everyone was careful not to mention [cancer], and then suddenly, one of the nurses let it out, this word, and suddenly - goodness me, is that what it is? So I think that was partly it, and I was on my own, and away from everybody, that was when I broke down more than anything else. It was my own fears as well. I mean, my mother died of cancer you see, and my grandfather. [L150 lymphoma 3 male age 49 joint (carer - sister, age47)]

This also extended to the desire to be clear about what would happen next. As Preston et al (1999) suggest, patients and carers sometimes enter a state of 'limbo' as they pass from one stage of care to another. Not knowing what is going to happen next is very uncomfortable, and patients may experience the situation as disempowering. There were many instances in our data that suggested this situation arose and was experienced as unpleasant. However, it was common for patients, and particularly carers, to act to move the situation on, usually through phone call enquiries.

Carer: We said, "Well what do we do now?" because we had no further appointments with

anybody. The lady doctor that we saw sent us round to see the secretary and she then made us an appointment. ... But up to us going I'm not sure what would have happened because we hadn't got any appointments at all. ... We felt that, and that's why she sent us - we were in limbo. [P53 wife (64) of man (72) with lung cancer at the palliative only phase]

Carer: Now this is the bit where we get a bit lost really because he told us and then there was just nothing for what seemed to us -

Patient: An eternity.

Carer: An eternity. It was quite a long time. I wrote it somewhere. [K238 man (72) with a recurrence of colorectal cancer. Carer: wife (69)]

Several reported that health personnel waited until the main carer was there to impart the 'bad news'. This was generally appreciated, and considered insensitive when it did not happen

Carer: "Could you come up on Friday for about 10 o'clock when he does his rounds?" ... I got up there and I was actually on the ward for 10 o'clock. And when I got to my wife she was in tears. And I said, "what's the matter?" She said, "I've got cancer" and they'd been and told her. ... It's a bit callous I think. [P250 husband (63) of woman (65) with lung cancer at the palliative only phase]

Examples of good 'bad news' practice not only included making sure the carer was present, but also allowing time for it to sink in, usually with the support of other staff such as nurses in attendance:

Patient: I think that initial, when you're actually told is very important. You need - we weren't rushed out of the consulting room. The nurse, she left us, and I think, even though you think you know, you just need that time to let it sink in. [L99 woman (46) at the end of first treatment for breast cancer]

The kindness and sensitivity of all staff was important to patients and carers at diagnosis and throughout in the cancer journey. One woman contrasted different approaches as she described one doctor just coming out with it on a busy ward at visiting time, while another took her into a small office and spoke with her more gently, giving information and time to ask questions:

Carer: They could explain it to you a bit kinder straight away and then you wouldn't be so upset. ... But she [doctor x] more or less gave me hope then. The other doctor who just told me straight off, I went away thinking he'll never come out, I thought that was it. [L98 wife (50) of man (53) with colorectal cancer at the end of first treatment]

Treatment options

Following on from diagnosis further information was also required by patients and carers about treatment options and plans. This was quite often presented as a reassuring process, when they learnt about the nature of their own cancer and the potential for recovery represented by the treatment plan:

Carer: When he said it was cancer what they could do, the course that he reckons, a lot of the apprehension disappeared. ... All I can say is that staff and everybody was fantastic. And you won't get any better treatment whatsoever. You know, efficient. They said what they were going to do and they did what they said they were going to do. [L99 woman (46) at the end of first treatment for breast cancer]

Carer: Because Mr [surgeon] handled it so well and explained every last detail, what might happen, if this happens, like say there's an infection, we'll give antibiotics, if you lose blood, we give you blood, he explained it all, even the possible things that could happen,

how they would deal with them. So that helped because you think what could go wrong. So all of that had been covered, so that's a weight off your mind as well. [P254 partner (20) of man (54) with recently diagnosed colorectal cancer]

Managing the diagnosis

Having been told the diagnosis and the treatment plans patients and carers then reacted in various ways. Initial shock was commonly described, but usually as giving way to a desire to 'get on with it' (see also Morris 1999). Preston et al (1999: 16), in a study of a general population of patients, suggest that the 'concept of progress is central to patients' views of care', and was associated with feelings of confidence and being in control. In our study acceptance was presented as helping progress; after the uncertainties of the diagnostic period things could then get moving and life could go on. However, acceptance was usually described as part of there being no option other than to learn to live with it.

Patient: I was very upset then, you don't want to die and all the rest of it. But after a week I thought well, come on, you must get on with it, there's thousands more, and at least there's something they can do. [L99 woman (46) at the end of first treatment for breast cancer]

Patient: I just accepted what they said and took it from there really. When that hits you, your life changes in an instant, doesn't it? I'm not a worrier, but I think some people perhaps worry more and play up easier. I'm more considered. I don't panic quite that much. I tend to accept. I mean, they say something like that, there is nothing you can do about it, you have got to accept, that's what it is. [L98 man (53) with colorectal cancer at the end of first treatment]

A few patients described difficulty in 'accepting', usually accompanied by some distancing of self from the knowledge.

Patient: I suppose the cancer, it's taken over, you can't control your own body. But I feel more, I suppose, in the last year I felt more back to me. Somehow for the first year or so I didn't relate, I wasn't me, it's very hard to understand. But you couldn't be in charge of being yourself, but I suppose at some point you realise you've got to get on with it. [P227 woman (49) with breast cancer at the palliative only phase]

What appeared as contradictions occurred in some interviews, as with this woman who when talking about her initial diagnosis said that it had never really 'sunk in', and that she kept it at a distance:

Patient: I still don't believe I've got it, even after all this time, it still hasn't really sunk in. If I did let it sink it, I think I'd just break down, so I just keep it to one side. [P164 woman (55) with breast cancer at the palliative only phase]

Later, however, she referred to having to 'buckle down' and 'do it', if not for herself, then for her family:

Patient: I think it was a relief when it was diagnosed, because you think oh it wasn't me just being daft and thinking I'd found something and I hadn't. Then at least you know what you are facing. Once you know that you've just got to buckle down and think, "Right, I've got to do it." If you don't do it for yourself you've got to do it for your children, for your husband, you've got to do your best and be positive. [P164 woman (55) with breast cancer at the palliative only phase]

This kind of evidence suggests that 'accepting' the diagnosis was not a straightforward step, but involved social context and having to maintain a relationship both with the cancer and with other

people. Accepting was more than a pragmatic response, but a way of reaffirming one's life world, which was often held in 'limbo', while the diagnosis and initial treatment were happening:

Patient: I've come to terms with it now, I just accept it now. I think it's like anything in life, you cannot sustain a high level of emotion, whatever the news is ... After the initial shock and the protective thing that everybody gets when they receive very bad news, which you go into a little twilight zone for a while, before the reality of it hits you. ... I think until I knew more about it, the possibility of death was very real. But I think I have overcome that now in that it doesn't bother me, I'm planning ahead, I've already booked two holidays for next year. ... I haven't been able to go this year, because of the treatment. There is a big degree of uncertainty there, I know that, and I think that I've a good chance of going into remission. [LI25 man (64) with recently diagnosed lung cancer]

Moment Two - end of first treatment

In the statistical analysis of the survey PNI data, there were two need items that were significantly lower for this moment than the others – 'Information about treatment plans' and 'Information about what to expect'. Many patients, having been immersed in diagnostic and treatment activity for some considerable time, 'know the ropes'.

The end of 'first treatment' was a very moveable feast, with different treatment trajectories both between and within tumour types. Some only had surgery, albeit major in the case of colorectal patients. Some just had chemotherapy (lymphoma patients), some just had radiotherapy (lung patients), but the majority of the sample had more than one treatment. Breast cancer patients almost always had surgery, and this was almost always followed by chemotherapy and/or radiotherapy. Colorectal patients usually had surgery and sometimes this was followed by chemotherapy. A few lung cancer patients had chemotherapy. The individual nature of the tumour, staging and clinical practice determined the treatment given. Some patients were involved in clinical trials (particularly lung cancer patients). Treatment tended to last for months at a time, especially when chemotherapy was involved. Among the survey sample 30% had recently had surgery, 13% had recently had chemotherapy, 11% had recently had radiotherapy and 22% had recently had more than one treatment.

It should be noted that moment two was the most difficult time to obtain data for in the project. This was because the other moments were more clearly marked clinically. We received referrals from consultant clinics, and it seemed that the moments around diagnosis, recurrence and withdrawal of active treatment were more clearly defined in the clinic setting. End of first treatment did not mean discharge, but continuation into review clinics, which meant that some people who were referred as moment 2 had completed their treatment quite some time previously. In addition, patients were often passed on to different consultants in the course of treatment (usually from surgeons to oncologists), and frequently these consultants were located in different hospitals. This meant that some patients were referred at the end of first treatment by surgeons, when they were continuing their treatment with oncologists. Thus we should treat moment two referrals with some caution.

However, with the interview sample we were able to obtain more detailed descriptions of the exact point in the cancer journey at time of interview, plus a history of their treatment trajectory. Nine patients and six carers were interviewed at the end of first treatment moment.

Being treated

The experience of treatment was described by nearly all the patient interviewees in some detail. In addition people sometimes described what they expected the treatment to be like, reporting what they had been told by health professionals and others. Surgery and the hospital stay, recovery time, radiotherapy or chemotherapy and travelling to the specialist unit were all mentioned. Generally

the treatment period was described as 'not as bad' as they'd thought it would be, although a few [n=8] had bad experiences with reactions to chemotherapy, or slow healing after operations. A few noted that it was the treatment which made them feel ill for the first time:

Patient: I was just about right up until everybody started curing me – I was playing badminton and everything – I was really well. So all the curers made me ill. I was all right before they started trying to fix me [laughs]. [K153 woman (69) with breast cancer at end of first treatment]

The length of time taken up by treatment, usually chemotherapy or recovery from an operation, disturbed a few people.

Patient: Well I think this going for the chemo is worse for me. It's because it just seems such a long time from the 21st of December to the 2nd of August. [B33 man (49) with colorectal cancer at the end of first treatment separate from mother (76)]

Ending treatment

The immediate time around the end of first treatment could be difficult. Having been swept up into the activity of treatment, often for months, its completion meant further adjustment. However, with the further passage of time and attendance at review clinics, patients who were successfully treated generally tried to put the experience 'behind' them. Being 'monitored' was viewed favourably as a way of being reassured. Indeed some patients entered clinical trials in order to be assured of extra attention.

Patient: I didn't want to go for my last chemo. I think it's because while you're going to chemo, you feel like you're doing something. You're trying to find the advantage in something, and I didn't want to go for the last one. [L99 woman (46) at the end of first treatment for breast cancer]

Patient: Well [my friend said] all this time that she's going to the hospital and getting these treatments that you're a very important person. It's a bit like when you have a baby and up until the moment you have the baby you're terribly important, and as soon as the baby's born nobody cares about you anymore, they're just interested in the baby. ... Because of the nature of cancer you feel as though if they say that's it, we don't want to see you anymore, you're losing that safety net. You want them to keep monitoring you to make sure it's not growing somewhere else. ... I wonder if that's part of the reason why you sign on for these trials because then you're monitored more closely and for longer and I think there's an element of you wanting to be looked after in that. [L490 woman (43) with recently diagnosed breast cancer]

Patient: At first you were dashing about, and you were seeing everybody, and then I think the scariest part was when I didn't see anybody, when I finished, my radiotherapy and he said "Right, we'll see you in six weeks." Six weeks and there's nobody, [laugh] there's nobody looking at me, or checking me. [P227 woman (49) with breast cancer at the palliative only phase]

Treatment was sometimes presented as a marker of the seriousness of the cancer:

Carer: There's been no talk of him having any more treatment so that's a [good] indication in itself. [P46 wife (71) of man (72) recently diagnosed with colorectal cancer]

However, lack of treatment or less being done than had been suggested was very worrying to some patients and carers, who speculated on the reasons for the change of plan:

Patient: [The oncologist] was going to do 13 blasts of radiotherapy and when we finally got to see him he said, "I'm only going to give you two - one on your lung and one on your back." ... Because it had spread to my back. ... I know they know best, but you think, "Well, it's gone from thirteen to two, was it not worth wasting their time?" And nothing is explained to you properly, you come away with a lot of questions. [K473 woman (41) with recently diagnosed lung cancer]

Carer: When we went to [the oncologist] he said, "What have you been told?" So [my husband] said to him, "It's a small cell cancer." So he looked and he said, "It's not small." So [my husband] said, "We were told small cell and it would be treated with chemo." So he just said, "Well, I won't be giving chemo." So that's [something I want to ask him] when I see him, "Why did you say you wouldn't give it? Was it a waste of time and money? Is it because he smoked?" [K198 man (61) with recently diagnosed lung cancer]

Being monitored

Being monitored after completion of treatment was presented as reassuring, but worries still occurred from time to time:

Patient: [Talking about his wife's cancer] She's all right now, but every so often, she has to go back for a scan. So then it's - What are they going to find? ... I mean it's all mumbo-jumbo, this sort of cancer and that sort of cancer. Why does the secondary bit come back? They said we've got to keep an eye on you for so long. And the longer from the operation, we stretch the meetings. So that's the panic button. Is everything going to be OK? [L124 man (55) with recently diagnosed lymphoma]

Worries about the cancer spreading were often mentioned, sometimes accompanied by expressions of needing to know more about the disease and services

Patient: I did say I don't want a fuss making, but I've had 3 weeks toothache, I had a bad back, it was as if I was weak, I was catching everything. And nobody - I went to the dentist, and of course the tooth wanted filling. ... But nobody said to me, and there was nobody to ring up and say over the phone - The cancer, is it gone, could it be spreading? And there's nobody you can talk to. [L185 woman (66) with recently diagnosed breast cancer]

Moment Three - first recurrence

In the statistical analyses three items were statistically significant for this moment, all showing raised need: 'Help in maintaining a sense of control in my life', 'Help in dealing with the unpredictability of the future', 'Support from a spiritual advisor'. Although at this point patients and carers know something of the services there are renewed worries about managing the illness and the implications of recurrence.

All 14 patients and carers who were at the recurrence 'moment' commented on the experience. In addition several interviewees from earlier 'moments' mentioned fear of recurrence, and some palliative respondents recounted something of the recurrence time. As with diagnosis, patients and carers wanted a prompt response to any suspected recurrence. Some noted that a good quality of life involved not worrying about recurrence, but getting on with your life. Others had worries or questions that needed reassurance. A few [n= 3] suggested that they 'knew' the cancer was still there and would come back one day. Being monitored was both reassuring and anxiety-provoking. A few [n=5] noted that they were getting (and needed) more help this time than in the cancer's first occurrence. Recurrence was different from diagnosis because patients and carers had already been 'initiated' into the cancer experience and knew something of the systems they would go through. It was, however, still a difficult moment and the implications for survival were different.

Prompt diagnosis and treatment for recurrence

Speedy action on the part of the services was again appreciated, and any delay added to worries.

Patient: With the secondary recurrence, I was whipped into [oncology unit], diagnosed, I had a scan very quickly, put on chemotherapy very quickly, and I've been seen by Dr [oncologist], and at the moment it's all going fine. [K102 woman (50) with a recurrence of breast cancer]

Carer: The doctor said, "We're not nursing you back this time, Mr M." Now this is the bit where we get a bit lost really because he told us he [referred us], and then there was just nothing for what seemed to us an age ... Once we got into the system again

Patient: It was all right. [K238 man (72) with a recurrence of colorectal 3 cancer. Carer: wife (69)]

Carer: But in my mind, as a lay-person without any knowledge of this, it seemed that there was far too long between when they suspected there was a problem at the time she went for her regular check-up to the time that everything happened. And it was at the beginning of it that I felt aggrieved, and I did feel aggrieved, and so did she, that it took about a month to get the x-rays. I thought they could have done it, perhaps a week after. We were told they were too busy, and I didn't think that was appropriate, I thought that was wrong in fact. [K245 husband (53) of woman (55) with recurrence of breast cancer]

A few described situations in which they had to be persistent in presenting their symptoms before the recurrence was confirmed:

Patient: Well the second time, I felt justified, "Well, I said it was there all along and it bloody is" [laugh]. ... But there again I wasn't feeling bitter about anybody because they hadn't done anything sooner, because it hadn't killed me and it hadn't gone anywhere else. So it just sat there and festered didn't it? It could have all happened a lot sooner, I suppose, which wouldn't have made any difference, it still would have happened. So the fact that I had those few years when I was feeling well, was perhaps a bonus. [K153 woman (69) with breast cancer at end of first treatment]

Being warned that it might recur

Many reported having the knowledge that the cancer might recur, usually accompanied by a reference to medical sources, although a few 'just knew' in themselves that it would come back.

Patient: [The surgeon] did warn me the possibility it could recur again. I don't suppose they can search out every little cancer cell can they? [B29 man (71) with colorectal cancer at the end of first treatment]

Carer: So for about ten years she was fine. She never missed a check-up and she was fine. She was aware that it would come back. She was certain that it would. But you put out it of your mind, don't you? [K245 husband (53) of woman (55) with recurrence of breast cancer]

Getting on with life

However, a good 'quality of life' was constituted as not letting the cancer dominate at any stage, either pre-recurrence or after it was confirmed.

Patient: But I want quality of what life I've got left. I don't care if I die young, I'd rather die young than live old and feel old, I'd rather feel - I have a man in my life at the moment. [K153 woman (69) with breast cancer at end of first treatment]

Patient: I've no time for anybody who's going to sit round and say, "Oh dear, I've got cancer, I'm not going to get better." They've told me they can't cure me, but who cares? Whatever life I've got left I'll enjoy it. I've had a hell of a life to be honest. [L280 woman (61) with a recurrence of breast cancer]

Patient: I could have just curled up and died in June, you know, but I didn't want to, I've got too much to do, well I've got [my son], I can't leave him. I've got my aromatherapy and it sounds silly [laugh] to say I've got too much to do. [K102 woman (50) with a recurrence of breast cancer]

Time between first treatment and recurrence was sometimes presented as valuable for various opportunities it gave, to enjoy life, to make changes, or to have time to come to terms with the cancer:

Patient: But I have six years, so I was able to do something in. And I changed my lifestyle, went and did something I wanted to do, and did it. [K102 woman (50) with a recurrence of breast cancer]

Carer: I think that after about 10 or 11 years I have really sort of absorbed the implications of all this gradually. [K245 husband (53) of woman (55) with recurrence of breast cancer]

Even a momentary break between appointments could be seen as an opportunity:

Carer: At one time, all we had, we had about 10 days of break, we'd no appointments, no hospital appointments or anything.

Patient: We came home and -

Carer: I said, "Right, come on we're going to get a week's holiday in".

Patient: We went to Malta. [L348 woman (63) with a recurrence of colorectal cancer.

Carer: husband (64)]

Being reassured

Some people were reassured by tests that did not show widespread of the cancer:

Carer: They have said that there was no sign of it anywhere else. So that's the big plus for us. [K238 man (72) with a recurrence of colorectal 3 cancer. Carer: wife (69)]

However, others with unexplained symptoms could be quite worried, even when tests were negative:

Patient: [I had a lot of pain] and I thought it might be linked. But the doctors here assure me it's not linked to the lymphoma at least, and I've had a bone marrow biopsy and that was clear, so goodness knows what it is.

Researcher: So you feel pretty reassured that it is OK?

Patient: Well no because it is still fairly serious pain.

Researcher: And you don't know what it is?

Patient: If it's not arthritis and not rheumatism, what else is there? There must be something fairly serious. [L150 man (49) with recurrence of lymphoma]

Where in the body a recurrence might be found was not well known by patients and carers:

Carer: Now [the oncologist] wasn't talking to us, he was talking to the student and he said, "This person has had cancer of the lower bowel where would you look for secondary?" And she didn't know. And of course we were all ears and he said "Well, it's lymph in the

groin.” ... Now we hadn't heard this at all, we didn't know anything about this. [K238 wife (69) of man (72) with a recurrence of colorectal 3 cancer]

Patient: I couldn't understand why he gave me a chest x-ray, but the doctor's just said today, because I asked him, it would be checking if my lungs were all right. He said they would do that to clear that you hadn't got any cancer in your lung. Now I didn't think of that of course. I couldn't understand why I had a bad back and he gave me a chest x-ray. [K133 woman (60) with recurrence of breast cancer]

Being monitored

Patients and carers mentioned moments of relative calm, when they were well and just going for regular review, which was usually followed by something happening, such as a symptom, which led into a recurrence being diagnosed:

Patient: [The routine scans] were all clear last year. ... And then in February this year I had a fall, I slipped on some ice outside ... They had a [closer] look at [the scan], they picked something up on my pelvic bone that didn't look right. [L472 woman (38) with recurrence of breast cancer]

Patient: [I had check-ups for 5 years] This year I was getting dreadfully out of breath, I really mean out of breath, I couldn't walk across this room without gasping, really gasping. So I went to see my own doctor. [L280 woman (61) with recurrence of breast cancer]

Concerns about monitoring other members of the family, because of genetic risk, were expressed by two patients.

Patient: It concerns me with my girls, because obviously they're be at risk now. But like [the breast nurse] said they will be put on a register and they'll be screened early. [L472 woman (38) with recurrence of breast cancer]

The implications

Recurrence was often presented as something which had to be 'got on with', as with the initial diagnosis, but the implications of deterioration were understood, despite a positive light being put on the situation:

Patient: There was another lady had cancer, she had the operation just after me, she got secondaries in her liver and she didn't last very long. Because then when you're told you've got it, abnormal cells, and breast cancer again you know, you sort of think to yourself well I wonder? ... It's difficult but you've got to look on the bright side of things. I mean if you let yourself get down, you're only making yourself miserable, which makes everybody round you miserable, and nobody has a life at all. You've got to keep yourself cheerful and keep yourself going. [L280 woman (61) with a recurrence of breast cancer]

Patient: I've had no choice but to get on with things, you know, for the sake of the children. I mean if I'm upset, they will be upset, won't they? [L472 woman (38) with recurrence of breast cancer]

However, recurrence was different to diagnosis in that it often brought poorer health and physical limitations [n=5]. In this situation patients often required more practical assistance. Adjusting to all this was presented as difficult, both practically and in terms of getting out and about. Where there was a carer who was not working the problems were presented as less, but those on their own had to rely more on outside help.

Patient: I can't go out and put my rucksack on and walk anymore. I can walk a certain

distance and obviously when it gets better, I'll be able to walk a little further, but I'm never going to be able to go up the Fells and all sorts, I'm never going to be able to do that again. And I think the biggest problem I have is the readjustment to that. ... I go into town with my mum, and we go in a taxi and we plan our route round and then come home, we don't spend a lot of time there, ... you are out for an hour, you are back in the land of the living, with people. I got all excited for going to hospital yesterday just to see [the oncologist] [laugh] . I said to [the nurse specialist], "This is ridiculous. I was getting myself all excited to come to hospital this morning." Because it was the fact that I'd got somewhere to go. [K102 woman (50) with a recurrence of breast cancer]

Patient: I'm finding it hard, I want to be up and go really. I'll sit a while and I'll think, I'll just go and do so and so, maybe it's just a little job like watering the plants or something. I don't like to sit too long but I'm finding I'm having to really. [K133 woman (60) with a recurrence of breast cancer]

Various sources of help in dealing with the increased living problems of recurrence were mentioned, such as neighbours, support organisations, social services, and work colleagues. In practical and emotional matters the mainstay was always constituted as close family, or failing that, a friend. Help with worries and symptoms was sought from health personnel, and they were constituted as helpful, but within a delimited area, and not in the day to day management of life with limiting physical problems.

Patient: We have this lady next door, she lost her husband shortly before Christmas with cancer and while he was practically dying, nearly every other day [she] would go up to see how I was. And then since then she's been round a few times, she's brought chocolates and all sorts of different things, hasn't she? God love her. And she rings up nearly every other day, or she comes round to see how we are. And T. and J. in the back, they rang up to see, did we need anything, did we need any help, and she said if you want any ironing, any baking or anything, just let me know. I mean, they've all got their own problems, but they've all been there. And P. next door, she bobs in and out. Because she said to [my husband], when we were going into [town], "If you take her and you want to come home, I'll pick her up." So you've always got loads of help like that. [L348 woman (63) with a recurrence of colorectal cancer]

Researcher: What's the kind of thing that you've most needed help with? That if it hadn't been there, things would have been really difficult?

Patient: Oh the house definitely, the house and the children, and shopping and things like that. When you're in the house most of the time anyway and you have to sit looking at what needs doing, it's very frustrating. [L472 woman (38) with recurrence of breast cancer]

Patient: At work it helped me to talk about it. If I have an off day, I'll just go and sit in the staff room and the girls will come in, "Are you all right?" "Yes, I'm fine just leave me". Where if I hadn't talked about it about the problem they would've thought, what's the matter with her? I think it's helped me and helped the family to keep them involved. I think it's helped me, I talk about it, if there's anything I'm not happy with I'll say it, to me it's no good bottling it all up. [K133 woman (60) with a recurrence of breast cancer]

The more severe the illness, the greater the need for outside help. Those that were relatively symptom free presented themselves as remaining self and family reliant.

Carer: It's just nice to know that somebody is interested and has offered help, you know, they have offered help, but we haven't actually needed it so far, so far we're OK. [K238 wife (69) of man (72) with a recurrence of colorectal 3 cancer]

Patient: I'm independent. I work hard at getting well.

Researcher: You look very well.

Patient: Thank you. Yes, everybody tells me that. The only trouble is I get no sympathy (laugh). Well, not that I want any. But I do work hard at it. There's only one I have to get back to now. And that's my playing golf. Now, I'm going to try next week to swing me club. If I can swing me club I am back to normal. Yes, if you're prepared to work at it and not let yourself become an invalid I think you can carry on like as normal. [P61 woman (65) with recurrence of breast cancer]

Moment Four - move into palliation only

Of the four 'critical moments' this moment produced the greatest number of statistically significant differences in the PNI analysis (see Chapter 5). Five PNI items were rated as more important by palliative care only patients than by those at other critical moments: 'Information about treatment plans', 'Information about what to expect', 'Information about medication and side effects', 'Help in maintaining a sense of control in my life', 'Support from a spiritual advisor'.

Nine patients and seven carers were interviewed at the 'palliation only' phase, having been told that the cancer was now terminal. Four female and five male patients, and five female and two male carers were interviewed. Apart from one daughter (who lived nearby her mother) all carers were spouses living with the patient. The average age of patients was 65 (range: 49-83), and of carers was 55 (range: 30-67). Four patients and four carers were dealing with lung cancer, two patients and one carer with colorectal cancer and three patients and two carers with breast cancer. We did not manage to interview any lymphoma patients and carers at the palliative care only moment. In the survey, only six patients in this category were referred and three returned questionnaires (plus two carers). In discussion with clinicians involved in the care of lymphoma patients it was pointed out that pinpointing the moment at which it is concluded that no further active treatment can be given is difficult. A cycle of treating frequent recurrences at shorter and shorter intervals is the most common scenario for those who will eventually die of the illness.

The time when palliative care only becomes the option is often marked by referral to palliative services, including hospices and Macmillan nursing. Across the whole interview sample, hospice services were mentioned by 13 patient and seven carer respondents. The association of hospices with death was spoken of by four respondents. Although none had been hospice in-patients, three had experience of attending hospice day care. Two had previous experience of hospices through relatives. Three spoke about being offered hospice services, but not having taken them up, although being aware that they might need them at a future date. All patients and carers at Moment Four spoke about hospice services, including community Macmillan nurses. All had been provided with some help from this sector. This was not surprising considering almost all referrals to the project for moment 4 came from hospice-based palliative care consultants. Those who attended the hospice [n=3] felt that they got good information, time from the staff, and the chance to ask questions. Two also particularly mentioned the 'jolly' atmosphere at Day Care (such as joking and being offered alcohol), although seeing co-patients deteriorate was upsetting.

To have choice

Two carers mentioned a desire that their patient should not have to go into the hospice when they deteriorated, although they qualified this with the possibility that they would need extra help and indications of their uncertainty about how the disease would develop, and what might happen.

Carer: If B. [my wife] becomes bed ridden, and I had to, I don't know, take her to the toilet, wash her, or whatever. But if it does ever get to that stage I think the Macmillan nurse will be spot on and get us assistance as required because B. said she doesn't want to go into a hospice unless she has to, do you? You want to stay at home all the time, which I don't

mind at all as long as I've got the back up from the Macmillan nurses. [K473 Husband (57) of woman (41) with recently diagnosed lung cancer]

Carer: Now is somebody going to come and say to me “J.[my husband] has to go into a hospice?” Because if it is possible for him, J. will stop at home, he is going to stop at home. He won't be going anywhere. ... I don't think I will be the only one who will end up being a carer who would like somebody to say “Now look you must expect this.” Are the Macmillan nurses going to come and take me over? I know a man who is so absolutely delighted with the way they have been and I would think they are an absolute God-send when people are really desperately ill. But will they come to the house so I can keep him at home? Will they come and say, “He must go into hospital for a week. He must go for a hospice for a fortnight.” Will they say, “He's got about a week to live, so we want him in the hospice and not at home?” I would like answers to things like that. [K198 lung 1 male age 61 separate from wife age 58]

However, another carer specifically mentioned he wanted his wife in the hospice at the end. He had no relatives nearby and his wife already required a lot of care due to a stroke just before her cancer diagnosis

Carer: I can realise that things are not as difficult at this time as they will be later on probably. But for my own peace of mind I've said that I want them let me know that things are getting particularly bad because I don't want her to be in the home, I'd rather her be in the hospice, because I know she's getting 24 hour care. That they can administer the drugs, they are trained to spot the signs, and one fear is that I don't want to wake up one morning and find that she's gone, you know what I mean. [P250 husband (63) of woman (65) with lung cancer at the palliative only phase]

Two patients were reluctant about the hospice, for its connotations of death in one case, but for another who had experience of the hospice, it was seeing others deteriorate, and wondering about the progression of her own disease:

Patient: [The] nurse asked me if I wanted to go into the hospice, or what, I said, “I'll not have time to go into the hospice. You may put me into hospice, but the following day I'll not be here”. [K327 woman (68) with lung cancer at the palliative only phase]

Patient: [The consultant] more or less said there was nothing they could do, so he said, “You're seriously ill.” So I thought, well that's it, signed your death warrant there, gone. And then when they said they wanted me to go to the hospice, well that was another nail in your coffin if you start going there. Because everybody I know that went to the hospice, hadn't been very long and they dropped off [laugh]. ...[In the hospice day care] there was 14 of us, and then all of a sudden, last week there was about 8 of us. ... So you miss these people and you think to yourself, “Oh heck.” I find that more difficult to come to terms with that than anything else because you start watching people then, from week to week, some look a bit poorly, some don't. And you think to yourself, “Oh God, am I going to get like this? [L348 woman (63) with a recurrence of colorectal cancer]

It is perhaps notable that in two of these quotes going into the hospice was constituted as something which might be done to them, a choice out of their control, and both these respondents lived on council estates – an indicator of low socioeconomic status.

To get good information and help with symptoms

The hospice was presented as a good source of information by patients

Patient: I couldn't get any information at all as to how long it's going to be or what it's

going to be like. But the people who are helping in that respect are down in the hospice. They're very, very good. [L139 man (81) with colorectal cancer at the palliative only phase]

After only two attendances at hospice day care one patient described the help the physiotherapist had already given him with a problem with cramp, and went on to say how the sister had reassured him on pain relief:

Patient: And even when I woke up I still hadn't got cramp, so I stopped in bed until seven o'clock.

Researcher: That was a treat?

Patient: That was what the first time in three months. ... So it was an eye opener. I've been taking a painkiller every night since and when I told them at the hospice about it, and [the sister] said, "Well, as far as your painkillers are concerned, you can take as many as you want. That won't trouble us at all. As you get progressively on we will provide you with stronger tablets or medicine to combat it, so just take them when you feel that it is necessary." [P53 wife (64) of man (72) with lung cancer at the palliative only phase]

His carer felt that the hospice staff would have the time to provide her with information she wanted

Carer: I know nobody knows the time and the place but you just feel I would like to know just a bit more about that. ... And the difference is, that they have plenty of time, to sit and talk to you. ... [The GP said] that was something that we would find quite useful at the hospice, if you had any questions these people have time to answer you. [P53 wife (64) of man (72) with lung cancer at the palliative only phase]

A cheerful atmosphere

Two who had attended hospice day care in a particular location [Blackpool] remarked on the cheerful atmosphere, which they found quite surprising

Patient: I mean they are always laughing and doing silly things, and acting the fool. I mean one lady reads us all our horoscopes and she always adds a bit [laugh]. And then they have pancakes and the nurses throw it and it got stuck up the ceiling. ... And I was most surprised because this vicar came in and he was doing dive bombers and all sorts and singing to Colonel Bogey. [L348 woman (63) with a recurrence of colorectal cancer]

The expectation that the hospice environment would be a constant reminder of cancer was overthrown by experience of attending

Patient: I find that when you go to the hospice, it is a relief because you don't want to, nobody wants to be talking about cancers all the time. Want to have all the different conversations. [L348 woman (63) with a recurrence of colorectal cancer]

That palliative services in the form of hospices and Macmillan nursing were resonant with cultural expectations that 'cancer = death' was indicated by many comments made in the interviews by those who had not experienced them, e.g.

Patient: You say 'cancer' it's - you know how long is it before we book into the hospice? [L124 man (55) with recently diagnosed lymphoma]

Despite efforts on the part of palliative care services to transcend this limited image and emphasise more of a longer term and symptom management approach (Higginson 1993), it clearly still lingered.

Carers and palliative care

As some of the quotes in this section and in the carers chapter already suggest, carers of people with a terminal cancer often expressed a need for more information and were particularly anxious about what to expect in terms of the illness progression. They also talked about wanting to know how the services worked and what kind of help was available from whom and when.

Carer: I don't know, maybe they [the Macmillan nurses] just concentrate when the patient is deteriorating. Maybe they don't come when somebody is sort of still able to walk about. But nobody explains that bit. [P71 wife (67) of man (83) with lung cancer at the palliative only phase]

Carer: The Macmillan nurse - twice she's been. But the last time she came, she says, "Well, I will keep in touch, but if there's anything you want you must ask, don't do it alone, because there's a lot of help out there." But it doesn't say what it is. [P250 husband (63) of woman (65) with lung cancer at the palliative only phase]

Anderson & Hopwood (1997) surveyed the needs of a small sample of lung cancer carers and found that 75% wanted more information. They also found a lack of knowledge about what services were available. Their survey results led them to produce an informative booklet. In our interviews the picture was one of people often knowing about services, but not knowing how they worked. Once patients had regular help from services, such as Macmillan nursing, there was generally a feeling that they now had a central person who could deal with many of their problems, symptom relief, emotional help, bureaucratic matters (such as medical systems, social services, the DHSS). Yet, accepting help was often embedded in comments about being able to manage for themselves and not needing help at the moment. For some of those who were deteriorating the help was appreciated, but did provide another 'marker' of their worsening circumstances, and a possible threat to identity.

Patient: I didn't know till the Macmillan nurse [started coming], I was a bit stuck then as to ... who to ask. You think, well it's not really the doctor's thing and it's not really the GP's, but it's only when she came. I'd actually talked to somebody who said, "Oh, have you not got a Macmillan nurse? They're very good. They are lovely." But I think, well I don't need a Macmillan [laugh], I can do things myself, I think that's how I've been trained. When you realise you can't do everything yourself, now I'm glad that she does do things like that and I don't have to do it. [P227 woman (49) with breast cancer at the palliative only phase]

Patient: I know [the Macmillan nurse], I know her because my father died of lung cancer two years ago and [she] was his nurse, so I was nursing my dad and I saw quite a lot of her. In one way it was rather nice when I discovered that she was going to be my nurse, but in another way it was a bit upsetting as well, but, I mean, she is a super lady. But, thankfully at the moment I don't need her. [L227 woman (55) with recently diagnosed lung cancer]

Patient: [The Macmillan nurse] phoned me up to see how I was getting on, I said, "Oh not so bad you know, all right." "Well, you're not causing me much trouble anyway," I said, "Oh, I don't cause anybody any trouble, I'm all right." ... At least I know there's somebody I can talk to that I can tell things that I couldn't tell my husband. If I complain, he'll say, "Oh you're moaning again." He doesn't understand, that's the stroke coming out. [L280 woman (61) with a recurrence of breast cancer]

Patient: I do most of the talking. I suppose so that [the Macmillan Nurse] knows how I feel, but she answers any queries I've got over the chemotherapy or how I'm feeling - should I be feeling like this? She's just someone to talk to, but she's very good. ... When you're feeling quite poorly after chemotherapy it's quite nice to have her here, because it's just

someone to talk to and you feel as if you're not the only one, there are other people out there going through the same thing. [P74 woman (50) with recently diagnosed lymphoma]

Adjusting to a changed physical status

Having to adjust to the new circumstances after the awareness that the cancer cannot be cured, and to more limited physical functioning and possibly distressing symptoms was presented in some of the interviews. Practical, emotional, spiritual, social and identity needs were constituted in the respondents' talk.

Patient: It's one of those things that I don't ever remember getting help from other people, I've always done it myself, and that's annoyed me more than anything, that's really got to me, not being able to do the things. I've tried, but it just doesn't work, I get out of breath so quickly now. Some of the jobs I don't even try to start them now, because I know very well that I wouldn't get very far. [P53 wife (64) of man (72) with lung cancer at the palliative only phase]

Patient: I do a lot of singing, and I can't stand up for any length of time so it's all right in rehearsals and practices and things like that but you can't go and sing in a concert and be the only one that's not standing up. So that's made a big difference. [L139 man (81) with colorectal cancer at the palliative only phase]

Carer: The hardest thing for me is to see [my husband] suffer, because he's such an active man, he's got - [crying]... On days like this he'd be out in the garden and our garden obviously looks wonderful this time of the year and my son does it now. And I think it bothers him a lot that he should be out there doing things. To see him like this it's not nice. [P295 wife (51) of man (63) with palliative lung cancer]

Patient: Because I can't work to the same extent. We have a lot of people coming on the phone and asking for one night [at our bed and breakfast business]. We won't take one nights now because we would have to get somebody in and we've got to pay them more than taking the person in one night. Before it didn't matter because I was there, I could get the beds done, and the bedrooms done and it didn't cost. [P308 woman with breast cancer at the palliative only phase]

Patient: I said to [my husband] "Why don't you join the gym?" because we were both going to join originally, but of course I haven't. And he goes there two or three times a week, which I think it's helpful for him to have some things to do himself when I'm not here [laugh]. Rather than just go to work and come home. [P227 woman (49) with breast cancer at the palliative only phase]

There were various factors and people who were presented as helping in this process. For example, spiritual support was presented as vital by those who had a strong faith. Many used the words 'what will be will be' in their discourse about their beliefs, suggesting that faith encouraged acceptance. Close involvement with a church or faith group gave not only spiritual, but also social and practical help. This couple described their Salvation Army friends coming to do the garden and re-decorate and went on to say:

Carer: I think our faith really has helped, hasn't it? Because with just being able to accept it and get on with it, and we both decided, well it is here and we've got it, but if you are going to be miserable about it, you are going to spoil what's left, and if you're going to be miserable about it, then people are going to stop asking, they are going to stop being concerned, aren't they, because they don't want to be with miserable people, do they? So we've just tried to say "Oh we're all right, you know, we're fine" and I think it pays off really. [P53 wife (64) of man (72) with lung cancer at the palliative only phase]

Fear of death was presented as ameliorated by faith, as this couple who were very involved with their local Anglican Church suggested

Patient: We are living in a shell, we are living in a borrowed shell.

Carer: All of us you mean.

Patient: It doesn't matter who you are, [indicating his body] that's got to go back.

Carer: We're all on limited time. [P295 man (63) with lung cancer at the palliative only phase. Carer: wife (51)]

However, active participation in a spiritual community was not necessary for some who had a strong belief. Talk about fear being resolved by faith was evident also for those who felt that their own internal faith was vital, yet presented themselves as not requiring external spiritual support

Patient: I'm a fatalist, what will be, will be, plus I've got great faith in God. ... The only thing I worry about is leaving my kids and [my husband]. That's the only thing, it's those that you leave behind. I'd be OK, I'd be out of pain and everything, I believe in heaven. ... I say my prayers at night. It takes me about two hours. [P164 woman (55) with breast cancer at the palliative only phase]

However, some felt that the church had not supported them in any way, despite their being religious

Patient: I've been rather surprised in the lack of [support from the church]. ... I have been active in church. I'm not a regular member, but with my singing I'm constantly seen at concerts at the various churches. ... I would have thought that the church people would have been aware of situations like this and sort of followed them up, but no, not a thing from any religious side of it. [L139 man (81) with colorectal cancer at the palliative only phase]

Practical help was forthcoming from friends, family, faith groups, and the health and social services. Help with retaining a social identity (feeling normal) was also important:

Patient: I've got one lovely friend who is great, she appears to the doorstep with a bunch of wild flowers sometimes. She came the other Friday, she said, "I've got the car, I've got a surprise afternoon off work, shall we go out?" So we sat in the car at Arnside and meditated and watched what was going on, so I had a complete day out. ... [friends who have children the same age] three of us go out once a week, and that's very supportive because it is taking me away from the house, getting me out, and catching up with the locals. Because it is a thing that has helped me, get to realise that there is still life outside the door, and catch up on the local gossip and what's going on at school, because they all go to the same school and things like that. It's nice, they've been very helpful, very supportive. [K102 woman (50) with a recurrence of breast cancer]

Patient: When the car was up and running I just got in the car and went [out] myself. And that is the biggest problem I have at the moment, I've become a prisoner and it's getting to me [so much] that I'm thinking, "Well, if I can't go out and do this and do some of the things I used to be able to. ... I might as well just sit here and let it happen." [L394 man (50) with recently diagnosed lung cancer]

Summary

In this chapter we have aimed to map the psychosocial needs associated with different critical moments in the cancer journey. While many of the challenges of cancer are pertinent to all four moments, such as 'keeping going', 'keeping positive' and 'maintaining relationships', each moment has its particular concerns and features. The time around diagnosis was described in the patient interviews in various ways, with an emphasis on it being a time of shock, or relief and confirmation. Being prepared for the 'bad news' consultation, whether through one's own suspicions or through hints from health care professionals, often figured as part of the patient or carer narrative surrounding diagnosis. The moment in which bad news was imparted was often vividly recalled and described. Any inattention or insensitivity from staff made things more difficult for patients and carers. Staff support and clear information, as well as clear plans of action carried out speedily, ameliorated the worst of the shock. The word cancer aroused fears, both through cultural connotations and through previous personal experience of other peoples' cancer. Patient and carer fears were often allayed through information and medical action, and by good prognosis and encouraging test results. Acceptance (because there was no alternative) was described by several patients, either as something almost instantaneous, or coming with time.

The time immediately around the end of first treatment could be difficult to manage. Having been swept up into the activity of treatment, often for months, its completion meant further adjustment, and sometimes a disconcerting sense of 'is that it?' However, with the further passage of time and attendance at review clinics, patients who were successfully treated generally tried to put the experience 'behind' them. Being 'monitored' was viewed favourably as a way of being reassured.

Recurrence differed from diagnosis in that patients and carers had already been 'initiated' into the cancer experience, and knew something of the health care systems. Prompt action was appreciated, and the value of monitoring confirmed. It was, however, a difficult moment and the implications for survival were variable. The task of 'getting on with life' tended to take on a different meaning, with renewed uncertainties.

The time when palliative care alone becomes the only option is often marked by patient referral to a new set of services, such as hospices and Macmillan nursing. Talk about the logistics of death, how, when and where, was more prevalent at this 'moment', particularly among carers. Patients more often discussed adjusting to physical changes and limitations, and the growing need to accept help from others, alongside the ways in which these changes affected social life and identity.

CHAPTER 9 Companions through cancer: the care given by informal carers in cancer contexts

Introduction

This chapter explores the care-giving experiences of the main informal carers of cancer patients, drawing on both the quantitative and qualitative datasets. Key findings are presented in two sections: i) the examination of the care work undertaken by informal carers; and ii), the exploration of the emotion work undertaken by informal carers. A concluding section considers the significance of our findings for cancer service provision.

The nature of informal care

It has long been recognised by medical sociologists and other health researchers that patients' illness experiences cannot be understood as individualised, socially isolated phenomena (Anderson & Bury 1988; Social Science & Medicine 1990; Bury 1991, 1997; Kelly & Field 1996). Spouses, partners, other family members and close friends actively participate in shaping the patient's illness experience, and *share in* this experience. The practical and emotional involvement of these socially significant others in patients' journeys through illness affects these companions' own lives, sometimes in profound ways (Anderson & Bury 1988). Particularly if they actively 'look after' people with chronic illnesses and long-standing impairments by undertaking practical *care work* tasks ('caring for') and/or by supporting them emotionally ('caring about'), they are now commonly referred to as 'carers' or 'care-givers' (Thomas 1993; Heaton 1999).

Social scientists and policy makers often use the term 'informal carer' to identify those people who undertake care work for kin or friends on an unpaid basis in the domestic domain (Thomas, 1993). Particularly in the 1980s and early 1990s in Britain, a significant body of literature was produced by feminist and other researchers on informal carers (Finch & Groves 1983; Green 1988; Arber & Gilbert 1989; Parker 1990; Ungerson 1990; Graham 1991; Twigg 1992; Twigg & Atkin 1994). Feminists drew attention to the extensive and gendered character of informal caring - it was seen as work undertaken mainly by women - and highlighted the negative consequences for women's social position of community care policies that shifted the burden of care from the welfare state onto women's shoulders (Finch & Groves 1983; Ungerson 1990; Thomas 1993; but see the critique by Morris 1995). This research, together with other developments, most notably the growth of campaigning groups of carers pressing for their contribution to be politically recognised and practically supported, led to carers becoming established as a prominent group on the health and social care policy agenda in the UK (Heaton 1999: 759). As a result the Carers (Recognition and Services) Act 1995 came onto the statute books (Department of Health 1995b), implemented in 1996, followed by the Carers and Disabled Children Act 2000 (Department of Health 2000b; see also Department of Health 1998). In 1998 the Office of National Statistics estimated the number of informal carers in Britain at 5.7 million (ONS 1998). What carers did, and the personal costs and needs involved in so doing, were widely socially acknowledged.

But does it make sense to talk of the spouses, partners, family members and close friends who 'look after' people with cancer as constituting informal carers? The enduring cultural image of cancer is of an acute and deadly disease that acts swiftly to end life. From this point of view the care role, at least in the *care work* sense, is one of short duration. However, the reality of cancer is otherwise. Whilst it is the case that cancer mortality rates remain obstinately high in industrial countries, cancers are now seen within medicine as a set of differentiated diseases with very variable rates of cure (WHO 1998). Lung cancer, for example, does fit the cultural stereotype - it has a very poor prognosis and is likely to lead to death not long after diagnosis (Coleman et al 1999). Hodgkin's disease, on the other hand, has a high survival rate: 72% at five years in 1986-90 in England and Wales (Coleman et al 1999). Breast cancer is somewhere in-between with a

survival rate averaging 66% at five years (1986-90, England and Wales) (Coleman et al 1999). The duration of periods in which symptoms are experienced, and of active treatment, is therefore variable for different types of tumour, and may last for some years. And there are increasing numbers of people in the population who no longer experience symptoms but are in remission rather than 'cured' of cancer, prompting Arthur Frank to speak of our 'remission society' (Frank 1995: 8). All of this means that, once diagnosed, cancer patients often carry their patienthood status for long periods of time. During what is referred to by many in the cancer services as the patient's 'cancer journey', there are likely to be times when levels of impairment are relatively severe so that informal care work is required, for example, whilst undergoing chemotherapy, surgery or palliative care. In addition to periods of informal care work, a cancer diagnosis also initiates a more continuous patient need for high levels of emotional support, for being 'cared about'. Precisely because cancer is culturally perceived to be a life threatening disease, people in close personal relationships with recently diagnosed patients have little choice but to engage in difficult emotion work (Hochschild 1979; James 1992; Bendelow & Williams 1998a) - both to help the person with cancer and to cope with their own distress. Thus it is certainly appropriate to use the term informal carer for people who undertake both care work and emotion work for their spouse, partner, family member, or close friend with cancer.

In the UK, alongside the growing policy awareness of the valuable role played by informal carers in the community in general, there has been increasing recognition in the cancer services of the importance of informal carers - both as supporters of cancer patients and as people who have cancer-related psychosocial needs of their own. This is well expressed in the Calman-Hine Report (Department of Health 1995a), the recommendations of which are currently re-shaping cancer treatment services nationally, and in the Department of Health's recently published *The NHS Cancer Plan* (Department of Health 2000a).

Patients, families and carers need access to support from the time that the cancer is first suspected through to death and into bereavement (Department of Health 2000a: 62)
Users and their carers should have choice, voice and control over what happens to them at each stage of their care (ibid: 66).

However, compared with a large literature on the psycho-social support needs of cancer patients in the literature on psycho-oncology, there is relatively little published research on the independent support needs of informal carers in cancer contexts (for examples, see Kissane et al 1994; Harrison, Haddad & Maguire 1995; Houts et al, 1991; Toseland 1995; Pitceathly & Maguire 1997; Katz, Boesch & Herzog 1998). Rather more attention has been paid to informal carers in the cancer palliative care literature, but their contribution remains relatively under-explored (see Fakhoury, McCarthy & Addington-Hall 1996; Rose et al 1997; Beaver, Luker & Woods 1999; Payne, Smith & Dean 1999; Rhodes & Shaw 1999; Rogers, Karlsen & Addington-Hall 2000).

Data Analysis

The questionnaire and interview data analyses were described in Chapter 3. For the analysis presented in this chapter, the emergent topic categories and analytical themes associated with carers' experiences were further considered in the light of the existing sociological research literatures on informal caring, gendered divisions of labour, and the illness-related experiences of family members. The experiences of the main informal carers in cancer contexts could be seen to be fundamentally bound up with care-giving in the two senses of care work and emotion work. In combination with the statistical analysis of the questionnaire data, it was also clear that this care-giving was associated with carer-specific psychosocial needs. This appreciation informs the structure of our presentation of the findings. We also posed the questions: do male and female carers in cancer contexts have similar experiences and play comparable care-giving roles? As carers, do men and women have similar psychosocial needs? Since there were similar numbers of female and male carers in our samples, we could explore these issues. Unless otherwise stated and

qualified, the interview data extracts presented here have typicality in the sense that they express something common to the majority of cases, either in general or in relation to a defined sub-group of cases under consideration.

Findings

The carer survey and interview samples were described in Chapter 4. It was noted that the majority of carers in both the survey sample (75%, n=196) and the interview sample (78%, n=25) were spouses or partners; thus we are looking mainly at informal caring in intimate couple relationships. Most carers were co-resident. Non-couple carers were usually other kin carers or close friends.

Care work and divisions of labour

Our survey and interview data analysis indicates that a cancer diagnosis often leads to changes in the nature and distribution of care work tasks within families and households. Informal carers find themselves engaged in a range of new caring activities. These changes tend not to happen immediately following diagnosis, but certainly occur during times when the person with cancer is in receipt of aggressive medical treatments, is very ill or is dying. This is echoed in the wider research literature on the impact on families of serious illness where it is suggested that illness can disrupt established divisions of labour associated with gender and generation within and beyond households (Anderson & Bury 1988; Twigg & Atkin 1994; Kelly & Field 1996). Researchers have found that housework, personal care tasks and other care work often have to be reallocated, and that the management of the illness frequently gives rise to new care tasks that need to be undertaken both by the ill person and by those around them. The quantity and quality of care work is likely to change over time as levels of impairment worsen or improve.

This variability is certainly reflected in our findings. In the survey, carers were asked whether the person they were caring for needed any help with activities of daily living (examples given were dressing, feeding, getting around the house). Of those who responded to this question (n=254), 58% reported that this was not the case whilst 29% and 13% respectively indicated that ‘a little’ or ‘a lot’ more help with such tasks was required. There was little difference between female and male carers in this respect. Table 25 shows that the extent of help needed varied significantly with the critical moment of the patient’s illness ($p<0.0001$), with higher levels of care work of this kind required when the cancer recurred or was in the palliative care only stage. Thus in the earlier stages of cancer, divisions of labour and care work loads may not be greatly affected, or are only disrupted around treatment episodes such as surgery, intensive chemotherapy or radiotherapy.

