

**Report to Dimbleby Cancer Care**

**Project: Complementary therapies and supportive cancer care:  
towards integration and holistic care?**

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University of Bristol**

## Summary

The overall aims of the study were initially as follows:

**Primary aims:** 1) To investigate cancer patients' and family members' needs for supportive care at different stages of the 'cancer journey', how far and in what ways they can be met through accessing complementary therapies in different cancer care settings. 2) To explore health professionals' understanding of the role of complementary therapies in supportive care for cancer patients and their families, and their needs for further information and training.  
**Secondary aim:** To investigate the facilitators and barriers to integrating complementary therapies into NHS cancer care.

I carried out an initial scoping exercise, reviewing the literature relevant to my field of study, and carrying out interviews with key informant in mainstream and complementary cancer care. As a result I clarified and finalised the focus of my project. The aims were achieved by carrying out my project in two centres offering complementary therapies to people with cancer. In both centres the focus of my research lay in the initial 'intake' interview (referred to as 'holistic assessment') at which new patients were able to tell their story, express their needs and work with the assessor to develop an appropriate package of complementary care. I used non-participant observation, sitting in on assessment sessions over a number of months, followed by interviews with patients and professionals. This gave rise to rich data on patients' experience of cancer, their un-met needs, the role of organisations outside mainstream care to provide crucially important support, and the process of decision-making around complementary therapies.

The secondary aim of investigating facilitators and barriers to the integration of complementary therapies into mainstream care is itself a huge project! From the work I carried out I am able to speculate on the transferability of a package of care that includes holistic assessment and follow-on complementary therapies into mainstream care. A more detailed interview study of mainstream health professionals' attitudes towards the integration of complementary therapies was funded separately and carried out in parallel with this project.

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## **Bibliography**

## **Abstract**

### **Background**

Previous studies have shown that people with cancer may experience considerable emotional and psychological distress at key points in their ‘cancer journey’ and often need support to manage the illness and its treatment. Patients’ supportive care needs, however, often remain un-identified and un-met. Advocates of supportive care recommend a ‘holistic’ approach that takes account of the whole person, not just the physical manifestation of their disease. The main aim of this study is to explore the role and value of ‘holistic assessment’, as used in some organisations that offer complementary therapies to cancer patients, as a means of detecting patients’ supportive care needs and facilitating access to appropriate therapies. A subsidiary aim is to consider the transferability of holistic assessment to mainstream NHS cancer care settings.

### **Methods**

Using case study methodology I carried out a qualitative study of the role and value of holistic assessment in two contrasting centres in the UK that offer complementary therapies to people with cancer. I observed and audio-recorded holistic assessment sessions and conducted follow-up interviews with participating patients, as well as focus groups and interviews with members of staff. Data were analysed using a combination of narrative analysis, thematic analysis and analysis of the assessment dialogue.

### **Findings**

Holistic assessment functioned as a patient-centred and relatively unstructured process. It played a dual role in the lives of people with cancer: decision-making and meaning-making. First, assessors were able to identify patients’ needs and support them in making informed choices about complementary therapies. Second, through telling their ‘illness stories’, patients were able to explore the impact of their disease and the personal meaning it has in their lives. Skilled professional input and a supportive holistic ethos at the organisations were important in facilitating these processes. The majority of patients valued the process of holistic assessment, although on occasions their expectations were not met or there were mis-matches in communication between patients and assessors.

### **Implications**

Holistic assessment may only be appropriate where a holistic approach to care is embedded in the organisation, for example a commitment to the provision of complementary therapies by professional therapists alongside curative treatment. This may prove to be a challenge to the adoption of holistic assessment and complementary therapies into mainstream NHS care. It may only be of real value if an organisation can offer services to meet the needs that are identified by the assessment process.

## 1. Introduction

Research evidence reveals that many patients with a cancer diagnosis have un-met supportive care needs, resulting in a poor quality of life,<sup>21-30</sup> one reason being that such needs are often not identified during routine treatment within the NHS.<sup>22;31-36</sup> From my previous study of men with cancer<sup>7;37</sup> and from my knowledge of the literature, I became aware that patients do not routinely have an opportunity to talk about their supportive care needs in the medical setting. Inevitably this is due to a mixture of time constraints within clinical consultations, uncertainty on the part of patients about disclosing their problems and concerns in that setting, and a reluctance on the part of clinicians to engage in communication about psycho-social issues, partly due to a lack of the necessary skills or a focus on treatment as a priority.<sup>33;34;38-45</sup> For patients who present with signs of serious mental disturbance, referral to psychiatric or psychological services may be available. However, there remain the majority of patients who may be experiencing emotional distress coupled with a lack of information or knowledge regarding self-care, and who may find it difficult to access support.

UK policy documents and reports, from the Calman-Hine report (1995),<sup>46</sup> the NHS Cancer Plan (2000),<sup>47</sup> the NICE guidance (2004)<sup>48</sup> to the recent Cancer Reform Strategy (2007)<sup>49</sup> make increasing reference to the importance of supportive care provision, but with as yet no clear guidelines for implementation or allocation of resources. Whilst the need for palliative care for incurable or terminal illness has long been established, the need for supportive care earlier in the disease trajectory and also following the end of successful treatment (to deal with the late effects of treatment), is increasingly being recognised.<sup>49-52</sup> However there is debate about how, where and from whom such support should be available.

At least 30% of the UK population of cancer patients are using complementary therapies as a means of accessing supportive care. Previous research that I have carried out suggests that one of the reasons why patients with cancer turn to complementary therapies is to fill perceived gaps in mainstream provision.<sup>7</sup> These gaps are not in the provision of treatment but in the process of care, such as a perceived lack of communication with clinicians, a lack of emotional and psychological support and advice about self-help strategies such as, for example, relaxation and nutrition.<sup>7</sup> Whilst there have been a number of studies, both quantitative and qualitative, exploring the general reasons why patients use complementary therapies,<sup>9;11;12;14;56-58</sup> little is known about the specific needs brought by patients with cancer to individual consultations and how these get translated into appropriate modalities of care.

It is clear that some people who wish to use complementary therapies find it difficult to access the necessary information and advice to help them make an informed decision about which therapies, if any, to adopt. Patients report that they receive little support from health professionals in their search and they often rely on informal lay networks.<sup>37;59;60</sup> There appears

to be a need for a trusted individual to help patients make guided choices as regards complementary therapies and, for many patients, this person would ideally be a health professional.<sup>7:61;62</sup> Currently however, health professionals may not have the knowledge or may feel that there is insufficient evidence for the effectiveness of complementary therapies to enable them to take on this role.<sup>37:63-65</sup>

Some organisations that provide complementary therapies for people with cancer offer an initial 'holistic assessment' to all new patients, before they use any of the therapies. The assessment ideally takes place with a health professional, for example someone with a background in nursing or counselling, who is knowledgeable about complementary therapies. Holistic assessment provides an opportunity for patients to express their needs, learn about the complementary therapies available and make a decision about which therapies would be appropriate. It provides a model of how health professionals, currently working outside mainstream cancer care, are taking a role in assessing patients' supportive care needs, and offering advice, information and recommendations for the use of complementary therapies. Maybe a model such as this could be transferred to other settings, possibly within mainstream cancer care?

## **2. Aims and objectives**

The main aim of the study was:

**To explore the role and value of 'holistic assessment', as used in some organisations that offer complementary therapies to cancer patients, as a means of detecting patients' supportive care needs and facilitating access to appropriate therapies.**

A subsidiary aim was:

**To consider the transferability of holistic assessment to mainstream NHS cancer care settings.**

In order to fulfil these aims there were a series of more specific objectives:

- ◆ To investigate the process of holistic assessment at two organisations providing complementary therapies to cancer patients, one of which operates independently from the NHS, the other with close links to the NHS.
- ◆ To investigate the key components of the assessment, the types of needs brought by patients to this consultation and how these needs are translated into a package of supportive care.

- ◆ To explore patients' and professionals' perspectives on the usefulness of holistic assessment for patients with cancer.

### **3. Methods**

I used a qualitative methodological approach as I wished to study a process (holistic assessment) and to investigate the meanings, experience and views of the participants of that process.<sup>66</sup> I used a case study design, based in two organisations that offered a similar service but differed from each other in ways that I felt were important and relevant to the research questions. The chief criterion of variation was the degree to which each organisation was integrated into mainstream NHS care. Both organisations were registered charities. One operated without any formal links to the NHS whilst the other received part of its funding from the local Primary Care Trust, employed NHS professionals amongst its staff and maintained links with each patient's clinical team. I felt that more could be learned about the potential transferability of holistic assessment to mainstream settings by studying the process in these two contrasting settings.

I used observation and audio-recording of holistic assessment sessions at each organisation, follow-up interviews with participating patients, and focus groups with the professionals carrying out the holistic assessments (the assessors). To describe the context for the study, I interrogated the websites and policy documents of each organisation, to establish their aims and objectives. I also obtained statistical data on the throughput and characteristics of patients coming to each of the organisations in a typical year. In order to capture the historical as well as the current perspective on the development and use of holistic assessment, I carried out interviews with the founders and current managers of each organisation. Throughout my time at the two organisations, I kept field notes and referred to these in order to supplement and further my understanding of the more formally collected data.

In this report I have concentrated on the data from the observations, interviews and focus groups.

#### **3.1 Sampling criteria for case studies**

##### ***Holistic assessment***

As the focus of the study is on holistic assessment, the main criterion for the selection of sites was the use of such an initial assessment appointment with all new patients.

##### ***Relationship with the NHS***

Because I wanted to consider the applicability of holistic assessment to mainstream NHS settings, I chose case sites that each had a different relationship with the NHS, in order to

compare and contrast different ways of working. For the purpose of this study, relationship with the NHS was defined using the following criteria:

- ◆ Funding source: whether or not any funding for the service comes from the NHS
- ◆ Information and referral: whether or not NHS personnel recommend or refer patients to the case study sites
- ◆ Communication about individual patients: whether or not NHS doctors are informed about patients' attendance and progress at the case study sites
- ◆ Professional background of staff: whether or not NHS trained staff are employed at the case study sites
- ◆ Location: Proximity or otherwise to NHS premises

#### ***Range of complementary therapies***

Rather than restrict the study to any particular group of therapies I decided to access centres that offered as wide a range of therapies as possible. I did, however, decide to exclude organisations offering alternative therapies, since their underlying philosophy and approach is unlikely to be transferable to mainstream care.

#### ***Payment for services***

Complementary therapy service providers vary in the charges made to patients. At one end of the spectrum are centres that offer all services free of charge. At the other end are centres that charge professional fees, with some subsidised services in between. I wanted to choose contrasting centres in order to include some diversity in the types of patients participating in the study and in the philosophy of the participating centres.

#### ***Types of cancer***

Sampling took place at the level of the organisation rather than the individual, and therefore the cancer diagnosis of participants was not a highly significant factor. However, to increase the potential transferability of the study findings to other settings, it was important to cover as wide a range of cancer diagnoses as possible. For example, one organisation that I considered as a study site only offered a service to patients with breast cancer. I eventually chose two centres supporting patients with all types of cancer.

#### ***Age range***

In order to increase the potential transferability of the study results I did not wish to restrict the study to any particular age range. The sites that I chose worked predominantly (or solely

in the case of site one) with adults. At site two, the service was occasionally used by children and their parents.

The characteristics of the study sites are summarised in Table 1.

**Table 1: Characteristics of the study sites**

	<b>Site One</b>	<b>Site Two</b>
Assessment method	Introductory holistic assessment	Holistic assessment and MYCAW*
Funding source	Charity fund-raising and fees to clients	Charity fund-raising and some PCT funding
Referral method	Self referral	Self referral plus suggestion and encouragement from NHS health professionals
Communication with NHS	Leaflets about the centre are available on request at the information centre of the local NHS oncology unit. Staff at the centre do not routinely contact the patient's medical team.	Leaflets and recommendations about the centre are given routinely to cancer patients in local NHS hospitals. Letters are routinely sent to all members of the patient's medical team after assessment session.
Professional background of assessment staff	All have a complementary therapy training; some also have counselling, psychotherapy or education qualifications	Mostly NHS trained nurses. One GP, one radiographer and one counsellor
Range of therapies	Acupuncture, aromatherapy, counselling, healing, integrated medicine doctor, meditation, massage, nutritional advice, reflexology, relaxation, shiatsu, visualisation	Acupuncture, aromatherapy, counselling, healing, homeopathy, hypnotherapy, massage, medical herbalism, reflexology, reiki, relaxation, shiatsu.
Payment for services	Professional fees charged to clients – occasionally 'donation only' for less affluent clients	Service is free of charge to patients
Types of cancer	All	All
Age range	Adults only	Adults and children
Location	Rural location in dedicated premises geographically distant from NHS sites	Urban location in dedicated premises geographically close to NHS oncology hospital

\* MYCAW (Measure My Concerns and Wellbeing<sup>240</sup>)

## **3.2 Research methods used**

I used a combination of observation, semi-structured interviews and focus groups.

### **3.2.1 Observation**

I decided to use non-participant observation of holistic assessment sessions as well as interviewing patients about their experience of holistic assessment. My rationale for observing these sessions was the opportunity to witness the interaction between patient and assessor as it occurred in its natural setting, rather than relying on later recall by the participants. Another advantage of using observation, particularly when researching into sensitive topics such as the experience of a life-threatening illness like cancer, is the opportunity it provides to learn about things that people might be unwilling to talk about in an interview. All sessions were audio-recorded using a digital recorder and transcribed verbatim by a professional transcription agency. I also kept field notes, noting any particular non-verbal behaviour that seemed important, or reflecting on the emotional tone of the assessment.

### **3.2.2 Semi-structured post-assessment interviews with patients**

I carried out semi-structured interviews with participants following their initial holistic assessment, in order to ask about their experience of and satisfaction with the consultation. The interviews were planned to ideally take place about a week after the patient's holistic assessment, allowing patients some time to reflect on the process and also time to have begun a course of therapy. Interviews took place at a location that was most convenient for the participant: generally their own home or a spare therapy room at the organisation. Whilst face-to-face interviewing was the preferred strategy, the geographical distribution of participants meant that this was not always possible and some interviews were carried out over the telephone. The face-to-face interviews tended to be longer (between twenty minutes and an hour and a half) than those carried out over the telephone (five minutes to forty minutes). I felt that the data collected over the telephone were of sufficient quality for the purpose of the study. In one case a participant chose email as the medium for this interview. All the interviews were audio-recorded using a digital recorder and transcribed verbatim. I was then in the position of having paired sets of data for each participant: the observed consultation and the subsequent interview.

### **3.2.3 Semi-structured interviews with professionals**

A range of staff at each centre were approached for interview, to investigate their views on holistic assessment and the role of complementary therapies in cancer care, the therapeutic approach they used and the potential for the integration of holistic assessment and complementary therapies into mainstream care.

### 3.2.4 Focus Groups with assessors

Once the holistic assessment observations had been completed, I conducted focus groups with the assessors at each site. The object of this was to hear from them how they perceived the role of the introductory or ‘holistic’ assessment. I was also interested to hear what particular skills they felt they brought to the assessment and how these related to their professional background

At the first study site, I conducted a single focus group lasting ninety minutes. At the second study site, I conducted two focus groups that were shorter as they were included in a regular assessor’s meeting. At all the group sessions I gained consent for audio-recording the discussions, which were later transcribed verbatim.

### 3.3 The sample

Research participants included individuals who had a professional or managerial role within each organisation, and were able to act as key informants, the assessors who carried out the holistic assessments and patients who attended for assessment.

#### *Key Informants*

From the staff interviews, data from just two of the interviews with individuals who acted as ‘key informants’ at each site were included in this report. In each case participants were chosen in order to provide a historical and a current perspective on the policy and practice of each organisation including the use of holistic assessment. Data from two key informants at each centre have been included in the analysis.

**Table 2: Description of key informants**

<b>Nature of informant</b>	<b>Site one</b>	<b>Site two</b>
Historical perspective	Founder and current member of the Board of Trustees	Founder and Life President of the Board of Trustees
Current perspective	Director of Therapy	Chief Executive

#### *Assessors*

All the assessors at each site were invited to take part in the study. At centre one, there were four assessors, all of whom also had other management or development roles within the organisation. At centre one, all four assessors participated in the study, consenting to my observation of their holistic assessments, and they all attended the focus group. At centre two there were eight assessors in total, all of whom worked part-time and did not have an additional role within the organisation. All eight of the assessors consented to participate in the study but by chance I only observed four of them in action in assessment sessions. The first focus group at site two was attended by five assessors and the therapy manager, a group

that included only one of the assessors whose sessions I had observed. The second focus group was attended by the other three assessors whom I had observed.

### *Patients*

Thirty-four patients consented to participate in the study. Prior to their holistic assessment appointment, an introductory letter and information sheet for the study was sent out to all new patients. On arrival at the centre I was able to meet each potential participant, answer any questions and gain informed consent to observe and audio record the session. All patients were considered eligible unless they had told the receptionist that they did not wish to participate. The refusal rate was low at both centres as shown in Table 3 below.

When I began my fieldwork in the two case study sites I planned to sample participants purposefully, aiming at maximum variation according to gender, age, type of cancer and stage of illness. In order to enhance the richness of the data I wished to include people with a wide range of illness experiences, including some typical cases (for example common types of cancer) and some extreme or deviant cases (for example unusual types of cancer).<sup>225</sup>

However, there were insufficient new patients attending the centres during my field work periods to allow for this approach, particularly at site two where fieldwork had to take place in short intensive blocks, owing to the geographical location. At site one which was more local, there was a lower than average rate of new patients attending during my fieldwork period since the organisation had recently moved to a new location and was not yet operating at full capacity.

Two other factors also contributed to reducing the potential pool of participants. First, it was not possible to recruit patients who arrived at the two centres with very little notice, since patients must have adequate time to consider the information and make an informed decision about whether or not to participate, as per the regulations of the ethics committee. This information was regularly mailed out to new patients in advance of their appointment.

Second, at both sites a high proportion of those attending for assessment were carers rather than patients and therefore were not eligible for the study. Initially I intended to include a subsample of carers in the study, in order to contribute to our understanding of the needs of this group. However, having carried out some carer interviews, I recognised the potentially rich data that they were generating and I decided that this perspective was beyond the scope of the present study and would be better served by a separate study.

As a result of all these factors, in order to achieve a reasonable sample size I approached all eligible patients attending for holistic assessment on the days that I was present, over a six month period. Hence, for pragmatic reasons, within the purposively selected study sites I recruited a 'convenience' sample of patients. Towards the end of data collection, I requested

that the research information only be sent to male patients, who were under-represented in my sample at that stage.

**Table 3: Description of patients**

	<b>Site One</b>	<b>Site Two</b>
<b>No.of participants</b>	20	14
<b>No.of refusals</b>	5	3
<b>Gender:</b>		
Women	15	10
Men	5	4
<b>Mean age (spread)</b>	52 (24-75)	56 (32-82)
<b>Marital status:</b>		
Married or cohabiting	18	8
Living alone	2	6
<b>Occupational group:</b>		
Professional	12	7
Clerical	5	5
Manual	3	2
<b>Occupation status:</b>		
In work (part-time)	5	2 **
Sick leave	8	5
Retired /Unemployed	7	7
<b>Cancer type:</b>		
Breast	10 *	4
Ovarian / Endometrial	5 *	2
Prostate	2	
Lung / Lung Lining	1	2
Lymphoma	2	1
Multiple myeloma		2
Oesophageal		1
Lachrymal gland		1
Liver	1	
Sarcoma		1
<b>Time since diagnosis:</b>		
Less than 6 months	11	9
6-12 months	3	3
Over a year	6	2

\* One woman had both primary breast and ovarian cancers and is listed twice

\*\* One in full-time work

#### **4. Description of study sites: Model of care and therapies offered**

Both of the study centres offer an initial holistic assessment followed by access to a range of complementary therapies for cancer patients and their supporters. Site one is located in a rural setting near a large city in the south of England, not near the NHS oncology centre, and it serves a national catchment area. Site two is located in a city centre in the north of England near the NHS cancer hospital and it serves a wide rural and urban catchment area. Both centres are registered charities supported by fund-raising. Site one receives no statutory funding. Site two receives 8% of its annual funding from the local PCT.

The range of therapies available at the study centres is fairly typical of complementary therapy providers in private practice and in some mainstream settings across the UK. Many complementary therapy providers, including the study sites, also offer sessions in counselling, creative writing and art therapy which are also available in mainstream care.

Both centres aim to offer an experience to their clients that contrasts with their experience of mainstream cancer care within NHS hospitals. This is reflected both in the physical environment and the time given to clients. To set up a facilitative environment, both centres have comfortable furnishings, bowls of flowers and, at site one, relaxing background music. A warm reception from staff generally includes a cup of tea. At both sites, the assessor comes to the reception area to meet the patient and show them to the consulting room. The assessment takes place over the course of an hour in a dedicated consulting room without interruption.

##### **4.1 Site one**

###### ***Model of care***

The model of care is based on promoting quality of life, preventive health care and long term health maintenance as opposed to specific clinical outcomes or survivorship. There is a commitment to helping people work on the deeper issues that cancer might unearth, issues that might have been previously overlooked but can be triggered by the onset of the illness. Such work requires the development of a good therapeutic relationship between the client and the centre and its staff over time. The centre will accept clients from anywhere in the country, and it offers two and five day residential courses, day courses, support groups and an out-patients service available for people who live near enough to access complementary therapies on a sessional basis. I conducted my research within the latter service, as I was interested in out-patient rather than residential support. In order to access complementary therapies, all patients must attend for an initial introductory assessment session.

### ***Choice of therapies***

Patients have open-ended access to therapy sessions, which they pay for at the market rate. This approach, as well as covering costs, is seen as a way of encouraging patients to value the service. There is an option for patients to sign up for 'donation only' whereby they pay what they can afford, but it appeared from my observations that this was not generally known by patients before they arrived at the centre.

## **4.2 Site two**

### ***Model of care***

The work of the centre is based on a problem-oriented brief intervention approach, a model that has been adopted for many counselling and psychological therapies.<sup>274</sup> At the outset, two opposing models had been considered: long-term therapy with a charge to patients (based on a psychotherapeutic model) or brief, focused therapy free of charge to patients. The latter model was adopted because of a commitment to providing a service for as many people as possible and to make the service available to all socio-economic groups, not just those who could afford to pay. The centre will accept patients from a defined local catchment area. An initial patient assessment was built into the process as a way of enabling an individual approach to supportive treatment.

The number of sessions available to any patient is restricted to a package of six (an assessment followed by four therapy sessions and a review). Owing to a recent funding crisis the centre has had to cut the number of actual therapy sessions per patient from six to four. My informant felt satisfied that this is still adequate to ensure the effectiveness of the intervention, having reviewed the literature on brief interventions. The centre is committed to evaluating the effectiveness of the intervention they offer through the use of outcome scales.

### ***Choice of therapies***

Site two offers the following therapies: acupuncture, aromatherapy, art therapy, counselling, healing, massage, medical herbalism, homeopathy, hypnotherapy, relaxation, reflexology, reiki and shiatsu. Most of the therapists have a background as a NHS professional. For example one of the healers is also a physiotherapist, and the homeopath formerly worked as a consultant haematologist. There has been discussion about employing psychologists at the centre but so far this proposal has been rejected on the grounds of cost. The service is free of charge to patients. All costs are covered by the organisation from its fund-raising activities. Therapies on offer at the centre are chosen on the basis of the research evidence where it is available, popular acceptability of therapies and also on the clinical records of patients who have passed through the centre.