For 21% of the carers surveyed, care work was already a significant feature of their lives prior to the patient’s cancer diagnosis either because they had children in the household (5%, n=14) or because they cared for other people in their kinship or friendship networks.

Table 25: Extent of extra help required by patients, reported by carers *N=254 cases (8 missing)*

	Extent of help needed by patient							
	None		A little		A lot		Total	
<i>Critical moment</i>	N	%	N	%	N	%	N	%
Diagnosis	91	67	33	24	12	9	136	100
End of first treatment	28	76	7	19	2	5	37	100
Recurrence	16	53	11	37	3	10	30	100
Palliative only	12	24	23	45	16	31	51	100
Total	147	58	74	29	33	13	254	100

In addition, a sizeable proportion of carers were already carrying out care work for patients prior to the onset of cancer because patients had existing long standing illnesses; in the patient survey (n=402), 36% had reported that they had a pre-existing ‘long standing illness or disability’. This

relatively high level of co-morbidity reflects the age distribution of the cancer patients (58 % of patients surveyed were aged 60 or above).

To make matters more complicated, 35% of carers surveyed had a long standing illness or disability of their own. The worsening of the patient's physical state sometimes denied them a long-standing source of practical support. Fortunately, carers could often call on care work assistance from others; in answer to the question 'At this time does anyone among your family and friends help you in ways that are over and above what they would normally do for you?' 53% replied in the affirmative. Informal carers of people with cancer are therefore often embedded in sets of caring relationships requiring both giving and taking. A cancer diagnosis thus has implications for the responsibilities of the main carer who may in turn require new kinds of practical support from other people. Like the ripple effects of a stone dropped into a pool, the diagnosis can have knock on care work effects, sometimes disrupting the lives of a large group of people. However, as writers in Disability Studies have reminded us in their critique of the way in which disabled people are wrongly portrayed as 'dependent' in feminist research on informal caring (Keith 1992; Morris 1995; Thomas 1999), there is usually *reciprocity* and co-dependency between 'patients' and 'carers' in caring relationships. We found evidence of this reciprocity at earlier critical moments in the cancer journey, but there was greater patient dependency during periods when patients were undergoing active treatments or were at the palliative care only phase.

In the interviews with carers, the household care work tasks most often remarked upon were cooking, cleaning, heavy housework, shopping and gardening. Where the patient was very ill then care work associated with personal washing/bathing, standing, dressing and toileting was also mentioned. In the context of serious illness, carers often commented on the tiredness and/or frustration they felt:

Carer: I counted up one day - because she lies on here and I sit over there - and within 10 minutes I was up 15 times. "Just put me pillow right, just pick me up, just put me down", you know, frustration really. [P250 husband (63) of a wife with lung cancer and a stroke (palliative moment)]

Carer: At one time I was lifting, doing all the shopping, doing all the bags, I found I was having to do everything. Whereas I used to rely on [him] for doing things, or I could nag him into doing things, you know. But I suppose our life has changed [in] a matter of three months, it's just totally changed. [P234 - female carer (50) of a husband (58) with colorectal cancer (palliative moment)]

The presence of children in the household, especially young children, added to carers' fatigue and difficulties:

Carer: [Our daughter] takes up a lot of time. [Sometimes] I'm not getting her to bed until about 10 o'clock at night, after I've done a day's work.... I've sympathy for single mothers, single parents who try and cope with that. It must be horrendously difficult. It's terribly wearing, it's terribly wearing. [P184 male carer (36) of a wife (32) with breast cancer (recently diagnosed)]

However, older children could also be a source of support in return:

Carer: The kids [have supported me]... especially when [my partner's] been in hospital. They check what sort of state I'm in really (laugh). I'd come in and they would make me tea and toast and things like that, just little things that help enormously. [L224 female carer (46) of a partner (50) with lymphoma (recently diagnosed)]

Did this care work reported on in the interviews and the questionnaire translate into expressed need? The psychosocial needs inventory in the carer questionnaire contained nine needs statements relating to ‘practical needs’. Asked to think about the importance of the needs statements in relation to *their own situation*, carers responded differentially, as shown in Table 26. ‘Help with any distressing symptoms’ was felt to be important or very important (hereafter referred to singly as ‘important’) for 34% of respondents, and ‘Help in dealing with any tiredness’ was important for 32%. ‘Help with childcare’ was only important for 9% of surveyed carers, reflecting the age distribution of cancer carers and patients. These percentages suggest that needs are felt and expressed by particular sub-groups of carers who share particular personal and social characteristics.

Table 26: Carers’ rating of the importance of practical needs (for themselves)

	Percentage rating item important or very important	Percentage rating item not applicable	Percentage Rating item not important
<i>Practical needs</i>	%	%	%
Help with any distressing symptoms	34	50	10
Help in dealing with any tiredness	32	48	12
Help with transport	29	50	14
Advice about food and diet	25	55	13
Help with housework	22	54	17
Help with financial matters	22	57	12
Help with getting out and about socially	19	57	16
Help in filling out forms	17	61	14
Help with child care	9	84	6

N=252 (10 missing cases)

A logistic regression analysis of these data offered some confirmation of this. The analysis related the importance rating of each practical need item in the psychosocial needs inventory to each of nine explanatory variables (clinical (patient) variables, sociodemographic, socioeconomic, and carer health status variables). Some interesting sub-group differences among carers were found. Not surprisingly, carers under the age of 50 were more likely than carers in older age groups to say that they needed help with childcare, and carers who had the use of a car had lower levels of need than those without for ‘Help with transport’. Carers who reported the highest levels of self-morbidity had increased levels of need for help with distressing symptoms, tiredness, transport, and financial matters. In relation to gender, female carers reported higher levels of need than male carers for a range of need items, including ‘Advice about food and diet’, ‘Help in dealing with tiredness’ and ‘Help with getting out and about socially’. A second logistic regression analysis, introducing eight additional response variables, showed that the following groups of carers had higher levels of need than others for a range of practical needs items: carers who looked after patients that required extra help with activities of daily living; and carers who reported a long standing illness or disability.

The interview data enriches our understanding of some of these findings, for example, the issue of transport provision - an important care work task. Carers explained that arranging and providing transport for the conveyance of patients to and from hospitals for consultations and treatments was usually their responsibility. This could be problematic, especially where the carer was in paid work or had other commitments. ‘Help with transport’ was important for over a quarter of the surveyed carers (29%) and, as we have seen, was related to the non-ownership or unavailability of a car. If the carer owned, or had access to, a car, and was not worried about fuel costs, then the burden of driving might be made light of:

Carer: All right, it's 82 miles a day. I can drive 82 miles a day every day for a year if it is

going to do any good. [K198 wife (58) of man (61) with recently diagnosed cancer]

Journeys of considerable distances were involved for some patients and carers in our study, particularly for those residing in rural areas. Five respondents said in interview that there were problems involved in driving long distances due to difficult roads, the inconvenience of the hospital's location, the discomfort incurred by the patient, and/or the costs to be borne. Public transport was deemed to be inadequate in many areas, with timetables, transfers and/or the costs rendering it impossible to use, even for short journeys (some patients were in receipt of financial assistance for travel expenses). In addition, there were comments about not wanting to use public transport because it was physically traumatic for the patient. Anaesthetics and some investigations and treatments, as well as the illness symptoms themselves, meant that patients would not be comfortable on public transport, even when accompanied. Car use was preferred whatever the difficulties. For example, in one interview with a married couple, the carer talked about how he had suffered a stroke at the same time as his wife was diagnosed with cancer but he ignored the doctor's instruction not to drive so that he could pick his wife up from the hospital:

Carer: Having been told I wasn't to drive, I promptly got the car out and motored back to the hospital (laugh). [L280 Husband (64) of woman (61) with breast cancer recurrence)]

Attention now turns from care work to emotion work.

Emotion work

In this section the emotional dimensions of care-giving are considered. Our data suggest that the management of emotion is a crucial aspect of what informal carers do in cancer contexts, and informs their own psychosocial needs. The concept 'emotion work', or emotional labour (Hochschild 1979, 1983), is very helpful here although we are aware that it has been critiqued (Craib 1995; Duncombe & Marsden 1998). Emotion work is the emotional effort made by individuals to manage their own feelings and those of others.

The sociology of the emotions is now a well established field of study (Craib 1995; Bendelow & Williams 1998a). Medical sociologists have recognised the value of this work and have contributed to its development (James 1992; Olesen & Bone 1998; Bendelow & Williams 1998b). Williams & Bendelow (1998: xvii) observe that '... emotions provide the 'missing link' between 'personal troubles' and broader 'public issues' of social structure; itself the defining hallmark of the 'sociological imagination' (Mills 1959)'. We endorse the view that emotions can be understood, sociologically, to be embodied biosocial phenomena that cannot be reduced either to the biological or attributed entirely to the processes of social construction (Williams & Bendelow 1998).

Emotion work is conventionally seen to be highly gendered: women do much of the emotion work in society, managing their emotions as well as those of men (husbands, partners, the men they do paid work for) as part of their subordinate social roles (Hochschild 1983). 'Men, on the other hand, are seen as being more rarely called upon to do emotion work, characteristically in the role of looking tough and being in control' (Duncombe & Marsden 1998: 213). Can such a gender perspective be sustained in the face of our data? The answer appears to be no. Our evidence suggests that cancer demands of both male and female informal carers that they become centrally engaged in difficult emotion work. However, women carers appear to be more likely to express emotional support needs.

Doing emotion working in cancer contexts is about managing feelings in order to sustain a sense of control over events, to stave off nightmares of death, loss and major life change, and to promote healing. Only among a very few patient and carer respondents was there any suggestion that carers were failing to provide emotional support, although there was certainly evidence of tension and difficulty. Of course, our study may have discouraged participation by respondents who were

having particular kinds of emotional difficulties and we cannot be sure that it is fully representative in this regard.

Dimensions of emotion work undertaken by informal carers are considered under a number of headings. It should be remembered, though, that these are analytical distinctions and that in lived experience these interact in a complex emotional web.

Emotion work: managing the feelings of the patient

In interview, almost all carers talked at length about the ways in which they tried to help the patient by engaging with, and influencing, patients' feeling states. One aspect of this emotion work involved ensuring that the patient did not feel alone or abandoned. It was a question of 'being there' for the patient, and often, of reassuring the patient that this illness would be 'faced together'. Being positive and 'keeping things normal', or as normal as possible, were also features of this dimension of emotion work:

Carer: I think if I had run away from it, the trauma that [my wife] was going through would have been vastly greater because you are actually making it into much more of a problem than it is. She's cheerful in herself, and as long as you keep cheerful and you keep busy doing things which are important to you, and you don't sit and dwell on it and feel sorry for yourself, then life not only goes on as normal, life is positive and life is enjoyable. On the other hand, I would have found it much more difficult if L hadn't coped with it as well. And vice versa, if it had got me down then I'm sure it would have got L down much, much more. So it's got to be a joint effort. And if the partner goes down with it, morale wise, then that must be partly the carer's fault. So the carer's got to share a positive view with the partner. [K239 husband (48) of woman (49) with breast cancer at the end of first treatment]

It was felt that hope and confidence should be displayed, as expressed by the following carer and as testified to by a patient:

Carer: And I said "You've got to think of it like this, these surgeons are tip top men, they do these operations like you eating a toffee apple or something like that." I said, "It's an everyday thing to them". So I said "Don't think about it, or try not to think about it". [My husband] said, "It's all very well for you", and I said "Well you've got to try not to [think like that]". [P46 female carer (71) of her husband (72) with colorectal cancer (recently diagnosed)]

Patient: Well my husband has helped me an awful lot, he's made me think more positive. I don't think I'd have been as positive without him. As time has gone, I am getting more positive. But he's there to make me positive all the time. And if I slip, he'll say, "Just don't talk so stupid!", you know, "You will get through this. We're all backing you, we're all behind you and you're going to do it!" So it's my husband, he's absolutely wonderful! [laughs]. [P74 female patient (50) with lymphoma (recently diagnosed)]

Despite this, in a minority of cases the carer's emotion work could be experienced by the patient as oppressively over-protective and was a source of tension. In a joint carer and patient interview, one patient put it thus:

Patient: I was getting to the point where I think he was over-protective in some ways, and he follows you around and I could strangle him, you know. And I said to him "go somewhere else. It's like creeping flaming Moses". And you tend to get a bit, I get very tired and I get tetchy with it, and because he tries to do his best, every time he does his best, it's his worst to me [laugh]. So he can't do right for doing wrong. So I think you need a day apart. [L348 female patient (63) with colorectal cancer (recurrence). Husband (64) is her main carer. Joint interview]

We were very struck by how common it was for the carer to talk about ‘facing this together’, particularly in spousal relationships. There was evidence that many carers and patients continuously negotiated and interactively constructed the shared reality of their plight (see also Morris 2001). Managing the patient’s emotions through taking on the illness mantle, through symbolically sharing in the illness, was a strong theme. In joint carer and patient interviews, this was suggested by the frequent use of the first person plural:

Researcher: How was it for you, though, being that quick [the diagnosis of cancer]? I mean, how did you feel in the middle of all that, do you remember?

Patient: I just felt numb really.

Carer: Better.

Patient: It was better.

Carer: Better for us because we'd no time to think about it. [P87 female patient (64) with breast cancer (end of first treatment). Husband (67) is her main carer]

It is interesting to note that some carers and patients in intimate couple relationships commented in interview on how, despite everything, the cancer experience had had some rewards in bringing them closer together:

Carer: I think it brought us even closer together. I mean we've always been close but I mean it's that threat of - of the possibility of dying through it - it makes you stop in your tracks and you think, well, this could be serious. Yea, there was time I felt despair, I felt there was no person to turn to in a lot of ways, no parents, you know. [L99 male carer (50) of his wife (46) with breast cancer (end of first treatment)]

Turning to our questionnaire data, one question asked ‘Are you able to talk freely about the illness with the person who you are caring for?’. Whilst only a few surveyed carers said that they could not do this ‘at all’ (n=7), a sizeable minority (n=45) said they could only talk to the patient about the illness ‘a little’; the remainder (n=201, 79%) said they could talk ‘a lot’. There were no significant gender differences in this ability to talk freely, but there were significant differences by the patient’s illness critical moment (p=0.005), shown in Table 27.

Table 27: Carers’ ability to talk freely to the patient about the illness

<i>Critical moment</i>	Ability of carer to talk freely to the patient about the illness					
	Could talk ‘a little’ or ‘not at all’		Could talk ‘a lot’		Total	
	N	% rounded	N	% rounded	N	% rounded
Diagnosis	23	17	111	83	134	100
End of first treatment	3	8	34	92	37	100
Recurrence	7	23	23	77	30	100
Palliative only	19	37	33	63	52	100
Total	52	21	201	79	253	100

N=253, 9 missing cases

These critical moment differences, indicating that talking about the illness was more difficult when the cancer had recurred or was in a palliative care only phase, are reflected in the interview data. The following exchange between a carer and patient in a joint interview indicated the tensions involved in not being able to talk freely:

Carer: [My husband] is not very good at dealing with illness, are you really? You don't like to talk about it?

Patient: Well really I've had no practice or anything like that.

Carer: I think, I don't know, I don't know what to say, but I think if we'd had somebody that could have sat and talked to both of us and got us both to open up a little bit we'd have been, I don't know, perhaps have been able to find it easier. I don't know to be truthful with you, or perhaps just to [talk to] me on my own. But even now we don't talk about feelings. You talk about the physical side because you can't get away from that, but I don't think you actually talk about what's going on in your mind. [P234 female (50) caring for her husband (58) with colorectal cancer (palliative care only)]

Emotion work around issues of death was particularly difficult:

Carer: Yes, it's hard talking about your partner dying really, and it was the other way round when I married B, she was going to look after me in my old age. B does worry that if and when anything does happen to her I'll be left on my own. [K473 Husband (57) of woman (41) with recently diagnosed lung cancer]

Carers' ability to talk openly to the patient about the illness did not necessarily mean that the carer always disclosed to the patient all the information they had about their condition. In the management of the patient's emotions, there were different degrees of openness. For example, one carer held the cancer diagnosis 'secret' from her son because he had a learning difficulty and knew that the cause of his father's death had been cancer. In another (joint) interview, there is the following exchange concerning the carer's withholding of information about her husband's surgery:

Patient: [The nurse] started explaining to me that I was going in for major surgery. I only had 3 or 4 days, but I started worrying in myself. If she [the nurse] hadn't have said anything I would have been perfectly all right, but she said "You know you are going in for major surgery don't you?"

Carer: 'Cause I was keeping it hidden from him.

Patient: And that turned the table on me. To me, I would sooner have not known.

Carer: But every person's different you see. Now some people like to know, but me knowing him, I was treating it as though it was an everyday thing. [P46 male patient (72) with colorectal cancer (recently diagnosed). Wife (71) is his main carer]

'Knowing' her husband's character also meant that another carer wished for information to be withheld:

Carer: He was taken into hospital three or four days before the surgery, to prepare him, and he then saw the consultant cardiologist, another abdominal surgeon consultant, and the ward doctor who would be there at the operation. All three of these people said, "you've not got a very good chance of surviving this". ... I'm so sad that they laboured this point. I suppose they did it so that he didn't have false hopes but I think it undermined him. Because he has to believe that he's going to be all right, and is all right. Whereas I'm the one who knows he's not going to be all right, and that way he's all right. [L303 female (67) caring for her husband (76) with colorectal cancer (recently diagnosed)]

As well as handling the feeling states of the patient, carers also had to assist in the management of the feeling states of other people - relatives and friends - in their wider social network, typically through acting as information gateways concerning the state of the patient. This is something we will explore elsewhere, but it is important to note that these 'others' were also often, in turn, an important source of support for the carer and the patient.

Emotion work: managing one's own feelings as a carer

At the same time as managing the emotions of patients, carers also had to manage their own feeling states - to do emotion work on themselves. Of course, we are making an analytical

distinction here because these emotional tasks are fundamentally interconnected: managing the self so that the patient feels better and vice versa. Carers often talked about this in terms of having to 'be strong' and to avoid 'giving way' to emotion:

Carer: I think one thing is that whatever happens you really have got to try and be very much there for whatever your partner wants. I think you have got to be very strong about it. It's terribly hard but I think that's what you have to do. [P184 male carer (36) of his wife (32) with breast cancer (recently diagnosed)]

Carer: Somebody said, "It must be hard for you", I said "no, it's not hard for me, it's J, J's got the problem, not me". He said "but it's affected you". I said, "yes, it's affected me, but I said I don't think about that, I think about her". Well, I just sort of feel in a way I had to look as though I wasn't being reached, for the sake of the kids as well. You know, I don't mind admitting in the meantime, in the farm buildings, I cried me eyes out. [L99 male carer (50) of his wife (46) with breast cancer (end of first treatment)]

Carers often expressed an awareness that there were expectations about how they should behave. We can suggest that they were cognisant of 'social feeling rules' (Duncombe & Marsden 1998), or 'normative guidelines' (Finch 1989) about the 'proper thing to do' in the circumstances: for example, putting the patient first, hiding one's own distress. These rules or guidelines were usually concurred with by the carer, but not always without difficulty:

Carer: And he [Personnel Officer said] "just how are you coping?". I said, "I don't know". He said "well you've got to be strong", he said "you've just got to be strong". And I thought afterwards, when [my husband] came home, I thought, well, why have I got to be strong? Why have I got to be strong, because I'm as vulnerable as anybody else? And I feel like I'm taking it all on my shoulders. [P234 female carer (50) of her husband (58) with colorectal cancer (palliative care only)]

However, carers did not always hide their feelings:

Carer: I think my husband perhaps doesn't admit to being worried. Whereas I admit it, and I think it makes it sort of hard together.

Patient: But I was worried obviously, but not as worried as you were.

Carer: No. No. [laugh] OK, personalities, isn't it? [K238 female carer (69) of her husband (72) with colorectal cancer (recurrence)]

Carers often had worries about their futures and these could not always be shared with the patient:

Carer: It's the first time he's ever said to me, "I'm not afraid to die"... And I don't know how I'd manage without him, I just don't know how I'd manage. I mean on the crude financial level he has an RAF pension which allows us to have a pleasant standard of living and that would instantly be halved and I don't know whether I could afford to live here with half the income coming in. But it isn't that, it's the supportiveness of him. [L303 female carer (67) of her husband with colorectal cancer (recently diagnosed)]

Did carers express their own need for emotional help or support in our survey? This varied among carers. The psychosocial needs index in the questionnaire contained a category on 'emotional and spiritual' needs consisting of 15 needs statements. The percentage of carers rating these statements as 'important' or 'very important' (for themselves) is shown in Table 28.

Table 28: Carers' rating of the importance of emotional and spiritual needs (for themselves)

	Percentage rating Item important or very important	Percentage rating item not applicable	Percentage rating item not important
<i>Emotional and Spiritual needs</i>	%	%	%
Hope for the future	70	19	7
Help in dealing with the unpredictability of the future	51	25	15
Help with any fears	45	37	10
Help with finding a sense of purpose and meaning	41	34	13
Help with any sad feelings	41	40	10
Time for myself	40	36	15
Help in dealing with feelings of others	31	50	10
Help with any loneliness	30	51	14
Opportunities for personal prayer	28	40	21
Support from people of my faith	27	44	20
Help with any anger	25	54	11
Opportunities for meeting others who are in a similar situation	23	40	21
Help with any feelings of guilt	17	59	14
Support from a spiritual advisor	17	51	23
Help in considering my sexual needs	9	62	19
<i>Category mean</i>	33	43	15

N=252 (10 missing cases)

Whilst some of these needs statements were thought to be important by a high proportion of carers, such as 'hope for the future' (70%) and 'help in dealing with the unpredictability of the future' (51%), there were much lower, but nevertheless noteworthy, proportions for other items such as 'help with any feelings of guilt' (17%) and 'help with any anger' (25%). In the main, carers tended either to see the items as important or as not applicable to them, indicating that if there is a need it is usually strongly felt. For example, some of the statements related to having a religious faith, such as 'support from people of my faith'. This was important for 27% of carers, with 44% saying that it did not apply to them. In the interviews, the emotional significance of church involvement was discussed by some carers and patients, usually in connection with the valued support received from members of the congregation, for example:

Carer: We're very fortunate because we are in the Salvation Army- we're Soldiers. And the support that we've had from all the people there has been absolutely tremendous, and really without that we would have been very much out on a limb, because we've only [lived here for 6 years]. [P53 female carer (64) of her husband (72) with lung cancer (palliative care)]

Our logistic regression analysis with the items in the needs category presented in Table 28 revealed a number of important sub-group variations in need among carers. For example, older carers (over 60) had a significantly lower level of need than did younger carers for items such as 'help in dealing with the unpredictability of the future', 'help with any sad feelings' and 'opportunities for meeting others who are in a similar situation'. The 70 years and over age group had lower levels of need for a number of additional needs items: 'help with any fears', 'time for myself' and 'help with any anger'. Female carers had higher levels of need than male carers for a range of items including: 'help with any fears', 'help with any sad feelings', 'help with any loneliness', and 'help with any anger'. There were other differences among carers associated with a range of other variables.

Summary

In the UK, the Calman-Hine Report (Department of Health 1995a) on cancer services acknowledged that the informal carers of cancer patients play an important role in cancer contexts, and have views and preferences that should be acknowledged alongside those of patients. The Department of Health's *NHS Cancer Plan* (Department of Health 2000a) refers many times to the need for cancer services to provide support for carers as well as for patients. Thus, there is growing recognition that carers have psychosocial needs that should be addressed within cancer support services. However, to date, the nature of the activities and needs of cancer care-givers has been relatively little studied and understood. This chapter throws a great deal of light on what such carers do, on their essential contribution through both care work and emotion work, as well as on some of their psychosocial needs.

- *Care work findings*: additional care work demands were an important feature of informal carers' lives in cancer contexts, although this varied with the stage of the patient's disease and with the presence of co-morbidity in patients. The carers' own morbidity status, together with their material and relational social circumstances, had an important bearing on their capacity to take on greater quantities of care work. Specific groups of carers expressed the need for help with particular practical tasks and with the personal effects of the burden of care work. Carers under the age of 50 were more likely than carers in older age groups to say that they needed help with childcare, and carers who had the use of a car/van had lower levels of need than those without for 'Help with transport'. Carers who reported the highest levels of self-morbidity had increased levels of need for help with (their own) distressing symptoms, tiredness, transport, and financial matters. In relation to gender, female carers reported higher levels of need than male carers for a range of need items, including 'Advice about food and diet', 'Help in dealing with tiredness' and 'Help with getting out and about socially'. However, we found no marked gender differences in the cancer-related care work burden on men and women overall. Carers who looked after patients that required extra help with activities of daily living had higher levels of need for support than others.
- *Emotion work findings*: emotion work was a key dimension of care-giving in cancer contexts. Carers worked hard to manage the emotions of the patient as well as their own feeling states, and these aspects of emotion work were intimately connected. Carers felt that they had to be, and often wanted to be, 'strong' and 'positive', and to try to maximise the sense of 'life carrying on as normal'. In doing this emotion work, carers, especially spousal carers, often symbolically shared in the illness and presented the struggle with the cancer as a joint one. On the grounds of their intimate knowledge of the patient's disposition, carers sometimes withheld or glossed information to minimise patient distress. Only a minority of carers found it difficult to talk freely with patients about the illness, but this was more likely to be difficult when the disease was in its later stages. The interview data clearly indicated that both male and female carers were heavily engaged in emotion work, but the questionnaire data on expressed emotional needs found marked gender differences. This suggests that women caregivers are more able to express emotional support needs. Younger spouse-carers (under 60 years) were also more likely than their comparison groups to express emotional support needs (after controlling for other variables), perhaps reflecting their struggle to accept the premature onset of a life-threatening disease among loved ones.

The gender-related findings reported here are significant in the context of recent UK policy development associated with informal carers (Department of Health 1995b, 1998, 2000b), and contribute to ongoing academic debates about the gendered nature of informal caring. Whilst our analysis has been informed in fundamental ways by feminist research and debate on informal caring in the 1980s and 1990s, and has made use of key concepts developed therein, we did not start out with an assumption that informal care-giving in cancer contexts would be an exclusively or predominantly undertaken by women (Arber & Gilbert 1989). Our evidence suggests that, in

cancer contexts, male informal carers are heavily involved in both care work and emotion work. The fact that male carers appear less likely to *express* psychosocial needs associated with their informal caring roles raises many questions for further research.

The research findings presented here can assist those providing cancer support services by increasing their sensitivity to the roles played by, and the potential needs of, carers. They can also assist in the better targeting of groups of carers who may share specific psychosocial needs. In addition, the findings alert service providers to the possibility that some carers, most notably male carers, may not find it easy or appropriate to say that they have support needs.

Finally, our discussion about the emotion work performed by carers revealed that they put the needs and interests of patients above their own. This means that carers are only likely to take up support services aimed at carers if they feel that these do not divert resources and attention away from patients. This suggests that service providers have to reassure carers that their needs are legitimate, that their contribution to cancer care is considerable and important, in short, that carers' needs count.

CHAPTER 10 **Informal carers of cancer patients: what are their unmet psychosocial needs?**

Introduction

This chapter considers the significant unmet psychosocial needs of the informal carers of cancer patients. It mirrors the analysis of patients' unmet needs presented in Chapter 6. In so doing it also provides further information on the overall prevalence of needs among main informal carers (cf. Chapter 5). As in the discussion of patients' unmet needs, a 'significant unmet need' is here defined as a need deemed important by the carer but which has not been satisfied. The primary data source drawn upon in this chapter is the carer questionnaire, particularly the psychosocial needs inventory (PNI) section. The secondary source is the follow-up in depth guided interviews with carers. While the needs of the carers of cancer patients are increasingly being recognised in health care policy documents (Department of Health 2000a), there is relatively little literature on these needs. A carer's psychosocial welfare is linked in symbiotically with the patient's. While the patient's needs tend to dominate, both parties stand to benefit from recognition of the carer's place in the scheme of things (Keller & Henrich 1999; Thomas et al 2001).

Analysis and explanatory variables: The technique of logistic regression was used to analyse the relationship between unmet need and a range of sociodemographic, socioeconomic and illness variables. We distinguish between two types of variable - 'people' variables (these describe the characteristics of the carers) and 'role' variables (these relate more closely to the role of 'carer' during the cancer journey). This is a pragmatic rather than fine distinction that helps in understanding the analysis.

The 'people' variables we have used are the carers' age, gender, their relationship to the patient, whether they have a religious faith, whether they are in paid work, whether they have other caring responsibilities, whether they have people to call upon for help, and whether they have a long-standing illness or disability of their own. In addition, there are two widely used indicators of socio-economic status among the 'people' variables: whether they are owner-occupiers of their dwelling (housing tenure), and whether they own or have use of a car/van.

The 'role' variables relating to the cancer journey are the nature of the patient's tumour, the patient's critical moment, the level of help needed by the patient in daily living activities, the carer's global health status (a combined morbidity and quality of life score from one section of the EORTC-C30 quality of life scale (Aronson et al 1993)), the carer's psychological well-being (General Health Questionnaire (GHQ) score, Goldberg 1988), whether the carer is able to talk freely with the patient about the illness, and whether the carer has been offered any formal support services. As the global health variable provides a measure of overall health, it subsumes long-standing illness and disability, which is therefore omitted from analyses which include global health.

Survey data: Of the 262 returned carer questionnaires, 10 had blank responses to the 48 need items and these carers together with those who had missing values for any of our explanatory variables are excluded from the analysis. Thus, the questionnaire dataset used in this chapter has 195 cases.

Results

How many significant unmet needs?

Table 29: Number of significant unmet needs among carers and patients

No. of significant Unmet needs	No. of carers	% of carers	No. of patients*	% of patients*
Nil	112	57.4	183	62.0
1	16	8.2	37	12.5
2	12	6.2	17	5.8
3-9	28	14.4	45	15.3
10+	27	13.8	13	4.4
Total	195	100.0	295	100.0

* These figures are derived from Chapter 6.

Table 29 displays the number of significant unmet needs amongst the sample of carers; 57% expressed no significant unmet needs, while 43% had at least one. The levels of significant unmet need amongst carers was higher than amongst surveyed patients, of whom 62% reported no unmet needs and 38% had one or more unmet need (however, the response rate was higher for patients and could distort the findings; current work is being undertaken to compare the responses where both patients *and* their carers responded).

While it is perhaps heartening to note that in the majority of cases important needs were being appropriately recognised and satisfied, the outcome partly reflects the stringency of the criterion following our operational definition - the need must be regarded as 'very important' or 'important' by the carer. Nevertheless, as Table 19 demonstrates, over one-quarter of the carers (28%) identified three or more significant needs which remained unmet. Clearly, there is a considerable range in the number of unmet needs experienced by carers.

Who are the carers who experience at least one significant unmet need? Can they be distinguished from those whose same needs are satisfied?

Identifying the carers who have significant unmet need

Table 30 sets out the carers in terms of the 17 variables used in the analysis for unmet need. Hence, it serves two purposes. Firstly, it describes (from the total column) the basic characteristics of the sample - that is, the sample is split evenly between males and females, fairly evenly distributed between four age categories. Nearly three-quarters (72%) of the carers are spouses or partners, three-quarters (75%) maintain they have a religious faith, most (85%) are in owner-occupied accommodation and have the use of a car (86%). One in five (21%) have caring responsibilities for others. Remarkably, over one-third (35%) have their own illness or disability. The majority (78%) is able to talk to the patient about the illness. Similarly, the majority (82%) has friends or relatives nearby; but only a minority (38%) has been offered supportive services. This series of carers split fairly evenly between those in paid work (42%) and those retired (44%), with the remainder indicating that they are looking after the home or the family (10%) or in some other situation (7%). In terms of the patient they are caring for, the patient's tumour is mainly either breast (42%) or colorectal (32%), and the majority (54%) are answering the questionnaire when the patient is at the stage of recent diagnosis.

Secondly, however, Table 30 identifies the variables that significantly distinguish between those carers who identify at least one significant unmet need from those who make no such claim. These variables are: the carer's relationship to the patient; whether the carer has other caring responsibilities; the carer's global health status; the carer's GHQ score; whether the carer is able to

talk freely with the patient about the illness; the patient's 'critical moment'; and whether the patient needs help with the activities of daily living. While interesting, taking variables one by one in this way can be misleading, because variables may inter-relate. By using logistic analysis the significance of each variable can be tested while controlling for the effect of the other variables.

The logistic analysis on whether or not carers had any significant unmet needs was carried out in two stages - using firstly the ten 'people' variables, and then with the addition of the range of 'role' variables (at this stage replacing 'long-standing illness/disability' with 'global health').

Using the Akaike information criterion (Lindsey & Jones 1998), there were three significant variables - relationship to patient, other caring responsibilities and the availability of friends/relations for help - when the ten 'people' variables were included. In brief, those carers in non-spousal and non-partner relationships with patients, or where the carer had other caring responsibilities, or where the carer did not have friends/relations to call upon for help, were much more likely (at a statistically significant level) to have at least one unmet need. These significant variables may appear unsurprising, but it also needs to be recognised that there are seven important carer variables - namely, age, gender, religious faith, work status, housing tenure, car ownership, and whether they have a long standing illness or disability - that do *not* significantly discriminate between those who claim to have significant unmet need and those who do not. Broadly, it is the type of social network one has, and the other caring responsibilities in which the carer is embedded, that seem to make the difference.

What happens when the 'role' variables - that are much more to do with the cancer journey itself - are introduced? Again three variables - relationship to the patient, the carer's global health status and the patient's critical moment - emerge as statistically significant in differentiating those with significant unmet needs from those who do not. In brief, those carers where the relationship to the patient was not a partner or spouse, or where the carer had poor health, or particularly where the patient's critical moment was at the palliative stage, were much more likely (at a statistically significant level) to have at least one unmet need. With this analysis one can recognise that it is the health of the carer rather than the type of illness of the patient which has the greater impact on whether there is likely to be significant unmet need. However, as stated before, the relevance of the carer's global health is associated with some aspects of the patient's illness, such as their need for help with the activities of daily living.

Table 30: Carer sample [n=195] by 17 variables used in the analysis for unmet need

Variables		Distribution (%) (n=195)	% with no unmet needs (n=112)	% with some unmet needs (n=83)
<u>Gender</u>	Male	50	64	36
	Female	50	51	49
<u>Age Group</u>	<50	26	45	55
	50-59	29	54	46
	60-69	25	65	35
	70 and above	20	69	31
<u>Relationship to patient*</u>	Spouse/partner	72	64	36
	Not spouse/partner	28	42	58
<u>Religious faith</u>	Has no faith	25	58	42
	Has a faith	75	57	43
<u>Tenure</u>	Owner occupier	85	57	43
	Other	15	59	41
<u>Use of car/van</u>	Yes	86	57	43
	No	14	61	39
<u>Caring responsibilities for others*</u>	Has caring responsibilities	21	43	57
	Does not have caring responsibilities	79	61	39
<u>Own illness /disability</u>	Has own illness/disability	35	53	47
	Does not have own illness/disability	65	60	40
<u>Patient's Tumour</u>	Breast	42	66	34
	Colorectal	32	56	44
	Lymphoma	11	43	57
	Lung	15	47	53
<u>Patient's 'critical moment'*</u>	Diagnosis	54	61	39
	End of first treatment	14	71	29
	Recurrence	11	52	48
	Palliative only	21	40	60
<u>Global health status*</u>	0-25 (%) (worst health)	4	13	87
	26-50 (%)	25	44	56
	51-75 (%)	44	58	42
	76-100(%) (best health)	27	75	25
<u>General Health Questionnaire score (psychological health) *</u>	9-12 (poor)	13	27	73
	6-8	25	57	43
	3-5	28	56	44
	0-2 (good)	34	71	29
<u>Able to talk to patient about the illness *</u>	Not able to talk much	22	42	58
	Able to talk a lot	78	62	38
<u>Patient needs help with daily activities*</u>	No help needed	62	66	34
	A little help needed	26	43	57
	A lot of help needed	12	44	56
<u>Friends/relatives nearby who could be called to help</u>	Friends/relatives nearby	82	60	40
	No friends/relatives nearby	18	44	56
<u>Has been offered supportive services</u>	Yes	38	65	35
	No	62	53	47
<u>Work situation</u>	In paid work	42	55	45
	Retired	44	65	35
	Looking after home/family	10	35	65
	Other	4	57	43

* significant at the 5% level using the chi-squared test (shaded)

What are the significant unmet needs?

There was a considerable range in terms of which needs items listed on the questionnaire were regarded as important or very important. As Table 31 shows, the top ranked item - 'Honest information' - was so categorised by 96% of the respondents - while the lowest item - 'Help with child care' - was identified by just 9% of the respondents. In fact, the pattern of responses shows that the prevalence of needs among carers was similar to those of the patients (cf. Chapter 5). Not surprisingly, both patients and carers want the best from health professionals (for example, 'Honest information', 'Confidence in health professionals I meet', 'Information about treatment plans', and so on), but many of the other needs reflected carers' current social positions in society. For example, in a series with predominantly older age groups, few had caring responsibilities for a child. While there may be personality differences between carers (that is, some people may be more easily dissatisfied than others), we focus largely on the relevance of *social* context to psychosocial need.

The next question to consider is whether this wide variety of important needs is indeed met satisfactorily. The last two columns of Table 31 highlight two complementary points. The more 'universal' needs are being generally met, while there tends to be a much higher proportion of significant unmet need in relation to some important needs identified by a minority of respondents. In broad terms, therefore, it would seem that most of the 'health care' needs are being met, while some of what might be termed as social needs are much more likely to present a higher proportion of significant unmet need.

This outcome becomes clearer in Table 32 that ranks significant unmet need items. It focuses on all the items where at least one in five of the carers reporting a need for the item rated it as a significant *unmet* need. So, for example, while only 19 carers regarded 'Help in considering my sexual needs' as important, over one-half (58%) claimed that their needs in this respect were unmet. Similarly, 64 carers - one-third of the sample - identified 'Help in dealing with any tiredness' as important, but 25 (or 39%) of these carers identified this as an unmet need. In fact, it is notable that when ordered by percentage of significant unmet need, the items emerging with the highest rankings are very different from those in Table 31, where the ranked order related to the proportions rating the item as important or very important.

Table 31: Carers' significant need and unmet need (ranked by % rating item as important/very important)

Need Item	Those rating item as important or very important		Those with significant unmet need in item	
	Number	%	Number	% *
Honest information	188	96%	19	10%
Confidence in the health professionals I meet	182	93%	11	6%
Information about treatment plans	181	93%	20	11%
Information given sensitively	181	93%	13	7%
Information about what to expect	180	92%	26	14%
Easy and quick access to doctors	174	89%	21	12%
Information about medication and side effects	172	88%	14	8%
Health Professionals who have time to discuss issues with me	171	88%	17	10%
Easy and quick access to health professionals other than doctors	168	86%	19	11%
Health professionals who treat me with respect	167	86%	9	5%
Support from family	166	85%	6	4%
Health professionals who listen to me	163	84%	9	6%
Advice on what services and help are available	163	84%	21	13%
Support from friends	163	84%	5	3%
Support from care professionals	149	76%	12	8%
Hope for the future	147	75%	23	16%
Access to other sources of information	142	73%	19	13%
Opportunities to participate in choices around treatment	134	69%	13	10%
Someone to talk to	127	65%	19	15%
Help in dealing with the unpredictability of the future	108	55%	26	24%
Support from neighbours	105	54%	4	4%
Help with any fears	98	50%	22	22%
Help with any sad feelings	89	46%	24	27%
Help with finding a sense of purpose and meaning	85	44%	11	13%
Time for myself	84	43%	19	23%
Help in maintaining a sense of control in my life	77	39%	20	26%
Help in maintaining independence in the face of illness	74	38%	18	24%
Help in dealing with the feelings of others	68	35%	15	22%
Help with any distressing symptoms	67	34%	15	22%
Help in dealing with any tiredness	64	33%	25	39%
Help with any loneliness	64	33%	16	25%
Help with transport	61	31%	12	20%
Opportunities for personal prayer	53	27%	1	2%
Advice about food and diet	53	27%	14	26%
Help with any anger	52	27%	16	31%
Support in dealing with any changes in the way others see me	51	26%	16	31%
Support from people of my faith	49	25%	1	2%
Opportunities for meeting others who are in a similar situation	48	25%	16	33%
Support in dealing with any changes in my sense of who I am	44	23%	14	32%
Help with housework	42	22%	10	24%
Help with financial matters	41	21%	16	39%
Help with getting out and about socially	40	21%	10	25%
Help with any feelings of guilt	39	20%	14	36%
Support in dealing with changes in my body or the way I look	37	19%	11	30%
Support from a spiritual advisor	33	17%	3	9%
Help in filling out forms	31	16%	8	26%
Help in considering my sexual needs	19	10%	11	58%
Help with child care	18	9%	3	17%

[n=195 cases]

* Percentage of those who rated the item as important or very important

Table 32: Carers' significant need and unmet need: top 23 items

(ranked by % with significant unmet need)

Item	Those rating item as important or very important		Those with significant unmet need in item	
	Number	%	Number	% *
Help in considering my sexual needs	19	10%	11	58%
Help in dealing with any tiredness	64	33%	25	39%
Help with financial matters	41	21%	16	39%
Help with any feelings of guilt	39	20%	14	36%
Opportunities for meeting others who are in a similar situation	48	25%	16	33%
Support in dealing with any changes in my sense of who I am	44	23%	14	32%
Support in dealing with any changes in the way others see me	51	26%	16	31%
Help with any anger	52	27%	16	31%
Support in dealing with changes in my body or the way I look	37	19%	11	30%
Help with any sad feelings	89	46%	24	27%
Advice about food and diet	53	27%	14	26%
Help in maintaining a sense of control in my life	77	39%	20	26%
Help in filling out forms	31	16%	8	26%
Help with any loneliness	64	33%	16	25%
Help with getting out and about socially	40	21%	10	25%
Help in maintaining independence in the face of illness	74	38%	18	24%
Help in dealing with the unpredictability of the future	108	55%	26	24%
Help with housework	42	22%	10	24%
Time for myself	84	43%	19	23%
Help with any fears	98	50%	22	22%
Help with any distressing symptoms	67	34%	15	22%
Help in dealing with feelings of others	68	35%	15	22%
Help with transport	61	31%	12	20%

[n=195 cases]

* Percentage of those who rated the item as important or very important

In fact, Table 32 probes a major difference between carers and patients. Using the same instrument (the PNI), carers identify a much larger number of unmet needs. There were only two items - 'Help with financial matters' and 'Help in filling out forms' - that breached the 20% criterion (or one in five persons identifying the item as an unmet need) among the *patients*, whereas there are 23 such items among the *carers*.

Among the patients the need items that were most likely to be unmet could be broadly divided into three main themes - managing daily life, the emotions, and social identity (Chapter 6). The items emerging in Table 32 for carers can be similarly divided but the concerns under each of these headings are much broader by comparison.

A number of the unmet needs were practical and to do with managing daily life (tiredness, finances, diet, filling in forms, housework, transport, dealing with symptoms). Others were related to managing emotional factors (guilt, anger, sadness, fears, uncertainty) social identity and relationships (sexual needs, meeting others in a similar situation, dealing with the feelings of others, changes in one's sense of identity, appearance, loneliness, social activity, having time for oneself, maintaining independence and control).

Some illustrations from the interview data

Questionnaire data is often devoid of context and can be difficult to understand. Interviews can often provide this context. We present some of our carer interview data under three headings: 'managing daily life', 'managing emotional life' and 'coping with identity and social relationships'. These serve as categories in a neat analytical framework, but life is more complicated than that, and these data speak of explicit and implicit connections between these three major areas of concern. We also consider a small number of carers who had *their own* significant unmet need for an item that appears at first sight to be relevant only to patients: 'Support in dealing with changes in my body or the way I look'.

Managing daily life

Carers frequently mentioned difficulties with transport and housework. Public transport was a problem for many of those without a car; often it required a financial outlay that was difficult for some, but was also cited as inconvenient and even threatening by a few. One woman described the strain of visiting her husband in hospital and then coming home to household tasks:

Carer: It was costing me £14 a week to go, and that was with my OAP bus pass, and I tried to claim, but because I am not claiming income support I can't claim bus fares. I also found that very tiring because I had to go from here to [x], change buses, and then go from [x] to the hospital. And then coming back I often missed my connection, and on Sundays, especially, I was waiting for two hours. And it was a bit traumatic. And by the time I got home I had to eat, and I didn't feel like it. But I thought, well I had to, because there was always washing to be done, and there was the garden to see to, there was the greenhouse to be watered, the beans to be watered, carrots to be watered. And he said to me one day, "Have you cut the lawn?" I said, "Lawn, what lawn?" He said, "That green stretch that's on the left". [wife of man (age 72) with recently diagnosed colorectal cancer]

All those we interviewed who had children spoke about having to manage child-related practical and emotional issues. While most managed with the help of family, friends and neighbours, they noted that it added extra difficulties:

Carer: [Our small daughter] takes up a lot of time, I'm not getting her to bed until about 10 o'clock at night, after I've done a day's work. And I've sympathy for single mothers, single parents, who try and cope with that, it must be horrendously difficult. It's terribly wearing. [husband (age 36) of woman (age 32) with recently diagnosed breast cancer]

The subject of finances and financial help was expressed forcibly in several interviews, particularly among those of working age. Financial issues were clearly practical, but were also often relevant to managing emotions and identity. In the following extract the value of working is assessed not only in monetary terms, but also in relation to the carer's need to maintain her separate identity.

Carer: The main problems we've been having are about financial help. No one seems to want to give us any sort of help at all. That has been the biggest problem. I've been trying to claim some benefits for him since November, since he first got diagnosed - at the moment we're only getting one and we didn't start getting that until about three weeks ago. So I was expected to support him. You know, there are even times when you consider, "Well, if I stop work would we be better off?" because I'd be able to claim. That's not what I want to do because I really enjoy my work, plus it's a kind of break for me as well. I know that sounds a bit cruel. [female partner (age 20) of man (age 54) with recently diagnosed colorectal cancer]

When carers talked about managing the distressing symptoms of the patient there were several instances where the carer described feelings of helplessness, which highlight the emotional impact of managing daily life in the context of cancer:

Carer: It's the pain, listening, watching the pain, everything else. I ring the doctor up and all they say is "Give her some more morphine, this is the only way you can do it", and I can't hack it. I'm that kind of person. I told them at the hospital that I can't, I couldn't sit there, I have to go and get out. I don't like to go drinking, I just go in the car, I'll go away and sit and listen to the wireless for an hour or something. [husband (age 49) of woman (age 54) with breast cancer at the palliative only phase].

Managing emotions

Carers were more likely to express feelings of guilt than were patients, and were also more likely to have a unmet need in this regard; 'Help with any feelings of guilt' was a significant unmet need for 36% of carers for whom this was an important need (see Table 31). The comparative figure for patients is 9%. At interview some carers expressed feelings of responsibility for the cancer, for example:

Carer: I was a bit angry that he'd actually got bowel cancer because we had always eaten 'high fibre', and try to get our four or five portions of vegetables a day.

Patient: And all the things that you are supposed to do.

Carer: I felt a bit guilty.

Patient: I think you felt 'why us?'

Carer: But the doctor said it really hasn't anything to do with that, it's just one of those things. You get a bit angry. And then I've been having problems with my own woman problems, I remember when he came in from work I was moaning about this, that, and the other. And then I felt guilty, "Did we miss it? Because I was nattering?" [wife (age 50) of man (age 53) with colorectal cancer at the end of first treatment]

The unpredictability of the future was also a cause for concern among carers, and this was linked to the issue of knowing what to expect. There were many instances, particularly where the patient was near the terminal phase, of the anxiety caused by lack of any clear idea about either the course of the disease or what services might be available during this difficult time.

Carer: I don't know what's going to happen in the future, whether it's going to get a lot worse, or whether things will happen where it makes things easier for me. I don't know because nobody's said. I feel that once this starts there should be a programme whereby professional people come in and tell you what's going on as well as the other things. That seems to be the big problem, just fear of the unknown. [husband (age 63) of woman (age 65) with lung cancer at the palliative only phase]

Support from family and friends, and health professionals, was mentioned as important in managing difficult feelings, but there were indications of significant unmet needs amongst carers in relation to professional help. This was connected with carers' lack of knowledge about where to go and what services were available, and also with a reluctance to 'bother' health professionals whose focus, quite rightly in the carers' view, was on the patient's needs rather than those of the carer (Morris & Thomas 2001).

Carer: I think the carer's questions are different to the person that it is happening to. I think your needs are different. I have been told [by health care professionals], "We are here for you and you can ring", but you are still thinking, well, the people that they are there to care for really are the patients. [wife (age 64) of man (age 72) with lung cancer at the palliative care only phase]

Managing social identity and relationships

Many carers raised issues relating to their own identity and social selves. They expressed how much life had changed for them, often very quickly. Their relationship with friends and social networks were often described as having changed:

Carer: There's only one or two [friends] that ring me, every two or three days or so. "Hi!" and they're positive, "How's he feeling? Has he had a good day?" And I appreciate that, that's very important. But as I say, it's disappointing. You find out who the real friends are. Some just don't bother to phone. [Wife (age 67) of man (age 83) at the palliative care only phase of lung cancer]

Carer: He's 49, but he's still my son. It does get difficult at times. I just feel that my friends don't come. I had a few friends, mind you, they're like me, they're getting older and they don't knock about the same, but there's hardly anybody opens our door, and that's upsetting to me because I'm the sort of person who likes people coming. [Mother (age 76) of man (age 49) with colorectal cancer at the end of first treatment]

Understanding particular responses

Eleven carers claimed they had a significant unmet need in 'Support in dealing with changes in my body or the way I look'. We were unsure what carers meant by this – was it tiredness, stress, the strain of caring which they felt was visible, perhaps involving the exacerbation of their own health problems? On examination we found that *all* these eleven carers were registering high levels of significant unmet need, spanning between 12 and 30 items each. Probing the need items they rated as significantly unmet was revealing. While numbers are small, it still seems evident that items concerned with identity and emotional state feature prominently, perhaps suggesting that they are a group of carers for whom the impact of the patient's cancer is particularly keenly felt in their own lives, and inscribed on their bodies. The interview data throw some light on this, for example:

Carer: I had all this with my eyes - it was like an allergic reaction. I've talked to a few people since, and one or two people have said that it is stress coming out. My friend at work, her daughter had meningitis, and her eyes all broke out the same as mine. And a lady in *Marks & Spencer's* stopped me as well, she said "do you know my eyes were like that, I was just the same as yours", and she had a crisis in her life. [Wife (age 50) of man (age 58) with colorectal cancer at the palliative only phase]

One carer's sense of self was profoundly tied up with her relationship with her husband, and the cancer seriously threatened this:

He's been such a lovely husband. I think I might end up in some asylum somewhere without him, you know, very difficult, because he's my rock. [Wife (age 67) of man with recently diagnosed colorectal cancer]

Ten of these eleven carers also identified 'Help in maintaining independence in the face of illness' and 'Help in maintaining a sense of control in my life' as items of significant unmet need. They seem to be struggling to cope with themselves more profoundly than with the immediate imperatives of coping with a patient.

As Table 29 has shown, over one-quarter of the carers (28%) have identified three or more significant unmet needs. These various needs often inter-relate in a complex manner. The crucial task is to consider how one might usefully respond.

Discussion and summary

It is now acknowledged that the informal carers of cancer patients play an important role in cancer contexts, and the need for cancer services to provide support for carers as well as for patients is recognised (Department of Health 1995, 2000a). This chapter has reported on research that has delineated the significant unmet needs of the carers of a wide range of cancer patients. We have found that carers of cancer patients often have significant unmet needs, and that in a minority of cases, such needs are multiple. In fact, carers have considerably more unmet psychosocial needs than do cancer patients themselves. This outcome reflects the comparative neglect of carers in real life contexts. The problems for many carers are both serious and complex, and potential solutions need to be addressed.