Both centres operate a policy of self-referral whereby the patients themselves make the first contact. Self-referral is seen as an important factor in patients' motivation to attend and their willingness to engage with the therapies.

At both sites, the inclusion of an initial assessment was built in at the start, as part of the model of care. In the view of the assessors, this distinguishes and strengthens their approach compared to other organizations working with people with cancer.

The assessment appointment aims to cover the following areas:

- ◆ the patient's main reason for coming and expectations of the centre
- ◆ their main concerns
- ◆ how the diagnosis is affecting the patient's life
- ◆ what significance having cancer has for the patient
- ◆ the patient's understanding of the prognosis
- ◆ the patient's own strengths, resources, and sources of support

## **5. Results**

There are three sections to the results: the focus groups carried out with the assessors, an analysis of patients' stories and an analysis of the interaction between assessors and patients.

### **5.1 Assessors' focus groups**

The focus group data were analysed using a thematic approach. In this section I explore assessor's interpretation of what actually takes place in holistic assessment sessions with patients, and the role or function of holistic assessment, as derived from the focus groups with assessors at each site. This will be examined in terms of five themes that emerged from the focus group data:

- ◆ the skill mix of the assessors
- ◆ space for patients to talk
- ◆ information exchange
- ◆ relationship building
- ◆ degree of structure or formality

### ***The skill mix of the assessors***

As shown in Table 1, the assessors at the two study sites have different sets of qualifications and experience. Whilst recognizing that an NHS background is important for the public face of the organization, the assessors at site two had mixed views about the importance of their nursing background in the conduct of assessments. Some felt it was very important since it enabled them to understand the terms used by patients and also to be alert to any significant signs and symptoms reported by patients. Others felt that as long as some members of the team had clinical knowledge they could support assessors who came from different backgrounds (for example the one counsellor in the team). They felt that whatever their background, the main requirement for assessors is the ability to provide empathic support to patients. Human qualities such as compassion and acceptance were seen as the most important attributes for assessors, be they intuitive or acquired through years of experience in the field.

At site one the emphasis was much more on assessors having qualifications and experience of complementary therapies. They emphasised the importance of offering an experiential rather than simply a cognitive understanding of what each therapy entails. At both sites, assessors talked about the importance of the supportive environment in which they worked. The existence of an organisational model of staff support through regular feedback, training, seminars, discussion and supervision enables them to support their patients better.

### ***Space to talk***

Assessors at both centres said that the most important function of the assessment is the opportunity for patients to talk, to be heard, to offload and to have some dedicated time for themselves. This is aptly summarized in this excerpt of a focus group discussion among assessors at site two:

*ASS1: Listening I think, is a big one, people are given the time.*

*ASS2: Giving them permission to talk about their fears and concerns.*

*ASS1: Saying that it's okay for you to centre in on yourself, to focus on yourself and talk about things that they might feel are indulgent perhaps or they haven't found another space in which to do that because they're very busy protecting other members of their family and their friends, and not having had that opportunity just for them to talk about what it's [cancer] really meaning for them, and how it's affecting them.*

*ASS3: And I think they can talk using their own words and their own language, and it is not a hospital appointment.*

They talked about the importance of providing a still space amidst the turmoil that many patients feel. Assessors must have the skills and flexibility to pick up cues and respond

appropriately to each person that comes through the door, each one of whom may bring a different approach to their issues.

At site two, one assessor coined the phrase '*applied counselling*' to describe the approach they adopted in giving patients space to talk while still fulfilling the overall task of the assessment, in terms of identifying an appropriate package of complementary therapies for the patient. They felt that such an approach was possible because of the skills they could draw upon from their mainstream health backgrounds:

*ASS1: But also I think as clinicians we're used to using ... because we're not trying to be counsellors ... we're not really being counsellors as assessors but we're sort of almost being ... it's kind of applied counselling isn't it?*

*ASS2: Yeah.*

*ASS3: It is.*

*ASS1: We are doing ... we are using counselling skills but we're using them in a way that's very much to the point and for the moment which I think as clinicians we have ... we're experienced in doing because you have to do that in other health settings, you have to respond to the moment in a way that's enabling for people. [Assessors' focus group site two]*

### ***Information exchange***

From the perspective of the assessors, two-way information exchange is a crucial part of the assessment. Information is needed from patients in order to make an assessment of their needs and to formulate an appropriate treatment plan. Information must also be given to the patient about the resources on offer at the sites to help them make a decision about what they want.

At both sites, assessors viewed the information role as also including sign-posting patients to other agencies if appropriate, to equip patients to help themselves, to give them tools for their boxes. This latter point is particularly true for site two which had more active contact with other local agencies, both statutory and charity-funded. At both sites information sheets on complementary therapies were available but only on request, for fear of overloading patients who may already be feeling overwhelmed. At site two leaflets were also available on other aspects of self-care such as relaxation and sleep. Assessors at both sites commented that information sent out in advance of the assessment was rarely read or absorbed by patients before coming for their appointment.

### ***Relationship building***

At both sites the assessment was viewed as an opportunity for patients to establish a relationship with the organization and with key individuals within it thus making it easier for them to return and engage with the services on offer. Assessors at site one did not generally

have any ongoing contact with the patients once they have been 'handed over' to a therapist. Any changes of therapy were negotiated directly with the therapist and the reception staff at the unit, but the assessor may see them again at review. At site two, each assessor acted as a linking person to guide patients through their experience of the centre, to negotiate any changes of therapy and to maintain contact with their medical team.

### ***Degree of structure or formality***

There were debates in all the groups about whether holistic assessment should follow a set protocol or should be open, flexible and responsive to patient need. Some favoured the 'blank sheet of paper' approach while others valued a more structured format. Assessors acknowledged the importance of their work being under-pinned by a model but stressed that it must not be too prescriptive. The assessors at site one said that there was '*no rigid structure*' to their introductory session but there was a recognition of '*appropriate areas*' to be covered. At site two the assessors all followed the same structure for the assessment as learnt in their comprehensive six month training period. Whilst they had a '*pretty formalized document*' to fill in, the bottom line for them was to be '*completely guided by what the patient says*'. As one assessor at this site phrased it: more important than the form is to let the patient '*just talk and talk or cry and cry*'.

## **5.2 Analysis of patients' stories**

The response to an opening question by the assessor such as '*What is your reason for coming here?*' usually resulted in patients taking the floor and telling long stories about their illness experience. In the evolving account, the initial problem cited often turned out not to be the main or only reason why the person was seeking help.

Once I realised that this was a recurrent way in which these consultations were being used, I decided that I wished to retain the integrity and individuality of patients' stories rather than apply cross-sectional thematic analysis to the dataset. So I decided to present the patients' accounts in a way that retains a sense of their whole story.

Following the tradition of other narrative analysts (refs) I developed a 'typology' of the stories told by patients in their holistic assessment sessions. This typology consists of three types of stories: factual, emotional and moral. Whilst I have identified three story types or levels there is inevitably overlap between the categories, with one type of story often merging into another.

Figure 1 shows these story types in diagrammatic form as concentric circles. The factual story resides in the middle ground of the patients' accounts, the emotional story is shown as a turning inwards to a more personal reflective account and then the outer layer represents the

face that patients are presenting to the world, the oughts and shoulds of how to behave in society or in the family as a sick person. The examples listed in the three boxes are all narrative types that occurred frequently across many transcripts. I also identified some over-arching themes that cut across the story levels. They are shown in the cloud bubble in Figure 1: a theme of '*loss*', a theme of '*duality and ambivalence*' and a theme of '*embracing or resisting change*'. Both the story categories and the over-arching themes emerged from the data rather than being used as *a priori* categories to steer the analysis. My aim is not to problematise any position taken by the patients but to further our understanding of their experience and how they present themselves in this particular help-seeking context.

**Figure 1: Typology of stories**

### **5.2.1 Factual stories**

Factual accounts generally involve a very detailed telling of symptoms, diagnosis and treatment or other themes, as shown in Figure 1, and are often characterized by long passages of monologue. Although the process of obtaining a diagnosis was often quite long and drawn-out, patients described how rapidly they then had to move on to treatment, often before there had been time to reflect on the process. The assessment is an opportunity to re-visit this story and try to make sense of the stages, seeking help to resolve the uncertainties. Some stories take the form of acts in a drama. Health professionals, family and friends all become actors in this drama.

For some patients the facts are dispensed with rapidly, in order to tell a deeper story. Others, particularly some of the male patients, stick to the factual story level for much of the assessment, possibly as a distancing technique, to avoid engagement with painful experiences and emotions. Many clues, however, are given during these accounts to the patients' underlying concerns and emotions, as shown in the examples below.

Below I give examples of some of the variety of 'factual' stories that I identified in the data.

- Life history stories
- Diagnosis stories
- Treatment stories

### **5.2.2 Emotional stories**

Some patients turn to their inner emotional story very quickly in the assessment, responding to the supportive and enabling consultation situation. For some this is evident in the overt expression of emotions such as tears, anxiety or anger, during the course of the assessment. For others the emotions are one stage removed, emotional states are described rather than expressed directly. In other cases, rather than explicitly articulating or expressing their emotions, they are implied and the whole interview can take on a particular emotional tone.

Examples of some of the variety of emotional stories that I identified in the data include:

- Conflicting emotions

- Dealing with a range of painful emotions
- ‘Abandonment’ experienced at the end of treatment
- Disbelief or acceptance of the diagnosis

### **5.2.3 Moral stories**

Moral stories are concerned with how ill people present themselves, how they want to be perceived or feel they ought to be perceived. about their disease’.<sup>289</sup> This can bring with it a sense of personal responsibility to show a ‘fighting spirit’ and beat the cancer, which may well be at odds with an individual’s emotional state and feelings.<sup>289</sup>

Examples of some of the variety of moral stories that I identified in the data include:

- Perceived pressure to ‘think positively’
- Taking personal responsibility for health
- Being strong for the family
- Legitimation of sick role and help-seeking

### **5.2.4 Over-arching themes**

I also identified a number of over-arching themes that emerged in patients’ stories that cut across all three story types and levels. The themes that I identified act as unifying concepts that draw together and summarise the experiences of patients, at whatever level they told their story. The themes also resonate with the findings from other studies of illness narratives.

#### ***Ambivalence and dualities***

It has been recognised and documented that the experience of cancer is fraught with uncertainties,<sup>4</sup> for example patients may experience uncertainty around the initial diagnosis and staging of disease, uncertainty about prognosis and about treatment expectations. Often, uncertainty may give rise to mixed emotions and ambivalent attitudes towards the illness and how to cope with it, sometimes representing apparently polarised options or dualities to be faced.

#### ***Loss***

Themes of loss, though not necessarily explicitly articulated, appear in many of the study patients’ narratives and at all levels of story telling, the factual, emotional and moral.

### ***Embracing or resisting change***

Two of the main thematic headings I developed while reading the transcripts were ‘Cancer as a life-changing event’ and ‘Hanging on to normality’ which seemed to summarise the contrasting positions that patients take up in their overall response to their disease: embracing or resisting the inevitable changes brought by a life-threatening illness.

In Appendix D I give two examples of patients’ stories that exemplify the analytic approach that I took.

### **5.3 Analysis of the process of holistic assessment**

The literature on medical and psychological consultations provides a potential source of explanatory models for the strategies that I observed in use by the assessors. ‘Six Category Intervention Analysis’ developed by the humanist psychologist John Heron in 1975 involves a simple but comprehensive model of the array of interventions, or verbal strategies, that a professional (doctor, counsellor or therapist) could use with their client.<sup>302</sup> I recognised each of the six types of intervention described by Heron, since they all appeared in the holistic assessment sessions.

The interventions fall into one of six categories. Heron labels the first three as ‘*authoritative*’ since the practitioner is taking a more overtly dominant or assertive role. The emphasis of the definition is on what the practitioner is doing:

- (i) **Prescriptive:** giving advice or instructions, being directive
- (ii) **Informative:** imparting new knowledge, instructing or interpreting
- (iii) **Confronting:** giving direct feedback within a caring context

The second set of three are labelled as ‘*facilitative*’ since the role of the practitioner is less obtrusive and more discrete, seeking to elicit some state of being in the client. The emphasis of the definition is on the effect of the intervention on the client:

- (iv) **Cathartic:** seeking to release emotion
- (v) **Catalytic:** encouraging the patient to be reflective, to discover and explore self-direction to carry beyond the practitioner-client situation
- (vi) **Supportive:** offering comfort and approval, affirming the patient’s intrinsic value

In summary, the facilitative interventions that aimed at providing empathy, support, encouraging patients to talk and express emotions were generally perceived by patients at both sites as beneficial. The more authoritative interventions were also generally regarded as helpful as a vehicle for providing advice and guidance about therapies and treatments to

patients who wanted or needed that. However, when the assessors became more directive or confronting with regard to patients' personal behaviour or emotions, then patient feedback was generally negative. Patients rarely arrived expecting or hoping to be confronted and they felt in some cases that such dialogue had not been handled sensitively. Some were critical of the skills level of the assessors in this respect. Clearly the nature and pacing of the various forms of intervention needs to be carefully monitored for each individual.

Assessors at both centres made use of the range of interventions discussed above, with perhaps a softer (i.e. more facilitative) style at centre one, and a more directive (authoritative) style at centre two. An overview of the data from the post-assessment interviews with patients confirms that there were mixed opinions about holistic assessment at both of the two centres, but the positive feedback outweighed the negative. The facilitative style was favoured overall by assessors at both centres and appreciated by the majority of the patients. A minority, however, at both centres, found the approach too nice. The style of information provision was generally received more positively at centre two, where it included a greater input of medical knowledge and a shorter overview of complementary therapies. Critical comments about holistic assessment sessions were made at interview by twelve of the twenty participants at site one, of whom four gave no positive feedback. Criticisms centred on a preference for direct access to therapists, in particular the in-house medical specialist. In addition, a minority did not find the emotional exploration and communication style helpful. This same criticism also appeared at site two. Here, all sixteen participants had positive comments to make about holistic assessment and half of the participants (eight) had no criticisms to make.

### **5.3.1 A model of patient – professional interaction**

This part of the analysis has a more theoretical aim: to consider whether holistic assessment can be positioned along a spectrum of health care consultation styles that has previously been described, and what contribution this study of holistic assessment might make to our understanding of consultation styles more broadly. In this section I present a model of the ways in which treatment decisions are made in holistic assessment which I hope will contribute towards the wider debates about the shifting power balance between patients and professionals in health care consultations.

#### **The model**

The four types of decision-making can be described as follows

- (i) **‘Advice: Assessor led decision’**
- (ii) **‘Confirmation: Joint decision’**
- (iii) **‘Access: Patient led decision’**

(iv) **‘Informed: Patient led decision’**

At first glance these types bear a superficial resemblance to the classic types of medical consultation that have been described previously, with the exception of the ‘Access’ type, which has no direct parallel. However, further analysis reveals that they all allow for a subtle level of patient empowerment that is not normally present in traditional consulting styles.

### **5.3.2 Patient empowerment, agency and trust**

Previous models of the consultation tend to describe a continuum of increasing patient involvement or power in the consultation from the paternalistic position where the professional (usually the doctor) holds the information and the power to make treatment decisions, through a model of shared decision-making to informed decision-making where the patient holds the information and the decision-making power. These models, however, only attempt to describe ideal types as markers along what is essentially a continuum, but the main point of interest lies in the shift in expectation that they represent in terms of the patient’s right to participate more actively in consultations and treatment decisions in modern day health care.

There is an implicit normative assumption that a greater degree of patient participation is a good thing, that access to information and decision-making power is generally sought by patients. The holistic assessment data from my two study sites suggests that, in this context at least, this is not necessarily the case. The situation appeared to be rather fluid, with patients and professionals casting themselves into different roles at different points in the assessment in terms of where the knowledge resided and how decisions were made.

The holistic assessment data call into question the usefulness of the rather ill-defined notion of patient empowerment: what does it mean and is it what patients really want? For example, the decision to approach one of the complementary therapy centres in my study is seen by the assessors as empowering for the patients in the sense that patients have chosen to take that step for themselves rather than being referred: a contrast to much of their mainstream care. There is also much in the literature to suggest that the decision to opt for complementary therapies is in itself experienced as empowering since the therapies tend to encourage self-help and do not carry the stigma of, say a psychological or social care referral.<sup>9-11</sup> The data presented in this chapter and the previous chapter, however, present an interesting paradox. It appears that the main reason why patients chose to attend these centres in this apparently empowering way is the opportunity they provide for them to reveal their distress, to ‘tell it how it really is’, to stop keeping up a brave front for a while: in short, to allow themselves to be vulnerable. Such a step is taken with the hope and trust that they will be met with a caring, skilful and knowledgeable response from the professionals. As shown in the previous chapter,

patients who tell their story in a non-judgemental setting may emerge with a clearer sense of their identity, hence empowering themselves by allowing themselves first of all to be vulnerable.

The patients' role in the assessment process can be understood through the concept of 'agency', a term that is used in sociological studies, and can be defined as '*purposeful action*'. It implies that actors (for example patients) have the freedom to create, change and influence events.<sup>311</sup> Early discussions of health and illness cast the sick person into a passive role in which their agency is limited to compliance,<sup>288</sup> but more recently there have been moves towards an expectation of more patient participation in treatment decisions and hence a more active role for the patient.<sup>178-180;190</sup> Complementary therapies have often been cited as an example of a medium through which patients are able to take an active role in their treatment,<sup>9-11</sup> in contrast to their traditionally more passive role in consultations with orthodox clinicians.<sup>190;262</sup> A recent focus group study with people belonging to cancer support groups looked at accounts of complementary and orthodox medicine from the point of view of the positioning of the patient concerning agency in treatment decisions. Whilst complementary therapies '*provided an opportunity for people to negotiate an active position in a limited domain of health care*', the other side to this was that '*the responsibility for health associated with taking active treatment decisions was problematic*'.<sup>290</sup>

Patients attending for an assessment at either of the two complementary therapy centres in this study are a good illustration of dealing with the dual nature of taking agency in treatment decisions; that is, the balance between the positive need to take some control set against the burden of taking responsibility for outcomes. These conflicting needs typify the patients in my study, who want to help themselves but may need advice and guidance on how to do so.

In order for patients to reveal their vulnerability and to negotiate a comfortable level of responsibility, patients must trust that the assessor can provide the right kind of support and care. The theme of trust also arises in respect to the provision of information and advice. In a previous study that I carried out it emerged that patients wanted information and advice from a trusted individual to help them to choose, appraise and access complementary therapies.<sup>37</sup> Transferring this to the assessment situation, it is important that patients can not only trust in the assessor's ability to care but can also trust in their knowledge base and have confidence in their advice. This is partly achieved by the patient choosing well-known and respected locally and nationally, and that specialises in cancer care, rather than approaching individual therapists in private practice. Patients said at interview that they felt they could trust the organisation and those who work there.

### **5.3.3 Decision-making about complementary therapies**

This study extends previous research into how people make decisions about complementary therapies. Most studies have tended to focus on how individuals make their decisions without the support of a knowledgeable professional. However, a previous study of men with cancer and their use of complementary therapies that I carried out, highlighted the need for a *'trusted individual'* to help in their decision-making process and showed how a family member or *'significant other'* might often take on this role.<sup>37</sup> In a recent qualitative study, Ohlen has explored the role of *'significant others'* from a patient's lay network.<sup>312</sup> They contribute to decision-making in several ways: creating a *'safe space'* for the patient to enable them to make a decision, making a collaborative decision by *'becoming a team'* or actually making the decision for the patient. This depends of course on the *'significant other'* *'holding the knowledge and experience of complementary therapies'*.<sup>312</sup> These roles mirror the kinds of roles taken on by the assessors in my present study, with a knowledgeable and trusted professional taking the part of the significant other. By using a professional rather than a lay supporter, it removes a possible source of tension for the patient, should their lay supporter hold different views from the patient as to the value of complementary therapies.

The role of the assessor in holistic assessment highlights the notion of *'relational autonomy'*, which describes the importance of relationship between individuals and the need for others to help in decision-making, as opposed to *'individual autonomy'* where no such help is required.<sup>313</sup>

### **5.4 Summary of findings**

Holistic assessment is a process that enables patients with cancer, at the two study centres, to discuss their supportive care needs with a qualified professional and to obtain at least some of their support through complementary therapies. Assessors at both centres described holistic assessment as a consultation that gives patients space to talk about their concerns and provides an opportunity for engaging in two-way information exchange, matching therapies to needs and building relationships between patients, individual assessors and the organisation.

By bringing multiple analytic perspectives to the observational data (analysis of patients' narratives, assessors' interventions and the interactive dialogue), I have been able to provide some detailed insights into the role and value of holistic assessment. The narrative analysis revealed the importance for patients of the opportunity to tell their story to a witness. This was perceived as therapeutic, and the value lay partly in the fact that the witness had no implicit agenda beyond supporting the patient. The narrative typology and over-arching themes that I developed showed how holistic assessment enabled patients to reach inside

themselves and talk about layers of their personal experience. A major theme was that of patients' exploring their sense of ambiguity about aspects of their experience. Many patients, for example, expressed ambivalence about revealing their vulnerability, and indeed their ambivalence about help-seeking at all, since they wished to retain a sense of personal strength. There was conflict between the moral imperative to appear positive and coping, and the reality of the pain being endured. I argued that by exploring these issues through narrative, in this case through a process of holistic assessment, patients were able to find some degree of resolution and clarity about their situation. As well as being therapeutic for the patients themselves, patients' narratives also provided an opportunity for the assessors to identify patients' needs, picking up on cues that could sometimes be quite subtle.

The analysis of the assessors' interventions shows how the telling of patients' stories was facilitated and guided by the assessors, in their attempt to create an environment that was supportive and yet provided more than simple empathetic listening. The techniques used by the assessors encouraged patients to open up to their emotions, share information and explore their concerns. Using Heron's model of '*Six Category Interventions*'<sup>302</sup> I showed how there was a fine balance to be achieved in the holistic assessment process between being assessor-led and patient-led. The role of assessors as both empathetic listeners and more directive agents revealed a duality that had to be skilfully negotiated.

The model of patient-professional interaction that I developed shows the shifting balance of power and responsibility between assessor and patient at different stages of the assessment. Both assessors and patients revealed themselves as the 'expert' at different times in the assessment in terms of their knowledge base in cancer treatment and complementary therapies. By breaking the assessment down into its component parts, I was able to demonstrate how patients were encouraged to feel personally empowered by the various processes of the assessment whilst at the same time enabling them to hand over some of the responsibility for making treatment decisions to a trusted individual (the assessor).

By inter-weaving data from patients' interviews into the analysis, it was possible to interpret the holistic assessment process in the light of patients' expectations and evaluations of the process. Instances of mismatches of expectations and reality were reported. For example, some participants did not have a clear idea of what holistic assessment would involve and were unprepared for the impact of revealing their inner story. Others did not understand the need for the assessment appointment and would have preferred direct access to the complementary therapists. Some participants had hoped for more of a counselling session, while others did not want a counselling approach. Mismatches of communication were also documented, as exemplified by instances where the balance between the assessor's facilitative and authoritative interventions felt uncomfortable for the patient. Occasionally patients

wished either for less empathy or for less challenge. Some participants at site one felt confused by being offered too many choices as regards complementary therapies, and felt that their individual preferences were not always respected. Some experienced this as information overload while others perceived it as a commercial promotion of the centre's services. Such negative instances are an important counter-balance to the broadly positive views of the process given by the majority of participants.

## **6. Discussion**

In routine health care, assessment is generally aimed at detecting patients' needs and facilitating access to appropriate resources. In the following sections I will consider how holistic assessment, as explored in the study centres of this project, functions in relation to these two objectives. I will also consider its intrinsic therapeutic value for patients.