- ◆ **Which carers have significant unmet needs?** Carers with significant unmet needs were more likely to be: i) those where the relationship to the patient was not that of a partner or spouse, ii) those more likely to have other caring responsibilities, and iii) those less likely to have friends or relations to call upon for help. Carers with unmet needs were also more likely to be: iv) in poor health themselves or, v) to be caring for a patient who had reached the palliation only phase in their cancer journey. This reminds us that carers, as well as cancer patients, are not all the same and different groups have different needs. In social terms those already socially disadvantaged - such as those with a limited network of social support as well as those in poor health - are less likely to have all their important needs met. These findings can assist in the better targeting of groups of carers who may share specific psychosocial needs.
- ◆ **What are the significant unmet needs of carers?** The majority of carers expressed the importance of needs such as having good relationships with health care professionals and receiving honest information, but few expressed dissatisfaction with these aspects of need, at least in the questionnaire. This suggests that cancer services are often successful in providing sensitive care and good information for both patients and carers, meeting a range of important needs; but other aspects of the cancer journey can cause significant difficulty for carers. Items of significant unmet need clustered around aspects of managing daily life, emotions, and social identity for a sizeable minority of carers. These are the same areas of significant unmet need that concern patients; however, carers have more of these concerns. Over one in four carers (28%) had three or more significant unmet needs. The interview data has revealed how the needs of some of these carers inter-relate in an intricate manner. These findings can assist those providing cancer support services by increasing their sensitivity to the potential and actual needs of carers.

The question arises as to how much cancer services should be involved in addressing the type of significant unmet needs of carers identified in this study. As in the case of the unmet psychosocial needs of patients, such carer needs may be considered beyond the remit of services primarily designed for the treatment of disease. However, there has been an increasing call for services to provide support over and above traditional clinical concerns. The multidisciplinary cancer team now includes a wider range of health care professionals than ever, due to the accreditation process set in train by the Calman-Hine Report (Department of Health, 1995a). Aspects of need such as financial support (and concomitant form-filling) *are* often addressed by specialist palliative services, specialist nurses, attached social workers and GPs. Emotional help *is* being given through counselling and charitable support organisations (although nation-wide coverage is patchy). Increasingly these services will assist patients, but it is a moot point whether they will reach carers in quite the same way.

While the carers in this series were broadly satisfied with the help they receive from professional sources within a more traditional but enlightened medical model, there are grey areas identified where particular groups of carers are experiencing serious problems unassisted. Some of these problems arise in the interstices of various care systems. To what extent is it appropriate for health

care professionals to become directly involved in considering the carer's sexual needs, or help with coping with feelings of guilt, for example? In addition, many of these problems are likely to continue or even magnify if the patient dies, and post-bereavement support for carers is potentially expensive in terms of time and resources.

We may need to recognise that the task of health professionals is to raise awareness of the importance of some of these issues to particular groups of carers, perhaps to refer carers to other social care professionals and sources of support as appropriate, and not to expect health professionals to deliver fully on their own. Satisfying the particular needs of some carers is beyond the remit of health professionals and it may be inappropriate to criticise the health care system in this respect. Indeed, for a significant minority of carers of cancer patients, their concerns will be just a further aspect of the general problems of living. Hence, some of these needs must be addressed more satisfactorily at a societal level.

Finally, carers can, of course, be their own worst enemy. Altruistically carers tend to put the needs and interests of patients above their own. This means that carers are only likely to take up support services aimed at carers if they feel that these do not divert resources and attention away from patients (see Chapters 9 and 11). This suggests that service providers have to reassure carers that their needs are legitimate, and that their contribution to cancer care is considerable and important. Only in this way can the noble aims of The NHS Cancer Plan (Department of Health 2000a) be realised.

CHAPTER 11 **Where does the carer stand in the medical setting?**

Introduction

Recent thinking about cancer service policy in the UK has highlighted the importance of recognising the needs of carers, but is unclear about the ways in which this might be done. Here we ask how carers negotiate their place in the cancer situation, and particularly how they identify their role in relation to the patient and the medical setting. Drawing on the carer and patient interview data, with some reference to the questionnaire data, we posit carers as taking part in a shifting process of 'carerhood' in which competing needs vie for satisfaction. Our evidence suggests carers actively negotiate the challenges of their position in dealing with issues of identity, support, and sharing. We conclude that when the carer's involvement in the cancer scenario is recognised and legitimated by others it is easier for them to attend to their own needs alongside those of the patient.

The following analysis focuses particularly on how carers negotiate their relationship with and in the medical setting. We found it helpful to use the 'journey' metaphor, commonly used in cancer discourse, to place the carer in the medical setting (Morris 1996). This was also useful in allowing us to see the involvement of the carer as a process, rather than a static phenomenon (Schumacher 1996).

How do carers negotiate their place in the cancer situation?

While active carers come from among those close to the person with cancer, taking on the identity of a carer involves further processes. We conjectured that 'people with those with cancer' would have to negotiate their place in relation to the patient, important others and the medical setting. There were often no clear signposts, such as the impairment of the patient, to thrust people into the role. The 'normative guidelines' (Finch 1989) for carers in general did not necessarily apply, and our sample described ways in which they became involved as carers to a greater or lesser extent. One of our findings was that the carers worked in the background to support the identity of the person with cancer. They were sometimes diffident about their position, especially in the medical setting, and yet were active in managing the illness situation.

The joint interviews with both patients and carers were useful in providing a picture of how pairs (mostly married couples) approached the cancer situation together. These interviews were conducted in a similar manner to those with individuals. During the interview the researcher aimed to allow the dyads to establish their own parameters for participation, although sometimes specific requests for one of them to expand on responses to aspects of the situation as 'patient' or 'carer' were made. Subsequently, we used a qualitative data analysis programme (QSR 1998) to check relative quantities of speech in the interviews. Interestingly, the only section in which carers in joint interviews demonstrated some hesitancy in becoming involved was in the initial 'telling-the-story' of the illness. Although many provided back-up details, there was a general deference to the patient as prime narrator, although the carer took a more active spokesperson role if the patient was in poor health. This was another piece of evidence for our growing interest in the carer's place in the cancer situation.

At interview the many ways in which carers and patients described the contribution of the carer to managing the cancer situation indicated carers' close involvement in all aspects of the experience. However, there were also many indications that sensitive issues accompanied the position of carer. Our data suggests that carers needed to position themselves in ways which sought to maintain the patient's dignity, respect the patient's centrality in the cancer drama, and yet allow the carer to

manage the situation in relation to their own needs as well. Tasks included being involved without taking over the situation, being helpful without dominating, managing change and yet maintaining normality threads from the pre-cancer time. Lynam (1990) suggested that people with cancer are active in managing their social support systems, and not merely passive recipients of support. Likewise with carers, we found them to be active in negotiating their place in the cancer scenario. Furthermore, our joint interviews particularly suggested that the pairing of cancer patient and carer may be viewed as an entity which is affected by the cancer experience. So, both parties not only have to negotiate the patient's needs, the carer's needs, but also the needs of the relationship in order to deal with the impact of the disease.

Where do carers place themselves in the medical situation?

Standing back

There were several indications of uncertainty about the carer's role in the medical setting. As noted, in joint interviews the carer usually remained quiet while the patient recounted the medical story. In addition, carers' talk often described reticence in entering the medical setting initially, and a privileging of the doctor/patient relationship.

Carer: I was a bit apprehensive about doing it, because there's still this patient-doctor relationship thing, but L. [my wife] made it fairly clear that she would like a second person there, and everybody seemed to accept it as normal on the medical side. I soon felt that I had to be there, there was no option. [Husband (48) of a woman (49) with breast cancer at the end of first treatment. Separate interviews]

Even those who were more forward reflected on whether they should 'butt in' to the medical encounter.

Carer: I think if [the doctor's] talking to a patient they like to be one-to-one, not someone at the side flying in and butting in all the time, so at times I have to keep my mouth shut a bit. In case I'm upsetting his concentration really with talking to [my wife] and trying to work the best out for her. [Husband (57) of a woman (41) with recently diagnosed lung cancer]

Starting off

Issues of confidentiality and the sanctity of the doctor/patient relationship meant that crossing the boundary into the medical world was more complicated for carers than patients. Yet most of the carers we interviewed managed to be present at most consultations. Studies have suggested that patients are happy for carers to know as much as themselves, but not more (Benson & Britten, 1996). Hence, for carers to enter the medical arena often required an invitation from the patient.

Carer: When it was her first chemo I went with her so she wasn't on her own, and I went with her to [hospital x] because she didn't want to go on her own. [Female friend (36) of a woman (38) with a first recurrence of breast cancer. Separate interviews]

In addition, others sometimes indicated to the carer what they should do.

Patient: One of my friends' husbands said to [my husband], "She can't go on her own", and he got really cross about it for some reason, and he made C. [my husband] come with me, which was very good actually as it turned out because I would have been worse for not having him there and having that support. [Woman (43) with recently diagnosed breast cancer. Just patient interviewed]

Health professionals have a requirement to maintain confidentiality, but in practice this is not often clear cut (Fitch 1994). In our study health care professionals were often cited as instrumental in

giving secondary permission for the carer to step in. When this happened carers expressed appreciation, and there were many examples of praise for the health personnel who welcomed them in.

Carer: I was impressed with Mr [surgeon] because he actually took the time to find out who I was, make sure I was all right, and introduced himself to me. And when we came out of there, even though we had probably some of the worst news you could be told, we felt good. [Female partner (20) of man (54) with recently diagnosed colorectal cancer]

Carer: Mum went in and within a minute or two a nurse came out and said “Will you come with your mum?” And I said “Well, does mum want me to be there?” And she said, “Oh yes, two's better than one”. So we went. [Daughter (49) of woman (76) with recently diagnosed breast cancer. Joint interview]

Conversely, while carers might feel that it was not their place to be forward, feeling actively excluded was difficult.

Carer: [Doctor x] never said anything, but I just got the feeling that really I was a bit superfluous, I would have been better not there. But I go, I don't always go in, but I go in for two reasons, and one is this, he's deaf, I've not brilliant hearing myself. I got the feeling that [doctor x] wasn't terribly happy about it, but I was invited in by the others, which makes a difference. [Wife (69) of man (72) with a first recurrence of colorectal cancer]

Moving on together

Although somewhat diffident about entering the patient's medical space carers made frequent comments on the importance of being involved and knowing what was going on. Our data support the findings of other studies that highlight carers' desires to be informed (Rose, 1997; Ericksson & Lauri 2000). Being involved in the medical encounter was presented by carers as enabling, and meant that they could more easily constitute the cancer situation as shared

Carer: It helped me because I felt that I knew as much as L. [my wife] and therefore enabled me to cope with the issues at the same time as L. was trying to cope with the issues. It wasn't done second-hand. I could see the emotions she was going through from the outside. I knew why. It must be an awful lot more difficult for a couple if the carer is having to adjust and discover what the partner is going through without the full picture, not only what was said, but how it was said. I mean, it must be a 100 per cent worse for both the patient and the carer not to be involved. [Husband (48) of woman (48) with breast cancer at the end of first treatment. Separate interviews]

Having a companion at consultations was presented as important for several reasons. The carer was generally considered more able to cope with the shock of difficult information, and retain what was said. The carer's direct involvement also meant that it was easier to keep track of what was going on, and to share the illness problem, especially when the patient was shocked or poorly due to the illness or treatment:

Carer: I've gone with him every time he's had an appointment, I've gone with him, they encourage you to do that. And if I've needed to ask them anything I was there at the time, you know. No, we've done it together really, haven't we?

Patient: We have indeed, yes. Yes, I don't know what I would have done if you hadn't been there certainly. [Wife (57) of man (64) with lymphoma at the end of first treatment]

Once acclimatised to their position carers frequently reported an important role as ‘organiser’ in checking, arranging and dealing with medical appointments.

Patient: [to carer] Oh yes, you're always here, you look after me, and make sure, and you do all the phoning and the ringing up and organising and what have you. [Man (53) with colorectal cancer at the end of first treatment. Wife (50). Joint interview]

Taking the lead

There were some instances in the interviews where carers clearly took the lead at points in the medical encounter. For example, some male carers took control at particular points in order to safeguard their wives' interests.

Patient: Fortunately my husband was with me and he said to the consultant, "Can you do it straight away?" And he said, "Yes". And he said, "Well, book her in straight away". So in a way he took control of that part of it. [Woman (49) with breast cancer at the end of first treatment. Husband (48). Separate interviews]

Carer: [My wife was worried about being on a mixed ward.] I had a word with the hospital and they arranged that she could have a side room and she got on very well indeed. And that actually relieved a lot of stress because a lot of people, myself included, I couldn't care less. But she was really, really, stressed. [Husband (53) of woman (55) with recently diagnosed breast cancer. Just carer interviewed]

There was one long-standing carer in our sample, the mother of a man with learning difficulties, who was also proactive in arranging ways to manage her son's operation and recovery.

Carer: I didn't want somebody that he had never met, that's difficult with somebody who's handicapped, you can't just do that. And so [the nurse] gave me the number for the Macmillan Nurses and I spoke to - actually one lady did come - because she said she'd be visiting him in the hospital. So I said could she come before that and at least meet him and let him see her. [Mother (71) of a man (38) with recently diagnosed colorectal cancer. Just carer interviewed]

There were signs that carers made an effort to support the patient's continuing autonomy, and help them to maintain a sense of independence. Carers who felt ambivalent about accompanying patients in consultations, unless invited in, provided evidence for this. Resisting the role of carer was sometimes presented as a way of supporting the patient's continued identity as a competent adult.

Carer: He blankly refused to do his insulin and [the nurse] and I sat and we talked to him and he kept saying, "My wife can give it to me, my wife can give it to me". So his wife was very hard and said, "No she would not give it to him." I said, "I'm there as a backup if you want it, but I'm not going to be there to do it." Because I said, "I might want to go out one day and spend all his money" [laugh] and I wouldn't be able to give him his injections. So he decided that he would give it to himself, so he does, and he does very well. [Wife (71) of man (72) with recently diagnosed colorectal cancer. Joint interview]

Stepping out

Carers had their own needs as well as tending to the needs of patients. Many interviews suggested that they sought to satisfy these needs in a variety of ways, while still rating them as secondary to the patient's needs. One area in which carers expressed strong needs was with regard to information. We had a section in the questionnaire which asked several questions about the importance of information - about 'medication and side effects', about 'treatment plans', about 'what to expect'. These items were all rated as important or very important by the large majority of carers, 87%, 90%, 90% respectively, higher in fact than patients' ratings (82%, 86%, 86%).

Carer: It's when I don't know something that I don't like it. And I think we have had so

little information in a way. [Wife (64) of man (72) with lung cancer at the palliative care only phase. Joint interview]

Information was obtained from health professionals in the main, but 69% of carers (67% of patients) rated 'access to other sources of information' as important or very important in the questionnaire, with carers who lived alone having significantly higher ratings for this item. In the interviews carers mentioned accessing other sources of information more frequently than patients. Charities, the Internet, libraries and personal contacts were cited as providers of additional information.

Carer: I've actually been burrowing away, being on the Internet, and pulled a lot of stuff off both for my own reference, and some of which I've given to A. [my daughter]. I've spent hours and hours really looking, finding out about the disease, and that's been a source of support for me. [Mother (51) of woman (26) with recently diagnosed breast cancer]

Carer: [My nephew's wife is a nurse] She was super, she phoned a lot and I was able to tell her the medical side of things. And she would explain what was happening and why they were doing this. She was great. [Wife (67) of man (67) with recently diagnosed colorectal cancer. Just carer interviewed]

Another way in which carers constituted legitimate needs separate from the patient was in a desire to acquire particular information which the patient might not wish to hear. This applied especially to the carers of patients with a poor prognosis, who wanted to know what to expect. It was notable that when this aspect of 'knowing' was discussed at interview it was only once a matter of going behind the patient's back, with all other instances involving the patient's consent.

Carer: I just don't have any idea what to expect. Now J. [my husband] certainly wouldn't like a doctor to turn round and say to him, "You've got 6 months, 12 months, or anything else to live." It sounds really mercenary, but I need to know things, because there are so many things need to be sorted. So I said to J., "I will want to ask [the nurse] things you don't want to know so I will talk to her on my own at some stage". So that was fine with him. [Wife (58) of man (61) with recently diagnosed lung cancer. Separate interviews]

Another aspect of the carers' 'stepping out' was in relation to their own needs for support. In the questionnaire we asked how important 'support from care professionals' was. 74% of carers indicated that it was 'important' or 'very important' (compared with 77% of patients). However, this was another area in which there was ambivalence in the interviews, as carers negotiated a position in which to satisfy their own needs in the face of the overwhelming needs of the patient. Health personnel spontaneously offered support to many, which was appreciated as legitimising their needs.

Carer: I got the feeling that everybody was sympathetic; they knew the kind of stresses that I would be going through. I felt supported as well. [Husband (48) of woman (49) with breast cancer at the end of first treatment. Separate interviews]

Carer: We met the Macmillan nurse and she says "How about you?" and I said "Oh I'm fine." She says, "Well you don't look it. I think you ought to have some help. How about having some aromatherapy? Leave it with me and I'll set it up for you." Which she has done. [Wife (57) of man (64) with lymphoma at the end of first treatment. Joint interview]

But many interviewees suggested that the health services were inadequate in addressing carer specific needs for information and support, as has been suggested in other studies (Anderson & Hopwood 1997; Eriksson & Lauri 2000). The understandable focus on the patient's predicament as the most serious concern led many carers to suggest that to take time for themselves was of

secondary importance. Comments that were made about support services indicated that carers felt that their patient and other patients (in general) needed the services more.

Carer: Everything was geared to you because you were the patient, which is right isn't it? It is right, you were the one that needed the physical help. But after that I felt as though I'd gone through a war mentally because I dealt with everything and I just didn't know who to unload it to. [Wife (50) of man (58) with colorectal cancer at the palliative care only phase]

Patient: I think [my husband] feels that because he's the carer, not the patient that they should - if there was any patient that [needed support] they should go.

Carer: [Someone] who would benefit from it. [Husband (57) and wife (41) with recently diagnosed lung cancer. Joint interview]

Nevertheless, five carers mentioned seeking help for themselves, mainly through primary care services. Several carers, however, did venture to suggest that it would have been good to have a service particularly aimed at them. Like the others, they felt that the main services should focus on the patient, but expressed their own need to have someone to talk to, some counselling, or a meeting separate from the patient in which they could discuss the implications of the illness. It was often carers of lung cancer patients, and carers who described themselves as very stressed, who expressed this desire.

Carer: But I do think from a carer's point of view, it would perhaps be nice to have a time when just carers could go, so that you don't feel that you are taking up the time that they are dealing with [patients]. [Wife (64) of man (72) with lung cancer at the palliative care only phase. Joint interview]

Not knowing who might provide for these needs was stated as a problem

Carer: When it comes to the emotional side, if you did need help you wouldn't know where to go, I wouldn't know where to go. I mean there's counselling, you could go to a counsellor, community psychiatric nurse, everything like that, there's people like that available, but how do you access them? [Female partner (20) of man (54) with recently diagnosed colorectal cancer. Joint interview]

Also the timing of help was mentioned by some

Carer: There isn't enough said. Mind you, the day they tell you is traumatic enough. You probably wouldn't take it in that day anyway. But I think a week later, there should be some follow up. Somebody should come and say, "Now this is what's going to happen." Or, "This is probably what is going to happen." [Wife (67) of man (83) with lung cancer at the palliative care only phase. Separate interviews]

Summary

While carers might adopt different positions at different times and under different circumstances, there were also indications that points in the cancer journey fell into certain patterns for carers. In the diagnosis phase carers were more diffident about their place, and often needed 'inviting in' by patients and health professionals. Experience of the medical setting led to greater confidence in their role for many, as they found ways of being involved and sharing aspects of the experience with the patient. However, carers' personal needs were more commonly expressed in relation to later phases, as they reflected on what would have helped them as carers. Therefore it is suggested that becoming a 'carer', and recognising oneself in that position, entails a process - stepping into the situation and moving on, usually with the patient, but sometimes separately.

The interview data displayed the paradox of carers' high levels of involvement alongside their uncertainty about their position in the medical setting. Carers' tendency to place their needs as secondary to those of the patient is understandable, but it does seem to suggest that carers may need some extra attention if their needs are to be satisfied. Carers' involvement in the cancer situation appears to help not only the carer, but the patient and the relationship between the patient and the carer. Issues around 'facing it together' require that carers are as well informed as the patient.

The qualitative nature of the data offers pointers as to how things might be made a little easier for carers in small ways. Being welcomed into the medical setting was a simple action, greatly appreciated by carers, allowing them to move on with the unfolding events. It also provided access to information, which our survey results suggest was of even greater importance to carers than patients. In taking up a legitimate place in the cancer scenario, carers may more easily attend to their own needs alongside those of the patient. While there were many examples of good carer support in the medical setting, there were fairly widespread comments by carers about not knowing where to go when they needed more help than was generally provided. Having designated, or more easily accessible, services for carers might ease this problem, but it should be noted that carers are only likely to take these up if they are persuaded that they are not taking anything away from patients.

Questions of confidentiality certainly need to be addressed in relation to the amount and type of information which carers desire, but this needs to be done in a flexible manner. Information and support is important to both patients and carers and our findings suggest that it would be beneficial in many cases for the patient/carer unit, rather than just the patient, to be the focus of care. Health care professionals may need to assess the levels of communication between patient and carer rather than have simplistic guidelines on confidentiality. The patients and carers in our sample may have been those who could most easily talk about cancer, but they demonstrated that many pairs are capable of deciding between themselves who needs what information, and that this is one way in which they support each other.

We have found it useful to consider 'carerhood' as an active process, rather than a fixed and passive state, and one in which competing needs vie for space. Our study suggests that carers must negotiate and legitimate their own position as part of this complicated process. The carers in our sample generally wished to position themselves in ways which supported the patient, but this meant that their own needs were often somewhat obscured. If carers wish to satisfy their own needs for information and support they face difficult and sensitive issues. We would suggest that health care professionals can help carers manage these issues through a clearer recognition of carers as a vital co-actors in the cancer situation.

CHAPTER 12 Good and bad practices from the patient and carer perspective

Introduction

This chapter summarises patient and carer comments concerning the ‘good’ and ‘bad’ aspects of the cancer services and professionals they encountered. It brings together the strongest ‘praise’ and ‘critical’ themes identified through analysis of the interview transcripts. These themes have been touched upon in other chapters but it is useful to bring them together here in concentrated form.

Good Practice

One of the project’s objectives was to identify examples of ‘good practice’ in meeting psychosocial need from the perspective of both service users and providers. This section deals with the views of the former (see Chapter 14 for providers’ perspectives). The ‘good practice’ category relates to the particularly favourable comments about aspects of the services experienced by both patients and carers. Just less than half (45%) of the 79 interviewees made comments coded as ‘praise’ for particular services or health professionals. In this section we draw heavily on transcript extracts, letting patients and carers speak for themselves. Consultants, GPs, junior doctors, Macmillan nurses, specialist breast and stoma nurses, community nurses, ward and clinic nurses were all cited as excellent in one way or another. Specialist oncology units in Lancaster, Preston and Manchester were highly regarded by many, as were hospices and the Lancaster cancer support services. Transport services also attracted some favourable comments. Those with stomas often mentioned the excellent delivery services available. The NHS as a whole was praised by a few.

The things patients and carers liked about these services and professionals were to do with efficiency and speed of delivery, and a sense of things happening fast and according to plan. Continuity, easy access, and being given time were also appreciated. The ‘attitude’ of health professionals was another important feature, with friendliness, genuine concern and clarity of information coming high on the praise list. Some carers spoke about being welcomed and feeling included as a boon to them. Together, these features added up to perceived high quality, supportive, care.

Patterns

Overall 49% of female and 40% of male interviewees made ‘praise’ comments. Of colorectal and lymphoma interviewees (patients and carers) around 40% praised some aspect of the services, while for lung it was 25% and for breast, 28%. Between 30-40% of comments came from three critical moments: diagnosis, end of first treatment and palliative care. Only 21% of moment three (recurrence) interviewees had special praise to give. The percentages of all respondents offering particularly favourable comments were 47% for patients and 44% for carers.

Efficient and fast services:

Efficient and fast services were an object of praise. Here are a few examples of positive statements:

Patient: Very pleasant at [Manchester] yes, they are very, very, good and they dealt with you on time, very quickly. I went in one day at 5 to 2 and they called me in at 2 o'clock...they were very, very, good. It's a nice place, nice, clean, tidy, well laid out, it's grand. [B29 man (71) with colorectal cancer at the end of first treatment]

Carer: All I can say is that staff and everybody were fantastic. And you won't get any better treatment whatsoever. You know, efficient and - they said what they were going to do, and

they did what they said they were going to do, and gone ahead and did it. [L99 husband (50) of woman with breast cancer (46)]

Patient: The NHS, people knock it but you know me and my husband think it's fantastic. You know I seem to have been seen very, very quickly for everything. [K133 woman (60) with a recurrence of breast cancer]

Patient: The important side is just that everybody's been so good and on the ball really, at finding things and treating it. So I mean they haven't wasted any time whatsoever. Everything they've found, I've been straight in, you know, and seen to, and that's it. [L472 woman (38) with recurrence of breast cancer]

Patient: Everyone's been really helpful, yeah, even when I was really down, you know, the doctor was out in no time, and like I say she got a psychiatrist out within a couple of hours! You know, and I've found everyone was really good, really helpful. [P74 woman (50) with recently diagnosed lymphoma]

Accessible services and easily available advice

Another valued quality of services hinged on good access to treatment and care, and readily available advice. Patients and carers particularly appreciated knowing that they could ring a health professional at any time.

Carer: knowing support from the medical profession [was there and helpful]. The young doctor [on the ward], the last word he said to us when he had the fever was, "Even if you get home, you come straight back if you are worried". So I've been told constantly just use the telephone immediately. [K167 wife (70) of man (69) with recently diagnosed colorectal cancer]

Patient: I think what's particularly good is that we've had an open line, a telephone line 24 hours a day.

Carer: And we can ring them [oncology unit] at any time, day or night, if we are worried, or even go up and call in if we are worried.

Patient: They don't make you feel that anything's too trivial to bother them with, you can phone them with absolutely anything. They make you feel very comfortable in doing that.

Carer: Yeah, they do.

Patient: That is so important, it really is. To know that that is there should we need it, and we've actually phoned them on a number of occasions. [L140 female, breast (26) and carer (mother, 51)]

Patient: We never had to call [the oncology unit] to say "I've got this problem", they were always available, somebody is available if something does go wrong, "ring us and we'll give you an answer", you know, "get you something, and tell you what to do." [L98 male, colorectal (53)]

Patient: It's been quite easy really... when I wasn't sure about one thing it was easy to just ring [the breast nurse] and say "can I come and see you?"...

They're busy people but there didn't seem to be any rush. I think this is the same right through. People are there and they do give you the time... I think the service has been first class. [K133 woman (60) with a recurrence of breast cancer]

Carer: The Macmillan nurse comes, and we talked to her about [a difficulty] and said we were a bit upset about it, and she said "well, do you want a second opinion?" So we thought about it and said we've nothing to lose. Yeah, we'll go for it. And it's gone from there, and since she's been involved with us and come round and said "if there is anything you want I'm on the end

of the phone”, she's been marvellous hasn't she really? [K473 Husband (57) of woman (41) with recently diagnosed lung cancer]

Heath professionals' with a 'good attitude'

Both carers and patients picked out particular health professionals in service settings for praise. Among other qualities such as kindness and consideration, it was their general attitude that was appreciated. Openness and responsiveness to enquiries was valued, as was 'taking time' and a willingness to give explanations.

Carer: It's not so much the surroundings, it's the attitude -

Patient: It's the people there, as soon as you walk in everyone's got a nice word to say and there's a lot of smiles, nothing is too much trouble, and they have a laugh and a joke with you. And if you ask a question, you get answers straightaway. [P254 male with colorectal cancer (54), partner (20)]

Patient: And I would just like to say that I've been treated magnificently by all the staff at [the hospital], ... there's a happy atmosphere, the staff are happy all the time, it doesn't matter what's happening, the staff are happy and the staff make the patients feel happy. [P280 female, lymphoma (49)]

Patient : But [the doctor] certainly went out of his way. And I was impressed when all me records came up here, even the piece of me that they took out, well it's on a stain, and he showed me upstairs on the microscope and, “This is part of you”. We looked at it, this lymphoma. [L150 male, lymphoma (49)]

Carer: He [the surgeon] just looked at me and he said “So much for All Bran” [laugh]. So that cleared the air then, so we both knew what to expect and I really gave him a lot of credit. In a layman's English they just told us everything that could be told obviously at that point, and obviously it was something that was going to be done NOW, as soon as possible. [K167C male, colorectal (69)]

Patient: We went to see [the surgeon] one night and he was an hour running behind. It was quite late when we got in to see him and he apologised straightaway for being late. I said “it doesn't matter”. And he said “well I'm supposed to be [somewhere else at 7.00pm]”, and it was about 10 to 7 then, and he'd still people waiting. But he never rushed you, he never, he sat and talked to you and he was really, really good. [L348 female, colorectal (63)]

Patient: All the staff, without exception, [at the oncology unit]... they've obviously been trained very, very well in how to deal with patients. Nobody is rude and some of the people who go for treatment are terrible moaners, because the treatment was running late on a number of occasions. Well that's fine, it happens doesn't it? People are sitting moaning about it, and I couldn't believe that anybody would moan about that sort of thing. And they would be rude to the staff as well but they never, they kept smiling, and I'm sure half the time it was through gritted teeth. They were absolutely super, really, and very encouraging - always wanted to know how you were feeling today. “Anything we can do to help?” “Remember the side effects you might have”, and so on. I really couldn't praise them highly enough. [L227 female, lung (55)]

Patient: They [the oncology unit staff] genuinely seem to care, if you ask them something they will go out of their way to try and find an answer. [L98 man (53) with colorectal cancer at the end of first treatment]

Carer: Genuine concern.

Patient: It is genuine concern.

Carer: Not just because they're employed at the end of the month, or whatever.

Patient: Yeah, it comes out in their manner ...When we went for that bone marrow we were treated like Queen Mother and Queen. [P164 female with breast cancer (55), daughter (30)]

Carer: Oh he's been great that Dr [oncologist], I've been with him, and he talks to you both... and explains things.

Patient: They all do there, all the nurses, don't they? [P2 woman (49) with breast cancer at the end of first treatment, husband carer]

Patient: The lady [nurse], she just held me, and of course I was crying. She was absolutely superb. [P234 wife (50) of man (58) with colorectal cancer at the palliative phase]

Patient: The facilities at the [oncology unit] are very, very, good indeed, exceedingly good. And they look after you very well... they treat me like a human being with fears and all the rest of it. [[P308 woman with breast cancer at the palliative only phase]

Carer: And all these wonderful people around us, and the Macmillan nurses and the hospital have been absolutely marvellous you know, you'd never get this anywhere abroad, all this treatment. I know from experience because you know I come from there. [P295 wife (51) of man (63) with lung cancer at the palliative only phase]

Patient: I found that the two operations were actually not what I'd always dreaded in life, they were actually great celebrations of life because I did come back, I was there, the anaesthetist was there and we had a joke. It was just like coming back from a party because it was just so wonderful to be alive [laugh]. So maybe I am - like they say about people who are converted to a particular religion are - always more enthusiastic than people who are born into it. This was my first experience of the National Health Service and I thought they did wonderfully well. [K239 woman (49) at the end of first treatment for breast cancer]

Help with transport

A few patients were very grateful for the assistance with transport made available to them:

Patient: And there was a car waiting for me to bring me home, it was fantastic. [B22 woman (76) with recently diagnosed breast cancer]

Patient: The transport was a boon. I mean I can rely on myself but I couldn't at the time. [My husband] can drive but some days he's good and some days he's not, and so I was a bit worried in case, if it wasn't good, then I couldn't get there. It was all sort of worrying, because 15 days is quite a lot. [P87 woman (64) at the end of first treatment for breast cancer]

Bad practice

This section focuses on those features of services and practices that patients and carers criticised or complained about in interviews. Interviewees tended to be very discriminating, offering praise where it was due *and* drawing attention to difficulties if these had been encountered. Complaints were usually made in the context of overall satisfaction with services. It should be remembered that we presented the study to service users as one that could help to 'improve services', so discussion of difficulties encountered was given legitimacy. We have summarised these findings under the main themes of waiting, hospitals, attitudes and money.

Waiting

To know what happens next (test results/operations/treatment)

Waiting for the outcome of test results or treatments was often portrayed by patients and carers as the worst of times. A sense of urgency was strongly felt, as were feelings of relief when action was

taken - something was happening at last. Some delays due to apparent mismanagement were evident. For example, appointments not coming through or only appearing after a considerable wait. In addition, for new patients there was a sense of not knowing what or when to expect medical intervention. An unnerving sense of delay was particularly acute for lung cancer patients, several of whom felt they were left in limbo after the diagnosis (see Chapters 7 and 8). Patients and carers very much wanted detailed information on the likely course of events, as well as about the illness itself.

In out-patients

Waiting around out-patients departments, and delayed appointments, was a common complaint, although generally qualified with an understanding of the importance for all patients of having enough time with the doctor. Clinics could be uncomfortable places too, especially for patients feeling particularly ill. Emergency visits to A&E were often described with horror both at the time taken and because of the nature of other clientele. The A&E department in a hospital in one study site appeared to be a particularly distressing place to be. However, the specialist cancer clinics (Macmillan units in Lancaster and Preston) were often held up as paragons of good experience in contrast to more generalist services.

For someone to visit

A particular cause of disturbance was the promised or expected home visit that did not occur. This was usually in relation to Macmillan nurses, but other community nurses and a physiotherapist were also mentioned. Sometimes one visit took place and no indication was given as to when the nurse or therapist would return. Some interviewees in the palliative care phase thought that once contact was made they would receive regular visits and were disappointed when this did not happen. This seemed to be a more common experience among lung cancer patients and carers, and patients and carers in one of the study sites.

Looking back in time - GP/consultant delay

There were several instances where, from the patient's or carer's perspective, a GP or consultant had caused delays in diagnosis. Accounts were given of some GPs attempts to treat the patient for weeks or months before referring, and a few consultants had failed to discover the cancer. Again, it was mainly lung cancer patients who experienced this problem. Two patients were actually considering making official complaints when their treatment was complete. Looking back, several patients wondered whether they might have stood a better chance if their cancer had been spotted earlier. Patients recounted being particularly distressed when a health professional had not believed their insistence that something was wrong.

Hospitals

The wards

Being on a general ward was a variable experience, with some patients praising staff and others speaking of it as a difficult time. Problems were encountered in a hospital in one study site, with morale among staff described as low, and care depicted as 'do-it-yourself'. Some examples are as follows. One man recounted being discharged when still bleeding heavily; he had to be readmitted as an emergency. A private patient on an NHS ward outlined problems he encountered with the NHS bureaucracy. One woman described her distress at being on a ward with many elderly and confused patients. Particular shortcomings in staff awareness of disability were described by the mother of a cancer patient with learning difficulties. A few respondents had difficulty in understanding the medical hierarchy on the wards. Many patients mentioned having seen numerous health professionals; whilst this was not necessarily presented as a problem, an appreciation of continuity of care suggested that people preferred to get to know a small number of health personnel whom they saw regularly.

Ambulances

Two patients described particular problems with the ambulance services and the attitudes of the ambulance drivers. One had made a formal complaint.

'Little things'

Hospital food was mentioned as a problem by a few patients. One carer described difficulty in finding the canteen in one hospital. Car parking at two hospitals also caused problems for carers and patients.

X-rays

Going for an X-ray seemed to be unpleasant in one hospital due to staff attitudes, mentioned by two patients.

Far away

Having to travel a long way was generally accepted, although the costs incurred by a few were a problem. Being far away from family and friends whilst an in-patient was mentioned as difficult by a number of patients. On the whole, patients and carers preferred treatments to be as close to home as possible.

Attitudes

Just a number

Interviewees really appreciated being treated as an individual. Particular health professionals who made them feel like a 'number' were criticised, even if this was qualified with an appreciation of the professional's clinical skill and a comment that most professionals were 'great'. Not being listened to and treated with respect is also of relevance here, with one formal complaint being made against an anaesthetist on this account. An overly pessimistic manner on the part of some professionals, especially doctors, was difficult for patients and carers to cope with, but insensitivity, particularly around diagnosis was a cause of great distress. Such insensitive treatment had occurred in at least six cases. Having privacy, and the presence of the carer, were deemed especially important in cases where the diagnosis was conveyed insensitively. Being 'warned' that the diagnosis was imminent and might be 'bad news' was described as helpful where it happened - as 'lessening the blow'. An unexpected diagnosis of cancer caused considerable shock and in a small minority of cases was given without psychosocial support from staff (see Chapters 7 and 8).

Being forgotten

As with the sense of being in limbo after diagnosis which some (particularly lung patients) felt, so feeling abandoned was cited as very distressing. This quite commonly occurred after a course of treatment was completed, or through the perceived mismanagement of systems, or through the lack of expected home visits.

Too much sympathy

In a few instances, nurses, in particular, were felt to be overly sympathetic, waving boxes of tissues around prematurely. A minority of other nurses were presented as seeing the patient as less than an adult, and as being overly patronising.

Money: The system and forms

If financial hardship was caused by the illness this was often a great source of distress. Welfare benefit services rather than health services were the object of criticism here. The system seemed impenetrable by many patients and carers, and the claim forms incomprehensible. The minority who struggled with the welfare system spoke at length about the difficulties encountered, and even suggested that it was worse than the illness. Some health care professionals, usually Macmillan nurses, but sometimes GPs or even consultants, had been instrumental in informing patients and carers of their entitlements, and/or helping to obtain benefits. Where this happened people were delighted.

Summary of the more serious bad practices

Some complaints were rather more widespread or heartfelt than others. Frequently the complaints were presented to the interviewer as 'minor' and outweighed by the generally good service received. Some were felt to be more serious and these are listed here:

- delayed diagnosis (in two instances, formal complaints were being considered);
- being left 'in limbo' (particularly lung cancer patients);
- not being given a plan of what to expect in terms of treatment and home visits;
- insensitive information giving by doctors (especially diagnosis);
- not being treated with respect (one formal complaint made);
- Some aspects of the service at a hospital in one study site were criticised (including ambulance services - one formal complaint made);
- difficulty in obtaining welfare benefits.

CHAPTER 13 Health professionals' perspectives on their roles in cancer care, with particular reference to psychosocial needs

Introduction

One of this study's aims was to examine service providers' perspectives on the nature of current service provision and its adequacy in meeting the psychosocial needs of patients and their main carers. A further aim was to identify examples of 'good practice' from these providers' point of view. The data of most relevance here was obtained through 39 structured interviews with a wide range of health professionals in the project's main stage (interviews with professionals in the project's pilot phase are reported in Appendix 3b). The interviews were structured around the following issues: the respondent's role in cancer care and in identifying and meeting psychosocial needs; links with other professionals and services; service effectiveness, service changes (see Appendix 7 for the interview schedule). This chapter reports on some of the findings generated through the analysis of 39 interview transcripts, focusing on: the ways in which professional groups' described their role in cancer care, with particular reference to psychosocial need; the theme of communication with patients and carers; and the theme of co-ordination between professional groups in cancer services. Chapter 14 reviews findings on the perceived strengths and weaknesses of current practice, with examples of reported 'good practice'.

The professional groups represented in the 39 interviews included: consultants, GPs, specialist nurses, dieticians, support service co-ordinators, and general managers.

Table 33: Interviews with health professionals by professional group and study site

Professional Group	Site 1	Site 2	Site 3	Total
Consultants	3	2	3	8
GPs	9	3	3	15
Nurses	4	5	0	9
Dieticians	1	1	0	2
Support Services Co-ordinators	2	0	0	2
Health Service Managers	2	1	0	3
Total	21	12	6	39

Health professionals found it difficult to estimate how many cancer patients they saw. Only a few had records which could be used to retrieve this sort of information. In addition, patients were seen more or less intensively at different times during the illness, and in different places (clinics, home, GP surgeries), involving varying amounts of professional-patient contact time and levels of discussion. However, it was clear that the specialist nurses spent more time with cancer patients on a daily basis than GPs, with consultants somewhere in between, as would be expected. Findings associated with each professional group is considered in turn.

Consultants

How consultants described their role

The main way in which the consultants described their role was as providers of diagnoses and treatments, that is, they dealt with the disease rather than the person with the disease in the first instance. They spoke of directing services and providing palliative care. Meeting psychosocial needs was not seen to be central to their role, although individual styles of practice differed. For example:

Consultant: I'm not sure that my own personal part of the service actually sets out to meet those [psychosocial] needs. I think the surgeon's job is to mainly to manage the cancer itself, though obviously you have to manage the whole patient as well and also to direct this service to a large extent. The psychological needs are built into the service, really, from the breast care nurses and also from other areas. Having said that, I think in most good breast units a lot of psychological support is provided by the surgeon. And I think that's reflected in the fact that patients don't want to be discharged. [GD1 consultant, breast, male]

Consultant: My contribution to cancer services is really diagnostic. ... If cancer requires treatment I'll hand the patient over to a surgeon who'll do the treatment... I tend not to do much in the way of treatment myself, very, very little. If the patient's actually dying of cancer then I carry on and give the patient the general palliative care. But my main contribution is really diagnostic. [GD3 consultant, gastro-enterology, male]

Consultant: Nurses look at patients, nurses look at people first and look at how their disease or condition impinges on them. Doctors look at the disease first and think about how the disease can be treated and then they think about how it affects the patient. I mean it's just the way we're taught. ... It may be didactic, and it may be different from the WHO definition of health... I suspect that we, even if we simply treat a lot of people and treat their cancers and pay no attention whatever to their psychological and social needs, we are still doing greater good for the community than if we hadn't treated them in the first place. I mean I think that's an arguable point of view, a contentious point of view. [HD1 consultant, breast, male]

Consultants and nurses

Recent policy recommendations aim to promote greater collaboration between doctors and nurses (Davies 2000; Salvage & Smith 2000). Davies calls for greater 'dialogue between people who have not yet understood what they can achieve in common' (Davies 2000: 1021). She suggests that doctors and nurses have not travelled far along this road, for historical and cultural reasons. The doctors and nurses we interviewed suggested quite a high level of appreciation of each other's skills, but varying degrees of collaboration. Doctors were particularly appreciative of nurses' skills in relation to addressing the psychosocial needs of the patient. In fact, there were clearly divisions of labour in operation such that nurses were often expected to deal with patients' psychological and emotional needs. Such allocations of responsibility are clearly gendered: many male doctors see nurses, as women, to possess qualities that enable them to engage with 'feelings' and emotions more successfully than can they (Annandale & Hunt 1999). Consultants frequently constituted the nurses as having the time, the approachability and the disposition to handle the psychosocial aspects of care:

Consultant: ... from my perspective I think the point of the service that works best is the care of the patient at the time of diagnosis. I take no credit for that whatsoever... it's very largely down to the breast care nursing service. I would typically spend no more than half an hour with somebody, an appointment in a clinic. There is a limit to what you can do in half an hour when you are talking to somebody. The breast care nurses spend a lot longer, they get to know the patients a lot better than I do. [FD2 consultant, breast, male]

Consultant: Basically, we do the two-stage approach. I tell the patient what's the matter and the nurse following me around in the outpatient [clinic] picks up the damage. Now I always thought when I was in training that it shouldn't be like [that], the doctor who gives the bad news should also be able to be there to pick up the pieces. But it's best, I realise now it's best done as a team approach - that the doctor gives them the bad news, and the doctor may be thanked for being so straight and honest, or the doctor may be sort of the 'baddy' in this. So once the doctor's gone out then the nurse can come round and say "Well you know" put her arm round, make them a cup of tea and get close and what have you, and repair some of the damage. ... And then the patient can open up and ask questions of the nurse. They can't to me

because they're just devastated by what I've said and try as I can I can't get round that situation. So we really need that follow-up service. [GD3 consultant, gastro-enterology, male]

Consultant: ...apart from moderate, moderately developed skills in giving people bad news, which of course vary from one doctor to another, apart from [that] we rely almost exclusively on people other than the primary clinician, if you like, to provide that sort of psycho-social support. Now in the breast unit we've got breast care nurses ... who are involved right from the word go. Most of our patients, or most of my patients with breast cancer, meet the breast care nurse often before they meet me and I rely very heavily on [them] to keep me informed about problems. ... There are two different approaches. I think nurses are instinctively better at it. [HD1 consultant, breast, male]

Interestingly, changes in the status of nursing in some areas of health care, such that they take on tasks formerly undertaken by medical professionals (Annandale 1999), is reflected in the following account:

Consultant: Over the years the nurses have tended to become more like junior doctors, because we haven't had any junior doctors, and they are highly skilled, very experienced and a very good opinion. In truth this unit runs on consultants and senior nurses. There's no doubt that the nurses are functioning now at a level which is as good as the best SHOs. I'm very dependent on their opinions, I trust them completely and they know the patients well, and if they ring up and say there's a problem, okay there's a problem. [FD3 consultant, haematology, male]

Consultants and communication with patients

The second quotation above indicates a fairly common division of labour related to the imparting of 'bad news' and the associated provision of psychosocial support: doctors do the former which nurses deal with the latter. However, most consultants demonstrated awareness that there must be 'good communication' with patients on their part – whether this involves the imparting of bad news or the giving of information about other aspects of treatment and care. Good communication was usually associated with the qualities of honesty, timing and creating a sense of confidence. Many consultants prized good inter-personal skills and sensitivity in other doctors and themselves.

Studies which have looked at consultant 'styles' have suggested that these professionals develop their own strategies and ways of viewing the patient which will affect the way they deal with communication (Britten 1991; Taylor, 1988). Britten (1991) suggests that doctors in favour of patient access to their medical information hold a more psychosocial model of illness than those who opposed such access. The consultants we interviewed tended to exhibit a psychosocial model of illness such that imparting bad news involved paying attention to matters of trust, personal manner, and the time and place of news and other information giving. Some talked about adapting the information to the patient and trying to assess the patient's informational needs, but lack of training and personal attributes were also configured as part of the 'lottery' of good information giving. Two consultants mentioned medical fallibility as a problem for which they had no solutions.

Consultant: Well, I think information is critical and we have long pursued the policy of openness even before it became the law to show patients their case notes and results and to try and explain what was going on and why we had come to the conclusions we had. I think if a patient or a carer has a good understanding of what the problem is, that's half the battle. Very often they can then come to terms with it, come to grips with it, and deal with it much easier. Now, you can't always do that, sometimes patients just don't understand, sometimes they don't wish to understand. They may be very young or very old. They just may not have the background, there may not be the common vocabulary and part of my job, I think, is trying to set the level in any discussion. ... I think that information may need to be repeated, partly because a lot of people are not used to taking on board new information and digesting it,

processing it. They may need that repeated. It's critical to keep the story straight. And that's the main reason for being honest I think. If you start to bend the truth or tell untruths then you'll be caught out and lose the patient's confidence. So we always try to be straight and honest, I hope we are not cruel or unkind and I know personally I always have a tendency to soften the edges a little, and if you think about the language you are using in these interviews with patients you often find that you've taken the edge off things. Hedging, little adverbs just to make things not quite so bad as they are. So, information all down the line, accurate and honest information, information that the patient can understand, clearly understand. [FD3 consultant, haematology, male]

Consultant: I'm fortunate at the moment in having a Trust grade surgeon who spent quite a bit of time in breast disease and he's also very good at establishing rapport with patients. The patients like him and get on very well with him, and he's got good inter-personal skills, but you don't always have that, [it's a] lottery. They're very variable and it makes a big difference. With some of my previous trainees, I've had to spend quite a bit of time afterwards picking up the pieces where they've not been as tactful as they might have, and so on. And so I'm very lucky with my present incumbent, he's very good at that. [GD1 consultant, breast, male]

Consultant: When I see a patient who's recently diagnosed with carcinoma, or even before you get to that point, I will try to address whatever issues arise and whatever it means for them really. I mean I don't go probing, but I may spend half an hour in the clinic talking to somebody, on several occasions. So I spend a lot of time talking about things which aren't necessarily clinical, I mean I spend a long time discussing what their life expectancy is, whether they might die from this, and what the implications might be and all these kind of uncertainties about life and the balancing of risks and those kinds of issues. [GD2 consultant, colorectal, male]

Consultant: Telling patients and their families - it's the breaking bad news that's the difficulty because people usually have no idea of this sort of thing that they're dealing with, especially younger people, no idea that they've got cancer. And it's really a matter of not hiding anything but letting the truth sort of trickle to them at a speed in which they can absorb it without wishing to absolutely devastate them straight off. ... Well bad news is bad news really... you can't take away all the nastiness of life, it can't be sanitised completely. [GD3 consultant, gastro-enterology, male]

Consultant: Usually the surgeon is the first consultant that the woman sees with the new diagnosis. I think it's quite important that whoever the person giving the diagnosis to the woman is does so correctly because how she views the hospital service that she is now going to will depend upon that to some extent, and how much confidence she has within that service. So that's quite an important first interface - between the patient and the surgeon. Confidence in the hospital service is very important because you are potentially going to recommend a lot of rather unpleasant treatments if it's surgical in the form of a mastectomy, if it's medical in the form of radiotherapy or chemotherapy. So it's very important that the woman feels confident that you're treating her as an individual and yet treating her with the best possible chance of eradicating or preventing further trouble with the disease. ... To be told that they've got breast cancer is a very upsetting experience. It can make some women extremely distraught immediately, or if not immediately certainly within days of being told of the diagnosis once they've had chance to think about it. So I think that one has to give as much time and as much empathy as is possible, not to overload someone with information in the first instance certainly, but to offer as much information as you think that particular woman can take at the first time, and then to offer avenues for further information and further questioning before the primary treatment takes place. That might be through breast care nursing service or it might be through further clinic appointments, or it might be through their General Practitioner, but most commonly a combination of the three. [FD2 consultant, breast, male]

Consultant: We are very much aware, as are most people treating cancer, that the psychological morbidity is considerable. I mean for years it wasn't recognised. When I was a medical student, it was just, "Well you've got cancer my dear, I'll remove it, and off you go". And we recognise that that's enormous. The actual surgeons and the medical clinicians have relatively little training in it apart from an increasing ability to recognise it. So almost invariably...it's ensuring that we discuss frightening, life threatening, health threatening things in an appropriate environment. [HD1 consultant, breast, male]

Consultant: From my point of view, in a sense, we always end up with dissatisfied customers, because the need, the basic need of all of our families is for information we can't give them, like how and when. I mean what they really want at the end of the day is to be well and we can't achieve that, so there are very deep psychological needs that will never be fulfilled for the patients or their families. [HD2 consultant, palliative, male]

In these extracts from interview transcripts, as in others accounts, the patient (and wider family) is very much positioned as a rather passive recipient of information. In the large literature on information giving in cancer contexts, the patient is usually similarly positioned (Fallowfield & Jenkins 1999; Fallowfield, Ford & Lewis 1995; Galloway, et al, 1997; Gray et al 1998; Meredith et al 1996; Slevin et al 1996; James et al 1999). Such studies emphasise that patients often wanted to be given more and wider ranging information than they actually received. In other chapters we too have reported that patients and carers often wanted more information. It may, however, be more helpful to think about patients as potentially active rather than passive with regard to information exchange, that is, as participants who would sometimes welcome the opportunity to express their information needs more openly and to shape the information dialogue more purposively. Some recent studies have taken an approach more in line with this such that the patient is positioned as an active, although unequal, participant in managing the information flow (for example, Leydon et al 2000; McWilliam, Brown & Stewart, 2000). These studies suggest that information sharing and relationship building are important for patients in the managing of information, and that dealings with the consultant take place in a wider context of social relationships. Some clinicians are also beginning to recommend this approach (Metcalf 2000), and NHS policy is advocating patient empowerment and partnership (NHS 2000).

Consultants presented themselves as very orientated to the patient and made little mention of carers. When asked about the psychosocial needs of carers these tended to be acknowledged but not elaborated upon. Consultants talked about carers less than other groups of health professionals, although both palliative consultants spoke about carers at greater length.