### **6.1 Detecting patients' supportive care needs**

This study broadens our understanding of the concept of 'needs assessment' by showing how patients' needs may be revealed and explored by enabling patients to recount their personal stories. In this study, patients' stories provided a window on their illness experiences, highlighting issues to be considered in formulating an appropriate care plan. Holistic assessment differs from the more formalised psycho-social assessment tools and procedures favoured in mainstream care, which rely much more on a question and answer or tick-box self-report format, with little scope for the exploration of individual concerns. Holistic assessment sessions are also different from other mainstream consultations in that a longer time is available, enabling patients to give a fuller picture of their presenting needs rather than the snippets that might be revealed in a typical consultation in a mainstream health care setting. The present study confirms Greenhalgh's view that stories may uncover or precipitate diagnostic and therapeutic options, which provide a useful precursor to engagement in appropriate treatment or supportive care:

*'The narrative provides information that does not pertain simply or directly to the unfolding events... Narratives of illness provide a framework for approaching a patient's problems holistically'.<sup>187</sup>*

Feedback from participants suggested that an opportunity of this kind had not been available to them in their mainstream care. Neither had their needs been assessed by a more formalised procedure, suggesting that their concerns had remained hidden from their treatment team.

This study stresses the important role played by the assessors in listening and responding to the patients' stories. Assessors were able to manage the personal discomfort that such stories

might provoke, which is in contrast to the frequently reported problem in clinical consultations where both doctors and nurses may curtail or block attempts by patients to tell their stories, for fear of being drawn into their emotional concerns. As a result, the maintenance of a comfortable professional distance is usually preferred.<sup>45;314</sup>

The range of skills and ‘interventions’ used by assessors to encourage and guide the narratives were generally valued by patients. By listening and responding to a patient’s story the assessors were able to provide empathetic feedback and encourage further open-ness on the part of the patient, which would eventually form a basis for choosing an appropriate therapeutic approach.

## **6.2 Providing access to complementary therapies**

Much supportive cancer care, and particularly the provision of complementary therapies, takes place outside of mainstream health care. Previous research, both my own and that of others, has shown how access to complementary therapies can be problematic for some patients, partly due to the lack of easily available and trustworthy channels of information or advice.<sup>37;59</sup> This study suggests that the process of holistic assessment is a good example of a mechanism for providing access to such therapies, via information provision, appropriate application of therapies, quality control and gate-keeping. These are each explored in turn.

### ***Information provision, appropriate application of therapies and quality control***

This study shows that holistic assessment provides much more than simply information about therapies or contact details for individual therapists. Holistic assessment in the context of the organisations in which I observed it, also fulfils the important function of quality control. Patients do not have to decide for themselves whether or not a particular therapy is likely to be helpful or whether an individual therapist is suitably trained, qualified and experienced. The assessor can provide advice and reassurance about the appropriateness of individual therapies, and issues of credibility, reliability and safety are taken care of by the organisations, in their recruitment processes and clinical governance arrangements. This is important because some studies looking at patients’ decision-making about complementary therapies have shown how patients seek guidance, ideally from health professionals but, in their absence, from other trusted individuals, often within their lay networks, to help them make an informed and sensible decision.<sup>37;59;312</sup>

In the absence of a process such as holistic assessment, the issue of whom to turn to for advice about the trustworthiness or credibility of a therapy can be a problem for patients. They may find it particularly difficult to engage in a discussion about complementary therapies with their medical team, for fear of alienating them<sup>61;62;315;316</sup> and instead may look to friends and family, the media, books and articles and the internet for advice.<sup>37;59;110;111;310</sup>

Health professionals have raised concerns about patients, particularly those using information from the internet, being ‘duped by charlatans’, who may charge large amounts of money for ineffective and possibly harmful treatments, and who may discourage adherence to conventional treatment regimes.<sup>65:112</sup> Holistic assessment carried out by knowledgeable professionals, as in the study centres, provides a positive model of the way that health professionals in other settings could intervene in this process by providing information, advice and guidance.

Patients themselves may also share such concerns about the reliability and trustworthiness of complementary therapies. The process of holistic assessment at a reputable centre, such as those in this study, can help allay any such fears. At interview, patients at both sites signalled their trust in the respective organisations as being well-known and well-respected locally and/or nationally. At site one the kind of quality assurance mentioned by patients concerned the centre’s national reputation and its endorsement by key public figures, such as HRH the Prince of Wales. The fact that the centre operates as a commercial organisation did, however, temper the centre’s credibility and trustworthiness for some patients. For example, the data showed that some patients interpreted aspects of the assessment as a kind of commercial sales talk which led them to question the motives of the staff in recommending various therapies and products. At site two quality assurance for patients resided partly in the implicit endorsement given to the organisation by local NHS providers, since leaflets about the centre are given out routinely as part of the patient information pack at the oncology hospital. In addition, any prospective patient caring to visit the website of either organisation will be able to see the list of medical consultants on the board of each centre, conferring a sense of medical legitimacy.

### ***The ‘gate-keeping’ role of holistic assessment***

Whilst patients wanted to feel reassured that they were getting the right therapies, assessors also wanted to make sure they were helping the right patients. At both centres, some patients arrived with inappropriate expectations of what the organisation might offer, and in this respect holistic assessment played a gate-keeping or screening role. Assessors could monitor and control access to the resources that were available, by screening out inappropriate patients whose needs did not match the resources on offer, for example those with a diagnosis other than cancer, or those with a major mental health problem whose needs might be better met elsewhere. There were no examples of this kind of scenario during my fieldwork period. However, this was potentially an important issue, particularly at site one where patients might arrive from anywhere, with little idea about what to expect. At site two, since most patients arrived via the local oncology centre, often following a word-of-mouth recommendation from a member of NHS staff, less screening was necessary.

At both sites, assessors also had concerns about patients who arrived with the idea that ‘alternative’ cures might be available. Holistic assessment provided an opportunity to clarify the ‘complementary’ nature of the therapies and to discuss the likely benefits of the chosen therapies. In this respect holistic assessment played an important role in the management of patients’ expectations of any complementary treatments. The study adds to our understanding of why patients with cancer might decide to visit a centre of this kind, offering a holistic approach to care that includes complementary therapies. Some patients already had knowledge about complementary therapies and were looking to access therapies via a reputable organisation. Others were looking for advice and help for dealing with specific aspects of their disease and treatment side-effects. Many were initially less clear about their exact precipitating factors, describing a more general sense of feeling stuck or unable to cope on their own, wanting help to move forward. Patients such as these needed guidance from the assessors to help clarify their needs and to choose a course of therapy. Holistic assessment provided for them the first step in this process, with the hope and expectation of further support through complementary therapies. At interview, patients such as these recounted how useful the assessment had been in clarifying what they needed and how they had welcomed the advice and sense of direction that the assessors gave.

### ***Patient feedback***

As an efficient mechanism for accessing complementary therapies, patients’ opinions about holistic assessment were divided. Satisfaction was generally higher at site two, where information, advice and guidance about complementary therapies was particularly welcomed, while at site one many patients already had some experience of therapies and expressed frustration at not being able to access therapists directly. Many patients attending site one, experienced information-overload and would have preferred a short written synopsis of available therapies rather than a lengthy discussion. At site two, patients, who were generally responding to a leaflet from the hospital had less specific expectations of holistic assessment in terms of accessing any particular therapy and valued the chance to discuss options.

Patients at interview generally felt that their needs had been identified and there were no accounts of unvoiced agendas.<sup>254</sup> Certainly all patients who wished it were referred for treatment. At site one there was a greater variation in the take-up of therapies, a greater degree of switching between therapies and a higher rate of non-attendance than at site two (see Appendix C) which suggests that the assessment and matching had been less efficient. At site two, the majority of patients engaged with the chosen therapy for the full number of allocated sessions, suggesting that the assessment and matching process was more efficient in that setting. This may have been aided by the use of the MYCAW scale to focus on the patients’ main concerns and it may also have reflected the fact that the patients attending site

two were less experienced and knowledgeable about complementary therapies and were therefore more amenable to the matching process. However, further qualitative follow-up, outside the scope of this study, would be needed to investigate longer-term satisfaction with the process.

### **6.3 The therapeutic value to patients of the process of holistic assessment**

This study has shown that the value of holistic assessment goes beyond assessment and access to resources. Allowing patients the space to '*tell their story*' and '*construct meaning from it*' were seen as an important component of holistic assessment in an evaluation of the work of centre two.<sup>276</sup> This suggests that there is a deeper, therapeutic aim built into the process.

The idea that health care consultations might carry therapeutic value is not new, but has generally been associated with sessions of psychological therapies such as psychotherapy or counselling where the consultation is designed to be a therapeutic intervention. There has also been some recognition that the interactive process taking place in other medical consultations can, in itself, be valued by patients and does in fact form an important component of care. This has been noted in a distinction recently made between the '*clinical effectiveness*' and the '*interpersonal effectiveness*' of care.<sup>317</sup>

It is in the field of complementary therapy research that much has been written recently about the therapeutic importance of the consultation process.<sup>166;168;169</sup> Much of the observed effectiveness of complementary therapies has been ascribed to aspects of the professional/patient encounter, and it has been argued that this may not be specific to any particular therapy but may reflect the interpersonal skills of the therapist, regardless of their trade.<sup>168</sup> In other words, complementary therapists may, in general, simply be good communicators, and it has been documented that patients respond favourably to an empathetic consultational style, be it mainstream or complementary.<sup>163;318</sup> However, not all authors subscribe to this view. For example, the authors of a recent observational study of homeopathic consultations suggest that, in respect to homeopathy, there are other factors at work, beyond this kind of generalised consultational empathy. The homeopathic consultation, as shown in their study, is characterised by particular healing attributes that are co-constructed by both practitioner and patient, such as patients' open-ness to the mind-body connection, the opportunity for patients to express aspects of their inner experience in the voice of their '*lifeworld*', and the possibility of disclosing traumatic events.<sup>106</sup> Holistic assessment may be another example of a consultation in which the professionals (assessors) offer more than just consultational empathy.

### ***The importance of patients' stories***

The study highlights the importance of patients' narratives in providing information about their concerns and needs. In chapters five and six I discussed the ways in which patients were able to explore important personal issues, offload difficult emotions and experience some relief of tension. This supports Greenhalgh's notion that patients' narratives are '*intrinsically therapeutic or palliative*'.<sup>187</sup> The majority of patients welcomed the opportunity to tell their illness story, be it at a practical, emotional or moral level or indeed combining inter-twining threads of all these layers.

As well as furthering our understanding of the process of holistic assessment, the study contributes more widely to the genre of story-telling research. Major themes emerged from the data: themes of loss, duality and ambivalence, and embracing or resisting change. These aspects of patients' experience help us to understand the way in which patients manage the physical, emotional and epistemological shifts of the cancer journey. Such themes have been written about before<sup>188:285:292</sup> but what is new in the present study is hearing them in the context of consultations taking place with health professionals, rather than in research interviews or in published auto-biographies.<sup>319-322</sup> The study also suggests that telling one's story in a holistic assessment session, for example, may be therapeutic only because it is being heard by a skilled professional, with a guarantee of confidentiality, and in the hope and expectation that further help or support will be forthcoming. This fits in with Hyden's idea that the power of a story is partly in the context of its telling,<sup>283</sup> the context in this case being a centre providing complementary therapies.

Story-telling can be seen as a powerful way of introducing the patient's perspective into the research agenda. Greenhalgh supports the use of narratives in research, in order to '*help set a patient centred agenda ... challenge received wisdom ... and generate new hypotheses*'.<sup>187</sup> Within the research literature, the narrative approach to illness experiences has tended to focus on chronic disabling conditions such as stroke,<sup>323</sup> chronic pain,<sup>186</sup> diabetes,<sup>324</sup> allergies,<sup>325</sup> rheumatoid arthritis,<sup>224</sup> or multiple sclerosis.<sup>285</sup> Apart from Frank's work, few studies have explored the illness narratives of people with cancer, particularly in a help-seeking context: a gap that this study goes some way to filling.

### **6.4 A model of the holistic assessment process**

Building on the different analytic strands of the observational data, I sought to develop a model of the holistic assessment process that shows how each of the separate components, played out by the individual 'actors', come together. In the model that I present here, I show how holistic assessment has a dual role in the lives of people with cancer: '*Meaning-making*' and '*Decision-making*'. When patients tell their stories in holistic assessment sessions they

are actively seeking to find a meaning to their illness, a framework for the ordering of their experiences.<sup>285;326</sup> At the same time they are engaged in decision-making, seeking a way forward to help them in their process, by deciding on a course of complementary treatment. I explore each of these processes in turn and then show how they inter-weave to provide an outcome that is congruent with each individual's perceptions of themselves at a particular point in their cancer journey.

#### **6.4.1 The timing of holistic assessment: a 'decisive juncture'**

One of the characteristics of the two study centres that was prized by the assessors was that they each operate a policy of self-referral. Whilst patients attending the centres may have been influenced by the recommendation of a friend or family member, a leaflet from the cancer hospital or, in the case of centre two, the recommendation of their specialist nurse, nevertheless each individual made a personal decision to take that step at that time. Each patient had reached a point in their illness trajectory where they decided to seek help. It has been documented that there are key points in the 'cancer journey' where patients are likely to feel particularly vulnerable,<sup>6</sup> but help-seeking will be triggered not only by a particular phase of illness or treatment but also by the way in which the experience of that phase impacts on the individual. The impact of different aspects of illness will depend on the meaning that the individual associates with it, and this will tend to reflect their individual value system and life experience. The significance of the way in which an individual constructs meaning has been highlighted by Fife in her work on adaptation to life-threatening illness.<sup>327</sup>

With regard to the participants in the present study, Table 2 (in chapter 4) shows the length of time since diagnosis when they approached the two centres. Whilst there was a noticeable cluster of patients who were within six months of diagnosis, and another one year or more post-diagnosis, they were not characterised by any particular stage of disease progression. The early group included patients who had just been diagnosed, some who were receiving primary treatment and some who were close to death. Similarly in the later group there were some who were in remission and others who were receiving palliative care. Whatever the stage of illness, participants can be characterised as having reached a point where they chose to embrace a holistic approach to their care. The term '*decisive juncture*' has been coined in the mental health field to describe the timing of patients' decisions to opt for treatment.<sup>328;329</sup> This concept may be important in understanding the timing and value of holistic assessment in the lives of people with cancer. Patients coming to the study centres and engaging in the process of holistic assessment are ready to accept help to explore their illness experience in a way that is personally meaningful to them.

I have shown in this thesis that holistic assessment has a dual role. Firstly, it provides an opportunity to identify patients' needs and facilitate access to therapies, and secondly it is a therapeutic process for patients. Through the use of narrative, patients are able to explore the meaning associated with their illness and find a way forward, with the support of complementary therapies. A search for meaning has been described as a key response to a traumatic event, such as the diagnosis of a life-threatening disease.<sup>327</sup> Meaning has been defined as:

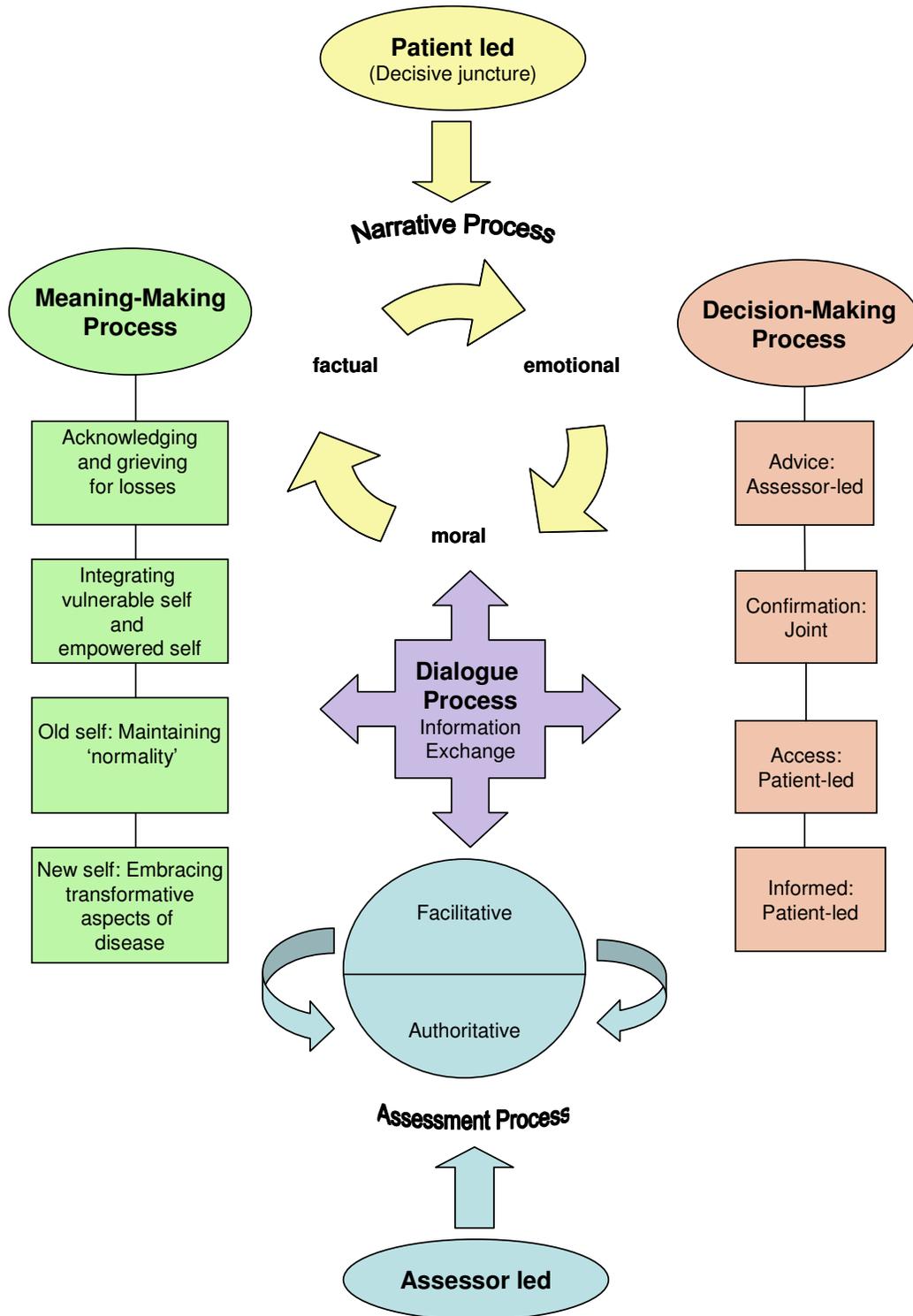
*'discovering a purpose to one's loss, or some positive explanation for occurrence of the negative event: it frequently includes finding an answer to the question, "why me?"'*<sup>327</sup>

The process of making meaning may be a fundamental part of adjusting to the reality of a life-threatening illness, one that can minimise the likelihood of serious psychological pathology.<sup>330</sup>

#### **6.4.2 Meaning-making and decision-making**

Figure 2 gives a graphical representation of the model of holistic assessment. The two outer columns represent the two parallel processes taking place in holistic assessment, which I have referred to as the 'Decision-Making Process' and the 'Meaning-Making Process'. The activities of the assessment are displayed in the central column, with the three elements of narrative, assessor interventions and dialogue. These three elements have been explored in earlier chapters and here I bring them together to show how each is dependent on the others. The contribution of the patient and the contribution of the assessor come together as shown by the central box that represents the dialogue between the two actors. There are arrows leaving the box in each direction, showing how the interactive dialogue supports all the processes of holistic assessment, none of which stand alone. The narrative process is led by the patient, whose illness story moves in a fluid way between different layers of their experience, while the assessor acts a witness. The assessor supports the story-telling process, using a combination of facilitative and authoritative techniques to guide the story and elicit or assess the patient's main concerns. Through the exchange of information about both the patients' experiences and about channels of support, in particular complementary therapies, the dialogue supports the patients' meaning-making and decision-making processes.

**Figure 2: A model of the holistic assessment process**



#### 6.4.2.1 Meaning-making

The meaning-making process is characterised by the themes that emerged in the analysis of patients' stories: 'loss', 'duality and ambivalence' and 'embracing or resisting change'. In figure 2, I have subsumed these themes into four conceptual categories of meaning-making. Dealing with loss remains as a key concept. The other themes relate to the impact of disease on perceptions of the self. The themes of 'duality' and 'ambivalence' are part of a process of 'integrating the vulnerable and the empowered self' while 'embracing or resisting change' is conceptualised as the desire either to return to the old' self or to move towards a new self. This fits in with the work of Brennan on patients' modes of adaptation to cancer in which he makes a distinction between '*coping*' and '*personal transition*'.<sup>330</sup>

#### *Acknowledging and grieving for losses*

The theme of loss echoes the work of Charmaz who broadened the concept of suffering beyond a focus on the physical, to include the '*multiple and spiralling*' losses associated with serious illness and the '*crumbling*' of an individual's self-image.<sup>292</sup> In holistic assessment one could observe some of the work of re-constructing the self in action.<sup>224</sup> For some patients it was the first time they had acknowledged and begun to grieve for their losses, taking a first step towards adjusting to their new reality. It enabled patients to name and begin to express unbearable emotions.

It has been suggested that the loss of a previously integrated view of the self can be repaired and that reflective story-telling can be conceptualised as an attempt to '*reconstitute and repair the ruptures between the body, self and world*'.<sup>224</sup> Williams' article on narrative re-construction highlights the inter-play between the physical, psychological and social aspects of the self. The telling of patients' stories on multiple levels in holistic assessment is a good illustration of the wide ramifications of the illness experience and the losses it involves. Bury has also stressed the importance of different levels of experience and suggests that patients' stories must go beyond the '*mundane aspects of experience*' in order to function as a vehicle for the '*repair and restoration of meaning*'.<sup>189</sup> This view developed largely as a reaction to an over-emphasis on the physical domain in the rather restricted medicalised understanding of suffering. However, it is important not to forget the physical or mundane aspects of experience. In the present study, while some patients in the study engaged in a psychologically or emotionally analytic way with their process of change, others told their illness story at a factual or mundane level, describing their adjustment process through the medium of bodily changes and disfigurement. Indeed other authors have argued for re-instating the importance of the physical and the mundane, since the '*physical aspects of living ... can be a prime focus for dealing with illness*'.<sup>331</sup>

### ***Integrating vulnerable self and empowered self.***

Much of the work of constructing meaning amongst study participants involved resolving some of the tensions implicit in their situation. This was particularly apparent in the need to integrate the vulnerable self and the empowered self. The decision to approach the complementary therapy centre was in itself triggered by both aspects of the self, accepting the need for help (i.e. the vulnerable self) whilst taking a positive step to get some help (i.e. the empowered self). Within the assessment, both in their narratives and in the decision-making process, patients were able to connect with their vulnerable self, letting go of the commonly accepted moral imperative to present themselves as thinking positive, 'coping well' or showing fighting spirit. They were at the same time able to engage with their competent or empowered self by choosing their preferred level of engagement with the discussion and decision about which therapies to adopt. In chapter five I showed how the decision-making process reflected the ways in which patients responded to the tension between agency and responsibility. I suggested that holistic assessment can encourage a sense of patient empowerment by allowing for a patient-centred agenda and decision-making but that not all patients wish to take up the opportunity to exercise agency, because of the notion of assumed responsibility for outcome. This resonates with Schwarz's concept of the '*paradox of choice*'.<sup>332</sup> The tension between agency and responsibility has been documented in other studies of patients' approaches to cancer care, both mainstream and complementary.<sup>290</sup>

### ***Concepts of self-hood: 'Old self' or 'New self'***

The process of meaning-making amongst study participants can be characterised by two opposing approaches: the desire to keep life as normal as possible and return to their old self or a willingness to embrace change and move towards a new self. Both these processes, the normative and the transformative, have previously been described in relation to the experience of cancer<sup>188,330</sup> and other life-threatening and chronic diseases.<sup>327</sup> They are sometimes referred to as 'adaptation' or 'adjustment' responses.<sup>330</sup>

The normative attitude (attempting to return to the old self) was exemplified in the present study by patients who struggled to keep their normal routine going, such as continuing to go to work, or to the gym, or to cover up the physical changes caused by the disease. The transformative approach (moving towards a new self) was shown in some patients' willingness to embrace new ways of living since their illness, exemplified by those who adopted a healthier diet, or decided to be more open and honest with friends or family, to change their work/life balance or to embrace a new spiritual dimension to their lives.