Consultant: On the whole, I think by the hospital part of the service the needs of the patient are catered for quite well. I'm not quite so sure about the carers, breast care nurses are probably better placed to answer because they see more of the carers. Us at the clinical end, we don't quite see so much of the carers, they often accompany the patient to a clinic but don't get involved in the interaction of the consultation very much usually... As I say I think the ones who slip through the net a little bit are the carers. The service isn't set up for them. [GD1 consultant, breast, male]

Communication with other health professionals

Consultants also spoke of the importance of good channels of communication between all health professionals involved in cancer services. Their main points of reference were the nurses, consultant colleagues and GPs. This was seen as an area where improvements in systems and practices were necessary, and sometimes underway. For example:

Consultant: I think that a wonderful thing that we have in this country is primary, not just general practice, but primary care. The GP and his team. The patients know the GP for years, they have confidence in the GP and the GP can see them in their own family setting, he can visit them at home. The important thing for me is to communicate very, very well with the GP. And I've got to tell the GP the clear diagnosis, formulation of management plan, give the GP the ability to refer back if necessary, and also to tell the GP what I told the patient. So he knows where we started from. And that's got to be done very, very quickly. ... The worst thing is when a patient who's in hospital diagnosed with having cancer, goes home, phones for the GP, and the GP goes round and he's no idea what's the matter with the patient, he's not heard from the hospital. That's the weakness. [GD3 consultant, gastro-enterology, male]

Consultant: I think we could improve our communication at times. There are a lot of things that we're trying to set up at the moment and we are in a state of flux setting up multidisciplinary meetings on a weekly basis. This is very important so that we input into the care of a woman with breast cancer throughout her disease process and throughout her primary treatment and follow up. It's too early to say how they're going to work. I think that there are times when we could just sit down and pick up the phone and communicate better between health professionals, and often we don't because it's 6 o'clock by the time the clinic is finished and you've lost the opportunity. But I think, by and large, I think it works reasonably well in the system that we have set up. I don't think it's perfect by any means but it works reasonably. [LD2 consultant, breast, male]

Consultant: I think we could have much stronger links with the GPs, I think that's a bit of a weakness. It's a bit different here to where I've been used to working, where usually the GP in primary care considers himself the key person who refers in and out. And so the GP decides who he'd like to come to the hospice, to day care, to palliative care clinics. [In contrast] the GP is a bit sidelined here. I don't think they are unhappy about it, but the way the system works is that the cancer support nurses pick [patients] up, maybe in the hospitals or [the oncologist's] clinic or wherever, and will refer them to me or to day-care, and the GP may know nothing about it at all. So then, [patients] come in here, we sort them out, and we ring the GP and say would like you to prescribe so-and-so and he says 'oh well I haven't seen this patient for six months', or whatever. So I'm aware that medically our links with the GPs need to be improved a lot. [FD1 consultant, palliative, female]

Consultant: Communication is absolutely the key really. The one thing that we try to do at the moment is to improve on our notification of deaths and discharges to GPs. But the problem isn't in a sense with us, the problem is with the GPs - they're not there 24 hours a day. So when a patient dies over the weekend, we have to wait until Monday to notify them. Monday morning - you try and get through to a GP's surgery on Monday morning [laugh] So as part of the new computer system that's going in we're able to send faxes from the computer in the offices, and so we're just looking at a system where as soon as the patient dies, the fax goes off to the GP.... so if a patient dies in the middle of the night, a fax will go off in the night, and it's there when then doctor goes in the next morning. [HD2 consultant, palliative, male]

Clearly, good quality communication between health professionals, and especially across primary, secondary and tertiary care, is an issue of great importance.

General Practitioners

The GP's role in cancer services

The National Cancer Plan (Department of Health 2000a) and the Calman-Hine Report (Department of Health 1995a) both place emphasis on the importance of primary care services in cancer treatment and support. A document produced by the North West Region NHS Executive (1999) about the accreditation process in primary care identifies a GP role in all aspects of cancer care from pre-presentation to palliative care. However, Summerton (2000: 1090) suggests that there is a 'dissociation between general practitioners and large parts of the care of patients with cancer'. Cooper & Pemberton (1996), in discussing the cancer services envisioned by the Calman-Hine Report, suggests that the role of the primary care team is not well described, despite it being a main focus of care.

Through the analysis of our GP interview data, a key theme to emerge was the relative marginalisation of GPs in cancer care. If GPs were involved in care it tended to be at the terminal stage of the disease. Being marginal was often, but not always, perceived to be problematic by GPs. Opinions and practices differed, with some GPs desiring greater involvement in the care of their patients with cancer whilst others were content to leave much of the care to specialist doctors and nurses in cancer treatment and palliative care services:

GP: There have occasionally been times when I've felt my involvement as a GP in cancer care has been marginalised. I'm not sure it's always intentional - so many good people are doing a good job, and the GP can get left on the outside. Okay, that's a position one can live with, but it is one of the few areas left in general practice where I think the GP can play a very major role which probably no-one else can play in quite the same way.... And to then have some attitudes from cancer care that the GP is rather peripheral is, well, something I'm not at ease with. I'm sure it's not always intentional. I'm sure there are some patients who don't want me as their GP getting terribly involved, but on the whole my experience is they do like their family doctor to be involved, and many a time they'll come back from seeing a specialist and they ask me what do I think and they do value that relationship of trust. [FGP5, male]

GP: [Patients] are plugged into palliative teams very frequently in this area and the GP is pretty often just seen to be a source of routine medication and calling *in extremis*. To an extent GP's can be marginalised because of the expertise of the palliative care teams that are around. And you can become quite de-skilled as well, I mean, that's the aside. So, on a personal basis, one would hope that we wouldn't ignore all the psychological and social problems, but I'm sure that we do, I'm sure that we do. [HGP3, female]

GP: What tends to be a pain is when [patients] are referred down to [cancer centre x or y] and [they] tend to latch on to the patient and everything has to be done down there and then, we don't get a look in. It's very difficult to work out what's going on and our perception from this end is that people are treated too aggressively for too long, and we tend to have communication difficulties I think is the best way of putting it, with regard to what we're going to do. [FGP3, male]

GP: I would say hugely in this area, if you send somebody off as a suspected cancer case by the time they come back diagnosed all these [specialist staff] are already attached to them. ... I've always been very happy to refer to them. I know in some ways it devalues oneself, and people feel deskilled - you send people out there for this and that and all you do is sit in the middle. But they've got the time and the skill and the expertise to do it, which I don't have, and that's the way it should go. So I think probably we are best at co-ordinating and ensuring that people get the most appropriate services, taking some small part and sometimes a large part in the delivery of what they need because some people will lean on us more than others for counselling and ensuring they are properly directed in getting what they need. [FGP2, male]

Overall, despite some misgivings, many GPs were happy to make full use of specialised services, and most would refer to the hospice. GPs also referred to the need to take account of differences among their patients and carers – people were variable in terms of their needs, demands and preferences.

Among consultants, opinions also differed about the proper role of GPs in cancer care. For example, one consultant felt that GPs should provide the major care to terminal patients whilst another thought that GPs did not always have the knowledge to treat dying patients:

Consultant: But similarly I'd leave [follow-up care] to the GP, I think that's an extremely important part of general practice and I don't believe in transferring that responsibility from the GP onto the hospice. [GD3 consultant, gastro-enterology, male]

Consultant: I mean we know that there are GPs in the area that don't appreciate what palliative medicines is about, and they're not likely to sell our services in the best light. I mean we have doctors who will say to us they don't need us because they know all about palliative medicine, or normally what they say is that they know all about terminal care, because they're [conflating the two]. [HD2 consultant, palliative, male]

The GPs' role in cancer care

When describing how they dealt with patients and carers' needs GPs nearly always started with their role as co-ordinators for cancer care, and as a point of interface with hospital services through referral mechanisms. They saw their job, first and foremost, as accessing the necessary range of services so that their patients' treatment and support needs could be met, acting, as it were, as the hub of a wheel:

GP: We certainly see ourselves as the first point of contact, and then pretty much co-ordinate the care... When there are problems the patients tend to contact us more often than they would contact the other services. [GP1, male]

GP: We certainly have a co-ordinating role in the diagnosis and treatment of cancer, and therefore in ensuring that patients and their families know what's going on, and that they are referred to appropriate agencies. People lean quite heavily on us sometimes and it's very flattering that they do. Being a cynic, I think it's probably because we are the only service which is available all the time. You can ring the doctor and you can go. [GP2, male]

GP: At the end of the day you're the patient's advocate, so you're just going in there to see what can be done from a medical side, and you're also trying to attend to the psychological, social, and spiritual sides as well. ... You're always pressurised for time as a GP, and so you are limited to how much you can do but ... you're rather the conductor of an orchestra, you involve people, other professionals, professions allied to medicine, in appropriate times and appropriate places, with the agreement of the patient. [HGP2, male]

GP: I've always been aware of the huge burden put on people collectively, patients and families, by cancer and have been a great advocator of having services to support them. It's not unique to cancer but it's a nice tidy one is cancer, and it's got itself a large niche in the health service and outside the health service which is very well supported. [FGP2, male]

Alongside a co-ordinating role, a directly supportive role in dealing with the treatment and psychosocial needs of patients and families was also described by most GPs. This frequently involved attempts to relieve distress and anxiety through providing information, explanations, and a 'listening ear', and showing empathy, as well as the provision of practical support. Offering support was sometimes situated in terms of their personal knowledge of individual patients, their

families and their circumstances:

GP: My function is supportive, educational and attending to their daily needs. [FGP5, male]

GP: ...my role is a supportive role for the family and the patient. I'm there to answer their queries, and try and help them make decisions as to treatment pathways, or pain relief needs, or whatever... If we do feel that there's a need for either assessment or counselling then the right people are contacted. That's what I feel I should be doing as a GP.[FGP7, male]

GP: Basically I start with my relationship with the patients. Hopefully the antecedent relationship, before the diagnosis is established, with all my patients is good. When the diagnosis is made I try to get closer even, to get the best possible rapport with the patient - make them aware of the fact that you're aware of how devastating the diagnosis has been to them. And that you're there for them if they need you.... They're often attending lots and lots of clinics - consultant clinics and radiotherapy clinics, whatever - but I think that they look upon us as the person they'd probably go to first if they had a problem. And I try to make that clear that I'm absolutely open to that, at any time. You know, if they're worried about something they can phone up and they can speak to me that day, or I can see them if necessary. [FGP8, male]

GP: I like to try and deal with the explanation of the actual illness. I mean a lot of people think cancer equals death, and they can't see any interval between the two, so I try explain what the diagnosis is, what it means, and try and give an outline of the options of treatment that might be available.... I try to give a reasonable kind of prognosis for the illness, in that way trying to address the overall fear about this terrible frightening affect of being diagnosed as having cancer.... So, to try and break it all down really into its individual parts - what is the cancer, what does that mean, how is it likely to go on from here, what can we maybe do about it, what's the prognosis, and what way we might be able to help. [GP3, male]

Reference was frequently made to variations among patients and carers, for example, in age, social circumstance, psychological outlooks and attitudes. This gave rise to variable support needs:

GP: There may be very specific groups of patients or families, it depends. If it's an unexpected cancer, somebody young, with a family, there's going to be a major upheaval. It might be slightly different if the patients are retired and have done all their life...one of them gets cancer, then the other one can often deal with that. [The carer] often may require some counselling afterwards and I think that's often provided by the hospice, if in fact the hospice is involved. [HGP1, male]

GPs and communication with patients

GPs placed a premium on good communication with patients and their carers, and suggested that this was often achieved. Valued qualities were being honest (or as honest as possible), giving time, being available and knowing the patient. Emphasis was also placed on the value of continuity – that the GP was a familiar and known figure to patients whose cancer diagnosis usually meant meeting a bewildering number of new health professionals:

GP: Over many years you know them extremely well and there is a relationship of trust, and even though I may not have all the answers they still like to talk to me. And one likes to feel that they know you are accessible. [FGP5, male]

GP: I think it's knowing the patient, it's the doctor-patient relationship or care team- patient relationship.... Perhaps knowing the relatives is important in some instances. [HGP1, male]

GP: I think the role of the GP is trying to provide a personal service when a lot of different

people are getting involved with a patient. A GP, certainly a single-handed GP like myself, is often, not always, in a good position to be able to help because you know, or you hope you know, at least some of the [patient's] background. My personal policy is that if I know somebody has terminal cancer, I will try and give them my home phone number so if they need a doctor out of hours they can get hold of me rather than having to go through the call-out [system] and get somebody who doesn't know them. Of course I don't do it all the time, and obviously there are times when you are not available, because you are otherwise occupied or you're away, but I do tell patients they can try ringing me at home first. [FGP6, male]

GP: Historically – for good or bad - we often give our telephone numbers to patients ourselves and just say “come in at the weekend, give me a ring if there's a problem”, so we do that still. It's nice for the patient. Sometimes it's very difficult for you when you have a family at home but we do often do it still. [GGP2, female]

GP: You know I've stuck around for a few years already, 20 years. So we tend to be known in a regular feature, and I think that in itself is a strength - when people are seeing lots [of professionals], and sometimes that can get confusing, lots of strange people only once, which can happen. So that's a strength for a GP if you like, to be the link. [FGP9, male]

GP: We try, we tend to have one doctor looking after them, the doctor of their choice.... we know the patient, we go back a long way with most of them. [HGP2, male]

However, many relatively new pressures in general practice were referred to, some of which impeded good communication with patients, and demanded better communication and co-ordination with other health professionals. The valued closeness to the patient was presented as threatened by organisational changes, especially developments in on-call and out-of-hours systems: the GP was becoming less a family doctor and more a care manager. Data on GP's responses to these developments was complicated their varying aspirations and by different service configurations and resources in the study sites.

GP: It's like the way 'On Call's' going at the moment. There's no way we could really carry on with it the way it used to be. That immediately means every night, and during every weekend, it's very likely that [patients/families] won't be contacting us as a practice. So it is spreading the care around a bit. That I don't like... I don't like the fact that it is creating difficulties with patient care, because different doctors are saying different things, so I do feel for that reason patient care is suffering, definitely. And it's likely to suffer more if we spread the On Call out even more, in the 6 to 10 [o'clock] slot in the evening. [GP7, male]

GP: I think that there is this inevitable tendency for continuing and personal care to disappear through the window as doctors see lack of sense in trying to be all things to all people, all day and all night. [FGP2, male]

A hospital consultant also commented on the impact of these changes:

Consultant: ...one thing that does disturb me sometimes is when a patient is at home, terminally ill and they are in pain or vomiting or something like that, they phone an emergency doctor who doesn't know the patient, comes to see them and sends the patient into hospital where the patient dies 12 hours later. Well, the last thing you want before [death] is an ambulance drive round the town. That is a failure, no question about it. The patient should have been managed at home. But it's a matter of hand-over information from the routine doctor to the on-call doctor, and that is something for primary care to put right. It doesn't happen very often but it does happen occasionally, which is sad. [GD3 consultant, gastroenterology, male]

GPs and communication with other health professionals

GPs often spoke of communication between primary and secondary care. This was generally considered to be better than it used to be, but not perfect, and prey to the potential for marginalising the GP. For example, the length of time it took for hospital specialists' letters about patients to reach GPs had created problems in the past for some GPs. GPs did not always feel fully informed:

GP: I think in general terms it does work well. Sometimes communication isn't as good as it might be, sometimes you are behind the story because they haven't kept you up to date, or maybe the cancer care nurses have got something organised which one might well approve of. You're not quite up on what's going on and what has already been done. You tend to catch up with the story but, as always, communication needs to be good, and hopefully for the most part it is. I'm not being greatly critical but there are times when you're left a little behind with what's going on and that then compromises what you can do. [FGP5, male]

GPs did not always see the fault as lying elsewhere:

GP: I think perhaps I could be better at communicating with more distant services around, because I'm OK amongst the primary health care team, but when it gets beyond that, I don't communicate as well as I should, or don't offer those services to patients as well as I could, or should, but maybe that's just because everything seems to have been [done], [patients] needs seem to have been met.... There're various evenings or working groups, or whatever, trying to improve GP awareness, and so on. But I have never got the time to go to half of these things. So I know I'm probably not aware of many of the services on offer, or people around, just because I haven't had the chance to really get to know these people. [FGP7, male]

GPs and nurses

As did the consultants, GPs praised as vital the role played by nurses in cancer care, mainly district nurses and Macmillan nurses, with health visitors caring for older adults and other professionals sometimes being mentioned too. Nurses were seen as important in getting things done for the patient, and as relayers of information to the GP, and in meeting patients' and carers' psychosocial needs. They were described by several as taking the lead in telling the GP when a patient in difficulties needed to be seen. Here are just a few of many similar comments:

GP: What I often find is that because we have fairly good communication with district nurses, between us we can often work out who it is that seems to have tapped in with the patient or the carer quite well. For instance, I've got a lady whose been diagnosed with carcinoma and it's metastasised. Now on the medical side she's fine, and I go in and deal with that, but she won't open up to me because she's so angry that this diagnosis was missed by another practitioner. Even though I've tried to explore that, she won't. But the district nurse is the person now who's addressing those needs, and the Macmillan nurse. I think the patient feels that she can express those sort of feelings. But I don't think she feels she can express it to me because I'm a doctor. [GGP1, male]

GP: Our service could expand and have more district nurses.... I do see over the years that I've been here, their workload has increased tremendously. They are very, very, busy and they are the mainstay of terminal care nursing, and it takes time, quality time. [GGP2, female]

GP: I think district nursing services definitely play an absolutely vital role, we're blessed with a very good district nursing team - superb... we know them all very well and they know me well. I can ring them any time, they ring regarding a patient and things can be done quickly that way, that's good. I like that. Certainly we use the services of the hospice Macmillan nurses, we use twilight nurses services locally, we have 'hospital at home' services which does

encompass the district nurses but is a more broad spectrum team. [GGP3, male]

GP: One thing about the Macmillan nurses is they tend not to leave any stones unturned. They'll always fast track the attendance lines if that's required via us. And prod us, you know. [FGP9, male]

GP: We work very closely with the district nurse team... we hear a lot of informal information coming back from the sisters. And they often alert us to potential problems before it gets to anyone asking for a formal visit. [HGP3, female]

Nurses

Nursing roles in cancer care

Cooper (1996) discussed the nurse's role in cancer services after Calman-Hine. Although she points out that there are many ways in which nurses can and will contribute, she also noted that there was little in the Report that was specifically about nursing. She suggested that nurses in primary care may 'represent the only constant link between all the agencies involved' (1996: 812). Nurses in our study were very aware of the psychosocial needs of both patients and carers, and they often presented their role as one of co-ordinating services and agencies to meet needs. There were differences between hospital and community based nurses, and between the areas of specialism. A range of specialist nurses provided care with different tumour types and at different critical moments. Macmillan and community nurses (district nurses) took more of a co-ordinating role together with a great deal of patient contact, while the breast and stoma nurses, although taking part in the organisation of care, were more focused on patient contact. Co-ordination and facilitation of services included alerting other professionals, such as GPs, hospice staff, and social workers to patient requirements. Patient contact involved mostly talking, providing information, assessing, counselling and giving general support. Only the community/district nurses mentioned 'hands-on' care. All the nurses mentioned the informal carer, and frequently indicated that they considered carer needs as well (more so than had GPs). Access, advocacy, empowerment and education were also themes which came through nurses' talk about needs. There was some mention of continuity of care and knowledge of patients and families, but this was not emphasised as much as it had been by GPs. As with doctors, time constraints were mentioned as a source of difficulty, requiring strategies of case prioritisation. Macmillan nurses, in particular, mentioned patients' and carers' high expectations of their service, not all of which could be fulfilled.

Macmillan Nurse: We set out to meet the needs of those newly diagnosed cancer patients and their families, and those patients who perhaps have got a recurrence of disease or who are in the palliation stage of the disease. So we hope to be able to co-ordinate the services that are available in the area, to give the patient and families the best possible care there is. And we are looking holistically at this, so we are trying to look at physical, psychosocial and spiritual needs..... We only go in if patients want us, we are not trying to impose our service on families and relations, we are trying to give them what they feel they need. [FN2, female]

Macmillan Nurse: I think sometimes there's perhaps an over expectation on the part of patients, that they think that we're going to be visiting weekly. I think that is perhaps due to advertising by, say, Macmillan itself. [We're a] saint-like person who's going to be come and visit and take all your problems away, and obviously that isn't reality... giving the logistics of the area, we can't possibly work to that extent. That's why we need to work as a co-ordinator and facilitator of care, and within the role of the specialist nurse. [FN4, female]

Breast Nurse: support, information giving, and hopefully empowering the people to access what services are available. I feel that is the support structure that we can give. Always give them a contact number so that it is an open door for both relative and patient to be able to contact us. And really, to be proactive to their needs and sign-post them onto the people that

they would need get information from.... I don't think we can tease the carer away from the patient, I see them as a whole if you will. [FN1, female]

Stoma Nurse: We see patients pre-operatively to explain the procedures they are about to undergo - that may or may not happen to them - and support them through the period of time they are in hospital and in the community until they feel confident to manage their own practical care. From a psychological point of view, we can be seeing these patients for many years. They'll come back to the clinic, or we'll carry on seeing them, and the psychological needs change depending on their circumstances. They might get married or they might lose a partner, or something like that, and it always makes an impact on the way they're going to cope... From a practical point of view it's never usually very long - 6 to 8 weeks and most people are up and away. [FN3, female]

Community Nurse: Often the initial referral is something that's a clinical need, such as a stitch removal or whatever. And, initially when we go in we're obviously aware there will be other issues around this, and I think sometimes when we go in, when we've done the task in hand, then we can go into other areas and see if there's any other needs that have not been met. Support for the family, for the patient themselves, and financial support as well which obviously is quite a big part. [HN5, female]

Nurses and communication with patients

Communication was the major part of the nurses' role, with patients, informal carers and other health professionals. Assessing individual patient needs for information, and being patient-led, came through strongly in the interviews. Nurses worked with the information from the clinic, often going through it with patients and carers, sometimes preparing patients for bad news. Effective communication required an understanding of patients' and carers' psychological states and social circumstances, together with great anticipation and sensitivity:

Macmillan Nurse: I think what's important for me is that when I first go and see a patient I perhaps talk a little bit about what a nice house they've got, and what a nice situation, or family - good family photographs, just to develop some sort of rapport. Then I always ask them to tell their story, so that I can pick up anything from them. So they're telling me their story and from that I can gather where they see there's been a delay in diagnosis, or what's been said to them, how they've been told bad news, how they've coped with that sort of crisis in their life, how they're family is coping... So I actually go with the patient's own agenda. Particularly their story, because that story carries through the whole journey, whether they get better or whether they go on to fail. That is a very, very important story for them to tell, and for you to acknowledge, that you know their story. Yes, very patient centred. [FN4, female]

Macmillan Nurse: I think it is so diverse and such an individual thing.... Trying really to fulfil what they think their need is rather than what I think it should be, definitely not to have a didactic approach, so that you feel your way, so that if they want the information you can give it, and if they don't want the information then you don't impose it on people. Try and have a very gentle approach to it all as well, because often when people have a diagnosis it's very much high drama for them, obviously it is because it has such an impact on people's lives, but if you can try and help them to calm that and work through it, then they look at it more logically for a solution. Whether there is a solution, and whether there is a cure is a different matter, but they can actually look at what they are having to work through and what they are up against, and give them the best possible help to get through that, in whatever way is feasible. [FN2, female]

Stoma Nurse: The biggest concern usually is 'am I cured of the cancer, is it going to recur?', and we can always support that by going down the histology notes and being as positive as you can. If it's a bad histology, I think we're fairly honest with these people, they usually go to

chemotherapy and radiotherapy and you need to be fairly supportive through that... A normal stool can become diarrhoea, or a diarrhoea stool can become constipated because of the radiotherapy or the chemotherapy, so you need to do quite a bit of counselling, prior to the commencement of whatever treatment is being offered. [FN3 stoma nurse, female]

Breast Nurse: A lot of patients you can tell the same thing over and over and over again, you can give them written information, and they still don't take it in because they're not listening to what you're saying, because you're not telling them what they need to know.... at the moment I can just target patients that I know are concerned about things, and target them to see them at home. because you get a lot more out [a home visit] - you see their carers and their families quite often at home, where you don't in hospital.... Now they have to wait when they go home for about 10 days before they get the results back and that can be a very upsetting time for them. Again we don't go up and give them results ... but what you can do is read a histology, you can have a very good idea in your own mind what they're going to be told, what they're going to be offered, and you can start to pave the way for that. So you can say things like "well if you did have lymph nodes involved in this point they would offer you such and such a treatment", so you're not breaking bad news to them, but your preparing them to have the bad news broken... And when [the doctor] comes out and says it, it's not such a shock because they've prepared themselves. [HN4, female]

Community Nurse:... what I would tend to do, if somebody had been diagnosed with a cancer and their prognosis wasn't particularly good but obviously [death] wasn't imminent, I would try and go and just introduce myself, to build up a rapport really, and make sure that they know where we are, and then they are not afraid when we come in. [HN5, female]

Nurses and carers

All the nurses spoke about the informal carer and their involvement, and recognised that carers had their own psychosocial needs. Interaction with the carer was deemed to be necessary, and sometimes essential. Services for carers were seen to be somewhat inadequate, especially around terminal care and bereavement.

Stoma Nurse: Well the practical considerations have got to be met in hospital, it's pointless sending a patient out of hospital if they can't manage their own [stoma] care. If they can't manage it then we need to involve a carer who is willing to manage it. If there isn't anyone, then we have to look at commercial carers who are going to be willing to go in on a pay basis. So we do a fair amount of training of many people who are becoming carers. [FN3, female]

Breast Nurse: The trouble with breast cancer is that it's involving a partner or a husband, and men still feel that they have to be the strong person, that they can't be upset, so they won't ask you things particularly, they won't tell you that they're distressed because they're not supposed to be, they're the ones who are supposed to be strong... I feel you have to separate them to actually get the information out of them. [HN4, female]

Macmillan Nurse: The carers are frightened. They're frightened of their loved one dying, they're worried, they're anxious, they feel that they're not doing enough for them, or they become worn out.... But I think if there was someone to support the carer on a more practical level than just being with them.. then that would actually help. And I don't think that people would bounce into hospital quite as readily as they do now. [FN4, female]

Macmillan Nurse: .. we quite often get [bereaved carers] 6 months down the line, after their loved one has died. We'll get a phone call from someone – 'so and so' is in a terrible state, she's not had any support, she's had nobody to turn to. She's actually gone through the bereavement on her own, and the whole of the coping with this illness and the death - they have actually done it themselves, with no support. [FN4, female]

Nurses and communication with other professionals

Generally nurses thought there was good communication between themselves and doctors, and with other health and social care professionals.

Breast nurse: Now the oncologists are much keener for us to be involved all the way down the line. I think they recognise how useful it is much more. Whereas Dr [x] used to be, “you cause more trouble because you tell women things” [laugh], and “If you're going to inform them then they're going to ask questions” they just wanted [patients] in and out. [HN4, female]

Breast Nurse: I'm very impressed actually with my contact with social services because they have always put in a good package of care for people that have an identified problem, and with occupational therapy. The district nurses go in and we liaise around what's happening with people. The hospice, again, we are trying to get multidisciplinary meetings together, so I feel it works well. [FN1, female]

Macmillan Nurse: ... we can call upon our complementary therapies to support our palliative care clinic, which is very very helpful and valuable. We've got a very good interactive system with the oncology unit, I am closely liaising with the consultants, the radiotherapists and the oncologists. And also, we have a very active day-care service, both medical and social. I feel that we have got a lot to offer families and we've also got expertise about getting all the [welfare] benefits that people are entitled to, so we would try and link that in if there is a need for patients... And we certainly work very closely with GPs but GPs maybe wouldn't have so many patients, each individual one would only have a few in the system. And we certainly also work very closely with the hospice. [FN2, female]

Some problem areas were reported, however, for example:

Stoma Nurse: If [the patient] shows signs of shock then the surgeon will probably say I'll get the stoma care nurse to come and see you. Now if he's on the ball, he'll ring me up or leave a message on my answer phone, if not he just puts a note through his secretary and it can take a long time. Occasionally with [town x] patients will actually be in hospital before we know about them. We will get the referral, but it's usually quite late, so we are working on a system at the moment to try and improve that. I think it's one we will ultimately improve, it's just finding a good system. [FN3, female]

Breast Nurse: I think the problem that we have is when we kind of get out ... of the hospital into the community [services], to go through the bureaucracy - you can't change things there. Hospital, you can change anything, you can get appointments arranged, you can do most of the things you want to do, dietician will see people quicker, you can go down to bone scan and say “can you fit this woman in?”. And anything within our influence is easy. It's when you get back into the community where you don't have the contacts that it can sometimes just take longer. [HN4, female]

Community Nurse: Sometimes I feel that not enough information is given to us - if you ring up and say “is the patient's aware of their diagnosis?”, “Oh I'm not sure”, and “I don't know” - and sometimes that's very hard, you're sort of going in treading on egg shells not knowing where the land lies, which is difficult. [At another point in the interview:] If [patients] want to stay at home we will try our utmost to support people at home... We have actually had a couple of incidents lately where we felt we failed people in that we have not been able to provide that support, to be honest, because it's been at a weekend or a Bank Holiday. We've not been able to access services quickly enough to, not necessarily support the patient as such, but to support the carer to support the patient, which I feel is a gap in the service really. Hopefully the PCG's are going to change that with reforms, and we'll have a more fluid and

integrated role with Social Services so that we can have a group of people that can provide a service. Because at the moment in this area we don't work with Social Services in the way that we would do a double-up - I'd meet somebody from Social Services there and we would give care together. It's completely separate roles, they might go in at one time and we'd go in at another. So I think they're hoping to integrate the roles. [HN5, female]

Stoma Nurse: The biggest gap is when a patient dies, we never find out. That is a real problem for us. It's awkward when we arrange open days, we have one open day a year here, and we mail everybody who is on our books, and if we haven't seen them for several years it's upsetting if a relative rings and says well you ought to have known he died 2 years ago. And I suppose we ought to address that. Quite how I'm not sure. We did think the other day that we might sit down and go through all the GPs and check at the surgeries with some of these people we haven't seen for a long time. We don't always know what's happened to some of our patients. [FN3, female]

Dieticians

The dietician's role in cancer care

We interviewed two dieticians. One was a manager in a community service context, the other was at senior level and hospital-based. They both saw their role as providing practical advice and support, and an individualised service. The accessibility of their service was emphasised. Psychosocial needs, as well as narrowly nutritional ones, were clearly a priority.

Dietician: The first thing is that we are very accessible so we will go where the patient needs us to go. So we will see people either at the hospice, or perhaps in day care at [the cancer support organisation] or at the hospice, or we will go to people's homes, or we will see them in hospital. And we go to nursing homes as well. And the second thing is that we do it by providing very, very practical advice rather than theoretical, technical advice. And all the advice we give is based on people's individual lifestyles, habits, and tastes. So it is based on us interviewing people about what they do now, what the gaps are, what they are wanting. And we will give them individual, personalised advice. We also back that up with literature, so we have a range of leaflets, and we hand write some things for people so that they only get something that is relevant to them.... [We also provide] a lot of education and training for other members of the oncology team, so that they can give advice as well. And again, it's very practical, pragmatic advice that we train people to give ... There's certainly a body of evidence to support providing a nutritional advice service to people with cancer. A weight loss is a major concern for patients and their relatives - and we know that if people are poorly nourished, they won't withstand their treatment as well, and their quality of life will be reduced, because you just haven't the energy to do what you want to do. It makes sense really, it's just common sense. And it's very distressing for people when they suddenly can't eat, emotionally distressing, if you suddenly can't swallow anything and you are watching yourself losing pounds and pounds a week. It's very frightening. So even if one can't do anything, talking that through with people can be helpful. We can't always make somebody perfectly well nourished because they might just be too ill, but you can usually halt their weight loss. You may not be able to help them put weight on, and it's hard to measure it, but quality of life is improved. [FPAM1 community based dietician, female]

Dietician: Things like access to somebody like myself, that's probably the first thing [I try to achieve], and then trying to address [patients'] issues, surrounding food and the menu system here, and comfort for them, really... It sounds very general, but I think we give individualised care and it's not something I can generalise at all. [HPAM1 hospital based dietician, female]

The community based dietician saw herself as very much part of the broader cancer team: 'Very much part of a team, that's one of the joys of working in it really, the very strong sense of team.

Go into the hospice and somebody makes you a cup of tea. Doesn't happen anywhere else in the NHS'. She goes on to say:

Dietician: A dietician attends the weekly meetings on the oncology unit, and we hope that every new patient is considered, "does this person need to see the dietician?" We have got some referral criteria which the [oncology unit] have got and which the Macmillan nurses are aware of here. It's best if we see people as soon on in the process as possible. If people wait until the patient has lost 4 stones before they refer there isn't a lot we can do. But as soon as it becomes apparent that there are dietetic difficulties, it is best if people are referred. So for example, if it is anticipated that somebody will have lots of problems with chemotherapy, it's best if we see them before. If somebody can't swallow then they should be being referred immediately, not waiting till they've lost 3 stone, and that does happen sadly. You know, if somebody has got a wound that is not healing they need referring. If somebody is going to have radiotherapy to their throat, they won't be able to swallow, we know that. They should be referred before a treatment. [FPAM1, female]

Dieticians and carers

One of the dieticians spoke specifically about carers:

Dietician: I think the carers often need something completely different from the patients themselves. In my experience, the carers want very much to feed the patient, which is a normal, natural thing to want to do, a very nurturing thing, and I spend most of my time telling the carer that that isn't always the way to go. Obviously food's very important but it's often much more important for the carer than for the patient.... Especially if the patient is debilitated in such a way that they can't help themselves, then the carer becomes really important. Even if they're not, it's nice to see the carer because you can just give quite a lot of reassurance really. [HPAM1, female]

Cancer support service co-ordinators

We interviewed two cancer support service co-ordinators in one of the study sites where there was a voluntary sector organisation dedicated purely to the psychosocial care of cancer patients and their families. Although tied in to the NHS services by close contact with the Macmillan nurses and the fact that the organisation had been in operation for around 15 years, there were some indications that the service was not fully utilised by some health professionals, and not very readily taken up by male patients and carers, as compared with female patients and carers. The importance of these kinds of support services is increasingly recognised; the North West Region NHS Executive (1999) specifically mentions the availability of counselling support, complementary therapies and social care support in palliative care in its Primary Care Accreditation document.

Referral of patients to the support service was obviously a critical issue for these co-ordinators. One commented that there were some GPs, district nurses, Macmillan nurses, health visitors and other professionals who did regularly refer patients, and sometimes patients and carers made a direct approach having heard about the service by word of mouth. Consultants were less likely to refer:

Support service Co-ordinator: The odd consultant [does refer]... some are very active for us, some are actively not, saying "it's kind of wishy, washy", and deliberately won't refer, and some who probably would but they're that busy, they forget. So we do get some [referrals that way]. [FTC1, female]

Evidence from other health professionals interviewed in the area the support service covers

suggests that the service is viewed positively by most, but with an acknowledgement by some that they had little knowledge of it, or that its specialisation could be seen as a threat to generalist skills. Here is a selection of comments from GPs about the support service:

GP: ... I've only been a GP here for nearly 6 years, and perhaps only once or twice have I actually been that aware of the counselling services offered there. And so perhaps I am not aware enough of all the services on offer. Whether it is a case of needing to drag myself round to become more aware of what's going on, or whatever, I don't know. [FGP7, male]

GP: We have counselling available across the yard here.

Researcher: But do you ever use that for cancer patients or do you use the [support organisation] services more for that kind of need?

GP: It's probably more likely to be through the [support organisation] actually, yes, because they are so good. So good at handling people with cancer, which means the other services get deskilled, if you like, because people with cancer tend not to get through to them, and they might then feel a bit anxious about it. [FGP9, male]

GP: I have acknowledged for a long time that whatever skills I have or haven't got in terms of dealing with psychosocial problems, the biggest constraint on us is time. An organisation like [the support service], although it's not endless, the one thing it has got is time. People there who are doing the psychosocial bit by whatever means, whether it be hypnotherapy or relaxation or whatever, they allocate to themselves time enough to do it and do it reasonably well, and so I've always been very happy to refer to them. I know in some ways it devalues oneself, and people feel deskilled if you send people out there for this and out there for that, and all you do is sit in the middle... But they've got the time and the skill and the expertise to do it which I don't have and that's the way it should go. [FGP2, male]

Meeting psychosocial needs of patients and carers

The support organisation aimed to tackle psychosocial distress as their main remit, with psychological needs being addressed through psychotherapy, and social contact needs being addressed through group involvement.

Support service Co-ordinator: What we aim to set out to meet is the reduction of anxiety and stress, that's the first and foremost. There are then other things - reduce isolation, or perhaps increase interaction with other people, or build up confidence. But it's basically reducing anxiety and stress as a primary purpose for us. [FTC1, female]

Support service Co-ordinator: I think the psychological and social needs that the drop-in centres set out to meet is giving a sense of companionship, which I think is really important, so, lack of isolation...health care professionals can be considerably supportive, but there's one thing that they can never do, which is actually know how it feels. That's a really strong element of what these drop-in centres provide, they actually provide a venue for people who have been going through the same kind of experiences to actually to share with each other. [FTC2, female]

Interviews with our patients and carers confirmed that, for many, an important source of information and reassurance comes from contact with other people who are, or have been, in the 'same boat'. A recent study suggested that women patients often valued the knowledge and experience of other cancer patients more than medical information (Leydon et al, 2000). The other health professionals we interviewed did not mention this aspect of the cancer experience. While programmes like 'Reach to Recovery' in the USA make use of experienced patients to support new ones, this kind of support tends only to be recognised in the voluntary sector in the UK. In fact, it has been suggested that health professionals may even discourage inter-patient contact (Costain Schou & Hewison, 1999). While certain ambiguities and hesitations around meeting other people

with cancer were expressed by our patient and carer sample, it seems that this is a part of the experience of cancer for many people, whether sought or avoided.

Support service Co-ordinator: The way in which newly diagnosed people are getting the support is that they are actually meeting people who are struggling with the same issues themselves. Sometimes it can be really practical things, for example, somebody will come out of clinic having been told that the next course of treatment will be radiotherapy. 'Where do you go for radiotherapy?' 'Oh God, I've never been to [hospital x]'. And they come to the drop-in and say 'I'm a bit worried about this', and somebody like myself would be able to say to them 'Oh, would you like to meet so and so? They've just come back from having radiotherapy'. So they have a very 'ordinary conversation', things like 'remember to pack a book and make sure you've got...' Those practical kinds of experiences actually support people. I think it meets different people's needs at different times. ... There is always an information table so people can gain information by coming to the drop-ins, but probably the most important information they gain is that very informal 'well don't forget your book when you go to [the oncology unit]' kind of information. [FTC2, female]

Support service Co-ordinator: Although on the outside you walk in and it just feels like a coffee morning, I think sometimes quite important things are going on, the reassuring things are going on. But of course the other thing that's going on, which I think is important in the journey of cancer, is that people are not just talking about cancer, they are talking about growing plants, and they're talking about their holidays and things like that.... [The support organisation] is saying that the ordinary human interaction that you enjoyed prior to your cancer is actually being encouraged and allowed as well. I feel that's quite good .. [Some people have a concern about] whether or not it was useful for patients who had just been diagnosed to come into a room with somebody who will be saying "well my husband died last week", and theoretically you would think it wouldn't work, you'd think it would be demoralising. But curiously it would seem that once you get above a certain critical mass of people, it does work OK. The truth is that although dying isn't an inevitability of cancer, I think that the feeling that one might die of cancer is probably almost inevitable... I suppose there is a way in which it is present really. Having said that, quite the converse happens as well, which is that somebody comes in having newly been diagnosed and who then meets up with somebody whose had an operation ten years ago and is still going strong, so you get an incredible range of interactions. All of the drop-ins are incredibly different from each other. [FTC2, female]

The organisation actively welcomed carers and bereaved carers.

Support service Co-ordinator: I'd like to do more with carers because the carer's in the position where it raises an awful lot of stuff for them, but they don't want to burden the person that they're sharing the cancer with because they've got enough on.... I'd like to offer group work to carers, setting up maybe a self-support group. And also I'd like to look at the younger persons. Because most people that come through this system are at least middle-aged or elderly, there's not as many young people. [FTC1, female]

Support service Co-ordinator: The bereaved [sometimes] will continue to come perhaps years after the event. In some ways I think that probably means that people have been able to find a place in themselves for that lost person by coming to the drop-ins. There is a lot of recent work done about bereavement, and in the past the model was that you should actually grow through grief and distance yourself from the dead person, and disconnect from them ultimately, and then move on. People like Tony Walter who've recently written books about bereavement are very much more inclined to feel that bereavement, successful bereavement, [means] that you actually find a place for that person to reside in you, but it isn't an overwhelming place, and it isn't one that actually means that you can't maybe establish another

intimate relationship, or whatever.... It's been particularly interesting for me to have Tony Walter as a model because otherwise I could begin to feel quite anxious that people who were bereaved say ten years ago are continuing to come, because either it makes you think that they're not getting what they want and they keep trying to get what they want. Or it makes you think that they've become very dependent and they've got stuck and they're not moving on.... And of course some people do decide not to come to the drop-ins and actually say things like 'it's been really useful to me but actually I want to move on and I don't want to associate myself with [it] anymore'. So people are as different as they are. [FTC2, female]

Health Service Managers

The role of health service managers in cancer care

We interviewed three health service managers, and asked roughly the same set of questions as were posed to health professionals. These general managers offered a wider perspective on cancer services, as would be expected. They mentioned the importance of planning, communication, and liaison between different parts of the service. Emphasis was also placed on making information about treatments available to patients. Managers suggested that while protocols and policies were important, they wanted to allow for flexibility so that individual needs could be met.

Manager: Obviously [the service must] try to maximise the number of years of life of any particular individual. I know that there has occasionally been criticism of the health service in that it tries to maximise the number of years, months and days, not necessarily looking at the quality of that life. I'm not sure what the approach is locally in terms of that, nor the degree of opportunities to patients to define treatment on the basis of information on likely outcomes. From my own personal perspective, that's the appropriate thing - that [patients] should be armed with as much information as possible. [However,] I don't think you can be naive and imagine that patients are always in the best psychological state to make a rational, informed, considered decision about that particular point. [FHM2, male]

Manager: So if you look at it in population terms, the strategy for delivering cancer care certainly accords with the national approach, certainly reflects levels of service you would expect to see in a population of the profile that we have. If you are asking me whether, on an individual basis, there is clarity in each case on the part of the patient in terms of understanding need, then I think we probably have quite a way to go in terms of the way we communicate, in terms of the way patients gain an understanding of what they can expect, and when they can expect it as their condition progresses. I think we've a long way to go in having a real dialogue with individual patients around whether they actually want us to undertake some of the care that is available. That's not to say that people don't give concern to it, but I think that's different to actually having a very open and honest dialogue with individual patients about the implications of some of the treatments and what that might mean in terms of their future life, and the quality of that life ... What we felt was unhelpful was if we said that with this X condition this is what you get from health care. Although that offers clarity, it reduces flexibility and it doesn't actually offer the opportunity, as easily, to respond to the varying needs. So we looked at identifying generic criteria rather than 'boxing off' for specific conditions and saying this is what you get and that's all you get. Because we thought that people are just not boxable in that way. [FHM1, female]

Summary

Consultants emphasised the provision of good clinical services, speedy and effective treatment, and information. Meeting psychosocial needs was not seen to be central to their role, although reported individual styles of practice varied in this regard. Consultants did, however, acknowledge that patients had psychosocial needs and that the way that the patient was handled in the medical context affected their psychosocial well being. Most consultants demonstrated awareness that there must be 'good communication' with patients on their part – whether this involves the imparting of 'bad news' or the giving of information about other aspects of treatment and care. Good communication was usually described as associated with the qualities of honesty, timing and creating a sense of confidence. Many consultants prized good inter-personal skills and sensitivity in other doctors and themselves. However, in relation to communication, the patient was very much positioned as a passive recipient of information. We have suggested that it may be more helpful to think about patients as potentially active rather than passive with regard to information exchange, that is, as participants who would sometimes welcome the opportunity to express their information needs more openly, and to shape the information dialogue more purposively.

Consultants expressed their strong reliance on nurses in dealing with the psychosocial needs of patients. There were clearly divisions of labour in operation in clinical contexts such that nurses were often expected to deal with patients' psychological and emotional needs. Such allocations of responsibility are clearly gendered: as male doctors, they saw nurses, because they were women (this was implicit), as possessing qualities that enabled them to engage with 'feelings' and emotions more successfully than could they (Annandale & Hunt 1999). Consultants frequently described the nurses as having the time, the approachability and the disposition to handle the psychosocial aspects of care.

Consultants also spoke of the importance of good channels of communication between all health professionals involved in cancer services. This was seen as an area where improvements in systems and practices were necessary, and sometimes underway. Very few consultants mentioned informal carers; with the exception of palliative medicine consultants, they were almost entirely patient-focused in their accounts.

GPs emphasised their role as co-ordinators for cancer care, and as a point of interface with hospital services through referral mechanisms. They saw their job, first and foremost, as accessing the necessary range of services so that their patients' treatment and support needs could be met. Most of the GPs interviewed also described their 'hands-on' supportive role in dealing with the treatment and psychosocial needs of patients and families. This frequently involved attempts to relieve distress and anxiety through providing information, explanations, and a 'listening ear', and showing empathy, as well as the provision of practical support. GPs presented the value of their service as residing in their accessibility to patients, their long-standing personal knowledge of the patient the carer/family (and vice versa), their ability to respond to the individualised needs of patients, and the provision of continuity of care. However, they identified a number of changes in general practice that undermined their ability to make the most of these values, particularly the on-call and out-of-hours arrangements. A key theme to emerge was the relative marginalisation and de-skilling of GPs in cancer care consequent upon the development of specialist cancer treatment and support services. If GPs were involved in care it tended to be at the terminal stage of the disease. Being marginal was often, but not always, perceived to be problematic by GPs; opinions and practices differed. GPs saw communication across the secondary-primary care interface as improving but far from perfect, but they did not always blame other parties for this. Many felt that they were not kept as fully informed as they would like about patient matters by specialist services providers. GPs certainly included informal carers as part of their remit. Like consultants, GPs acknowledged their reliance on nurses in meeting the psychosocial needs of patients, both directly and indirectly.

Unlike GPs, the nurses we interviewed tended only to meet the patient and carers/families in connection with cancer diagnosis and treatments, and as specialist nurses they were usually involved with specific tumour types or critical moments. Of all professional groups, the nurses spoke the most about psychosocial needs, and frequently saw themselves as co-ordinators of services to meet such needs. They were very sensitised to patients' and carers' emotional needs and understood that the psychosocial needs of patients and carers are located in these individuals' wider social contexts and networks of relationships. Nurses seemed to prefer a mode of practice that minimised patient and carer distress by anticipating needs and 'heading off' distress and difficulty. Their skill in this was bound up with a patient-centred practice. Interaction with informal carers was deemed to be necessary, and sometimes essential. Support for carers within services was seen to be somewhat inadequate, especially around terminal care and bereavement. Overall, nurses thought there was good communication between themselves and other health and social care professionals, though some specific service communication difficulties were identified.

Dieticians, who naturally had a strong focus on needs surrounding food and diet, were also patient-centred, and conveyed a strong sense that managing 'food matters' was tied in with addressing wider emotional and psychological needs – for both patients and carers. The two co-ordinators of support services interviewed in one study site were centrally involved in meeting the psychosocial needs of both patients and carers, their main focus being the emotional and companionship needs of these clients. Emphasis was placed on the great psychosocial benefits that can accrue when patients and carers meet together, sharing their experiences and knowledge. The pattern of referrals of patients to the support service by health professionals was identified as a little patchy, and, indeed, a few professionals had commented on their lack of information about this service. The health service managers did not have direct contact with patients, and gave an overview of services and policies. They were aware of the importance of meeting patients' psychosocial needs, but tended to emphasise their requirement to develop services that enabled patients to obtain full information about services and treatment options, and to be more actively involved in making care decisions.

CHAPTER 14 **Health professionals' perspectives on service changes, strengths and weaknesses**

Introduction

The preceding chapter outlined the roles of a range of professional groups in cancer care in general, and in meeting psychosocial needs in particular. In discussing their roles, professionals referred to some strengths and weaknesses in services and practices. This chapter reports further findings concerning perceived service strengths and good practices, as well as service gaps and weaknesses, drawn from the analysis of data from the same 39 structured interviews with health professionals. The sample of professionals interviewed consisted of: consultants, GPs, specialist nurses, dieticians, support service co-ordinators, and general managers. The following study aims are addressed: to examine service providers' perspectives on the adequacy of current services in meeting the psychosocial needs of patients and their main carers; to identify 'good practice' in the meeting of these psychosocial needs from the point of view of health professionals.

It should be emphasised that the interviews with professionals took place at a time when there were many changes either occurring, or imminent, in cancer services. The impetus for change, or more rapid change, was both the implementation of the Calman-Hine Report (DOH, 1995) recommendations, and on-going regional and local reviews of services. The process of accreditation of services for Cancer Unit status was underway. The interviews occurred post-Calman-Hine, but before the publication of The National Cancer Plan (Department of Health 2000a). This sets the policy and service development context for much of the professionals' comment reported below. In the interviews, two questions were posed about the nature of change and its likely future impact (see Appendix 7).

It is helpful to open the chapter with a selection of responses from professionals on the subject of service change. These tell, in the main, of expected service improvements, of change for the better. Despite the considerable service alteration set in train by the Calman-Hine Report, and the increases in future workloads that were perceived to be on the horizon, the national and regional directives following on from the Report were largely welcomed. These were spoken of as fitting with, and giving further impetus to, local developments that were either already underway, albeit at a slower pace, or had been proposed. Key areas of change discussed by interviewees and reported here are as follows: surgical and medical specialisation; funding and resource issues; the establishment of multi-disciplinary teams; improved data gathering and the move towards evidence-based practice; the availability of local expertise; closer working with voluntary organisations; and palliative care provision. As will be evident, consideration of service change and improvement frequently highlighted areas of perceived current, or recent, service gaps and weaknesses. While many of the issues discussed did not directly concern psychosocial needs, it is clear that the matters in question relate to both to the occurrence of psychosocial need among patients and carers, and to professionals' ability to effectively address psychosocial need. A sound bedrock of cancer treatment services is required if psychosocial difficulties are to be both prevented (in so far as these are related to experiences of services), minimised and fully responded to.

Following a discussion of themes concerning change, service strengths and weaknesses will be considered in turn.

Service change and improvement

Surgical and medical specialisation

The Calman-Hine report was constituted as galvanising action and formalising either existing or desired ways of working, for example, greater surgical specialisation:

Consultant: The first thing and the most fundamental thing that's changed is that two and a half years ago there were five surgeons in our department treating breast cancer, there are now two, so that's changed dramatically. That's concentrated the expertise... it's certainly concentrated the numbers of patients and therefore, hopefully, the interest of the individual surgeons in the disease, and, hopefully, the expertise. If nothing else, in a subject which is to some extent practical, it does make you slicker, there's no getting away from the fact that you are getting better at doing every particular operation if you do it more often. [FD2 consultant, breast]

Consultant: I think the other big change of Calmanisation is the concentration of the work in a small number of hands, although it hasn't been all that evident [here] because that was happening anyway by the time Calman came along. There was already two of us doing the bulk of the work, and all it did really was to persuade those of us, those surgeons who were still doing a bit of it to drop the bit that they were doing. [GD1 consultant, breast]

GP: I've noticed that hospital consultants tend to specialise in particular diseases more, which I suppose must be good. [FGP3]

Some increased funding and resources

It appeared to professionals that some, albeit limited, additional funding and resources - usually in the form of extra specialist nurses - were being fed into the care system in the wake of Calman-Hine. This was very much welcomed.

Consultant: And Calman released a bit of money, it got us an extra breast care nurse. Previous to that we had two part-time nurses employed by the community, not fully trained breast care nurses. So that bit's come in partly on the back of Calman. [GD1 consultant, breast]

Consultant: When I started here we had one breast care nurse who did breast care and stoma care, and we've now got four who do breast care and stoma care. When I started here they were giving chemotherapy to lung cancer patients in the outpatient clinic, with no specialised nurses helping out there, and they've now got three. [HD1 consultant, breast]

Consultant: ... that's doubled essentially, the breast care nursing facility. The other thing that's changed, which is quite dramatic, is that we now have a specialist breast clinic whereas previously all patients with breast disease were seen in general surgical clinics in [town x]. Now they are seen in two dedicated breast clinics. [FD2 consultant, breast]

Breast Nurse: Calman's all the things that we wanted... ... because before we had five general surgeons doing breast surgery over three hospitals. That was ten clinics, you couldn't cover it. There was half a full-time equivalent breast care nurse where you needed three, it's the same with the colorectal, they're just starting to actually realise what the workload is we do here [FN4, female]

However, not all health professionals saw the Calman-Hine Report as initiating significant or sufficient change through the release of funding:

Consultant: There's a lot of things that we just can't get right until we've got some more resources. I'm going to a meeting in which we are going to try and find out how we can best seize a part of the national pot for lung cancer services, of which some £68,000 is due from

that pool. We need to redesign the chest clinic, and until we've got things like proper diagnosis set up. The money that we've been offered nationally is simply totally inadequate for the job. We've got to start there, then [we can] look at the social consequences and the psychological consequences of the treatment that we're giving people. [HD1 consultant, breast]

Consultant: Every five years there seems to be a new bright idea. It really doesn't make a lot of difference. The same job has to be done, the same people are there. You know, there might be different opinions to how you achieve it, but it's the same job, the same amount of money, and same pressures, I'm not sure it will make a lot of difference. [HD2 consultant, palliative]

Team building and working

Team building, and bringing multi-disciplinary specialist teams together to oversee patient care, was mentioned as an important, meaningful, and real change in the wake of the Calman-Hine recommendations.

Consultant: [At the breast care meeting we have a 'radio-pathology, everything, get together']... In the last six months we've introduced that. That's when I get to find out [about things]. And then I make the referral to plastic surgeons, I make the referral to clinical psychologists. ... It's a case that if you can only see dimly, you have no idea of how much there is to see. ... The system's working, the system is hugely better than it was ten years ago... When I was a student in the late 60s the job of the hospital was to treat the condition and then they walked outside the door and went home and then it was somebody else's problem. [HD1 consultant, breast]

Consultant: You get together and you discuss what is the best way to treat women, either on an individual basis or on a collective basis... That concept has put together groups of surgeons, groups of radiologists, and nurses and oncologists to actually concentrate their expertise and to bring out guidelines which, hopefully, will give the best treatment to that population. Those are the things that I think have changed dramatically in the last few years. [FD2 consultant, breast]

Consultant: I think there's nothing in Calman that we, in our dreams, have not thought that we would like to achieve. ... never thinking that it would come quite as quickly as it has. Calman has made that possible. [For example, town x] is emerging as a centre and our patients are now being dealt with there, not at [hospital y]. Prior to that we very rarely had anything at all to do with patients who were going to the oncologists at [hospital z] and [hospital y]. ... So Calman has made a lot of things possible. He's helped us to develop the team within [hospital z], which is our prime hospital we work with. And what it's really doing is helping us to develop palliative care within the community. To enhance palliative care... the idea is to enhance it... [At another point in the interview] ...under the Calman-Hine Report, the social worker is a member of the core team, in the specialist service, in the in-patient unit day hospice, and so on.... hopefully we're now just at the point of making the change. [HD2 consultant, palliative]

General manager: ... changes have included additional staff, very particularly in the specialist nurse area. And more of a focus on [identifying] a common approach, to try and avoid the different messages from different professionals. So there's more team working, greater awareness of professionals working together and supporting people. Hopefully that will be of help. More of a focus on breaking bad news and subsequent support. [HHM]

Dietician: There is a specialist nursing group that is responsible for [implementing] Calman, and I am the dietetic representative for the region on it... so I am very well placed... That group is responsible for producing pathways of care for nursing... and for the pathways of care that have been developed for all the different cancer sites there is a dietetic input. I haven't done them all, my job is to find to somebody who know about that particular cancer

site and get them to produce it. So that's been a very good venture. It's great to be so involved. And those pathways of care [will be] joined with the medical pathway of care, which will then inform what each cancer site/cancer unit should be doing about treating a particular cancer. ... The other thing that has happened is that, for dietetics, we now have a regional oncology network for dietitians who work in cancer and that's been really good for our profession because those of us who work in cancer as a speciality can share our expertise and knowledge with the people who work in cancer as generalists. [FPAM1 dietician]

Improving data gathering, information systems and the move towards evidence-based practice

The accreditation processes for cancer unit status required a considerable amount of clinical and service data gathering and the development of protocols, highlighting the need for effective and efficient data recording and processing systems. The immediate impact of this was mentioned mostly by consultants:

Consultant: The paper work got off tremendously [laugh], now I've got to prove we're doing all the things we've been doing all along...for accreditation. We've got to put it all down on paper... the statistics, the data gathering, has improved dramatically. I think that is one of the things Calman has done, improved data gathering. [GD1 consultant, breast]

Consultant: I think the Calman structure has galvanised us into action. ... It's also been an opportunity for us to emphasise the critical importance of collecting work-load and outcome data, which I think is probably another area of weakness, our outcome data is a bit feeble. And I think any unit in this business must know how it's doing. So yes, Calman has been a good thing, we wouldn't disagree with any of it....

[At another point in the interview] What we are bad at is the business-like organisation of bits of paper, and form filling and protocols. We know intellectually that there's very good evidence that a lot of treatment must be protocol based, that we must enter trials, we must fill the forms in, that we must have neat guidelines - so that if we were all run over by a bus tomorrow another crew could come in and take-over. We are very bad at that. And if you look at the back office it's a riddle. We do try occasionally to get on top of it but then we get busy and it needs some very neat, organised person with plenty of time to get it right. And that's certainly a major objective in the coming year.... It's not that we haven't written the protocol, it's just that it is quite difficult to keep everything in order. I think being short-staffed doesn't help. So it may be that if we had more people who had more time, then we would get the papery side of things better. [FD3 consultant, haematology]

Wider questions of standardisation and evidence-based practice, together with new developments such as the setting up of Primary Care Groups (PCGs), were on the minds of many professionals. Nurses were the only group that talked about linking these developments in with the need for education and training.

General manager: The government's trying to say that there are certain standards of performance that patients should be able to expect are also going to have quite important influence, particularly accreditation. [There are] going to have to be better protocols, and adherence to protocols is going to be monitored. That may well be saying that the role of the GP is to do a review at x months or whatever, and if that was monitored you might start seeing some of the fluctuations in performance start to change. ... So I think there's going to be a lot more pressure on standardisation of primary care. [FHM2]

GP: One of the exciting things in primary care is the idea of clinical governance and protocols and things, which I'm sure will be good for cancer care... that could be very challenging and exciting, but quite what it will do I don't know.... Whatever area we deal with, the idea of having some best practice guidelines on what we should be doing could effect quite

significantly general practitioners' behaviour. As long as it's drawn up by general practitioners in [at the] primary care groups level it could be a very good thing. Presumably someone at some point could look at how general practice is related to cancer, and look at what the best practice is, and try and make sure we come up to that. [FGP5]

GP: Probably what's going to happen is there's going to be a lot more protocol around. I don't know, I'm sure there're going to be lots of changes over the next 5 years. I must say, I take the slight ostrich approach - I don't know quite how it will affect us. I don't know, I don't know. [GP3, female]

GP: I would have thought there will be a lot of changes in the next five years with primary care groups, clinical governance, education and training. That will standardise care I think. And also address care problems - patchy care or problems in care. And then we'll have the National Institute of Clinical Excellence telling us what best practice is, and then you'll have people trying to put that into practice at grass root levels. [HGP2]

Stoma nurse: The big change coming our way is going to be the cancer steering group. We are wading through the literature to make some suggestions and protocols that we've got to adhere to. And we are sending ourselves on the colorectal course in May. [We are] somewhat afraid of not knowing what we are talking about, although reading through the report, I think we are already doing a great deal of what they suggested without probably being aware of it. [FN3]

Support Service Co-ordinator: I think there's going to be an awful lot of change.... We have to tighten up and become more professional. Somebody said the other day "like a business with a heart", which is kind of awful because no one here would like to think of it as a business. But that's the way that we're moving and people want statistics and proof that we're value for money ... so I think more and more we're going to be pulled into figures, statistics, proof, documents which we've never been part of. That will be very difficult here because we've never worked that way. [FTC1 manager, therapy]

The availability of local expertise

Although not a direct outcome of the Calman-Hine Report, a new and geographically proximate Cancer Centre had recently opened, serving the emerging Cancers Units in the three study sites. In addition, Macmillan funding had helped provide a new oncology unit with in-patient and day care facilities in one of the study sites. These developments were reported upon in terms of the welcomed location of specialised treatment services closer to home, something that was seen to be of advantage to patients.

GP: I think services are being developed - we now do have a consultant in palliative care, we have a consultant oncologist who comes from [town x] to the local hospital. Services are available, where they weren't before. If somebody needed radiotherapy, 5 years ago they had to go to [town y], now at least [town z] isn't quite as far. [FGP6]

Macmillan Nurse: I think there's been an enormous amount of change in the past three and a half years. There will be enormous changes happening in terms of where chemotherapy is delivered. We've now got radiotherapy much nearer. I now do a clinic with them - that's good. [FN4]

Community Nurse: People going for treatment don't have the journey, because that does upset people. The actual physically getting from A to B, and then worrying about is the transport going to come, are they going to get there on time, the traffic, who's going to go with them? people with children - they've got to sort those kids out - very, very, difficult. But with [town x], the distance isn't as great and if they're having any after-effects, nausea or vomiting, it's not as bad for them to get out, so they have definitely benefited from that, I think they seem much

better. [HN5]

Stronger linkages with the voluntary sector

Voluntary sector organisations, including hospices, were presented as becoming more centrally involved in the team approach to cancer services, as well as changing their own approaches to care. Once again, this development was approved of.

General Manager (community care remit): I think the links with voluntary organisations such as the Macmillan nurses and the hospices are very much more robust, and the role that these organisation have in sustaining the quality of life of people in their home situation is a focus for me.... If you look at the profile of the support that is available for psychosocial needs, it is very much more focused into the community. You don't see people having to go away into institutionalised care and I think that that is entirely appropriate. So the major changes for me, apart from the hi-tech stuff ...in a more acute setting, is the significant development around sustaining people in their own homes with as normal a lifestyle as possible. [FHM1]

General Manager: I think there is now more direct partnership with some of the voluntary organisations. [HHM1]

Consultant (hospice based): Calman coming in coincided with me going into the hospitals, so I am seeing people over there earlier whereas before I only saw the very late stage ones that were passed to us.... So there's plenty of room in the hospital to [follow up] the Calman idea of people getting palliative care from the time of diagnosis. [FD1, consultant, palliative]

Macmillan Nurse: I think that the hospice has changed in the last few years, last 2 or 3 years really, because of Calman, and because the palliative care service is seen as having a much broader remit now. The idea of hospice and hospice admission has changed, I mean people don't come in so much for respite now, they used to plan two week admissions into hospice, and that's all gone now. People come in for a reason, and quite rightly so, I'm not in any way being critical of that, because you're try to serve a greater number of people aren't you? But it has changed, I suppose our links are still very, very strong but for perhaps different reasons. [FN2]

Support service Co-ordinator: [Referral to our service has been] opened out...so that anybody can refer in. We've officially done that but still a huge majority of referrals are from Macmillan nurses. And [now] we'll make an assessment of where [the client] is at, and their difficulties, and what we can offer. [FTC1 manager, therapy]

Palliative care provision

Those professionals who spoke about palliative and terminal carer frequently indicated that there currently was, and should be, a move to improve the nature and quality of care, including better support for patients and carers to facilitate a home death.

GP: There is a trend that if people can manage death at home that's what they would like to do, and that's happening more. These outreach teams that facilitate that have certainly made it more of an option. [GP5]

Macmillan nurse: It's a new scheme that has been piloted by Macmillan. [Assistants] do very basic tasks, like housework, picking the children up from school, the things that actually need to be done, and if they're not done then the whole system falls apart. Like getting the shopping, doing the washing, enabling the patient, the carers perhaps, to have a sleep in the afternoon so they can carry on through the night. It's just those very basic practical skills, which add up to an enormous workload really, an enormous problem if they're not met. [FN4]

Service strengths

All of the above sets the context for reviewing the ways in which professionals identified current service strengths in addressing and meeting the psychosocial needs of patients and carers. We found that in discussing areas of service strength, professionals tended to dwell on treatment services, and did not always relate these directly to meeting psychosocial need. Nevertheless, strengths in treatment services were seen, quite appropriately, to have indirect consequences for both the occurrence of, and the ability to effectively address, psychosocial need. Areas of strength considered here are as follows: the efficiency and effectiveness of service delivery; the accessibility of services; good communication; knowledge of patients and families; service choice; a good network of services; and providing general support.

Efficient and effective delivery of services, and service accessibility

Some consultants and GPs, in particular, cited the efficient and effective delivery of services as an area of strength in cancer care. These included diagnostic, surgical and other services. Effective service delivery was described in terms of ensuring that patients received all that they needed, and that the team of professionals worked together well in the interests of the patient.

Consultant: I think we are very good at diagnosis. We're accurate and rapid... Leukaemia at the [hospital] gets diagnosed quickly and accurately. [FD3 consultant, haematology]

Consultant: In the hospice, I think we're pretty good at what you might call the whole of symptom control, I don't just mean the medical side, but the medical, the nursing, the social side. ... Just getting that whole package together for them, I think we are quite good at that. [FD1, consultant, palliative]

GP: I don't think anyone with a cancer problem has ever fallen through the net, ever. Certainly not since I've been here. I always feel there's been lots and lots of backup. I mean if something's been missed... somebody usually picks up on it fairly quickly, so I don't think there's ever been a problem of anybody missing anything. [FGP7]

GP: The strengths must be- if we're looking at it strictly medically first, in picking up a diagnosis, being alert to a diagnosis, which is what we're here for. Distinguishing a change of routine, and a change of pattern, and a change of illness in a person, and that's always a difficulty. [HGP3]

Along with these strengths went the speedy delivery of services, and quick and easy access to services. Both doctors and nurses mentioned these features:

Consultant: I think that we meet the aims of seeing patients early in the clinic. I think that in most instances, in most patients, we are able to diagnose their cancer early, although not in everybody - there are times when we don't, unfortunately, manage to do that. In terms of the speed from the diagnosis of the disease to the treatment of the disease, we usually offer the first treatment whatever that may be, and it's usually surgery, within two weeks of the diagnosis. [FD2 consultant, breast]

Stoma nurse: I think our strength is that we always get patients referred promptly. It's very rare that a patient slips through the net unless they have an emergency, well anything could happen in the night. But we nearly always get a referral, which is good, and we are then able to site these people for their stoma. So they've got a good chance of coping with it in a decent position on their abdomen, as opposed to not managing it because it's in a crease somewhere, which does happen. [FN3]

Support service Co-ordinator: The strengths? Not keeping people waiting, people being

contacted immediately... and it's the general ambience, the feel of it is incredibly welcoming... People get incredibly attached to [the support organisation]. [FTC1 manager, therapy]

Support service Co-ordinator: I think the drop-ins are best at not having the discharge policy, that's quite significant. ... Because people get an enormous amount out of [the support organisation], and people sometimes want to stay connected, and they can't in any other part of [the cancer service]. So it's good in that people can feel secure, that the door is always open. [LTC2 manager, therapy]

Communication

The quality of communication with patients and with other health professionals was a notable theme in most interviews. Communication was an integral part of the work they all did, and sometimes a cause of problems (see also the service 'weaknesses' section). However, many constituted good communication with patients, carers and other health professionals as a strong feature of cancer services.

Consultant: From our particular point of view, one of the great strengths is communication. We're all aware of the importance of communication, we try to find every way we can to make sure that people are up to date, know what they're doing and so on... But also one of the great strengths is the way we're structured and the fact that all of the services are under one management, all work together, meet together, kept up to date. Within the organisation generally, not just looking at a patient level, there's great emphasis on communication. [HD2 consultant, palliative]

Consultant: I think a wonderful thing that we have in this country, is primary care, not just general practice, but primary care. The GP and his team. The patients know the GP for years, they have confidence in the GP, and the GP can see them in their own family setting, he can visit them at home, rather than [here]. The important thing for me is to communicate very, very well with the GP. [GD3 consultant, gastro-enterology]

GP: I always like to feel that I do have a fairly good communication with the family, you know the close family, and the patient involved. [FGP7]

Knowing the patient and the family

In relation to both general needs and psychosocial needs, the idea of knowing the patient and carer well was presented as an area of strength by the GPs. This was also noted in the previous chapter.

GP: The vast majority of us have seen our patients for a fair few number of years. The vast majority of our patients feel comfortable in our environment. We're gatekeepers to the secondary services, tertiary services and we are liaison points for all the community facilities. If we're alert to what the patient needs, we can plug them in to all sorts of things. I would hope that GP's look at the whole patient, not just the physical diagnosis. I would be sympathetic to their psychological needs. I might need a bit of prompting [on the welfare benefit] things, but I would hope to be alert to it. [HGP3]

Providing choice

Providing choice was described as an area of strength by two doctors, one in terms of treatment choices, and one in terms of the range of service options available to patients:

Consultant: In terms of allowing the patient to participate in her choice of treatment, I think we do that where possible. Now there aren't many times from the purely physical viewpoint, in terms of treating the cancer, where it is not appropriate to offer a choice of treatment... One has to point that out in case the woman is not aware that choices are often available in breast

cancer. But as far as we can, we do that as well as we can. [FD2 consultant, breast]

GP: I think patients in this area are very lucky. They have a very good service and there are a variety of support mechanisms available which patients can opt in or opt out of, depending on their individual needs. So I think the service is very good in that it's not a regimented system. It's on offer and the patient can pick and choose. I think that's very good. [FGP5]

A good network of services

Several health professionals in one study site expressed the belief that the way that complementary services worked together was a feature of service strength, and that this network of services covered most psychosocial needs. This was particularly mentioned in relation to designated cancer services, such as the oncology unit, support organisations, as well as the hospice.

GP: I feel that there are lots of agencies to call upon if we do need their help. They're fairly easily mobilised in [this town]. I've only really practised here -you meet colleagues from other areas and you do become aware that maybe [this area] is quite well off in that respect. [FGP8]

Breast nurse: I do think that there is a very good service here, very good support system compared to other areas. [FN1]

Consultant: I mean there has been a long tradition in this [town] of emotional, psychological and practical support. I view all treatment of disease as either specific or supportive, and if you talk about the supportive side then I actually think we are reasonably good at it. [FD3 consultant, haematology]

Macmillan nurse: We've got a very good interactive system with the oncology unit the new unit in [town x]. I am closely liaising with the consultants, the radiotherapists and the oncologists. And we have a very active day care, both medical and social. I feel that we have got a lot to offer families and we've also got expertise about getting all the [welfare] benefits that people are entitled to, so we would try and link that in if there is a need for patients. It's also trying to be there at the right time for people.... I think co-ordinating for people, we're good at that, trying to meet the needs when they arise, trying to anticipate the needs, as well, of patients and families. I hope we are good at that. [FN2]

Macmillan nurse: On the whole, [the service] is integrated, and everybody is valued within the service, and there are open channels of communication. I think they are actually very good, having worked in different places. [FN4]

Dietician: Many places don't have any dietetics involved in cancer care particularly in the community. We've got it in the hospital and the community. [FPAM1]

Providing general support

A minority of respondents thought it was hard to judge what was a particular strength since there was little or no objective evidence to show how well they were doing. In a significant number of interviews with health professionals, strengths were presented in very general terms.

Consultant: I think that we are quite a nice bunch of people, on the whole the people involved in this are doing it because they want to, because they are interested in it. They put their backs into it and nobody here is working their standard hours. The doctors and the nurses work far more than their contracted hours. Not only physically doing the job, but also peripheral things - fund-raising stunts, giving talks in the evening - this sort of thing. So I think you could say that we are reasonably dedicated to the job, which I think comes across. [FD3 consultant, haematology]

GP: Yes, I think it works reasonably well. I'm not saying it can't be improved, but I think it by and large seems to work very well. [FGP6]

Breast nurse: It works well, it does work well. ... You have lots of good contacts, you've been here a long time, people are well aware of you. [HN4]

Service gaps and weaknesses

Health professionals drew attention to a number of service gaps and weaknesses. Some problem areas have already been touched upon in the discussion of service changes above, and in the previous chapter. This section adds to the picture. Weaknesses were sometimes identified in areas otherwise reported as strong – most notably, concerning the effectiveness of communication between professionals and patients, and among professionals. Additional areas of weakness discussed below are: some difficulties in accessing specialist mental health services; shortcomings in palliative care services; and time and resource constraints, including waiting times.

Communication

It has already been noted that health professionals spoke a great deal about communication, both with patients and carers, and with their colleagues, and as we have seen this was considered an area of strength by some. Some specific difficulties in communication systems and practices are now outlined (see also the previous chapter).

Communication with patients and carers

GPs, especially, indicated that they often relied on the patient or carer to contact them if there was a problem, and so those who do not make contact may miss out on help that could otherwise be of benefit. For example, some GPs mentioned that occasionally patients might 'slip through the net' if they expect a busy GP to re-establish contact (for follow-up visits, for example). Follow-up systems were partly to blame:

GP: I suppose one of the weaknesses is... we don't often make specific follow up arrangements. Like a hospital follow-up appointment is written down. If the patient doesn't come... we tend to say, oh well, he'll see me in a couple of months, and leave it at that. So I won't be alerted if someone doesn't come... somebody might be sitting at home quite miserable. 'Nobody cares about me'. But we wouldn't know that... Another [example of slipping through the net] would be somebody who appears to be straightforward, and there's nothing to be done. But after a few months we discover that that person's actually been quite depressed, and it's all been centred round the cancer issues, which nobody's picked up because we thought that person was OK. [LGP9]

The need for better communication with patients about specific potential problems was mentioned by a consultant:

Consultant: obviously sexual functions and so on are affected in some way after any major operation, but particularly in pelvic surgery. And that's something about which, I am aware, I don't particularly ask about, I mean warn about, I think we need to do that really. [GD2 consultant, colorectal]

And communication with particular groups of patients could be an area of weakness:

Community Nurse: ... a gentleman had been diagnosed with [cancer of the colon]. He'd actually been given the diagnosis and that was it, he was sent home, there was nobody there for him to chat to... I think that he needed someone to speak to because he was absolutely devastated. He was sent home, and it wasn't really followed up. [HN5]

This was contrasted with the very good support available to women with breast cancer.

Communication systems within and between services

Liaison and sharing care with other health professionals was prone to some failings, sometimes leading to patients 'slipping through the net'. Here are a few examples (see also the previous chapter). The problems were usually associated with systems and structures:

Consultant: The only gap we have really is where there are social problems as opposed to psychological problems, but it's often difficult to know where the line is, one blurs into another set very often. The way Social Services are structured doesn't really allow me to have a defined social worker. We're supposed to have for the breast cancer accreditation procedure, but the way Social Services are defined, there is the hospital social worker, there is the community social worker, and they talk to each other and they refer patients, but there is never any form of joint care or anything like that.... Whereas our breast care nurses [deal with patients] within the hospital or the community, so there's better continuity through the breast care nurses. Our social work side, the way Social Services is set out, doesn't allow the same sort of continuity, and from our point of view. we can't consistently refer to the same social worker quite so easily. [GD1 consultant, breast]

Consultant: The part of the service that I feel is perhaps the least well provided for at the moment... are those patients coming back with recurring disease, and that is no criticism on any other part of the breast care team. The reason I say that is that when they first get diagnosed with a relapse, it is my personal opinion that it is almost as upsetting, if not more so, than their original diagnosis. It's different but it's probably as upsetting for them. And at the moment the lines of communication, the way that the patient is handled - through from what is usually the surgical clinic through into the oncology clinic, through into palliative care if appropriate - are perhaps not as smooth as they are at the time of diagnosis. That is a personal perspective, I could be wrong, and it's certainly not a criticism on any other special team. If anything it's more a criticism on my side for not having the follow up channels to put patients through more smoothly to more appropriate specialities than mine. [FD2 consultant, breast]

Stoma Nurse: The referral system could be improved with patients that go to out-patients, have a diagnosis given to them and told they will be sent for in the next fortnight. We don't always get that referral very quickly. It goes through the internal system where the secretary types out the letter, then it is posted to us. It can be a week and that's a long time for a patient to be panic stricken about something that is going to happen to them. [FN3]

Service gaps - specialist psychological help

Several health professionals, particularly those in one of our three study sites, identified a gap in services for a small number of patients who were seriously distressed by their cancer. They felt that these patients needed the additional support of mental health expertise such as clinical psychology or skilled counselling. It was a question of the absence of such support, or the difficulty of obtaining a speedy referral. A minority of cancer patients whose needs were acute and immediate, brought on by the occurrence of cancer, needed to be seen by mental health specialists quickly. Moves were afoot in two of the locations to find a way of providing a speedier and more designated service. Health professionals also described ways in which they had managed to find psychological support for some of their patients - through primary care counselling, the cancer centre, community psychiatry and cancer support organisations. The following extracts are from health professionals in one study site:

Breast Nurse: We keep saying we need something and everybody else says "no you don't". The hospice doesn't believe in clinical psychologists and the surgeons think 'you deal with the counselling so you deal with the clinical psychologists'.... We need a clinical psychologist.... There's only a handful of psychiatrists that are interested in breast disease

or cancer or things around that in the country... the problem is if you find a patient you think needs a psychiatrist, they need some kind of intervention - it doesn't happen very often - but if you need that it's very difficult because then you have to go through the GP who may not always think that that's appropriate, when you know very well that it is appropriate. The word psychiatrist frightens the patients to death, but sometimes they need some kind of drug treatment... Clinical psychologists will take referrals directly from us, but the problem is the waiting list... You may have someone that you feel your counselling skills aren't enough for, you can hold them, but they have other problems that are completely out of your range, and there's an 11 month wait to see a clinical psychologist. [HN4]

General manager: [Services] will keep on expanding. I think locally in terms of direct psychological support from, perhaps, clinical psychology professionals... Clinical psychology has not generally been widely available and that's an area for a defined group of patients. ... for those patients that the specialist nurses and others identify as needing support beyond their abilities. I'm not sure that it's terribly easy moment. [HHM1]

GP: There was a woman, she had dreadful anxiety post-mastectomy, and I would have assumed that the nurse practitioner specialised in breast care would be able to address all this. I spoke to them and they backed off, which I was very surprised at, saying 'Oh no, no, no can't deal with that'. So I approached our community mental health team and they backed off and said 'Oh no, no, that's too specialised for us'. So this woman was left in limbo which was most unsatisfactory. It's only when you come up against extreme examples like that, I suppose, [that] you realise there is a gap for that patient. We coped, but I had made assumptions that I shouldn't have done, really. [HGP3]

Consultant: [If specialist help is required] our next port of call in the form of clinical psychology is very, very, sadly lacking. ...the average waiting time to see a clinical psychologist is, I think, 15 weeks and there's stacks of evidence that... up to 50 - 60% of patients with cancer can benefit from trained clinical psychological intervention. [The director] from the hospice would say nearer 70% of people requiring palliative care would benefit from clinical psychological intervention. And with this in mind we're actually putting together a Business Plan to try and employ a clinical psychologist with a full-time interest in cancer.... the people who are sufficiently trained are so hopelessly overloaded that you can't get anybody to see [patients] before probably fairly profound psychological damage is done. [HD1 consultant, breast]

A similar problem was identified in another study site by one respondent:

Consultant: I think our links with our psychiatric and psychology colleagues are poor. I've recently written to [a] psychiatrist at the [hospital x] and asked her if she would look into that for us, because it's fairly rare, but there are times when women at various stages along their pathway, from the diagnosis onward, cannot be supported adequately by the services that we have talked about today. And when that happens, when they get true psychiatric or psychological illness, then they are going to need to see somebody who is more expert in that field than anybody in the primary breast care team.... Getting that extra help at the moment isn't always as easy as it should be really, and that's why I am really looking to see if we can find somebody who might have an interest in this area, who will be prepared to say, 'well okay, I'll be the one at the end of the telephone for these very small number of women who are really struggling and I'll be the one that will see them early', either psychiatric or psychological. I can only think of about half a dozen women over the past year or so who I've actually felt that was appropriate for. And that's partly because of the very, very strong, very good voluntary services... in this area. If you went to another area where cancer care services were not as strong you would probably find there were a lot more people who needed psychological and psychiatric input. [FD2 consultant, breast]

Palliative care services

Although palliative care services were generally valued by the health professionals, and felt to be doing a good job, there were some comments on difficulties encountered in this area. Changes in hospice services and their care approach meant that it was less easy to provide speedy access to a bed, or to acquire respite care for relatives. And the hospices were perceived to be under greater pressure than previously.

Consultant: I think we could do better because we get the referrals, and they are all emergencies, and nobody's seen it coming, and often, when you scratch the surface, this problem was coming for 5 or 6 days. And we are not involved until the last minute. If we were much more structured, some of these patients that are waiting would be in, some of them that are currently in wouldn't be here, but somehow we've got to get our act together a bit better. I don't know how we do it really, I just feel it could be better. ... The [hospice]...for the people it reaches meets the needs extremely well, but I think we are aware of quite a large number of people that we can't reach because we are pretty stretched in doing what we do. Today we have about 8 or 10 people on a waiting list, and there is no sign of them getting in. [FD1 consultant, palliative]

GP: I think that the hospices are wonderful but very over-stretched, and I think there's not enough hospice support for patients with families unfortunately. But I can't blame them, they work very, very hard, there are just not enough beds... families are very frightened of bringing terminally ill patients home, they worry about how they're going to cope. They worry about the future, how they're going to manage. But if we sat down and explained to them 'look we can help you, there's a good primary care team here, we can offer you everything at home' perhaps the need for hospices would be lessened. We have had problems for carers, and again no disrespect to the groups themselves... there's not perhaps enough overnight carers to take [over from] the relatives who are exhausted sometimes, and not getting enough sleep. [GGP2]

GP: [the shortage of hospice beds is a problem]... We recently had someone who needed to go into hospice and they ended up going into hospital and dying on a general medical ward, which was far from ideal. [Hospice y] is excellent, but it needs more money to get bigger to provide the same service. [FGP3]

There was also some feeling that adequate, responsive, community-based services were not in place to compensate for pressures on hospices (such as hospice-at-home, 24-hour care, or nursing home expertise). Nursing care, and twenty-four hour care issues were mentioned by a range of professionals:

GP: There isn't a big sitting service so that the carer can go to sleep, or have a good night's sleep, or have a break, go out for four hours and do some shopping, which is quite difficult. There's a big hole in the terminal care there I think. ... You can't live up to their needs. If they want somebody to sit in with them all night, it's not available. The hospice isn't available at the drop of a hat, you have to wait for a meeting. ... There's a bit of a gap, you can't have somebody sitting in 24 hours a day, there isn't that provision.... For quite a few people these days, with the break-up of the nuclear family, you've got patchy coverage from families, so you often get an elderly person dying where the spouse is elderly with very little input apart from professionals, and that can be a bit difficult, especially when it comes to lifting. [HGP2]

Community Nurse: We try and offer a service but because we haven't got access to a 24 hour service, which some people need for support to actually stay at home... that's when I feel that we have perhaps failed people, because they can't have their last wish, in a way, which is sad... There is a night service that you can access for palliative care, but then there's a gap in the early hours, when people get worried really, and that's when they say "well who can I get

hold of at that time?’ And the answer...if they needed somebody, would be the ambulance service, which isn't the right service at all, is it? [HN5]

Macmillan Nurse: I think the gaps that I would see in this service are perhaps in the hands-on nursing... There's often a gap in the service because we can only get Marie Curie nurses for 2 nights a week, and that just isn't enough. What happens is that patients' carers get worn out, and end up bouncing into hospital, or the hospice, because we don't have enough grass roots, hands-on, basic care. Obviously the district nurses can't be there 24 hours a day but I think if we had more care in that sense that I think the community may well be managed better for the patient and the carers. I think that's a huge hole for them, that there isn't that support. Also we don't have a night nursing service - I'm not sure it's always needed but given the fact that we can only get Marie Curie 2 nights a week, then that's another huge hole in the service.. That's the biggest problem, caring for patients that are dying at home, is that they - the patients and carers need somebody going in, perhaps not with very specialist skills, but with basic empathy, listening, communication, caring skills, who will support the patient and family. [FN4]

The division between the responsibilities and funding systems of health and social services was also an issue mentioned by some:

Consultant: What I would like to see is a coming together of Health and Social Services in the area [for the] advanced and terminal care of patients, but at the moment there's still a battle of who's responsible, is it the health visitor? Social services?. And so on. I think that's very divisive, and because of that patients don't get care... In a sense you're going back partly to the idea of generic palliative care in the nursing home and so on. That's an area I'd like to see developing. We get to the stage where we have to hand patients on, we can't afford to keep people here a long time, there's always people waiting to come in. We don't mind handing patients on as long as we don't see in a week or so's time, maybe, things deteriorating again and they end up back either with us or in [hospital x], that's a bit soul destroying...

One of the things that we're not able to do very much of these days is true respite. Patients often come to us with a tag respite, and we take a lot of those in, but it's not true respite. Because respite really is the family who are saying 'look I need a break, can you give us a fortnight in July?', it's pre-booked and they know they can have that. Now we just can't do that. The other group, they are called respite, but I don't believe are truly, are the patients who, the family are saying 'look we can't cope with this situation we need help', and when you look at it the reason they can't cope and they need help is that the patient has deteriorated. And what you need is for the patient to come in, you can stabilise them again, give them pain control again... then they go back home again. The family now can cope because you've stabilised it. So it's two different groups...the first group we don't have the capacity [to respond to] now, as we used to. [HD2 consultant, palliative]

General Manager (community care remit): The inter-relationship between the health system and the voluntary organisations and social services [has changed]. Despite the fact that you have all these dreadful stories about the divides and the discrepancies, and they are real in so far as we all work with cash limited budgets and we work in systems that have different cultures, but despite that I think that there is a real impetus to work collaboratively around that. [FHM1]

Time and resource constraints

Health professionals often stated that being extremely busy and having limited time meant that they could not give as much attention as they would have wished to patients for psychosocial support. Time limits effected their accessibility and levels of contact with patients, and case prioritisation often had to come into play. As indicated in the previous chapter, the consultants were clear that their clinic time was heavily circumscribed, and GPs also described necessarily short consultation times. Both, however, suggested that they tried to allow more time for those

with cancer. Doctors varied in their view of the amount of time available to other health professionals. Sometimes other staff were seen to have greater time flexibility such that they could engage in more holistic patient care; sometimes other staff were seen to be under considerable work pressure. On their own part, non-medical health professionals did feel time and work-load constraints, and frequently mentioned increasing pressures. Nurses and dieticians both suggested that they were victims of their own success. Once again, systems, structures and limited resources were often seen as the source of the problems.

Consultant: I would typically spend no more than half an hour with somebody, an appointment in a clinic. There is a limit to what you can do in half an hour, when you are talking to somebody. The breast care nurses spend a lot longer, they get to know the patients a lot better than I do. And I think that's a part of the service we do reasonably well at, provided that the breast care nurses have the time and are not under too much pressure. [FD2 consultant, breast]

GP: I think the weaknesses are just time factors. We can't always visit [patients] every day, as would be nice, because of the time factor. That's one of the weaknesses, and that applies to all the agencies. District nurses, I'm sure, would often be happy to go in daily but [don't have time][But] most of us regard these as very high priority patients, and somehow you find the time. [FGP8]

GP: I suppose providing time and support and someone to talk to [is important]. We don't always have time in the practice to do that - neither ourselves nor our nurses. Sometimes district nurses are able to help in that respect. Certainly the Macmillan nurses get our district nurses to do a lot of work for them. That's where [the cancer support organisation] usually come in, because they have more people, who aren't necessarily professionally trained, but offer general support. So, I suppose in that respect there is a hole in the service. [FGP3]

GP: I think the nurses are very stretched and it's difficult for them. There's not enough immediate support. It is a crisis, sometimes, and you need help that night, and it's very hard to get it. The nurses try their hardest, it's a problem perhaps for the patients and the carers. [GGP2]

Macmillan Nurse: I would have episodes of care for people now and that's come in really in the last maybe year or two. Partly led by Macmillan and partly led by the fact that one can become overwhelmed by the numbers that you're dealing with because you've got this 'take all' policy and you don't turn anyone away, and we don't have any waiting lists. So, when I see patients and families, I would try to deal with the issues that are most prominent, and if I feel that they can be left then... I can then take them off my case load as it were, and put them into my pending case load and leave it to them to get in touch with me, and sometimes, of course, we don't get that right. There just doesn't seem any other way to do it. [FN2]

Community Nurse: You just have to assess the situation and see what you think they would need really.... time is such a precious commodity and, often, we haven't got the time. [HN5]

Waiting times

It was acknowledged that waiting times were a cause of distress to patients. The points of delay associated with the administering of tests, or conveying of test results, were identified by a number of health professionals. Several schemes to try and minimise the time patients spent waiting for results were referred to.

Consultant: This is the problem with a breast lump: a woman is found to have a breast lump, which is probably not going to be cancer, but she obviously thinks it is cancer. There's the huge anxiety that's brought to an end by 'it isn't cancer after all'.... [If it is] at least the patient knows where she stands. And it is trying to compress that diagnostic process into a couple of

hours rather than a couple of months [laugh] - that's what it used to be, it used to be a couple of months. Now it's coming down to a couple of hours, and it can only be a couple of hours if the patient is in an organisational system which delivers [the diagnosis] to a house. [GD3 consultant, gastro-enterology]

Consultant: If somebody comes through to the clinic and they are picked up as having new symptoms of bone pain, the first thing that I would do is arrange for them to have some screening blood tests and plain x-rays of that area. And then they would need an isotope bone scan. Well, it's quite common for patients to wait for 10 days, maybe 2 weeks for the isotope bone scan, not always, sometimes you can ring through and get an urgent appointment, but not always. ... So that's immediately a delay and a concern, and then they would come back with that result 2 weeks later to the surgical clinic...then I have to arrange for them to see one of my colleagues, whoever I think would be more appropriate in either the clinical or medical oncology clinic. We can sometimes get them into the next clinic, but that might even be the following week, and if the next clinic is full it might be the clinic after that or the clinic after that. So there can be a delay of another 3 weeks or so sometimes, and then another delay before treatment is instituted. One of the reasons we are having the multidisciplinary meetings is to try to get rid of that so that I can flag up immediately somebody who has been recognised as having a recurrent disease. [FD2 consultant, breast]

Summary

This chapter aimed to report findings on health professionals' perspectives on the adequacy of current services in meeting the psychosocial needs of patients and main carers. Whilst this has been achieved, much of the interview data reported relates not to psychosocial needs specifically, but to the meeting of patient treatment and care needs in general. In part, this reflects the fact that from health professionals' points of view, psychosocial needs are seen to be either secondary to, and separable from, treatment needs (typically the view of hospital consultants and general managers), or as inextricably bound up with treatment and care needs (typically the view of palliative care consultants, GPs, nurses, dieticians and support service managers). For the latter groups, meeting psychosocial needs is embedded in 'the everyday' of their care work with patients and, for some, with carers too; another way of putting this is that these professionals practice holistically. Thus it is not always possible to single out service strengths and weaknesses, gaps and good practices, in relation to meeting psychosocial needs specifically.

The quality of treatment and care *per se* is also relevant to considerations of psychosocial need because it can have a profound bearing on the psychological and emotional state of patients and carers. For example, as we report in other chapters, the worries, anxieties and practical difficulties experienced by patients and carers are very much shaped by treatment-related factors such as the speed with which diagnosis occurs and test results are conveyed. Many psychosocial needs are generated and/or exacerbated by treatment encounters. It is thus appropriate to report health professionals' perspectives on the broader features of cancer services in their localities. In this spirit, the discussion has identified those aspects of the services that professionals consider areas of strength, as representing 'good practice', together with perceived service gaps and weaknesses. It follows that the meeting of psychosocial needs is addressed with varying degrees of directness and immediacy.

Our interviews with health professionals took place at a time of considerable change in cancer services - during the post Calman-Hine Report (Department of Health 1995a) period of service accreditation and reorganisation. The first half of the chapter reviewed professionals' views on service change and development. The story was generally one of welcomed innovation and improvement, and this inevitably brought to light some areas of recent or current service weakness. Service improvements were seen to lay the foundations for better all-round patient care. The 'change' themes reported were:

- beneficial surgical and medical specialisation;
- welcomed injections of funding and resources, especially in the form of increased numbers of nurse specialists;
- welcomed developments in multi-disciplinary team building, and greater emphasis on team working;
- welcomed improvements in data gathering systems - supporting the move towards protocol development, evidence-based practice and the greater standardisation of practice;
- the welcomed availability of more localised expertise through the setting up of cancer units and centres;
- closer and improved working with voluntary organisations (including hospices, and cancer support organisations);
- welcomed developments in palliative care provision, including better support for patients and carers to facilitate a home death.

The second half of the chapter considered health professionals' replies to questions on service strengths, good practices, and gaps and weaknesses – with particular reference to the meeting of psychosocial needs. It was noted that some of the themes discussed were signalled in the preceding chapter.

Service strengths and good practices were identified as follows:

- ◆ the efficiency and effectiveness of service delivery, cited particularly by some consultants and GPs;
- ◆ the speedy delivery and accessibility of some services;
- ◆ communication – with patients and among professionals – was seen by some to be of very good standing;
- ◆ good personal knowledge of patients and families – cited by some GPs as a key strength (see also previous chapter);
- ◆ the availability of treatment and service choices – mentioned by a small number of doctors as a strength;
- ◆ the existence of a good network of complementary cancer services, ensuring the coverage of all needs including the psychosocial - seen as a service strength in one study site.

Gaps and weaknesses in services were reported as follows:

- ◆ communication with patients was seen by some to be an area of service weakness. Issues cited were: system problems (for example, patient follow-up and tracking systems in general practice); the relative lack of communication with patients on specific issues (for example, sexual functioning); or the relative lack of supportive communication with some groups of patients (for example, colorectal) compared with others (for example, breast);
- ◆ communication with other health professionals – poor liaison and information sharing sometimes meant that patients 'slipped through the net'. These were usually related to systems problems;
- ◆ perceived difficulties concerning the availability of specialist mental health professionals (clinical psychologists, psychiatrists) in situations when a patient was in extreme and severe distress. This was a particular difficulty in one study site;
- ◆ shortcomings in palliative care services. Changes in hospice services and their care approach meant that it was less easy to gain speedy access to a bed, or to acquire respite care for relatives. Hospices were perceived to be under greater pressure than previously;
- ◆ time and resource constraints. GPs and community based nurses frequently stated that being extremely busy, and having limited time to give to patients, curtailed the amount of attention they could give to psychosocial needs. Case prioritisation often had to come into play;
- ◆ some treatment waiting times for patients were seen as an area of service weakness, and a source of patient psychological distress.

Despite these gaps and weaknesses, cancer services were seen to be ‘doing a good job’ and as improving overall, both in general, and in meeting the psychosocial needs of patients in particular. As noted in the previous chapter, carers needs were far less likely to be mentioned, certainly by hospital consultants. The significant service changes underway were welcomed, and perceived to be leading to improved patient treatment and care. On the whole, better psychosocial support for patients was thought to be implicated in this general advance in cancer care.

CHAPTER 15 Study summary, conclusions and recommendations

Key features of the study

This observational study set out to assist cancer service providers in better understanding the nature of the psychosocial needs of patients and their informal carers. With the recent publication of *The NHS Cancer Plan* (Department of Health 2000a) containing a strong emphasis on meeting the psychosocial support needs of patients, carers and families, the findings reported are particularly timely and relevant. The study's focus on service users' perspectives also adds to its value. Particularly relevant points in *The NHS Cancer Plan* are as follows:

Patients, families and carers need access to support from the time that the cancer is first suspected through to death and into bereavement.⁴

Users and their carers should have choice, voice and control over what happens to them at each stage of their care.⁵

In three study sites, the perspectives and experiences of patients and carers have been explored through the analysis of both quantitative and qualitative datasets. Our operational definition identifies the main informal carer as: that lay person whom a patient identifies as being in a close supportive role and as 'sharing most' in their illness experience. In addition, structured interviews with health professionals have thrown light on both their roles in cancer treatment, care and support services and their perspectives on services' strengths and weaknesses in meeting the psychosocial needs of patients and carers.

Psychosocial needs defined

We have paid attention to a wide range of psychosocial needs bound up with living with cancer, adopting a sociologically informed approach that gives more emphasis to the 'social' in the psychosocial than is customary in psycho-oncology. It is the needs that underlie emotional and psychological distress, rather than this distress itself, which has been of interest. That is, psychosocial needs are not equated with clinical manifestations of psychological morbidity, and our study has not been concerned with measuring such morbidity. In summary, our understanding of psychosocial needs is as follows:

Psychosocial needs are embedded in features and qualities of life and social relationships that, from the viewpoint of patients and informal carers, are necessary, important, or critical to their psycho-emotional ability to live with the knowledge and social consequences of cancer, and thus to their ability to hold themselves and their social worlds together.

It is important to note that we have not constituted cancer patients and carers as passive participants in their cancer dramas, as objects of the social behaviours of others or of social circumstance. Rather, like any individual, the cancer patient or carer has volition - is a social actor who is actively engaged in the creation of his/her cancer experience.

The research project had the following objectives:

1. To identify and document patient and main informal carer psychosocial needs, and to consider

⁴ Ibid: 62

⁵ ibid: 66

- how patients and carers believe these could best be met.
2. To explore patient and main informal carer experiences of specialist cancer services, with particular reference to psychosocial needs.
 3. To examine service providers' perspectives on the nature of current service provision and its adequacy in meeting the psychosocial needs of patients and their main carers.
 4. To identify examples of 'good practice' in meeting psychosocial need from the perspective of both patients/carers and service providers.

These can be usefully expressed in the form of the following key questions about psychosocial needs:

- What are these needs?
- Which needs are most prevalent?
- How, if at all, do needs differ among patients and carers in relation to clinical (tumour type, critical moment) and social characteristics. In short, what is the distribution of needs: who has what needs?
- Are patients' and carers' needs being met?
- What can patients' and carers' experiences tell us about how needs could best be met?
- What are health professionals' perspectives on these needs and whether they are being met?

Data analysis has confirmed the existence of both general and group specific psychosocial needs in a range of areas that previous research has dealt with in a fragmentary fashion.

Taking account of variability

To accommodate the possibility that psychosocial needs may differ among groups of cancer patients and carers, the study design built in variability by recruiting patients who differed by tumour type and illness phase. Patients with the following tumour types in three study sites were eligible for inclusion: breast, colorectal, lymphoma, and lung. Among these patients, those eligible were within one month from four 'critical moments' in the cancer journey: diagnosis; the end of first treatment; first recurrence (notification that the cancer had returned); and the move from active treatment to palliative care.

As well as variation by tumour type and critical moment, analyses have also focused on psychosocial need differentials associated with a range of social characteristics, especially gender and socio-economic status (as measured by housing tenure and use of or access to a car/van). Variation was also addressed by locating the study in three adjacent geographical sites (Health Authority districts) in North West England, served by a single Cancer Centre. These study sites varied somewhat in their demographic composition but consisted of both urban and rural localities. Whilst it had been our intention to examine patterns of psychosocial need by ethnicity, poor patient referral in the study site with a higher minority ethnic population made this impossible and the findings are based on an overwhelmingly white sample.

Methods

Study design and data collection methods

The study required a design that could bring quantitative and qualitative research methods into dialogue. From the outset, the research team recognised the value of utilising both quantitative and qualitative methods without making either approach subsidiary to the other. Throughout the life of the project (six month pilot phase and 30 month main-stage phase, 1997-2000) we moved between these modes of data collection and analysis, using the insights from one to inform the other. Quantitative methods involved descriptive cross-sectional surveys of patients and main informal carers. Qualitative methods involved in depth guided interviews and focus group discussions with patients and carers, together with semi-structured and structured interviews with health professionals. Key elements of the main-stage study were as follows:

A descriptive cross-sectional survey with two branches – a) patient survey, b) carer survey. This involved the postal distribution of a self-completion questionnaire pack to a consecutive sample of 1000 adult cancer patients (aged above 18 years) referred to the study with the assistance of 21 participating consultants and their staff in outpatient clinics in the three study sites over a period of one year. Carers were recruited to the study via initial contact with patients; the questionnaire pack contained a letter asking the patient to pass the carer questionnaire to the person who helped and shared most in their illness. The questionnaires were entitled 'Your needs in illness' and no reference was made to 'cancer', as requested by an NHS Ethics Committee.

In depth guided interviews with a purposively selected sub-sample of surveyed patients (n=47) and carers (n=32) who had returned questionnaires and indicated their willingness to be contacted for a follow-up interview. The purposive selection was informed by the need to include a range of men and women living with different tumour types, at different critical moments, and in different socio-economic and other social circumstances.

(iii) Short structured interviews with a purposively selected sample of health professionals (n=39), focusing on four topics: a) identifying patient and carer psychosocial needs; b) links with other services; c) service effectiveness in meeting needs; and d) service change. With a few exceptions, the professionals who participated in the research were practising in hospital, palliative or primary care settings, and included: consultants (n=8), GPs (n=15), specialist nurses (n=9), dieticians (n=2), general managers (n=3) and support service co-ordinators (n=2).

A list of 48 psychosocial needs statements was developed in the project's pilot phase for use in the patient and carer self-completion questionnaires, referred to overall as our *psychosocial needs inventory* (PNI). Carers were instructed to complete the PNI with reference to *their own* needs. The PNI items were later grouped into seven needs categories: needs related to interaction with health professionals (nine items); information needs (five items); needs related to support networks (five items); identity needs (five items); emotional and spiritual needs (15 items); practical needs (eight items); childcare need (one item). The psychosocial needs inventory has proved to be a relevant, discriminatory and sensitive survey instrument.

Data analysis

Survey data

Frequency distributions and selected cross-tabulations for all single and composite variables were produced, and multivariate logistic regression analyses were undertaken on each of the 48 need items in the PNI using a range of questionnaire response variables.

Interview data

All interviews were fully transcribed and entered into a qualitative analysis computer programme. Interviews were coded and analysed for defining characteristics, topics and themes.

The psychosocial needs inventory (PNI) categories and items

<p><u>Health professional needs</u></p> <p>Confidence in the health professionals I meet. Health professionals who have time to discuss issues with me. Easy and quick access to doctors. Honest information. Health professionals who treat me with respect. Information given sensitively. Health professionals who listen to me. Easy and quick access to health professionals other than doctors. Opportunities to participate in choices around treatment.</p>	<p><u>Emotional and Spiritual needs</u></p> <p>Hope for the future. Help with any fears. Help in dealing with the unpredictability of the future. Time for myself. Help with finding a sense of purpose and meaning. Help with any sad feelings. Help in dealing with the feelings of others. Opportunities for personal prayer. Opportunities for meeting others who are in a similar situation. Help with any loneliness. Support from people of my faith. Help with any anger. Support from a spiritual advisor. Help with any feelings of guilt. Help in considering my sexual needs.</p>
<p><u>Information needs</u></p> <p>Information about treatment plans. Information about what to expect. Information about medication and side effects. Advice on what services and help are available. Access to other sources of information.</p>	<p><u>Identity needs</u></p> <p>Help in maintaining independence in the face of illness. Help in maintaining a sense of control in my life. Support in dealing with changes in my body or the way I look. Support in dealing with any changes in the way others see me. Support in dealing with any changes in my sense of who I am.</p>
<p><u>Support network needs</u></p> <p>Support from family. Support from friends. Support from care professionals. Someone to talk to. Support from neighbours</p> <p><u>Practical-child care need</u></p> <p>Help with child care.</p>	<p><u>Practical needs</u></p> <p>Help with any distressing symptoms. Help with transport. Help in dealing with any tiredness. Advice about food and diet. Help with housework. Help with getting out and about socially. Help with financial matters. Help in filling out forms.</p>

Findings

Patient and carer sample characteristics

Survey samples: Despite unevenness in referral patterns across the study sites and an overall patient survey response rate of 40% (402/1000), the patients and carers who did return completed questionnaires represented a broad enough spectrum of experience and psychosocial need to enable us to generate meaningful results. The sample's representativeness was adequate for the study's purposes, enabling us to meet all but one of our original project objectives (comparison between study sites). The numbers of patients and carers associated with particular tumour types, and at specific critical moments, was sufficient for valid and robust statistical analyses. Response rates varied by tumour type (lymphoma, 58%; breast, 55%; colorectal, 33%; and lung, 26%) and by critical moment (diagnosis, 50%; end of first treatment, 47%; first recurrence 62%; and move from active treatment to palliative care, 19%). Whilst 40% might appear to be a low overall response rate for a social survey it has to be remembered that these patients were grappling with serious diseases. It is not surprising that the response rate for a self-completion questionnaire was low for patients in receipt of palliative care only, and we very much value the information we obtained from those that took the trouble to participate in the study at such a stage in their lives (for ethical reasons reminder letters were not sent to patients in this category). If patients at this critical moment were to be excluded from the sample then the overall response rate rises to 51%.