Patients who wish to normalise their illness experience illustrate Frank's notion of the '*Restitution*' narrative<sup>188</sup> and those who use illness as an opportunity for personal growth and

change fit with Frank's notion of the '*Quest narrative*'<sup>188</sup>. With regard to personal growth and change, much has been written about the transformative power of complementary therapies.<sup>98;333;334</sup> Holistic assessment may, in the context of the study sites, have provided a first step in some patients' engagement with a process of transformation. For many others, neither process was established. Frank's category of '*Chaos*' more aptly describes some patients' perceived predicament,<sup>188</sup> and holistic assessment was an opportunity to express this.

Brennan, working in the field of psycho-oncology, comments on how these '*adaptation responses*' take time.<sup>330</sup> As Fife also points out, meaning-making is a dynamic interpretive process,<sup>327</sup> and in holistic assessment we can but capture a point in time along the continuum of this process. Brennan talks about '*private reflection*' as a good adjustment strategy but suggests that it is likely to be more helpful if it is done with another person, to avoid a possible descent into unhelpful worry.<sup>330</sup> Holistic assessment provides patients with the empathetic support to articulate, understand and re-integrate recent events and feelings.

Another area of tension was evident in the way participants talked about their mainstream cancer treatment. The tension of continuing to adhere to invasive treatments which were both potentially curative yet brought pain and discomfort on a number of levels, was apparent in many of the patients' stories. Data from this study suggests that two different strategies were in evidence. Individuals who were working towards integrating a new sense of self were perhaps more able to accept and withstand treatment or were able to take a positive view of the lifestyle changes that their illness precipitated. Those who were more intent on normalising their experience and returning to their former self often struggled to come to terms with the painful reality of treatment, but did gain comfort from keeping up a semblance of normality in, for example, their appearance or the maintenance of regular activities.

#### **6.4.2.2 Decision-making**

In chapter six I developed a typology of decision-making as observed in holistic assessment. The four types now appear in the right hand column (Decision-Making Process) in figure 2. In chapter six I argued that they are subtly different from previously documented types of consultations taking place between health professionals (generally doctors) and their patients, since they all provide elements of patient empowerment. I re-considered the notion of patient empowerment and suggested that it reflects more than simply input into decision-making. Patient empowerment is enacted in holistic assessment by patients setting the agenda, feeling supported in both being strong and vulnerable and participating in discussion and decision-making at their chosen level of engagement. In the model in figure 2, the type of decision-making flows out of the meaning-making process, but not in a rigid way. There is not a simple one-to-one correspondence between meaning-making and decision-making strategies.

Integrating the vulnerable and the empowered self is played out in the discussion and decision-making in a variety of ways. Some patients, for example, may feel exposed and vulnerable having told their story and may wish to assert themselves by discussing self-help strategies and choosing therapies. Patients who are open to the transformative effects of their illness and are creating a new sense of self may take the lead in choosing therapies to support this process. Those who are seeking to return to their old self may defer to the assessor to help them choose therapies that are more focussed on relieving symptoms and treatment side-effects. In this way, the meaning-making, discussion and decision-making processes contribute to a coherent, patient-centred whole.

### **6.5 Variations on a theme of holistic assessment: differences between the two centres**

To a large extent, the data that I presented in the previous chapters were drawn from both centres equally and illustrated similar themes and processes taking place across both sites. Patients tended to present with similar kinds of concerns and to take the opportunity to tell their stories, be they at a practical, emotional or moral level. The meaning-making and decision-making processes were evident at both sites. However there were some differences between the centres in the discussion and decision-making aspects. At site one, the discussion about therapeutic options was generally in the vein of encouraging patients to take on board a broad holistic package, to include say bodywork, a mind-body therapy and a self-help approach such as nutrition that might, in combination, cover all aspects of their wellbeing: physical, emotional and spiritual. This partly reflects the fact that resource availability depended on the patients' ability to pay rather than an organisational quota system.

At site two, the outcome of the assessment was a course of sessions with, generally, a single therapist, to be reviewed after four sessions. As discussed in chapter four, this approach conforms to a brief intervention model of working and is in line with the organisation's commitment to providing a service that is free of charge to patients and also to distributing finite resources amongst as many patients as possible. The MYCAW scale was introduced towards the end of the assessment, to act as a focussing device to steer the choice of therapies. Patients were invite to write down their two main concerns and then to rate them, along with their general sense of wellbeing, on Likert scales. In my observations, the practical effect of this was that the holistic assessment acted as a kind of funnel or filter. At the start there was a wide open brief, where patients could pour in what they chose. This then became narrowed down to a specified set of measurable and achievable outcomes. It could be argued that, as a model of working, it is in effect reductionist rather than holistic. But in fact this approach, although it may appear to contradict an ideological commitment to holism may simply be a

comfortable and expedient outcome for both patients and professionals, given the limitations on resources.

The holistic approach was, however, maintained at centre two once the patient began to receive their therapy sessions. Even though a primary concern had been identified (be it, for example chemotherapy-induced nausea, sleeplessness or repetitive anxious thoughts), the chosen therapy would treat the whole person, since this is the nature of complementary therapy treatments and indeed the underlying philosophical principles on which their claims to efficacy are based.<sup>79:333;335</sup> The range of therapies and the training and experience of the therapists was broadly the same at both sites so whether a patient went on to receive one or several therapies, the approach of the therapists was similar at both sites.

## **6.6 Models of patient participation**

In this section I briefly consider the study findings in the light of the literature on patient participation in health care consultations more broadly.

I have suggested earlier in this thesis that one of the most important characteristics of holistic assessment is its patient-centredness, whereby the patient's rather than the clinician's concerns steer the agenda. Neither assessors nor patients took on the roles of the traditional paternalistic model which would put the patient in a passive position and the assessor as repository of all the information and decision-making power. Although a large number of participants opted for the Assessor-led decision, it was from the more active and engaged position of inviting the assessor to take on the role of '*agent*'.<sup>309:336</sup> In this model, the assessor holds the information about therapeutic options and their task is to ensure that they understand the patient's preferences, in order to decide on their behalf. It has been suggested by Gafni et al in a study of decision-making, that this model is not popular in medical consultations because it requires the clinician to elicit and interpret individual patients' preferences rather than simply transferring standardised information to enable the patient to decide.<sup>336</sup>

The 'informed' model in my typology has a near parallel in the classic joint decision-making seen in some doctor-patient consultations, but even here, the decision-making in holistic assessment was weighted more towards the patient's choice. This kind of scenario, more akin to the meeting of experts, has also been documented in other studies such as Belle Brown's study of breast cancer patients who showed a preference for a consultation in which knowledge about possible treatment issues resided equally in both parties, and patients were happy to take the lead in decision-making.<sup>161</sup> Patients like these were among the participants of my study, those who had a clear view on what treatment they wanted before coming for

their assessment and who were merely seeking confirmation of their choice or access to their preferred therapy.

This study shows that patients vary in the level of involvement that they want in different aspects of the consultation. This mirrors findings from studies of mainstream consultations and reveals the complexity of health care consultations and the subtle ways in which patient participation can be enacted.<sup>190;192;337</sup> Fallowfield, for example, has argued that taking an active part in consultations can help reduce patients' anxiety and depression.<sup>36</sup> However taking an active part does not necessarily equate with making a treatment decision. The important point for patients is feeling that they have been given adequate information so that they understand the decision being made.<sup>338</sup> Protheroe makes a similar distinction between patients wanting to '*have choice*' but not necessarily wanting to '*make a choice*'.<sup>337;339</sup> Echoing the findings of the present research, other studies have suggested that the degree to which patients want to be involved in discussion and decision-making may vary according to the nature and severity of their illness and how much responsibility they want to take on.<sup>192;337</sup> Some authors have recognised the need for a '*fine discrimination*' about patient preferences.<sup>192</sup> Greater participation can bring with it the burden of responsibility for outcome and some patients who are severely ill or anxious may prefer a more passive role.<sup>339</sup> In the present study, many patients preferred to trust the assessor to suggest the most appropriate option, rather than assume that responsibility.

This finding reminds us that, at a time when patient choice and participation in health care are actively encouraged and promoted, patients may also feel vulnerable and '*seek attachment figures to help them feel safe*'.<sup>340;341</sup> This is the other side of the coin in the holistic assessment sessions: patients welcomed the opportunity to express their vulnerability, their difficulties and their emotional distress. Burkitt Wright suggests that '*rather than being partners in care, patients need to feel safe in a caring relationship with a trusted expert*'.<sup>163</sup> Concepts of patient-centredness and patient empowerment must be broad enough to reflect the fact that patients need to be at times pro-active, at times vulnerable, to take the lead sometimes and at other times to defer to professionals.

## **7. Implications for mainstream cancer care**

In this section I re-visit the second aim of the study: 'To consider the transferability of holistic assessment to mainstream NHS cancer care settings', by considering the wider implications of the study for mainstream cancer policy and practice. This is followed by some recommendations for further research.

## 7.1 The 'holistic' model and the 'medical' model

I have described a participatory model of holistic assessment and shown how it operates in two organisations that offer a follow-up holistic package of care based in the provision of complementary therapies. The fact that a commitment to holism is embedded in the two study organisations raises questions as to whether such a process is indeed transferable to mainstream settings which are operating according to a different paradigm: the medical model. Complementary therapy centres, as compared to mainstream settings, are based on different principles and priorities that are likely to lead to different expectations on the part of both patients and professionals about what will happen and how it is appropriate to behave.

Complementary therapies are often characterised by their holistic approach to health and illness, an approach that is valued by therapists and patients alike.<sup>7;9;12;333</sup> The characteristics of holistic assessment that made it valuable and helpful for both patients and professionals may well reflect a consulting style that has more in common with complementary therapy consultations than it does with mainstream health care consultations. For example, some of the features of a holistic assessment appointment such as the extended consultation time, attention to the patient's personality and personal experience, patients' involvement in their own care, and the opportunity for help in making sense of their illness and treatment are also valued by patients attending complementary therapy consultations.<sup>166;167;169</sup> It may be, in fact, that the way in which holistic assessment is carried out is strongly influenced by the fact that it is embedded in an organisation offering follow-on complementary therapies. This may limit the potential transferability of holistic assessment into mainstream care unless it forms part of a wider package of holistic supportive care.

In mainstream health care consultations, the medical model means that individuals tend to conform to a traditional '*sick role*',<sup>288</sup> focussing on their symptoms and the physical aspects of their illness in the belief that this is what is expected of them. In contrast, at the study centres, individuals are encouraged to reflect on their experience and to take a part in developing a strategy for support, which would empower them to cope with their illness. They are being treated as 'people with an illness' rather than 'patients'.

Within mainstream consultations, doors may be opened for patients to discuss their factual stories but rarely their emotional or moral stories. Holistic assessment opens doors to all aspects of patients' experience and legitimates the telling of multi-layered stories. To achieve this in a mainstream setting would require a change in professional roles and identities in order to take on board the underlying principles of holistic care, in which support and quality of life take equal place beside curative treatment with its goal of increased survival.

The difficulties in transferring holistic assessment to mainstream settings may also resonate with a deeper philosophical question as to whether holistic assessment is conceptualised as the first step towards fixing a problem or as part of a process of personal transformation, perhaps supporting the patients through the kind of identity shifts that have been described for individuals coming to terms with the implications of the cancer journey.<sup>6</sup> The problem-solving approach may be more aligned with mainstream health care practice, and in this respect study site two represents something of a mid-way position with its emphasis on mainstream health professionals, mostly nurses, as assessors and the use of MYCAW to focus on specific concerns or problems. Nevertheless the patient-centred approach to the consultation at site two allowed for the same degree of narrative exploration as at site one, and assessors at both sites had the back-up of knowing that this therapeutic work would be continued during subsequent complementary therapy consultations.

Another issue that might be of concern to mainstream health professionals is whether or not the skills of the assessor and the process of assessment are robust enough to detect serious psychological pathology, enabling an appropriate referral to be made if necessary. There might be understandable concerns that such cases might slip through the net. Holistic assessment does not, for example, make use of any formal screening tools that might act as a safety-net. Whilst this might in practice be a potential limitation of holistic assessment, it reflects a fundamentally different perspective between the holistic model and the medical model. The holistic approach tends to normalise patients' experiences whilst within the medical approach there is a tendency to pathologise distress.<sup>354</sup> The approach to assessment in the study centres aims to provide support for any issues presented by the patient rather than looking for a clinical diagnosis. The issue of what constitutes the normal and the pathological is an important one, much debated within psychiatry,<sup>354</sup> and too wide-ranging a topic to explore here. However, whilst helping patients to accept that their experiences are normal, it is important that assessors are also on the alert for the kind of un-remitting distress that might need specialist psychological referral.

## **7.2 The transferability of holistic assessment**

Following the NICE recommendations for regular assessment of the supportive care needs of patients with cancer at regular points along their cancer journey,<sup>48</sup> it is worth speculating on how holistic assessment might operate in a mainstream setting. This study suggests that much of the value that patients ascribed to holistic assessment reflected the ways in which it differs from mainstream care. The length, manner and style of the assessment sessions provided a welcome contrast, for participants, to their NHS consultations. Patients generally rated the qualities and skills of the assessors highly, be they nurse trained or counselling trained. They appreciated their role as someone outside their medical team who was able to listen. An

important finding of this study, however, was that for most patients, empathy was not enough. Patients also wanted advice and guidance which they had not been able to find elsewhere. Some signalled this by referring to the limitations of their communication with the nurses in their NHS team, expressing their frustration that the nurses might provide a listening ear but had no resources on offer to actually help them.

The present study describes an approach to holistic assessment that is in sharp contrast to that proposed by mainstream organisations working within supportive cancer care. For example, the '*Holistic common assessment of supportive and palliative care needs for adults with cancer*' proposed by the Kings college research team, in response to the NICE recommendations,<sup>82</sup> seeks to be holistic by covering a broad range of specified domains, with ninety-four questions to be completed within thirty minutes. In contrast, holistic assessment as observed in the study centres, rather than seeking to cover a pre-conceived list of domains, puts the emphasis on the patients' agenda. An important finding of this study is that holistic assessment was not necessarily valued by participants because it was wide-ranging (i.e. covering specified domains) but because it focussed in on issues of importance to the individual. The observations revealed that when direct questioning was used by assessors it was not always welcomed, particularly if it was aimed at broadening the scope of the discussion. However, interventions used by assessors with the aim of deepening the discussion of an issue that had already been raised were more likely to be welcomed.

### **7.3 The 'who' and 'where' questions**

In considering which health professionals might be likely candidates for the role of assessors in mainstream cancer care, it is important to consider the necessary skills required for the role of assessor and the likely setting in which assessment might be carried out.

#### ***The skills base of the assessors***

The Kings College proposals made in response to the NICE guidance suggest that both the clinical nurse specialist (CNS) in the hospital setting and the general practitioner (GP) might be possible candidates for the role of assessor. However, holistic assessment could not be simply adopted in mainstream care without some kind of change in the professional culture of provider organisations. It might involve an expansion in the professional role of, say a doctor or nurse, to allow for the role of assessor, involving the acquisition of not only new skills but a new perspective. Encouraging patients to tell their inner stories and being able to respond appropriately may conflict with professional roles as they are currently established. However, the development of the clinical nurse specialists (CNS) in cancer care is one positive example of role expansion. CNS are expected to:

*'provide invaluable support and advice on social issues, finances, support networks available and other aspects of life that are affected by cancer'.<sup>355</sup>*

They are also expected to take on a role in psycho-social assessment. One NHS trust, for example, has suggested that:

*'at nurse-led clinics, the Clinical Nurse Specialist will carry out regular assessment of the physical, mental and social needs of patients and ensure that these are met'.<sup>356</sup>*

Further research is necessary to evaluate the role of the CNS and to explore the extent to which it the role might incorporate that of holistic assessor.

Authors such as Maguire have pointed out that both doctors and nurses have a tendency to engage in blocking behaviours that actively discourage patients from making disclosures, such as offering advice or reassurance before any problems have been identified, explaining away distress as normal, attending only to physical issues, switching the topic and jollyng patients along.<sup>314;357</sup> They may block patients from telling their stories by adopting a question and answer communication style or by allowing bureaucratic and administrative procedures to dominate their interaction.<sup>45</sup> Such blocking or '*distancing*' behaviour may reflect a fear of '*unleashing uncontrollable emotions*',<sup>45;156;357</sup> an anxiety about becoming too emotionally close to their patients, or a concern that they may not have anything to offer them. In the study sites, the assessors had the back-up of knowing that all their patients would be able to receive ongoing support from the team of complementary therapists. Assessors must therefore be equipped, at minimum, with appropriate levels of information and expertise to enable them to offer advice about ongoing support, be it access to complementary therapies, if available, or access to other local resources such as self-help groups, counselling sessions, or referral to more specialised services such as a psychologist or a nutritionist.

Health professionals may also feel that they lack personal and practical support from colleagues and supervisors to enable them to do this work, echoing the importance expressed by the assessors in the present study for the support of their professional team and institution. Support for assessors took the form of regular supervision, team meetings, a strong commitment to team working and informal opportunities to off-load with colleagues. On a positive note, the opportunity to carry out holistic assessment in mainstream care, particularly if it were coupled with some supportive care such as complementary therapies, might be rewarding for health professionals themselves. In an area of work where the professionals' primary tasks revolve around providing painful and distressing treatments, holistic assessment might deepen their relationship with their patients and give them something positive and supportive to offer.

### ***The importance of trust***

One interesting and somewhat paradoxical finding of this study was the importance of the role of a 'trusted' health professional with whom patients felt able to open up, tell their story and from whom they felt able to accept advice, a finding that concurs with my previous research.<sup>37</sup> The paradoxical element is the fact that the assessors were completely unknown to the patients before their holistic assessment, contact with them would inevitably be short-lived and yet they trusted them. Patients' trust was based on the legitimisation of the organisation, as discussed in chapter seven, the informal and friendly atmosphere at the two centres and the patient-centred consultation that holistic assessment offered them. One might hypothesise that it was the confidentiality and separation from their medical team that was important in enabling this trust, although patients at site two also valued the feedback that was transmitted to their mainstream clinicians. One can only speculate as to how the right kind of trusting relationship might develop in a mainstream setting. In theory such a relationship might already exist with a patient's GP or specialist nurse, and that could be developed. On the other hand it may be that some degree of separation from the clinical team is optimal.

### ***The role of primary care***

As mentioned in the literature review, the potential role of primary care in supporting patients with cancer has been recognised in several key Government policy documents, including the NICE guidance,<sup>48</sup> the Quality and Outcomes Framework (QOF) targets<sup>54</sup> and the Cancer Reform Strategy.<sup>49</sup> For example, the implementation of a six month post diagnosis follow-up appointment, as included in the QOF targets, could be a key opportunity for an assessment and supportive intervention by a member of the primary care team. The idea of primary care as an appropriate setting for psychosocial assessment, information provision and service delivery for cancer patients appears in other studies.<sup>164;358</sup> On the positive side, there are slightly fewer constraints in primary care than in oncology outpatients in terms of time or the need to provide complex treatments.<sup>164</sup> However this appointment would need to be more than a standard ten minute general practitioner consultation if patients' needs are to be fully explored. Plans would need to be put into place as to how long such an appointment should last, what the expected outcome might be and how continuity of care might be provided so that the patient is not simply given a one-off assessment and then abandoned. One model might be, for example, a series of shorter appointments rather than one lengthy session. However, the fragmentation that has taken place in primary care whereby continuity with a team has replaced continuity with an individual clinician, may mean that it is hard to build up sufficient depth of relationship to open the doors to patients' inner stories.

The present study certainly suggests that patients value assessors who have some expert knowledge, ideally clinical experience with cancer or complementary therapies, coupled with

highly developed interpersonal skills. As generalists working with a busy and wide-ranging caseload it may not be feasible for GPs to equip themselves with the specialist knowledge or skills necessary to carry out holistic assessment. Other candidates for the role of assessor might be practice nurses or nurse practitioners, with suitable training. Holistic assessment is, however, only likely to flourish in primary care if there is a suitable follow-on service available. There are some examples of such a service, though not in cancer care. For example, holistic assessment as a means of accessing a specific service via primary care (in this case for people with musculo-skeletal problems) has been piloted recently in Bristol and Bath. In both cases holistic assessment is followed by a service that provides a range of therapeutic options including complementary therapies<sup>359</sup>. The role of primary care professionals acting as '*referrals facilitators*' for designated support services has also been piloted for patients with psycho-social problems (but not, so far, with cancer).<sup>165</sup>

#### **7.4 The 'how' question**

The findings of the study suggest that holistic assessment works well as a relatively unstructured process. This is in sharp contrast to the recommendations of the Kings College report in which a highly structured tick-box approach is advocated.<sup>82</sup> Structured assessments using standardised tools may miss the crucial aspect of holistic assessment that gives it its value: the subjective story of patients' experiences. Standardised tools give an objective view of issues that can be conveniently categorised but not the inside story of how the individual patient is experiencing those issues. In order to do so, a number of conditions may need to be in place: a facilitative setting, un-interrupted time and individual assessors who are highly trained, skilled and knowledgeable.

A commitment to holistic assessment using either approach has resource implications, especially in order to adhere to the NICE proposal for regular assessment of all patients at all stages of the cancer journey.<sup>48</sup> There are a number of issues to be considered: the availability of professionals with the necessary time and skills to carry out assessments, the cost of training and the availability of resources for follow-on support. It may be more cost-effective to use holistic assessment as a targeted intervention to be available either by self-referral or by encouragement from health professionals, rather than available to all. This may also be more appropriate, given the findings of this study that patients are more likely to be receptive to help when they have reached a personal decisive juncture in their illness. In the study centres, the assessors stressed the motivational importance of patients themselves making the decision to attend. In order to encourage less articulate or less confident patients to come forward, holistic assessment could be offered in either primary care or secondary care as a targeted resource following identification of distress through the routine use of an ultra-short method

such as the '*Distress Thermometer*' which has been piloted recently in cancer care both in the USA and the UK.<sup>360-363</sup>

A return to a more holistic perspective in mainstream health care is likely to be important more generally, not just in cancer care, given the increasing survival of patients with long-term and chronic conditions. Holistic assessment is only likely to have a role in mainstream care if it forms part of a professionally led specialised '*holistic service*'. A model for how such a service might look is provided by the recent development of diabetes centres, such as the one set up by the Newcastle PCT.<sup>364</sup> Assessment, education, care and advice on self-management are all provided by a multi-professional team with links to primary and secondary care and the community.