The achieved patient sample was 66% (n=264) female and 34% (n=138) male. Patient age ranged from 26 to 83 years, with an average age of 57; 15% were aged under 50, 26% were aged 50-59, 28% were aged 60-69, and 31% were aged 70 or older. Ninety-seven per cent of patients who indicated their ethnicity described themselves as white.

Completed questionnaires were returned by 262 informal carers. Sixty four per cent of returned patient questionnaires were accompanied by completed carer questionnaires. Because carers were effectively recruited by patients, we cannot give a meaningful carer response rate. The achieved survey sample of carers comprised of almost equal numbers of male and female carers: women (51%), men (49%). The age range of carers was 16 to 88 years, with a mean age of 58 years; 25% were aged under 50; 29% were aged 50-59; 26% were aged 60-69; 20% were aged 70 or above. Ninety-nine per cent of carers who recorded their ethnicity described themselves as white.

Interview samples: 20 male patients and 12 male carers were interviewed, as were 27 female patients and 20 female carers. All tumour types and critical moments were represented in the patient and carer interview samples, and purposive selection ensured a broadly representative range by age and social circumstance.

The majority of carers in both the survey sample (75%, n=196) and the interview sample (78%, n=25) were spouses or partners or patients; thus our findings concern mainly informal caring in intimate couple relationships. Most carers were co-resident. Non-couple carers were usually other kin carers or close friends.

Patient psychosocial needs

The prevalence of psychosocial needs: survey findings

Twenty-five of the 48 PNI items were rated as important or very important (hereafter referred to singly as 'important') by more than 50% of the patients. The highest ranked were the 'health professionals', 'information' and 'support network' needs categories (important for 85%, 80% and 75%). Almost all patients wanted the best from health professionals, for example, to have 'Confidence in the health professionals I meet'; 'Health professionals who have time to discuss issues with me'; 'Health professionals who treat me with respect'.

Needs items in the 'identity', 'emotional and spiritual' and 'practical' categories were rated important by smaller proportions of patients (47%, 37% and 36% respectively). However, within these categories, some individual items scored highly - for example, having 'Hope for the future' (70%) and receiving 'Help in maintaining independence in the face of illness' (60%).

The number of respondents who recorded the items as 'not applicable' to them heavily influenced the scores. Thus, if a need was identified, it tended to be strongly felt. For example, the childcare need item was only of relevance to some younger patients with dependent children (7% of all patients rated this need as important).

Are the psychosocial needs of cancer patients satisfied? Identifying significant unmet needs: survey findings

- We defined a 'significant need' as a need that is deemed to be important or very important by the patient; it became a 'significant unmet need' if it was also perceived as not satisfied (rated 4 or 5 on the satisfaction scale).
- Approaching two-thirds (62%) of cancer patients surveyed indicated that they had no significant unmet needs. In the majority of cases, important needs were being appropriately recognised and satisfied, although this outcome partly reflects the stringency of the significant unmet need criterion. The exception is the item, 'Opportunities to participate in choices around treatment': two-thirds (67%) of the sample identified this item as important, and over one in ten of these patients felt that this was a significant unmet need.
- There is an overall trend of satisfaction of needs associated with interactions with health professionals and services, with information receipt, and with social support from family, friends and health professionals. This reflects well on health care professionals who, in the great majority in this study, were perceived by patients to be treating them with the respect, courtesy and concern that they expected.
- Whatever the personal cost to family and friends in responding to need, the questionnaire data suggests that there was rarely a significant shortfall on their part from the patients' perspective.
- In contrast, approaching one in five patients (18%) identified either one or two significant unmet needs; a further 15% identified between three and nine unmet needs, while a residual 4% indicated ten or more unmet needs.
- Significant unmet needs were mainly what might be termed 'social and emotional' needs. The need items that represent real difficulty for some patients can be broadly divided into three main themes - managing daily life (such as managing diet, tiredness, housework and child care), managing emotions, and dealing with changes in social identity. For example:
- While only 63 surveyed patients (21%) regarded 'Help with financial matters' as important or very important, over one-third (35%) felt that their need in this area had not been met satisfactorily. 'Help in filling out forms' was a need for 58 patients (20%) and a significant unmet need for 24% of these.
- 'Advice about food and diet' was a need for 112 patients (38%) and a significant unmet need for 19% of these.
- 'Opportunities for meeting others in a similar situation' was a need for 100 patients (34%) and a significant unmet need for 15% of these. 'Help in dealing with the unpredictability of the future' was a need for 160 patients (54%) and a significant unmet need for 13% of these. 'Help with any sad feelings' was a need for 130 patients (44%) and a significant unmet need for 14% of these.

The distribution of psychosocial needs: selected survey findings

There are sub-group variations in psychosocial need. Levels of need vary by both clinical and social characteristics. This study is unusual in examining socioeconomic variations in psychosocial need. For example, whilst epidemiologists and sociologists have long reported that cancer mortality and morbidity trends display the familiar socio-economic gradients, and that there are serious health inequalities associated with cancer, our evidence suggests that psychosocial needs also vary by indicators of socio-economic status (after controlling for other variables).

Age: Significant age effects were found for 25 of the 48 PNI needs items, suggesting that younger cancer patients often have a higher level of need than older patients for a range of psychosocial issues. For example, ‘emotional and spiritual’ needs showed significant differences for age with higher levels of need among younger patients with the exception of ‘Support from a spiritual advisor’ (higher among those aged 60 and above). This consistent age effect may indicate lower expectations of the health services and other domains of life on the part of older adults, or that younger cancer patients do actually have greater needs.

Gender: A gender effect was found for ‘Access to other sources of information’ and ‘Support from care professionals’ where women had significantly higher levels of need than men. Women had significantly higher levels of need than men for three items in the ‘identity’ needs category. For all needs categories, where there was a gender effect its direction was consistent: women had higher levels of need than men. Thus women may actually have greater psychosocial need than men, or perhaps this gender effect endorses the conventional wisdom that women are more likely to express their psychosocial needs than men.

Tumour type: For ‘health professional’ needs, there were some significant differences by tumour type, with colorectal patients having a significantly lower level of need compared with patients with other tumour types for six of the nine items. We have no ready explanation for this. Breast cancer patients had a significantly higher level of need for ‘Opportunities to participate in choices around treatment’, even after controlling for age and gender. This might reflect public awareness about different treatment options for breast cancer. Lung cancer patients had a higher level of need than did those with other tumour types for ‘Help in dealing with the feelings of others’.

Critical moment: Palliative care patients were more likely to require information about medication, ‘what to expect’ and treatment plans than patients at other critical moments. ‘Help in maintaining a sense of control in my life’ was a significantly higher level need for patients at both first recurrence and palliative care than for patients at other critical moments. ‘Support from a spiritual advisor’ was a significantly higher level need for patients at recurrence and at the move to palliative care; those at the recurrence stage had a higher level need for ‘Help in dealing with the unpredictability of the future’.

Socio-economic status: Patients of lower socio-economic status (non home-owners) had significantly higher levels of need for all ‘practical’ needs items including: help with transport, advice about food and diet, dealing with tiredness, help with housework, help with financial matters, and help with filling out forms. For one of the markers of socioeconomic status (use of a car/van), the more affluent patients had a significantly higher level need for six of the nine items in the ‘health professionals’ category, perhaps reflecting their higher expectations of health professionals and services.

Morbidity (global health status): Across all categories, needs tended to become significantly greater as health status declined, with one important exception: ‘Help in considering my sexual needs’ was a higher level need for those in better health than for those in poorest health.

The distribution of significant unmet needs among cancer patients: survey findings

Our survey analysis did not identify tumour type or critical moment as markers for significant unmet need (this contrasts with the interview findings, see 3.4). This suggests that help from health care professionals is not located unevenly as far as clinical characteristics are concerned.

Patients entering their cancer journey with any of the following characteristics were statistically more likely to have at least one significant unmet need: being younger; having a long-standing illness or disability; not owning/having use of a car; not having a faith. In other words, patients with these pre-illness characteristics were at greater risk of experiencing significant unmet need. When ‘illness’ variables were also taken into account, a further three statistically significant ‘risk’ factors are added: not being able to talk freely to the main carer about the cancer; having social activities interfered with by the illness; and having financial difficulties.

These findings suggest at least two things. First, another dimension of documented cancer health

inequality is that there are higher levels of significant unmet need amongst those who are relatively socially and economically disadvantaged. Second, those with higher levels of social support and social capital, through participation in church activities for example, are less likely to have significant unmet needs.

Cancer services were less responsive to non-clinical aspects of the cancer experience that cause significant difficulty for important minorities of patients in particular circumstances. There were certainly examples of good practice in attending to some of these needs reported by patients in the study sites. For example, help with financial need (and concomitant form-filling) was sometimes given by specialist palliative services, specialist nurses, attached social workers and GPs; emotional help was being given through NHS linked counselling and charitable support organisations; but there was still significant unmet need in this area.

Some aspects of significant unmet need relate to problems that arise in the interstices of various care systems (health, social service, voluntary) and it is currently not the responsibility of health care professionals to become directly involved, for example, in arranging home care assistance or child-care.

Informal carer psychosocial needs

This study considered the psychosocial needs of the main informal carers of cancer patients *as well as* those of patients. In so doing, the study has thrown a great deal of light on what such carers do - on their essential contribution through both care work (household and personal care work tasks) and emotion work (managing the emotions of the patient and their own feeling states).

Care work survey and interview findings

Additional care work demands were an important feature of informal carers' lives in cancer contexts, although this varied with the stage of the patient's disease and with the presence of co-morbidity in patients. The extent of extra help needed varied significantly with the critical moment of the patient's illness, with higher levels of care work required when the cancer recurred or was in the palliative care only stage. Thus in the earlier stages of cancer, divisions of labour and care work loads may not be greatly affected, or are only disrupted around treatment episodes involving surgery, intensive chemotherapy or radiotherapy. Like the ripple effects of a stone dropped into a pool, the diagnosis can have knock-on care work effects, sometimes disrupting the lives of a large group of people. However, there was also evidence of *reciprocity* and co-dependency between patients and carers, especially at earlier critical moments.

The carers' own morbidity status, together with their material and relational social circumstances, had an important bearing on their capacity to take on greater quantities of care work. Specific groups of carers expressed the need for help with particular practical tasks and with the personal effects of the burden of care work. Carers under the age of 50 were more likely than carers in older age groups to say that they needed help with childcare, and carers who had the use of a car/van had lower levels of need than those without for 'Help with transport'. Carers who reported the highest levels of self-morbidity had increased levels of need for help with (their own) distressing symptoms, tiredness, transport, and financial matters.

Female carers reported higher levels of need than male carers for a range of need items, including 'Advice about food and diet', 'Help in dealing with tiredness' and 'Help with getting out and about socially'. However, we found no marked gender differences in the cancer-related care work burden on men and women overall. Carers who looked after patients who required extra help with activities of daily living had higher levels of need for support than others.

Emotion work survey and interview findings:

Emotion work was a key dimension of care-giving in cancer contexts. Carers worked hard to

manage the emotions of the patient as well as their own feeling states, and these aspects of emotion work were intimately connected.

Carers felt that they had to be, and often wanted to be, 'strong' and 'positive', and to try to maximise the sense of 'life carrying on as normal'. In doing this emotion work, carers, especially spousal carers, often symbolically shared in the illness and presented the struggle with the cancer as a joint one.

On the grounds of their intimate knowledge of the patient's disposition, carers sometimes withheld or glossed information to minimise patient distress.

Only a minority of carers found it difficult to talk freely with patients about the illness, but this was more likely to be difficult when the disease was in its later stages.

Both male and female carers were heavily engaged in emotion work, but the questionnaire PNI data on expressed emotional needs found marked gender differences. This suggests that women caregivers are more able to express emotional support needs than their male counterparts.

Younger spouse-carers (under 60 years) were also more likely than older carers to express emotional support needs, perhaps reflecting their struggle to accept the premature onset of a life-threatening disease among loved ones.

Carers generally put the needs and interests of patients above their own, and often struggled to see their own needs as legitimate.

Carers' active involvement in the cancer drama generally helped not only the carer to cope, but the patient too, as well securing the relationship between the patient and the carer. In interview, carers and patients often presented the cancer as something they were 'facing together', and this required carers to be as well informed as patients about the illness.

Carers' significant unmet needs: survey findings

As in the patient data analysis, a carer 'significant unmet need' was defined as a need deemed important by the carer but which had not been satisfied. Carers often had significant unmet needs, and in a minority of cases such needs were multiple. In fact, whilst carer psychosocial needs, as measured by the PNI, had matched the pattern for patients fairly closely, when it came to significant unmet needs carers had considerably more unmet psychosocial needs than did cancer patients themselves. The problems for many carers were both serious and complex.

What are the significant unmet needs of carers?

The majority of carers expressed the importance of having good relationships with health care professionals and receiving honest information, but few expressed dissatisfaction with these aspects of need.

Over one in four carers (28%) had three or more significant unmet needs. Items of significant unmet need for a sizeable minority of carers clustered around the following: managing daily life (tiredness, finances, diet, filling in forms, housework, transport, dealing with their own symptoms); managing emotions (guilt, anger, sadness, fears, uncertainty); and social identity and relationships (sexual needs, meeting others in a similar situation, dealing with the feelings of others, changes in one's sense of identity, appearance, loneliness, social activity, having time for oneself, maintaining independence and control).

Which carers had significant unmet needs?

Carers with significant unmet needs were statistically more likely to be i) those where the relationship to the patient was not that of a partner or spouse, ii) those more likely to have other

caring responsibilities, and iii) those less likely to have friends or relations to call upon for help. Carers with unmet needs were also more likely to be, iv) in poor health themselves or, v) to be caring for a patient who had reached the palliative care only phase in their cancer journey. Those carers already socially disadvantaged – such as those with a limited network of social support as well as those in poor health – were less likely to have all their important needs satisfied.

Carers in medical contexts: interview findings

Whilst our carer survey results indicated that carers' needs concerning their interactions with health professionals were largely satisfied, the carer interview data highlighted an area of difficulty for carers: their place and role in medical settings.

Given their active role in cancer contexts, carers often felt unsure, and sometimes uncomfortable, about their place in medical settings. Could/should they join the patient in clinical settings, and participate in discussions with doctors and nurses, or stay out? Did health professionals want them there? Guidance on these matters was needed from clinic staff.

Carers appreciated clarification of their 'place' and the limits to their involvement in clinic environments. They were particularly in favour of being invited and welcomed 'in' by health professionals, and thereafter fully involved. This reflects the fact that many patient and carer couples see the cancer as something they are 'fighting together'.

For many carers, participation in medical encounters led to greater confidence in their role. They found new ways of being involved and sharing aspects of the cancer experience with the patient. Being provided with information (clinical, service-related) was often of more importance to carers than to patients (confirmed in the survey findings). Many interviewees suggested that the health services were inadequate in meeting carer specific needs for information and support. This contrasted with carer survey findings which suggested that information needs were largely being met.

While there were many examples of good carer support in medical settings, carers often expressed uncertainty about where to go if they needed more psychosocial support.

Patient and carer interview findings for tumour type and critical moment

Whilst the survey data analysis did not reveal many statistically significant differences among patients by tumour type or critical moment, the interview data analysis suggested that there were some important variations in experience associated with these variables.

Tumour type

The four tumour types involved different treatments and survival trajectories. This shaped the experience of patients in terms of services encountered, treatments received and perceived survival chances.

Common initial perception that 'cancer = death' among patients (and carers) gave way to more nuanced understandings of the risks associated with specific tumour types; this generally eased the psychosocial management of the illness. Information given by health professionals played a central role in this process. The manner in which information was given, its quality, and its specificity and relevance to the individual, were very important in moulding the processes that enabled patients and carers to manage the cancer and continue with life.

With its particularly poor prognosis, those dealing with lung cancer were confronted with difficult questions, such as whether to obtain more detailed information on 'what to expect'. Some lung cancer patients and carers felt abandoned and isolated because intervals between appointments

could be long and because there was usually no clear-cut treatment plan. Referral to hospice and palliative services tended to help with these feelings. The carers of lung cancer patients reported particularly high levels of anxiety.

Breast cancer patients described being swept into a reassuring whirl of treatment activity. Breast cancer patients had designated nurses who were an important point of contact, information and psychosocial support. Their desire to be monitored after the completion of treatment was frequently mentioned. Breast cancer differs from other tumour types in that it is rare for patients to feel ill prior to diagnosis; this meant that there was sometimes a lingering disbelief about the cancer. Body image was important since treatment tended to disfigure, especially with loss of hair through chemotherapy.

Colorectal patients also had body image and identity issues to deal with, especially when there was stoma formation; this was often presented as limiting social activity. Surgery was often major and the time taken to recover from this and any chemotherapy regimens was frequently difficult to come to terms with. While stoma nurses, and the ease of obtaining supplies of necessary appliances, were praised by several patients and carers, a lack of advice about food and diet was an important problem for a few.

Lymphoma patients differed from those with other tumour types in having no surgery beyond a biopsy. Their treatment experiences centred around chemotherapy and the hospital unit which delivered this. Lymphoma patients often reported feeling quite ill prior to diagnosis, and diagnosis was frequently a lengthy process. Hence, for lymphoma patients, it was often a relief to be diagnosed, to finally know what was wrong.

Critical moment

While many of the challenges presented by cancer were pertinent to all four moments, such as 'keeping going', 'being positive' and 'maintaining relationships', each moment had its particular concerns and features:

The time around diagnosis was variably described, with an emphasis on 'shock', or in some cases on 'relief' through confirmation. Being prepared for the 'bad news' consultation, sometimes through prior hints from health care professionals, often helped to 'soften the blow'. At this time any professional inattention or insensitivity made things more difficult for patients and carers. Staff support and the provision of information, together with the speedy implementation of clear plans of action, ameliorated the worst of the shock for both patients and carers.

Patient and carer fears were often allayed through full information receipt and prompt medical action, and by a good prognosis and encouraging test results.

The initial period following the completion of treatment could be difficult to manage. Having been swept up into the activity of treatment, often for months, its cessation meant further adjustment for patients, and sometimes a disconcerting sense of 'is that it?'. However, with the further passage of time and attendance at review clinics, patients who were successfully treated generally tried to put the experience 'behind' them. Being 'monitored' was viewed favourably as source of reassurance. Recurrence differed from diagnosis in that patients and carers had already been 'initiated' into the cancer experience, and knew something of the care systems they would meet. Prompt medical action was appreciated, and the value of monitoring confirmed. 'Recurrence' was, however, a difficult moment since survival was once again in doubt. The task of 'getting on with life' tended to take on a different meaning, with renewed uncertainties.

The time when palliative care alone became the only option was usually marked by patient referral to a new set of services, such as hospices and Macmillan nursing. Preoccupation with the logistics of death - how, when and where - was more prevalent at this 'moment', particularly among carers.

Patients, alongside the ways in which these changes affected social life and identity, discussed adjusting to physical changes and limitations, and the growing need to accept help from others.

Good and bad practices from the patient and carer perspective: interview findings

Summarised here are the focal points of patients' and carers' explicit praise or criticism of services. Interviewees tended to be very discriminating, offering praise where it was due *and* drawing attention to difficulties if these had been encountered. Complaints (being made formal in a few cases) were usually made in the context of overall satisfaction with services.

Good Practices

- efficient and fast health care services;
- accessible health care services and professionals (especially being able to telephone a professional at any time if a difficulty arose);
- easily available information and advice;
- health professionals with a 'good attitude' (kindness, attentiveness, being caring, responsiveness; willingness to impart information and give explanations, openness);
- help with transport (for a minority of patients with transport needs).

Bad practices

- having to wait and experiencing delay (for diagnostic attention, for test results, for treatments);
- distressing in-patient experiences on a few hospital wards (for example, encountering low staff morale, staff inattention, poor quality of care, being discharged too early; lack of clarity about staff roles and status; poor quality hospital food; visitor car parking problems)
- ambulances: two patients described particular problems with the ambulance services;
- lengthy journeys between home and treatment centres (these were considerable for some patients and carers);
- health professionals with a 'bad' attitude (for example, being treated as 'just a number'; being treated insensitively, especially around the time of diagnosis; not being listened to; not being treated with respect; an overly pessimistic manner on the part of some professionals, especially doctors)
- being made to feel forgotten, abandoned or 'in limbo' by the health care services (a particular problem for some lung cancer patients and carers; also a problem for some among those who had completed active treatment; something that sometimes occurred when promised or expected events such as home visits did not materialise).
- difficulties in obtaining financial support from welfare services. Welfare claim forms and systems were sources of considerable confusion and distress for some patients and carers experiencing financial hardship. Assistance from health and other professionals in this area was greatly appreciated.

Health professionals' perspectives on psychosocial needs and the adequacy of their services in meeting these: interview findings

The self-described roles of health professionals in cancer care, with particular reference to meeting psychosocial need

Consultants

Consultants emphasised their role in the provision of good clinical services, speedy and effective treatment, and information. Meeting psychosocial needs was not deemed to be central to their role, although reported individual styles of practice varied in this regard. Consultants did, however, acknowledge that patients had psychosocial needs and that the way that the patient was handled in the medical context affected their psychosocial wellbeing. Most consultants demonstrated

awareness that there should be ‘good communication’ with patients – whether this involved the imparting of ‘bad news’ or the giving of information about other aspects of treatment and care. Good communication was usually described as associated with the qualities of honesty, timing and creating a sense of confidence. Many consultants prized good inter-personal skills and sensitivity in other doctors and themselves. However, consultants very much positioned the patient as a passive recipient of information. We have suggested that it may be more helpful to think about patients as potentially active rather than passive with regard to information receipt and exchange, that is, as participants who would sometimes welcome the opportunity to express their information needs more openly, and to shape the information dialogue more purposively.

Consultants expressed their strong reliance on nurses in dealing with the psychosocial needs of patients. There were clearly divisions of labour in operation in clinical contexts such that nurses were often expected to manage patients’ psychological and emotional needs. Consultants frequently constituted the nurses as having the time, the approachability and the disposition to handle the psychosocial aspects of care.

Consultants also spoke of the importance of good channels of communication between all health professionals involved in cancer services. This was seen as an area where improvements in systems and practices were necessary, and sometimes underway. Very few consultants mentioned informal carers; with the exception of palliative medicine consultants, these professionals were almost entirely patient-focused in their accounts.

GPs

GPs emphasised their role as co-ordinators of cancer care, and as a point of interface with hospital services through referral mechanisms. They saw their job, first and foremost, as accessing the necessary range of services so that their patients’ treatment and support needs could be met. Most of the GPs interviewed also described their ‘hands-on’ supportive role in dealing with the treatment and psychosocial needs of patients and families. This frequently involved attempts to relieve distress and anxiety through providing information, explanations, and a ‘listening ear’, and showing empathy, as well as through the provision of practical support.

GPs presented the value of their service as residing in their accessibility to patients, their long-standing personal knowledge of the patient the carer/family (and vice versa), their ability to respond to the individualised needs of patients, and the provision of continuity of care. However, GPs identified a number of changes in general practice that undermined their ability to make the most of these values, particularly the on-call and out-of-hours arrangements. In fact, a key theme to emerge was the relative marginalisation and de-skilling of GPs in cancer care consequent upon the development of specialist cancer treatment and support services. If GPs were involved in care it tended to be at the terminal stage of the disease. Being marginal was often, but not always, perceived to be problematic by GPs; opinions and practices differed. GPs saw communication across the secondary-primary care interface as improving but far from perfect, but they did not always blame other parties for this. Many felt that they were not kept as fully informed as they would like to be about patient matters by specialist services providers. GPs certainly included informal carers as part of their remit.

Like consultants, GPs acknowledged their reliance on nurses in meeting the psychosocial needs of patients, both directly and indirectly.

Nurses

Unlike GPs, the nurses we interviewed tended to meet the patient and carers/families only in connection with cancer diagnosis and treatments, and as specialist nurses they were usually involved with specific tumour types or critical moments. Of all professional groups, the nurses spoke in greatest detail about psychosocial needs, and frequently saw themselves as co-ordinators of services to meet such needs. They were very sensitised to patients’ and carers’ emotional needs

and understood that their psychosocial needs are located in these individuals' wider social contexts and networks of relationships.

Nurses seemed to prefer a mode of practice that minimised patient and carer distress by anticipating needs and 'heading off' distress and difficulty. Their skill in this was bound up with a patient-centred holistic practice.

Interaction with informal carers was deemed to be necessary, and sometimes essential. Support for carers within services was seen to be somewhat inadequate, especially around terminal care and bereavement.

Overall, nurses thought there was good communication between themselves and other health and social care professionals, though some specific service communication difficulties were identified.

Other professionals

Dieticians, who naturally had a strong focus on needs surrounding food and diet, were also patient-centred, and conveyed a strong sense that managing 'food matters' was tied in with addressing wider emotional and psychological needs – for both patients and carers.

The two co-ordinators of support services interviewed in one study site were centrally involved in meeting the psychosocial needs of both patients and carers, their main focus being the emotional and companionship needs of these clients. Emphasis was placed on the considerable psychosocial benefits that can accrue when patients and carers meet together, sharing their experiences and knowledge.

They identified the pattern of referrals of patients to the support service by health professionals as being a little patchy.

The health service managers interviewed did not have direct contact with patients, and gave an overview of services and policies. They were aware of the importance of meeting patients' psychosocial needs, but tended to emphasise a requirement to develop services that enabled patients to obtain full information about services and treatment options, and to be more actively involved in making care decisions.

Health professionals' perspectives on the adequacy of services in meeting psychosocial needs

Much of the professionals' interview data related not to meeting psychosocial needs specifically, but to the meeting of patient treatment and care needs in general. In part, this reflected the fact that from the health professional's point of view, psychosocial needs were either secondary to treatment needs (typically the view of hospital consultants and general managers), or inextricably bound up with treatment and care needs (typically the view of palliative care consultants, GPs, nurses, dieticians and support service managers). For the latter groups, meeting psychosocial needs was embedded in 'the everyday' of their care work with patients and, for some, with carers too; another way of putting this is that these professionals practiced holistically. Thus it was not always possible to single out service strengths and weaknesses, gaps and good practices, in relation to meeting psychosocial needs specifically. In addition, the quality of treatment and care per se is also relevant to considerations of psychosocial need because it can have a profound bearing on the psychological and emotional state of patients and carers. For example, the worries, anxieties and practical difficulties experienced by patients and carers were very much shaped by treatment-related factors such as the speed with which diagnosis occurred and test results were conveyed. Many psychosocial needs were generated and/or exacerbated by treatment encounters. It was thus appropriate to report health professionals' perspectives on the broader features of cancer services in their localities. In this spirit, we identified those aspects of the services that professionals considered areas of strength, as representing 'good practice', together with perceived service gaps

and weaknesses. It follows that the meeting of psychosocial needs is addressed with varying degrees of directness and immediacy.

Our interviews with health professions took place a time of considerable change in cancer services. Discussions occurred during the post Calman-Hine period of service accreditation and reorganisation. With regard to service change and development, the story was generally one of welcomed innovation and improvement, and this inevitably brought to light some areas of recent or current service weakness. Service improvements were seen to lay the foundations for better all-round patient care. Cancer services were seen to be 'doing a good job' and as improving overall, both in general and in meeting the psychosocial needs of patients in particular. The significant service changes underway were welcomed, and perceived to be leading to improved patient treatment and care. On the whole, better psychosocial support for patients was thought to be implicated in this general advance in cancer care.

The 'change' themes reported were:

- beneficial surgical and medical specialisation;
- welcomed injections of funding and resources, especially in the form of increased numbers of nurse specialists;
- welcomed developments in multi-disciplinary team building, and greater emphasis on team working;
- welcomed improvements in data gathering systems - supporting the move towards protocol development, evidence-based practice and the greater standardisation of practice;
- the welcomed availability of more localised expertise through the setting up of cancer units and centres;
- closer and improved working with voluntary organisations (including hospices, and cancer support organisations);
- welcomed developments in palliative care provision, including better support for patients and carers to facilitate a home death.

Service strengths and good practices were identified as follows:

- the efficiency and effectiveness of service delivery, cited particularly by some consultants and GPs;
- the speedy delivery and accessibility of some services;
- communication – with patients and among professionals – was seen by some to be of very good standing;
- good personal knowledge of patients and families – cited by some GPs as a key strength;
- the availability of treatment and service choices – mentioned by a small number of doctors as a strength;
- the existence of a good network of complementary cancer services, ensuring the coverage of all needs including the psychosocial - seen as a service strength in one study site.

Gaps and weaknesses in services were reported as follows:

- communication with patients was seen by some to be an area of service weakness. Issues cited were: system problems (for example, patient follow-up and tracking systems in general practice); the relative lack of communication with patients on specific issues (for example, sexual functioning); or the relative lack of supportive communication with some groups of patients (for example, colorectal) compared with others (for example, breast);
- communication with other health professionals – poor liaison and information sharing sometimes meant that patients 'slipped through the net'. This was usually related to system problems;
- perceived difficulties concerning the availability of specialist mental health professionals (clinical psychologists, psychiatrists) in situations when a patient was in extreme and severe

- distress. This was a particular difficulty in one study site;
- shortcomings in palliative care services. Changes in hospice services and their care approach meant that it was less easy to gain speedy access to a bed, or to acquire respite care for relatives. Hospices were perceived to be under greater pressure than previously;
 - time and resource constraints. GPs and community based nurses frequently stated that being extremely busy, and having limited time to give to patients, curtailed the amount of attention they could give to psychosocial needs. Case prioritisation often had to come into play;
 - some treatment waiting times for patients were seen as an area of service weakness, and a source of patient psychological distress.

Conclusions

This study has generated many findings and conclusions can be drawn for each. However, it may be of greatest assistance to cancer service providers if we present in brief only the *main concluding points* here.

What are psychosocial needs?

Rather than narrowly equating psychosocial need with psychological distress and anxiety, it is helpful to think broadly about what these needs consist of. Our research has demonstrated the usefulness of identifying potential needs, for both patients and carers, associated with:

- ◆ interaction with health care professionals and the quality of professional practice (social and interpersonal skills, communication styles, demeanour);
- ◆ the quality of care systems and procedures (accessibility, rapidity of treatment and other interventions);
- ◆ involvement in treatment and health care decisions;
- ◆ information requirements and opportunities;
- ◆ social support networks – their range and quality, both lay and professional;
- ◆ emotion, feeling states, worries and anxieties - about self and others;
- ◆ spiritual concerns;
- ◆ challenges to self-identity - body and self image;
- ◆ practical needs - managing daily life and the demands of treatment.

Our study suggests that it is particularly helpful for practitioners to think about both patients and carers as people who actively shape their experiences and psychosocial states. If given access to resources (especially information, prompt medical attention, ready access to health professionals, emotional support, practical assistance) they can usually manage their psychosocial states in positive ways, so minimising the danger of developing acute psychological distress.

Which psychosocial needs are most prevalent?

The needs of importance to the great majority of cancer patients and carers relate to:

- ◆ their need for particular qualities embodied in health care professionals and systems - sensitivity, receptivity, honesty, respectfulness, speedy access, involvement in treatment decisions (for many but not all);
- ◆ their need for information – about what to expect, about treatments, timetables and schedules, about services and additional sources of information;
- ◆ their need for social support – from family, friends *and* health care professionals;
- ◆ their need for hope for the future and help in maintaining independence.

Important minorities and sub-groups of patients and carers had a range of additional psychosocial needs in the ‘emotional and spiritual’, ‘identity’ and ‘practical’ domains. In particular, patients and carers in lower socio-economic groups had higher levels of practical need than those in more affluent circumstances. Professionals need to be alert to these sub-group variations so that support

and assistance can be appropriately targeted.

What needs are unmet, and who has unmet needs?

The needs identified by the great majority of surveyed patients and carers as important or very important were largely satisfied. This reflects well on health care professionals and systems in the study sites, and current successes should be acknowledged and built upon.

However, using a stringent criterion for defining an unmet need in the survey analysis, we have identified a range of unmet needs together with sub-groups of patients and carers who are at greatest risk of having unmet needs. The patient and carer interview data has thrown further light on unmet needs, problems and difficulties.

- ◆ Unmet needs among notable minorities of patients and carers tended to involve needs in the emotional, identity, and practical domains. This included needs such as: assistance with financial matters and welfare claims; advice about food and diet, help in dealing with the unpredictability of the future and sad feelings; help with housework; help with sexual needs (especially among carers).
- ◆ Those with the following characteristics were at greatest risk of having unmet needs. *Patients*: being younger; having a long-standing illness or disability; being socio-economically disadvantaged; not having a faith; having difficulty in talking freely to a carer about the cancer; having social activities disrupted by the cancer; having financial difficulties. *Carers*: those who are *not* the partner or spouse of the patient; those with existing caring responsibilities; those with few people to call upon for help; those in poor health themselves; those caring for a patient who is in the palliative care only phase.
- ◆ An important finding is that carers had considerably more unmet psychosocial needs than did patients themselves. The problems for an important minority of carers were both serious and complex.
- ◆ Lung cancer patients and carers often felt abandoned by services and isolated because intervals between appointments could be long, and there was usually no clear-cut treatment plan. Professionals should be alert to the particular difficulties experienced by cancer patients and carers dealing with a cancer that has a poor prognosis and fewer treatment options.

A focus on carers

The crucial role played by informal carers in cancer contexts has been highlighted in this study.

- ◆ Carers' success in managing their own psychosocial needs has an important bearing on their ability to support the patient and to address the patient's needs. The implications for the patient's well being are generally profound.
- ◆ Carers undertake vital care work and emotion work.
- ◆ Carers, especially spouse carers, often position themselves as 'jointly fighting this illness'. This means that they want, and need, to share in all aspects of the cancer journey.
- ◆ In the light of the above, carers often want to be alongside the patient in medical encounters, and thus to be party to the receipt of information about treatments and care. However, we found evidence of carer uncertainty about if, how and when they would be 'allowed' to participate in medical encounters (for example, being present during doctor-patient consultations, asking questions). We suggest that, with due regard to the necessary ethical considerations and personal circumstances, carers should be given clear signals about the potential for their involvement in medical settings, with an emphasis on their being 'invited in' and 'welcomed' wherever possible.
- ◆ We suggest that greater attention should be paid to the psychosocial needs of carers, and designated support services for carers should be available.

The perspectives of health professionals on psychosocial need

The health professionals interviewed demonstrated varying degrees of appreciation of the range of psychosocial needs of patients, and especially of carers. Nurses had the greatest understanding of these needs, whilst consultants, in general, had the least (with the exception of consultants in palliative medicine).

- ◆ Consultants tended to see their role, not surprisingly, as patient and treatment focused. They generally relied heavily on nursing staff to deal with the emotional and psychological needs of patients. However, on the whole they had an awareness that their style of practice and manner of engagement with patients impacted significantly on patient psychological wellbeing, and drew attention to the importance of 'good communication' with patients. Very few consultants mentioned carers, and patients were viewed as rather passive recipients of information.
- ◆ GPs, who were very well placed to address psychosocial as well as clinical needs, identified a number of changes in General Practice (especially on-call and out-of-hours arrangements) that undermined their ability to make the most of their position. Some GPs would welcome the opportunity to play a greater role in cancer care, noting their current marginal position. In general, they would like to be fully informed about their patients' treatments.
- ◆ Current and on-going changes in cancer services were largely welcomed by health professionals, and deemed to be bringing about service improvements. Especially welcomed were: surgical and medical specialisation; increased funding and resources; developments in multi-disciplinary team-building and team working; the geographical localisation of expertise; improvements in data-gathering systems tied in with protocol development and evidence-based practice; developments in palliative care provision; closer and improved working relationships with voluntary sector organisations.
- ◆ As well as identifying areas of good practice in relation to meeting psychosocial needs, some gaps and weaknesses were also identified by a range of professionals: communication with patients (systems, styles and coverage of issues); communication with other health professionals; perceived difficulties in accessing specialist mental health professionals for patients in extreme distress; some consequences of changes in palliative care services (for example, pressure on beds and reducing opportunities for respite care); time and resource constraints; excessive waiting times for some patients.

Recommendations

The recommendations arising from this study concern the professionals who deliver specialist cancer services, the structure of the services, and the information systems which link the various elements of the services together.

Understanding and identifying psychosocial needs

- ◆ There should be more widespread appreciation of patient and carer psychosocial needs among health professionals in cancer services. This would assist in improving the quality of care.
- ◆ Practitioners should have a full understanding of the ways in which both patients and carers can actively and positively shape their cancer experience. They should assist patients and carers in gaining access to the resources that enable them to manage their psychosocial states in positive ways, so minimising the danger of developing acute psychological distress. Resources include: information, prompt medical attention, ready access to health professionals, emotional support, and practical assistance.
- ◆ Cancer specialists should receive more training in communication skills.
- ◆ Patients and carers, either together or separately, should be encouraged to disclose concerns about the emotional, social and practical implications of their situation.
- ◆ Identifying psychosocial needs should be part of routine patient and carer assessment.
- ◆ Professionals should be alert to the sub-group variations in psychosocial need and unmet need so that support and assistance can be appropriately targeted. Our findings provide a useful guide.

- ◆ The multidimensional and socially situated perspective on psychosocial need developed in this study should be reflected in the education, training and current practice of health professionals in cancer services.

Responding to psychosocial need

- ◆ Patients should be allocated a 'key worker' – an appropriate professional to whom the patient and their carer can turn during their cancer journey, in the first instance, for information and advice.
- ◆ Sufficient time should be given in medical consultations to enable patients to be involved in treatment decisions, not only at diagnosis and relapse but also in palliative care.
- ◆ The cancer nurse specialist role is well established for breast cancer, and much valued by patients. Equivalent support should be made available to all cancer patients. This will require substantial investment by service providers.
- ◆ Information systems should enable rapid transmission of laboratory and radiological data to clinicians who should inform patients without delay of relevant results.
- ◆ Where social (emotional, identity, practical) needs arise, professionals can do much to assist in their alleviation either by offering support themselves or by directing the patient to other sources of support and assistance.
- ◆ Cancer services should facilitate easy access to counselling, relaxation, psychotherapy, dietetics, and practical advice for those who need it. These interventions should be part of statutory service provision.
- ◆ Gaps and weaknesses in services identified by the professionals in this study should be addressed.
- ◆ The sense of abandonment felt by many lung cancer patients and carers should be addressed.
- ◆ All professionals should share comprehensive clinical information rapidly between primary and secondary care so that there is a consistent approach.
- ◆ The role of GPs (and other primary care based professionals) in cancer care should be reviewed, with consideration given to the opportunities that are lost if they are relatively marginalized in cancer care.
- ◆ Current professional and service successes in meeting psychosocial needs should be acknowledged and built upon.

Informal carers

- ◆ Professionals should pay greater attention to the role played by, and the psychosocial needs of, informal carers. This would benefit both carers and patients.
- ◆ With due regard to ethical considerations and personal circumstances, carers should be given clear signals about the potential for their involvement in medical settings, with an emphasis on their being 'invited in' and included in discussions wherever possible.
- ◆ Designated support services for carers should be available. However, professionals should appreciate that carers 'put the patient first' and are sometimes reluctant to seek support for their own needs lest this diverts resources away from patients. Carers need reassurance that their needs are legitimate.

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APPENDIX 1 Summary of the research proposal

TITLE: How can cancer services best meet the psychosocial needs of patients and their main carers? A study of user experience of cancer services with particular reference to psychosocial need.

Research project funded by the NHS North West Regional Executive.
Mid-January 1997 to mid-January 2000

AIM

In the wake of the *Report by the Expert Advisory Group on Cancer* (1995) (Calman-Hine Report), this study aims to inform decisions about the nature of non-surgical specialist cancer services delivered in the Region's 'Cancer Units' in relation to the psychosocial needs of patients and main carers. Needs will be examined in the broader context of the patient and carer experience of these services. Because they are delivered by specialist staff, it is the non-surgical services that are of interest in this project. These include radiotherapy, chemotherapy, palliative care and related support services.

OBJECTIVES

'Provider' focused research objective

1. To examine service providers' perspectives on the nature of current service provision and its adequacy in meeting the psychosocial needs of patients and their main carers. Service providers are likely to include: physicians, surgeons, nurses, social workers, the professions allied to medicine, complementary therapists, counsellors and spiritual advisors.

'User' focused research objectives:

2. With particular reference to psychosocial needs, to explore patient and main carer experiences of non-surgical specialist cancer services. Patients to be included in the study will have one of the following common malignant neoplasms: breast, lung, colorectal, lymphoma. These cancers have been selected because: i) they are among the most common, ii) they make high demands upon non-surgical specialist cancer services, and iii) they ensure that the study includes a mix of cancers common in both men and women. All patients in the study will be over 18 years of age.
3. With particular reference to psychosocial needs, to compare patient and main carer experiences of cancer services within and between three 'Cancer Units'.
4. To document patient and main carer defined psychosocial 'needs', and how patients and carers believe these could best be met.

Policy and Practice Development

5. To identify examples of 'good practice' in meeting psychosocial needs from the perspective of both patients/carers and service providers. This includes consideration of the support needs of staff providing psychosocial support to patients and carers.

PLAN OF INVESTIGATION: 3 year project. Mid-January 1997 to mid-January 2000

PHASE 1: 13 months- Pilot stage: 6 months, mid-Jan 1997 to mid-July 1997; Second stage: 7 months, mid-July 1997 to mid-Feb. 1998

PHASE 2: Fieldwork stage: 17 months, mid-Feb. 1998 to mid-July 1999

PHASE 3: Write-up, dissemination: 6 months, mid-July 1999 to mid-Jan 2000

Cancer Unit Selection:

Before the research project begins in January 1997, the three Cancer Units for inclusion in the study will have been selected. The three Units will ideally be located in the northern half of the NW region and accredited in two or three of primary tumour types (lung, breast, gastro-intestinal) and/or Palliative Care (ibid:8). Units will be selected following discussion with lead clinicians in the first instance. The project will require the agreement and support of key staff in the proposed participating Units.

PHASE 1, 13 months

Pilot stage (6 months)

The pilot stage will lay the methodological and procedural foundations for the main stages of the project. Towards the end of the pilot stage, we will have finalised the research design and will once again seek the approval of the relevant Ethics Committees for the continuance of the project.

The purpose of the pilot stage is to explore the feasibility of our outline research design and to develop data collection instruments: a self-completion questionnaire on psychosocial need for use with patients and carers, and a semi-structured interview schedule on psychosocial need. Semi-structured interview schedules for use with cancer unit staff will also be developed in the pilot stage.

Contact with patients and their main carers during the pilot stage

1. During the pilot stage it will be necessary to conduct exploratory individual interviews with c.20-25 patients who have one of the four tumour types (breast, lung, colorectal, lymphoma). This interview data, in combination with information from the psychosocial literature and other (non-patient) sources, will enable the research team to design the patient self-completion questionnaire and finalise the items to be included in the semi-structured interview schedule. These interviews will be conversational in style but will be loosely structured around the following themes/questions:

- A review of the patient's personal 'cancer journey' (key dates and stages from the patient's point of view). The patient's own account of their illness.
- The patient's experience of, and perspective on, services encountered and treatment received.
- Patient identified sources and gaps in psychological, emotional and social support - both from within the health care system (formal support) and from wider social support networks (informal support - family, friends etc.).
- Patient identified psychosocial problems and difficulties during their 'cancer journey'
- Patient assessment of what has been, and what might have been, the most helpful and effective ways in which these 'psychosocial' needs were/could be addressed.
- Patient identified 'best practice' in connection with psychosocial support.

2. Six focus group discussions (max.10 participants in each) will be held with patients and/or informal carers in the pilot stage. These will assist the research team in the further clarification of issues of psychosocial need and support. These discussion groups will involve members of existing patient/carer cancer support groups and networks. The groups will be approached and invited to involve their members in a focus group discussion.

3. One of the tasks in the pilot stage will be to establish exactly how best to involve the patient's 'main carer' in the research. We believe that the 'carer' perspective on their own psychosocial need, and on the needs of the person they care for, is a vital part of the study. However, we are aware from previous research that the perspective of the carer and that of the patient may differ, and that data collection should ideally take place with patients and carers independently (separate interviews, separate questionnaires). However, this is not always practicable, and it may be possible to design one self-completion questionnaire that has separate 'patient' and 'carer' sections. All of this needs testing out in the pilot stage. We intend to pilot both 'joint' and 'separate' data collection methods with patients and carers with the patients (and their carers) identified in (1) and (2) above.

4. Patient and carer 'consent' procedures will also be piloted in this first stage of the project.

Stage 2 (7 months)

The second stage of Phase 1 will involve the detailed description of those non-surgical specialist cancer services in the three Cancer Units selected, although preliminary work on this will have begun in the pilot stage. Particular attention will be paid to mapping the *pathways through the services: from diagnosis through to recovery or palliative care*. These are the 'routes' into and through the services typically travelled by most patients who have one of the four types of neoplasm specified (breast, lung, colorectal, lymphomas). Research related to the first objective will commence: to examine service providers' perspectives on the nature of current service provision and its adequacy in meeting the psychosocial needs

of patients and main carers. Other relevant data will be gathered on all-cancer incidence, mortality and patient throughput in connection with the work of the three cancer units.

Phase 1, second stage: summary of methods

Objective: Identifying the pathways through the services.

Method: Mapping the routes through discussions with cancer unit staff (as appropriate); documentary and statistical review; observation.

Objective: Examining service providers' perspectives.

Method: Interviews with key members of staff in each of the service provider groups associated with the Unit: physicians, surgeons, nurses, social workers, the professions allied to medicine, complementary therapists, counsellors and spiritual advisors. Additionally, some staff with senior management responsibilities will be interviewed.

Objective: Identifying relevant epidemiological data on cancer.

Method: Accessing the regional Cancer Registry and relevant research literature.

Objective: Gathering patient throughput data and assessing its adequacy as an information base for a Cancer Unit.

Method: Accessing hospital and cancer unit information systems.

Establishing sampling procedures

Patients who meet the criteria for inclusion in the study will be identified from the cancer unit patient information systems, and the detail of the clerical procedures involved in the selection and notification of patients (to the researcher) will be finalised. If there is a carer involved in providing support to the cancer patient, s/he will also be invited to participate in the research by filling in a 'carer' section of the questionnaire, and may be involved in a follow-up interview. The detailing of the sampling procedure in each cancer unit will have begun in the pilot stage.

PHASE 2, Objectives 2-4, 17 months

Main-stage data collection from patients will commence and finish in phase 2 and will be through a) self-completion questionnaire, and b) follow-up in-depth interviews. In identifying the psychosocial needs of patients with the four tumour types (and their carers), it is important to consider how these may vary at different stages in the 'cancer journey'. There are a number of 'critical moments' in any cancer trajectory. We would suggest that in general terms these critical moments are: diagnosis, the end of first treatment, any time of relapse, and the time of withdrawal of active treatment. The sampling procedure to be followed in each of the Cancer Units selected will a) ensure sufficient numbers of each of the four tumour types (lymphomas are, however, significantly less common) and, b) ensure that patients at different stages in their 'cancer journey' are included. The detailing of the sampling procedure will have been finalised in Phase 1. Safeguards will be set in place to avoid contacting patients either close to the time of diagnosis or when the patient very ill (or contacting relatives following the death of a patient).

Stages in the survey design.

1) *Preliminary research* in Phase 1 will have identified the themes and issues to be explored in the questionnaire and in-depth interviews.

2) A *questionnaire survey* will be undertaken involving the majority of patients (and carers) with one of the four tumour types (lung, breast, colorectal, lymphomas) who are in contact with the cancer unit services in the three localities in a 6 month period: to obtain a total achieved representative sample of 1,200 patients (plus carers) across the three Cancer Units. The self-completion questionnaire will be 'user friendly' in design and no more than four A4 pages in length. The questionnaire will generate data with which to carry out meaningful statistical analysis in relation to the study objectives 2, 3 and 4.

3) *Follow-up semi-structured in-depth interviews* will be carried out with a purposive sample of patients and carers using the questionnaire returns as the sampling frame. It is likely that in-depth interviews will be conducted with 66-84 patients (plus main carers) overall, (22-28 from each of the three cancer units) - ensuring a mix of tumour types and 'critical moments' in each locality. The interviews will generate essential qualitative data which can play both an explanatory role in relation to the questionnaire findings, and facilitate an understanding of the broader social context in which psychosocial needs emerge and can best be addressed. Towards the end of the interview, patients will be asked to complete the Hospital

Anxiety and Depression Scale (HAD) (Zigmond & Snaith 1993). This brief questionnaire takes only a short time to complete and generates useful information. The use of the HAD Scale will also maximise consistency between Lancaster based research projects, most of which use the Scale (it is also used by the Lancaster CancerCare charity). Interviews will be conducted in patients' homes, or elsewhere if more convenient/appropriate for the patient.

PHASE 3, 6 months

Objective 5; final analysis; dissemination 6 months.

- Completion of analysis and write-up
- Identification of examples of good-practice in meeting psychosocial need from the perspectives of both patients/carers and service providers
- Consideration of the support needs of staff providing psychosocial support to patients and carers.
- Start of dissemination.

ETHICAL ISSUES

Careful consideration has been given to ethical considerations in the design of the proposed research. Ongoing consideration and review of ethical matters will be a feature of the project. The way in which patients and carers are approached will require great sensitivity and research professionalism. The proposal will require approval by NHS Ethical Committees in three districts. A key issue for ethical committees will be the protection of patients and carers from potentially distressing information being revealed to them through the research process. For example, some patients may not know that they have a cancer diagnosis, and some may be in denial. In the pilot stage, attention will be given to the practical consequences of these issues.

APPENDIX 2 Questionnaire pack papers

Letter which accompanied the questionnaires:

ABOUT THESE QUESTIONNAIRES AND OUR STUDY

This study is being conducted by a research team at Lancaster University, with the support of medical and other staff at your local hospital. It has been approved by the Local Research Ethics Committee appointed by the Health Authority. This is a large scale study which is taking place in three hospitals in the North West over the course of three years.

Aims of the study

The aim of the study is to find out from you, as patients and carers, what you feel your support needs are during illness. We want to know what kinds of services and support might make life easier for you at this time. This research has been commissioned by the NHS in the North West to help them think about how they can best set about improving supportive care for patients and their carers.

People's experience of illness

We realise that there will be a wide variety of experiences among people, but we hope that, by getting the views of many people in many different circumstances, we can produce a report for the NHS which is wide-ranging. Therefore everyone's experience is of interest to us, and we would very much like you to take part, if you feel you can. There is, however, no obligation to do so.

Confidentiality

Whether you choose to fill in the questionnaire or not, your NHS treatment will remain the same. The study operates under a strict code of confidentiality, and the health professionals treating you will not know whether you have taken part or not. No information about individuals will be passed to NHS staff. The researchers at the University, who receive your replies, are independent academics. In addition the information you give will be protected by the Data Protection Act.

What we would like you to do

Please take a moment to look at the questionnaire. We have tried to make it as short as possible, but there is a lot we want to know! You will notice that there is a questionnaire for you, as a patient, and one for your main carer. **We have left it up to you to pass the carer questionnaire on to the appropriate person.** However, we feel that some people might wonder who we mean, so we thought we'd offer some pointers to help define this. A carer:-

- ◇ is the person who springs to mind as most involved in supporting you through illness, often a husband, wife, or partner, but sometimes a relative or a friend;
- ◇ can be a man or a woman of any age who may or may not live with you;
- ◇ does not necessarily do physical tasks for you, such as cooking and cleaning - for example, they may provide company and/or emotional support;
- ◇ is NOT someone who is paid to look after you (e.g. a nurse or home help).

Please note:

We understand that not everyone will have a ‘main carer’. Also, some carers will not wish to participate. If you want to take part, but you do not have a carer, or your carer does not want to fill in the questionnaire, we still want to hear from you. You may return the uncompleted carer questionnaire to us with your reply.

Likewise, if your carer wishes to take part in the questionnaire and/or the interview, but you don’t, we would also be happy just to hear from your carer. They can return your uncompleted questionnaire in the envelope along with their reply.

HOW TO TAKE PART

If you decide you would like to take part in this study, this is what you should do:

- ◇ Please sit down with the questionnaire and fill it in, as soon as you have time.
- ◇ Don’t spend too much time on your answers; your first thought is probably the best.
- ◇ There are no “right” or “wrong” answers.
- ◇ Please try and answer every question, although if there are some you can’t manage, just leave them out. We would still like to hear from you.
- ◇ Please read the INVITATION TO INTERVIEW at the back of the questionnaire, and think about whether you would like to do this. We understand that a face-to face interview will not suit everyone, but we would like to see some of you in order to get some more detailed information. On the other hand, some people may prefer to talk with an interviewer, rather than complete any forms. If this is the case for you or your carer, we would still like to hear from you. You can send back the questionnaire with just the last page filled in.
- ◇ Lastly, post the completed questionnaire/s to us in the pre-paid envelope (no stamp is needed).

If you would prefer the questionnaire in a large print format, or need help with filling it in, or if you have any queries or comments, please let us know using the pre-paid envelope.

اگر آپ اس سٹی (پڑھائی/مخالصہ) میں شامل
ہونا چاہتے ہیں، مگر آپ کو سوالنامہ مکمل کرنے میں مدد کی ضرورت
ہے، کیونکہ انگریزی (انگلش) آپ کی مادری زبان نہیں ہے
تو ہماری سرکے دیئے ہوئے لفافے میں ہمیں اطلاع دیں۔
لفافے پر ٹکٹ لگانے کی ضرورت نہیں ہے۔

જો આ અભ્યાસમાં તમારે ભાગ લેવો હોય પરંતુ, તમારી મુખ્ય ભાષા ઇંગ્લિશ નહિ હોય અને પ્રશ્નાવલી ભરવામાં મદદની જરૂર હોય તો મહેરબાની કરીને અમોને જણાવો. આ સાથે સ્ટેમ્પ મારેલ પરબીકિયું વાપરવા મોકલેલ છે.

Thank you very much for reading this letter

Sara Morris, Research Associate

Carol Thomas, Lead Investigator

your needs in illness project

patient questionnaire[★]



Institute for Health Research, Lancaster University, Lancaster, LA1 4YL

☐ ☐☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

[★] We include a patient questionnaire here for illustration purposes. The carer questionnaire was very similar, but with a different validated quality of life scale. If you would like to obtain copies of the questionnaires, please write to us and we would be happy to supply them.

If there are boxes ☐, please \checkmark them as appropriate

SECTION 1 ABOUT YOUR HEALTH NOW

1. What is the name of your current illness? *Please be as specific as you can :*

2. When was this illness diagnosed by doctors? *Please give the date as near as you can.*

Date: /

day month year

- 3. Apart from this current illness**, do you have any other long-standing illness or disability?

☐ No

☐ Yes If YES, *please could you say what:*

4. What **stage** would you say you are at now with your **current** illness?

Please tick one box which most closely describes this.

☐ My illness has been diagnosed very recently and I have **not** begun hospital treatment

☐ I am having hospital treatment for the first time.

☐ I have finished my hospital treatment, but I still have check-ups.

☐ My illness has returned after a period of time following hospital treatment.

☐ I am having hospital treatment for a second or subsequent time.

☐ I am no longer having hospital treatment because further treatment would not be effective (although I may still have medical help with my symptoms)

☐ None of the above apply to me. *Please explain*

5. If you **are currently having** (or have very recently had) hospital treatment, please indicate which type:

You may tick more than one box:

☐ chemotherapy ☐ radiotherapy ☐ surgery ☐ other ☐ not sure

6. During your current illness, does anyone amongst your family or friends take care of you in ways which are over and above what they would normally do for you?

☐ Yes, someone is caring for me in this way ☐ No

If YES, are you able to talk freely about your illness with the person who is you main carer?

☐ No ☐ Yes, a little ☐ Yes, a lot

SECTION 2 ABOUT YOUR DAILY LIFE NOW

	No	Yes
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2
Do you have any trouble taking a long walk?	1	2
Do you have any trouble taking a short walk outside of the house?	1	2
Do you have to stay in bed or a chair for most of the day?	1	2
Do you need help with eating, dressing, washing yourself or using the toilet?	1	2

Please answer all of the following questions by **circling the number** that best applies to you. There are no “right” or “wrong” answers.

During the PAST WEEK:	Not at All	A Little	Quite a Bit	Very Much
1. Were you limited in doing either your work or other daily activities?	1	2	3	4
2. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
3. Were you short of breath?	1	2	3	4
4. Have you had pain?	1	2	3	4
5. Did you need to rest?	1	2	3	4
6. Have you had trouble sleeping?	1	2	3	4
7. Have you lacked appetite?	1	2	3	4
8. Have you felt nauseated?	1	2	3	4
9. Have you vomited?	1	2	3	4
10. Have you been constipated?	1	2	3	4
11. Have you had diarrhoea?	1	2	3	4
12. Were you tired?	1	2	3	4
13. Did pain interfere with your daily activities?	1	2	3	4
14. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
15. Did you feel tense?	1	2	3	4
16. Did you worry?	1	2	3	4
17. Did you feel irritable?	1	2	3	4
18. Did you feel depressed?	1	2	3	4
19. Have you had difficulty remembering things?	1	2	3	4
20. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
21. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
22. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following **TWO** questions please circle the number between 1 and 7 that best applies to you:

1. How would you rate your overall health during the past week?

1 2 3 4 5 6 7
 Very poor ←—————→ Excellent

2. How would you rate your quality of life during the past week?

1 2 3 4 5 6 7
 Very poor ←—————→ Excellent

SECTION 3 WHAT MAKES IT EASIER TO LIVE WITH YOUR CURRENT ILLNESS?

Below you will find a list of needs which people sometimes have when facing illness.

We would like you to go through the list in two ways:

- ◆ First, ask yourself “how important has this need been to me, **over the past few weeks?**”, and circle the appropriate number on a scale from 1 to 5 :

1= not at all important 2= not very important 3= neither important nor unimportant 4= important 5= very important

- ◆ Second, ask yourself “how satisfied has this need been for me, **over the past few weeks?**”, and tick the appropriate box on a scale from 1 to 5 :

1= not at all satisfied 2= not very satisfied 3= neither satisfied nor unsatisfied 4= satisfied 5= very satisfied

If the statement does not apply to you, tick the box under “DOES NOT APPLY TO ME “

Getting or having the following:	DOES NOT APPLY TO ME	HOW IMPORTANT?					HOW SATISFIED?				
		←					→				
		NOT AT ALL IMPORTANT				VERY IMPORTANT	NOT AT ALL SATISFIED				VERY SATISFIED
		1	2	3	4	5	1	2	3	4	5
◇ Information about medication and side effects	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Information about treatment plans	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Information about what to expect	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Honest information	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Confidence in the health professionals I meet	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Information given sensitively	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Health professionals who listen to	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Health professionals who have time to discuss issues with me	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Health professionals who treat me with respect	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Easy and quick access to doctors	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Easy and quick access to health professionals other than doctors	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Access to other sources of information	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Advice on what services and help are available	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Opportunities to participate in choices around treatment	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with finding a sense of purpose and meaning	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Hope for the future	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Opportunities for personal prayer	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support from people of my faith	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support from a spiritual advisor	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5

Getting or having the following:	DOES NOT APPLY TO ME	← HOW IMPORTANT? →					← HOW SATISFIED? →				
		NOT AT ALL		VERY IMPORTANT			NOT AT ALL		VERY SATISFIED		
		1	2	3	4	5	1	2	3	4	5
◇ Help in dealing with the unpredictability of the future	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support in dealing with any changes in the way others see me	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help in maintaining a sense of control in my life	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support in dealing with changes in my body or the way I look	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support in dealing with any changes in my sense of who I am	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help in maintaining independence in the face of illness	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with housework	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with transport	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with child care	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ help in dealing with any tiredness	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Advice about food and diet	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with financial matters	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help in filling out forms	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with any distressing symptoms	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support from family	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support from friends	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support from neighbours	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Support from care professionals	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Someone to talk to	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with any loneliness	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with getting out and about socially	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Opportunities for meeting others who are in a similar situation	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with any fears	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with any sad feelings	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with any anger	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help with any feelings of guilt	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help in considering my sexual needs	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Help in dealing with the feelings of others	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5
◇ Time for myself	<input type="checkbox"/>	1	2	3	4	5	1	2	3	4	5

SECTION 4 ABOUT THE SERVICES YOU HAVE USED

1. a) What is the name of the hospital where you have had **all** or **most of** your treatment for this illness?

Please write its name here:

- b) If you have also attended **other** hospitals for this illness, please write their names here: *(Please also include any hospitals in the private health care sector)*

2. a) Have you **been offered** any support services for people with your kind of illness? (e.g. massage, counselling) ☐ No ☐ Yes

If YES, what was offered?

- b) Have you **made use** of any of these services? ☐ No ☐ Yes, a little ☐ Yes, a lot

3. During this time have you used any 'complementary' or 'alternative' therapies **which are paid for privately** (i.e. not available on the NHS)? ☐ No ☐ Yes, a little ☐ Yes, a lot

[illegible]

SECTION 5

IN WHAT WAYS MIGHT SERVICES BE IMPROVED?

Thinking about your experience of this illness, do you have any suggestions or comments to make on ways in which the health service could provide better support to people in your position? *(Please write in the space provided)*



SECTION 6 ABOUT YOU

The answers you give will only be used for statistical purposes to make sure that this survey represents a wide range of people. We do not need to know your name for this survey.

1. Are you: *Please tick::* ☐ Male ☐ Female
2. How old are you? *Please write your age in the boxes:* years
3. Are you: ☐ Single (never married) ☐ Living with a partner ☐ Divorced/separated ☐ Widowed
4. Do any of the following usually live in your household with you? *Please ✓ all that apply*
- ☐ Wife/husband/partner ☐ Child(ren) ☐ Parent(s) ☐ Other relative(s)
- ☐ Friend(s) ☐ I live alone ☐ Other
5. Do you have any close friends or relatives living nearby who you can call on for help? ☐ Yes ☐ No
6. Do you have caring responsibilities, for example, caring for children or adults who need extra help with daily living activities? ☐ Yes ☐ No
7. Please tick the box which best describes your accommodation:
- ☐ Owner-occupier(s) (owning the property outright or buying the property through a mortgage or loan)
- ☐ Renting from a private landlord or Housing Association ☐ Renting from the Council
- ☐ Living in temporary accommodation ☐ Other
8. What is the name of the town/village/place where you live?
- Please write here* _____
- What is the **first** part of your postcode? (*You don't need to give the whole postcode*)
9. Do you, or anyone in your household, own or have regular use of a car or a van? ☐ Yes ☐ No
10. Which of the following **best** describes your **usual** situation? *Please tick one box*
- ☐ I am in full-time paid work. ☐ I am in part-time paid work. ☐ I am retired
- ☐ I look after the home ☐ I am unemployed ☐ I am in full-time or part-time education (school/college/university) and family full-time
- If you are in paid work, what is your job? _____
11. Do you consider yourself to be: *Please tick one box.*
- ☐ White ☐ Black-Caribbean ☐ Black- African ☐ Black-Other
- ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese
- ☐ Any other ethnic group (*please describe*) _____
12. What country were you born in? _____
13. Is English your first language? ☐ Yes ☐ No
14. Do you have a religious faith? ☐ Yes ☐ No
- If YES, what is your faith? _____

LASTLY, PLEASE COULD YOU FILL IN TODAY'S DATE: /

day month year

please turn over

We are very grateful to you for filling in this questionnaire. Please return it in the envelope provided as soon as you can

INVITATION

We would like to carry out face to face interviews with some of the people who return this questionnaire, so that their illness experiences and needs can be explored in more detail. An interview would take about an hour, and be arranged at a time and place to suit you.

Would you be willing to be interviewed? ☐ Yes ☐ No

If you have said yes, we need you to give us your **name, address and telephone number** so that our researcher can contact you to arrange a meeting.

So, please give these details **ONLY** if you have said ‘yes’ to the invitation to be interviewed. *We do not need these details if you have said ‘no’.*

Please print clearly:

Your name: _____

Your address: _____

Postcode: _____

Your telephone number (with the code): _____

Please note that not everyone who indicates a willingness to be interviewed will be contacted - a sample of people will be selected to get a broad range of experiences.

If there is anything else you would like to tell us in writing, please feel free to write it down on a separate sheet of paper and return it to us with this questionnaire. We would be very interested in what you have to say.

APPENDIX 3A Pilot study with patients and carers

Focus groups

The pilot study included five focus groups with patients and carers drawn from the population of those attending cancer support service drop-ins. These drop-ins are organised by the CancerCare organisation, and take place weekly in each location. Volunteers run them, and specialist nurses often attend. The groups have been in existence for about ten years. They operate an open door policy for all people involved with cancer in any way.

The focus groups were arranged through consultation with the administrator at CancerCare, who allowed us to distribute information sheets about the project in the regular newsletter. Our researcher then arranged to visit the drop-ins, and discussed the project with the volunteer organisers, identified potential participants, and arranged a date for the focus groups. Prior to the group our researcher spoke individually with potential participants, and provided them with information sheets. Written consent was obtained and the groups took place in the second half of the drop-in. As all the drop-ins were held in community facilities, such as Church Halls, it was possible in each case to find a separate room in which to conduct the group. The groups, which lasted about an hour each, were taped and subsequently transcribed. All groups took place in April and May 1997.

Site	male	female	patient ⁶	carer	bereaved	average age
Lancaster	2	5	1	7	7	67
Morecambe	3	4	3	6	5	70
Kendal	1	4	4	2	1	47
Windermere	0	5	2	4	4	58
Ambleside	0	6	5	3	3	72
Totals	6	24	15	22	20	61

Table 1: Composition of focus groups by gender, relationship to cancer, and age.

It was considered important for the focus groups that participants understood what taking part involved. The organisers of the service and the individual volunteer facilitators at each location were concerned that people who were still emotionally ‘raw’ from the encounter with cancer should not be asked. Thus it was arranged that they should identify potential participants for our researcher to approach. This was done, and worked well. However, it means that sample recruitment involved a screening process that was out of the hands of the researchers.

The preponderance of female participants was to be expected, given that the majority of users of CancerCare services⁷ are women (75%). Likewise people who have been bereaved form a sizeable proportion of the users (around 20%). The age of participants spanned the range 33 to 78 years, with an overall average of 61 years. The main body of the project is concerned with specific tumour types and critical moments. The focus groups did not adhere to these criteria, as we did not wish to limit the selection of participants, and also because we wanted to gain a broader and more general picture from this part of the pilot data. Thus the groups contained bereaved people and long-term survivors, as well as those who had experience of tumour types outside our range⁸.

⁶ Several participants had experienced cancer from several perspectives, as patients, carers, and bereaved.

⁷ While a database is kept on the users of CancerCare services, specific data about users of the drop-ins is not kept, due to their informal nature.

⁸ We confine the main study to patients with the three commonest tumours (lung, colorectal and breast) and a medically treated tumour (lymphoma).

Individual interviews

For the individual pilot interviews we aimed to obtain a range of patient situations, covering the four tumour types and the four ‘critical moments’⁹, which the main study will target. These patients were identified through the Consultant medical oncologist and the Consultant haematologist, who ascertained their willingness to take part. Subsequently our researcher telephoned, explained in more detail about the pilot study, and arranged interviews. Carers were approached on an opportunistic basis, and several interviews were joint patient/carers events. The interviews took place in July and August 1997. They all lasted at least an hour and were tape-recorded and transcribed. In all eight patients and four carers were interviewed. Table 2 sets out some of the characteristics of this sample.

	male	female	age	lives alone	lives with spouse	carer interview	tumour type	critical moment
L1		✓	31		✓		breast	1
L2		✓	50	✓			breast	4
L3	✓		37		✓	wife	lymphoma	2
L4		✓	43		✓		lymphoma	4
L5	✓		79		✓	wife	lymphoma	1
L6	✓		49		✓	wife	bowel	3
L7	✓		39	✓			lymphoma	3
L8	✓		51		✓	wife	lung	1
Total	5	3		2	6	4		

Table 2: Some characteristics of the respondents for individual interview

The sampling aimed to achieve interviews with people with different tumour types and who were at different critical moments. All tumour types were covered, although there was a preponderance of lymphomas. All critical moments were generally well covered, although there was only one participant at the end of first treatment. The male / female ratio was reasonably balanced, although no male carers were available for interview. The sample’s average age was 47 years. Apart from two they lived in the rural areas around Morecambe Bay. By occupation they appeared to be generally middle class apart from two, with a farmer, a researcher, a teacher, a self-employed worker in the tourist industry, a farm worker, a petrol station manager, a factory worker and an industrial engineer.

⁹ We define critical moments as within a month of :

- 1 - being newly diagnosed
- 2 - finishing first treatment
- 3 - being diagnosed with a recurrence
- 4 - being referred for palliation only

ANALYSIS OF THE PILOT DATA

ANALYSIS OF THE FOCUS GROUP INTERVIEWS

A content analysis and grouping by emerging themes was undertaken for the focus groups in order to highlight issues which would be relevant for our main study's questionnaire. A summary of themes emerging from the different groups follows.

Context

The drop-in groups from which the focus groups were drawn were open to all who had experience of cancer, both patients and carers. Some were in the throes of dealing with it and some were long time survivors or bereaved carers. However, there were many comments from people in all sorts of situations on the value of attending the drop-in groups. Frequently comments were made by one of the focus participants that received strong reinforcement and agreement from the others. Sometimes the same point was raised in several of the groups. We have drawn on these 'strong' instances to compile a list of the main points made in relation to needs.

How the drop-in groups helped

Social contact

The drop-ins provided 'somebody to talk with'. This was constituted as important in several ways. Contact with people in a similar situation was valuable because:

- **they understood what the person was going through**

Well I think when you can come to the drop in and talk to one another about things and you know one of you's worried about something, you can still talk about it and you don't feel as if you're burdening any of them because everybody's, (*chuckle*) everybody's helping (*several voices - general agreement*)

Someone that has been in that position, then they know exactly how you feel

- **positive role models**

When my wife came here she met people who had the breast removed and they were still alive after twelve years, so that give her some hope, so we had a reasonably good summer

- **additional information about the medical system, services and resources**

We have the booklets downstairs that you can look at and there's always the chance that there's somebody else who's had the same as you or at least you can talk to them about how they felt
Yes, that's all you need is somebody

Just to sit down and say this is going to happen (*several voices - general agreement*)

Patients get into the system, and so learn about places, but carers don't

- **help with 'little' worries**

You've always got somewhere to come to and talk to and to talk with everybody else you can sort of discuss little things

- **an opportunity to share and make friends**

It isn't just taking you know that helps you, it's giving as well

I've made a lot of friends that I wouldn't have had otherwise

- **a chance to have fun and a shoulder to cry on**

We have fun, we play darts, we have a laugh and dominoes and we have trips and we, I mean people, it could be an anniversary, somebody can be upset so somebody takes them and you go and sit quiet in another room. You can have a cry with us

sometimes you need to be with someone who's cheery and other times you need to see someone to tell your troubles to

Thought we'd all be just sitting around talking about cancer but we came got him here with a struggle and he thoroughly enjoyed

- **ameliorating feelings of loneliness for bereaved carers**

I was coming before my husband died and I knew if I hadn't come back I wouldn't have gone anywhere (*laughter*)

I was seventy when my husband died and I started to learn to drive, anything, anything to get me out of the house and I joined everything that was going for bereavement, I'd do anything just to get out, it's the loneliness

- **a chance to talk to people outside the family situation**

Talking as you wouldn't to your family

I did have someone to talk to, sometime you just feel it, it's hard to always find someone to talk to, you talk to the same people and sometimes I just want someone else to talk to

- **a place to admit difficult feelings**

You don't like to sometimes admit that you're giving in, the pride is there

Being in the medical system

As well as discussing the benefits of the drop-ins the focus groups were replete with short personal narratives, which illustrated both ways in which needs were met and unmet in the health service system.

Met needs

- **information**

They were right good with you and anything you wanted to know they'd tell you

Being able to ask questions and get truthful answers

Oh yes, they tell you everything. I mean, when you are in hospital they say I'm putting this needle in because of so and so, they really do

It helped me, it helped my husband because a lot was explained by the doctor at the hospice. The doctor at the hospice alleviated his symptoms quite a bit and gave him a few more good weeks, sorted his drugs out which made him feel better and when he feels better it gave us a chance to talk to one another

- **access**

It was nice to know they were at the end of a phone.

You could go in [to the ward] anytime and you could talk to the nurses.

The district nurses were absolutely brilliant because I used to call them out and ten minutes after I'd need them again and they never murmured and they came again.

Well, she said but here's my card ring me you see. Well just knowing that's a comfort.

I think I've got a big cold sore on my lip you know, its not as if it's running rampage he said well I could have done a house call, but as soon as I was diagnosed he was great, he was on the phone all the time. He even agreed to do my blood tests at home instead of keep going down to Christies stuff like that. It saved us a lot of time. You know, just to nip up to the surgery and have your blood tests done and everything.

- **having time for you**

There was a doctor there then, and he was brilliant and he'd sit there and he was one of them, he had a lot of time for you and he'd sit there and he'd do a drawing of what it was and I could relate to that. Another doctor telling you some at I hadn't a clue what he was talking about but you can understand pictures.

Well, it was only if I went to him [GP], but he I've always felt you know he's very approachable and I once went and he sat just listening to me for half an hour.

- **being treated with sensitivity**

They make you feel you're been cared for and there's folks there and they're doing the best they can where in other areas you don't always think that.

If you've got a good GP and you've had a long relationship with them and you've got a terminal illness and where they know you they know how you can cope.

My GP was brilliant with me after I'd lost wife, you know, afterwards. He couldn't come because I live in one place and he does surgery in other but there's different surgeries like so he used to send another doctor down to see how I was.

- **having confidence in the medical staff**

They had to wait while they got the result of biopsy you see but he was very tactful and I had confidence in the man, that's a big thing, if you have confidence in the doctor.

Within a couple of hours of being in the ward and seeing the understanding and the way they treated the patients my confidence grew.

My GP was one of the practice doctors down at the hospice so I felt in very safe hands with him, which must be a big thing.

- **financial help**

The Macmillan nurses helped, where the social worker had told me there was no help available.

- **worries about children**

Yes, well I, I was worried sick in case I didn't survive because of my son, he still needed support and I really was, and I remember going to my GP and saying to him if things don't go well with me how many years have I got, and you know he said now look you're going to be all right, I said now come on it doesn't always work that way, Oh right, he said well you've got about seven years then. I said, well that's fine, that'll get [my son] through University and hopefully into a job so that put my mind at ease, it did.

- **support for the carer**

Every aspect of the hospice - the relatives get cared for as well, which for me was very important as well. I got looked after as much as my husband.

Unmet needs

- **information**

If you ask the questions, from my experience with them, they will tell you but again there's the shock factor, somebody says something to somebody and you're horrified and you can't think of what to say can you, you can't, you don't know what the next question is and you go into shock yourself.

Oh well we're going to send you to Christie's now, so well, how long? Oh I don't know, they'll let you know. Now, from then till we went to Christie's was about three month but there was nothing in between. You know, we were worried, we were both worried sick because we hadn't a clue what went on.

This is a black area in between and surgeon says right you're going to Christies or Preston now if you go and what happens in between. There's nobody to help you, there's nobody to tell you anything, it's frightening because you don't know what's happening and that's why they want somebody to, you know, to I don't know, calm you down, tell you you know really what does go on.

I've found that lack of information is the worse thing really. When our son was ill, we just couldn't find out anything at all. You would ask questions, you know, about how you found out what's wrong and they just wouldn't tell you.

Nobody would tell you anything at all and you'd persistently ask and ask and ask and you'd go back and you ask again and you just nowhere, nobody tells you.

I found out quite by chance what exactly he had from a junior foreign doctor who was only here for six months and he actually told me what I wanted to know. He presumed I did know and that's how I found out what was wrong with him.

The difficulty is because you've never been involved with them, you don't know what there is, you don't know where to go.

Yes, that's all you need is somebody just to sit down and say this is going to happen (*several voices - general agreement*)

She wanted to ask so many questions and she couldn't get answers. She kept on asking and asking and she seemed to be a nuisance, she felt she was a nuisance by asking.

- **access**

If you'd got the GP out you would have got probably a locum and he wouldn't have known what's wrong, he doesn't know her history, he doesn't know anything so he's only guesswork isn't it so he finishes up sending them to hospital anyhow.

With the GP to let the carer go on as long as possible. Unless they complain about anything they don't do anything. They don't sort of volunteer and say you need this or you might need this or anything.

If you can remember to ask at the time but you go home but you think, I should have asked that and there's no real way you can communicate back and especially at Kendal if you go in for an operation you don't see your consultant because he only comes on the day of the operation.

Unless you remember the questions at the, at your appointment time, you know, when you go

home there's no sort of person you can ring up or anything like that to ask about your specific case. I think you can sometimes ring up the ward and ask in general but not specifically about yourself.

When people are told that treatment is abandoned and there is nothing more that they can do or try to do, rather than just have to walk out of that room and be in an absolute whirl, you know, somebody should be there to say, well just you know come and have a cup of tea and just to say well, we'll phone you up and we'll come and see you tomorrow or a Macmillan nurse will come and see you this week and just talk things through with you because you just walk away from there absolutely isolated (*several voices at once*) you can't take it in, you don't know what's happening you just cos [my husband] just kept saying well what does that mean, what does that mean, cos he was desperate and it's just a very lonely feeling.

They had just been told treatment was abandoned and they said to me they were asking me, what do we do, where do we go, we've no appointment, we're desperate, they're stopping everything and I said well that's just how I felt when we were told, treatment stops, sorry you know, tough, off you go and muddle amongst yourselves.

- **having time for you**

I was given three minutes, to say your husband's cancer's back, he's dying, he can go in the hospice.

You were told and you went out into the, into the general area and the shock hadn't hit you until you were sort of a little while out and there was nowhere to go and have a cup of tea or a nurse on hand and I think where you could have a cup of tea and just collect yourself together because I got back into the car and drove home and I was shaking in the car.

I was, terrified and those fears need to be allayed, you need to be able to talk to someone who will convince you that, well to feel that you're dying, you going to suffer tremendously that needs to be dealt with first, I feel.

The hospital itself didn't necessarily give you all the psychological support that you might need, you know including proper treatment but being in contact with the Macmillan nurse, and eventually with Cancer Care, does sort fill that void but at the hospital it's very much telling you the treatment and what's going to happen, not so much on the how you are coping with it.

If they had taken me aside in a room and say, if there had just been that person who could have taken me aside and said your husband's terminally ill.

- **being treated insensitively**

I mean one trainee doctor said to me once, gee, it must be tough when you don't know how long you've got and somebody said to me, well you should report him.

Quarter to eleven on a Friday night and the cancer hit a vein and it brought black stuff up and I rang the hospital and the two ambulance men came, they left the door wide open and they were laughing and giggling.

They told my husband and I was shocked really cos he isn't, wasn't the sort of person that could take it. He went down after that, he gave up.

They just told her as though they were telling her she'd got a boil somewhere, or something, you know and she'd come out on her own, breaking her heart crying.

You know, you came out thinking, he said everything was great you know you'd be elated and as you coming out of the door he would say but you're not out of the woods yet, so that meant

you went down again.

- **having confidence in the medical staff**

You've only got the SHOs coming round the ward and they don't know anything, in fact you know more about your treatment than they do.

In our case I had to look after my husband so you just want to know how to cope with it. Is this expected and is this behaviour normal for his condition and even at home whenever I asked anybody if was always oh I don't know, you have to ask the doctor. Well how do you ask him when you've not even got an appointment to see the guy and you ask him and he says well we don't know and I came away totally totally with no confidence in the services.

- **worries about children**

help telling them, someone for them to talk to [10/11 year olds] kids wouldn't go to what was offered [youth service].

- **financial help**

but have to pay for a lot of it [cleaning] and when a couple have given up their jobs cos of illness, we couldn't afford it, so other family helped after work, and we sent own young kids out shopping.

- **support for the carer**

It would be nice if patients could be encouraged to communicate with their loved ones because my wife wouldn't talk about it at the end. That means we carry the burden, the carers, because even after they've died you've not finished with them, you know.

I mean, I will never, ever forget the fact that the last thing my mother asked me to do I didn't do [because of the way the ward was organised] and nobody will take that away from me and so I think the anger is there.

She has about three months to live but don't tell her, you mustn't let her know what's wrong with her and I thought this was awful. I mean it was, it was awful for me, keeping it from her.

Orientation

There was one issue commonly discussed in the groups which centred on the way people became oriented to the system and what it had to offer. This was presented as generally involving a point either sooner or later, at which the patient and carer got linked in to the additional services. This was generally constituted as very helpful. But getting in to the 'system', just finding out what help they could receive, was often problematic for many. It must also be noted that the participants in the focus groups had all made this transition, because they attended CancerCare, and so represented people who had successfully accessed additional services. The value of CancerCare in helping people access further resources was mentioned frequently in the groups (see earlier section). Other cancer patients and carers might well go through the cancer experience without ever connecting with specialised cancer services outside the hospital. Getting to know what is available and accessing help was sometimes brought about through chance, sometimes through crisis, sometimes through asking for help.

But sometimes there's problems getting into system.

Once you get to it it's an Aladdin's cave but you've got to get through to it (*several voices at once*).

But until you complain then, then the system clicks in and everything happens.

I asked for them in that sense there wasn't really the, you know, it wasn't, it didn't come on a

plate in that sense you have, you had to ask for it.

The priest at church said, has nobody been to you? I said no, so [the Macmillan nurse] happened to go to my church and I met her and otherwise I think we would have completely slipped through the net.

[When my wife went to the cancer centre] I was looking for caravan sites and houses I could go in because I didn't know the area or what it was like and then when we got there, we found out, oh there's a hostel here you can go in there but it was only by chance that I got to find this out when we got there and then you know I went to see welfare worker and that and then I got into hostel so we was all right.

ANALYSIS OF THE INDIVIDUAL INTERVIEWS

A narrative analytical approach was taken with the individual interviews. This involved paying attention to the structure of the talk engendered by the interview. Note was taken of the sequence in which the story unfolded, and of the juxtaposition of the various themes that emerged. These accounts begin to indicate ways in which the medical services shape the experience of patients, but also that the patients have personal contexts which also contribute to its shaping and mean that certain aspects become points of reference in the person's telling of the story.

A summary of each of the individual interviews is presented here as a case study, with an indication of the main concerns which participants raised in the course of their narratives.

Case 1 – newly diagnosed breast cancer

- A young woman in her early 30s, newly diagnosed with breast cancer. Lived in the countryside with husband, horses and dogs. Both sets of parents are nearby. The husband works away for part of the week. No children.
- Diagnosis had taken a year. She was post surgery, but awaiting chemotherapy.

Concerns which came through strongly:

Action- she felt better now that things were happening - this was related to it 'taking her mind off things', but also to a sense of something to aim for, and the achievement of a sense of moving through the stages. When she had questions they felt urgent.

Information about the plans - having come out of hospital and awaiting chemotherapy, she felt rather isolated and out of touch with her treatment plans. She repeatedly returned to this theme, and described it as needing to know what was going to happen, and not quite trusting that someone was there organising it in the background, because she couldn't see it happening. She didn't know how it all worked. And on two occasions she had been let down by staff [1 doctor, 1 nurse]. She acknowledged that it was hard for her to take in information, though, she was 'hazy', and she had to keep checking things.

Control - knowing the schedule gave her some sense of control - she could prepare herself and answer other people's questions. But she indicated that control was not a matter of taking decisions, and she described herself as 'at the mercy of doctors and their knowledge'. Expertise was highlighted as valued, and she talked about needing to trust staff to know what they were doing and co-ordinate her care.

Hope - more information also gave more hope. A positive approach coupled with honesty was appreciated, but she was guarding against a 'rollercoaster' of highs and lows by trying to be 'realistic'. She also referred to the importance of meeting other patients, who were in a similar boat, but were still 'human'.

Being a person - not being forgotten about was important to her [this had happened twice]. She felt it was a 'selfishness born out of fear', but really appreciated it when people were friendly and found time for her.

Inconvenience - travel was a slight inconvenience, as were waiting times at the hospital, and

waiting around for home visits, although in the situation this was not of major importance as long as things were happening.

Case 2 – advanced breast cancer

- This woman in her 50s lived alone in Morecambe. She had been a teacher, and appears to be well-off materially. Her husband died 2 years ago, and she has no children or other close family.
- Most of her treatment took place in the Christie as she used to live in Manchester. She was in the palliative stage of breast cancer (first diagnosed in 1990).

Concerns which came through strongly:

Facts - although satisfied with the treatment at the Christie, her most recent treatment had not been given with all the 'facts'. She had appreciated the Lancaster honesty and time taken with her, and has now transferred to this area. She described being 'rushed' along, as part of the 'herd', and time not being given for her to have things 'spelt out' at the Christie. She gave two examples of failing to obtain the facts under these circumstances.

Access - although living alone she felt well supported by the services. Knowing there was someone there to help her was very important to her.

Independence - This was very important to her and she mentioned ways in which this was supported, eg getting a disabled sticker for her car, being able to phone and order to the local shop which would deliver.

Case 3 – end of first treatment for lymphoma

- This man in his 30s, suffering from lymphoma, lived with his wife and young children at a rural petrol station.. The family was of Indian origin and the extended family had come into play with parents and siblings and cousins helping in practical ways. His English was a bit unclear and his wife joined in the interview part way through.
- He was reaching the end of his first treatment, and was keen to get it over and done with.

Concerns which came through strongly:

Time - his main complaint was that the diagnosis took so long, when he was in constant pain. In India they would have been less careful and diagnosed him quicker, but the treatment would have been poor or non-existent.

Limitations - social activities had been curtailed for the family. The patient was afraid of getting an infection, and the wife spoke about the children and not having time to take them on outings.

Children - three young children needed child care, which was supported by the extended family. The wife noted with appreciation that the children were welcomed on the ward, even though they were noisy.

Information - this was not as highlighted as in some of the other interviews, but the wife talked about the doctor's explanations as being helpful in seeing them through the treatment, and the fact that the relatives were also spoken with.

Talking - although not much was said about this the wife did mention that there were people who she felt she could talk to – e.g. Health Visitor, the staff on the oncology ward.

Diet - the dietician was mentioned as very helpful in the context of loss of appetite and their religious diet.

Case 4 – advanced lymphoma

- This woman in her 40s was in the palliative stage of lymphoma. She lived with her husband and 17 year old son in the Lakes. They were self-employed prior to the illness.
- I interviewed her in the hospice. Her husband was not there.

Concerns which came through strongly:

Aims - Carrying on - not letting the illness dominate had been a major concern. She had continued to organise the family while ill, through planning rather than physical activity. She felt she had accomplished something this way, and was peaceful, because she felt she had helped her husband and son have a future. And, although she had been continuously ill, or on treatment for the past 3 and a half years, she was very grateful for the time. Yet she had tried to keep life as normal as possible as well, and spoke of the importance of people in the family having space from each other. She had undertaken new activities, like painting, and made a lot of use of the CancerCare services, which she praised as making her life possible through her illness.

Finances - being self-employed had been difficult. It took her a lot of effort to claim financial support, at a time when she was feeling very ill. She felt someone to help with filling forms etc. Would have been very good. Her husband had given up work to look after her, because she was on strong chemotherapy.

Information - she had always asked lots of questions. She also spoke of the value of being prepared, knowing from the beginning that one day the treatment would fail to work. Like another interviewee, she felt that the primary health care team did not have the specialist knowledge that was needed.

Access to help - having been very involved with ward 3A, she described it as her 'third arm'. The Macmillan nurses and CancerCare had also supported her. Therapists had been out to treat her at home when she was very ill. Although not a practising Christian she mentioned that the vicar had been giving home visits. Living in a small community had been isolating at times, because little support had been offered, and people had kept away. Without the help of the services she felt her positive attitude could not have been maintained. The distance she lived from the hospital also made life hard, as she had to attend frequently and it cost a lot in terms of petrol and time.

Outings - in relation to the members of the family have 'space' to continue their own lives, she felt it would have been nice if someone could have taken her on outings.

Case 5 – newly diagnosed lymphoma

- This man aged 79 was newly diagnosed with lymphoma. He lived with his wife, and had a daughter nearby who had given him a lot of practical support through the illness. He was a retired factory worker and lived in a Lake District town.
- At the end of the interview I had a few words with the wife, who said it had been very stressful for her - with extra household tasks, a problem with getting him out of the bath, and his 'bad moods'. This was a case for interviewing patient and carer separately.

Concerns which came through strongly:

Trust - This elderly man was definite in his willingness to trust staff. The consultant's decision was accepted without question. He said that staff wouldn't be there if they couldn't do the job, and that to worry about this would 'set you back'. He admired the nurses' lack of 'moaning' and instant attention to his needs, but was slightly surprised that they could deliver intravenous infusions. Although he had only been with his GP for 3 years he felt that he knew his history. He also accepted waiting times, because 'you don't expect to go straight in'.

Information - He admitted he found it hard to retain information, but that he only asked one question. His daughter knew more than he did, because, as she told him, she asked a lot of questions. However, he appeared to have retained the warnings about chemotherapy side effects, as he spoke of being very frightened when he unexpectedly spiked a temperature. He also spoke of his fear, which he did not share with anyone, that he would end up with a colostomy like a friend of his. Hence, he was much relieved that it was a lymphoma, which could be treated with drugs, rather than surgery.

Transport - On one occasion he had to remain in hospital overnight because no-one could pick him up, although generally his daughter drove him to and from the hospital. He lived in Kendal, and is having his regular chemotherapy there. However, at first all his visits were to Lancaster, until he mentioned that it would be easier for him to go to his local hospital to a nurse.

Extra support - He spoke about being offered a home-visiting nurse, but was vehement in his refusal, as he wasn't ill enough, and others needed her more. He said he was happy with the phone

numbers he had (GP, specialist hospital oncology nurse and oncology unit), and was 'spoilt for choice' if he should have a problem. His wife's recounting of the 2 hours it took to get him out of the bath, and the fact that he did not get in it any more, indicated that they had a problem, which could have been helped by a visiting nurse, but which they chose to cope with alone.

Finances - He was surprised to learn that he could apply for extra financial help because of his illness. The GP first mentioned it and his daughter took it on, as he 'couldn't make head nor tail' of the form. The specialist hospital oncology nurse also spoke about it and said she would help if the application was refused.

Case 6 – recurrence of colorectal cancer

- This 49 year old manager had recently had a recurrence of his bowel cancer. He lives with his wife and young son in a Lake District town. His firm have been very good to him in several ways, mainly by keeping him on full pay for the entire time of his sickness. There are no relatives nearby and both sets of parents are elderly.
- His wife joined in the interview part way through.

Concerns which came through strongly:

Information (related to experience of staff) - This couple spoke a lot about information, about its amount, timing and the communication style of various personnel. They identified several areas in which these affected their experience of the illness. They wanted 'facts', and these had sometimes been reassuring, for example, when initially diagnosed they felt death might be immanent and were reassured to hear, when they asked, that, even with no treatment, he would live a couple of years. Yet, information at other times had been too much to 'absorb' (despite his high level of education), and when they felt there were differing accounts and lack of certainty among the doctors, this was very distressing. They didn't like 'speculation', and were suspicious that sometimes they weren't being told everything. They became 'twitchy' and highly sensitive to hints and clues. The way in which information was given was vital to them, and they described several instances in which doctors had been 'bad-mannered', 'cold' or not on top of the facts. They noted that an optimistic, 'upbeat' approach was preferable to a negative, pessimistic one, and they felt they had experienced both. They had been the victims of administration mix-ups, although both times a quickly following phone call from a nurse or medical secretary had eased their minds. They also noted the indignity of out-patient clinics, where being positioned on a lower level than the doctor and often half-undressed, with little space for the wife to be present, made communication difficult. They had developed strategies to overcome this disadvantage. Some doctors they trusted, because of their positive attitude or plain-speaking.

Time - Their approach was to deal with each stage of the treatment sequentially, so that 'getting over first stage before thinking about the next' was important in coping with the disease. There was a desire to get chemotherapy over with and it was progressively more distressing with each treatment. They did say that the first diagnosis was much worse than the secondary, because the initial diagnosis had meant they were in 'a trance' for a week.

Children - Child care had been a major problem for them, as they did not normally need it. There was no relative or friend or paid help who they normally turned to. The child was 6 at the time of the first diagnosis and had obviously been affected by the situation. He refused to go to the hospital and this meant that sometimes the wife could not accompany her husband to appointments although she wanted to. She also noted that the illness had put a greater workload on her in terms of child care and household tasks.

Fear - Fear of infection was a factor which meant that social life was curtailed.

CancerCare - They had both used this in crisis, but felt that at other times they should not use it so that others who were in more need could. They were surprised by what a good service it was, and the expertise available. Knowing it was there, even when not using the facilities was a comfort. They were told about the services by various health personnel, but were encouraged to go by a friend who knew it. The wife mentioned that the social aspect of meeting others was good, but the husband used it more functionally and for specific aims, and said he would feel uneasy about

socialising with people there.

Other people - They did, however, come into contact with others with cancer, and the husband mentioned a work mate who it was easy to talk with. They compared their situation with others with cancer, and were encouraged by 'survivors'. Being in the 'same boat' was again mentioned. There had been some difficulties with acquaintances who avoided them, and the difficulty of answering an everyday greeting of 'how are you?' was mentioned. Telling elderly parents was also a difficulty.

Case 7 – recurrence of lymphoma

A 39 year old farm labourer who lived alone in a council house in a small village. He had a recurrence of previously treated lymphoma.

Concerns which came through strongly:

Recent bereavement – A recent bereavement was brought up right at the start of the interview and presented as more distressing than the cancer. He had lived with his father all his life until the father's death. His lymphoma and his father's stroke had coincided, and thus the past 22 months had been the worst time in his life. At diagnosis he broke down and cried, 'I thought well that's it'. Telling his father was hard, but he 'managed' to do it himself. Losing his father 'cut a big hole in my life'.

Work – he had always worked, and described his life as 'work, work, work' until the illnesses. He felt his perspective had changed now and work was less important. He had returned to work part time after the initial treatment and until the recurrence. He found not working made the days very long, and he would like to go back if he ever could. But he felt he was adjusting somewhat, as he now had it in his mind 'that I won't be able to do what I was doing before'.

Transport – Unable to drive for some time due to the illness, his brother-in-law had driven him, and he had taken the train to Manchester for treatment there.

Support – He had been to CancerCare for a 'talk', and they 'seemed to think I coped with it pretty well'. The nurses in the hospital had become 'friends'. He had a few friends and some family locally, and the village community 'kept an eye out' for him. He did however suggest that the nurses were the best support as 'normal people they don't understand really'.

Finances – He was angry that he was having to use up his savings, but felt that money can't 'put you right'. When asked if he needed any help he said that he would like to have some money coming in.

Recurrence – Finding the recurrence was described as the worst thing, because it meant he had to go through 'all that again': 'I knew what sort of treatment I would have to endure ... because before I was walking into like a darkness'. He realised that he will 'never be away from hospital, the check ups and such like'.

Independence – He wanted to be as independent as possible: 'I want to stop here on me own as long as I can'. He felt that accepting help 'makes you feel incapable of doing things yourself, don't it?' He felt he needed a car otherwise he would be very isolated.

Case 8 –newly diagnosed lung cancer

- A 51 year old farmer who was newly diagnosed with lung cancer. He lives with his wife and three teenage children on his farm in a village location.
- His wife (aged 50) was also interviewed, both separately and jointly.

Concerns which came through strongly:

Diagnosis – the time taken for diagnosis was related as a saga, with appointments almost weekly for two months, but one in which he had no worries 'I still never even thought about cancer. Didn't enter my head'. Diagnosis was therefore a huge shock followed by an awful weekend. Telling the children and his mother was particularly difficult.

Carer concerns - The future implications for his wife were worrying, both in managing the farm work and nursing her husband. She described her anger that it should happen at a time when the

children were almost grown and she had more time for herself – ‘my life’s gone on hold’. Her reaction had been strong and unexpected ‘Because I just lost it, and I’m very stoic, and I never - things don’t particularly bother me’. It came on top of a traumatic time with her daughter recently having had an accident. She found backup support from the Macmillan nurse and from CancerCare.

Uncertainty - How much the chemotherapy regime he was about to embark upon would limit his activities was the current concern for both patient and carer. Being self-employed and running a farm meant there were also financial concerns attached to these uncertainties.

Hope - The patient made several hopeful statements, suggesting he might be here in 20 years time at one point, but also suggesting he also understood that it was control rather than cure that was being offered – ‘But at the moment it is not curable but it is controllable. So we’ll go for what we can get.’

Change and normality – A massive change had come to them through the cancer diagnosis. While the husband was trying to minimise and plan for the change, his wife was much more aware that things would never be the same again: ‘because things that are normal just aren’t normal’

Support – The patient had been given a cup of tea after his diagnosis but then left alone.

Questioned about this experience he said that he would have liked someone to just sit with him at that time: ‘or even sat with me. Which was probably what I needed at that time, I would think.

Even if nothing was said, if there was somebody there if I wanted to say something, but there was nothing.’

However, specialist support services had kicked in soon afterwards and the wife particularly had made use of them: ‘So we were informed but I would think that I would have hated somebody who lived on their own, to go home, and not know about any of these services, and put up with what we put up with that weekend. That must be the absolute end’

FOCUS GROUPS AND INDIVIDUAL INTERVIEWS - CATEGORIES OF NEED

- **access to somebody to talk to**¹⁰
 - staff** (approachable and available)
 - to get information on disease and treatment¹¹
 - clear information about what will happen next
 - to ask about 'little things'
 - to get access to other services¹²
 - others with experience of cancer**¹³
 - to know they are in the same boat
 - to compare notes/ share experiences
 - to see that they are not so badly off
 - to see long term survivors
 - people to have a laugh and cry with
 - company (especially bereaved)
- **time**
 - quick diagnosis
 - to speak with staff, ask questions and be listened to
 - quick access to staff when questions feel urgent
- **hope**
 - fears of instant death allayed
 - something to aim for
 - spiritual needs
 - confidence in the expertise of the staff
 - positive attitude in staff
- **action**
 - feeling something is happening
 - getting it over with (eg chemotherapy)
 - keeping going
 - new activities
 - being 'got into' the system
- **practical help**
 - children**
 - childcare
 - help with telling them
 - help for the children
 - to feel they are welcome in medical settings
 - housework**
 - medical aids**
 - prostheses, stoma bags, etc
 - mobility**
 - transport
 - outings
 - financial**
 - information and form filling
 - dietary advice**
 - eg Muslims, and loss of appetite
- **to trust in staff**
- **help to maintain self and relationships**
 - being treated 'like a person'**
 - told the truth
 - listened to
 - knowing that others care
 - not feeling like a 'burden'
 - to feel some sense of control / pride in ability to cope
 - help with family relationships**
 - encouraged / chance to talk (eg symptom relief makes it easier)
 - respite care/ space away from each other/ someone outside the family to talk to
 - help with reassurance for each member
 - help with guilt

¹⁰ timing important -different at different stages - need for information is acute and urgent at the beginning.

¹¹ but not everyone wants to know.

¹² In the focus groups there was a strong feeling that access to CancerCare was a matter of 'chance'.

¹³ not everyone wants to get very involved, but all mentioned the importance of seeing and knowing about others with cancer.

APPENDIX 3B Pilot Study Research on Cancer Services

Cancer Services in the North West

An important aim of the project is to map out the 'landscape' of cancer services in the participating locations. This is taking place against a background of rapid change, instigated by a national review of cancer services (Association of Cancer Physicians, 1994), and the publication of the *Report of the Expert Advisory Group on Cancer* (1995) (Calman Report). Thus our mapping will need to be flexible and incorporate different views with the passing of time. During the three years of the project we will aim to maintain a close eye on the changes which are happening. In order to do this we will not only be relying on data from the main stage of the project (1998/9), but will need to make use of information from the pilot study (1997) as our starting point. This paper instigates this process with a detailed mapping of the services extant in the first half of 1997, taking pilot interviews with health professionals, and informal observational data as its main source.

The pilot

The pilot study took place in the first half of 1997, and included interviews¹⁴ with 28 personnel in Lancaster and the South Lakes, 16 in Blackpool and 19 in Blackburn (detailed in Table 1). In addition to those in Lancaster two specific psychosocial services for cancer patients and families in Preston were visited. Further information on services was gleaned from attending clinics and from informal discussions and visits with personnel. At the same time interviews and focus groups were in progress with patients and carers in the area served by Morecambe Bay Health Authority.

Table 1: Pilot Phase interviews with professionals

		<i>Lancaster area</i>	<i>Blackpool area</i>	<i>Blackburn area</i>	<i>Totals:</i>
<u>Hospital</u>	Management	2	0	2	4
	Consultants	6	4	4	14
	Specialist Nurses	1	4	1	6
<u>Hospice</u>	Doctors	1	1	1	3
	Nurses	2	1	0	3
	Social Worker	1	1	1	3
	Other	3	0	0	3
<u>Community</u>	GPs	4	2	3	9
	Nurses	4	3	4	11
	Social Workers	1	0	0	1
	Other	1	0	1	2
<u>Non-health Personnel</u>	Racial Equality Officers	0	0	1	1
	CHC Officers	2	0	1	3
<u>Totals:</u>		28	16	19	63

The aims of the contacts with health personnel were threefold:

- I. to establish contact and begin to discuss access to patients for the main study;
- II. to gain a picture of the way services are organised and of the main patient 'routes' through the system;
- III. to obtain service provider perspectives on the needs of cancer patients and their main carers.

¹⁴ Interviews with professionals lasted between 20 minutes and one hour, and were conducted at the participant's place of work. In the main notes were recorded at the time of interview, but some were tape recorded for ease of reference, and were later partially transcribed.

The landscape

A general ‘map’ of the services is presented in Figure 1. The majority of patients begin their journey with the GP, where presenting symptoms may or may not be investigated¹⁵ initially prior to referral to a Consultant. In some cases of extreme symptoms a patient will be admitted to hospital, either through Accident and Emergency or occasionally via a GP referral to the ward. At the other end of the spectrum individuals may have no symptoms and come to the services through routine screening¹⁶.