In terms of location, it may be an advantage for holistic assessment to take place in a location that is separate from a cancer treatment centre, to enable patients to relax, open up and talk as freely as they did in the study centres, particularly if they need to offload, criticise or get support for difficulties they are encountering in their NHS treatment. This point was also highlighted in Mercer and Reilly's study of homeopathic consultations at an integrated complementary and orthodox medical care unit. Participants were positive about the close involvement of the facility with mainstream NHS care but preferred the less '*clinical*' feel to the physical environment.<sup>166</sup> In another study, Chatwin suggests that patients are more likely to feel at ease and talk more freely in a less institutional setting, where there are fewer bureaucratic structures and a greater sense of informality.<sup>299</sup> Within cancer care, a model of support has been developed in Maggie's centres that exist geographically close to but separate from cancer hospitals, where information, advice and psychological support are available on a drop-in basis.<sup>364</sup> These centres employ the specialist services of counsellors and psychologists but do not as yet embrace complementary therapies or holistic assessment.

## **7.5 Suggested ingredients of a 'good' holistic assessment**

Combining the results of the study and knowledge gained from the literature, I make some suggestions in this section for key points to be considered in the design of a holistic assessment service.

Thinking first of all about the setting, holistic assessment should ideally take place near to but not within hospital premises, or at a local primary health care centre. Assessors should be available for patients to access via both secondary care and primary care in order to help patients to manage the moves across the interface that inevitably take place through the cancer journey. Depending on the setting and the availability of staff, all patients could either be offered the opportunity for holistic assessment, to be taken up if they so wish. Leaflets advertising the service should be available routinely in primary and secondary care.

Alternatively, a brief assessment tool could be used to identify those patients in need of a full holistic assessment appointment, offered regularly in primary or secondary care. Holistic assessment should take place in an un-interrupted space, either as a single hour-long consultation or as a series of shorter appointments with the same assessor. The presence of a family member or supporter should not be encouraged but should be an available option if the patient chooses it.

Holistic assessment should be carried out with a trusted individual who is knowledgeable about available supportive care and resources, who could, for example be a member of nursing staff in either primary or secondary care, or the patient's general practitioner. Assessors need to have adequate training in communication skills and the use of therapeutic strategies. Holistic assessment should ideally be carried out by someone who is not part of the patient's immediate treatment team in case patients wish to reflect on any difficulties they are experiencing with regard to their treatment or their relationship with the clinical team. Communication with other members of the patient's care team is, however, important. A summary of the assessment should be written in medical notes or in letters sent to the medical team, or assessors should attend multi-disciplinary team meetings. Rather than being seen as a separate one-off process, holistic assessment of patients' support needs should be integrated into and underpin the clinical package of care.

Holistic assessment should ideally act as a precursor to or be part of ongoing support rather than just a one-off consultation, although the therapeutic value, for some patients, of a single consultation has been noted. Although there is a role for active listening alone, health professionals are unlikely to be committed to holistic assessment if they don't think they have anything to offer in response, an issue that receives scant attention in the NICE guidance and the Kings College proposals. Holistic assessment may need to be linked to the provision of a follow-on holistic intervention, or a range of interventions from which patients can make an informed choice, for example counselling, support groups and complementary therapies. Different outcomes will be appropriate for different people. Some will be looking for regular ongoing specialist support be it, for example, complementary therapies or psychological counselling. Others may benefit from a series of listening appointments. For others, it may be sufficient to provide information and sign-posting to available resources, which patients can then access by themselves.

In terms of information provision, clear written information should be made available to patients about the process of holistic assessment and subsequent therapeutic options that are available, prior to their appointment. An informative leaflet, such as 'What to expect on your visit for holistic assessment' could be included in an introductory information pack. Since the study has shown that the process and outcome of any holistic assessment will depend to some

extent on the prior knowledge, experience and expectations of the patient, the initial phase of the assessment should be concerned with exploring these issues and clarifying the aims of the session.

## **8. Recommendations for further research**

In order to assess the feasibility of transferring a model of holistic assessment, with or without follow-on complementary therapies, into mainstream care, an important initial step would be to investigate health professionals' attitudes in both primary and secondary care towards such a proposal. Using a grant from the South-West GP Trust, I have initiated a qualitative study interviewing key professionals in primary and secondary care. Interviews have been carried out by a researcher under my supervision, and I will take responsibility for data analysis.

In order to assess the feasibility of providing holistic assessment in mainstream care, I propose a pilot study for a trial of holistic assessment in a primary care setting, provided by a suitably trained professional (for example one of the nursing staff). One arm of the study could include in-house provision of complementary therapies since many practices have complementary practitioners on site. Another arm could include the provision of information and advice on self-care plus contact details for local support organisations. The trial should include cost-effectiveness.

Following the recommendation in the NICE guidelines that the needs of the whole family be included in supportive care strategies, I propose a qualitative study of the needs of carers and/or family members of a patient with cancer. This would complement and extend the work carried out by Soothill and others.<sup>365</sup>

I also propose an evaluation of the role of the Cancer Nurse Specialist in the light of the NICE recommendations for assessment and the findings of this study. This might involve an ethnographic approach including observations and interviews with nurses and patients.

## **9. Concluding comments**

This thesis provides a working example of a holistic approach to supportive cancer care. Two contrasting models of holistic assessment have been presented, but the similarities between the processes studied at the two centres outweighed their differences. In centre one the model of holistic assessment worked independently from the NHS while at centre two the same process worked equally well with closer links to mainstream care. The added value of the approach at centre two was the legitimisation that a close connection with NHS care conferred on the centre in the eyes of the patients who attended. At centre one, many patients were keen to have an appointment with the in-house doctor. This suggests that patients value the integration of the holistic and the medical models of care.

During my study of holistic assessment, the importance and depth of the process became apparent to me. As an observer I was witness to many personal stories of patients who were attempting to come to terms with a life-threatening illness and its treatment, and to deal with the consequences. The importance to patients of a context in which they could exert some control over the agenda and also express their vulnerability became clear.

Whilst holistic assessment is not necessarily linked to the delivery of complementary therapies, there are some examples of where a modified form of assessment with follow-on therapies have been successfully developed within mainstream cancer care. Whilst many hospital trusts offer some complementary therapy input from volunteer therapists, generally without holistic assessment, there are a few examples of a fuller, professionally led and run service. For example, the work at centre two from this study has recently expanded to include outreach into local hospital wards, chemotherapy and radiotherapy units. At a major London hospital, a similar process is in operation to support in-patients with cancer, sickle cell and thalassaemia.<sup>366</sup>

The challenge to mainstream care is to increase the commitment to supporting patients in a holistic way or to providing access to other organisations that can provide this kind of care.

## Appendix A: Study participants at site one

Study name	Marital status	Age	Occupation	Employment Status	Time since diagnosis	Cancer site	Stage of disease
Anna	Co-habiting	41	Meat-packer	Part-time	2.5 years / 4 months	Breast and ovarian	Mid chemo for second cancer
Martin	Married	50	Lorry-driver	Sick leave	2 months	Non-Hodgkins lymphoma	Pre-treatment
Peter	Married	49	Security porter	Sick leave	2 years	Prostate	Recurrence and pre-treatment
Helen	Married	54	Drama teacher	Sick leave	5 months	Breast	Post-op mid-chemo
Celia	Married	56	Dental nurse	Part-time	1 yr and 7 months	Breast plus lung secondaries	Recurrence mid-treatment (palliative only)
Simon	Married	32	RAF Engineer	Sick leave	7 months	Hodgkins lymphoma	Post treatment (remission)
Rosemary	Married	49	Secretary	Unemployed	4 years	Breast	Post treatment (remission)
Arthur	Married	64	Insurance assessor	Retired	4 months	Liver	Post treatment (terminal)
Jenny	Co-habiting	46	Designer	Sick leave	2 months	Breast	Post-op pre-radiotherapy
Pauline	Married	60	Teacher	Retired	One year	Ovarian	Post treatment (remission)
Karen	Co-habiting	43	Literature Development worker	Part-time	2 months	Breast	Post-op pre -chemo
Judith	Married	63	Teacher	Retired	3 months	Ovarian	Post-op mid-chemo
Patricia	Married	50	Teacher	Sick leave	3 months	Ovarian	Post-op mid-chemo
Anna	Married	63	University lecturer	Retired	2 years	Breast	Remission
Paula	Co-habiting	24	Arts producer	Part-time	3.5 years	Breast	Mid hormone treatment post-op
Louise	Married	43	Teacher	Sick leave	2 months	Breast	Mid pre-op chemo
Clive	Divorced	70	IT consultant	Retired	One year	Prostate	Post-op pre-radiotherapy
Linda	Married	57	Secretary	Sick leave	3.5 months	Lung lining	Mid-treatment (palliative only)
Dorothy	Widowed	75	Secretary	Retired	2 years 7 months	Ovarian	Recurrence and pre-treatment
Cynthia	Married	51	Designer	Part-time	One month	Breast	Pre-treatment



## Appendix B: Study participants at site two

Study name	Marital status	Age	Occupation	Employment Status	Time since diagnosis	Cancer site	Stage of disease
Susan	Married	53	Home Maker	Retired	1 yr and 7 months	Breast	Mid hormone treatment post-op post-chemo
Evelyn	Widowed	67	Legal secretary	Retired	3 months	Lung	Mid-treatment
Stephen	Single	56	IT Programmer	P/T	4 months	Non-Hodgkins lymphoma	Mid-treatment
Ruth	Widowed	82	Ex RAF wife	Retired	1 yr and 9 months	Sarcoma	Post-treatment
Marion	Single	61	NHS Manager	Retired	2 months	Endometrial	Post-op pre-radio
Sylvia	Married	32	Teacher	Full time work	3 weeks	Multiple myeloma	Post-diagnosis pre-treatment
Alan	Married	57	IT Manager	Sick leave	4 months	Oesophageal	Mid-treatment
Lesley	Married	47	Local Govt officer	Off sick	3 months	Breast	Post-op mid-chemo
Amanda	Single	60	Teacher	Retired	One month	Ovarian	Post-op mid-treatment
Sheila	Married	42	Commercial manager	Sick leave	11 months	Breast	Mid-treatment
Paula	Married	33	Senior Pensions Administrator	Sick leave	One year	Lachrymal gland	Post-treatment
Charles	Married	53	Businessman	Retired	6 weeks	Multiple myeloma	Pre-treatment
Jenny	Married	61	Accounts Office Manager	Sick leave	4.5 months	Breast	Post-op pre-chemo
Keith	Divorced	62	Plumber	Retired	One year	Lung	Post-treatment

## Appendix C: Patient trajectories

Code	Pathway to study centre	Previous experience of complementary therapies	Reason for coming	Therapies booked and received
1 / 1	Advert in local paper	None	Emotional support following diagnosis	Massage (1) Healing (1) Counselling (DNA)
1 / 2	Recommended by someone who worked there	Herbal remedies / Supplements	Curiosity / See what is available Information on diet and supplements	Massage (1)
1 / 3	Previous experience of the Centre	Reflexology / Reiki	Let out stress	Doctor (1) Self-help techniques (1) Art Therapy group
1 / 4	Previous experience of the Centre	Nutrition / Supplements Meditation / Massage	See the doctor Support through chemotherapy Support for daughter	Aromatherapy (1 & DNA) Self-help techniques (1 & DNA) Doctor (DNA) Residential course
1 / 5	Recommended by friend who had been there	Herbal remedies / Supplements Reflexology	Can't cope alone anymore	Nutrition (1) Doctor (2) Acupuncture (3 & DNA) Healing (4 & DNA)
1 / 6	Recommended by wife	None	Feel abandoned at the end of treatment Nutritional advice	Nutrition (DNA & 1)
1 / 7	Recommended by friend who had been there	Homeopathy / Massage Counselling / Supplements Reflexology / Reiki	Feel abandoned at the end of treatment Nutritional advice Massage for lymphoedema	Nutrition (1 & DNA) Aromatherapy (8) Reflexology (5) / Review
1 / 8	Persuaded by daughter	Reflexology	Family hope for better quality of life	Massage (1)

<b>Code</b>	<b>Pathway to study centre</b>	<b>Previous experience of complementary therapies</b>	<b>Reason for coming</b>	<b>Therapies booked and received</b>
1 / 9	General awareness	Homeopathy / Bowen technique Nutrition / Supplements Yoga / Reiki / Acupuncture / Chinese herbs / Massage / Reflexology	See the doctor Nutritional advice Back-up and reassurance for CAM use	Nutrition (1 & DNA) Doctor (DNA)
1 / 10	General awareness	Nutrition / Reflexology / Mindfulness	Post-treatment support Nutritional advice for ileostomy management	Doctor (1) Nutrition (1)
1 / 11	Word of mouth / Google	Homeopathy	Uncertain Curiosity / See what is available Help to manage fatigue	Doctor (DNA) Nutrition (DNA)
1 / 12	Recommended by friend who had been there	Reiki	Help to calm down Help with loss of confidence	Counselling (7) Healing (1) Review
1 / 13	Internet / Recommended by family member who had been there	Massage / Emotional work	Nutritional advice Self-help	Nutrition (1) Residential course
1 / 14	Previous experience of the Centre	Chi Gung / Meditation / Healing / Acupuncture / Counselling	Support for husband See if there are any new therapies	Nutrition (DNA)
1 / 15	Recommended by friend who had been there	Nutrition	Post-treatment support Fertility advice Relationship counselling	Counselling (1 & 5DNA) Massage (1) Aromatherapy (DNA)
1 / 16	General awareness Newspaper article / Internet	None	Sort out family issues Counselling Relaxation / poor sleep	Nutrition (1) Aromatherapy (1 & DNA) Counselling (1 & 4 DNA) Self-help techniques (DNA)

<b>Code</b>	<b>Pathway to study centre</b>	<b>Previous experience of complementary therapies</b>	<b>Reason for coming</b>	<b>Therapies booked and received</b>
1 / 17	Recommended by friend who had been there	Osteopathy / Chiropractic	Pre-treatment advice Dealing with side-effects of radiotherapy Dealing with fatigue	Doctor (1)
1 / 18	Recommended by friend who had been there	Reiki / Reflexology / Supplements	Dealing with fear and depression Counselling	Doctor (DNA) Nutrition (DNA) Healing (DNA)
1 / 19	General awareness / Newspaper article	Yoga /Supplements / Reflexology	Residential course wanted Nutritional advice	Healing (1) Nutrition (1)
1 / 20	Recommended by someone who worked there	Herbalist / Reiki / Nutrition / Massage / Kinesiology / Acupuncture / Essiac / Psychotherapy	Guidance for integrating CAM and conventional treatment	Nutrition (1) Healing (3) Doctor (2 & 2DNA)
2 / 1	University research study recommended	Acupuncture / Aromatherapy	Deal with hot flushes caused by Tamoxifen and Irimidex	Acupuncture (4)
2 / 3	Leaflet at hospital / Recommended by a patient who had been there	Reiki / Hypnotherapy / Reflexology	Someone to talk to Poor sleep / reluctance to take medication	Reiki (1) Hypnotherapy (1) Reflexology (3) Review
2 / 5	Recommended by specialist nurse at hospital	None	Help to get through chemotherapy Poor sleep	Healing/Physiotherapy (5) Review
2 / 6	Cancer Support Centre at the hospital / Recommended by a patient who had been there	Massage	Pain relief sought for neck and shoulder	Acupuncture (4) Review
2 / 7	Recommended by specialist nurse at hospital / Recommended by friend who had been there	None	Help with adjustment to diagnosis Anxiety management / Recurrent thoughts / Poor sleep	Aromatherapy (2) Hypnotherapy (4) Review

<b>Code</b>	<b>Pathway to study centre</b>	<b>Previous experience of complementary therapies</b>	<b>Reason for coming</b>	<b>Therapies booked and received</b>
2 / 8	Specialist nurse at hospital gave leaflet	Counselling	Curiosity / See what is available Relaxation	Herbalist (1) Reflexology (3) Review
2 / 9	Macmillan nurse gave leaflet Oncologist recommended for post-treatment recovery	None	Dealing with side-effects of chemotherapy Relaxation	Shiatsu (2)
2 / 10	Leaflet from hospital Recommended by work colleague whose wife had been there	None	Pain relief for anal fissure caused by chemotherapy	Reflexology (6) Review
2 / 11	MacMillan nurse / Specialist nurse / Chemotherapy nurse	Reflexology / Counselling	Help with adjustment to diagnosis	Counselling (4 & 1 DNA)
2 / 12	Advised by specialist nurse	Massage / Aromatherapy	Calm down / Reduce blood-pressure to prepare for reconstruction surgery	Acupuncture (4)
2 / 13	Leaflet from sister	None	Post-treatment support Deal with fear of recurrence	Counselling (4)
2 / 14	Information pack from doctor at hospital	Acupuncture	Curiosity / See what is available / Deal with back pain	Acupuncture (DNA) Discharge
2 / 15	Information pack from nurse at hospital / Recommended by a patient who had been there	Reiki / Aromatherapy / Indian Head Massage / Yoga / Shiatsu	Curiosity / See what is available	Shiatsu (3)
2 / 16	Persuaded by daughter who had leaflet from hospital	Massage	Headaches / Mobility problems	Massage (2)

## Appendix D: Two patients' stories

### Marion's story

Marion is a 61 year old woman, single and living alone. She had been diagnosed with endometrial uterine cancer two months before attending centre two. Within her assessment are some long monologues or narrative sections where she tells her story chronologically from first symptoms through to the present day. Although at first the cancer appeared to be early stage, tests following surgery revealed that the disease had spread, was more significant than at first anticipated and necessitated radiotherapy treatment.

### Structure

Like many stories I heard, Marion's account takes the form of a drama, with successive acts being played out. The other players in the drama are her doctors (consultant and GP) and her sisters who live a hundred miles away. In looking at the structure of the story, it is possible to distinguish Labov's six stages (ref). Marion opens with a brief summary (stage 1): here she indicates that the ensuing narrative will be both factual and emotional:

*I mean, I ... my symptoms only started in July and I, I think I've been on such a rollercoaster ...*

Orientation (stage 2): She has already oriented the listener in time and soon expands on the place, situation and participants as the story unfolds with visits to her GP, consultants and family. The complicating action (stage 3) or sequence of events are told clearly and chronologically as she takes us through tests, diagnosis and surgery. (See her factual story below). As Labov points out, the soul of the narrative is the evaluation (stage 4) where the teller indicates the significance or meaning of the events that have been described.<sup>281</sup> At this point Marion evaluates the impact of the diagnosis and staging of the disease and this leads her into the emotional story that deepens and extends the preceding factual account:

*And when I got the news on Monday night, I was at home. Well, I, I couldn't take it in, as you can imagine, because I was fully expecting good news and I was just hoping to put all of this behind me, because even ... I mean, endometrial cancer is one of the best ... if you're going to get a cancer, it's one of the best to get, and it's one of the, the easiest to treat, and certainly if it's you know, low grade and it's stage one, then you can forget about it. You're cured. So I was fully expecting that news and so that night, I just ... [sighs] [short pause][sniffing] Well, [sounding tearful] I was shocked. I just shook and shook and shook. [crying].*

The resolution section (stage 5) of Marion's story comes in her decision to seek help for her emotional state, choosing a path that avoided the use of medication:

*So I don't know, it's just ... I think it's just this huge period of adjustment. So that's what really brought me, because I was in such a distressed state that I, I certainly don't want to take sedation. I really don't, it's not the answer. It made me decide that I just wondered whether, you know, complementary therapies of one kind or another might be able to help me.*

Finally in the coda (stage 6) Marion moves outside her absorption in the narrative and returns rather self-consciously to the present:

*I don't know how I feel, I'm just rattling on here.....*

### **Content**

Marion's story is told from a perspective that deepens as the interview progresses. First she presents the 'story about the illness',<sup>283</sup> a story that corresponds with Robinson's 'medical' narrative<sup>285</sup> or Kleinman's 'first level of meaning'.<sup>186</sup> In my own schema I refer to this as the 'factual story' in which she recounts her initial symptoms and visits to the doctor. Soon, she moves into what I am calling the 'emotional story', which corresponds to the 'personal experience narrative'<sup>281;283;285</sup> and Kleinman's second level: the 'intimate meaning'.<sup>186</sup> She introduces it in this way:

*This just felt like a double crisis for the family. [short pause] And it's so ... I think it's just been, just this terrible black fog.*

Finally we hear the moral story. This gives us clues about the 'cultural meaning' of distress with its 'moral exemplars of how pain and loss should be borne', and corresponds to Kleinman's third level of meaning.<sup>186</sup> Part of Marion's response to her illness could be interpreted as culturally conditioned: a moral imperative, as an independent professional woman, to present herself as successful and not disturbed by personal problems or negative thoughts, thoughts that must be counterbalanced by positives:

*Because there are days, you know, when I've been having ... I mean, these thoughts haven't been with me you know, like this morning I'm feeling fine, at least I was, until I ... I was feeling fine, and I ... I mean, part of you says, you know, I mean, I've had a fantastic life, and I know I'm only sixty-one but I have had, you know, a superb life. Not one bit of it would I ever change at all. I've lived life. [short pause] [sighs] I think one of my hallmarks, you know, boundless enthusiasm, [sniffs] I just don't like having to think about, think about **me**, and this and [sighs] but however, I've had, I've had very positive thoughts as well as feeling very pessimistic.*

As we look in more detail at Marion's story, examples are given of the story types I have identified as emerging across my dataset, as outlined above and shown in figure 1. Marion's story is a good illustration of 'biographical disruption' a concept developed by the sociologist, Bury.<sup>286</sup> He describes how serious illness can dramatically cut across and disrupt an individual's anticipated life trajectory. He recognises the important psychological and social functions that patients' illness narratives can fulfil.<sup>286</sup> Like for many others, Marion's

illness came as a terrible shock, a 'bolt from the blue' at a time when she was preparing to enjoy her retirement from a demanding professional career. There are elements of a victim story here. Why me? Why now? The emotional tone of much of Marion's story is one of anger, sometimes implied and sometimes overtly expressed, as in this extract:

*I had a very senior job in the health service. I found it was, it was very stressful and, and I decided I wanted to retire because I just couldn't, I just didn't want that level of responsibility and the stress any more in my life, but it took me nearly two years to actually, to settle down and to really start to enjoy ... because I, I'm sort of used to going at, you know, a hundred and ten miles an hour all the time, so I suppose at the moment I'm pretty angry that I'm just now really enjoying my retirement. I know I work part time but that really stimulates my brain and I really enjoy it. I'm doing lots of interesting things, and then this has just come like a huge bombshell and my family are devastated.*

The drama of Marion's story is at times reminiscent of a horror story, as her narrative of initial optimism gradually gives way in stages to a new and horrifying reality, a process I have referred to as 'creeping diagnosis'. Shock, horror and disbelief permeate her story:

*I mean, I ... my symptoms only started in July and I, I think I've been on such a rollercoaster because all the initial sort of tests and investigations were very sort of, you know, suggested no particular problems. I started ... post-menopausal bleeding, so the minute I got my first symptom, off I went to my GP who you know, said, you know, look, 99.9% of people don't have problems, you know, so ... and then I went off and had some investigations and saw a consultant and even they were very borderline, but they decided to go ahead and do a hysteroscopy, which happened in August and, and that showed pre-cancerous cells and again, I was told you know, very tiny, you'll be, you'll be fine... The consultant said that, certainly before and afterwards the surgery, very straightforward, you know, nothing looks untoward at all ... And, and then he rang me up on the Monday night with the, with the news that it's just so much more advanced.*

A major theme in the story is having to cope with uncertainty. Some of the difficulties recounted in Marion's story revolve around the uncertainties that she is experiencing about diagnosis, treatment and prognosis. Whilst she has only recently been diagnosed and is at an early stage in her treatment, she is already haunted by fears of recurrence:

*I suppose, it's just, it's just coming to terms with this and I, I don't know, it's just the terrible thoughts going through my head. And it's the future that of course I just feel ... the uncertainty, it's just ... and the last thing, and this is the thing that really concerns me is becoming neurotic about my health. It worries me enormously because I, I think I've got quite a neurotic personality to begin with, but I'm not ... I don't focus on my health particularly. Well, I say I don't, I'm, I have really worked hard to become healthier and ... so I probably do think about my health but I don't, I don't sort of think about every ache and pain that I have, obviously. So I don't know, it's just ... I think it's just this huge period of adjustment.*

Marion's story is full of unresolved dualities and contradictions, which cause conflict and give rise to ambivalence about how to manage her emotions, her self-image, her family relationships and her need for support. This could be summarized by a description (mine) such as 'I am functioning but I am also falling apart'. She is a professional woman, recently retired from an NHS management post, where she had been in charge of a large staff team. A recurrent theme in her story is her feeling of losing control of her life. She wants to present herself as a competent person but this is in conflict with her need to also express her vulnerability and need for support. Here she is able to admit to her struggle which she rationalizes by conceptualizing her neediness as merely a temporary and passing phase.

*P: I'm fairly confident, you see, that ... well, I say I'm fairly confident, I'm not confident at all, if I'm honest, at the moment, but I, I feel the phase that I'm going through now will either begin to lift or it will begin to change. It, it has to. I, I can't live like this, and a lot of the time I'm relating very well to people. I'm functioning. I'm not, you know, I, I am functioning.*

*A: You're able to be rational, aren't you, most of the time?*

*P: Yeah, of course I am, most of the time. It's at night and in the middle of the night that I'm finding it the most difficult because I'm, I'm on my own and, and I can't start ringing people up and ... wouldn't dream of it. I ... so yes, I think I do need some help to get through this period but I, I'd quite like something that's going to also help me to look forward as well.*

This struggle between wanting to feel in control and yet wanting to acknowledge her vulnerability also plays itself out in her ambivalence about help-seeking. She describes how hard she finds it to allow herself to place any reliance on others and her ambivalence about drawing closer to her family.

*P: Both my sisters are in ... you know, they're younger than me and they've both got families. I, I think the thing that's really hit, I think [crying] upset me a lot is I have some lovely nieces and nephews and I'm not particularly close ... well, I am close to them, but geographically we're not close, [yes] but every one of my family have been in touch with me and, and I've got to say last week if one more of them had said to me I love you, auntie [crying] I'd have just screamed [sighs]. [short pause] [crying] I don't know why I'm crying, I really don't. Sorry, I've been using your tissues.*

*A: You carry on. You carry on ...*

*P: ... I didn't bring any at all.*

*A: ... there's plenty more where they came from.*

*P: I haven't really cried for a few days now. I thought I was really beginning to turn a corner. Oh. [sighs] So yes, I ... because I, I live alone, I'm finding it hard to be so reliant on other people. Once I start driving again, that'll get, that'll be fine, you know, I have to be ferried down here, off to the dentist tomorrow. It all takes up people's times, but I, I think it's been given, well, I know it's been given with, with loving care, so ... and I would do exactly the same for them.*

Marion ends her story on a note of gratitude. She is grateful for the opportunity to talk and she reflects on the importance of being able to explore and express her emotions in this setting which contrasts with feeling unable to do so with her family.

*P: It's been, been good to talk about it.*

*A: Yeah, yeah.*

*P: I can't [crying] do this to my family.*

*A: You want to protect them too much, don't you?*

*P: Yeah. [sniffs] I'm sure I'll be fine. I'm so. [crying]*

*A: That's okay. [short pause]*

*P: Fine. Thank you very much. It's really nice to meet you.*

Marion's experience of telling her story may have set her on the path described by Bury, whereby individuals facing the biographical disruption of illness '*reconstruct a coherent self in narrative*'.<sup>286</sup>

### ***Summary of Marion's story***

Marion's story is a good example of the range of emotions and the level of distress that can be experienced by someone facing a diagnosis of cancer, including shock, uncertainty, anxiety and anger. It also illustrates the conflicting needs to appear positive and yet acknowledge vulnerability. This has implications for patients' ability to seek and accept help at this difficult time, a process that, in Marion's case was facilitated by the exploration and discussion during the holistic assessment session, a process that she valued highly.

I now turn my attention to a second story, this one from a male patient who attended centre one.

#### **7.2.1 Martin's story**

Martin is a 50 year old long distance lorry driver who is married and had been diagnosed two months previously with non-Hodgkins lymphoma. His drama unfolds during some long monologues, in which the other key players are his doctors and his wife, who is chronically ill with a back problem. Like Marion, Martin experienced the difficulties of creeping diagnosis

but whereas Marion's experience was rapid, Martin's trajectory was much slower, with repeated visits to the doctor, tests and uncertainties until the final diagnosis eighteen months later.

### **Structure**

Martin's introduction is short, and indicates that the story will be factual:

*Well basically I've ... just a very brief medical history if I can be brief.*

The 'orientation' sets the scene by orienting us in time, place, situation and participants:

*I ended up about 18 months ago, I was at work, I was a long distance lorry driver, driving in Europe on tour, you know for like a music group, so I was away for a long time and I started to feel bad. I saw a doctor in Rome, told me to drink lots of water and eat fruit. I was then driving with another person from Rome to Oslo non stop ... when I got to Oslo I saw a doctor there.*

The complicating action or series of events is recounted with great attention to detail. It covers a long period of GP and hospital visits, tests and uncertain diagnoses.

*When I got to Oslo I saw a doctor there who then told me I had pneumonia, you know and 2 days previous I was told I had you know dehydration. So I went into hospital in Bristol and they treated the pneumonia... And they said okay off you go, but I still never felt right and I had these pains in my legs and it just kept recurring on and off and so I was having these blood tests and my blood tests were never right 18 months ago. You know and eventually you know I'd go to my GP, he would say well there's something wrong here you know just keep trying these tests maybe it's deep vein thrombosis, maybe it's this, maybe it's that and you know eventually I saw a rheumatologist who said I think it's an immune disorder, you'll probably have to take some pills but rather than just give you the pills we'll do an MRI. And when they did the MRI they then found that I had dark spots on the MRI which looked like myeloma. I then had a ... they then telephoned me while I was at work and she told me this, so I then came home and I saw the ... I went to the oncology, haematology department the next day and they did the bone marrow... But it then showed not myeloma but non-Hodgkins lymphoma, at a low grade but into the bone marrow which I think puts me at stage 4 automatically I think.*

Martin's 'evaluation' comes when he reflects on how fortuitous it was that the cancer was eventually detected, and then only because he made repeat visits to doctors about another unresolved, and possibly unrelated, complaint (leg pain):

*I really wouldn't have known, I would have just thought oh I just feel tired a bit, I'm getting old you know and maybe I'm a bit lazy as well and I've spent my time sat on my backside driving a truck, you know 10 hours a day for 5, 6 days a week sometimes. You know for god knows how many years and maybe I'm just too used to being on my backside and not really doing too much and you know I've just ... because I've ... I'd been feeling sort of slightly fatigued but not enough that you could say you know, you know really bad or anything ..... I just thought well I've got a bit lazy. Everybody else thought I was lazy as well ...*

The 'resolution' of this story comes as Martin describes how his tests have been referred to more senior doctors:

*They've got somebody ... they're certainly not clear which you know shows that it does seem to be quite complicated. And it's not just gone to an ordinary laboratory it's gone to a professor at F. [name of hospital]*

Martin does not conclude with a coda or return to the present, but instead he immediately launches into another story, this one about his wife's illness. After once more returning to his own story, to amplify it further, the assessor intervenes to guide him back to the present, by discussing which complementary therapies he wishes to consider.

### **Content**

Once more, dualities and contradictions appear in the story. There is much less of the 'emotional story' compared to Marion's. It is more of a 'factual story' that is very detailed. Rather than expressing overt emotions, he emphasizes his difficulties by re-telling the same scenes several times. This may be an attempt to engage the listener and make sure that his difficulties are heard. However, at the same time, the lack of emotional content serves to keep the listener at arm's length, and maybe serves to distance the teller himself from painful experiences and feelings. This duality finds expression in his ambivalence about help-seeking, a theme also noted in Marion's story.

*So it's not a case of you know I don't want to accept that I may not be able to look after myself and my wife, yeah if I can, I can you know. I don't really want to sort of call on help, you know while I sit on the sofa not feeling too bad with people running round doing things for me.... So I don't really want to do ... I want you know to get help when I really need it I guess, not start asking people to do this now when I could probably do it myself anyway.*

Another major duality that Martin explores in his story is a conflicting view of his medical team, some of whom he portrays as incompetent (for example, not paying sufficient attention to early symptoms) and others he has more confidence in as in these two quotes:

*... the consultant said well you look better, you've put on weight off you go. Didn't even give me another blood test.*

.....

*Yeah I'm actually ... you know I'm happy with the haematologist who's been treating me, you know I feel confident ... he's a decent enough chap to have to deal with.*

His contrasting experiences mean that he doesn't know how much he can hand over his care and trust his medical team. The effect on him has been to force a change from a person who had no interest in medical things to someone who now regularly checks up on his condition

and treatment protocols using the internet. In this way he has been gradually taking more control over his illness, as in this extract below:

*At that point I just thought ... you know I thought oh well I don't know anything about this ... But they don't explain anything to you, they don't say well you know you've got pneumonia that's why you're feeling like ... they did a lot of tests, they couldn't find out ... I was probably a typical chap, just didn't want to know anything about medical stuff, anything come on TV, newspapers, I'm not interested in medical things..... So that ... so I've sort of looked on the internet and seen what drugs aren't so bad and ones which may work, and I'm sure he mentioned some of them because he was looking at 2 types of chemotherapy. One was the more sort of tried and tested one over a longer period but quite a strong group of drugs or a more new ... it's just recently been accepted by the organisation called NICE. And just very recently in the last few months been recommended for first use with low grade non-Hodgkins lymphoma which normally before these ... this new drug it had only been recommended for high grade or low grade if it hadn't responded before.*

There is a 'moral story' embedded in Martin's account. To legitimate his having come to the centre to seek help, much of Martin's story is a description of how disabling he finds his condition, which is compounded by having to take care of his disabled wife. He lays his story out with all its difficulties, without feeling compelled to present a 'coping' face. However, near the end he begins to back off from the idea of help, minimizing his difficulties and referring to 'others' who might need help, but not himself, although not entirely closing the door to the possibility of requesting help in the future.

*A: So it might be worth thinking about like I say acupuncture or reflexology might.*

*P: I don't feel I need sort of counselling, I guess.*

*A: No. It's there.*

*P: It's ... you know, I can understand a lot of people would need it because you know, it's very sort of distressing. I haven't been greatly distressed by it really.*

*A: If you, if you decide, or if you change your mind, it's here, you can just phone up.*

*P: Yeah. Because you can never be completely sure about yourself really.*

*A: No. And it can be a long journey through a cancer.*

*P: Yeah. And you know, this is the easy bit really.*

*A: Well I don't know that it's easy, but it's ...*

*P: You know I'm past the shock.*

Martin ends his story by deciding to continue with self-help through information seeking. He decides to browse the bookshop shelves to look for reading material rather than engaging in any complementary therapies.

## Bibliography

- (1) Cancer Research UK. Statistical information team.  
<http://info.cancerresearchuk.org/cancerstats/>, accessed on June 1st 2008
- (2) Cancer Research UK.  
<http://info.cancerresearchuk.org/cancerstats/mortality/timetrends/>, accessed on June 1st 2008
- (3) Cancer Research UK. Archived news.  
[http://science.cancerresearchuk.org/news/archivednews/cancer\\_number1fear?version=1](http://science.cancerresearchuk.org/news/archivednews/cancer_number1fear?version=1), accessed on June 1st 2008
- (4) Brennan J. Cancer in context: a practical guide to supportive care. Oxford: Oxford University Press; 2004.
- (5) We are Macmillan. Cancer support.  
[http://www.macmillan.org.uk/Get\\_Support/Dealing\\_with\\_cancer/Dealing\\_with\\_cancer.aspx](http://www.macmillan.org.uk/Get_Support/Dealing_with_cancer/Dealing_with_cancer.aspx), accessed on June 1st 2008
- (6) Turton P, Cooke H. Meeting the needs of people with cancer for support and self-management. *Complementary Therapies in Nursing and Midwifery* 2000; 6(3):130-137.
- (7) Evans M, Shaw ARG, Sharp DJ, Thompson EA, Falk S, Turton P et al. Men with cancer: is their use of complementary and alternative medicine a response to needs unmet by conventional care? *European Journal of Cancer Care* 2007; 16:517-525.
- (8) Thorne S, Paterson B, Russell C, Schultz A. Complementary/alternative medicine in chronic illness as informed self-care decision making. *International Journal of Nursing Studies* 2002; 39:671-683.
- (9) Ritvo P, Irvine J, Katz J, Matthew A, Sacamano J. The patient's motivation in seeking complementary therapies. *Patient Education and Counseling* 1999; 38:161-165.
- (10) Sollner W, Maislinger S, DeVries A, Steixner E, Rumpold G, Lukas P. Use of complementary and alternative medicine by cancer patients is not associated with perceived distress or poor compliance with standard treatment but with active coping behaviour: a survey. *Cancer* 2000; 89(4):873-880.
- (11) Truant T, Botoroff JL. Decision making related to complementary therapies: a process of regaining control. *Patient Education and Counseling* 1999; 38:131-142.
- (12) Verhoef MJ, Balneaves L, Boon H, Vroegindewey A. Reasons for and characteristics associated with CAM use among adult cancer patients: A systematic review. *Integrative Cancer Therapies* 2005; 4(4):274-286.
- (13) Cheetham PJ, Le Monnier KJ, Brewster SF. Attitudes and use of alternative therapies in UK prostate cancer patients-isn't it time we were in the know? *Prostate cancer and prostatic diseases* 2001; 4:235-241.
- (14) Downer SM, Cody MM, McClusky P, Wilson PD, Arnott SL, Lister TA et al. Pursuit and practice of complementary therapies by cancer patients receiving conventional treatment. *British Medical Journal* 1994; 309:86-89.

- (15) Ernst E. Prevalence of use of complementary/alternative medicine: a systematic review. *Bulletin of the World Health Organisation* 2000; 78(2):252-257.
- (16) Harris P, Finlay IG, Cook A, Thomas KJ, Hood K. Complementary and alternative medicine use by patients with cancer in Wales: a cross sectional survey. *Complementary Therapies in Medicine* 2003; 11(249):253.
- (17) Molassiotis A, Fernandez-Ortega P, Pud D, Ozden G, Scott JA, Panteli V et al. Use of CAM in cancer patients: A European survey. *Annals of Oncology* 2005; 16:655-663.
- (18) Rees RW, Feigel I, Vickers A, Zollman C, McGurk R, Smith C. Prevalence of complementary therapy use by women with breast cancer: a population-based survey. *European Journal of Cancer* 2000; 36:1359-1364.
- (19) Sparber A, Bauer L, Curt G, Eisenberg D, Levin T, Parks S et al. Use of complementary medicine by adult patients participating in cancer clinical trials. *Oncology Nursing Forum* 27(4), 623-630. 2000.
- (20) Sparber A, Wootton JC. Surveys of Complementary and Alternative Medicine: Part II. Use of Alternative and Complementary Cancer Therapies. *The Journal of Alternative and Complementary Medicine* 2001; 7(3):281-287.
- (21) Wen K-Y, Gustafson DH. Need assessment for cancer patients and their families. *Health and Quality of Life Outcomes* 2004; 2:11.
- (22) Wright EP, Selby PJ, Gould A, Cull A. Detecting social problems in cancer patients. *Psycho-Oncology* 2001; 10:242-250.
- (23) Whelan TJ, Mohide EA, Willan AR, Arnold A, Tew M, Sellick S et al. The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. *Cancer* 1997; 80:1518-1524.
- (24) Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. *Cancer* 2000; 88:225-236.
- (25) Lintz K, Moynihan C, Stegina S, Norman A, Eeles R, Huddart R et al. Prostate cancer patients' support and psychological care needs: survey from a non-surgical oncology clinic. *Psycho-Oncology* 2003; 12:769-783.
- (26) Cowley S, Bergen A, Young K, Kavanagh A. A taxonomy of needs assessment, elicited from a multiple case study of community nursing education and practice. *Journal of Advanced Nursing* 2000; 31(1):126-134.
- (27) Heaven CM, Maguire P. The relationship between patients' concerns and psychological distress in a hospice setting. *Psycho-Oncology* 1998; 7:502-507.
- (28) Jacobsen PB. Screening for psychological distress in cancer. Patients: Challenges and opportunities. *Journal of Clinical Oncology* 2007; 25(29):4526-4527.
- (29) Ashbury FD, Findlay H, Reynolds B, McKerracher K. A Canadian Survey of Cancer Patients' Experiences: Are Their Needs Being Met? *Journal of Pain and Symptom Management* 1998; 16(5):298-306.

- (30) Stevenson C. Surveys in complementary therapies: assessing the needs of people with cancer [Review]. *Complementary Therapies in Nursing and Midwifery* 1995; 1(4):110-112.
- (31) Newell S, Sanson-Fisher RW, Girgis A, Bonaventura A. How well do medical oncologists' perceptions reflect their patients' reported physical and psychosocial problems. Data from a survey of five oncologists. *Cancer* 1998; 83:1640-1651.
- (32) Harrison J, Maguire P, Ibbotson T, Macleod R, Hopwood P. Concerns, confiding and psychiatric disorder in newly diagnosed cancer patients: a descriptive study. *Psycho-Oncology* 1994; 3:173-179.
- (33) Maguire P. Improving communication with cancer patients. *European Journal of Cancer* 1999; 35(10):1415-1422.
- (34) Sollner W, De Vries A, Steixner E, Lukas P, Sprinzi G, Maislinger S. How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counselling? *British Journal of Cancer* 2001; 84(2):179-185.
- (35) Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer* 2001; 84(8):1011-1015.
- (36) Fallowfield L. Psychosocial interventions in cancer. *British Medical Journal* 1995; 311:1316-1317.
- (37) Evans M, Shaw A, Thompson EA, Falk S, Turton P, Thompson T et al. Decisions to use complementary and alternative medicine (CAM) by male cancer patients: information-seeking roles and types of evidence used. *BMC Complementary and Alternative Medicine* 2007; 7:25.
- (38) Schofield PE, Butow PN. Towards better communication in cancer care: a framework for developing evidence-based interventions. *Patient Education and Counseling* 2004; 55:32-39.
- (39) Detmar SB, Aaronson NK, Wever LDV, Muller M, Schornagel JH. How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality-of-life issues. *Journal of Clinical Oncology* 2000; 18(18):3295-3301.
- (40) Detmar SB, Muller MJ, Wever LD, Schornagel JH, Aaronson NK. Patient-physician communication during outpatient palliative treatment visits. An observational study. *Journal of the American Medical Association* 2001; 285(10):1351-1357.
- (41) Heaven CM, Maguire P. Training hospice nurses to elicit patient concerns. *Journal of Advanced Nursing* 1996; 23:280-286.
- (42) Boyes A, Newell S, Girgis A, McElduff P, Sanson-Fisher R. Does routine assessment and real-time feedback improve cancer patients' psychosocial well-being? *European Journal of Cancer Care* 2006; 15:163-171.
- (43) Van der Kam WJ, Branger PJ, Van Bommel JH, Meyboom-de Jong B. Communication between physician and with patients suffering from breast cancer. *Family Practice* 1998; 15(5):415-419.

- (44) Ford S, Fallowfield L, Lewis S. Doctor-patient interactions in oncology. *Social Science & Medicine* 1996; 42(11):1511-1519.
- (45) Heaven CM, Maguire P. Disclosure of concerns by hospice patients and their identification by nurses. *Palliative Medicine* 1997; 11(4):283-290.
- (46) Calman K, Hine D. A policy framework for commissioning cancer services. 1995. Department of Health and the Welsh Office.
- (47) Department of Health. The NHS Cancer Plan. 2003. London, England, Department of Health.
- (48) National Institute for Clinical Excellence. Improving supportive and palliative care for adults with cancer - The manual. 2004. London, England, National Institute for Clinical Excellence.
- (49) Department of Health. Cancer Reform Strategy. 2007. NHS.
- (50) Lethborg CE, Kissane D, Burns WI, Snyder R. "Cast Adrift": The experience of completing treatment among women with early stage breast cancer. *Journal of Psychosocial Oncology* 2000; 18(4):73-90.
- (51) Shanfield SB. On surviving cancer: Psychological considerations. *Comprehensive Psychiatry* 1980; 21(2):128-134.
- (52) Maher EL. Anomic aspects of recovery from cancer. *Social Science & Medicine* 1982; 16:90-912.
- (53) Brown R, Butow MJ, Tattersall MHN. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. *British Journal of Cancer* 1999; 80(1/2):242-248.
- (54) Department of Health Quality and Outcomes Framework (QOF). <http://www.dh.gov.uk/en/Healthcare/Primarycare/Primarycarecontracting/QOF/index.htm>, accessed on June 1st 2008
- (55) Cancer Research UK. Cancer Research UK's strategy 2009-2014. 2009. London.
- (56) Boon H, Brown JB, Gavin A, Kennard MA, Stewart M. Breast cancer survivors' perceptions of complementary/alternative medicine (CAM): Making the decision to use or not to use. *Qualitative Health Research* 1999; 9(5):639-653.
- (57) Risberg T, Kassa S, Wist E, Melsom H. Why are Cancer Patients Using Non-proven Complementary Therapies? A Cross-sectional Multicentre Study in Norway. *European Journal of Cancer* 1997; 33(4):575-580.
- (58) Balneaves LG, Kristjanson LJ, Tataryn D. Beyond convention: describing complementary therapy use by women living with breast cancer. *Patient Education and Counseling* 1999; 38:143-153.
- (59) Longo DR. Understanding health information, communication, and information seeking of patients and consumers: a comprehensive and integrated model. *Health Expectations* 2005; 8:189-194.

- (60) Cornford CS, Cornford HM. I'm only here because of my family: a study of lay referral networks. *British Journal of General Practice* 1993; 49:617-620.
- (61) Tasaki K, Maskarinec G, Shumay DM, Tatsumura Y, Kakai H. Communication between physicians and cancer patients about complementary and alternative medicine: Exploring patients' perspectives. *Psycho-Oncology* 2002; 11:212-220.
- (62) Robinson A, McGrail MR. Disclosure of CAM use to medical practitioners: A review of qualitative and quantitative studies. *Complementary Therapies in Medicine* 2004; 12(2), 90-98.
- (63) Verhoef M, Mulkins A, Oneschuk D, Carlson L. Cancer patients' understanding of evidence. *Focus on Complementary and Alternative Therapies* 2004; 9 (1): 56.
- (64) Ernst E, Filshie J, Hardy J. Evidence-based complementary medicine for palliative cancer care: does it make sense? *Palliative Medicine* 2003; 17:704-707.
- (65) Ernst E. 'If it helps my patients...' Perspectives on complementary medicine. *Clinical Medicine* 2004; 4(3):242-243.
- (66) Pope C, Mays N. Qualitative methods in health research. In: Pope C, Mays N, editors. *Qualitative research in health care*. 3rd ed. London: BMJ Books; 2006.
- (67) Cambridge dictionaries online.  
<http://dictionary.cambridge.org/>, accessed on April 14th 2009
- (68) Daniel R. Holistic approaches to cancer: general principles and the assessment of the patient. In: Barraclough J, editor. *Integrated cancer care*. Oxford: Oxford University Press; 2001. 18-30.
- (69) World Health Organisation. Preamble to the Constitution of the World Health Organisation as adopted by the International Health Conference, New York, 19-22 June 1956 and entered into force on 7 April 1958.  
<http://www.who.int/about/definition/en/print.html>, accessed on June 1st 2008
- (70) Doyle D, Hanks G, Cherny N, Calman K. *Oxford textbook of palliative medicine*. 3rd ed. Oxford: Oxford University Press; 2009.
- (71) British Holistic Medical Association. Welcome to the British Holistic Medical Association.  
[www.bhma.org/new\\_site/index.php](http://www.bhma.org/new_site/index.php), accessed on June 1st 2008
- (72) Barraclough J. *Integrated cancer care*. Oxford: Oxford University Press; 2001.
- (73) National Council for hospice and specialist palliative care services. Definitions of supportive and palliative care. Briefing paper 11. 2002. London, NCHSPCS.
- (74) Jeffrey D. What do we mean by psychosocial care in palliative care? In: Lloyd-Williams M, editor. *Psychosocial issues in palliative care*. Oxford: Oxford University Press; 2003.
- (75) Barnes PM, Powell-Griner E, McFann K, Nahin RL. Complementary and alternative medicine use among adults: United States, 2002. *Seminars in integrative medicine* 2004; 2(2):54-71.

- (76) Astin JA. Why patients use alternative medicine. *Journal of the American Medical Association* 2009; 279(19):1548-1553.
- (77) Wyatt GK, Friedman LL, Given CW, Given BA, Christensen Beckrow K. Complementary therapy use among older cancer patients. *cancer practice* 2001; 7(3):136-144
- (78) British Medical Association: The professional association for doctors. [www.bma.org.uk](http://www.bma.org.uk), accessed on June 1st 2008
- (79) Zollman C, Vickers A. ABC of complementary medicine: What is complementary medicine? *BMJ* 1999; 319:693-696.
- (80) Select Committee of Science and Technology Scientific Report. Complementary and Alternative Medicine. House of Lords. 2000. London, UK Parliament.
- (81) Asadari-Lari M, Packham C, Gray D. Need for re-defining needs. *Health and Quality of Life Outcomes* 2003; 1(34).
- (82) Cancer Action Team. Holistic common assessment of supportive and palliative care needs for adults with cancer: Assessment guidance. Cancer Action Team. 2007. London.
- (83) Maggie's cancer caring centres. <http://www.maggiescentres.org/maggies/maggiescentres/home/home.html>, accessed on April 14th 2009
- (84) Kohn M. Complementary therapies in cancer care. 1999. Macmillan cancer relief.
- (85) The gold standards framework: a programme for community palliative care, <http://www.goldstandardsframework.nhs.uk/>, accessed on June 1st 2008
- (86) Cunningham AJ, Edmonds C, Phillips C, Soots KI, Hedley D., Lockwood GA. A prospective, longitudinal study of the relationship of psychological work to duration of survival in patients with metastatic cancer. *Psycho-oncology* 9, 323-339. 2000.
- (87) Gysels M, Higginson IJ. Improving supportive and palliative care for adults with cancer: Research evidence. 2004. London, National Institute for Clinical Excellence.
- (88) White P. Complementary medicine treatment of cancer: a survey of provision. *Complementary Therapy Medicine* 1998; 6(1):10-30.
- (89) Katz AE. Flavonoid and Botanical Approaches to Prostate Health. *The Journal of Alternative and Complementary Medicine* 2002; 8(6):813-821.
- (90) Wilkinson W, Gomella LG, Smith JA, Brawer MK, Dawson NA, Wajzman Z et al. Attitudes and use of complementary medicine in men with prostate cancer. *The Journal of Urology* 2002; 168:2505-2509.
- (91) Boon H, Stewart M, Kennard MA, Gray R, Sawka C, Brown JB et al. Use of complementary/alternative medicine by breast cancer survivors in Ontario: prevalence and perceptions. *Journal of Clinical Oncology* 2000; 18(13):2515-2521.

- (92) Cheetham PJ, Le Monnier KJ, Brewster SF. Attitudes and use of alternative therapies in UK prostate cancer patients-isn't it time we were in the know? *Prostate cancer and prostatic diseases* 2001; 4:235-241.
- (93) Richardson M, White JD. Complementary/Alternative Medicine and Cancer Research. A National Initiative. *cancer practice* 2000; 8(1):45-48.
- (94) Richardson MA, Sanders T, Palmer JL, Greisinger A, Singletary SE. Complementary/alternative medicine use in a comprehensive cancer centre and the implications for oncology. *Journal of Clinical Oncology* 2000; 18(13):2505-2014.
- (95) Montbriand MJ. Alternative therapies as control behaviours used by cancer patients. *Journal of Advanced Nursing* 1995; 22:646-654.
- (96) Moore RJ, Spiegel D. Uses of Guided Imagery for Pain Control by African-American and White Women with Metastatic Breast Cancer. *Integrative Medicine* 2000; 2(2/3):115-126.
- (97) Billhult A, Dahlberg K. A meaningful relief from suffering. Experiences of massage in cancer care. *Cancer Nursing* 2001; 24(3):180-184.
- (98) Mulkins AL, Verhoef MJ. Supporting the transformative process: Experiences of cancer patients receiving integrative care. *Integrative Cancer Therapies* 2004; 3:230.
- (99) Correa-Velez I, Clavarino A, Barnett AG, Eastwood H. Use of CAM and quality of life: changes at the end of life. *Palliative Medicine* 2003; 17:695-703.
- (100) Fellowes D, Barnes K, Wilkinson S. Aromatherapy and massage for symptom relief in patients with cancer: a systematic review. 2003. *The Cochrane Library*.
- (101) Wilkinson S, Barnes K, Storey L. Massage for symptom relief in patients with cancer: a systematic review. *Journal of Advanced Nursing* 2008; 63(5):430-439.
- (102) Fellowes D, Gambles M, Lockhart-Wood K, Wilkinson S. Reflexology for symptom relief in patients with cancer. 2003. Submitted to Cochrane.
- (103) Vickers A. Can acupuncture have specific effects on health? A systematic review of acupuncture antiemesis trials. *Journal of Royal Society of Medicine* 1996; 89:303-311.
- (104) Mackenzie MJ, Carlson LE, Munoz M, Specia M. A qualitative study of self-perceived effects of mindfulness-based stress reduction (MBSR) in a psychosocial oncology setting. *Stress and Health* 2007; 43(1):59-69.
- (105) Walker G, de Valois B, Davies R, Young T, Maher J. Ear acupuncture for hot flushes - The perceptions of women with breast cancer. *Complementary Therapies in Clinical Practice* 2007; 13(4):250-257.
- (106) Thompson TDB, Weiss M. Homeopathy - what are the active ingredients? An exploratory study using the UK Medical Research Council's framework for the evaluation of complex interventions. *BMC Complementary and Alternative Medicine* 2006; 6(37).
- (107) Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S, Rozmovits L. How the internet affects patients' experiences of cancer: a qualitative study. *British Medical Journal* 328(7439), 564-570. 2004.

- (108) Ziebland S. The importance of being expert: the quest for cancer information on the Internet. *Social Science and Medicine* 59(9), 1783-1793. 2004.
- (109) Wilson P. How to find the good and avoid the bad or ugly: a short guide to tools for rating quality of health information on the internet. *British Medical Journal* 2002; 324:598-602.
- (110) Pandolfini C, Bonati M. Follow-up of quality of public oriented health information on the world wide web: systematic re-evaluation. *British Medical Journal* 2002; 324:582-583.
- (111) Ernst E, Schmidt K. 'Alternative' cancer cures via the Internet? *British Journal of Cancer* 87, 479-480. 2002.
- (112) Schmidt K, Ernst E. Assessing websites on complementary and alternative medicine for cancer. *Annals of Oncology* 2004; 15:733-742.
- (113) Hanks GW, Robbins M, Sharp D, Forbes K, Done K, Peters TJ et al. The imPaCT study: a randomised controlled trial to evaluate a hospital palliative care team. *British Journal of Cancer* 2002; 87:733-739.
- (114) Smallwood C. The role of complementary and alternative medicine in the NHS. 2009. London, FreshMinds.
- (115) Jonas WB. The evidence house: how to build an inclusive base for complementary medicine. *Western Journal of Medicine* 2001; 175:79-80.
- (116) Thompson T, Feder G. Complementary therapies and the NHS. *British Medical Journal* 2005; 331:856-857.
- (117) Baum M. An open letter to the Prince of Wales: with respect, your highness, you've got it wrong. *BMJ* 2004; 329:118.
- (118) Baum M. May 2006: Doctors' campaign against alternative therapies. Re Use of 'alternative' medicine in NHS. *Times Online* 2006 May 23.
- (119) Shang A, Huwiler-Muntener K, Nartey M, Juni P, Dorig S, Sterne JA et al. Are the clinical effects of homeopathy placebo effects? Comparative study of placebo-controlled trials of homeopathy and allopathy. *The Lancet* 2005; 366(9487):726-732.
- (120) Lewith GT, Broomfield J, Prescott P. Complementary cancer care in Southampton: a survey of staff and patients. *Complementary Therapies in Medicine* 2002; 10(2):100-106.
- (121) Ben-Ayre EFM, Stashefsky-Margalit R. Approaching complementary and alternative medicine use in patients with cancer. *Journal of Ambulatory Care Management* 2003; 27(1):53-62.
- (122) Wilson K, Ganley A, Mackereth P, Rowswell V. Subsidized complementary therapies for staff and volunteers at a regional cancer centre: a formative study. *European Journal of Cancer* 2007; 16:291-299.
- (123) Tovey P, Broom A. Oncologists' and specialist cancer nurses' approaches to complementary and alternative medicine and their impact on patient action. *Social Science & Medicine* 2007; 64:2550-2564.

- (124) Department of Health. Building on the best: Choice, responsiveness and equity in the NHS. 2003. London, The Stationery Office.
- (125) Thomas KJ, Coleman P, Nicholl J. Trends in access to complementary or alternative medicine via primary care in England: 1995-2001. Results from a follow-up national survey. *Family Practice* 2003; 20:575-577.
- (126) Robotin MC, Penman AG. Integrating complementary therapies into mainstream cancer care: which way forward? *The Medical Journal of Australia* 2006; 185(7):377-379.
- (127) Botting DA, Cook R. Complementary medicine: Knowledge, use and attitudes of doctors. *Complementary Therapies in Nursing and Midwifery* 2000; 6(1):41-47.
- (128) Tavares M. National Guidelines for the use of complementary therapies in supportive and palliative care. 2003. London, England, The Prince of Wales's Foundation for Integrated Health.
- (129) Hughes S, Thomson A. Evaluation of the national guidelines for the use of complementary therapies in supportive and palliative care. 2005. London, The Prince of Wales's Foundation for Integrated Health.
- (130) Mackereth P. Complementary and alternative therapies in cancer care: greater evidence and greater organisation of provision. *European Journal of Oncology Nursing* 2004; 8(1):1-2.
- (131) Boon H, Verhoef M, O'Hara D, Findlay B. From parallel practice to integrative health care: a conceptual framework. *BMC Health Services Research* 2004; 4:15.
- (132) Fawzy FI. Psycho-social interventions for patients with cancer: What works and what doesn't. *European Journal of Cancer* 1999; 35(11):1559-1564.
- (133) Sheard T, Maguire P. The effect of psychological interventions on anxiety and depression in cancer patients: results of two meta-analyses. *British Journal of Cancer* 1999; 80:1770-1780.
- (134) Trijsberg R, van Knippenberg F, Rijpma S. Effects of psychological treatment on cancer patients: A critical review. *Psychosomatic Medicine* 1992; 54:489-517.
- (135) Bucher JA, Loscalzo M, Zabora J, Houts PS, Hooker C, Brintzenhofesoc K. Problem-solving cancer care education for patients and caregivers. *Cancer Practice* 2001; 9:66-70.
- (136) Newell SA, Sanson-Fisher R, Savolainen NJ. Systematic review of psychological therapies for cancer patients: Overview and recommendations for future research. *Journal of the National Cancer Institute* 2002; 94:558-584.
- (137) Docherty A. Experience, functions and benefits of a cancer support group. *Patient Education and Counselling* 2004; 55:87-93.
- (138) Campbell HS, Phaneuf MR, Deane K. Cancer peer support programs - how do they work? *Patient Education and Counseling* 2004; 55:3-15.

- (139) Davis C, Cohen R, Apolinsky F. Providing social support to cancer patients: A look at alternative methods. *Journal of Psychosocial Oncology* 23(1), 75-85. 2005.
- (140) McArdle JMC, George WD, McArdle CS, Smith DC, Moodie AR, Hughson AVM et al. Psychological support for patients undergoing breast cancer surgery: a randomised study. *British Medical Journal* 1996; 312:813-816.
- (141) Barker C. The value of home support for cancer patients. *Nursing Standard* 1997; 11:34-37.
- (142) Edelman S, Bell DR, Kidman AD. A group cognitive behaviour therapy programme with metastatic breast cancer patients. *Psycho-Oncology* 1999; 8:295-305.
- (143) Moorey S, Greer S, Bliss J, Law M. A comparison of adjuvant psychological therapy and supportive counselling in patients with cancer. *Psycho-Oncology* 1998; 7:218-228.
- (144) Sandgren AK, McCaul KD, King B. Telephone therapy for patients with breast cancer. *Oncology Nursing Forum* 2000; 27:683-688.
- (145) Cunningham AJ, Phillips C, Lockwood GA, Hedley DW, Edmonds CVI. Association of involvement in psychological self-regulation with longer survival in patients with metastatic cancer: An exploratory study. *Advances in Mind-Body Medicine* 2000; 16:276-294.
- (146) Cunningham AJ, Edmonds C, Phillips C, Soots KI, Hedley D., Lockwood GA. A prospective, longitudinal study of the relationship of psychological work to duration of survival in patients with metastatic cancer. *Psycho-Oncology* 9, 323-339. 2000.
- (147) Watson M, Homewood J, Haviland J, Bliss JM. Influence of psychological response on breast cancer survival: 10-year follow-up of a population-based cohort. *European Journal of Cancer* 2005; 41:1710-1714.
- (148) Kiecolt-Glaser JK, Glaser R. Psychoneuroimmunology and Cancer: Fact or fiction? *European Journal of Cancer* 1999; 35(11):1603-1607.
- (149) Ussher J, Kirsten L, Butow P, Sandoval M. What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science & Medicine* 2006; 62:2565-2576.
- (150) Arraras JI, Wright S, Greimel E, Holzner B, Kuljanic-Vlasic K, Velikova G et al. Development of a questionnaire to evaluate the information needs of cancer patients: the EORTC questionnaire. *Patient Education and Counseling* 2004; 54:235-241.
- (151) Richardson A, Sitzia J, Brown V, Medina J. Patients' needs assessment tools in cancer care: Principles and practice. 2005. London, King's College London.
- (152) Arora NK. Interacting with cancer patients: the significance of physicians' communication behaviour. *Social Science & Medicine* 2003; 57:791-806.
- (153) Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a cancer research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet* 2002; 359:650-656.

- (154) McWilliam CL, Brown JB, Stewart M. Breast cancer patients' experiences of patient-doctor communication: a working relationship. *Patient Education and Counseling* 2000; 39:191-204.
- (155) Detmar SB, Muller MJ, Wever LD, Schornagel JH, Aaronson NK. The patient-physician relationship. Patient-physician communication during outpatient palliative treatment visits: an observational study. *Journal of the American Medical Association* 285(10), 1351-1357. 2001.
- (156) Maguire P, Booth K, Elliott C, Jones B. Helping health professionals involved in cancer care acquire key interviewing skills-the impact of workshops. *European Journal of Cancer* 1996; 32A(9):1486-1489.
- (157) Rogers MS, Todd CJ. The 'right kind' of pain: talking about symptoms in outpatient oncology consultations. *Palliative Medicine* 14(4), 299-307. 2004.
- (158) Mishler EG. *The discourse of medicine. The dialectics of medical interviews.* Norwood, NJ: Ablex; 1984.
- (159) Barry CA, Stevenson FA, Britten N, Barber N, Bradley CP. Giving voice to the lifeworld. More human, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Social Science & Medicine* 2001; 53:487-505.
- (160) Launer J. Uniqueness and conformity. *QJM* 2003; 96:615-616.
- (161) Belle Brown JB, Stewart M, McWilliam C. Using the patient-centered method to achieve excellence in care for women with breast cancer. *Patient Education and Counseling* 1999; 38:121-129.
- (162) Fogarty LA, Curbow BA, Wingard JR, McDonnell K, Somerfield MR. Can 40 seconds of compassion reduce patient anxiety. *Journal of Clinical Oncology* 1999; 17(1):371-379.
- (163) Burkitt Wright E, Holcombe C, Salmon P. Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *British Medical Journal* 2004.
- (164) Pascoe SW, Neal RD, Allgar VL, Selby PJ, Wright EP. Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care. *Family Practice* 2004; 21(4):437-442.
- (165) Grant C, Goodenough T, Harvey I, Hine C. A randomised controlled trial and economic evaluation of a referrals facilitator between primary care and the voluntary sector. *British Medical Journal* 2000; 320:419-423.
- (166) Mercer SW, Reilly D. A qualitative study of patient's views on the consultation at the Glasgow Homoeopathic Hospital, an NHS integrative complementary and orthodox medical care unit. *Patient Education and Counseling* 2004; 53:13-18.
- (167) Luff D, Thomas KJ. "Getting somewhere", feeling cared for: patients' perspectives on complementary therapies in the NHS. *Complementary Therapies in Medicine* 2000; 8:253-259.
- (168) Steinsbekk A, Launso L. Empowering the cancer patient or controlling the tumor? A qualitative study of how cancer patients experience consultations with complementary

and alternative medicine practitioners and physicians, respectively. *Integrative Cancer Therapies* 2005; 4:195-200.

- (169) Mercer SW, Reilly D, Watt GC. The importance of empathy in the enablement of patients attending the Glasgow Homoeopathic Hospital. *British Journal of Cancer* 2002; 52:901-905.
- (170) Greenhalgh J, Meadows K. The effectiveness of the use of patient-based measures of health in routine practice in improving the process and outcomes of patient care: a literature review. *Journal of Evaluation in Clinical Practice* 1999; 5(4):401-416.
- (171) Willard LD. Needs and Medicine. *Journal of Medicine and Philosophy* 1982; 7:259-274.
- (172) McLachlan S-A, Allenby A, Matthews J, Wirth A, Kissane D, Bishop M et al. Randomized trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. *Journal of Clinical Oncology* 2001; 19:4117-4125.
- (173) Velikova G, Booth L, Smith AB, Brown PM, Lynch P, Brown J. Measuring quality of life in routine oncology practice improves communication and patient well-being: A randomised controlled trial. *Journal of Clinical Oncology* 2004; 22(4):714-724.
- (174) Detmar SB, Aaronson NK. Quality of life assessment in daily clinical oncology practice: a feasibility study. *European Journal of Cancer* 1998; 34(8):1181-1186.
- (175) Pruyn JFA, Heule-Dieleman HAG, Knegt PP, Mosterd FR, van Hest MAG, Sinnege HAM et al. On the enhancement of efficiency in care for cancer patients in outpatient clinics: an instrument to accelerate psychosocial screening and referral. *Patient Education and Counseling* 2004; 53:135-140.
- (176) Wells T, Falk S. The patients' written word: a simple communication aid. *Patient Education and Counseling* 2003; 54(197):200.
- (177) Maguire P, Faulkner A, Regnard C. Eliciting the current problems of the patient with cancer - a flow diagram. *Palliative Medicine* 1993; 7:151-156.
- (178) Department of Health. Patient and public involvement in the new NHS. NHS Executive, editor. 1999. Leeds, Department of Health.
- (179) Department of Health. The NHS Plan: A plan for investment, a plan for reform. NHS Executive, editor. 2000. London, Department of Health.
- (180) Jones IR, Berney L, Kelly M, Doyal L, Griffiths C, Feder G et al. Is patient involvement possible when decisions involve scarce resources? A qualitative study of decision-making in primary care. *Social Science & Medicine* 2004; 59:93-102.
- (181) Department of Health. Patient and public empowerment: Local involvement networks. [http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/DH\\_076366](http://www.dh.gov.uk/en/Managingyourorganisation/PatientAndPublicinvolvement/DH_076366), accessed on February 5th 2009.
- (182) Department of Health. Expert Patient programme. [Gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/ProgressOnPolicy/ProgressBrowsableDocument/DH\\_4102757](http://Gov.uk/en/Aboutus/MinistersandDepartmentLeaders/ChiefMedicalOfficer/ProgressOnPolicy/ProgressBrowsableDocument/DH_4102757), accessed on February 6th 2009

- (183) Wilkinson S, Kitinger C. Thinking differently about thinking positive: a discursive approach to cancer patients' talk. *Social Science & Medicine* 2000; 50(6):797-811.
- (184) Frank AW. Illness as moral occasion: restoring agency to ill people. *Health* 1997; 1(2):131-148.
- (185) Frank AW. Health stories as connectors and subjectifiers. *Health* 2006; 10:421-440.
- (186) Kleinman A. *The Illness Narratives: Suffering, healing and the human condition*. New York: Basic Books; 1988.
- (187) Greenhalgh T, Hurwitz B, Skultans V. Narrative based medicine: Why study narrative? *BMJ* 1999; 318:48-50.
- (188) Frank AW. *The Wounded Storyteller: Body, illness and ethics*. Chicago: University of Chicago Press; 1995.
- (189) Bury M. Illness narratives: fact or fiction? *Sociology of Health and Illness* 2001; 23(3):263-285.
- (190) Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? *BMJ* 1999; 319:780-782.
- (191) Wiles R, Higgins J. Doctor-patient relationship in the private sector: Patients' perceptions. *Sociology of Health and Illness* 1996; 18(3):341-356.
- (192) Coulter A. Paternalism or partnership? *British Medical Journal* 1999; 319:719-720.
- (193) Rycroft-Malone J, Latter S, Yerrell P, Shaw D. Consumerism in health care: the case of medical education. *Journal of Nursing Management* 2001; 9(4):221-230.
- (194) Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine* 1997; 44(5):681-692.
- (195) Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine* 1999; 49:651-661.
- (196) Snape D, Spencer L. The foundations of qualitative research. In: Ritchie J, Spencer L, editors. *Qualitative research practice*. London: Sage; 2003.
- (197) Denzin NK, Lincoln YS. Introduction: The discipline and practice of qualitative research. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research*. 2nd ed. London: Sage; 2000.
- (198) Strauss A, Corbin J. *Basics of qualitative research: techniques and procedures for developing grounded theory*. 2nd ed. London: Sage; 1998.
- (199) Jaye C. Doing qualitative research in general practice. *Family Practice* 2002; 19(5):557-562.
- (200) Morse JM. Interviewing the ill. In: Gubrium JF, Holstein JA, editors. *Handbook of Interview Research*. London: Sage; 2002. 317-328.
- (201) Geertz C. *Works and lives: The anthropologist as author*. Cambridge: Polity; 1988.

- (202) Geertz C. *Local knowledge: Further essays in interpretive anthropology*. London: Fontana; 1993.
- (203) Lincoln YS, Guba EG. Paradigmatic controversies, contradictions, and emerging confluences. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research*. 2nd ed. London: Sage; 2000.
- (204) Seale C. *The quality of qualitative research*. London: Sage; 1999.
- (205) Harding G, Gantley M. Qualitative methods: beyond the cookbook. *Family Practice* 1998; 15(1):76-79.
- (206) Bryman A, Burgess RG. *Developments in qualitative data analysis: an introduction. Analyzing qualitative data*. 1994. 1-17.
- (207) Malterud K. Qualitative research: standards, challenges, and guidelines. *The Lancet* 2001; 358:483-488.
- (208) Denzin NK, Lincoln YS. Entering the field of qualitative research. In: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research*. 1st ed. Thousand Oaks: Sage; 1994.
- (209) Neimeyer GJ. *Constructivist Assessment: A casebook*. Newbury Park: Sage; 1993.
- (210) Hammersley M. *What's wrong with ethnography?* London: Routledge; 1992.
- (211) Giddens A. *New rules of sociological method*. 2nd ed. Cambridge: Polity; 1993.
- (212) Schwandt TA. Three epistemological stances for qualitative inquiry. Interpretivism, Hermeneutics, and Social Constructionism. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research*. 2nd ed. Sage; 2000.
- (213) Hart C. *Doing a literature review*. London: Sage; 1998.
- (214) Silverman D. *Doing qualitative research*. London: Sage; 2000.
- (215) Blaikie N. *Approaches to social enquiry*. Cambridge: Polity; 1993.
- (216) Lincoln YS, Guba EG. Paradigmatic controversies, contradictions, and emerging confluences. In: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research*. 2nd ed. Thousand Oaks: Sage; 2000.
- (217) Yin RK. *Case study research*. 3rd ed. Thousand Oaks: Sage; 2003.
- (218) Stake RE. Case studies. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research*. 2nd ed. London: Sage; 2000.
- (219) Matza D. *Becoming Deviant*. Englewood Cliffs, NJ: Prentice Hall; 1969.
- (220) Hammersley M, Atkinson P. *Ethnography: principles in practice*. 3rd ed. Abingdon: Routledge; 2007.
- (221) Riessman CK. *Narrative analysis*. Thousand Oaks: Sage; 1993.
- (222) Tedlock B. Ethnography and ethnographic presentation. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research*. 2nd ed. Sage; 2000. 455-486.

- (223) Riessman CK. Analysis of personal narratives. In: Gubrium JF, Holstein JA, editors. *Handbook of Interview Research*. London: Sage; 2000.
- (224) Williams G. The genesis of chronic illness: Narrative re-construction. *Sociology of Health and Illness* 1984; 6(2):175-200.
- (225) Patton MQ. *Qualitative Research and Evaluation Methods*. 3rd ed. Thousand Oaks Sage: 2002.
- (226) Sutton RI, Staw BM. What theory is not. *Administrative Science Quarterly* 1995; 40:371-384.
- (227) Atkinson P. 2007. Personal Communication
- (228) Becker HS. *Tricks of the trade: How to think about your research while you're doing it*. Chicago: University of Chicago Press; 1998.
- (229) Blumer H. What is wrong with social theory? *American Sociological Review* 1954; 19:3-10.
- (230) Patton MQ. *Qualitative Research and Evaluation Methods*. 3rd ed. London: Sage; 2002.
- (231) Kubinyi H. Chance favors a prepared mind. *Journal of Receptor and Signal Transduction Research* 1991; 19(1/4):15-39.
- (232) Kronman J, Waldo Emerson R. Three unpublished lectures of Ralph Waldo Emerson. *The New England Quarterly* 1946; 19(1):98-110.
- (233) Malinowski B. *Argonauts of the Western Pacific*. London: Routledge and Kegan Paul; 1922.
- (234) Fetterman. *Ethnography step by step*. London: Sage; 1989.
- (235) Ragin C, Becker H. *What is a case?* New York: Cambridge University Press; 1992.
- (236) Feagin JR, Orum AM, Sjoberg G. *A case for the case study*. Chapel: University of North Carolina Press; 1991.
- (237) Simons H. *Towards a science of the singular*. 1980. Norwich, University of East Anglia, Centre for applied research in education.
- (238) Becker HS. Cases, causes, conjunctions, stories, and imagery. In: Ragin CC, Becker HS, editors. *What is a case? Exploring the foundations of social enquiry*. Cambridge: Cambridge University Press; 1992.
- (239) Marshall MN. Sampling for qualitative research. *Family Practice* 1996; 13(6):522-525.
- (240) Paterson C, Thomas K, Manasse A, Cooke H, Peace G. Measure yourself concerns and wellbeing (MYCaW): An individualised questionnaire for evaluating outcome in cancer support care that includes complementary therapies. *Complementary Therapies in Medicine* 2007; 15:38-45.
- (241) Greene JC, Caracelli VJ, Graham WF. Toward a conceptual framework for mixed-method evaluation designs. *Educational Evaluation and Policy Analysis* 1989; 11(3):255-274.

- (242) Pope C, Mays N. Observational methods. In: Pope C, Mays N, editors. *Qualitative research in health care*. London: BMJ Books; 2006.
- (243) Gold R. Roles in sociological fieldwork. *Social Forces* 1958; 36:217-223.
- (244) Junker B. *Field Work*. Chicago: Chicago University Press; 1960.
- (245) Anderson R, Crabtree B, Steele D, McDaniel R. Case study research: The view from complexity science. *Qualitative Health Research* 2005; 15:669-685.
- (246) Fontana A, Frey JH. Interviewing: The art of science. In: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research*. Thousand Oaks: Sage; 1994.
- (247) Warren CAB. Qualitative interviewing. In: Gubrium JF, Holstein JA, editors. *Handbook of interview research*. Thousand Oaks: Sage; 2001.
- (248) Merton RK, Fiske M, Kendall PL. *The focused interview: A manual of problems and procedures*. 2nd ed. New York: Free Press; 1990.
- (249) Rubin HJ, Rubin IS. *Qualitative interviewing: The art of hearing data*. Thousand Oaks: Sage; 1995.
- (250) Sturges JE, Hanrahan KJ. Comparing telephone and face-to-face qualitative interviewing: a research note. *Qualitative Research* 2004; 4(1):107-118.
- (251) Carr ECJ, Worth A. The use of the telephone interview for research. *NT research* 2001; 6(1):511-524.
- (252) Shuy RW. In-person versus telephone interviewing. In: Gubrium JF, Holstein JA, editors. *Handbook of interview research*. Thousand Oaks: Sage; 2001.
- (253) Evans M, Kessler D, Lewis G, Peters TJ, Sharp D. Assessing mental health in primary care using standardised scales: can it be carried out over the telephone? *Psychological Medicine* 2003; 34(1):157-162.
- (254) Barry C, Bradley CP, Britten N, Stevenson FA, Barber N. Patients' unvoiced agendas in general practice consultations: qualitative study. *British Medical Journal* 320, 1246-1250. 2000.
- (255) Kitzinger J. Qualitative research: Introducing focus groups. *BMJ* 1995; 311:299-302.
- (256) Barbour RS, Kitzinger J. *Developing focus group research: politics, theory and practice*. London: Sage; 1999.
- (257) Kreuger RA, Casey MA. *Focus groups*. 3rd ed. Thousand Oaks: Sage; 2000.
- (258) Evans M, Stoddart H, Condon L, Freeman E, Grizzel M, Mullen R. Parents' perspectives on the MMR immunisation. *British Journal of General Practice* 2001; 51:904-910.
- (259) Sternberg RJ, Horvath JA. *Tacit knowledge in professional practice*. Mahwah, NJ: Lawrence Erlbaum Associates; 1999.
- (260) Riessman CK. Strategic uses of narrative in the presentation of self and illness: A research note. *Social Science & Medicine* 1990; 30(11):1195-1200.

- (261) Heron J. Six Category Intervention Analysis. 1975. Guildford, Human Potential Research Project, University of Surrey.
- (262) Gask L, Usherwood T. ABC of psychological medicine: The consultation. *BMJ* 2002; 324:1567-1569.
- (263) Collins S, Britten N, Ruusuvaori J, Thompson A. Patient participation in health care consultations. Maidenhead: McGraw Hill; 2007.
- (264) Silverman D. Analyzing talk and text. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research*. 2nd ed. London: Sage; 2000. 821-834.
- (265) Katz J. A theory of qualitative methodology: The social system of analytic fieldwork. In: Emerson RM, editor. *Contemporary field research: A collection of readings*. Boston: Little, Brown; 1983.
- (266) Heidegger M. *Being and time*. 2nd ed. New York: Harper and Row; 1927.
- (267) Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S, Rozmovits L. How the internet affects patients' experience of cancer: a qualitative study. *British Medical Journal* 2004; 328:564.
- (268) Gee JP. A linguistic approach to narrative. *Journal of Narrative and Life History* 1991; 1(1):15-39.
- (269) Behar R. *Translated women: Crossing the border with Esperanza's story*. Boston: Beacon; 1993.
- (270) Mason J. *Qualitative researching*. 2nd ed. London: Sage; 2002.
- (271) Bertaux D, Bertaux-Wiame I. Life stories in the bakers' trade. In: Bertaux D, editor. *Biography and Society: The life history approach in the social sciences*. London: Sage; 1981.
- (272) Glaser BG, Strauss AL. *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine de Gruyter; 1967.
- (273) Gerson Institute. *Healing and preventing disease the natural way*. <http://www.gerson.org/>, accessed on January 15th 2009
- (274) Counselling and Psychotherapy Training Institute. *Brief Intervention Psychological Therapies Awards*. <http://www.cpti.info/pages/academic-psy-therapies.html>, accessed on April 16th 2009
- (275) Hughes P. 2007. Personal Communication
- (276) Peace G, Manasse A. The Cavendish Centre for integrated cancer care: assessment of patients' needs and responses. *Complementary Therapies in Medicine* 2002; 10(1):33-41.
- (277) Paterson C. Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey. *British Medical Journal* 1996; 312(7037):1016-1020.

- (278) Kirk P, Kirk I, Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *British Medical Bulletin* 2008; 328:1343.
- (279) Penny Brohn Cancer Care. Setting the standards in cancer care. <http://www.pennybrohncancercare.org/>, accessed on June 1st 2008
- (280) Burke K. Introduction: The five key terms of dramatisation. In: Burke K, editor. *A grammar of motives*. New York: Prentice-Hall; 1945.
- (281) Labov W. The transformation of experience in narrative syntax. In: Labov W, editor. *Language in the inner city: Studies in the Black English vernacular*. Philadelphia: University of Pennsylvania Press; 1972.
- (282) Paget MA. Experience and knowledge. *Human Studies* 1983; 6:67-90.
- (283) Hyden L-C. Illness and narrative. *Sociology of Health and Illness* 1997; 19(1):48-69.
- (284) Bury M. Illness narratives: fact or fiction? *Sociology of Health & Illness* 2001; 23(3):263-285.
- (285) Robinson I. Personal narratives, social careers and medical courses: Analysing life trajectories in autobiographies of people with multiple sclerosis. *Social Science & Medicine* 1990; 30(11):1173-1186.
- (286) Bury M. Chronic Illness as biographical disruption. *Sociology of Health and Illness* 1982; 4(2):167-182.
- (287) Maher EJ, Makin W. Life after cancer treatment - a spectrum of chronic survivorship conditions. *Clinical Oncology* 2007; 19:743-745.
- (288) Parsons T. *The social system*. London: Routledge and Kegan Paul; 1951.
- (289) De Raeve L. Positive thinking and moral oppression in cancer care. *European Journal of Cancer Care* 1997; 6:249-256.
- (290) Bishop FL, Yardley L. Constructing agency in treatment decisions: negotiating responsibility in cancer. *Health* 2004; 8(4):465-482.
- (291) Etherington K. *Becoming a reflexive researcher*. London: Jessica Kingsley; 2004.
- (292) Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness* 1983; 5(2):168-195.
- (293) Goffman E. *Presentation of self in everyday life*. New York: Doubleday; 1959.
- (294) Tritter JQ, Calnan M. Cancer as a chronic illness? Reconsidering categorization and exploring experience. *European Journal of Cancer Care* 2002; 11:161-165.
- (295) Kelleher D. *Diabetes*. London: Routledge; 1988.
- (296) Kahane DH. *No less a woman: Femininity, sexuality and breast cancer*. Alameda, CA: Hunter House; 1995.
- (297) Lapsley H, Barnett H, Clarke S. Journeys with young adult mental health consumers. *The Australian Community Psychologist* 2006; 18(3):19-25.

- (298) Heath C. The opening sequence in doctor-patient interaction. In: Atkinson P, Heath C, editors. *Medical work: Realities and routines*. Farnborough: Gower; 1981.
- (299) Chatwin J, Collins S, Watt I, Field R. A feeling of equality: Some interactional features that build rapport and mutuality in a therapeutic encounter. In: Collins S, Britten N, Ruusuvoori J, Thompson A, editors. *Patient participation in health care consultations*. UK: McGraw Hill; 2007.
- (300) Gafaranga J, Britten N. "Fire away": the opening sequence in general practice consultations. *Family Practice* 2003; 20(3):242-247.
- (301) Calgary Cambridge guide to the medical interview-communication process. [http://www.gp-training.net/training/communication\\_skills/calgary/guide.htm](http://www.gp-training.net/training/communication_skills/calgary/guide.htm), accessed on June 1st 2008
- (302) Heron J. *Six Category Intervention Analysis*. 1975. Guildford, Human Potential Research Project, University of Surrey.
- (303) Li S. 'Symbiotic niceness': constructing a therapeutic relationship in psychosocial palliative care. *Social Science & Medicine* 2004; 58:2571-2583.
- (304) Street A. *Nursing replay. Researching nursing culture together*. Melbourne: Churchill Livingstone; 1995.
- (305) Weiss M. The informed patient: friend or foe. *The Pharmaceutical Journal* 2007; 278:143-146.
- (306) Newman J, Vidler E. Discriminating customers, responsible patients, empowered users: Consumerism and the modernisation of health care. *Journal of Social Policy* 2006; 35(2):193-209.
- (307) Perakyla A, Ruusuvoori J. Components of participation in health care consultations. In: Collins S, Britten N, Ruusuvoori J, Thompson A, editors. *Patient participation in health care consultations*. Maidenhead: McGraw-Hill; 2007.
- (308) Kenny T, Wilson RG, Purves IN, Clark J, Newton LD, Newton DP et al. A PIL for every ill? Patient information leaflets (PILs): a review of past, present and future use. *Family Practice* 1998; 15(5):471-479.
- (309) Evans RG. *Strained Mercy: the economics of Canadian health care*. Toronto: Butterworths; 1984.
- (310) Ziebland S. The importance of being expert: the quest for cancer information on the Internet. *Social Science and Medicine* 59[9], 1783-1793. 2004.
- (311) Bilton T, Bonnett K, Lawson T, Skinner D, Stanworth M, Webster A. *Introductory sociology*. Basingstoke: Palgrave Macmillan; 2002.
- (312) Ohlen J, Balneaves LG, Bottorff JL, Brazier ASA. The influence of significant others in complementary and alternative medicine decisions by cancer patients. *Social Science & Medicine* 2006; 63:1625-1636.
- (313) Christman J. Relational autonomy, liberal individualism and the social constitution of selves. *Philosophical Studies* 2004; 117(1/2):143-164.

- (314) Wilkinson S. Factors which influence how nurses communicate with cancer patients. *Journal of Advanced Nursing* 1991; 16:677-688.
- (315) Sollner W. How to improve communication between physicians and cancer patients about use of complementary and alternative medicine? *Psycho-Oncology* 2003; 12:203-204.
- (316) Hann DM, Baker F, Denniston MM. Oncology professionals' communication with cancer patients about complementary therapy: a survey. *Complementary Therapies in Medicine* 2003; 11:184-190.
- (317) Campbell SM, Roland MO. Defining quality of care. *Social Science and Medicine* 200; 51:555-585.
- (318) Anfossi M, Numico G. Empathy in the doctor-patient relationship. *Journal of Clinical Oncology* 2004; 22(11):2258-2259.
- (319) Frank AW. *At the will of the body*. Boston: Mariner Books; 1991.
- (320) Gearin-Tosh M. *Living Proof*. London: Scribner; 2002.
- (321) Diamond J. *C because cowards get cancer too*. London: Random House; 1998.
- (322) Picardie R. *Before I say good-bye*. London: Penguin; 1998.
- (323) McCrum R. The night my life changed. In: Greenhalgh T, Hurwitz B, Aaronson NK, editors. *Narrative based medicine*. London: BMJ Books; 1998.
- (324) Goldie P. Narrative, emotion and understanding. In: Hurwitz B, Greenhalgh J, Skultans V, editors. *Narrative research in health and illness*. Oxford: Blackwell; 2004.
- (325) Lauritzen SO. Lay voices on allergic conditions in children: parents' narratives and the negotiation of a diagnosis. *Social Science & Medicine* 2004; 58:1299-1308.
- (326) Fitzpatrick R. Lay concepts of illness. In: Fitzpatrick R, Hinton J, Newman S, Scrambler G, Thompson J, editors. *The experience of illness*. London: Tavistock; 1984.
- (327) Fife B. The role of constructed meaning in adaptation to the onset of life-threatening illness. *Social Science & Medicine* 2005; 61:2132-2143.
- (328) Karp A. Taking anti-depressant medications: resistance, trial, commitment, conversion, disenchantment. *Qualitative sociology* 1993; 16(4):337-359.
- (329) Malpass A, Shaw A, Sharp D, Walter F, Feder G, Ridd M et al. "Medication career" or "Moral career"? The two sides of managing antidepressants: A meta-ethnography of patients' experience of antidepressants. *Social Science and Medicine* 2009; 68:154-168.
- (330) Brennan J. Adjustment to cancer - coping or personal transition? *Psycho-oncology* 2001; 10:1-18.
- (331) Kelly M, Field D. Medical sociology, chronic illness and the body. *Sociology of Health and Illness* 1996; 18(2):241-257.
- (332) Schwartz B. *The paradox of choice: why more is less*. New York: Harper Collins; 2004.

- (333) Koithan M, Verhoef M, Bell IR, White M, Mulkins A, Ritenbauch C. The process of whole person healing: "Unstuckness" and beyond. *The Journal of Alternative and Complementary Medicine* 2007; 13(6):659-668.
- (334) Canales MK, Geller BM. Surviving breast cancer. The role of complementary therapies. *Family and Community Health* 2003; 26(1):11-24.
- (335) Verhoef MJ, Casebeer AL, Hilsden RJ. Assessing efficacy of complementary medicine: Adding qualitative research methods to the "Gold Standard". *The Journal of Alternative and Complementary Medicine* 2002; 8(3):275-281.
- (336) Gafni A, Charles C, Whelan T. The physician-patient encounter: The physician as a perfect agent for the patient versus the informed treatment decision-making role. *Social Science & Medicine* 1998; 47(3):347-354.
- (337) Protheroe J, Bower P. Choosing, deciding, or participating: what do patients want in primary care? *British Journal of General Practice* 2008; 58:603-604.
- (338) Maguire P, Pitceathly C. Key communication skills and how to acquire them. *BMJ* 2002; 325:697-700.
- (339) Barnett J, Ogden J, Daniells E. The value of choice: a qualitative study. *British Journal of General Practice* 2008; 58:609-613.
- (340) Bowlby J. *The making and breaking of affectional bonds*. London: Routledge; 1998.
- (341) Salander P, Bergenheim T, Henrikssen R. The creation of protection and hope in patients with malignant brain tumours. *Social Science and Medicine* 1996; 42:985-996.
- (342) Arborelius E, Bremberg S. What can doctors do to achieve a successful consultation? Videotaped interviews analysed by the 'Consultation Map' method. *Family Practice* 1992; 9(1):61-67.
- (343) Thorsen H, Witt K, Hollnagel H, Malterud K. The purpose of the general practice consultation from the patient's perspective - theoretical aspects. *Family Practice* 2001; 18(6):638-643.
- (344) Wileman L, May C, Chew-Graham CA. Medically unexplained symptoms and the problem of power in the primary care consultation: a qualitative study. *Family Practice* 2002; 19(2):178-182.
- (345) Mays, Pope. Quality in qualitative health research. In: Mays N, Pope C, editors. *Qualitative research in health care*. London: BMJ Books; 2006.
- (346) Lincoln Y, Guba E. *Naturalistic enquiry*. London: 1985.
- (347) Ritchie J. The applications of qualitative methods to social research. In: Ritchie J, Lewis G, editors. *Qualitative Research Practice*. London: Sage; 2003.
- (348) Lewis G, Ritchie J. Generalising from qualitative research. In: Ritchie, Lewis G, editors. *Qualitative Research Practice*. London: Sage; 2003.
- (349) Vincent C, Furnham A. *Complementary Medicine*. Chichester: John Wiley and Sons; 1997.

- (350) Paterson B, Thorne S, Crawford J, Tarko M. Living with diabetes as a transformational experience. *Qualitative Health Research* 1999; 9(6):786-802.
- (351) Ahern K. Ten tips for reflexive bracketing. *Qualitative Health Research* 1999; 9:407-411.
- (352) Finlay L. "Outing" the researcher: The provenance, process and practice of reflexivity. *Qualitative Health Research* 2002; 12:531-545.
- (353) Mantzoukas S. Issues of representation within qualitative research. *Qualitative Health Research* 2004; 14:994-1007.
- (354) Kleinman A. The normal, the pathological, and the existential. *Comprehensive Psychiatry* 2008; 49:111-112.
- (355) Cattini P, Knowles V. Core competencies for clinical nurse specialists: a usable framework. *Journal of Clinical Nursing* 1999; 8(5):505-511.
- (356) NHS Greater Glasgow and Clyde. Clinical nurse specialists are a vital link in the chain. <http://www.nhsggc.org.uk/content/default.asp?page=s1010>, accessed on March 12th 2009.
- (357) Booth K, Maguire P, Butterworth T, Hillier V. Perceived professional support and the use of blocking behaviours by hospice nurses. *Journal of Advanced Nursing* 1996; 24:522-527.
- (358) Barclay L, Vega C. Recommendations for primary care of the patient with cancer. *American Family Physician* 2007; 75:1207-1214.
- (359) The complementary health clinic. Looking after your wellbeing. [www.chcbristol.co.uk](http://www.chcbristol.co.uk), accessed on April 14th 2009
- (360) Trask PC, Paterson A, Riba M, Brines B, Griffith K, Parker P et al. Assessment of psychological distress in prospective bone marrow transplant patients. *Bone Marrow Transplantation* 2002; 29:917-925.
- (361) Roth AJ, Kornblith AB, Batel-Copel L, Peabody E, Scher HI, Holland JC. Rapid screening of psychologic distress in men with prostate carcinoma. *Cancer* 1998; 82:1904-1908.
- (362) Akizuki N, Akechi T, Nakanishi T, Yoshikawa E, Okamura M, Nakano T et al. Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. *Cancer* 2003; 97:2605-2613.
- (363) Jacobson PB, Donovan KA, Trask PC. Screening for psychologic distress in ambulatory cancer patients. *Cancer* 2005; 103:1494-1502.
- (364) Newcastle NHS Primary Care Trust. Diabetes services <http://www.newcastlepct.nhs.uk/services/community-health-services/diabetes>, accessed on April 16th 2009
- (365) Soothill K, Morris SM, Harman JC, Francis B, Thomas C, McIlmurray. Informal carers of cancer patients: what are their unmet psychosocial needs? *Health and Social Care in the Community* 2001; 9(6):464-475.

(366) University College London Hospitals. Cancer-Complementary Therapy Team.  
[http://www.uclh.nhs.uk/GPs+health  
care+professionals/Clinical+services/Cancer/Complementary+Therapy+Team](http://www.uclh.nhs.uk/GPs+health+care+professionals/Clinical+services/Cancer/Complementary+Therapy+Team),  
accessed on April 16th 2009