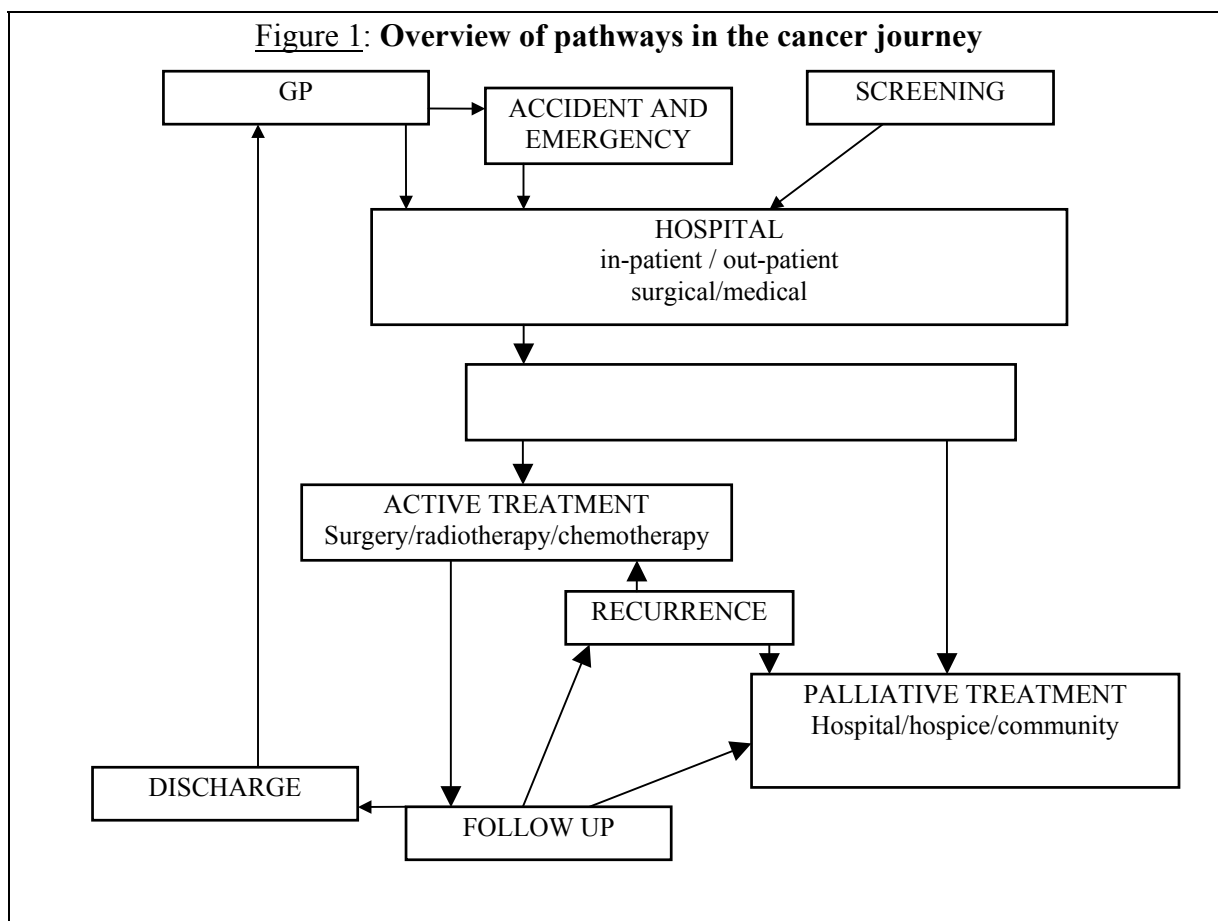
The majority of patients are referred to an out-patient clinic. Times between referral and appointment vary widely depending on tumour type. Some patients may be referred to the ‘wrong’ Consultant initially (e.g. orthopaedics for a lymphoma patient with a painful neck), but eventually find their way to the appropriate doctor. Diagnosis follows further tests, either as an in-patient, a day case, or while remaining an out-patient. Some results come through more quickly than others, and the ‘bad news’ consultation usually takes place in the clinic setting a week or more after investigations. The patient will then be commenced on treatment, or referred straight to palliation. The type of tumour determines the range of treatment options, as will be discussed below.

At the end of first treatment the individual continues to attend review clinics for variable amounts of time. Intervals between appointments lengthen as time goes on, but for some continue for years, while others are discharged back into the community sector quite quickly. Recurrences are mainly discovered by the patient, although some are found in clinic. At this point the patient returns to the cycle begun at diagnosis, and may receive more or different treatment, or be judged for palliation only.

This general overview of routes gives a rough outline of the main routes through cancer services. However, to examine the terrain more closely requires a smaller scale. The data suggest that service provision varies in three ways. These are:

a) by tumour type; b) by phase of disease; c) between geographical areas .

Each of these will be examined in more detail in the following sections.

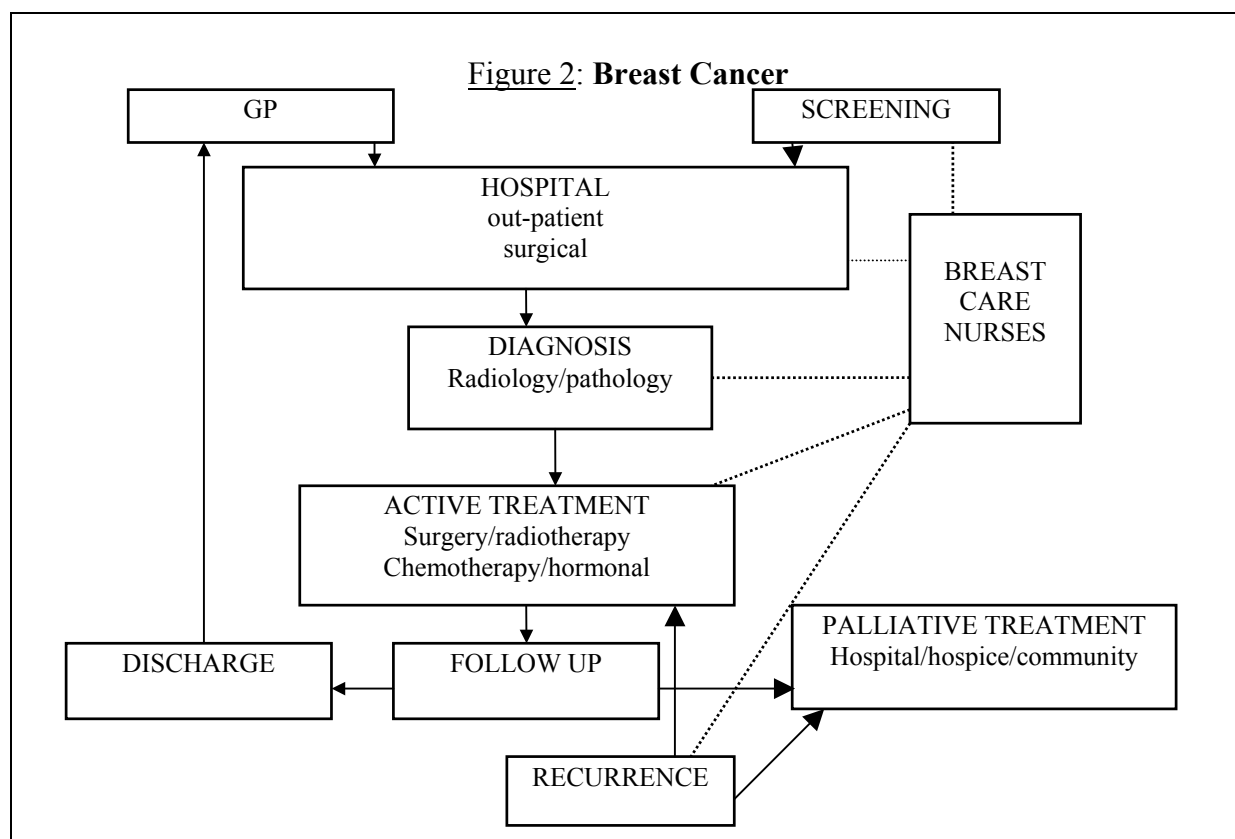


¹⁵ e.g. X-rays, blood tests.

a) Tumour type

Breast (Figure 2)

Of our four tumour types breast is the one for which routine screening is available. Screening operates by means of a 'round' of GP surgeries in the area covered by the Screening Unit. While the majority of breast cancer patients (and all those outside the ages of 50-64) come to the services through finding a symptom, the sub-group of women whose tumour is found through screening have a different starting point from patients with other tumours. The lack of any 'illness' or symptom prior to being diagnosed means a more abrupt and shocking start to the cancer journey.



Another major difference for breast cancer patients is the employment of specialist nurses. While there are Macmillan nurses who see patients with any tumour type¹⁷, and Stoma Nurses who see the sub group of colorectal patients who have had stoma formation, breast cancer patients are the only ones to have nurses specifically dedicated¹⁸ to their care. The way the work of these nurses is organised varies geographically, but all three areas have at least one breast nurse, and all have recently expanded, or are in the process of expanding, this service. Breast Nurses in Morecambe Bay and Blackburn are Community based, as is the nurse assigned to breast screening in Blackpool. This means that much of their work involves home visits to patients in the community. The exception to this is the position of the Breast Nurses in Blackpool who are hospital funded and based, and conduct their work within its walls.

¹⁶ In this study this only applies to breast cancer patients.

¹⁷ Especially around palliative care, although they are at present trying to change their 'image', and see patients who are earlier in the cancer journey. Macmillan nurses are associated with, and still operate mainly within, terminal care.

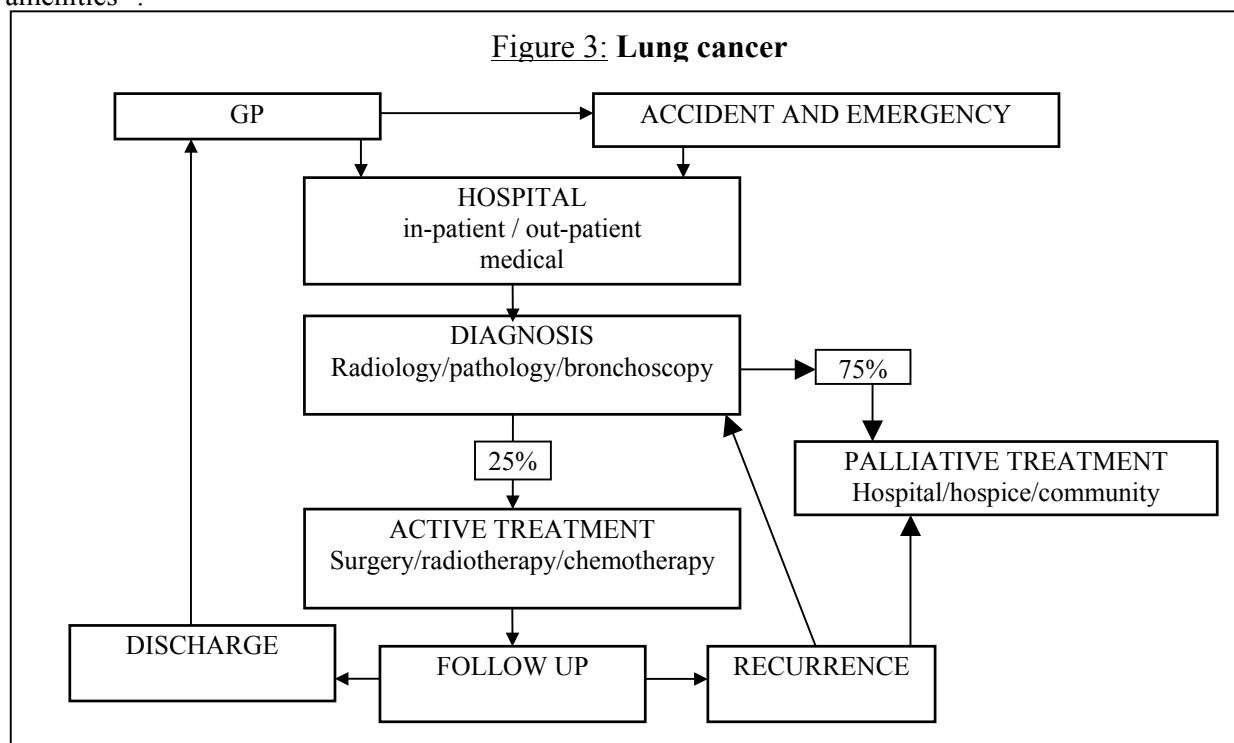
¹⁸ This is a fairly recent phenomenon - the first breast care nurses came to post in the 1980s, and now nearly all areas of the country have some designated breast nursing service.

In terms of treatment breast cancer patients usually have investigative surgery as a day case (Fine Needle Biopsy). Results come through quickly in all areas and surgery for diagnosed patients happens within a few weeks. Most have either a wide excision or a full mastectomy and are in hospital for several days. Post-surgery routine treatment for those who have had wide excisions is a 15 day course of radiotherapy, which until recently has taken place in Manchester for patients in all three locations. This is still the case for Blackburn patients until Phase II of the Preston development comes on line. Referral of Morecambe Bay and Blackpool patients to Preston began in early 1997. For those breast cancer patients who are assessed as needing chemotherapy, those in Blackpool and Blackburn still travel to the Christie hospital in Manchester. However, in Morecambe Bay most can receive this treatment locally, and there are small oncology facilities in both the Lancaster and Kendal hospitals¹⁹.

Lung cancer (Figure 3)

Lung cancer patients enter the system through medical out-patient clinics in the main, although a few are emergency admissions. The characteristic which sets these patients apart from the others is the frequency with which they move straight to palliative care. Around 75% of newly diagnosed patients are referred directly for palliation only. The others are assessed for surgery and approximately 10% have operations. Of those 15% who do not, chemotherapy and radiotherapy comprise both active and palliation options. Surgery for all three locations takes place in Blackpool, with outreach assessment clinics in the local district. Chemotherapy takes place in the Regional Centre (Manchester) for Blackburn, while both Blackpool and Morecambe Bay have local facilities for the majority of patients. All radiotherapy takes place in Manchester or Preston.

Due to the large numbers of patients who are for immediate palliation, the Macmillan nurses and palliative care team are involved, often soon after diagnosis. Some patients move out of the care of the hospital consultant to the GP or palliative team, but others remain with the Chest Physician, and care is shared informally. Chest Physicians tend not to discharge patients, but will often continue to follow-up as a form of psychosocial support for as long as the patient needs it, or is capable of attending the clinic (the aim being that the patient does not feel abandoned as a 'lost cause'). Five-year follow-up is the norm for those that do survive. And decisions as to which clinic/service the palliative patient might attend are often made on the basis of where the patient has established trust, as well as on local amenities²⁰.

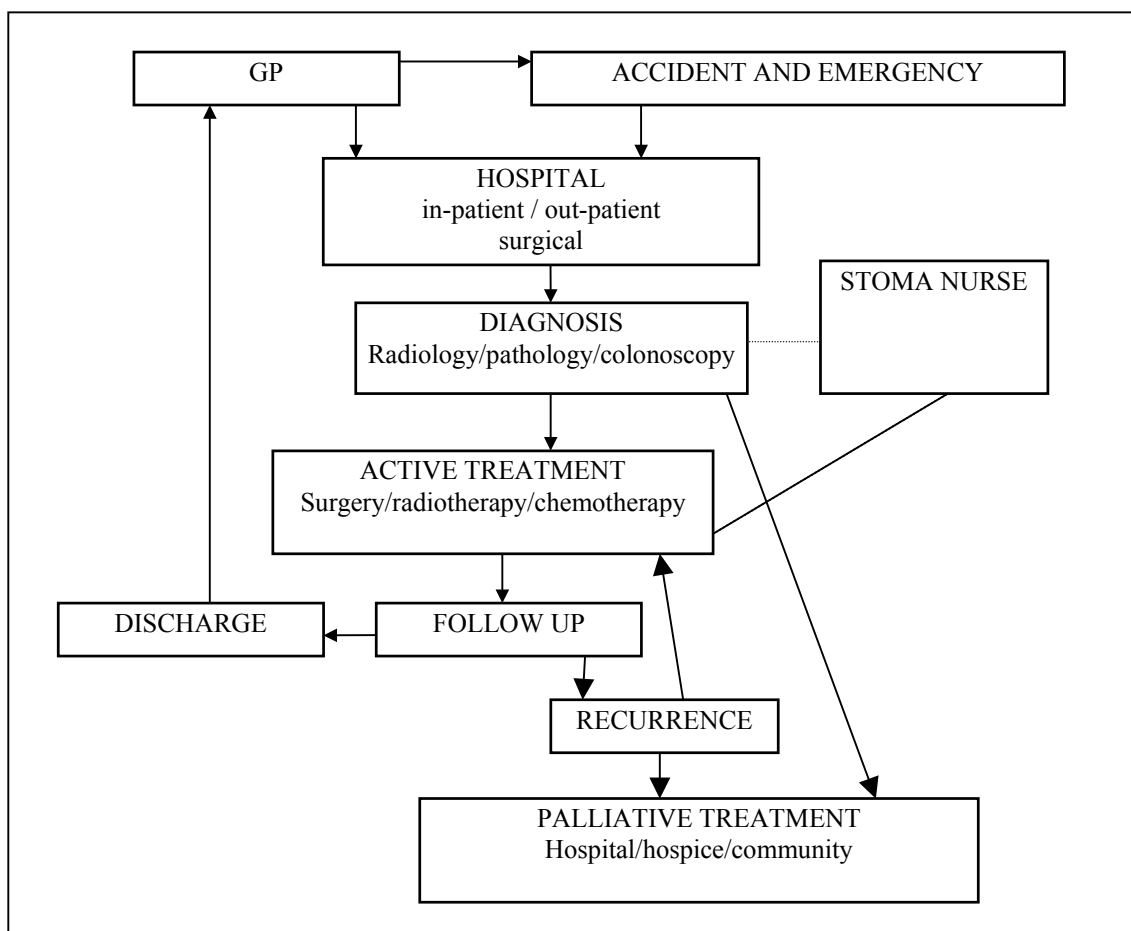


¹⁹ The Lancaster unit is in the process of expanding in 1997, and moving into larger, purpose-adapted facilities. The Kendal facilities moved off a medical ward and into a purpose adapted suite early in 1997.

²⁰ Such as the size of the hospice, the presence or absence of palliation clinics, the facilities for the chest clinic.

Colorectal cancer (Figure 4)

Figure 4: Colorectal cancer



Like breast, colorectal cancer patients are mostly initially treated by surgery, with the possibility of additional chemotherapy and radiotherapy (mostly for under 75s). But unlike the situation with breast cancer patients, waiting times for surgery tend to be longer (up to 6 weeks), operative mortality and morbidity is greater, there are no specially designated clinics, and no specialist nurses. Only those that have formation of stoma will meet the Stoma Care Nurse, but her expertise is not solely with cancer patients, and it appears that she usually offers more practical advice, rather than focusing on psychosocial support. There is, however, some focus on sexual needs, but this is often in relation to practical measures to help deal with impotence.

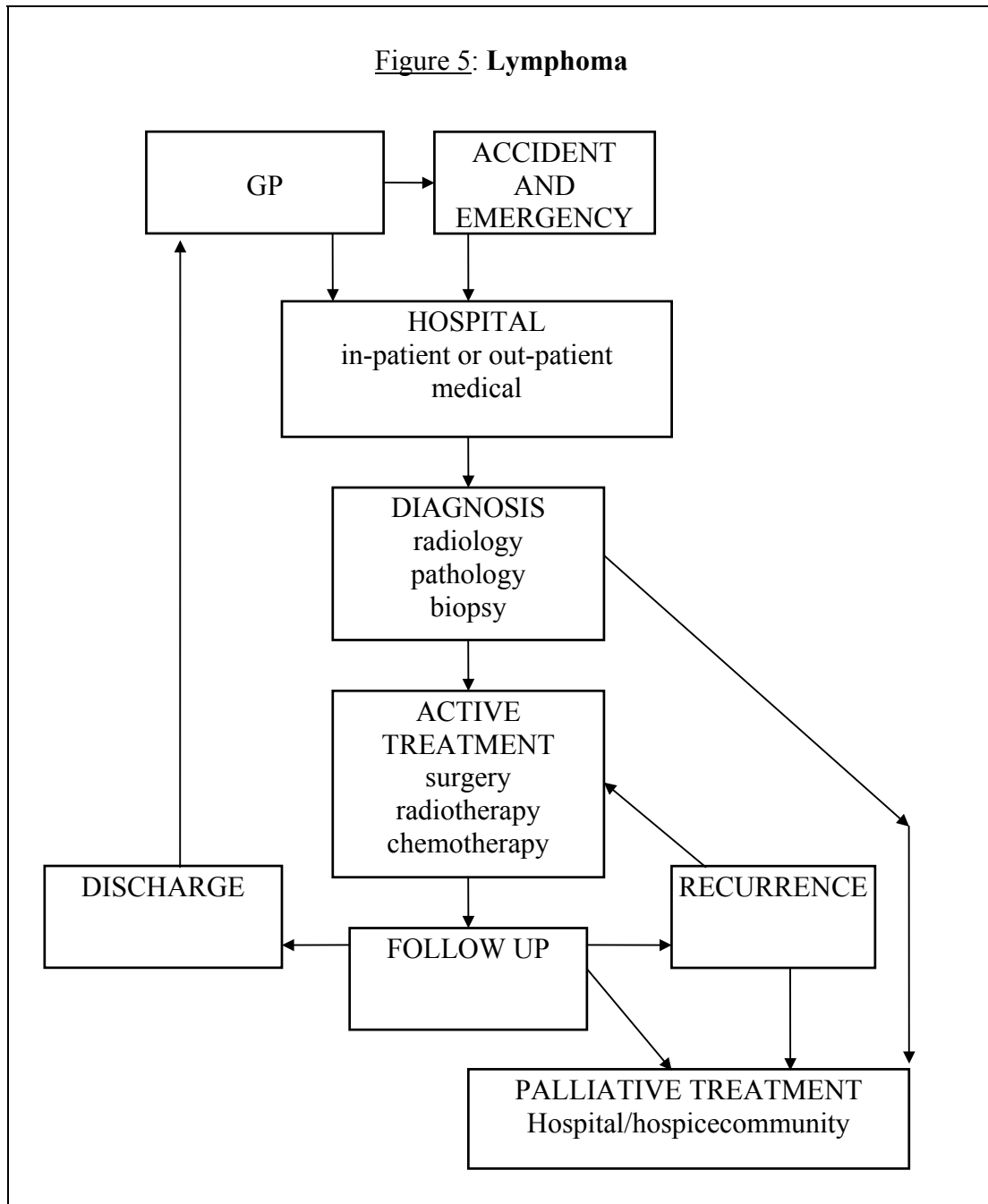
Colorectal patients are usually spread around several surgeons and clinics and may arrive in hospital as emergency admissions. While lead surgeons in colorectal problems had been established in all areas, it was admitted that GPs in Blackpool still tended to refer to any surgeon. In Lancaster it was pointed out that the numbers and the tendency for some to be admitted as emergencies meant that it was difficult to confine these cancer patients to particular surgeons. Length of follow-up is 5 years, but some surgeons do not discharge patients, and some said they tended not to pursue more than one follow-up clinic with the very elderly.

Lymphoma (Figure 5)

Unlike the other tumour types, the management of lymphoma is almost exclusively medical. The numbers of patients are small²¹, and chemotherapy is the main treatment. In all three locations the

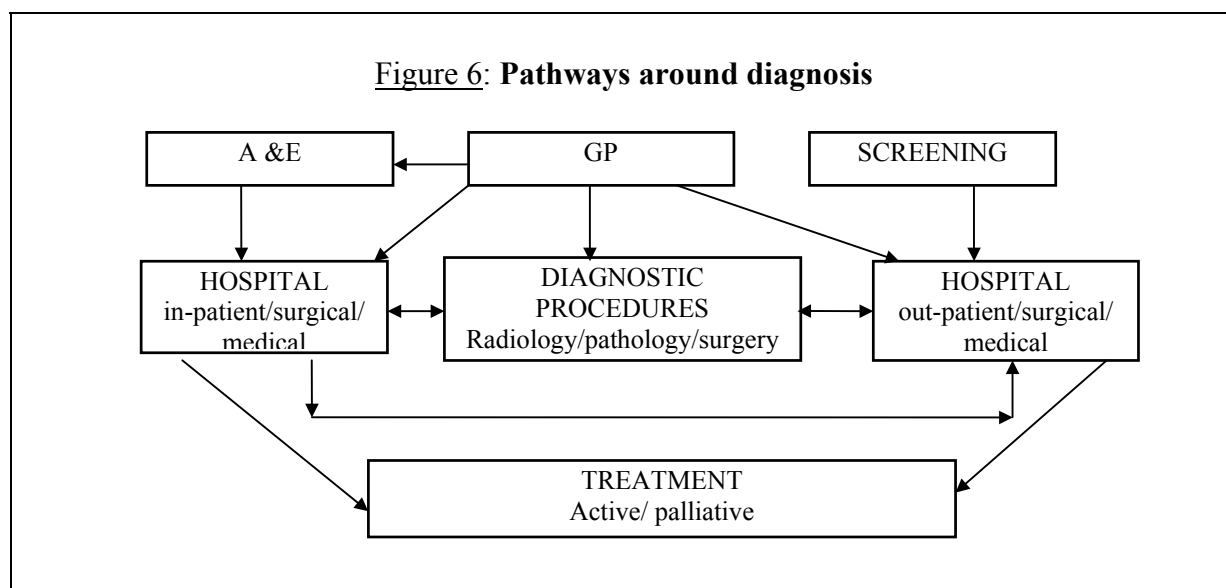
²¹ Blackpool is the largest and has around 50 new cases a year .

haematology unit is the focal point for diagnosis and treatment and patients become very familiar with the unit. Seen initially in out-patients, a 'staging day' is arranged, at which tests are administered and treatment regimes decided. There may be a lump biopsy as a surgical day case. Treatment is given on an out-patient, day case and in-patient basis as appropriate. Unusual treatment regimes are administered at the Christie, as with all tumour types. Some patients have stem-cell transplants in Blackpool. Patients tend not to be discharged, but at the end of treatment there is an assessment to ascertain remission. Although there are no specialist lymphoma nurses patients have contact with the same staff during their treatment, and can easily phone their unit for advice.



b) Phase of disease

Diagnosis (Figure 6)



For all patients diagnosis takes place after referral to hospital services. A very few very elderly patients may not be referred, and some may refuse to attend (or to have their relatives attend). Referral is usually through the GP, although, as discussed, for breast cancer it may be through screening, and for lung, colorectal and lymphoma it may be through an emergency hospital admission. Diagnosis may be very quick, a matter of weeks, (as in the case of breast screening) or may be more prolonged. Causes of delay may be patient reluctance to seek help, GP delay in referring, or mis-referral of patients.

Radiology plays a large part in diagnosis. Either prior to hospital referral, or once under the care of a hospital Consultant, patients may be sent to the diagnostic radiologist for CT scans, X-rays, barium enemas, or Ultra Sound (US) examinations²². GPs may use this service to decide which specialism is appropriate for a particular patient. The Consultant Diagnostic Radiologist I interviewed in Lancaster suggested that this visit could be a very anxious one for the patient. Diagnosis or ‘warning’ can sometimes be given immediately, but mostly results are forwarded to the GP or Consultant, who sees the patient. Results, although immediately apparent to the Radiologist, take about a week to get to the GP, but are quicker within the hospital. The patient is given instructions on how to get the result at the end of the visit, and tends to perceive results as taking a while to decipher. The radiologist felt that different modalities, such as US and CT scans, engendered different relationships with the patient. While CT scan was distancing, with large equipment, and US examination was much more intimate, with more doctor/patient interaction. However, like other doctors Radiologists differ in their styles of patient interaction, and while some may be willing to build up a relationship with the cancer patient, others may be more reserved.

Once tests have been performed and diagnosis confirmed, the ‘bad news’ consultation usually takes place in general Consultant Clinics, surgical in the case of breast and colorectal cancer, and medical for lung and lymphoma. There are designated breast clinics in Lancaster and Blackburn, and a clinic which is mainly breast patients in Blackpool. The proportion of malignancies to benign disease is around 1:13 in such clinics (Lancaster surgeon). None of the other tumour types have dedicated clinics. Lung patients attend the chest clinic, which may be located in out-patients, or have its own facilities. Lymphoma patients attend haematology clinics, which are generally self contained units, attached to pathology or oncology. Colorectal patients are more scattered across general surgical clinics. Although the move to have designated surgeons may confine them somewhat, the numbers involved, and the not-

²² Radiological assessment of the breast is performed by specialist radiologists in the screening clinic for the location, for both screened and symptomatic women, although some may be referred to general radiology clinics for US, or other modalities when spread of disease is suspected.

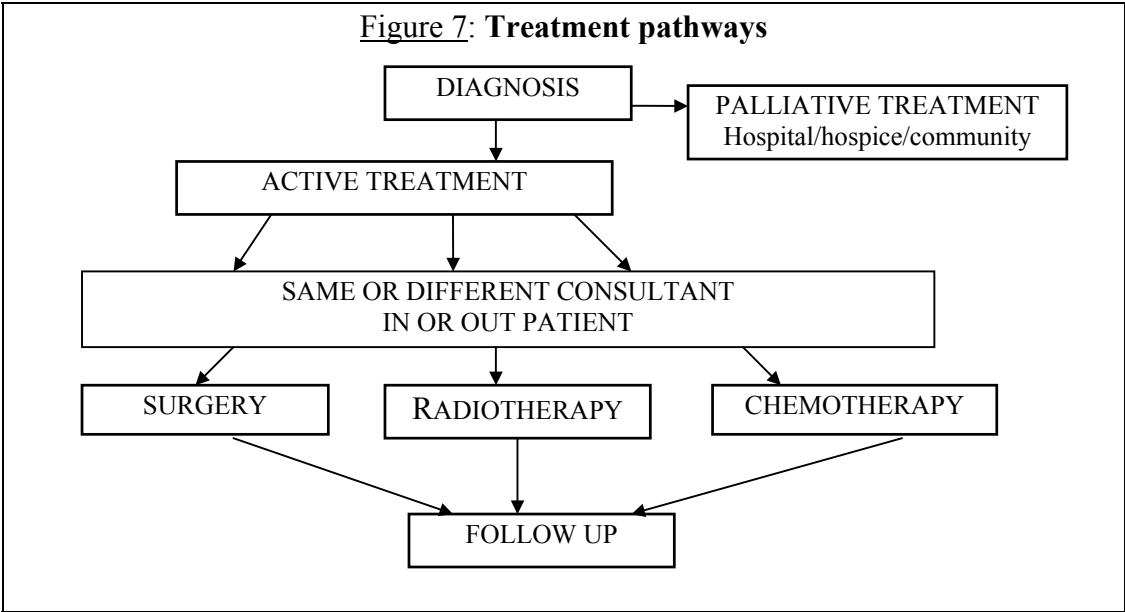
uncommon diagnosis through emergency admission, mean that non-specialist surgeons are more often involved than in the other cancers.

First treatment (Figure 7)

From diagnosis the patient moves into active treatment where possible. This may take the form of surgery, radiotherapy, chemotherapy, or hormonal treatment, or a combination of these. Surgery is usually performed in the local hospital²³, but all radiotherapy is conducted in either Preston or Manchester. Chemotherapy may be undertaken locally, but many patients still have to travel to Manchester from Blackburn and Preston from Blackpool, and people from all areas with rarer tumours or more complicated treatments make these journeys. Out-reach clinics from Preston and Manchester are the norm, however, so that the patient only has to travel for the treatment and not for initial and review consultations.

The time taken for first treatment to be complete varies greatly. Surgery alone can mean a period in hospital, depending on the type of surgery. Radiotherapy courses can vary from one session to several weeks, and chemotherapy regimens often take months to complete. Those having a combination of treatments take longest to complete, as different interventions tend not to overlap, but be delivered sequentially.

Several specialisms may be involved at the time of treatment. For example, a patient may be under the care of a surgeon, and referred for treatment to an oncologist, or they may be under a medical Consultant and referred to a surgeon for treatment. Often these referrals mean follow-up appointments too. There is the potential for some patients to see many different doctors, let alone nurses and other health personnel in the course of diagnosis and treatment. However, Consultants seemed to be aware of the problem of ‘too many clinics’, and generally informal arrangements were in place to ensure the patient did not have to attend too many follow-up clinics. Mostly this involves the patient remaining with the original Consultant, and being referred back after treatment.



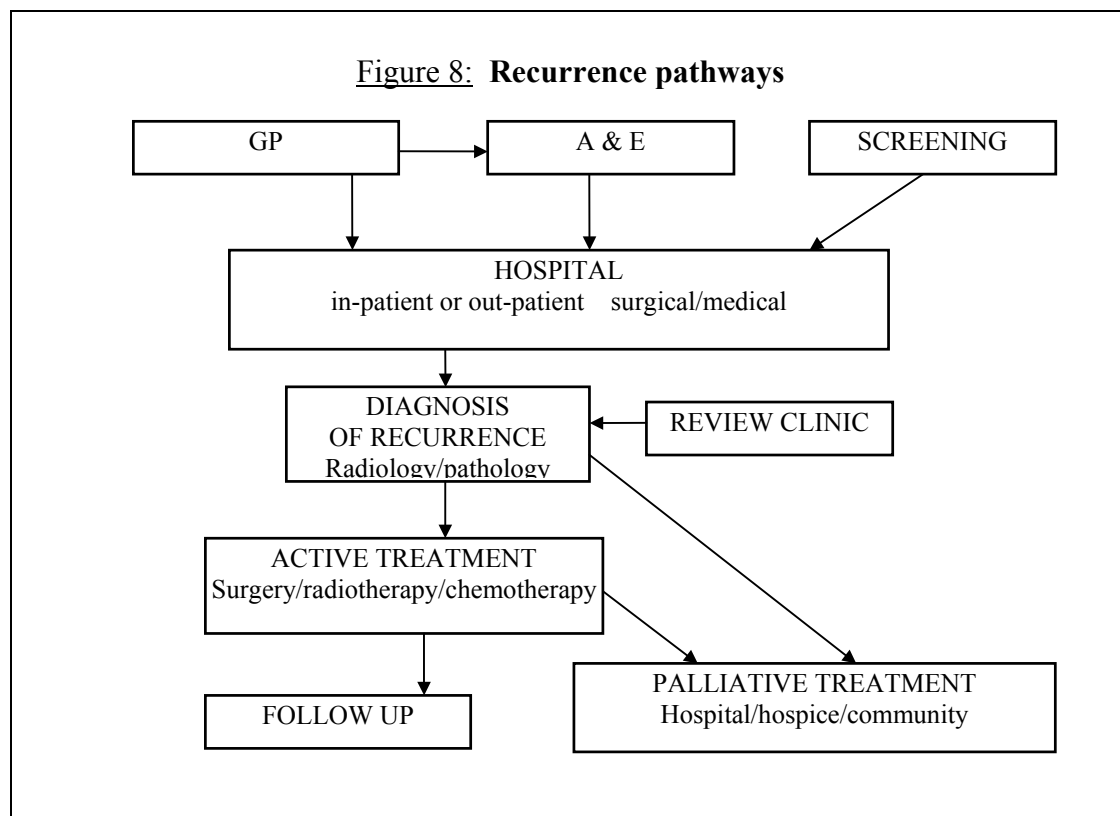
Recurrence (Figure 8)

After completion of the first batch of treatment patients are followed-up by review clinic appointments. These tend to be quite frequent at first, but space out as time goes on. The five-year point is often significant as the point at which patients are considered ‘survivors’, and discharge from services will

²³ Lung surgery for the three locations only takes place in Blackpool.

take place for many. Some Consultants never discharge patients. In breast cancer there are now some initiatives to discharge patients back to the GP for follow-up after two years. This is based on the admitted failure of review clinics to pick up recurrences. In all tumour types it is usually the patient who finds signs of a recurrence between appointments. However, review clinics are also posited as a strategy for reassurance of the patient.

At recurrence the patient is assessed again for treatment, and similar pathways are followed as with diagnosis. If active treatment is appropriate there may be a new Consultant to meet, e.g. the oncologist, or the chest physician, depending on first time treatment, and the site of secondaries or recurrence. Some patients may move to palliative care only at this stage, but still may meet other health personnel, such as the Oncologist, or the Palliative Care Consultant, or Macmillan Nurses. Radiology again plays a part at recurrence, so that some patients may build up a relationship with the radiologist over several consultations. At recurrence the Radiologist's uncertainty about disclosure is gone, as the patient has been in the system for a while and 'knows the ropes'. Thus this is often a more relaxed consultation than the initial diagnostic meeting. The observation that recurrence is a less stressful and anxious time for patients (and staff) was expressed by several Consultants.



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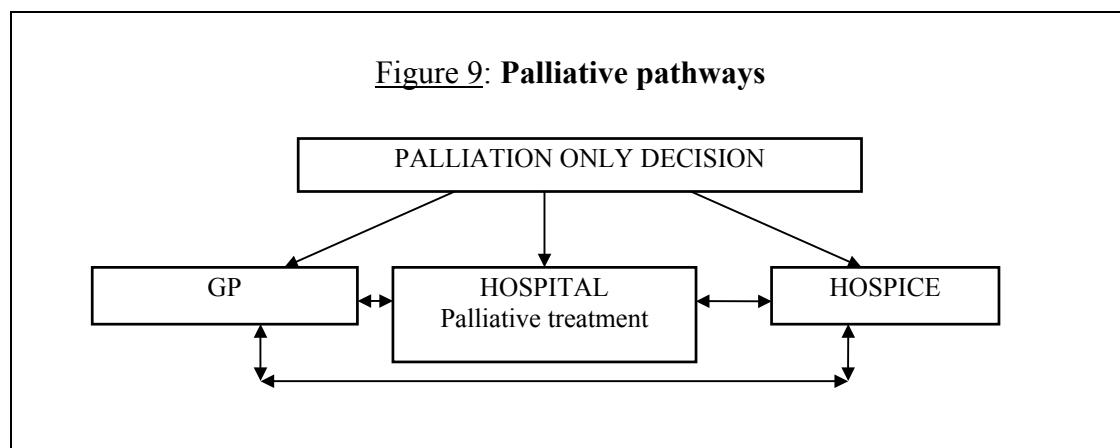
Palliation (Figure 9)

When no active and potentially curative treatment can be offered, the patient moves into the palliative area. This may happen earlier or later in the cancer journey, or not at all. Palliation can take place in the

hospital, community, or hospice, and often all three. Palliation may involve hospital services, as surgery, chemotherapy and radiotherapy may be used to ease symptoms. In the community, GPs and Macmillan nurses are involved, and hospices offer a range of palliative and terminal support. Specific palliation clinics operate in some areas, and day care in hospices may offer medical as well as social facilities.

GPs' approach to palliative care varies. Some are very keen to see their patients through this phase, and view continuity as part of their role as a family doctor. Some have a special interest in terminal care, often with nursing staff to match. Others are happy to pass their patients on to the palliative care team and hospice. This spread of approach was apparent in all three districts.

Macmillan nurses are generally attached to hospices, but mobile within the community and hospital. In Blackpool there are specific hospital as well as community Macmillan nurses. They play an important role in liaising between the different sites of health care. Along with specialist social workers and district nurses they can provide services to help the patient remain at home in the terminal phase. They recommend patients to the hospice, although official referral is through a doctor/doctor contact.



c) Geographical Areas

Morecambe Bay

The Morecambe Bay area is rural in comparison with the other two locations under study. It is served by a District general Hospital smaller hospitals in Kendal and Morecambe. It is unusual in having the services of a Consultant Oncologist - a function served in the other areas by out-reach doctors from Preston and Manchester. A Preston therapeutic Radiologist and Oncologist does however also provide a visiting service. There is a small oncology ward with in patient and day case beds. Staff on this ward are trained to give chemotherapy. In addition the Kendal hospital has an Oncology Specialist nurse, who can administer treatment, and a recently developed small day unit. There are no Macmillan nurses based in the hospital as in the other areas. A Breast Screening Unit is located at Lancaster, which also serves the Blackpool area.

It is also unusual in having a psychosocial support service (charity-funded) for cancer patients and their families. This organisation, CancerCare provides social support in the form of drop-ins, complementary therapies for relaxation, and art and craft opportunities. It has been in operation since 1981, steadily growing in scope, and acquiring buildings in both Lancaster and Kendal. All cancer patients and their families may take the opportunity afforded by these services, and people usually hear of them through the specialist nurses, although GPs, and hospital personnel sometimes introduce people to the services. The only similar set-up of any size locally has recently been founded in Preston. Additionally in Preston a self-help organisation, the Gentle Approach to Cancer, has been in operation for many years. It offers complementary therapies and support, and some people from Blackburn (as well as further afield) attend. A small branch of this organisation also functions in Blackpool. In Blackpool

one of the Breast Care Nurses also offers aromatherapy sessions to her patients, but this is confined to women who have come through breast screening.

The hospice is large for the population covered. It is also unusual in having employed its own social worker as part of the Palliative Care Team, rather than having a social worker in an out-reach post from social services. Another social worker with a special remit for cancer patients and their families is located in the main social work offices in Lancaster.

Blackpool, Wyre and Fylde

Blackpool is the largest of the three areas. It has a large district general hospital on one site, and a facility in Fleetwood with GP beds. It differs from the other locations in having a Cardiothoracic unit. In addition the haematology unit provides all treatment (apart from radiotherapy) for its lymphoma patients, including stem cell transplant. A Day Unit for this chemotherapy is located in the hospital, but is considered very small. Some in-patient beds are available on the haematology wards. It was pointed out to me that haematology in Blackpool has large charity funds, from which it pays its chemotherapy trained nurses. There are plans for a new purpose built Oncology Unit.

Blackpool also has a large teaching hospice, two-thirds funded by the local trust. In addition to the three Macmillan nurses based in the hospice there are two based in the hospital, a recent innovation which aims to provide better links between the hospital, community and hospice. Apart from the nurse who deals solely with screened women, the Blackpool Breast Care nurses share breast and stoma work and are based in the hospital. In the other areas these specialist nurses are located either in the community or hospice.

Blackburn, Hyndburn and Ribble Valley

This is the most urban of the locations under study, and also has the highest ethnic minority population of all three. It is served by a district general hospital and two less acute facilities nearby. There is a small community facility in Clitheroe, which has some GP beds. The Breast Screening Unit which serves the area is located at Accrington. There is only one breast care nurse in Blackburn, but she has two assistant nurses who cover breast screening. There are three Macmillan nurses located in the hospice, and the hospital has had a Macmillan nurse post for the past five years. Although the majority of patients go to Manchester for chemotherapy, some is carried out on the Medical Planned Admissions ward. The haematologist has a specialist support nurse, who can administer chemotherapy, and two other nurses are also trained to do this.

Blackburn has a small hospice for its size, with only 9 beds. It is NHS run, and the Palliative Consultant covers both Blackburn and Burnley (pop: 600,000). It offers a hospice at home service, but this does not provide 24 hour cover. There is day care, and also an out-patients palliative clinic. Currently a pilot scheme is running in Darwen for home care, providing a bank of health professionals who will provide all sorts of health and social care as needed. A clinical psychologist is attached to the hospice, but also has a wider remit for 'chronic illness' in general, and is located in the psychiatric hospital.

APPENDIX 4 Fieldwork support papers

Study Information Sheet

The psychosocial needs of patients and carers study [January 1997 to January 2000]

This study is being conducted by researchers at Lancaster University with the support of medical and other staff at your local hospital.

The aim of the study is to find out from patients and carers what you feel your support needs are, and have been, during illness. We want to know what kinds of services and support might make life easier during the illness.

Some patients and carers are being asked if they would participate in an interview with a researcher about this. The interviews will be tape recorded, with participants' permission, and take about an hour to complete. If you agree to take part you will be asked some very general questions, so that you have the opportunity to tell us what is, and has been, important for you.

All the information you give us will be held in strictest confidence and will not be passed on to a third party in a form which can lead to the identification of individuals. Participating in the study will not affect your medical treatment in any way.

The study is being funded by the NHS and the findings will ultimately be used to improve the range and nature of support services on offer to patients and carers. The study will take 3 years in all, so please do not expect any immediate changes in services. The research to be carried out has been approved by the local Research Ethics Committee appointed by the Health Authority.

We would like you to take part, but if, for any reason, you do not want to, you are completely free to refuse. Likewise, if you have initially agreed, and then wish to withdraw, you may do so without any problem. In neither case will we ask for any explanation, and there will be absolutely no adverse consequences for you.

If you have any questions about the study, you can contact one of the following people:

Project Researcher:	Sara Morris	Tel: 01524 594126
Project Leader:	Carol Thomas	Tel: 01524 594092

Consent Form

The psychosocial needs of patients and carers study

The patient/carer should complete the whole of this sheet.

Circle yes/no as appropriate

Have you received and read the information sheet? Yes / No

Have you had the opportunity to ask questions and discuss the study? Yes / No

Have you received satisfactory answers to all of your questions? Yes / No

Have you received enough information about the study? Yes / No

Do you understand that you are free to refuse to participate in this study at any time? Yes / No

I hereby consent to participate in this study

Patient/carer signature:.....Date.....

Name (BLOCK CAPITALS).....

THE INFORMATION SHEET MUST ACCOMPANY THIS FORM

APPENDIX 5 Note on the Kansas/Missouri Studies

The Kansas/Missouri studies were particularly helpful in the generation of a psychosocial needs inventory because these researchers had set out some ten years earlier on a similar mission: ‘...to identify the needs of the noninstitutionalized patient with cancer as defined by patients, primary care givers, and nurses, and to identify the needs of the primary caregivers as defined by the same three groups of subjects’ (Wingate and Lackey 1989: 216). The needs of informal primary care givers became the particular focus of later studies in this series, resulting in the development of a 90 item *Home Caregiver Need Survey* (HCNS). We obtained permission to make use of use the HCNS, adapting it to our research requirements in the British context. Given the importance of the HCNS in our attempts to generate a listing of cancer patients’ (and carers) psychosocial needs, it is appropriate to give an account of the initial Kansas/Missouri research.

In the first study, Wingate and Lackey (ibid) were interested in identifying the full range of needs, including the somatic or ‘physical needs’ of the patient (for example, the management of symptoms) which are beyond the scope of our study. They stated that ‘For the purposes of this study, need was theoretically defined as a drive toward rectifying a perceived (real or imagined) deficiency in equilibrium’ (ibid: 223) - a definitional approach that, although abstract, does have a passing resemblance to our own: *psychosocial needs are features and qualities of life and social relationships which, from the patient’s viewpoint, are necessary, important or critical to their psycho-emotional ability to live with the knowledge and social consequences of having cancer, and thus to their ability to hold themselves and their social worlds together.*

Wingate and Lackey’s purpose was to develop a validated and reliable needs instrument for use in clinical research and practice contexts. Like ourselves, they saw a major weakness of all previous attempts to generate such an instrument as residing in the practice of defining needs from the point of view of health care professionals and academics rather than from the point of view of patients and informal care givers:

[In previous research] Items for the instruments were generally formulated from a review of the nursing and medical literature, and only rarely were patient or family member/care-giver opinions utilized with regard to instrument development. Clearly, the instruments so developed are prescriptive in nature, that is, the investigator prescribes need items either using predetermined theoretical categories of needs or a checklist of needs. In this study, our intent was to use naturalistic inquiry to determine actual needs as described by patients and care givers themselves with no limits imposed by the theoretical framework, the investigators’ experience, or the literature sources (ibid:218).

The Wingate and Lackey study (ibid) required three groups of adult subjects: noninstitutionalized cancer patients, primary [informal] care givers, and nurses in completing two forms of an open-ended instrument, the Object Content Test, to elicit their perceptions of the needs of cancer patients and their primary care givers (ibid:219). These patient forms carried the questions ‘What are my needs as a cancer patient?’ and ‘What are the needs of the person caring for me?’, respectively. Patients were asked to simply write down a list of the needs which occurred to them. Informal care givers and nurses undertook the same exercise with appropriately re-worded questions. The content analysis of the patients’ needs items generated seven *categories of need* (utilizing various reliability testing techniques). These categories of need were as follows:

- Information needs
- Household management needs
- Physical needs of the patient
- Psychological needs
- Spiritual needs
- Legal or fiscal needs
- Other needs

An additional category, respite needs, was included in the care givers’ categories of need. The ‘Wingate-Lackey Model’ of care givers needs became the conceptual basis for the HCNS (Hileman et al 1992).

APPENDIX 6 Patient and Carer Interview Support Materials and Interview Schedule

INTERVIEW SCHEDULE

Pre-interview

- Introduction
 - emphasise that we want their experience - that it is valid, even ‘little things’
 - why they were chosen - wanted a range of people, places, situations
 - details about confidentiality - will not be named or identifiable, even if we use their words
 - answer any questions
- Consent Form

Interview

1. Follow questionnaire section 1:
 - begin with checking where person is now with illness, referring to questionnaire
 - get them to tell the story using route map [Interview Document1] to map out sequence of health service visits
2. Follow questionnaire section 2:
 - if there are any answers which need explaining - or a high score
3. Follow questionnaire section 3:
 - picking out aspects which need expansion or explanation
4. Follow questionnaire section 4:
 - especially if person has been offered, or used CancerCare etc.
5. Move on to support map [Interview Document 2]:
 - get them to talk about who has supported them, in what way, how helpful this has been, and where they would place them in terms of closeness
 - also any unhelpful experiences
6. Follow questionnaire section 5:
 - expand on what they have written
 - or ask if there is anything they want to say, if they haven’t written anything
7. A general question about whether there is anything else they would like to say that has been important to them, or they think might help us
8. Ask what advice they might give to someone finding themselves in a similar position
9. Administer the HADS [Interview Document 3]
10. Ask if they would like to write anything, assuring them there is no obligation, and if so, leave them with a piece of paper [Interview Document 4]
11. Thank you

Interview document 1: Route through services

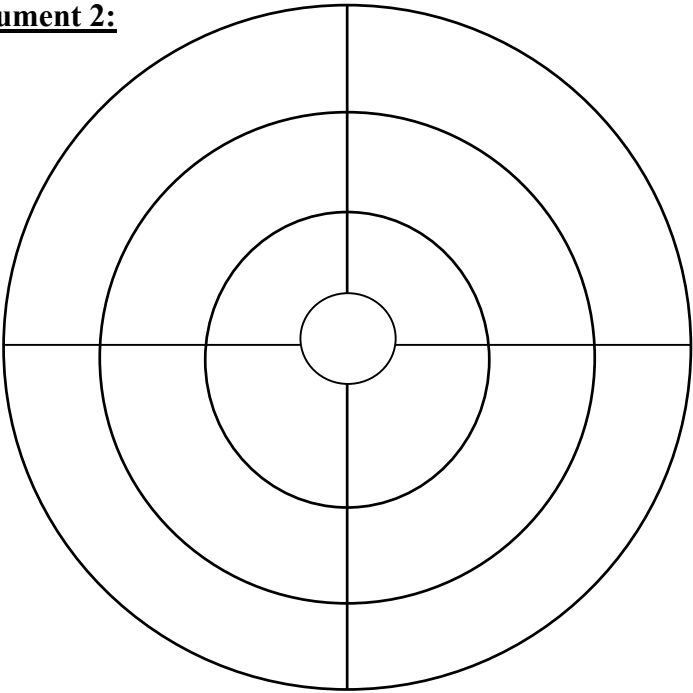
Interview document 2:
Support map

FAMILY

HEALTH
PERSONNEL

FRIENDS

OTHERS



Interview Document 3: The Hospital Anxiety and Depression Scale

Please read the following statements and place a tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

1. I feel tense or 'wound up':

- ☐ Most of the time
- ☐ A lot of the time
- ☐ Time to time, occasionally
- ☐ Not at all

2. I still enjoy the things I used to enjoy:

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little, but it doesn't worry me
- ☐ Not at all

4. I can laugh and see the funny side of things:

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, but not too often
- ☐ Not at all

5. Worrying thoughts go through my mind:

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, but not too often
- ☐ Only occasionally

6. I feel cheerful:

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

7. I can sit at ease and feel relaxed:

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

8. I feel as if I am slowed down:

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

9. I get a sort of frightened feeling like 'butterflies' in the stomach:

- ☐ Not at all
- ☐ Occasionally
- ☐ Quite often
- ☐ Very often

10. I have lost interest in my appearance:

- ☐ Definitely
- ☐ I don't take as much care as I should
- ☐ I may not take quite as much care
- ☐ I take just as much care as ever

11. I feel restless as if I have to be on the move:

- ☐ Very much indeed
- ☐ Quite a lot
- ☐ Not very much
- ☐ Not at all

12. I look forward with enjoyment to things:

- ☐ As much as I ever did
- ☐ Rather less than I used to
- ☐ Definitely less than I used to
- ☐ Hardly at all

13. I get sudden feelings of panic:

- ☐ Very often indeed
- ☐ Quite often
- ☐ Not very often
- ☐ Not at all

14. I can enjoy a good book or radio or TV programme:

- ☐ Often
- ☐ Sometimes
- ☐ Not often
- ☐ Very seldom

Interview Document 4: Anything extra

Your needs in illness study

If, after the interview, you think of anything else you would like to say, please write it here.

We guarantee that anything you write will be treated confidentially.

Please use this paper (add additional sheets if you wish) and return to the address below.

Thank you.

APPENDIX 7 Health Professional Interviews - Support Materials and Interview Schedule

Questions for health professionals

1. About the service meeting needs

What needs does your service set out to meet?
How well do you think these are met?
What view do you have of patient and carer needs?

2. About links with other services

[Use the cancer services map on next page]
Where are you in the network of cancer services?
Who do you collaborate with?
Who sends people to you?
Who do you send people to?
How well does the network you are involved in work?

3. About effectiveness

What is the part of the service you are involved in *best* at?
What is it *worst* at?

4. About change

Has anything changed since Calman in your part of the service?
What changes do you think will happen in the next 5 years?

5. Any other comments?

Male Female Age _____

Job title:

Employed by:.....

Specialist training?.....

.....

How many cancer patients seen in a week (approx).....

Are you part of a cancer unit.....

CANCER SERVICES MAP

Referrals from:

YOU

Referrals to: