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Communication and information: the experience of radiotherapy patients.

by

Karen Gamble

February 1996

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B.Phil. Degree in
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"There is evidence to indicate that through examining the particular significances of a person's illness it is possible to break the vicious cycles that amplify distress. The interpretation of illness meanings can also contribute to the provision of more effective care....This key clinical task may even liberate sufferers and practioners from the oppressive iron cage imposed by a too intensely morbid preoccupation with painful bodily processes and a too technically narrow and therefore dehumanizing vision of treatment..."

Arthur Kleinman, M.D.
"Suffering, Healing and The Human
Condition", (1988, p.9)

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ABSTRACT

The purpose of this study was to explore patient's own descriptive accounts of their experiences of having cancer and undergoing radiotherapy treatment. The respondents involved were suffering from either cancer of the head and neck region or lung cancer.

The study focused on "information-giving", in particular eliciting data about misconceptions, missing information and valued information. In addition, material which described another, perhaps unconscious level of communication between health professionals and patients was drawn from the interviews.

The methodology employed was of a qualitative nature and predominantly influenced by "grounded theory" (Glaser and Strauss, 1967), where the meanings attached to events are described and explained. However, the "phenomenological" perspective was also influential, in which significance is given to the "lived experience" of the participants (Morse and Johnson, 1991).

The method used to obtain data was "interviewing", via semi-structured, audio-taped interviews. Data gathering was approached by way of obtaining "narrative accounts" or stories from the respondents. Thus, the analysis chapters are arranged in a temporal fashion, representing the beginning, middle and "sense of an ending" to the stories (Sarbin, 1986).

Three underlying themes emerged from the analysis; hope, fear and uncertainty. The study investigated these themes, and explicated the relation of them to various events. For instance, "hope" occurred in relation to treatment and faith in the hospital staff. "Fear" occurred in relation to recurrence of the cancer and death. "Uncertainty" was noted in connection with prognosis and treatment options.

There was also evidence to suggest that health professionals played a role in boosting or decreasing self-esteem (similar to Charmaz, 1983). In particular, this study highlighted that there seemed to be a desire from the cancer sufferers' to obtain a verbal acknowledgement from staff, of the adversity they had overcome.

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CHAPTER ONE

INTRODUCTION

This study was developed because of a desire to hear about the experiences of having cancer directly from those who were suffering from the disease. The opportunity to realize this desire became possible when I commenced a Research Nurse post at an institution which encouraged nurses to undertake their own research. Thus, whilst I continued my Research Nurse role, in particular gathering data to be used in evaluating a new radiotherapy treatment protocol, I was able to pursue my personal research interests.

The area I wished to study is considered to be under the heading of "quality of life", where the experience of illness is the principal factor to be investigated. This can contain many facets, e.g. fears of death, deterioration in physical well-being, psychological adjustments and adequacy in the control of pain.

I was especially interested in communication as related to "information giving", because this played a large part in my own work as a Research Nurse. (For instance, I gave cancer sufferers information about medical research, including the pro's and con's of different treatments). Therefore, the way that cancer sufferers perceived the value, accuracy, style and adequacy of information-giving by health professionals, became a central feature of the project.

It was also necessary to gather data which would illustrate the particular impact of a cancer diagnosis. This was in order to give a sense of context, for example the background of fear and uncertainty about prognosis, which would not be possible if "information-giving" was considered in isolation.

Structure of the thesis

The "literature review" focuses on "information giving" (from the doctor's, nurse's and patient's perspectives); and the bearing that the advice and care of health professionals has on the patient's experience of serious illness.

The "methods and methodology" chapter depicts the background and rationale of the study, and highlights the chosen method of obtaining data, namely interviewing. These interviews were semi-structured, audio-taped and elicited a "story" or self-narrative. The purpose of these stories was to help make sense of the experiences, enabling in-depth analysis and the ability to link communication issues to "real-life". There were no attempts made to verify or discount these stories. The explicit conviction of this study is the comprehension of the cancer experience, as seen through the eyes of those suffering from it.

Hence the purpose of the study and analysis chapters, can be said to be, to provide a "patient-led" understanding of the following two concerns;

a) the impact of the cancer diagnosis
upon the cancer sufferers' lives

b) information-giving by health
professionals, regarding cancer and
its consequent radiotherapy treatment.

The thesis is completed with chapters relating to a discussion of the findings, conclusions drawn and recommendations for future practice and research.

CHAPTER TWO

A REVIEW OF THE LITERATURE

INTRODUCTION

Communication is a complex interaction, and as Lichter (1987) points out, "A basic source of difficulty is the assumption that the message in the mind of the transmitter is passed unchanged to the receiver" (p.30). In fact, our own individual history, culture, and beliefs will influence the interpretation of the message.

Further, Frey et al (1991) suggest, "..communication is a broad, abstract term..." and that, "..the first step most researchers take is carving out and defining the precise piece of the big communication pie they will investigate" (p.21).

The definition to be utilised in this study is, "**communication is the management of messages for the purpose of creating meaning**" (Frey et al 1991). This has been chosen because it covers both an "information-based" view of communication and a "meaning-based" view.

The information-based view originates from a behavioral perspective, where it was perceived that there is a deliberate attempt to pass information from one person to another (Austin 1955; Frey et al 1991). This type of perspective is relevant for instance, regarding the planned attempts in cancer care to provide information about treatments and their side-effects.

The meaning-based view derives from the phenomenological perspective, where communication was seen as "a process of attributing meaning to people's actions and developing a relationship between people" (Frey et al 1991, p. 27). In the context of cancer care, this could refer to some of the verbal and non-verbal cues conveyed by health professionals to cancer sufferers, about their value as fellow human beings. This sort of position also fits well with Mead (1934) who felt that by acknowledging the messages sent by others, we inform them that they are recognised as individuals and worthy of attention.

Many researchers findings reflect the toll that cancer and its treatments can exact on physical and psychological functioning, body image, social and spiritual well-being (e.g. Weisman 1979, Lichter 1987, Holmes 1988, Knight and Field 1981, Price 1991). Such consequences of the cancer experience has implications for communication in the health care setting. Patients needs to communicate their needs to those caring for them and it is incumbent upon health professionals to attempt to anticipate and meet those needs.

Structure of chapter

A critique of a selection of literature, conducted in the context of communication and health care will be presented. This will be grouped into four sections, the first three dealing with the "information based" perspective as it relates to cancer care. These studies were chosen because they illustrate the difficulties of the three main protagonists in this research, i.e. doctors, nurses and patients.

The fourth section (i.e. meaning based perspective) deals with the impact which information can have on the experience of illness, thus enhancing or diminishing quality of life.

Some key characteristics of communication in the health-care setting.

Language is a key characteristic of communication. It may be conveyed through speech, via books, posters, documents and letters in written form. Potter and Wetherall (1989) identify why social researchers should be particularly interested in language.

> "Its very familiarity sometimes makes it transparent to us. Yet imagine conveying a complex idea ......without language" (p.5).

Potter and Wetherall (1989) continue that communication often involves "abstract notions" and "delicate shades of meaning". They conclude that this requires a shared terminology, understood by all parties concerned in the communication event. Thus, the following literature sections are primarily concerned with language.

Message form can vary from culture to culture and is linked in with code. There can be different languages, and dialects. Jargon can be employed to signify a special group, and help keep others from understanding and so remain as out-siders. (Berger and Bradac, 1982). From personal experience, I vividly recall my own insecurities when I heard my first nursing "hand-over", where patients had undergone "L.F.T.'s, U & E's, F.B.C.'s".

Hymes (1962) felt that "setting" is particularly significant in some of the problems of communication. For instance, communication between a husband and wife will be very different from communication between a doctor and patient. One possibility in this situation is misinterpretation of language, as when Fiore (1979) highlighted that some children in hospital were interpreting "dye-injection" as "die-injection" and "bone-marrow test" for "bow and arrow test". Or, when Coulthard and Ashby (1975) discovered that the most frequent types of exchange between a G.P and patient are those where the doctor is eliciting information from the patient, and that the doctor often blocks unrequested information.

Non-verbal communication or 'body language' is also important. For instance, eye-contact within an interpersonal communication event, can improve rapport and enhance understanding (La Crosse 1975), as well as helping to control turns at speaking (Potter and Weatherall 1989). Although it is often helpful to meet someone's gaze, excessive gaze can be interpreted as being 'stared at', intensifying an upsetting situation (Ellsworth et al 1978). Facial expressions can be very telling about our emotional state, e.g.happiness, shock, sadness, confusion and fear (Buckman 1992).

Body posture, movement and use of touch can also convey our attitudes and feelings. We may nod our agreement, shrug away our lack of knowledge or interest, lean forward in our keenness to be attentive or backwards to indicate our rejection (La Crosse 1975, Buckman 1992).

INFORMATION GIVING RELATED TO CANCER CARE

Doctor's dilemmas

In the U.K., it is generally accepted to be the doctor's task to deliver "bad news". This is confirmed by amongst others, McIntosh (1977), Bond (1978), Buckman (1986), and Cassileth, et al (1980). Fallowfield (1993) has suggested that, despite including teaching about communication skills in medical curricula, there is still insufficient preparation for doctors to give such "sad and bad news". She concludes that this causes stress for both doctors and recipients of the bad news.

Brewin (1991) described three ways of giving bad news - bluntly, accepting the distress caused; kindly, but without offering support and empathetically with positive support. Fallowfield (1993) proposes that junior doctors receive little help in learning to give bad news in the manner of Brewin's better third option, and advises improvement via practical guidelines as well as detailing two specialist courses run for doctors.

Further research by Ford et al (1994) investigated whether oncologists can detect distress in their out-patients and how satisfied they are with their performance during "bad news" consultations. They concluded that out of the five oncologists studied, only one oncologist's ratings was consistently comparable with the patients' own scores. Clinicians tended to under-rate the distress of their patients and were satisfied with their own performance during interviews. The researchers feel, once again, that this may reflect the poor standard of training that doctors receive regarding communication skills. However, the work of Maguire (1985) suggests that some clinicians are simply better able than others to pick up cues for further information. For instance, doctors who avoided eye contact and asked mainly closed questions were unlikely to initiate disclosure of psychological problems (Davenport et al 1987).

Buckman (1986, 1988, 1992) addresses the practical difficulties in giving "bad news" and providing support for very ill patients. In 1986, he explored why this issue is so difficult, and concluded that obstacles included fear of being blamed (analogous with "shooting the messenger" in ancient times), fear of the unknown (e.g. talking to dying patients), fear of an uncontrolled reaction from the recipient, fears of having insufficient medical knowledge and personal fears about illness and death.

Buckman (1988) re-explored the problem (with particular emphasis for lay-persons) giving suggestions to ease difficult situations (e.g. quietly holding someone's hand when talk is difficult, or admitting to "not knowing what to say"). In his most recent book (1992), he concentrated on health professionals, giving advice about positive body language through posture, asking open questions and acquiring listening skills. He also gave examples of straight-forward phrases to use in eliciting how much information varying individuals may require, calling it a "crucial step".

Nurse's communication skills

Bond (1978) examined the processes of communication in a radiotherapy department, using observation as her primary method of data collection. She observed few interactions between nurses and patients that lasted more than three minutes. For those patients who required lengthy physical care, conversations concerned symptoms, the treatment regimes and some light-hearted social chatter. The time together was rarely spent in inquiries about the social or emotional consequences of the patient's disease. In fact, nurses seemed quite adept at blocking any cues from the patient to explore such issues. (This blocking aspect recurs as a finding in Wilkinson 1991).

Whilst several studies suggest nurses are adept (Wilkinson, 1991, 12, 83), Nurse tory is implicit

that

This may have been partly explained by McIntosh (1977) when he discovered that nurses felt that only the doctor should tell the patient their diagnosis, and so nurses tended to perpetuate the euphemistic terminology or avoid the subject. Bond (1978) also concluded that the nurses in her study were Nurses became fearful of divulging information in case because ~~they thought~~ that the patient may become morbid which in traditional thinking, could ill harm v. upset & them. In addition, this may lead to a the patient ~~who is~~ emotionally difficult to + control, highlighting the nurses 'breach of the Drs communication territory so blocking tactics helped maintain some command of the situation (correlating with the work of Buckman 1986).

Field (1989) has tackled the problem of why some nurses behave this way and avoid such discussions. He studied communication about cancer within various health care settings. He found that a ward where the nurse-in-charge gave emotional support to her staff, encouraged openness between the staff and patients, acting as a role-model herself, encouraged a greater capacity for patient self-disclosure. Conversely, he also found that in wards where the opposite situation existed, patients and staff tended to keep their questions and concerns to themselves. Field deduced from this work that nursing cancer patients can be stressful and all too revealing about one's own fears of death and dying. The solution lay in education of the nurses, not only about cancer patients concerns, but also how to define and manage their own fears.

Wilkinson (1991) specifically sought to learn how nurses facilitate or block communication overtures, and how aware the nurses are of their behaviours. She also investigated the significance of personal background factors, which might influence nurse-patient interactions.

Wilkinson's research was conducted at both a specialist oncology hospital and a general hospital. Fifty-four nurses took part. There was a triangulation of methods involving interviews and questionnaires. Contextual data was also recorded, as Wilkinson worked in a supernumerary capacity on the wards.

Three nurse - patient interviews were recorded with each patient, covering newly diagnosed patients, those admitted with a recurrence and those admitted for palliative care. The questionnaire was administered by the nurses, and included questions about anxiety levels and fears of death. Wilkinson then followed this up with a semi-structured audio-taped interview to discuss the communication skills of the nurses during the interviews with patients.

Wilkinson's main finding was that nurses tend to fall into one of four groups vis a vis communication skills. A small group of nurses were good at facilitating further exploration of a problem. The majority used blocking tactics, to avoid further details being revealed.

The nurses who had completed the post-basic oncology course were the best facilitators. In addition, the busiest ward was in the general hospital and yet this had the most facilitators. Wilkinson comments that although difficult, this shows that with a will, even busy wards can nurture good communication skills.

There were other factors which detract from nurse-patient communication. Bond (1978) had highlighted ward architecture and work organisation. The open setting of wards and departments do little to guarantee privacy. For example, curtains between beds form a meagre barrier. 25yrs on – This finding remains relevant for many ~~older~~ hospitals to day ~~and was also a finding in Wilkinson's work~~.

Wilkinson's results also implied that those 'in charge' can be critical role models and supporters (similar to Field 1989). Nurses who wished to talk openly, but had serious reservations, were poor facilitators. Even those nurses who had completed specific communication skills courses appeared to be no more competent in communicating than those nurses who had not. The implication being that current training on these courses needs to be evaluated.

One important cautionary note about the analysis and consequent conclusions in Wilkinson's (1991) study, is highlighted by Lancely (1993, personal communication). It is that this project does not seem to take account of patients' blocking tactics. That is, the transcripts of Wilkinson's work do not appear to have been analyzed with regard to where patients initiated a change or avoidance of the subject. For example, Potter and Weatherall (1989) investigated turn-taking in interactions. Though one participant may dominate, the other participant does also take part to some extent. So there is some doubt that nurses are always responsible for the change of subject, or avoidance of further exploration of feelings.

Patient's desire for information

McIntosh's (1977) study was important because he attempted to uncover the needs of cancer patients with regard to diagnosis. Although disclosure of the cancer diagnosis is not such a contentious issue currently with a widespread acceptance that explicit details should be given, this work still has a lot to teach us about how and why we still find it difficult to deliver "bad news". It also provides early evidence that individual needs were not being met by health professionals.

When McIntosh (1977) undertook the project "Communication and Awareness in a Cancer Ward", it was a common policy that patients with cancer were not given explicit details about their diagnosis. How this situation was handled by the patients and staff is clearly described. McIntosh also interprets the results in order to give an "explanation-by-understanding".

Euphemistic terminology was frequently used when referring to the diagnosis. To illustrate, doctors told patients about "nasty" or "suspicious" cells.

McIntosh felt that many patients knew or suspected their diagnosis and that although some wished to have their suspicions confirmed, a proportion wished to remain "uncertain".

He found that despite doctors professing to individualise information, most patients were left uncertain as to their diagnosis, because on the whole information was pretty standardised. Only those able to ask in forceful terms were actually told their true diagnosis. Nurses, too, supported this standardised procedure. They were aware that very few patients were in full possession of the details of their disease, and would join in with the euphemistic terminology.

McIntosh suggested that those wishing to remain uncertain were preserving hope. He concluded that the policy of 'not telling' suited most patients.

Jones (1981) found that around half his sample of 200 cancer patients wanted explicit information about the diagnosis, whilst around half preferred uncertainty. He resolved that any "telling" or "not telling" policy was doomed to dissatisfaction for one half of the cancer population. Thus he advocated not being explicit, unless asked to do so by the patient.

A period of denial can be helpful for some patients in coming to terms with their illness. For instance, Benner and Wrubel (1989) suggest that for some, denying and avoidance may be a way of seeking emotional respite, to allow time whilst patients come to terms with what has happened and their prospective treatment.

Nevertheless, other research by Cassileth et al (1980) suggests that the percentage of those wishing to be told their diagnosis is far in excess of fifty percent. The implication is that, in order to make informed decisions regarding cancer treatments, an explicit diagnosis must be confirmed. They also felt that information can promote "hope", because it prevents needless worries, e.g. that treatment is going according to plan.

In contrast, Steptoe et al (1991) found that patients can also 'buffer' out unwanted information, or avoid gaining more information than they feel they require. Their study was instigated to assess patient satisfaction with communication, medical knowledge and the coping styles of patients with metastatic cancer. They were particularly concerned with the psychological issue of how individuals normally cope with stress and studied the contrasting strategies of information seeking and information avoidance.

In their literature review, they found that in health-related settings the information-seeking style is associated with preventative health-care, enquiries about imminent tests and treatments. In such research the "Miller Behaviours Style Scale" is often utilised, which sorts the 'monitors' (information seekers) from the 'blunters'(information avoiders). Steptoe (1989) adapted this to an abbreviated form.

Steptoe's earlier work, (Steptoe and Sullivan, 1986), indicated that satisfaction with information-giving, would be, ".. less a function of factual knowledge than of patients' preferences for information versus avoidance in stressful situations" (p. 628). Additionally, past research had implied that "monitors" actually adapt less well to medical procedures than do "blunters". It was therefore decided to augment this further investigation (1991) by assessing stress levels.

Seventy-four patients that had been admitted for re-assessment of their treatment, were approached by one of the interviewers, who presented the study as a survey about the hospital and how patients coped with their illness. The measures utilised included seven, five point scales, covering how 'happy' the patients were with the information given to them about their diagnosis, tests and treatments, possible future experiences and potential side-effects. Satisfaction with their overall care was appraised via three further questions regarding atmosphere and levels of attentiveness of staff, within the hospital.

The results demonstrated a generally high level of satisfaction with the care and information provided. There was a correlation between cancer knowledge and general medical knowledge. Satisfaction with care was greatest in older patients, though age was not related to satisfaction with information. The number of years of education of patients seemed to have little bearing upon satisfaction. Likewise, social class did not appear to be significant in relation to anxiety or psychological coping style.

Most importantly, those patients scoring higher on levels of cancer knowledge were less satisfied with the information provided. The completely satisfied group had lower information-seeking tendencies than all the other groups, as well as scoring lower levels on the anxiety and depression scales.

These findings may help account for the patients whom McIntosh (1977) found, who chose "uncertainty" rather than explicit details of their illness. Steptoe et al (1991) wish to point out however, that they do not advocate a decrease in efforts to improve communication skills. What they do suggest, is that information be given 'sensitively', so that patients can select the things that are important to them, and come to terms with their illness according to their own personality traits.

Derdiarian (1987) recognised the problem of tailoring information to meet individual cancer patients needs. She developed her own tool, the 'Derdiarian Informational Needs Assessment' (DINA). Derdiarian designed this tool to be implemented at or very near the time of diagnosis. She initially compiled a theoretical framework, including the elements below;

> a) "appraisal", where the potential risk of harm is evaluated and what support measures are available to promote damage limitation.
>
> b) "coping", where she used the definition by Lazarus (1966) referring to "cognitive and behavioral efforts to master, tolerate, or reduce external and internal

> demands and the conflict among them"
> (p.108).

Derdiarian links appraisal and coping by citing Cohen and Lazarus (1979), suggesting that coping is thought to increase when the harm or threats are appraised as manageable. And, as Cohen and Lazarus (1979) also indicated that "information seeking" may be one mode of coping, Derdiarian contends that information may assist reconciliation between the individual, the threat or harm and the appraisal and coping strategies. She also acknowledges that information may be avoided, with an example from Cohen and Lazurus (1979), who found that those who avoided information showed similar levels of coping following the strain of an operation. This is comparable to the 'blunters' in the work of Steptoe et al (1991) work. Derdiarian also accepts that situational variables can influence coping behaviours.

After completing this review of the literature, Derdiarian found that the nature of the information seeking needs of cancer patients seemed to fall into four categories. There were disease concerns, personal concerns, family concerns and social concerns.

The sample of 60 patients were asked to complete the DINA within 1 - 15 days of diagnosis. Results were presented according to the groupings used for "information seeking" categories. The main findings were that women required more information about their prognosis and psychological well-being. Men attached more importance to information regarding tests, physical well-being and spouses. The differences that did emerge did tend to be influenced by age and stage in life. For example, younger patients were more concerned with job/career relationships.

Patients with local or regional disease tended to need more information than those with extensive disease. Patients seemed to prioritise the most urgent threats, for instance, information regarding prognosis (in contrast to McIntosh 1977) and treatments was deemed to be more pressing than knowledge about tests.

It is not indicated how long the DINA takes to complete or how it is administered (e.g. self or with help). And, as Derdiarian's own results show, in the initial stages, the 'life or death' threat to survival seems to be of most concern. So, perhaps 1 -15 days is too early after the diagnosis to elicit the total concerns of the patient (e.g. regarding family or work). The questionnaire perhaps, could be modified and parts of it given at a later date, to be most effective. In addition, if the DINA were to cross the Atlantic, differences in culture between America and Britain may necessitate changes. For instance, one of the "operationalisations" of the questions is via patients loading a 'dollar value' to prioritise their concerns. This monetary theme may not be easily accepted in the British culture.

Derdiarian's work is founded on the belief that many patients will seek information in an attempt to manage or adjust to their diagnosis. It also wishes to identify those patients who do not wish to gain information about certain aspects of their disease process. But, as Derdiarian acknowledges, certain adjustments may be needed for future use, aided by a wider testing of the tool.

Luker et al (1995) in the U.K., were also keen to establish individual informational preferences for cancer patients. Their research was based upon earlier work performed in Canada by Degner and Beaton (1987), which investigated decision making in "life-death" situations. Luker et al (1995) derived their sample from the breast cancer population and consequently the results may not apply equally to other cancer sufferers. Nevertheless, their research has highlighted a potential problem, that is, as patients are currently encouraged to be active in decisions about treatment, (e.g. via The Government's "Patients Charter") how are they supported? Indeed, do all patients really wish to undertake this more active role?

Data were collected via a structured interview and included demographic and family history. Additionally, a questionnaire eliciting a prioritising of informational needs, i.e. covering physical, psychological and social aspects of care was administered.

A decision making role was established with a choice of five statements of preference, defined on separate cards. Luker et al describe these key statements as ranging "..from keeping control and playing an active role through sharing control and playing a collaborative role to giving away control and playing a passive role" (p.12).

In addition, each statement was accompanied by a cartoon, which helped clarify the meaning of the statement. The cards were presented two at a time, until an overall preference order was found, which then defined the most preferred role in decision making.

This system would appear to be a relatively simple and yet, effective way to facilitate communication in the health care setting. Though, one reservation might be how this system copes with changes over time, that is, the need for re-evaluation.

Much of the literature so far has focused on "whether to tell" and "what to tell", another area is improving the retention and understanding of information given. McHue et al (1995) researched the efficacy of audio-tapes in facilitating greater satisfaction with care by cancer patients. This was thought to be helpful by increasing patient recall of consultations and thus reducing anxiety. (This followed the work of other researchers, who had found such recordings useful). The current work sought to further clarify the efficacy of giving audio-tapes by introducing randomization to the investigation and including cancer sufferers' with varying diagnoses (rather than a sample consisting solely of breast cancer patients).

The study was "clinician blind" where, having been told not to change their usual interview style, consultations with 117 patients were tape-recorded. But, after the consultation, patients were randomised, with only half receiving the recording.

The interviews themselves were of a particular nature, that is they were concerned with "bad news". Either newly diagnosed patients received details about the diagnosis itself, or more established patients received news about recurrent or progressive disease.

Prior to the interviews, baseline measures of general health and anxiety state were collected via the General

Health Questionnaire (Goldberg, 1986; Davenport et al 1987) and the Hospital Anxiety and Depression Scale (Zigmund and Snaith, 1983). These questionnaires were repeated after the interviews. Those in the tape group were also given an "attitude to tape" questionnaire and both groups in the study were given an "information retention" questionnaire. (This could be compared with the original information given in the tape-recorded interviews).

A total of 78 patients completed the study, with 46 in the tape group and 32 in the control group. (Some patients had died, some had dropped out and one patient had demanded to have a tape recording). There was a diverse range of diagnoses, e.g. carcinoma of the breast, lung, bowel and testes. The majority, i.e. 40, of the tape group and 29 of the control group were women. Approximately half of each group had a good prognosis.

Discussion of the results of the study revealed that poor prognosis patients who had received a tape had deteriorated when assessed by the General Health Questionnaire (1987). Additionally, in line with Hogbin et al. (1992) it was conjectured that, in the context of "bad news", tape recordings may be detrimental to those who employ denial as part of their usual coping strategy. In fact, although the tape-recordings aided recall, the researchers were unable to demonstrate a concurrent reduction in psychological distress.

McHue et al (1985) conclude that:

> "audio-tapes may be a useful adjunct to good clinical practice in good-prognosis patients, and do certainly seem to be valued by the patients' themselves ..... (but) it is not valid to recommend their use uncritically to all patients" (p391).

They concur with discussion of the cancer diagnosis and treatment, but suggest that "re-exposure" to such disturbing information may disrupt the use of denial as a coping mechanism.

Damian and Tattersall (1991), also trying to improve communication in cancer care, provided letters which gave a summary of their most recent consultation, for a randomized group of patients. They concluded that patients who received a letter following consultation were subsequently more satisfied and reported better recall of information. They acknowledge that almost half the patients receiving bad news found the letter distressing, but stated that the vast majority were still pleased to have received the letter. In addition, many patients stated that they would have liked "good news" to be written "in black and white".

THE IMPACT OF INFORMATION-GIVING ON THE EXPERIENCE OF SERIOUS ILLNESS

In line with the previous sections, Parson (1951) advises us, and Kestenbaum (1982) concurs, that specialised knowledge can lead to an inequality of power in care relationships. Kestenbaum phrases it this way:

> "Obligations to the wounded humanity of the patient fall squarely upon the professional because inequalities in the relationship place all the power on his side" (p18).

Further, Kestenbaum suggests that it must become "second nature" for health professionals to "live" their knowledge and skills. He also talks about this being rooted in the professional's mental attitude. What happens when this is achieved successfully and what happens when it goes wrong?

Accordingly, it is crucial to supplement the first sections, by examining the impact of information-giving upon the experience of serious illness. This part of the literature review relies on literary auto-biographical accounts. This is because such accounts give a rich and in-depth insight into this phenomenon. As Kleinman (1988) suggests, by understanding the illness experience as it is lived, it is sometimes "..possible to break the vicious cycles that amplify distress"(p.9).

Isolation

Although not suffering from cancer, Sacks (1984) makes a plea about the way a lack of information can contribute to a profound feeling of isolation for patients. After a bizarre accident, his exuberant physical life-style was threatened by a frightening loss of feeling in his leg. He described himself as losing, "... a symbolic and affective 'imago'...part of (his) inner photograph"(p.63). This was compounded by a dearth of explanation about the reasons for his poor recovery and especially, the likely outcomes.

He appreciated that such explanations are not always easy or possible to give, but the portrayal of a lack of empathy (e.g. the cheery and dismissive attitude of one of his surgeons) merely made him ruminate further on his own imagined worst outcomes.

In his book (1985) written about his work as a doctor, he recalled this experience when one of his neurological patients reported a sudden and profound lack of sensation in one side of his body. Sacks tried to bridge the communication gap by at least imparting that he believed in the man's distress (despite the fact that there was a lack of evidence for a physical cause) and gave what information he could about the future. Fortunately, this man recovered, at which time he was able to inform Sacks of the value of his understanding.

Murphy (1987) also reported a profound sense of "removal" similar to Sacks' (1984) feelings of isolation. He suffered from a chronic spinal cancer, which was made worse by the avoidance of others. He characterised this reaction by saying that people behave as if such debilitating illnesses were "catching". The stigma Murphy surmised stemmed from "society", which secretly perceives the danger in the randomness of many serious illness. He goes on that this causes a "deepening silence" which in part could be bridged by sharing information.

Uncertainty

Davis (1960) in his research about young polio victims and their parents has also indicated the stress that uncertainty can engender. He found that where the news was bleak regarding physical recovery, it was evaded. He concluded that this enabled the doctors to avoid "scenes" or lengthy consultations, though he admitted that such evasion may be unwitting. Nevertheless, where it was possible to end uncertainty and there was a failure to do so, the parents seemed precluded from making realistic plans for their children's futures.

In this sense, Rumbold (1986) anticipates that information, even "bad news", sensitively given, can promote "hope" in the broad sense of the word. He defines hope in this context as "referring to an idea, a vision or a wish, concerning the future, an expectation of something which is desired" (p.59).
He feels that the implicit medical interpretation limited to "cure" is too narrow.

Hence, Rumbold's view of hope involves a "realistic assessment" of the situation, which should be shared with the patient. Then, attention can be focused upon promoting the quality of life as well as (or instead of) survival.

Misconceptions

Saillant (1990) collected the life history of a Canadian breast cancer sufferer, in the course of an anthropological project. She realized that this cancer sufferer became more and more concerned about what at first appeared a trivial problem, but which took on more significance as her disease progressed. That is, the patient was confused about the use of heat on her breasts, e.g. had it caused her cancer, would it make it worse? As she explained that some health professionals had told her that she should not wash for three months.

Further, following a course of treatment for a recurrence, the patient divulged to Saillant that she wanted "to know everything", which included details of her prognosis. Significantly, she did not verbalise this to the doctors and Saillant suggested that more opportunity to ask for information should be provided. Lack of this opportunity caused problems, e.g. in the event of a worsening of her condition, the patient wondered would it be "worthwhile" to trouble the doctor. She also regretted a cancer operation she had undergone, as there had been little discussion as to the purposes of it and it had not helped to cure her.

Loss of control

Another indication of the "power" of health workers over their patients, comes from Murphy (1987). Murphy vividly depicts his distress at the realization of the consequences of his chronic illness:

> "But what depressed me above all else was the realization that I had lost my freedom, that I was an occasional prisoner of hospitals for some time to

> come, that my future was under the
> control of the medical establishment...
> I was..confronting a new way of life, a
> career of being 'sick'" (p 17).

In one instance, Murphy managed to negotiate for some measure of control, by way of a joint decision over whether or not to be admitted for treatment of a skin ulcer (i.e. a pressure sore, which was a consequence of his wheel-chair bound disability). He appreciated the sharing of information from this doctor, which enabled him to see the justification of such an admission.

Coming to terms with illness

More seriously, Murphy (1987) also appreciated the candour of one of his consultants regarding his life expectancy, which though long-term, involved a deteriorating physical ability. This had enabled him to come to terms with his illness, and whilst keen to demonstrate, "Hey, its the same old me inside this body!", he saw "..each day as a life-time's work, each birthday a miracle" (p58).

Decision making

Fiore (1979) and Brohn (1987) emphasise the active role that they wished to play in the decision making about treatment. Firstly, Fiore, a psychologist suffering with testicular cancer was alarmed when he sensed that an exploratory operation might end with removal of his testicle. He recalled that the reassurances that, "..one testicle was enough for any man" (p 284) were ineffective. Having refused an orchidectomy (removal of the testicle) he was finally convinced when his consultants shared with him the information that he had also developed a secondary growth on his lung.

Regarding his subsequent therapy he recalled,

> "..that my lack of control over, and information about, when chemotherapy would end and whether or not it would be followed by radiation had kept me feeling helpless". (p.285)

In the light of this, in consultation with his oncologist, he took the decision to end his chemotherapy because he prioritised that he needed to "return to health and strength" and that the chemotherapy was expected to have only a marginal benefit to cure. Indeed, five years later, at the time of writing the article, Fiore was still fit and well.

Brohn (1987) reached a point in her illness, where after a period in a "retreat" run by a religious order, she realized that she needed to exert more influence over the decision making regarding her treatment. She approached her radiotherapist, who was advocating further treatment in order to promote the chances of cure from her breast cancer. A discussion ensued and they reached an amicable understanding, whereby treatment would not be given, but that "the door was open" to further consultations should the situation alter.

In relation to this, Gregg et al. (1989) intimate that a factor in adjustment to serious illness is the attitudes of care-givers, including health workers. If all attention is "focused onto the disease itself, rather than onto the individual... unnecessary dependency is often unwittingly fostered" (p.8). This can cause additional stress and a worsening of symptoms.

CONCLUSION

This body of literature has illustrated that a lack of offering information can exacerbate damaging feelings of isolation. It can also interfere with the possibility of coming to terms with serious illness. It can lead to feelings of lack of control over one's own care, which could be construed as a further insult upon self-esteem.

In contrast, sensitive information-giving could facilitate more independence, a realistic outlook and the freedom to seek any necessary aid in maximising quality of life.

A note of warning is sounded by some studies, with many authors adding a proviso to full and frank information-giving. That is, that not all patients desire full information. This can inhibit defence mechanisms, such as denial or avoidance, which have been shown to improve psychological and even physical outcomes for some patients (Greer et al 1979; Watson et al 1984; Watson et al 1988).

Nevertheless, the studies do seem to agree that information should be offered, but more importantly, should meet individual requirements. The words of Thorne (1988) seem particularly apt;

> "How and what (health professionals) communicate to patients seems to make a significant difference in the success with which they unravel the "existential uncertainty" resulting from their encounters with the disease. From the patient's perspective, communications as health care professionals plays an important role in shaping the illness

experience" (p.172).

The conclusions of the literature review are accordingly;

- health professionals do make an impact upon the experience of serious illness by information-giving and how they conduct themselves.
- information must meet individual needs
- more research is necessary to extract these individual needs for information.

Morse and Johnson (1991) suggest researchers seek to "clarify or correct" current understanding about the experience of illness, by investigations which capture the patient's own perceptions via in-depth descriptions. Additionally, Kleinman (1988) has counselled that the illness experience is best explained in "common sense ways" that are readily understood by both lay persons and health professionals.

Without "in-depth" descriptions it remains difficult to define the problem from the patient's perspective. For as useful as questionnaires can be, they are by nature confined to the researcher's prior assumptions.
My own research project is thus attempting to tap patients' own descriptive accounts of their perceived

experiences when they have a lung or head and neck cancer. This has then been analyzed for particular reference to information-giving.

CHAPTER THREE

METHODS AND METHODOLOGY

This chapter chronicles the strategy and process of the study. Thus, it will describe:

- an introduction to and history of the project
- the aims of the study
- the research strategy
- pilot work
- the main study, design and recruitment
- a discussion of ethical issues
- researching 'in the field'
- research method - interviewing - details of the data analysis
- summary

Introduction and history of the project

In April 1990, I commenced my "Research Sister" post, within the "Head and Neck Unit" of an Oncology Specialist Hospital. I had already worked at the hospital for just over two years, initially training to gain an Oncology Nursing Certificate, then working as a Staff Nurse and later as a Sister, on the Rehabilitation

Unit.

Having had this sustained contact with cancer sufferers, I became curious to know the patients' own perceptions about having cancer and its impact upon their quality of life. Also, what part Health Professionals play in the adjustment to the cancer diagnosis, subsequent treatment and clinical "follow-up".

My new role meant that I was responsible for a group of patients who were part of a large, multi-centred radiotherapy project, sponsored by the Medical Research Council. The study was called "CHART" (see appendix 1 for extracts of the CHART protocols) and the subjects included were suffering from cancer of the head and neck or lung regions. I was obliged to keep regular contact with these 'CHART' participants, in order to collect the required data for our institution. In turn, this continued contact with cancer sufferers gave me an opportunity to pursue my own research interests.

My interest was "quality of life", which was already integral to the CHART study. CHART recorded their data via two questionnaires (i.e.'The Rotterdam Symptom Checklist', De-Haes et al 1983; and 'The Hospital Anxiety and Depression' scale, Zigmund and Snaith, 1983). My approach differed, aiming for descriptive data rather than data of a quantitative, survey nature.

Unfortunately, my research knowledge did not match my enthusiasm at that time and it became clear that I needed a grounding in research methods. I had already studied with the Open University and so I enroled on the "Research Methods in Education and the Social Sciences" course in 1991. This I successfully completed by October of that year, whilst I was simultaneously writing a research proposal, gaining ethical approval, and completing some of the initial 'pilot study' interviews. At this point the hospital 'Non-Medical Research Coordinator' lent a guiding hand.

The development of the project reached another phase, when in January 1992 it was accepted to be registered for a B.Phil. degree with the Open University. This brought it under the supervision of Jessica Corner (Ph.D), Head of Academic Nursing at the hospital, and Jeanne Katz (Ph.D) a lecturer in the "Department of Health and Social Welfare", at The Open University. This formed the starting point of the main study.

Aims of the study

The study was to be descriptive in nature, eliciting the subjects' own perceptions. The intention was to provide a "patient-led" understanding of the following two concerns;

a) the impact of the cancer diagnosis upon the cancer sufferer's lives;

b) the value of the information imparted by health professionals regarding cancer and its consequent radiotherapy treatment.

Research Strategy

In order to serve my research concerns, a qualitative approach was taken to the data gathering, utilising the method of semi-structured interviews. These interactions were tape-recorded and later fully transcribed. Strauss & Corbin (1990) propose that qualitative research is:

> "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification. It can refer to

> research about persons' lives, stories, behaviour, but also about organizational functioning, social movements, or interactional relationships." (p.17)

This mainly 'inductive' approach is well used in social science. 'Inductive theory', suggest Field & Morse (1985), is generally descriptive, where the researcher's main purpose is to perceive the significance of settings or events. ("Deductive theory", utilised to a lesser extent in this project, is based upon drawing inferences from previous research to deduce potential relationships).

Social investigators using this approach may justify their stance by arguing that meaning and interpretations are not fixed entities. They are generated through social interaction and may change over the course of time (Brynner and Stribley, 1979). These sorts of changes may be difficult to capture in survey and experimental research projects.

Those working with a qualitative perspective may also stress the need to see social life within the general context of a "culture, subculture, or organization as a whole" (Atkinson, 1990). This holistic approach, for the purposes of this study, means that one must gather data about the individual which do not just dwell upon the topic under review. For instance, patients' perceptions of their disease might be influenced by their relative dying of cancer, or the fact that they live alone without any social support network.

It may also be influenced by society itself; as illustrated in Susan Sontag's book, "Cancer as a metaphor" (1986), where, via an extensive search of popular literature, she uncovered many negative (and unfounded) associations between cancer and personality traits. For example, the assumption that suppression of emotions can be a cause of cancer.

Within a qualitative strategy, Stern et al. (1982) suggest that "Grounded Theory" is ideally suited to investigate "social psychological problems". For example, in the nature of those discussed above regarding cancer.

Grounded Theory

In this respect, this project has been influenced by the methodology of "grounded theory", although phenomenology where the lived experience of the participants is significant (Morse and Johnson 1991) has undoubtedly also played a role in the study's rationale.

Morse and Johnson (1991) propose that "grounded theory" has its origins in ethnography and symbolic interactionism. They feel that ethnography supplied some of the methods used, such as interviews and participant observation. Whilst "symbolic interactionism", first developed by George Herbert Mead in 1934, "posits that humans act and interact on the basis of symbols which have meaning and value for the actors" (Stern et al, 1982 p. 203).

Such 'symbols' could, for example include euphemistic language, body language, ".. style of dress, regional accents and personal wealth" (Stern et al.,p 203, 1982). In similar vein, Goffman (1959) has described how we try to present a certain image of ourselves to the world, and how in turn, we interpret our world through those who interact with us.

Stern et al. (1982) have even drawn parallels between nursing and the Grounded Theory approach. They reviewed the way in which nurses and other investigators have used Grounded Theory, and feel that:

> "... the process called nursing occurs in a natural rather than a controlled setting. Like Grounded Theory, nursing process involves a constant comparison of collected and coded data, and

> collection of additional data to
> verify or reject hypotheses" (p.201).

"Constant comparison" is thus a fundamental part of Grounded Theory. In practical terms, this means using the technique that Glaser & Strauss (1967) define as "theoretical sampling", which they describe as "the process of generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect and where to find them, in order to develop his theory as it emerges" (p45). An example of "constant comparison" in this project, is that the initial interviews suggested there was a severe problem, for some head and neck cancer patients, with the unexpectedly copious saliva during treatment. Consequently, further probing of this area was continued in subsequent interviews and compared with what had already been said.

The tape-recordings and the transcriptions were used throughout my research to develop theories or themes, about the meanings the illness held for those in the study. Hence, the theories "fit" the data, precisely because they have emerged from it. Lincoln and Guba (1985) explain this process is:

> "...essentially a synthetic one, in
> which the constructions that have

> emerged (been shaped by) inquirer-source interactions are reconstructed into meaningful wholes". (p333)

In this context, Glaser and Strauss (1967) define "theories" or "constructs" as "a strategy for handling data in research, providing modes of conceptualization for describing and explaining" (p.3).

Glaser and Strauss (1967) indicate that such exploratory hypothesis building requires enough evidence to establish a proposition. Also, that in the first instance, this does not need to be based upon an in-depth verification, so as not to frustrate the generation of a new hypothesis. In effect, the method works by comparing new data with that which has already been produced, and seeing whether it fits with the established categories or prompts the researcher to create new ones.

This qualitative strategy, therefore, attempts to yield a naturalistic impression of the individuals own thoughts and feelings, rather than imposing or limiting the individual with the researcher's theoretical concepts. The researcher is constantly asking how and why people are behaving the way that they are doing. As Atkinson (1990) stated, what cultural resources and previously required knowledge do people already possess, which bear upon the situation.

The use of literature

The use of literature in this type of research can be limiting in the initial stages. Strauss and Corbin (1991) suggest that whilst one needs to have read enough about the area of study to have some working knowledge of it, intensive literature reviews before data collection may bias the researchers perspectives about their chosen area of study. Thus, some "freshness" borne of a certain amount of naivety could free the researcher of prior assumptions, perhaps provoking the discovery of new, or the contradiction of previously accepted knowledge, about social phenomena. Only once the project has started and theories are emerging, should the investigator refer back to the literature to check if this is a previously known category, and if so, what other researchers have said about it.

In the preparation for this study, I had some knowledge about the radiotherapy treatment the patients would receive, including expected side-effects. I later sought studies where the investigations were rooted more in the sciences of sociology and psychology, to see what they could offer. Accordingly, the guiding principle of "learning", in this type of research fieldwork, was upheld (Atkinson, 1990).

Gaining Access to the field and the subjects

> "The identification of a locale for research is only the start of a complex process of "getting in" and "getting started".Problems of access arise in most contexts although they are not equally complex in all cases. Places and situations differ in the extent to which they are 'open' to observation.
>
> P.Atkinson, Open
> University Course,
> DE304, Block 3B, p.64

There were a number of "Gate-Keepers" who could grant or withhold permission to pursue my project. This began with my medical colleagues, some of whom "hold the purse-strings" to the research budgets from which my salary is paid. Their permission was reasonably swift, although I recorded in my field-notes that one Medical Consultant, unused to Social Research methodology, "... isn't sure of what I'm trying to achieve".

Another 'hurdle' concerned the balancing of my role as "Research Nurse" (from which I was earning my living) with that of "Social Researcher". The medical project, 'CHART', from where my own participants are drawn, has various aspects to its data collection. One is the afore mentioned 'Quality of Life' questionnaires, and another, the data surrounding the costs of treatment. These elements are collectively named the "Health Technology Assessment" and are collated by a satellite group under the auspices of the Medical Research Council. Representatives of this group visit each participating centre once or twice a year, to ensure that the proforma's are correctly completed and understood.

On their first visit, we discussed my project in conjunction with our hospital Non-Medical Research Coordinator. Unfortunately, communication seemed to breakdown, with the satellite group feeling that my project would be in danger of causing a bias to the results of their own research. This caused much angst all-round, but eventually it was agreed that this would be an unlikely outcome and my project could go ahead.

It was also then critical to have my project approved by our institution's "Ethics Committee". This committee includes hospital Medical Staff, Nursing Staff, General Practitioners and Lay Persons and their permission must be granted before a research project can be commenced. When a research proposal is forwarded to the committee, they circulate it to all members, so that they can prepare their questions. I was informed when my proposal was to be formally reviewed and invited to attend to field questions about it. Though a daunting prospect beforehand, in the event this was reasonably straightforward.

I was subsequently notified in May 1991 that the project had received approval, provided that I adjusted my "Information Sheet" for the patients. (I had omitted including a paragraph letting the patients know that they could withdraw at any time from the study, without being obliged to give a reason). Also, I was expected to use the hospital's "Written Consent" forms with the informants.

Informal gate-keepers

Atkinson (1990) has commented that a researcher may be required to negotiate with more than one gatekeeper, passing through diverse types of endorsement in order to pursue a project. In my case, I would say that the nursing staff in the Out-patients Department formed another set of "gate-keepers" even after the official barriers had been overcome. Their co-operation was essential as I needed them (particularly in the pilot work) to witness the patients' written consent and also to help furnish venues for the interviews.

Ethical issues in interviewing

"Knowledge <u>of</u> man is not neutral in its import, it grants power <u>over</u> man as well."

Robert Freidrichs.
A Sociology of Sociology, 1970, p.164

As Antle-May (1991) suggests, the ethical issues in relation to interviewing "parallel those about human research in general" (p 199). That is, that ethically, research can only be justified if the potential benefits of its results outweigh any risks of potential harm to the study's subjects (World Medical Association, 1964).

Interviewing can stimulate the respondent towards much introspection, maybe even a catharsis of emotions. This was certainly true of some of the interviews that I conducted. Some of the participants cried, some recalled experiences that had made them angry. One man (Barry) gave me the sense that he had never previously reflected in-depth about his experiences with cancer. He was overcome with emotion when he remembered the currently averted threat of debilitating surgery, where he would have lost both his larynx and his tongue. We had to stop talking for a few minutes, whilst he cried, then I acknowledged how dreadful it must have been for him. To give him breathing space, I also returned to a topic we had been discussing prior to the interview. Thus, I recalled his having told me how he had previously been through another serious illness, meningitis. This gave him the chance to go into detail about it again. Later, we returned to the difficulties of the debilitating 'head and neck' surgery.

As a researcher in this field, it is vital to try to anticipate the possibility of such overwhelming emotions. Time must be allowed for a "de-briefing" period after the taped interview, where further emotional support can be offered. Subsequently, if necessary, provision should also be made for on-going support. In this respect, I was fortunate in knowing the available facilities to support the patients, e.g. social workers, psychological support team. Indeed I did refer some patients to the support services, who gave specialist advice and counselling.

Another separate issue that Freidrich's (1970) work has raised about scientific research, is that there is an implicit or explicit commitment towards change. The researcher must ultimately make some value judgements. For example, in my project, I may have had to decide what to do, if severe criticisms had emerged about a particular doctor or nurse. As H.W. Smith (1975) comments,

> "The researcher cannot really opt out by 'doing nothing'. No choice is a choice" (p.10).

In this sort of example, I would have had to weigh-up the future welfare of patients against betraying the confidentiality promised to my informants.

Antle-May addresses this sort of concern, by concluding that ethical issues of this nature will be resolved according to the investigators " ...previous experience, skill level, and judgement based upon the surrounding circumstances" (Antle-May 1991, p 200).

In fact, for this research project, there were other ethical safe-guards beside my own judgement. First, as mentioned in "Gaining Access to the Field", the project had to be passed by an "Ethics Committee". Secondly, there was continual advice and support from my degree supervisors.

Pilot Work

The interviews in the pilot study took place before I registered for the B.Phil. degree. Nine patients participated; three men with lung cancer, two women and four men with cancer of the head and neck region.

At that time, the plan was to conduct four short interviews (each to have a maximum of around half an hour), with each subject, on the following time-table;

1. Pre-treatment
2. Three weeks from start of treatment
3. Six weeks from start of treatment.
4. Six months after treatment completion.

There were six broad areas that were covered in the tape-recorded interviews. These concerns included the effects of treatment and the cancer diagnosis, support from staff, family and friends and eliciting strategies for coping.

The interviews were mainly carried out within the Hospital Out-Patient Department, in the clinical rooms normally used for medical consultations. I attempted to change the venue to more conducive surroundings whenever possible, e.g. the "private" suite's sitting room. (See "Researching in the Field" and "Reactivity" later in this chapter, for more discussion concerning "setting").

I also tried to organize cups of tea or coffee to "break the ice". This gesture seemed to be appreciated, perhaps because such a familiar social gesture helped to "normalize" the situation. Nevertheless, there were times when either the participant or myself were in too much of a hurry with other commitments, for such niceties.

Implications for the main study

These initial interviews provided a learning experience. For instance, I realized that rather than approaching them as a "conversation" (Burgess 1984) I was still in questionnaire mode, trying to make my way doggedly through the "six broad areas" of interest specified in my research proposal. There was little flexibility for returning to a topic, or any lengthy further exploration of an engaging one. This may have been partly due to my lack of interview experience. Perhaps also, as already hinted at, the pressure to get on with other things. For example, for the patient, treatment appointments, and for me, other patients to attend. Still, the interview schedule seemed to demonstrate a pattern regarding the data.

The first interview took place when the subject was relatively new to the hospital and just becoming accustomed to their diagnosis, let alone the outcomes involved in their treatment. Consequently, these interviews tended to be rather short - the subjects did not seem to understand the questions. The second and third interviews tended to produce lists - that is, lists of side-effects of treatment and lists of foods the subjects had managed to eat or not been able to eat.

Again, perhaps these interviews could have been more productive with better management. For instance, allowing more time and encouraging descriptions of experiences rather than of "facts" like food intake.

The final interview, at six months post-treatment, seemed to be the most interesting. The subjects were no longer involved in the activity of treatment and were attempting (with varying success) to return to their own sense of normality. Many had been thinking about what had caused their cancer and some were aware of the limits as well as the helpfulness of follow-up clinic visits. And, in the research projects that I had read about radiotherapy side-effects, none had gone beyond a three month period, and I was interested in what happened after this time, for instance, did the post-radiation "tiredness" persist.

The more fertile nature of these post-treatment interviews is endorsed by Morse and Johnson (1991) who recommend interviewing when subjects have completed the experience of treatment, as they concur that during treatment there may be little time or energy for reflection.

Following registration of the project for the degree my supervisors and I discussed the implications of this initial work. Consequently, the interview venue was changed to the "patients own home" wherever possible, and was to be conducted six months post-treatment. (Permission was gained from the Ethics Committee for this change). I decided to conduct the interviews in my own clothes rather than hospital uniform.

It was hoped that these changes would serve the following purposes:

a) the participants would be more likely to be open and relaxed in their own environment;

b) if I was not in uniform, the participants would (possibly) be less likely to view me as a nurse and as such intimately tied with the medical establishment, promoting more candour;

c) some of the pressure of "other imminent commitments" would be removed.

Having considered the options carefully, I opted for a single interview technique at six months. It was anticipated that these interviews would be much more in-depth and probably of longer duration than those in the pilot work.

The interviews in the main study were also going to be more in keeping with the spirit of Charmaz (1990) who has detailed how interview questions can be phrased and directed. They can be;

1) short-face sheet
2) informational
3) reflective
4) feeling
5) ending.

She goes on to say that when rapport has been established, the researcher "... can bring in reflective and feeling questions" (Charmaz 1990, p 1167).

Accordingly, I began to concentrate on the "reflective" and "feeling" types of questions. I compiled a more 'open' catalogue of possible avenues of questioning. This was to be used as a guide, rather than a prescriptive list, where all the questions must be answered (see appendix 3).

I focused on the feelings the interviewees had about the cancer itself; their reflections upon the illness experience with special reference to the information that they recalled receiving about their illness and its treatment.

The vehicle for eliciting these perceptions was through the subject's narrative or "story", as Mishler (in: Narrative Psychology' ed. T.Sarbin, 1986, p5) observed that, "...the interview serves as an instrument for story making and story-telling".

Armed then with this interview experience, and building on the data already gathered, I embarked upon the "Main Study".

The main project - design and recruitment

To summarise, the design of the main study was to interview the participants at home, using a semi-structured interview format. This would take place six months after treatment had been completed. I would continue to audio-tape the interviews, but would not be in hospital uniform.

I approached potential participants with a revised information sheet, to be sent to their homes (see appendix 2). Included with the letter, were a reply slip and stamped addressed envelope. One gentleman declined at this letter stage, with a "sorry but no" added to his reply slip. Due to the regulations imposed by the hospital ethics committee, subjects do not have to give any reason for refusing to take part. It may be speculated that this gentlemen felt such talk was unhelpful, as this had been the case with a female head and neck cancer sufferer who had refused to take part in the pilot study.

Two other patients (one male and one female, both with head and neck cancers) were too ill to be interviewed, and in fact have since sadly died. They asked their relatives to telephone me to explain and to wish me well with the project.

Once an affirmative response had been received, I made contact by telephone to arrange a mutually convenient time and place to meet. Despite my intention to interview patients at home, four patients were actually interviewed in the hospital after all. This was because one female interviewee resided in Spain and only stayed with friends here, and three male patients seemed much keener to be interviewed at the hospital, after their scheduled attendance at the Out-Patient Department.

Respondent characteristics

As stated above, the patients in my project were taken from a larger population within the hospital, who were eligible for the "CHART" study.

The criteria, extracted from the CHART protocols for lung and head and neck cancer patients (1990) defined eligible patients as:-

- over 18 years of age
- having inoperable non-small cell carcinoma of the bronchus, confined to the thorax or squamous cell carcinoma of the head and neck region
- having no evidence of distant metastases
- having no co-existing disease prejudicing survival
- treatable by a radiotherapy technique which could be used in both arms of the trial
- being willing to have adequate follow-up
- be performance status o or 1, using the "World Health Organization"(WHO) scale (i.e. 0 = able to carry out all normal activity without restriction; 1= restricted in physically strenuous activity but ambulatory and able to carry out light work).

According to the CHART protocols, these patients were randomised to receive either a short (12 day) course of radiotherapy or the longer "conventional" or "established" six weeks of treatment. The CHART protocol meant that its participants formed a "probability" or "random" sample, because they had a known chance of selection at the outset of the study.

The participants in my research (i.e. nine patients in the pilot study and fifteen in the main project) were extracted from this group, constituting what Burgess (1984) terms an "opportunistic" sample. All patients in the CHART study were considered as eligible and invited to participate. There was no attempt to ensure a representative sample of the population, as time constraints meant that I needed to recruit all those willing to "volunteer".

This "opportunistic" sampling could have meant that there was a risk that the characteristics of those who participated caused some bias to the study, e.g. if the majority of the subjects had by coincidence been non-drinkers or predominantly female, in contrast to the larger population. In the event, problems of this nature did not occur. (The issue of a "representative" sample is addressed in further detail later in this chapter).

Morse and Johnson (1991) stress that "good informants" are crucial to the success of a study. That is, they must be willing and available, have knowledge about the topic under review, and articulate. In fact, I had a little trepidation regarding two of the respondents being "articulate" as they were known alcoholics. In spite of this, on the appointed interview day they were not only sober, but gave interviews that possessed great insight about their illness and candour about their drink problem.

Characteristics of the sample

The fifteen patients in the main project comprised ten males and five females, with diagnoses of "head and neck" or "lung" cancer.

Their ages range from 42 to 72 years, with a mean of 62 years. All of the patients taking part were caucasian, except for one black male, originally from Jamaica but a long-term resident in the U.K.

Their social class distribution was ten "Working Class", i.e. social grouping C2 and D, in the Registrar General's Scale, and five "Middle Class", i.e. social grouping A, B, C1 in the same scale. (Ref., Office of Population Census and Surveys 1970, Registrar General's Classification of Occupations, London HMSO.)

There were four married females and one widowed female, six married males and one widowed male. There were two men who were separated from their wives and one single male.

The respondents had diverse backgrounds. The following vignettes describe six respondents and give a flavour to illustrate the bare numbers represented by the above statistics.

Charlie was a widower, aged 74 years. He had retired from being a School Bus Driver and suffered from lung cancer.

Jimmy was married and 67 years old. He had retired as a Railway Labourer and suffered from oral cancer.

Mary was married and 47 years old. She was an ex-Beautician, now doing part-time voluntary work in an institution for the blind. She was suffering from hypopharyngeal cancer.

Philip was separated from his wife and 42 years old. He was a Brewery Engineer and suffered from oropharyngeal cancer sufferer.

Maggie was married and 69 years old. She was a full-time Housewife and suffered from lung cancer.

Tom was a single male, aged 47 years and an unemployed Building Labourer. He was a laryngeal cancer sufferer.

Similarities between the sample and the larger population

Calder (1979) suggests that one "simple check" about the representativeness of a sample, is to compare the distribution of the main characteristics of the sample with the population from which it is drawn.

In fact, the demographic characteristics of the sample mirror those of the larger CHART study. In addition, they are also fairly representative of the characteristics of those patients with these types of cancers within the U.K.

The fact sheets issued by the Cancer Research Campaign (CRC 1993, Factsheets 11-Lung and 14-Oral/Pharyngeal) demonstrate that for lung and oral-pharyngeal cancers (separate fact sheets for laryngeal cancer not yet available) these diseases are commoner in men than in women, generally at a ratio of 2:1. The age distribution means that the majority of cases, in both diseases, occur in people over the age of fifty.

The Cancer Research Campaign information also indicates a strong link between tobacco consumption and developing head and neck or lung cancer. There is also a strong reverse gradient between smoking and social class, the prevalence of smoking being highest in social class 1V and V. All but one of the patients in the main study were either current or ex-smokers.

Marital status seems to be significant in the incidence of smoking, with widowed, divorced and separated men more likely to be smokers than single or married men (General Household Survey 1988, Foster K, Wilmott A and Dobbs J HMSO 1990). Six males were married, four of whom had given up smoking either recently (since diagnosis) or in the last five years. Four men that were single/separated/widowed were current smokers.

Although there is not such a strong relationship of smoking and marital status in women, of the five, one married and one widowed female were current smokers.

Alcohol is considered as the "second major risk factor for oral cancers of the pharynx, oesophagus, larynx and liver" (Cancer Research Campaign 1993). Strong evidence exists that alcohol acts synergistically with tobacco to multiply the risk of oral cancer, (Blott, 1992, cited in the factsheet). In practice this means that the more one drinks alcohol and the more tobacco one consumes, the greater one's chances become of developing a cancer of the head and neck region. Within the head and neck sample in my study, two males were known alcoholics (who had a history of "failed" treatment for their alcoholism). Five other head and neck cancer patients had a history of heavy alcohol consumption (i.e. greater than the Health Education Authority's recommendations for a safe weekly consumption).

Sample size

The type of field work chosen necessitated a relatively small sample size. Nichols and Beynon (1977) remark about their own similarly small sample that:

> "They aren't special people, or people who we think have anything more special to say than anyone else.....they are simply five of the two hundred we talked to about their lives, their futures and their pasts" (p.78).

Margaret Mead, a social researcher who employed the traditions of anthropology, comments that sampling of this nature is not: " a version where 'n' equals too few cases. It is simply a different kind of sampling" (Mead, 1953 p.654).

Thus, the richness and depth of the data gathered provide the justification for the limited number of participants.

Field-work in your own setting

As Atkinson (1990) points out, "It is often tempting to choose a research setting in which you already play a role.."(p.62). This research decision possesses a number of disadvantages as well as "attractions".

The attractions can include the fact that one already has access to the field - on this occasion, the hospital, its clinics and patients. I had a legitimate role and was well-acquainted with the hierarchies and general day to day functioning of the institution. In other words, I had the opportunity to make valuable contacts and pick up some of the overt and more subtle "do's" and "don'ts", which would ultimately help oil the wheels of getting my own project off the ground.

Burgess (1984) also agrees with Atkinson that research in your own setting has some drawbacks. He summarises these issues by stating that the main problems are "..recognising culture patterns and interpreting meaning attached to events.." (p22), because the researcher fails to see the significance of some events (e.g. customary occurrences). Burgess (1984) adds, that this can lead to "bias, oversimplification, prior judgement and the inability to separate observation from feeling" (p.22).

Lipson (1991) counsels that in order to reduce these difficulties, "...before anyone tries to do research in their own culture... go outside it first" (p 72). This unfortunately, was not possible within the practical constraints of time and money, in this project.

Lipson, (1991) also concludes that the researcher in this situation fares better if she, "...knows herself very, very well inside and has a good mentor to bounce things off at all times" (p 72). Indeed, working with cancer sufferers has provoked much inner reflection, particularly about major life issues, e.g. life-threatening illness, loss and grief, and love of life. In addition, my degree supervisors fulfilled the role of mentors in this context.

To conclude this section, Field and Morse (1985) suggest that an "insider" may be better placed to understand meanings and events. So, although I concede that my relationship to the setting has disadvantages overall, I feel my background has been advantageous, similar to that described by Faithfull (1990) where a "more natural interaction and rapport" occurred with those researched.

Method of field-research - "interviewing"

> "Interviewing is the predominant mode of data collection in qualitative research. Indeed, as a way of acquiring information, interviewing is an element so central to qualitative methodology that complexities and controversies associated with it are often overlooked. Assumptions about interviewing as a research process are widespread, that is, that everyone "knows" how to do it and that interview procedures vary little, regardless of the nature of the research question or approach. Further, despite its importance to most types of qualitative research, relatively little time and attention are paid to the number of challenging and/or controversial aspects of research interviewing which face investigators".
>
> Antle May, K. (1991, p.188)

The purpose of this section is to discuss some of the "challenges" which Antle May highlights, with relation to this project.

Developing interview skills

Firstly, I mainly developed my interviewing skills whilst in the process of collecting data for the pilot study. I conducted one formal interview with the fifteen patients in the main study, and most of these took place at the patients' own homes. (They lasted about three hours, with an average of one and a quarter hours of taped discourse.)

Antle May (1991) comments that an often unique aspect of interviewing, is that "unlike other forms of data collection, in which skills can be readily learned and independently evaluated, research interviewing tends to be a solo endeavour, characterised by 'on the job training', with few well-recognized criteria against which competence can be judged" (p.195).

Emotional support for the researcher

In relation to interviewing often being a "solo endeavour", this type of project often involves researchers recurrently absorbing the sadness in the lives of others. (For instance, Cannon 1989, vividly describes her emotional distress when researching breast cancer sufferers). In my own study, I found listening to recordings of people who had already died was particularly disturbing. For example, it was difficult not to be profoundly moved by Barry, when despite many fears about surgery, he so valued life; and knowing that ironically he died rather suddenly of pneumonia aged only forty-seven.

It may be worthy of concern to provide opportunities to allow off-loading of the type of feelings such projects can induce. Peer group sessions can be useful in this respect, but perhaps informal individual counselling could also be made available occasionally.

Interview Procedures

Antle May (1991) also discusses another often vaguely represented "challenge" regarding interviewing in qualitative research, which is a "precise description of interview procedures" (p.189). As she states, firstly, this is made difficult because a "variety of interview styles is likely to be used", and available terminology may make these styles difficult to describe. Secondly, often the "identity of informants, timing, structure and even the content of interviews require adjustments by the investigator in response to ongoing data collection and analysis" (p.189). This would seem particularly true of this project, as such changes are inherent in the "grounded theory" approach adopted by the researcher.

After completing the interviews in the pilot study, I felt that the most useful information, for the purposes of my study, was yielded at the six month interview. This may be because the patients were no longer completely absorbed in the anticipatory or "getting through" phase of treatment and, in addition, they had recovered from most of the acute physical side-effects. In interviewing at six months, I anticipated that allowance was made for the time and space to reflect back on what had occurred, without allowing so much time to elapse that memories were too vague.

The structure of the interviews was changed from the pilot study to the main study (as discussed in the "pilot study outcomes") and I devised an "aide-memoir" (see appendix 3) to take along to the interviews.

The format in the grounded-theory approach is usually an unstructured or semi-structured one. Unstructured interviews may be defined as "those that do not reflect preconceived ideas about content or flow and are done with little or no organization" (Polit and Hungler, 1987, p.229). Semi-structured interviews may be defined as those organized around areas of particular interest, whilst still allowing "considerable flexibility in scope and depth" (Polit & Hungler 1987, p 230). Semi-structured interviews were the style most closely adhered to in this research project.

Reactivity

Definitions about the style of interviews, like those above, do not necessarily give sufficient credence to the fact that the researcher's own prior information, experience or opinions will also have a bearing upon the content of the interview. Even when interviews are intended to be unstructured, the strangeness of the setting or situation may produce talk which differs considerably from that which might occur if the interviewee was in a natural situation, i.e. one uncontaminated by the presence of the interviewer (Atkinson 1990).

The interview is dependent not only on the responses of the informant, but is also a two-way communication process. As Joan Smith, who completed a biography on Harry McShane based on a lengthy series of interviews says:

> "Another interviewer would have produced a different book...The very act of questioning makes the interview a joint production and the book depends on who is asking the questions as well as who is answering."
>
> (Smith in McShane p270. 1978)

An example of reactivity within my project concerned my nursing background. One participant, Bill, remarked that he had not weighed himself for months, but had weighed himself that day because of my visit. This reflects the practices in the out-patient clinics, where patients are regularly weighed. Though I had never weighed Bill, he associated me with the clinic, and in turn, the clinic with concerns over weight loss. Hence, despite my efforts to distance myself from the hospital in this context, it is questionable I was successful in this case.

Reflexivity

It is also important to mention "reflexivity" here, where the researcher is required to make "explicit in (his) research report the process by which the data findings were produced" (Open University, Research Glossary 1980). In other words, the part that you as a researcher have played, in the forming of the data, must be acknowledged.

Atkinson (1990) further explains this term, by describing the researcher as;

> "...not unlike that of all new recruits,
> novices and 'out-siders', except that
> he remains aware of the process of

> learning and develops such self-awareness as a resource in data collection and analysis.."(p.53).

Hence after most of the interviews I wrote a "reflexive account" (an example of which is given in appendix 4). In addition, the rest of the "interview" section is designed to provide an insight into my conduct as a researcher in the interviews.

Establishing a rapport

Primarily, the experience gained by this point helped me to know how to open up the interview with the patients, and how to establish or maintain a rapport in order to gain information from the informants. ("Rapport" in 'Webster's College Dictionary', 1991, is defined as a "relation, especially one that is harmonious or sympathetic").

Rapport of this nature assists the researcher in gaining the confidence of the informant, which may facilitate them to voice their true (e.g.criticisms) or difficult feelings (e.g.fears of death) to the interviewer. In this project, this type of communication was built-up in three ways. Initially, because I was already known to the informants via my nursing role. Though it is difficult for me to prove that this led to a breaking down of some barriers to communication, the fact that the participants were willing to allow me into their own homes, may demonstrate that some degree of trust had been established.

Secondly, broader cultural references, i.e. apart from those created by the background of the researcher as a nurse, can also affect data collection. For instance, the social class of the interviewer and respondent. In the case of this study, my parentage and quite possibly my accent, place me as "working class" whereas my current profession (and husband's profession) place me as "middle-class". Ten of the patients interviewed were "working class" and five were "middle class" ("class" being coded according to the Registrar General's scale.) In view of this, I feel that a reasonable basis of commonality did exist between the informants and myself. (Cornwell 1984, discusses these sorts of problems in the methodology chapter of her book).

Thirdly, I was careful to allow time for a preliminary "warm-up" period before the formal audio-taped interview. Examples of "neutral" topics could be answering questions about my recent wedding, how easy it had been to reach their home, and drawing the respondents out concerning other safe topics, e.g. their house or flat.

The warm-up period was also a good time to inform the participants that I did have an agenda (be it a rather flexible one), so they would receive some guidance on the areas to be covered, and not left floundering. I also clarified that there were no 'right' or 'wrong' answers to the questions, and I could check that the audio-tape recorder was acceptable. (Audio-taping will be explored later in this chapter).

On some occasions, this warm-up period revealed an unforseen problem. That was, that it had not been made explicit to the patient in the information sheet, that the interview was meant to be conducted when the patient was on their own. Three of the patients did not ask/expect their spouses to leave the room. As the oversight was my own, and in one case in particular, it was impractical to ask the spouse to allow privacy (there was no other suitable room for them to occupy) the interviews went ahead with the spouse present for most or all of the interview.

In all cases, the spouse made very little verbal contribution to the interview - though this was not specified as a condition of staying by the interviewer. It is difficult to know the impact of the spouse's presence on what was said; occasionally the spouse did "prompt" by such phrases as "Well, you did say ...". (This is recorded within the verbatim accounts). So, to this extent the spouses may have influenced the responses, by aiding the patients memory or helping draw them out. Nevertheless, I had wished to obtain the patients' own individual perceptions, which may have been inhibited by their spouse's presence.

Conducting the taped discourse

The taped interview was in the spirit of Graham (1984), where she describes "Surveying through stories". Graham describes how she tried to tap into her informants' perceptions on early motherhood by encouraging them to give a narrative of their experiences. In a similar way, I encouraged the patients to give a narrative of the events leading up to and since their cancer diagnosis.

My most usual phrasing, to commence the taped part of the interview was, "So, perhaps you'd like to start with what took you to the doctor's in the first place Mr./Mrs. X? What made you decide you needed to see the doctor?" This was often enough to spark a monologue of events, with the patient pausing only to try to organise them in chronological order up to the present time. I listened throughout this initial narrative without interruption, as once started, most of the patients seemed to need to work through their story, perhaps "get it all off their chests"? (Shakespeare, et al. 1993, share valuable reflections on such aspects of research practice. For instance Atkinson, in chapter five, describes some of the problems in relating to the participants, including enabling people to "talk freely").

After hearing the accounts, I then raised particular areas of interest. For example I might ask, "So, at the beginning, you think the G.P was unwilling to say it was cancer, although you kept asking him?".

As Antle May (1991) suggests, the goal of this format is to "carefully subordinate" one's previous knowledge and observations in order to discover the informant's own perspectives on the issue. Therefore, the informant's own story "serves to structure the interview as it unfolds" (Antle May 1991, p 191).

This style worked well for most of the patients, although I recall (rather painfully) that not all of the interviews flowed so easily. And, even in those "easier" interviews, there were difficulties or misunderstandings. Some examples of this were, when the informant had to be encouraged to voice any criticism of staff, or when the informant was reluctant or unable to discuss their feelings about their diagnosis. In these instances, I drew on a variety of tactics, like temporarily changing the subject, or perhaps re-wording the question. I also tried to stress that any criticisms were of great value, as they could contribute to an improvement in the future care of patients.

Retaining some consistency

Another issue of "getting the story" is retaining some form of consistency whilst still remaining open to follow pathways which patients themselves choose. A degree of consistency is vital if the "constant comparativeness" of 'grounded theory' is to be utilised and any conclusions drawn. To some extent, consistency may be more likely with one interviewer. This is because when more than one person is conducting the interviews, extremely careful communication must take place between the interviewers, in order that the same areas are reasonably covered in the same sort of depth, at as many interviews as possible.

Following on from this point, Antle May (1991) suggests that 'consistency' in this type of research does not necessarily mean asking all the informants exactly the same questions. Instead, questions or areas of interest which appear important should be asked of as many informants as possible, so as to inform subsequent interviews. In addition, preparing for each interview by taking a provisional note of questions to be asked of the informant, preceded by a review of data thus far gathered, will help reduce some of the dangers in inconsistency. This was certainly the case in this project.

Clarifying wording problems

Throughout the interviews, I attempted to remember that 'lay terms' had to be used in order to avoid confusions. For instance, the term 'side-effects' was later substituted by 'bad-effects' when talking about the radiotherapy, as one of my supervisors suggested that patients may misunderstand it. Likewise, terms the patient used had to be clarified as often as possible, e.g. the patient declaring they knew 'something was wrong', or that they had the 'Big C'.

Audio-tape recording

The interviews were tape-recorded, rather than, for instance, taking notes, to assist in the data analysis. Wilkinson (1991) notes that a reason for not using an audio-tape recorder is that it invades personal privacy and thus distort the way in which a respondent communicates. Therefore, tape-recording can enhance the dangers of reactivity where the information the researcher is receiving not necessarily being a true reflection of the respondent's thoughts and feelings.

In fact, it is important to acknowledge that the possibility of reactivity is a problem of social research in general and is not limited to interviewing via tape-recordings. For example, Goldthorpe et al (1974) found that in their survey of social class, some respondents wished to present themselves in a certain manner to the interviewer. This resulted in them claiming a higher social class than that to which they actually belonged according to the Registrar General's scale.

Indeed, Wilkinson (1991) felt that in practice the dangers of reactivity with audio-taping were minimal, and that in her experience, people liked to take part in research that allows them to vent their feelings about their illness. This does not necessarily apply to all patients (e.g. one patient refused to participate in my study, as she perceived such talk to be unhelpful).

However, it did appear that the tape-recorder caused little undue inhibition. Most respondents seemed to ignore the machine within a few minutes of the start of the interview. This was probably most striking in relation to major issues, such as the feelings of uncertainty that clustered around the possibilities of a poor prognosis and imminent death.

At least two respondents (one in the pilot and one in the main study) displayed signs of overt anger, related to their care, within the tape-recordings. Four interviewees (one in the pilot and three in the main study) cried within the taped part of the meeting, relating to either despair about their diagnosis, debilitating treatments or their future outlook.

These types of strong feelings are difficult for respondents to falsify, whereas more ambiguous phrases, e.g. unqualified praise for hospital staff, are easier to say and perhaps thought of as more socially acceptable. Cornwell (1984) had to overcome the difficulties of "public" versus "private" accounts in her research. She commented that a strategy which helped to deflect people from giving "public" accounts is by asking them to "tell their story". This was the general strategy of this study and wherever possible, I attempted further probing to gain any specific sources of praise.

A related problem of audio-taping may arise when a respondent says one thing on tape and then contradicts this after the tape-recorder has been switched off. This occurred with one gentleman who praised the staff unreservedly on tape, but who had quite a different story to tell in the "de-briefing" period. It emerged that he (and his wife) felt that their last out-patient visit, to obtain important test results, had been most uninformative with the doctors and nurses being curt and dismissive. So, it may be that the tape-recorder itself made him more conscious of confining himself to what he felt were acceptable comments. As Hockey (1985) states, the tape-recorded interview method relies on the goodwill of the respondents to give honest answers.

There would seem to be three ways to help address this issue in order to promote a true picture in the data analysis. Firstly, emphasising to interviewees that criticism of staff can be constructive and helpful. Secondly, assuring the respondent that anonymity will be protected. Lastly, as in the example above, giving the opportunity for comments to emerge after the recorder has been turned-off and then making notes as soon as is practicable. (One supervisor suggested the use of a portable dictaphone for this purpose).

In association with this last issue, another method to counteract loss of information could be in the prompt post-interview formulation of a "reflexive account". This can also be useful in compensating for the absence of recordings of non-verbal communication. Of course, video-recordings can be an option for some researchers in this respect, but given the time, skill and costs involved, not often the most convenient one.

The transcriptions

I transcribed a number of interviews myself, including four in the main study. The aim was to further immerse myself in the data, by reliving the interview and recalling as much "body language" (e.g. facial expressions, averting gaze) as possible. A 'Medical Secretary' transcribed the remainder.

Diers and Schmidt (1968) conducted a study comparing the amount of information recorded in transcripts as opposed to the tape-recordings. Not surprisingly, they found a loss of data. Their suggestions for increasing the reliability of the data included the use of good quality tape-recorders, training transcribers and training coders into the background of the interactions.

My tape-recorder was "adequate" rather than "high-quality". Nonetheless, I have tried to maintain the quality of the transcripts, partly by doing some myself and partly by checking them afterwards. I also trained the other transcriber regarding the nature of the interviews and I was the only "coder" of the data.

Details of the data analysis

"Inductive analysis...begins not with theories or hypotheses, but with the data themselves..." advise

Lincoln and Guba (1985, p333). Analysis of this descriptive data was performed in the following sequence, in the same way as Reiman's example, which is quoted here (from chapter 5, in Munhall and Oiler, 1986):-

1) Transcription of the tapes
2) Realisation of significant statements
3) Formulating meanings, i.e. the various contexts of the phenomenon
4) Developing clusters, i.e. themes common to all of the subjects descriptions.
    (i) Referring back to the original description in order to validate them.
    (ii) Noting discrepancies.
5) Finally a description of the phenomenon, from integration of the above results.

A time consuming, but nevertheless invaluable aid to moving through this system of data analysis was familiarizing myself with the data. Initially this was achieved by combining listening to the interviews with normal daily activities, e.g. whilst driving or cooking. Further, on one occasion (per tape) I sat quietly and wholly concentrated in order to make copious notes. In the spirit of the "grounded theory" principle, I allowed the interviews to "talk to me". That is, to try to put aside preconceived ideas and listen to the story as seen through the eyes of the cancer sufferers. The impressions gained at this time gave a strong feeling for how the analysis should be handled and represented.

I designed a "flow chart" of the cancer experience shown in table 1 (p. 93). This then formed the basis of seeking out clusters of statements and demonstrated that three underlying themes were present, i.e. hope, fear and uncertainty.

The practical aspect of forming the "clusters" was via opening files on a computer - rather than a traditional "cut and paste" method. (Being able to type rapidly influenced this choice). For instance, "being told" the cancer diagnosis emerged as one category, and the transcripts were then combed for data about this particular theme. The initials of each of the participants were recorded in the file, under which all of the statements and/or references to "being told" were exhaustively extracted from the transcripts in turn. In addition, the notes made from listening to the tapes helped pin-point particularly significant areas within the transcript.

Inductive data analysis, such as this, is suggested to be a "process for making sense of field data" (Lincoln and Guba 1985, p 203). Thus, the data in this study was then arranged in a chronological fashion, so as to provide an accessible and meaningful description of the cancer experience, with particular emphasis on communication issues.

SUMMARY

This project has had two major phases. Firstly, before it was registered for the B.Phil. degree, when I was busy gaining research methods knowledge, access to the participants and conducting the initial pilot work interviews. Secondly, after it was registered, conducting the main interviews and realizing that as a researcher, I am drawn instinctively towards encouraging participants to tell the "story" of their experiences.

A key phase for eliciting cancer sufferers' "stories" seemed to emerge from the pilot work as being six months from treatment. This became the timing for the interview and the venue was altered to the patients' own home in an effort to maximise the possibilities of rapport.

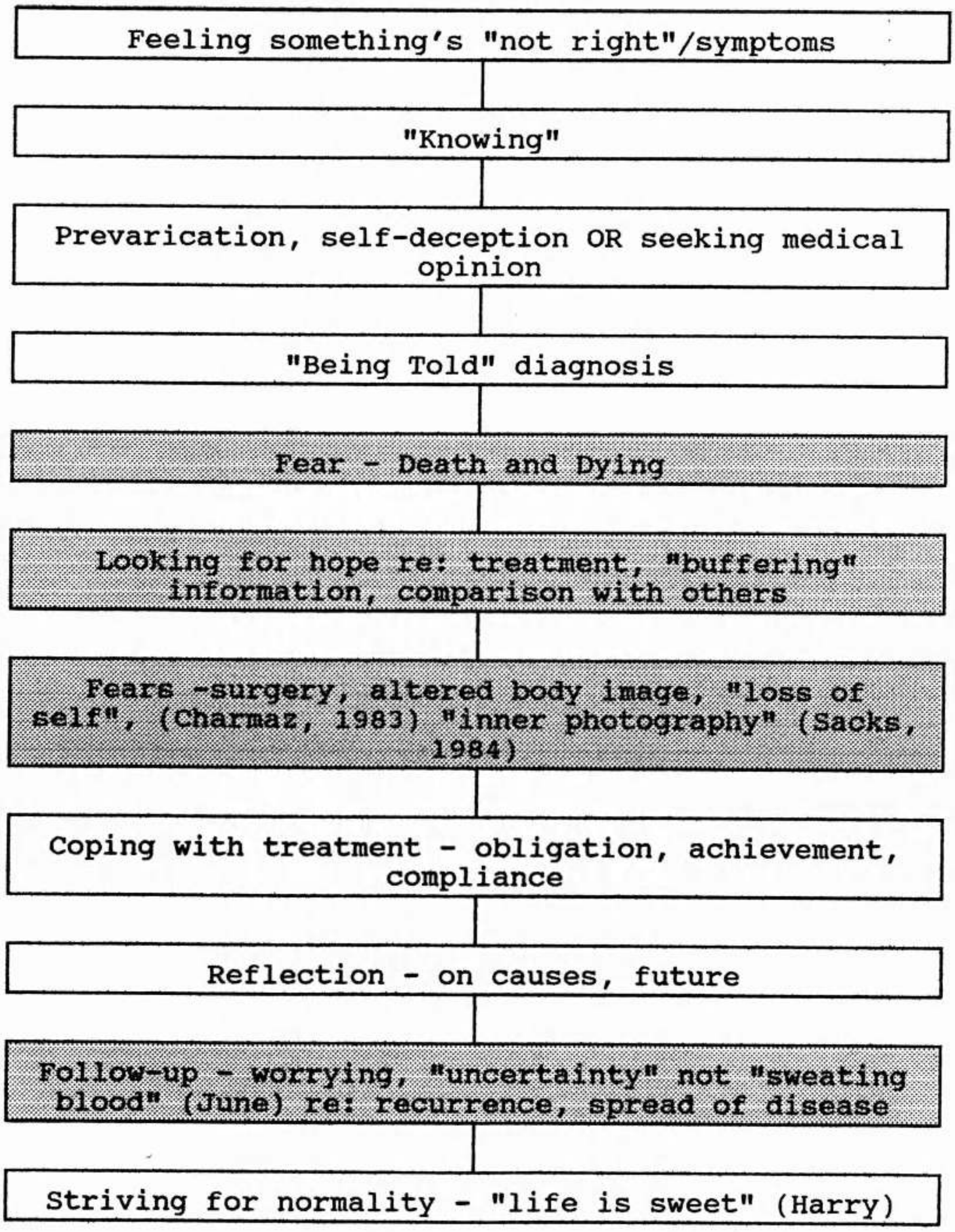
The semi-structured interview method was, as Antle-May (1991) has suggested was basically "learnt on the job", though with the aid of supervision and guided reading my skills improved. Tape-recordings were utilised to optimise the accuracy and breadth of data recorded, whilst it is acknowledged that tape-recorders can alter the content of interviews.

This type of methodology has its limitations, in that it tends to prohibit access to large numbers of participants and cannot produce statistically significant work of the type presented in surveys. Nevertheless, with careful handling, it contributes insights and understanding that are not usually made possible by quantitative work.

Finally, the data was formed into clusters concerning emergent themes, and arranged so as to represent a collective story about the experience of having cancer. This story, told in the following analysis chapters, is a powerful one, where three underlying themes are repeated, i.e. hope, fear and uncertainty. The analysis elaborates upon these themes, giving insight into problem areas regarding communication between health workers and cancer sufferers.

Table 1

Flow Chart - The Experience of having cancer/ Patients' stories.



Note: Shaded boxes show feelings that were present throughout the cancer sufferers' stories.

CHAPTER FOUR

ANALYSIS - A REFLECTION OF THE NARRATIVES

INTRODUCTION

Dr Oliver Sack's (1984) prefaces his book, which vividly recreates his own story as a patient, with the following quote;

> "Medicine always claims that experience is the test of its operations. Plato therefore was right in saying that to become a true doctor, a man must have experienced all the illnesses he hopes to cure and all the accidents and circumstances he is to diagnose...... Such a man I would trust. For the rest guide us like the person who paints seas, rocks and harbours while sitting at his table and sails his model of a ship in perfect safety. Throw him into the real thing, and he does not know where to begin."
>
> The Complete Essays of Montaigne,
> 3.13, Stanford University Press

The phrase, "Such a man I would trust", seems to be a key phrase in this quotation. For, whilst it may be true that one does not have to break a leg to appreciate that the results would be painful, without the actual experience, one may miss the finer points: for instance, the debility and loss of independence, and more subtly, the alienation of part of one's own body (Sacks, 1984). Yet, neither doctors, nurses or other health professionals can "....have experienced all the illnesses (he) hopes to cure and all the accidents and circumstances (he) is to diagnose."

Plato was perhaps trying to direct us to the importance of "empathy". To have empathy means "spiritual, intellectual or emotional identification with another." (Oxford English Dictionary, 1991)

Thus, in the pursuit of such empathy, the analysis chapters will explicate the prominent issues that emerged from the cancer sufferers' narratives, by giving the researcher's insights into and explanations of the subjects' experiences.

The following chapters are also meant to furnish the reader with a comprehensive representation of the experiences of the subjects in this study. For, as Conrad (1990) observes, "I am increasingly conscious how, in our search for conceptual themes and meaning, our analytic method 'shatters' and disembodies data from the individuals who produce it" (p.1258).

The interviews are thus re-told as a "story" or narrative. This approach has been taken in an endeavour to maintain the integrity of the individuals, by presenting their experiences in context. This is in the spirit of Sarbin (1986) who points out that the interpreter (in this case, the researcher) is themselves a storyteller, and that respondents do more than merely respond in interviews. In effect, they are producing a self-narrative. He defines such narratives or stories as a;

> "..symbolized account of actions of human beings that has a temporal dimension. The story has a beginning, a middle, and an ending (or as Kermode (1967) suggests, the sense of an ending). The story is held together by recognizable patterns of events called plots. Central to the plot structure are human predicaments and attempted resolutions" (page 3).

The analysis data is arranged in a temporal fashion. The first part represents "The Beginning", and describes the initial stages of the cancer experience. This section includes the concept of "knowing" something is seriously amiss before receiving an expert opinion. Thereafter, the problems of seeking medical aid and having the cancer diagnosed. Then, the almost knee-jerk reaction, that having cancer is perceived as indicating an imminent death, is highlighted.

The section entitled "The Middle" captures the subjects' reflections upon the possible causes of their cancer. Also, their hopes and fears about their treatment, their relationship with the hospital staff and how they endured the radiotherapy. The difficulties of "loss" (e.g.loss of years to live, loss of physical abilities, loss of social standing) is featured in this section.

The third part deals with "A Sense of an Ending". It is deliberately not called "The Ending", as at the time of the interviews, each of the subjects were still involved in regular "follow-up" visits to the hospital clinic. Accordingly, one of the main focuses in this segment is "follow-up", encompassing the feelings that the lack of an unequivocal statement of "cure" induces and the gnawing fear of recurrence. Associated with these issues, is whether the subjects perceived that their treatment had been successful. Finally, how the subjects adjusted their lives and strove for a sense of normality is examined, e.g. a father continuing to keep house for his adult son.

There is a proviso within this temporal representation, that three concepts seem to be ever pervasive. They are, "hope", "fear" and "uncertainty". For instance, "hope" in the first chapter is partly related to some subjects vainly desiring that the diagnosis will not turn out to be cancer. In the next chapter, "hope" is partly related to the subjects aspirations about treatment. "Fear" and "uncertainty" are also recurrent, perhaps most importantly of all, in relation to the possibilities of being cured or dying of the cancer.

CHAPTER FIVE

"THE BEGINNING"

INTRODUCTION

> *"I thought to myself, I've got the dreaded C"* (Bill)

In order to give the subjects a spring-board into their story, they were invited to think about what had prompted them to seek medical aid. This "beginning" is probably open to debate, i.e. just when do we decide that "something" is wrong with ourselves? Nonetheless, it provided a practical solution to enable the interviewees to start reflecting upon their experiences.

In support of this approach, Murphy (1987) and Wilkie (1993) commence their own biographical accounts of their cancer experiences, by recounting the troublesome symptoms that forced them to seek medical opinions.

"Knowing"

In fact, in both of the biographies cited above and for some of the subjects within this study, it emerged that a dual levelled "knowing" (Benner and Wrubel, 1989) occurred. There was a self-knowledge, and later the "expert" knowledge confirming one's worst fears. Will explained, *"As I said, I had an inkling, I wasn't quite so surprised, but I was taken aback, for a couple of days, I was taken aback certainly."*

Bill told me,*"I was saying to my grandson,...I said I know what I've got, and its a bit dodgy and I'm telling you now, she doesn't even know this (referring to his wife) ..and the doctor saw me, Mr S. said what do you think, I said cancer, he said yes. So it was confirmed then, what I thought I had, which I told my grandson.."*

The signals towards such knowing, usually involved outward bodily symptoms, e.g. lung cancer sufferers coughing blood, or laryngeal cancer sufferers experiencing deterioration of their voice.

Significantly, the self-knowledge aspect of "knowing" appears to be more complex than merely acknowledgement of signs and symptoms. An instinctive or intuitive facet to "knowing" (Benner & Wrubel, 1989) seems present too, which does not involve trained expertise (as that of a doctor) but a deep seated knowledge about oneself.

In the cases of Murphy (1987) and Wilkie (1993) this intuitive "knowing", led to a non-acceptance of alternative explanations of their problems. These were either of a reassuring type (e.g. that the problem was of a much lesser nature than cancer) or a disconcerting one (that the problem was rooted only in the mind). Esther and Mary both endured such a gap from their self-knowing that they had cancer, to a medically expert confirmation. For instance, Esther, a British subject who resides in Spain, rejected the reassurances of two Spanish doctors that all was well, and returned to England to seek further opinions. She remarked that the first doctors had said, its "*nothing to worry about, it's a (benign) polyp*", and remarked of the British Cancer Specialist, "*I finally got to the right one.*"

Some of the subjects interviewed went through a period of prevarication between their self-knowledge and expert confirmation. Harry exemplifies this, when after seeing his GP, he remembered,"*I didn't trouble to go back to the doctor, I thought to meself, if he wants me, he'll find, soon find me, you know? Hoping, I felt alright, that everything'd be alright.*"

The phrase "don't go looking for trouble" springs to mind, in these cases. Why pursue bad news? Although it is unlikely that the subjects managed to remain completely untroubled whilst taking this approach, it was still one step-up from having the dreadful news confirmed - there was still room for hope. They might be wrong, it might not be cancer.

Murphy (1987) poses an alternative explanation when he relates his thoughts about this type of "denial". He says,

> "My denial was not so much a refusal to acknowledge what had happened, was happening, and will happen to me - there is no suppressing this - as an unwillingness to accept its consequences in my daily life." (Chapter 7, p132)

This type of "unwillingness" may be another reason why people hesitate to pursue the true extent of their diagnosis in serious illnesses, such as cancer. It is to keep the fabric of their life intact as long as possible.

"Becoming a patient"

Nevertheless, once involved with the medical profession their symptoms or feelings of "dis-ease" were investigated. (In this sense, I use the term "dis-ease" as different from "disease". As Kleinman (1988, p3) suggested, "disease" is the problem as seen from the professional's perspective, whereas I regard "dis-ease" to imply Kleinman's interpretation of the patient's "innately human experience of symptoms and suffering").

Lung cancer sufferers underwent an unpleasant biopsy of their lungs via a "bronchoscopy". Many of those with cancer of the head and neck region had "examinations under anaesthetic" to obtain biopsies and sophisticated 3D x-rays (computerised tomography scans) called "CT scans".

These tests were remarkably well tolerated on the whole. They felt "*...it had to be done.*" (Harry) Though difficult as some of these investigations were to endure, Charlie realized that it was because "..*they were finding out what sort of cancer I had*", presumably the inference being that this had to be known, before appropriate treatment could be given. Maggie remarked, in relation to the bronchoscopy, that she felt she could "*...accept most everything.... because its for me, isn't it?*".

Co-operation of this nature could be due to unwritten expectations of the sick. Talcott Parsons (1951) noted that in fact, the "obverse of the physicians obligation to be guided by the welfare of the patient is the latter's obligation to 'do his part' to the best of his ability" (p.438). He explained that this was because "Society" had a vested interest in maintaining as many healthy people as possible, to fulfil other roles, e.g. at work, in the home. In order to help maintain the support of "society" (e.g. family, work-place, health professionals) it is incumbent on the ill-person to co-operate with treatment.

The cancer diagnosis and the preservation of hope

After the tests, it was time to "be told"; that is, that their diagnoses would be explicitly made known to them. Their "something" now became "cancer".

In his important study in the 1970's McIntosh (1977) investigated exactly what cancer sufferers were told about their diagnosis, and found that euphemistic 147 phrases (e.g.nasty cells) were often used by doctors to avoid being candid with their patients. Nowadays, the trend is to be much more truthful about the diagnosis (although reticence regarding prognosis still seems to remain, and this will be discussed later in this chapter.) All of the subjects in this study were aware that they had "cancer", although, some of them commented that even now, not all doctors were willing to acknowledge their diagnosis. Mary was perplexed by her GP's attitude and told me:

> *"But do doctors on the whole think people would rather not know? I mean, I am thinking of my own GP who is frightfully nice and I like him....but it was a sense of relief when somebody said what*

it was actually."

And, like Mary, even if some of the subjects found certain doctors still loathe to be explicit about the diagnosis, they did eventually reach one who would be frank with them. How was this achieved? As Lichter (1987) points out, there is much more to communication than purely words. Many of the subjects were given a cue as to what was coming by the expression on the doctor's face, Harry recalls "...*He didn't have a smile on his face and I knew there was something wrong, because he was a jolly sort of a chap..*" and Maggie simply said, "*I knew by the look on his face..*"

For some of the subjects, the doctor asked them what they thought was wrong, for instance Bill when he said, "..*and the doctor saw me, Mr S. said, 'what do you think', I said 'cancer', he said 'yes'*".

Alternatively, the patient themselves might ask, for example, Jimmy saying, "..*I said, is it what I'm thinking doc? She says 'I'm afraid so'*. (On further questioning, Jimmy told me, it was cancer that, "..*he was thinking*").

The doctor telling Jimmy that she was "..*afraid so..*" suggests she was trying to communicate her sympathy, that is, she understood how bad this news was for him.

Other doctors were even more straight-forward, and actually did express that they were '*sorry*' (Harry, Ivy). Philip felt that things had been done rather more abruptly, e.g. He stated that the doctor "..*didn't beat about the bush*" but that he didn't "..*know how subtle they can be*" in those circumstances.

Ivy recalled that the doctor had said, "*It's a tumour, and it's malignant, and it's cancer.*" She also remembered that he had explained the terrible pain in her ear was from the '*poison*' coming out of the tumour in her tonsil.

Some of the subjects did not recall the exact words that the doctor had used, but did feel that they knew that their diagnosis was cancer from that point onwards. Harry also mentioned that the fact that he was being sent to a hospital known to specialise in cancer treatments left him in little doubt, and also initially increased his fear, he remembered;

> *"Well, I was with my son-in-law, I says, 'I've got to go to the (Cancer Hospital) he says, 'Oh, blimey', just like that, I said, 'Oh its o.k., and I-I came home and oh, the only thing is The H..... everybody feared the name of that place."*

McIntosh (1977) attempted to find out if cancer sufferers preferred to have their diagnosis glossed-over, although this was difficult to elicit - as he could not ask those who did not explicitly know their diagnosis. He felt that probably those not explicitly told were, in the main, being assessed correctly by the doctors. That is, that they wished to remain "uncertain", despite the fact that he felt that many of them did know or suspect their diagnosis.

In order to reflect upon current practice, the subjects in this study were all asked by the researcher, if they had wanted to be told in 'outright' terms that they had cancer. They all felt that they did, and furthermore, that it would have been pointless not to be told. Maggie expressed that she would "*much rather be told*", though, "*.. it is a bit of a shock and you do wonder how its going to turn out, how its going to end*". Philip commented, "*There's no point in saying come back next week, if it's there, it's there..*"

If McIntosh felt that those who seemed to be avoiding explicit knowledge of their cancer diagnosis were preserving hope, how then did the subjects in this study preserve their hope? Some dealt with it by what seemed to be a minimising of their diagnosis to terms with which they could begin to cope, for example Harry referred to a "*...small tumour*" and Charlie talked about a "...*touch of cancer..*" (Although it may also be that the doctors who told them their diagnosis were phrasing it in these terms to soften the blow.)

Alternatively, Philip and June thought about how they had dealt with crises in the past. Philip said he "....*put it to the back of my mind, well I'll deal with it tomorrow...*" and "*I just switched off,*" as he had in the past, with severe financial problems (that affected his marriage and the possible loss of the family home). June reflected that many other severe illnesses (tuberculosis, a life-threatening haemorrhaging stomach ulcer and long-term emphysema), had not managed to get the better of her and she did not "..*eat, live and sleep cancer... it was completely almost forgotten*". (Regardless of the fact that in June's case this was not the whole picture, as she also mentions other members of the family who had died of cancer and it had obviously had a great effect upon her. Most notable of these past reactions, was that she admitted to becoming an alcoholic after the death of her sister, who died of leukaemia.)

Others preserved hope by looking ahead to the treatment and this will be discussed in detail in the next chapter. Maggie is unique in this study, in that she came from the hospital after being told her diagnosis, with the impression that there would not be any possibility of treatment. She recalls coming home in despair and looking around her house as if she was not going to be able to do that for much longer. Fortunately, within a few days she was called to see a Radiotherapist and told that she would be treated, and then she thought "*I'm a lucky person.*"

Cancer and the fear of death

As the last quote suggested, a diagnosis of cancer can, and usually does, make the sufferer assume that the disease will be fatal. This feeling may be more prevalent at some times in the 'cancer career' than others, but does not appear to ever recede completely. Certainly, the thought that their life may be fore-shortened was the reaction for all of the subjects in this study. This type of feeling is vividly illustrated by the following quotes:

> "*He just sort of, 'Harry, I'm sorry', he said,'You've-' I said, 'Leave it out', and I said, 'Well, how long have I got?*"
> (Harry)

> "*Well, I never made a Will out, for a start and I was worried about my son, and er all that....and I made a Will out. Which, that was something I've never*

> *done, but I done it now, I done the Will..*" (Charlie)

> "*...I said, am I gonna die or something?*" (Philip)

> "*Actually, I thought, Oh my God, I must get this place, you know if I am going to die, I must you know, get this place tidy for James....*" (Mary)

Three of the subjects (Esther, Harry, and Charlie) all talked about feeling "choked" after being told the diagnosis. The graphic picture of being choked and deprived of life-giving oxygen, again depicts the life-threatening implications of the diagnosis.

So, it seems that despite efforts by health professionals to promote the success of treatment for cancer, generally the perception persists that having cancer means having a fatal disease. This perception is not without some justification, which may account for its persistence. Lung cancer sufferers have a particularly bleak outlook; the Cancer Research Campaign (Fact Sheet, 1992) stated that lung cancer causes a quarter of all cancer deaths in the UK and 6% of all deaths. Indeed, of the six lung cancer sufferers in this study, five had died within two and a half years of diagnosis. (Maggie is alive, and is in remission with her lung cancer but has developed a second primary cancer of the breast.)

Early diagnosis with most cancers can greatly increase the possibility of a complete cure. For instance, of those whose oral cancers are detected at an early stage, around 50% will be alive ten years later (Cancer Research Campaign, Oral Cancer Fact Sheet,1993.) However, all the patients in this study had not been diagnosed at the optimum early stage, and were in a continuum from moderately advanced to later stage cancer. Therefore, their pessimistic reaction to their diagnosis was not entirely misplaced. Not surprisingly, despite the knowledge that many of their patients do appear to have a limited prognosis, the doctors were quite often reluctant to be pinned down to a time limit. When Charlie (a lung cancer sufferer) asked if his treatment would "*..do (him) any good?*" the doctor told him he "*...would live a very long time*". When Jimmy asked "*How long have I got to live?*", the doctor told him that "*Nobody knows how long they've got to live.*" These avoidance tactics are wholly understandable in the context that it is very difficult to predict an individual's response to treatment, even with the benefit of previous statistics. (Although it is sometimes portrayed in films, novels etc. that doctors can tell someone categorically that they will be dead in for example, six months.) People do occasionally survive against all odds.

It is also understandable that a doctor, as a fellow human being should be reluctant to deliver the catastrophic news that in his/her experience the cancer sufferer would be dead within even a vaguely estimated time-limit. In such circumstances an individual's hope that they may be the exception to the rule, or that new treatments may become available would be hard to maintain.

Still, in some instances, cancer sufferers do appear to wish to know if their disease is likely to prove fatal in the foreseeable future. This could be to plan the time left, e.g. organizing the home for those left behind (exemplified by Mary, who talked about getting the house tidy for James, her husband) or like Bill and Will, to help them to decide about whether or not to have treatment.

And, in some instances, doctors do give such guidance about prognosis if requested. Bill had explained to his doctor that he felt:

> *"...if you've got to be a younger fella..*
> *And I erm thought it was a bit of a*
> *tragedy, but at 72 I didn't think so....*

but supposing I don't want to go,
supposing I didn't start my treatment
because I feel well...."

He recalled the doctor told him," ... *without the treatment it would just get bigger and bigger.... you would have to have an operation then*". So Bill decided to continue with the treatment. This problem was perhaps not entirely resolved, because Bill was sure he would never want the operation (removal of his larynx) as he felt it would "*change (his) personality*". So, presumably if he does ever get a recurrence of his disease, he will ask about the outcomes once again. He thought that if he could carry on as he was, with "..*something to tide me over till the end*", he would refuse a laryngectomy.

Will also needed information to enable him to balance the risks of treatment with the risks of the cancer. In the initial stages of his lung cancer, he had been told that surgery was risky, but his best hope of cure. He told the surgeon, "..*then the risk of surgery was* ***minimal*** *if er I was going to die of cancer in any case.*"

Not all patients want to be made aware of their prognosis. Harry asked his doctors at the time of diagnosis "*How long have I got?*", but later after treatment, expressed that he did not want any further information about prognosis, should his condition deteriorate (which sadly, it did within twelve months of diagnosis). His request was documented in his medical notes and was adhered to in the out-patient department. Abrams (1969) has noted this type of change that cancer sufferers may undergo, in the amount and type of information that they request. She felt that at the initial stage, the subjects anticipate a cure and are generally more optimistic. They are also more likely to be able to cope with some idea about prognosis. Then as they progress in their "cancer career" they may retreat from discussion of the fatal aspect of their illness, if treatment is not proving successful.

Coping with the cancer diagnosis

Weisman (1979) tried to give prescriptive advice on how to cope with a diagnosis of cancer and its consequences. He used ten key points, including, for example, "Focus on solutions, or redefine a problem into solvable form" and "Accept support, be assertive when necessary". He felt that "hoping is coping" but, as can be seen in the examples given from this study, it would seem simplistic to assume that one type of advice would suit all cancer sufferers needs.

In their criticism of Weisman, Benner and Wrubel (1989) say that:

> "The point is to recognize that patients will meet this situation with their own particular coping history meanings, and resources. They cannot simply 'choose' a way to cope with the situation if that way does not fit their own history and resources" (p.279).

So it can be seen that to tell Philip "To avoid avoidance", (Weisman 1979) when that was part of his usual coping tactics would be useless. Or, advising Ivy, an extremely nervous widow, who had always relied on her husband and then her sons to sort things out, to "be assertive" would be inappropriate.

Likewise, Edward (from the pilot study), Barry and June, mentioned difficult experiences from their past, from which they had survived, which helped put the cancer experience into perspective. Barry explained, "*As a lad, polio was the disease not to get, ..TB..you don't hear of polio now...the other thing at the back of my mind, I had meningitis..and if I survived that when all these wonder drugs weren't around...*". June, as mentioned earlier, reflected upon the other severe illnesses she had already endured and Edward had indicated that he had known much worse fears during his time as an Army Captain in the Second World War.

It is not that sufferers are continually stoical about their diagnosis. Wilkie (1993) wished to dispel the myth that all cancer sufferers become "nice" people, who battle "bravely". Her account of her illness "..isn't about how facing death made me a better and nicer person" (taken from preface). Tom did not seem to undergo this type of metamorphosis either, and for instance, remained aggressively adamant that lead poisoning had caused his cancer. (Not only in the interview, but he also wrote to his doctors to try to get them to support his claim for compensation against his employers.) He co-operated by attending his radiotherapy treatment, but had refused surgery. Thereafter he felt that the surgeon "*...had washed his hands of us...and they were on about kicking us out, sending us to .....* (another hospital.)

In similar vein, when asked at the conclusion of their interview, if they had anything further that they wished to add, Barry said, "*It's all been an experience, one which I could have done without, if you like, given a choice...*" and George remarked, "*I've only learnt that I didn't want it, why me?*"

So, for the subjects, after the difficulties of being told the diagnosis the next step was to accept treatment. Although as mentioned, this would bring a sense of hope for most of the subjects, there would also be the prospect of painful and distressing ill-effects from the treatment. In this connection, Parsons (1951) realized that,

> "..the burdens the physician asks his patients and their families to assume on his advice are very often severe. They include suffering - you 'have to get worse before you can get better'.... they include the risk of death, permanent or lengthy disablement, severe financial costs and various others." (p442)

This suffering in order to ultimately recover, is based upon the sick persons' trust in his physician, although he/she does not possess the technical competency to judge the doctors authority (Parsons 1951). This is also perhaps returning here to Montaigne's sense of "such a man I would trust."

In this light, the final quote of this section is by Sacks (1984). He indicates the sorts of difficulties in communication between health professionals and patients, when he describes his feelings of living under the shadow of a severe health threat (albeit not of his life, but of serious disability) and he realizes his vulnerability as a 'patient'.

> "..I became all of a sudden desolate and deserted, and felt...the essential aloneness of the patient, a sort of solitude.... desperately now I wanted communication, and reassurance.." (p.60)

In other words, any patient with a serious illness, (in the present context those with cancer) cannot easily dissolve their relationship with the doctor and other health professionals.

The cancer sufferers are poised between accepting their diagnosis and embarking on essential, though demanding treatment (which is the focal point of the next chapter). They are reliant upon health professionals to give advice and reassurance at this difficult time.

CHAPTER SIX

THE "MIDDLE"

> *"There's only two options, you either die or you'll be cured.."*(Barry)

> *"..yes, well, its just like being told what you got, you got to either accept it or, go and chuck yourself under a train!* (more quietly) *In a figure of speech."* (Harry)

INTRODUCTION

Hope related to treatment

As indicated earlier in the analysis, many of the subjects fixed their sights firmly on the forthcoming treatment, as a way of promoting and maintaining hope. Some of the subjects seemed to feel that it was indeed incumbent upon them to have such whole-hearted belief. This was most likely to be in order to improve their chances of success, as if positive thinking would make it so. (George had even obtained a book on "positive thinking").

Benner and Wrubel (1989) have noted that in the "treatment phase", the cancer sufferer "..may experience a lessening in anxiety...simply because the situation is now clearer, the goals are clearer, and the tasks and demands are clearer" (p 279). The following quotes depict these sorts of feelings;

> "*..I-I didn't intend it not to succeed.. that's my attitude......o.k., you've got cancer, there's no decision or choice there ....the radiotherapy, there was nothing really to talk about* (have the treatment) *....and get on with your life.*" (Barry)

> "*I knew I'd have radiotherapy, and it would help an awful lot, and it did, it took the poison from the tumour..*"(Ivy)

> "*As I say, while they're trying these new things and that, it gives you half-a -chance,* (pauses for a second) *well, I won't give in, if I can help it, no way.*" (Harry)

> "*In my mind, I was thinking 100% that the radiotherapy was going to cure me..*" (George)

These aspirations were often intertwined with implicit faith in the doctors and their skills, to decide on the best type of treatment for them. A more abstract confidence in the hospital and the abilities of all its staff also existed. This is illustrated with the following excerpts;

> "..*the confidence that* (was) *inspired*
> *...it was very reassuring..this was a*
> *God's send, a lifeline, from what I was*
> *going through..*" (Barry)

> "*I don't know what type of treatment...*
> *scan..find out..they'll know what remedy*
> *.....whatever the doctor done is helping*
> *....everyday, different equipment..so,*
> *I'm pretty satisfied.*" (Ralph)

> "*I just left it in the doctor's hands,*
> *that they knew what they was doing.*"
> (George)

> "*In my opinion, the job that they've*
> *undertaken to do, whether it be*
> *physiotherapist, or doc- ,*
> *radiotherapist, they're always trying to*
> *do the best they* <u>*can*</u>*...I-I think*
> *everybody's got their talents.*" (Will)

> *"I've had implicit faith in whoever's hands I'm in. I would never, it wouldn't bother me, they can tell me to do anything and I would do, I can stand all the pain in the world, which I have done, haven't I?"* (addressed to wife, Bill)

This last citation from Bill is interesting in that, he repeatedly reported his faith in the doctors and other health professionals, but in fact, was also very reluctant to have treatment. First, the radiotherapy, when he wondered what would happen if he did not have it, "*..because he felt well.*" Secondly, he was under threat of a laryngectomy (removal of the voice box) if his cancer recurred. This he also felt he would be reluctant to undergo, as such a radical operation would "*change* (his) *personality.*" Possibly such a contradiction of absolute faith, yet reluctance to undergo recommended treatments, merely illustrates the true magnitude of what is being asked of some cancer sufferers. That is, even though the sufferers perceive that treatment will be a very damaging experience and are reluctant, ultimately they will comply because they want to live. So, as Bill phrased it, ".. *you've got to have implicit faith in them.*" (In the next section, "The Sense of an Ending", the subjects thoughts about whether such faith was well-placed, will be related.)

Being in a Specialist Hospital

At this point, it may be useful to examine some comments that the subjects made about the fact that their treatment took place in a Specialist Oncology Hospital. Initially, this had proved frightening for Harry, when he expressed, "*..oh, the only thing is The H..., everybody feared the name of that place-*". He went on to explain, "*..till you find the hospital, then you find what a lovely entrance there is.....I just got to go up there and get it seen to ...*".

Mary talked in similar vein when she said, "*..obviously with the H..., and everybody knows about the H....*" For her it meant a clear signal that she had cancer, when her own GP had been reluctant to be candid. The Specialist Hospital's more frank approach was appreciated by her (as discussed in "The Beginning" section) and after tests at the hospital, she recalled feeling, "*..I just felt I was in, if something could be done for me, then it would be done..*"

Bill was unhappy about being sent to his local hospital for treatment, and was relieved when his treatment was transferred to the Specialist Hospital. He conveyed these feelings with, "*..And er I was a little bit surprised when* (sent to the local hospital) *..I didn't fancy that at all to be honest. I know I shouldn't say* *that, but I didn't, I just had faith in the H..."*

The above comments imply that for these patients, treatment within a Specialist Hospital offered them security, for instance giving them high expectations about the standard of care they would receive.

Being in a Medical Research Study (CHART)

Research is often carried out in Specialist Hospitals, and this issue could be closely related to the positive feelings about the hospital. Stiller (1989) suggests that being part of a medical research project in a Specialist Hospital, can be advantageous to the patients. It does seem to follow that for a number of the subjects, the fact that they were in the study was perceived to be beneficial, i.e. something new was being tried that was more promising (Harry, Barry, George, Ralph, Will, Charlie).

For others, it was almost an irrelevance that they hardly acknowledged, in that once again, their tacit approval for whatever the doctor advised was evident. For some, it was almost a mixture of the two approaches.

The reason for the 'tacit agreement' to any treatment, may be partly explained by the work of Steptoe et al (1991). They found some correlation between a lack of higher education and the decreased likelihood of seeking further information. Indeed, many of the subjects involved in this study, had not gone on to further education.

Steptoe et al, noted though that far out-weighing this, the major variable appeared to be the person's usual coping mechanisms. So, whatever the age, sex or social class of the individual, if evading further information was their usual coping style, cancer sufferers would readily agree to whatever the doctors recommended.

The following quotes characterize the above opinions;

> "*...experimental stage...had a lot of success..gave me a lot of <u>hope</u>*" (Esther)

> "*If there was anything to be told, that was necessary, you'd have told me.*" (Jimmy)

> "*Didn't think much about that...I was under the impression it would cure it... more fierce, to bombard it.. I just left it in the doctors' hands that they knew what they was doing...*" (George)

> "*I was happy when I was told there'd be*

> *two conventional treatments..the choice wasn't <u>ours</u> at the back of my mind, I was hoping I would be chosen for CHART..."*
> (Barry)

Two people made altruistic remarks regarding the study being of benefit for others as well as, hopefully, for themselves. They said;

> *"I didn't mind. If it helps someone"*
> (Philip)

> *"Oh no, frankly, I think, if you've got cancer, what difference does it make anyway?..Well, I mean, if you, either, if it's going to help somebody, what difference does it make to me?"*. (Mary)

There was an absence of negative quotes about being in such a medical study. This may reflect one of the limitations of the study, in that such comments may have been forthcoming from those who refused to take part. For instance, some of the patients who had refused to take part in CHART cited an unwillingness to commit themselves to being an in-patient (a necessary requirement should they draw the twelve day treatment).

Information about the treatment

The facets of "information giving about treatment" investigated in this study, encompassed the following concerns:

a) the possibility of success

b) the choice or possibility of any alternative treatments

c) the side-effects of treatment

There was a variety of responses from the subjects about the quantity and quality of specific information given to them by the health professionals. Some recalled helpful information. What seems most remarkable, is that despite some instances of dissatisfaction with specific information, there often remained a general feeling of satisfaction with the hospital. One subject was the exception to this (Tom), who denied any information having been given, and was also much less satisfied with his overall care.

These varying and sometimes conflicting feelings will now be discussed.

a) The possibility of success

Although, in earlier parts of the analysis, closely related issues to this have been examined (i.e. hopes about treatment, information about overall prognosis). I would like to quote some examples of what the subjects recalled about how the doctors indicated the chances of "cure", specifically in relation to their current treatment.

June seemed to recall quite a lot of information, but was still left with the feeling that "*Dr X is not very forthcoming with information - like a politician!*" Fallowfield et al (1987) had found a similar situation with breast cancer patients, when even in the presence of substantial amounts of information, fifty per cent still stated the information had been inadequate.

June recollected being given a statistical analysis of the chance of success, in the first instance by a surgeon, who gave her a 90% chance of cure. And then by the radiotherapist, who did not agree, saying "*No, I'll give you 60%, not a 90% chance of cure.*" With this assessment, she remarked that she decided not to "*..pry any more*". Sutherland et al (1990, p443) deduced from her own research on "informed consent" to treatment, that "visual representations could be used effectively to supplement the key concepts... such as probabilities". This may have been helpful in ironing out such differences of opinion, if for instance June had been given written information at the outset, to take with her to other doctors.

Harry (a lung cancer sufferer) remembered:

> *"...and then DR C had us in...he said, I told you didn't I, we can't cure it, he said, but we can prolong it, he said, and er he said, I told you what I was gonna do, now get on with it, you know? He's a good chap, do you know him, do you?"*

In this way Harry was disabused of a hope of cure, but the doctor had tried to restore the prospect of some future years to live, a case of 'positive uncertainty'? Likewise, Charlie (another lung cancer sufferer) had a comparable experience, when he asked the doctor about the radiotherapy, saying, *"..will that do me any good, doc?"* He was told, *"Yes, you'll live a very long time"*.

Esther simply recalled that the doctor had said, *"..best treated, my type of cancer with radiotherapy."* (and so she endured her treatment, despite the fact that having a mask made, to keep her head still for treatment was *"... like being buried alive"*).

It seems, then, that many of the subjects in this study were prepared to accept treatment and "hope for the best", that is tacitly understanding that the doctors were giving them their best option (rather like the comment above by Esther).

The exception to this sort of tacit agreement to recommended treatment was Tom, who came to have radiotherapy when he refused surgery. He vividly recounted his horror, when on the weekly ward round, the doctors had discussed his case, with a view to removing his larynx. He told me:

> *"That was the best, when one of the surgeons..he's going to cut us, take me voice box, take everything out, I couldn't talk* (because of a temporary tracheostomy which prevented speech) *...he was, he was telling about twenty of them, you know when they all come round. He must have felt that I couldn't hear,* (because) *I couldn't speak, ...and he was describing how they were going to take me voice box out, take everything out of here, ...when I got the nurse on me own, I said no, there's no way they're going to do that like!"*

The surgeon had also told him in reply to "*What's the chances, if they operate?*" that it was "*fifty-fifty.*" Tom explained his refusal by saying, "*I'd rather be dead like, if you couldn't talk..*" and it seemed that a fifty-fifty chance of cure was not sufficient to combat the proposed permanent loss of his voice. Tom did not feel that the radiotherapists had given him any similar information about statistics and the chance of cure, all he could remember was that one radiotherapist told him "*..we'll have you right, don't worry* (chuckles) *nice lass her......she gave us a bit hope anyway, you know, she had personality,..and she said, if you prefer, she said, I'll burn that..*".

As stated above, Tom was very unhappy about what he viewed as a complete lack of information, saying that "*No, nobody told me anything, nobody gave me any insight*". When asked if he had asked any questions, he replied, "*Be serious, when do you get a chance to ask anyone anything!*" He commented that the type of discussion we were having in the interview should have happened "*six months ago...if someone had sat in the first instance...given a little sketch..*" In spite of this, Tom, in his own words, had in fact received some information regarding both surgery and radiotherapy, though what is obvious is that it was not all he wished it to be.

It can be seen that, with the few exceptions of Tom and June, the doctors seemed reluctant to give statistical assessments of the chances of a cure. They relied upon broad terms in the ilk of "we'll get you better" and "we'll control it" to communicate a positive attitude towards the forthcoming radiotherapy. The difficulties here are probably similar to those already discussed, for doctors giving a prognosis.

b) The choice or possibility of any alternative treatment.

Amongst the lung cancer sufferers, George was simply told at the outset that it was "*too dangerous to operate*". Harry would have preferred surgery, and asked "*Can't they operate?*", but was informed by the nurse, "*No, no chance, because (of its position)... under the gullet*".

Will had been told that surgery was his best chance of cure, but that it was not without serious risk. He replied, "*..if surgery was the best way, then I'd take it, whatever the risk was, I couldn't see, if the others weren't going to cure er er cancer, then the risk of surgery was* ***minimal*** *if er, I was going to die of cancer, in any case.*" His decision was acted upon, but the attempt was aborted after the tumour was assessed in the operating theatre. He was then left with a large wound, having had no curative surgery, which he realized was due to "..*the location of the tumour, they said, they wouldn't chance it.*" I asked him how he felt at this difficult time, when radiotherapy was offered as, what had been intimated to be, a second-best alternative. He answered, "*Well, I just hoped there would be something else* (hesitated a second) *I was very pleasantly surprised in a way - that there was something else*".

Charlie was told about surgery, but urged to forgo it in favour of radiotherapy. He told me, "*Well, they turned round, they were thinking about taking one of me lungs away, and at my age, at seventy-four...they reckon well, its a bit er er one way or the other, but they said if I was willing to try the* (radiotherapy) *treatment..*".

Bary and Esther with cancers of the head and neck region, were originally assessed by their local hospitals to need surgery. This was put to them in honest and graphic terms and they were consequently very frightened. Esther would have had to have part of her tongue and an area at the back of her mouth removed, and the doctor explained that it "*would leave a very large hole,* (and be) *very debilitating*" and that she would thereafter require speech therapy. When later reviewed by the radiotherapist, she recalled being "..*very relieved not to have to have the operation...*"; that its prospect had been "*more upsetting than anything*".

Barry broke-down in tears when he remembered the likelihood of his operation. He told me, "*..the surgery was major surgery... I might lose my larynx, I might lose my tongue... and at that stage, well, if I have surgery, would the cancer re-form...*(there was) *no guarantee, ... then, Dr B. said...radiotherapy, keep your tongue, keep your larynx...leave all thoughts of surgery behind me... put off the stay of execution.. I was only a few days off that surgery..*".

Both Esther and Barry were aware that surgery remained a possibility if their cancer recurred, which is perhaps indicated in the words of Barry, "*... put off the stay of execution*". This must be a very difficult shadow under which to continue to conduct one's life.

June also with head and neck cancer, had noted that the option of surgery was briefly touched upon. As a long-term emphysema sufferer she "*... didn't think* (she) *could stand it with* (her) *chest*" and the option quickly evaporated. This example demonstrates that cancer sufferers can have other serious medical problems both before and after treatment. This fact is sometimes overshadowed by the spectre of cancer.

c) Information about the side-effects of treatment.

In this sub-section, some examples of incorrect information will be highlighted as well as the imparting of helpful details. In addition, short-comings as perceived by the subjects, will be included.

Mary gave an example of misinformation, when she recollected the following, "*Oh, um, what to expect, I was told not to use deodorant, which turned out to be wrong and that upset me frightfully!...* (it) *upset me more than anything.*" (The advice regarding a deodorant would have been appropriate perhaps for a breast or lung cancer sufferer undergoing radiotherapy, but was not applicable to Mary).

She was also unfortunate in the lack of some (as she saw it) crucial information, regarding the difficulties of coughing-up copious, nasty tasting and sticky saliva. Her description ran;

> "*But, I, nobody told me it was going to be like that er, the coughing up, I mean. Yes, I thought you know this was unique, and what have I got wrong with me now. If I had known something like that was going to happen I would have been prepared for it. But maybe somebody did*

> *tell me, but I can't think that they did .....I mean I could fill a carrier bag with this stuff in the night... (towards the end of treatment) when I was going on the tube to Hammersmith, I used to get quite, er er agitated,because you know this coughing used to sound so dreadful..."*.

(Despite all this, Mary retained a confidence in the hospital staff, remarking that she had a "*sense of security,..because everybody knew what they were doing*"). The production of such saliva is a known and short-term side-effect of treatment. At risk patients are often warned about it, but not, it seems of the severe disruption expectoration of it can induce. Ivy mentioned this type of coughing and Alfred (from the pilot group) bitterly complained about this issue. Ivy had found it embarrassing, and Alfred found that it had a detrimental and cumulative effect on his general health, when it shattered many a night's sleep.

Ivy and George both had a sense that they had received the greater part of information from the hospital information booklet, about radiotherapy. Ivy referred to this a couple of times, and how she had refrained from asking the staff questions, saying, "*I didn't bother anyone about that, I thought its all in the books to read..I just used to read it*". And George, stated that he thought, "*Oh well, I got this today, looked in the book... fell to the pattern.*" Whilst this demonstrates the usefulness of such books, and the value of making them available, it is perhaps not advisable that these subjects felt it was their main source of information regarding the side-effects of treatment. For instance, there seemed to be some confusion with what would be likely side-effects, e.g. nausea and vomiting was mentioned by both subjects. In fact, this is an unlikely symptom for their radiotherapy, though it is mentioned in the book in relation to treatment for other parts of the body, e.g. abdomen and pelvis.

In addition, George had become distracted with the idea that he was radio-active from the treatment. In fact, he had never been radio-active from his type of radiotherapy, but he wondered "*How long does the radiation from you, that goes into you, how long is it before it leaves you?*" and "*Is it the radiation that's in your body that causes you to have these bad days?*" (Here, he was thinking about the severe tiredness he was still experiencing.) He had not asked the staff at the hospital, and the booklet had not provided answers to these questions. It may be that this idea had been planted inadvertently by medical staff. As the researcher has observed, doctors explain the cumulative effects of treatment and its sequelae by saying that "... the radiotherapy goes on working after treatment has stopped." They mean that the <u>effects</u> of the treatment are still apparent, not that the patients are ever radio-active.

Whilst Jimmy had a generally high opinion of the hospital staff, stating, "*I felt great Karen- everyone's so placid, wonderful* - (I) *will never forget it as long as I live!*" He also admitted that, "*I had radiotherapy, and I didn't know what that was doing to me... I said nothing, I was amazed that the doctors and nurses kept asking me if I had any pain... I was frightened.*" The reason for this absence of knowledge could be that at the time of presenting to the hospital, Jimmy was an in-patient at a psychiatric unit to "dry out" from his alcohol addiction. He was lucid initially, but after transferring to the oncology hospital to begin treatment, he lapsed into taking alcohol spasmodically. In between, he sometimes suffered withdrawal symptoms and was consequently hazy about the treatment details. Yet he can recall the concern about his pain, so it may be that he would have been able to retain other information, had it been forthcoming. It does appear that his fear could have been reduced, had more effort been made to make him aware of his treatment.

Another head and neck cancer sufferer, June, felt she was told what to expect, that it was "*good to be told*" for example that she would have "*acute discomfort*" and an "*ulcerated mouth*". She was also aware that long-term, her mouth would be drier than normal (once the sticky saliva stage passed). Esther had been warned that her mouth would feel drier long-term too, and in the short-term, she would have difficulty eating (due to soreness) and so she was "*satisfied*" with the information that proved to be accurate.

Philip was philosophical, when he was told that he would lose the beard he'd had for twenty years, due to the effects of the radiotherapy on the hair follicles. The reason he'd grown it, was because he was "*fed up with shaving*", so was not as upset about it as some men may have been in the same circumstances.He also remarked that staff had cautioned him that he would feel tired as the treatment progressed, that it would "*weaken the tissues or something..*". He wryly stated that this would be a "*good excuse not to do anything at home!*". He felt that he had wanted to know what to expect, as "*some people may start to panic*" but that he had felt it "*seemed very straightforward*".

In a similar stance, Bill was "*glad*" to be warned about the ill-effects of treatment, so that he would not panic. He recalled that "*everything that happened to me was right, what er I was told would happen*". This type of phrasing was echoed by Ralph, Harry, Charlie and Barry. In addition, Will recalled that the doctor had intimated the severity of the treatment by his description of it. Will said, "*I think the most, the thing that impressed me was, 'it's a type of x-ray, that you* ***never*** *had before.*"

Getting through treatment

As indicated, the subjects had to endure a daunting experience when complying with their radiotherapy treatment. There would be a number of short-term side-effects, and then, for many, the dawning realization that there would also be some permanent side-effects.

The issue of long-term effects will be described in the "Sense of an Ending" chapter. Here it is relevant to present the subjects feelings about the experience of treatment and its short-term ill-effects. These comments cover the side-effects of treatment, the experience of being in hospital and the impression made by the radiotherapy machinery (in order to clarify the comments the appropriate cancer diagnosis is indicated).

> "*... but I couldn't stop in...its like being in prison... couldn't talk, couldn't eat... it was a lot easier for me* (to travel). (Tom, head and neck cancer sufferer, talking about being admitted to hospital.)

"*..loss of taste buds... these things are not horrendous things,.. if you're told* (that they are going to come back) *each day, you're getting nearer your goal... you're given a target... there's light at the end of the tunnel*". (Barry, also a head and neck cancer sufferer).

"*The first few days, I didn't take a lot of notice of it, but towards the end, it got me down, it really got me down.*" (George)

"*...the only thing is, is laying on those hard thingies* (x-ray couches) *you know, and although you're not there for very long, you* (chuckles) *you get up feeling an oldie,...... I was counting off the times, you know, how many more times I'd got to go, and got to the last one, and that was lovely wasn't it..?*". (Maggie)

"*Even the kitchen lady used to tell me off!" Couldn't drink tea, coffee... when I did get home, have a good cup of tea, no, it tasted just the same... took me nearly two weeks..*" (Ivy, a head and neck cancer sufferer)

> *"..they give me er this therapy, and it kept going on one side, and moving all round it, different places, and er, I kept on, I couldn't eat, couldn't go to err toilet a lot, and I was still in the dumps, you know..."* (Charlie)

> *"..and you feel nothing obviously, you hear the buzz of the machine going around, you feel no pain nor nothing and its only a matter of seconds... but erm as I say, its a funny thing, a funny experience really, especially if you were going in to have surgery, which I'd rather have had really, once you wake up, you know its done and no worries, but this is a different kettle of fish!"* (Harry)

It appeared to me, that for each of the subjects there was one or more factors which enabled them to endure the radiotherapy treatment. Some of these factors have been explored in other sections, namely;

i) faith in themselves, often based upon overcoming testing experiences in the past (see "Coping with the cancer diagnosis")

ii) faith in the hospital staff, often based upon the air of confidence and efficiency exuded by them (most explicitly seen in "Hopes about treatment")

iii) the will to go on living (demonstrated in "Cancer and the fear of death", "Hopes about treatment" and will subsequently be seen in "Striving for normality" in chapter seven)

It is now intended to go into more detail regarding two other facets which have not yet been described in this study. These forthcoming sections will discuss (iv) "coping by identifying with others" and (v) "support from family and friends".

(iv) Coping by identifying with others (e.g. to help combat uncertainty, anxiety and feelings of isolation.

It emerged from my data that many of the subjects gained some relief from the realization that cancer was a common disease. Though, like Charlie (quoted below) this could also be distressing, it did appear to make them feel that there could be people worse off than themselves. This sort of reaction is in line with the work of Molleman, Pruyn and Ad van Knippenberg (1986) and Cohen and McKay (1984). Cohen and McKay refer to this as part of a "buffering" process, against the stress of the illness.

In this vein June recalled, "*..it does you good to sit in a hospital like that...as when you're told, you think you're the only one who's got it,..but, you're one of many..*" She also remembered that she often felt her illness was probably "*much milder*" so she never "*felt sorry for* (herself)".

George and Harry also drew comfort from seeing other patients experiencing similar treatment to themselves. George observed, "*Well, they're more or less the same, just going for treatment..just like me, some days they're good, some days they're not..*" And Harry talked about "*gaining confidence*", not only from the hospital staff, but from, "*..the company of others, that's in the same boat as you, you don't see 'em laying about, well, I didn't, moaning any, there was a chap, I gave him my 'phone number..*"

Mary derived hope for her prognosis, from the experience of a friend with cancer. She told me, "*My friend who, she had breast cancer, and the week before last, she was, she has been seen, you know for the last twelve years, and she doesn't have to go any more.*"

Charlie vividly recalled the more disturbing experience of meeting a young child with cancer. He told me, "*..and I got into the ambulance, and I said, 'hello son', and I talked to him and his mother says, he's got leukaemia...and they're the people I feel sorry for...so she turned round and said, I've got some bad news...he's only got two years to go...a little kid...I thought, oh blimey..* (almost crying)."

Interestingly, there seemed to be another element of social comparison, that is, comparing oneself with the wider population, some of whom may unknowingly have cancer. This was demonstrated by Michael (in the pilot study) Barry, Harry, and Tom, and some of their comments are detailed below;

> "*..doesn't know he's got it..*"(Tom referring to a work-mate who also suffered lead-poisoning in the same work-place)

> "*A person in the street, he may have it and he doesn't know, he may die, and the post-mortem would say, he died of cancer.*"(Barry)

> "*..when I look around there, there's thousands, and there's people walking round there, don't even know they got it*

themselves, do they, you see?" (Harry)

There may even be a note of bitterness in these comments, at the unfairness of some people being "blissfully unaware" of their unfortunate disease. Perhaps because such people are carrying on with life as usual, as some part of themselves would really rather have done. It is also likely that the opposite belief existed, that they feel fortunate to have been diagnosed and treated, in order to have the chance to go on living. Paradoxically, there may even be a mixture of both emotions.

In addition Charlie talked about the possibility of G.P.s sending all their patients for chest X-ray's, to "*prevent all this cancer*", which has similar connotations. (This opinion raises another topical research subject, that of associating "screening" with "prevention" when that is patently not its function. Unfortunately, it was not possible to examine this area further in this particular study).

It is clear from some of these extracts, that the role of such "social comparison" is not without its negative side (e.g. causing Charlie's distress). Another "negative" instance was when Esther, compared her recovery with Barry who had the same type of tonsillar cancer, and had received identical radiotherapy at the same time as her. She wondered, after telephoning him for a post-treatment chat, "*...why hasn't mine cleared up..*", when he declared that his throat was back to normal. This was obviously discouraging and a problem she sought reassurance for, at her next appointment with the doctor.

It remained that the feeling that others were "*in the same boat*" (Harry) seemed to fill a particular void for some. Perhaps by providing a sense of true empathy, for instance support could be felt just by looking around the out-patient department and knowing that one's experiences were not unique. This could be in relation to the sort of "..isolation and essential aloneness of the patient.." Sacks (1984, p 60) described, which may sometimes be more likely to be breached by others who share the same severe stresses.

b) Support from family and friends.

Emotional and practical support from family and friends can ease the experience of having cancer and its demanding treatment. It is described as another aspect of "buffering" by Cohen and McKay (1984). And a host of other research papers (e.g. Charmaz 1990; Krause 1991; Morse and Johnson 1991) have indicated the benefit of such support, wherever it is possible. The subsequent citations bear witness to this assistance;

> "..*with the help of my wife..they* (the family) *supported me in every way nice.. they never came to tell me anything bad..*"(Jimmy)

> "*You're lucky if you've got a good family..*(they) *like a good discussion, - will get books on it and look it up. Say, you've got a good chance of being cured*". (June)

> "*My wife....she's inclined to do more for me, she does a hell of a lot more than she used to, inclined to worry more* - (she says) '*sit down, take it easy*'. (George)

Five of the men and four of the other women also had "significant others" from whom to draw support, varying from help with transport, practical support for recuperation and emotional comfort.

This was at first rather perplexing, when of those who did have the support of others at home, only one person (June) spontaneously mentioned talking about the cancer with her family. For example, when asked if he discussed his disease with his wife, Will replied, "*If she wants to, but I don't really start a conversation....If she feels there's something she wants to talk about, but she doesn't talk about it a great deal either...*". (This same gentleman's wife did not have the same reluctance in clinic, where she would come armed with a written list of questions).

On reflection, this situation is perhaps not so puzzling, when it is considered that the subjects may have been protecting their loved one's from their worst fears. Alternatively, they may have simply have been trying to live as normally as possible at home. So, talk about symptoms e.g. sore throat, difficulty eating, were acceptable due to their temporary status. But, talk about more serious consequences, e.g. death or loss of speech were less likely to be broached. In the relative sanctuary of the home, they were too disruptive to contemplate with their loved ones.

Tom, Ralph and Philip, were not so well supported outside the hospital. Tom and Ralph because their close family lived too far away to be able to offer much help. Tom talked about always having been capable of looking after himself and felt he did not need his parents to come and care for him. Nevertheless, he was keen to get back into his usual social world of going to "*the pub*", which suggests he may have needed more social contact.

And, Ralph, bitterly recalled his wife leaving him, and taking their children to return to Jamaica some years before. He now wrote regularly to his daughter, but wished that his wife had not gone, leaving him to rely only on distantly related relatives in this country.

Philip had limited help from his estranged wife (their relationship had long been deteriorating before his diagnosis). But, he told me in the interview that he had always been rather a loner, and so for example, he relished his new solo accommodation.

Thoughts about the causes of their cancer

Cancer of the lung has a strong research-based association with smoking cigarettes (Cancer Research Campaign Factsheets, 1991). Cancer of the head and neck region has a similar aetiology and in addition, there appears to be a synergistic effect between smoking cigarettes and drinking spirits (Cancer Research Campaign, 1991).

As all of the subjects in the study (except Esther) had been or were current smokers, and some consumed a large amount of alcohol, health professionals advised them of the dangers of smoking and/or drinking alcohol. This was either in response to the subjects questions or to encourage future life-style changes. In both these diseases, it can be perceived, that the subjects may be made to feel the authors of their own misfortunes. This could result in feelings of guilt, regret or the rejection of such assumptions and as such, affect coming to terms with the illness.

From the time of knowing the diagnosis and during the treatment phase, there will have been much time for reflection regarding the cause of their illness. Some of the subjects had accepted that smoking and alcohol had influenced contracting their cancer and changed their life-styles accordingly. Some accepted but could not change. For others, there was complete rejection of any association between these habits and their disease. They formulated other theories, which perhaps provided a reason for their illness, which did not incur feelings of personal guilt or regret and permitted continuance of these social habits. As it will be seen that, for some subjects, smoking and drinking alcohol was an integral part of their lives. Therefore, elements of this section could equally belong in the following section on "loss", as to forfeit them could cause potential losses too great to contemplate.

For those with cancer of the lung, Health Professionals do not usually emphasise cessation of smoking, as it is often perceived to be of little help, their disease is already going to prove a fatal one. But, some of them had already made an association and felt it best to give-up, like George who explained, "..*thought it was cancer - packed up smoking...cause of meself, I was frightened, I thought it was making it worse..*". Although, the same gentlemen also thought the following, "..*it's possible I could have caused it, through smoking......., but then again you can catch lung cancer without smoking, can't you, so, I'm not 100% sure about that...*". Clearly, this second comment could be concerned with enabling himself to cope with his diagnosis, which was even harder if he did completely accept that he had caused his own illness.

Barry in similar vein reported, "..*years ago, I smoked cigarettes, then, I smoked cigars, as soon as it was diagnosed...they said, do you smoke? I said, no longer...*" and later, "..*certain things in life, petrol fumes, cigars...I don't know if you could put it down categorically to smoking, but it can't help*".

Charlie (with lung cancer) had not given-up smoking, but realized its relevance and so brought it up for discussion with his doctor. His recollection of this recorded, "....*but, can I have a cigarette when I, yeah, by all means, have one, but don't have too many, you know, and at my age, you know, that's all you could do, you see. Only I don't go dancing or anything...*". This last comment implies that Charlie understood the reasons for quitting or cutting down, but that both he and the doctor assessed that it was one of the few pleasures he had left.

Both Jimmy and Philip completely accepted the role that smoking and alcohol had played, though neither felt it possible to give them up. They had both had unsuccessful treatment for their alcoholism in the past. Jimmy told me, " *..the main problem was drink, I've been drinking all my life...that can catch hold of you*". Philip said, "*I've been abusing my body with alcohol from an early age...* (its) *played a good part in it..my body's been able to take a lot of stuff, but, its getting its own back now...just retribution*".

Bill did give up smoking after his diagnosis. He had worked out the implications before the doctor diagnosed his cancer, saying, "*Urm, smoking, I have always been a bit bullish about it, you know and erm, I thought to myself, I've got the dreaded C. I just had an idea that that is what I had*".

Harry had given up smoking many years before, due to severe circulation problems in his legs. He reflected, "*Er, they say its a good thing in that respect, but, bit late now, ...if it causes it, which they reckon it do*". But, Harry also joined the ranks of those who had other explanations to understand why they had cancer, and he queried the smog he had inhaled as a bus driver many years ago.

As noted, Esther denied ever smoking (and her alcohol intake was said to be minimal) but, she was exposed to passively inhaling the smoke from her husband's cigarettes. For Esther though, this was not the most relevant factor, she explained, "*.. I remember him coming in last winter with a log fire and my husband, who was smoking, and I had this sore throat and this winter we didn't have a log fire, whether it was that I don't know..*". In other words, she thought the smoke from the log fires may have caused the cancer. This seems a much more palatable explanation than that one's husband (who seemed very supportive and caring) had contributed to your life-threatening illness.

June admitted, "*...whatever you've got, smoking doesn't help..*" though she added,"*.. but (it) doesn't cause illness*". She continued to smoke, despite (or perhaps because of the) consequences of incapacitating obstructive airways disease, a stomach ulcer and head and neck cancer.

Tom and Ivy were strident in their rejection of smoking as a possible cause of their illness. (In Tom's case, he also rejected alcohol intake). In the interview, Ivy a seemingly very mild mannered lady, became her most assertive on the issue of smoking. It emerged that one of her two sons and his wife were adamant that she stop, and forbade her smoking in their house, much to her displeasure. So, this was a thorny problem. In reply to my asking if she thought smoking may have contributed to the cancer, Ivy replied:

> "*No, I don't think so Karen,..for all these years, I've had a cigarette...I do not think smoking caused that...*(I've been) *smoking since 18, if the smoking caused that cancer it would have come before I reached 70... people who have never smoked get cancer....never been cancer in my family..people* ***die*** *of cancer, lots of them have never smoked*".

This lady indicated that she had no intentions of giving-up smoking. Instead, fastidious in her own household cleaning, Ivy embraced the theory that germs she had caught whilst cleaning an ill neighbours flat, had done the damage. She remembered:

> "*..it would be filthy, it was dirty, really, really dirty, I'd wear gloves - I have a feeling the last time I went up there, he was in bed, the flat was filthy...I picked up a germ, and having*

> *a weak chest it went down into my throat..".*

Tom repeatedly talked of the lead-poisoning he had endured due to his building work, as the only cause of his illness. He felt that as a specialist centre, we should be trying to find the cause of the cancer and saying that it was smoking and drinking was "*easy*" and that any "*ordinary*" doctor could tell you that. He went on:

> *"As I say, I would have thought they would have been looking into how I got it, you know there's nobody asked me what, you know, like you're supposed to be here to try and cure cancer, surely, like I say, I've got lead poisoning. I would have thought, somebody would have been interested in associating, trying to associate the lead poisoning with the cancer....".*

He had no intention of giving up either smoking or drinking alcohol. He emphasised this by telling me, "*You might as well give up living as well, mightn't you, if you stop drinking and you stop smoking, what else do you do, you know that's all I do...*"

The difficulties of loss

Arthur Kleinman in Suffering, Healing and the Human Condition (1988) likened some chronic illnesses to "sponges", which "..soak up personal and social significance from the world of the sick person" (chapter 2, p 31). To a great extent, this appears to describe the situation of the cancer sufferer. It has already been seen that the choice of one's social habits (i.e. smoking and alcohol intake) are infringed upon. One also loses (either temporarily or permanently) one's social role, be it for example, housewife, breadwinner, spouse or parent. This happens because the illness itself is frightening and distracting, and its treatment demands both physical and emotional resources.

Literature such as Kleinman (1988) concerned with chronic illness, can be useful when examining the many losses the cancer sufferer endures. Other examples could include, Anderson and Bury (1988), Williams (1993) Radley (1993) Charmaz (1983) Gregg (1989). Chronic illnesses are long-term, involving plateaus and gradual disability (but are not necessarily the cause of death). The course of cancer tends to have a sharper downward trajectory and is usually the cause of death; though modern cancer treatments do often prolong life even if they cannot always cure it. Meantime, difficulties of loss occur in everyday life. To draw some parallels between chronic illness and cancer may be enlightening.

For instance, Williams (1993) talked about the chronically ill struggling with the potential loss of independence. This was seen in Ivy, who didn't want to become "..*a problem to* (her) *two sons* ...". Williams postulated that for such people, the "*pursuit of virtue*" via for example, cleanliness in the home, can demonstrate retention of independence, and this would also seem to fit Ivy.

Charlie also took great pride in keeping house for his adult son, a task he continued to do at the time of the interview. He told me, "*Well, I was thinking of my boy, in the first place, because there's only me who gets him up for work of a morning and I cook all his meals and all that. And a young boy on his own, I don't think he'd cope the same as an older person...*". In order to do this, he had to forgo other activities and go to bed in the evenings at eight O'clock, missing the social time he may have shared, after his son returned from work.

Radley (1993) suggests this sort of coping, is perhaps a "metaphor using the body". That is, as in the case of Charlie, that the "ill person" is not continuing to keep house to prove they are completely cured, but to show that they can carry on despite their ailments. Charmaz (1983) points out that reducing some activities in order

to maintain one's self image in others, assists in restoring a sense of "freedom of choice".

Like Charlie, fatigue was also problematic for George, who told me, "*..tomorrow, I can get up tomorrow morning, after a good night's sleep and feel pretty groggy and so peculiar and er lifeless and exhausted.*" He went on that such "*off days*" made him "*..wonder if its getting worse..*". These days of tiredness could occur without warning and he would have to stay in bed. It also meant that the social pursuit of country walking he shared with his wife, had to be curtailed, because he couldn't "*go for long walks*". Additionally it infringed on his time with his grand-children. Though he was a relatively young "grandad", he could not do too much physical activity with them, because he got, "*..a bit short-winded, ... running about after them, playing football*".

Harry described a practical problem of lack of stamina, when he remembered the difficulties of shopping, saying "*...I had to stand against the wall, carrying a couple of bags, course I can't now, fighting for me breath...*".

Tom, Philip and Barry all had work related losses, with varying outcomes. Barry was fortunate in this respect in that his loss was temporary and his employers understood his health problems. Philip had sympathetic employers too, though he told me:

> "..*my only worry at the moment is how the firm are going to take it..they can only keep on paying for so long..* (they might ask) *when are you going to be capable of working...would I be capable to work?*".

In fact, he was never going to be capable of undertaking his old job. At the age of 44 years, with three young children, this was a major worry. As a result of his interview, at Philip's request, I enlisted the help of his consultant to write to his employers. This enabled a speedy and in Philip's view, very satisfying early settlement of a pension and lump sum. As gratifying as the lifting of this financial burden was, it could not replace the satisfaction of "*camaraderie*" and "*something* (useful) *to do*" (Philip).

For Tom obtaining a job was crucial, as he had always been a casual worker on building sites, and was consequently relying on unemployment benefit (plus any other benefits which the Social Workers could arrange for him). He asserted:

> "*So, eventually, I will get a job, I wouldn't be coming here ..there's no way I'm gonna lose a shift to come here, simple..... I'm sick of doing nowt,*

> *aren't I, I could live this life great if they'd give us £300 quid a week... I must get a start now..".*

This was going to be difficult, as not only had he suffered laryngeal cancer, but additionally there had emerged a chronic knee problem. The physiotherapists felt this was general "wear and tear" related, with little hope for improvement.

Barry, Bill, and Esther were all unpleasantly aware of the possibility of severe physical debilities if they had to undergo surgery for recurrence (e.g. loss of voice). These potential losses were not only of function, but as Sacks (1984) phrases it, there is also an, "..inner loss ..both 'photographic' and 'existential'"(p50).

These latter concerns are tied-up with what is currently known as 'altered body image'. Price (1990) suggests that to support an adequate personal body image, one must balance 'body reality', against 'body ideal'. That is, making the way we really appear as close as possible to the "picture in our heads" of how we should like ourselves to be. We do this by the way we present ourselves to the out-side environment, i.e.'body presentation'. Taking this model into account, it is obviously much more difficult for those for example, who undergo mutilating head and neck surgery, to close the gap between "body reality" and "body ideal".

To some extent, this area has already been explored in the sub-section of "treatment options". Nevertheless, the two quotes below may indicate once more the strength of feeling of some of the interviewees on the difficulties of preparing for potential losses of this nature;

> "*..the thought of losing my voice and having a stoma in me throat..well, it doesn't bear thinking about...If at the worst, I lost my voice you don't come into this world talking..I could still drive me car...*(etc) (joking with wife, he demonstrated a black sense of humour, saying)... *better stop at Halfords, get a motor horn - one hoot for yes, two for no*". (Barry)

> "*I'd rather snuff it...three months when I couln't talk and it was* ***agony****, I'd rather be dead*". (Tom)

Another more abstract type of loss is the absence of a feeling of certainty about the future. For instance, plans may become much more short-term, and the subjects talked about taking one day at a time. Bill made a very practical alteration in this respect, when he told me that his usual practice of changing his car two yearly had stopped. After all, why take on such a financial incumbrance, when the future was so uncertain?

Additionally, Will highlighted how dreadful uncertainty about prognosis can be for one's family. He had to steel himself to try to explain his illness to his teenage children. He recalled;

> *"I - I think it took me a couple of days to summon up the courage... well, they couldn't live with it, if they didn't know really, and I thought, if you made a bit of a thing, you, you can't just ignore nothing, if they knew there was something* (stops)*... They just said, alright Dad, I don't know how they took it, erm probably I don't think the* (younger) *girl knows a great deal, she doesn't, but the boy thinks a great deal*". (Will)

It is clear that with all these types of real and potential losses, it would also be easy to lose self-esteem, or as Charmaz (1983) phrases it, "suffering such losses results in a diminished self" (p 169).

Importantly, Charmaz (1983) featured how health professionals can assist in promoting a positive self-image in their clients. She felt that:

> "When ill persons receive positive reflections of self in interaction and take them as credible and real, they are more apt to regard themselves positively. But when demeaned and discredited by those to whom they attach significance - even during the briefest of interactions - then maintaining a positive self-image becomes problematic". (p181)

This theory seems to fit well with much of the data examined thus far, in that there are multiple examples of appreciation for the positive assistance of health professionals. The subjects may not always remember any explicit information, but they recall how they were received. They mention, "kind words", a sense of humour, a feeling of efficiency in their care. They also remember when there seemed to be inadequacies, e.g. the lack of a safe environment to ask questions in clinic.

In conclusion, the data in this chapter seems to have demonstrated that even where there are feelings of dissatisfaction with specific information (e.g. inadequate preparation about copious saliva for Mary) there often remained an overall satisfaction with general care.

This may yet again implicate the vulnerability of cancer sufferers' in their need to keep faith in their health care team. It becomes even more incumbent upon health professionals to listen to patients carefully, when criticisms may not be openly expressed.

The next chapter also reveals patient vulnerabilities. It deals with the longer term "costs" of treatment, as well as the uncertainties of follow-up visits and the efforts needed to re-establish a sense of normality.

CHAPTER SEVEN

THE "SENSE OF AN ENDING"

> *"..everybody, I mean, providing you've got your faculties, everybody wants to live on .... 'Cause life is so sweet!".*
> (Harry)

> *"...only, if I hadn't had the treatment, I don't think I would be here, because, it was going to get worse, wasn't it?".*
> (Maggie)

INTRODUCTION

In the face of death, life itself can become reaffirmed, or as Harry phrased it, "..*so sweet!*". In this situation, Benner and Wrubel (1989) remind us that,

> "A life threatening diagnosis, such as cancer, confronts the individual with his or her finitude and temporality... (and)...hearing that one has a life-threatening illness causes the individual to reflect on his or her life with a new perspective...". (p.295).

In this section, this feeling of gratitude for survival, teamed with hope for day to day living, will be illustrated. Additionally, it becomes evident that this gratitude exists, despite the toll taken by the side-effects of treatment. (Demonstrated in "Getting Through" treatment, in the "Middle" chapter).

Indeed, some cancer sufferers were left to bear permanent ill-effects from their treatment (to be explored in detail later in this chapter). Nevertheless, it was usually perceived that the only alternative, had surely been death. Hence it was generally understood that deterioration in any aspect of quality of life, had been unavoidable. In the light of this, a kind of philosophical thinking appeared to evolve about the success of treatment. This philosophical stance will now be depicted.

Balancing gratitude for survival against the "costs" of treatment

> *"Well, I don't think my side-effects have been too ghastly, I mean, you know, I could be dead, couldn't I...".*
> (Mary)

> *"So, I'm not disappointed at all!..I can walk quite well, and my respiration's*

quite good now. There's only one trouble I have left, that is, I can't carry anything, any weight". (Will)

"*No, he said there was no guarantee that it would (help breathing) but, he said, it might help your breathing, but um, alright so, I'm back where I started, and I'm not breathing very well, but I'm still here aren't I, I'm still alive, even if I can't do what I want to do, I can still do things in, you know slow motion, sort of thing, not going mad*". (Maggie)

"*Things they forget to mention.... everyone is different, they can't predict..but you don't think of that.... felt philosophical about it..well, biding time.. till it gets better, or stuck with it... If I hadn't had the operation, what would it be like now, how bad would I be now? I'd be* (in hospital) *just waiting for cancer to take its toll*". (Philip, who had undergone an operation for recurrence of his cancer).

> "..*you enjoy* (life) *more, you've come back from death's door... The only difference is that, is the* (lack of) *saliva, and that is an inconvenience ... other than that life is back to normal*..". (Barry)

Perceived improvements in well-being after treatment

In contrast, three of the subjects did talk about an improvement in overall well-being, after the radiotherapy treatment. Most participants however, are not saying that they feel better than before the onset of their disease, just that since then, the treatment has ameliorated problems.

These perceptions, whilst demonstrating the added benefits treatment can give, may be linked with the philosophical thinking out-lined above. This is probably most applicable for the lung cancer sufferers, Will and Ralph. For, in reality they had both suffered a steep decline in health, due to their disease. Perceiving benefits from treatment (besides that of survival) could be part of "making the best of things".

This was probably not so for Tom (a laryngeal cancer sufferer) for whom treatment certainly did appear to have clear benefits -reducing pain, improving swallowing, breathing and speech.

> *"No complaints, pretty satisfied, pretty satisfied.. My body feeling better".* (Ralph)

> *"I feel a lot better than I expected to a year ago. A lot better.. I wasn't actually hoping for anything, I was, I was hoping to feel __better__,* (pauses) *help me in a better standard of life. When I first started treatment, my er my circulation in my legs, was so bad, I could hardly walk. And er, my respiration was shocking!* (Now) *I can walk quite well, and my respiration's quite good ...I-I think the most amazing thing that's happened to me is, that, the visible thing, that's my actual __skin__ texture! I-I'm really amazed about that! Because prior to any treatment at all, my skin texture was grey, so, the whole of my body is now, a normal fresh colour! I'm really pleased about that!".* (Will)

> *"I felt one hundred percent better...* (the treatment) *hurt like...but it wasn't as painful afterwards as I'd suffered the*

> *previous six months..at least I could breath and swallow...I'm a thousand per cent better than I was, put it that way...*". (Tom)

Detailed descriptions of the lasting ill-effects of treatment

As suggested in the last section, for some cancer sufferers', survival was attained "at a price". To illustrate the problems, whilst maintaining clarity, the following descriptions are split into the two groups of "lung" and "head and neck" cancer sufferers.

Lung Cancer Sufferers

For the lung cancer sufferers, the effects were predominantly related to breathing problems (though this predicament is also due to damage caused by the cancer itself). Accordingly, consequent effects upon the general constitution included, markedly decreased physical stamina, reduced appetite and less capacity to work or enjoy leisure time. These ill-effects are now illustrated, within the context of every-day life.

> "*..and er, when I started the treatment, I never had this cough, I got a cough now all the time, and I keep on bringing*

up phlegm, and I never had that...
but, I don't feel any better than
when I first went, well, I feel a bit
worse, because I'm coughing and
bringing up phlegm. And, and, if I
want to go to toilet, too, I've got
to take tablets now (for constipation)
...... Only I don't go out dancing or
anything, I used to be a lovely dancer
...because by the time the day is
finished, I'm ready for me bed! And
I'm in bed at eight o'clock..".
(Charlie)

".. on the whole, I'm not too bad, but as I say, I cannot walk very far, and when the doctor says to you, why can't you, (chuckles) *well, you do what you can, and you're not going to push your luck, are you? Cos, I did go shopping with my daughter one day, and erm, I just stood, I said, I can't walk any further, I've got to stop. So, we stood there, and it was raining too, and I just stood until I got a breather...".* (Maggie)

"I wonder, cause of these bad days (i.e.exhaustion) *is it the radiation*

> *what's in your body, that causes you to have these bad days..".* (George)

Head and Neck Cancer Sufferers

Some of the head and neck cancer sufferers (i.e. those with cancers of the oropharynx and hypopharynx) had permanent problems with insufficient saliva production. Saliva is essential as a lubricant and also possesses an anti-bacterial action. Consequent problems for this group were difficulties in eating, swallowing, speaking for long periods and serious deterioration in the health of the teeth. Those with cancers in the laryngeal region could have alterations in the quality of their voice, e.g. hoarseness.

Descriptions of these detrimental effects upon quality of life, for this collective group, is now recounted.

> *"Well, that is the worst, that is a nightmare for me, actually, I mean really, I can't say I enjoy food at all... I find I start things and it sticks to the roof of my mouth.... But it worries me, this weight. I would not be quite as agitated but, you know, knowing that every calorie is important.. I ought to be more than seven stone... I*

found I was leaping on the scales every day... I can't taste things, but I don't know, I have to try... a lot of things I like, like bread and potatoes, I really can't eat without being so uncomfortable. It sticks in my mouth all of the time. I have to drink a gallon of water to get it down and I lose interest... Cakes I do like now, which I never did before, but my teeth are so on edge, I can't eat it." (Mary)

"*I'm alright actually, you know, apart from the talking business, and if I do carry on talking, I'm down like I am now..*". (i.e. very hoarse, Bill)

"*No, I can't eat this, I can't eat that.... forced myself to try things... after a while I found my taste buds were coming back and the saliva wasn't as bad*". (Esther)

"..(mouth) *dry and sticky..if you have it long enough, you learn to live with it...thought after a while things would fall back into place..*(doctor says) *no,* (the treatment) *destroys good cells as*

> *well as bad*". (June)

In the context of the above descriptions, given by both the lung and head and neck cancer sufferers', Benner and Wrubel (1989) remark that,

> "rehabilitation needs to include an assessment of the alterations experienced in embodiment and a renewed sense of bodily integrity" (p 293).

They also cite the work of Bard and Sutherland (1955), where a breast cancer survivor described that her self-perception had become dominated by a feeling of fragility, approaching life like a "boiled egg" liable to break her "shell" at any moment. This type of feeling is echoed in the quote from Maggie, where she talks about the desire not to "*push your luck*".

All of the quotes above, exhibit very real deteriorations in "bodily integrity". Benner and Wrubel (1989) go on to relate this to feeling "whole", and suggest that more research is needed about this phenomenon to aid rehabilitation for cancer sufferers. So, it seems that any sense of feeling "whole" has necessarily to be defined differently from that which existed before the cancer diagnosis and its treatments.

Doubts about being cured by treatment

Taking into account then, that many of the sufferers' did not actually "feel better", there was no common-sense criteria by which they could judge that their cancer was cured. For, despite the common belief that the treatment had been worthwhile, predominantly because of survival, there lurked fears that there was a lack of proof about cure.

Though this was rarely verbalised to the doctors, there appeared to be little acceptance that the vague statements that they were "doing well" or that the doctors were "pleased" with their progress, meant cure. It seemed that rather than bolstering confidence in the hopes of longevity, these encouragements were paper-thin. The subjects knew they were not categorically cured.

Davis, as far back as 1960, found a similar veil of uncertainty drawn over the outlook for children with polio in the same way that being "cured" of cancer is evaded. Davis (1960) concluded that doctors did not have the training to handle this very disturbing type of situation.

It should be stated that some doctors cited in this study did outline their opinion on cure (e.g. Harry's doctor stated openly that he was not be able to cure his lung cancer). Nevertheless, most of the subjects were left with equivocal feelings about being cured. These doubts will now be specified.

> *"Oh yeah, I'm sure it must have been worthwhile...except that I know there's something wrong with me, you know, I know there's something there, and all I'm hoping and praying is that er it will stay there and let me carry on as I am..."*. (Bill)

> *"..<u>if</u> they showed you the x-ray, like they did when I first had it, they showed it <u>after</u>, then you'd know they'd done their job. ...like when you have a car, you go in and have it serviced, you come out and you can have someone to have a look at it, and see if they done the job! What they supposed to have done. But, er, this way, I'm not, I'm only going by word"*. (Charlie)

> *"Well, they're pleased, but it doesn't please you so much, because you're only pleased because they're pleased, but you*

don't know....I suppose it was my own fault, I should have said, well, you're pleased, but why are you pleased? And, is it clearing up?". (Maggie)

"Yes, I don't think about it, I just know I have it, I don't think it goes.." (Ralph)

"Nobody's told us anything, you know.. is it coming back, is it gone for good... is the cancer gone.. could it come back?". (Tom)

"Yes, I was concerned and then um, I thought well actually, I wonder if they are telling me the truth about it, or whether it... well, I would hope that they would tell me the truth, because I don't think I am stupid, and I really think that, I personally think that it is better to know something, I suppose lots of people don't..". (Mary)

"And they were very pleased, they said, it er it had reduced quite a bit, and er, there was still some there, but <u>what this meant</u> in actual fact, I don't know,

> *its liable to grow again, or it, its liable to continue to reduce. I don't really know, don't think they were quite sure...Yes, well, I mean obviously you can't see exactly what's going on inside...*". (Will)

Will accepts that they were "*unsure*" because he appreciated the doctors could not accurately gauge "*what's going on inside*". Nonetheless, in such cases, it remains that many cancer sufferers are respecting the doctor's dilemma in not pursuing what the terms "*pleased*" and "*controlled*" really mean. Either because;

a) they realize that it does mean they are not cured

b) they realize the doctors cannot cope with telling them

c) they realize that the doctors do not know how to tell them that they themselves remain uncertain.

Alternatively, the patients themselves are avoiding or "buffering out" (Cohen and McKay, 1984) unwanted information, in order to cope with the situation.

Relevant to this communication problem, Thorne (1988) deduced from her own research, that "how" and "what" is communicated to cancer sufferers makes a notable difference to the success with which they clarify and come to terms with the life-threatening aspect of their disease. She concludes that particular communication skills and special qualities are thus required of health care providers.

The role of clinical "follow-up" with cancer recurrence

Following treatment then, the subjects become locked-in to an often lengthy series of follow-up visits. The rationale being, the earlier further disease is detected, and supplementary treatment given, the better the chances of prolonging survival. Or, in the case of progressive (terminal) disease, follow-up may be continued in order to help control distressing symptoms e.g. pain.

Of course, the length of follow-up is dependent upon length of survival. It is thought that most cancers have a higher risk of returning in the first two years after treatment (e.g. Cancer Research Campaign Factsheets). Though even cancer sufferers who are disease free after five years, will probably still be invited to attend, even if only once a year.

Thus the pattern of follow-up visits to the hospital Out-patient Department, is often weekly immediately after treatment. Thereafter, it is gradually spaced out, progressing to monthly, two monthly, three monthly, etc., providing that all is well. (Out-patients often term this as "being promoted", demonstrating that they appreciate the significance of this spacing, in terms of the likelihood of the cancer recurring).

Most of the subjects in this study, being six months from the completion of their treatment, were attending every two or three months, depending upon their consultant's wishes. (Except Philip who attended for monthly as he had already had a recurrence of his cancer).

These hospital appointments could be another source of conflicting emotions within the subjects. On the one hand, they could be comforting, i.e. being checked by an expert and given assurances that at that point in time, there appeared to be no signs of recurrence. On the other hand, there could be the build-up of anxiety before-hand. Would they be "clear" of disease? Would they have the opportunity and the confidence to ask about any niggling worries? Would they, in fact, receive the dreaded news that the cancer had returned?
Accordingly, the subjects seem to recall metaphorically "holding their breath" before appointments, and giving

a "*sigh of relief* (when) *given the all-clear*" (George).

But, it is also evident that any reassurance is not long lasting. The threat of spread or recurrence of the cancer seems to hover often in the background and sometimes more menacingly. (This will be also be explored further in the section on "Fears about spread and recurrence of the cancer").

Firstly though, examples of how the subjects expressed their ambivalent feelings regarding follow-up can be traced in the following quotes:

> "(The staff were) *very patient, don't feel I've been rushed -wonder how they can spare all the time that they do.... keep my fingers crossed... wonder how they can be so sure...* (I) *don't dwell on it..try to forget it...*" (i.e. between the appointments). (Esther)

> "*... don't sweat blood from one visit to another... don't go to sleep thinking cancer... everything I asked about I was told, given an honest answer, if they didn't know, they said so... better than pipe dreams..*". (June)

"(The doctor) *doesn't want to see me till next May, so it must be o.k... I accepted it, the only way I think I'd know if there was anything more again, I'd get pain again... I've taken their word for it... they know what they're doing.. I believe when they tell me you're doing well.. I have to.. He did leave me a bit quickly.. he's a busy man .... he's got others to see... he did what I came up for him to do.. You cannot tell if you are cured, it would take at least five years ...*". (Ivy)

"*Who do you ask? .. you know what its like..get your prescription..* (there's) *no privacy..go 'cap in hand'... So, I'll have to come here indefinitely?.. Couldn't I go and see my own G.P.? ... Even if you're gonna snuff it, tell you you're gonna snuff it, but nobody told me nowt..*". (Tom)

"*I'm not against* (follow-up) *or anything ...* (its) *quite straightforward, clear..* (I've) *been quite satisfied... nervous, nervous for the result* (of tests) *in case it hasn't shrunk it, but it was a* *good result, so I was quite happy...... when I have off days..* (I) *wonder if its getting worse, but then at the same time, I'm told that its shrunk....* (about a week before a visit).. *er, am I gonna get a bad result?.. well, I suppose it would be a shock, you know... I don't think I'd know what to do.. I feel positive it is o.k".* (George)

"I felt good, I felt good, when I spoke to the doctor, that morning, and he said its gone, I was in the pink then - I was ... I wouldn't ask anyone except the doctor (nurses) *mightn't have the experience.... anything I wanted to ask, I asked straight.. I wonder if it will come back somewhere else?".* (Jimmy)

The importance of test results in the follow-up clinics

Often integral to being given an "all-clear" were various tests, including computerised scans, biopsies and x-rays. Two of the subjects remarked about the non-urgent way of handling test results. That is, though they were anxiously awaiting the outcome, the doctors underestimated the importance of the results to them.

Mary cited the procedure known as a "needle biopsy" performed in clinic, on a lump in her neck. At the next appointment, she expected the results of this and assumed that they were significant to her treatment. She felt that the doctors had forgotten about the biopsy, until she reminded them of it. Busy clinics are perhaps to blame for this problem. Nevertheless, good practice normally means doctors reviewing medical notes before a consultation.

> *"I said, what happened about the other nodule? And he had obviously not remembered and he went to look at the papers, and they were noted to be there on the neck scan, and the C.T., and they were negative..* (on the biopsy)". (Mary)

Maggie and her husband were perplexed when following a computerised scan, the results were to be withheld until her next appointment three months hence.

> *"..and on the last couple, we've gone up to the x-rays and scans, and we've got no information from that whatsoever".* (Maggie's husband)

> *"He thinks the same as I do, that it should have been the other way round,*

> *you know, have the scan, which is more deep than the x-ray, and had a visit to the doctor the following week, or whatever. 'Cos, even when I come out of the scan, the chap said to me there, he said, 'are you going to see the doctor?', and I said, 'no, not for three months', so he said 'oh well, make sure..when you do see the doctor that you ask about the scan. ...* (The doctor) *said if you felt, you know, that you wanted to go up there, you could, but you sort of took that as if you were in any problems, you know don't you..?*". (Maggie)

So, although Maggie's doctor had given her "permission" to contact him with "*problems*", Maggie doubted whether this covered discussing test results. The underlying reason for this situation, in the case of lung cancer, may be that there is little further active treatment available. The doctors see little urgency in pursuing the results. For instance, Maggie's scan was taken due to her participation in the CHART medical research study, to assess the efficacy of treatment.

The fear of cancer "spread" and recurrence

Even with or without test results, it has become clear that for most people, suffering a serious illness of this nature, means it is your fate to fear its recurrence. Also the known and unknown consequences of its return. This has been mirrored by Benner and Wrubel (1989) and in the work of Sutherland (1955). In other words, a heightened sense of one's vulnerability is often the result of a serious illness. Fears of this nature are exemplified in the quotes below.

In addition, a unique almost "alien" dimension to cancer is sensed, i.e. in the way that the cancer is referred to as almost an independent and uncontrollable invader (especially underlying the quotes from George, Bill, Philip and Jimmy).

> "*If I get pain, I get a bit worried.. I think sometimes, I do worry about it a bit - if my neck pulls a bit, I think, please don't let it be anything.. I don't want to be a problem to my two sons... I don't ever want to be ill again.. is it going to keep recurring... I'd much rather go like my husband* (who died with emphysema)... *I'd have to do something* (referring to past attempts at

suicide, when she was depressed after her husband's death)". (Ivy)

"No, sometimes I feel, you know in myself, you know, it has shrunk, but has it grown somewhere else, has a piece dropped off.. is it possible a piece has dropped off or something, you know a live cell?". (George)

"Tell you Karen, what's making me think I've got it again - you hear so much (newspapers, t.v.) *and they say it comes back again.. I wonder if it will come back somewhere else?"*. (Jimmy)

"..there's something around the corner, something's gonna go wrong.. its gonna come back". (Philip)

"..the only time I've wondered... every morning when you shave, examine my neck ..is there another lump?". (Barry)

"If it is coming back, in a bit of time ..and I would be getting treatment.. I don't know what type of treatment." (Ralph)

"Well I really, I suppose I would like somebody to say to me, right well, you know, if you're not well in six months, too bad, but if we haven't lost you, you will be o.k. (chuckles) *one way or the other.. be brave or Father Christmas won't come"*. (Mary)

"I've lost a lot of friends and erm there is a couple of them that've just died.. in your records.. and they died, didn't they, so I don't know whether this will stay where it is, or go down there, I don't know. I don't really know. I know it is a spreading thing". (Bill)

"Dr X says, er the first x-ray after the (treatment), *he said, 'well its gone, its cleared up and* <u>*now*</u> *as far as you're concerned, its finished!.. well, its there you know, its like you trying to buy your own house, its lovely, then you start thinking, oh, what's behind it, you see, it isn't so easy as it looks!"*. (Harry)

Striving for a sense of normality, six months after completion of the radiotherapy treatment

The analysis is concluded with a depiction of the ways in which the sufferer's continued to strive for a sense of normality. This is a difficult task in the face of the fears, anxieties and uncertainties catalogued in the preceding sections.

Certainly, this first quote from Philip, stands as an example of just how difficult it can be to return to any sense of normality. He displays conflicting thoughts about the added trauma of "salvage surgery" for recurrent head and neck cancer. It had been expected that this would be very mutilative surgery, but thankfully in the event, it had not. Though he had not lost his tongue, it still seems to have been a shocking emotional experience. Additionally, physical normality was impeded by an infected and grossly swollen face and poor articulation of speech. A further impediment being that extra post-operative nutrition had to be continued by Philip at home, using a small tube inserted into his stomach, via the abdominal wall.

> *"It hasn't affected me that bad -*
> *otherwise I wouldn't still be smoking-*
> *just can't stop.* (After the operation)
> *I didn't know what to feel, thought,*

> *should be feeling something... maybe it as too much.. expecting whole new life... It's now back to the way it was... I should feel something.. now I think its too good to be true....* (looking at the t.v., people laughing) *I should be like that, going out, meeting people you haven't seen for a long time.. seeing people worse off..* (I) *want to lead a normal life.. its taken 2 years off my life, might as well switch off until it gets better, pointless trying to work..* (or) *go for a beer Sunday lunch-time... No, don't have any thoughts* (about the future), *well nothing definite, can't see anything great, marvellous happening, will plough on till I die....* (I'm) *not ambitious... This is just two or three years out of my life, or something, then it'll be back to normal..I hope* (laughs)".

(Incidentally, some irony in experiencing cancer was evident to Philip and he did have one positive thing to say about it. Dogged by financial worries for many years, he did feel that "..*put cancer in a letter*" to creditors, and they will "..*back off!*").

Like Philip, it seems integral to the human condition to aspire to revert "..*back to normal*". This can also be seen to be parallel with those suffering chronic illnesses e.g. Kelleher, 1988, refers to diabetic sufferers "normalizing"; and Scambler and Hopkins, 1988, talk about "accommodating epilepsy in families", (in: "Living with Chronic Illness, ed. R. Anderson and M. Bury, 1988).

In fact, the succeeding narratives on what the subjects were now able to undertake and draw satisfaction from, appear to be the product of adjustment to a re-defined "normality". (Also proposed in the section about the ill-effects of treatment).

This involved things like, pacing oneself for physical activities and being philosophical about things that could no longer be enjoyed (for instance, by off-setting losses against the relief of surviving at all, a focus of the section about the "success" of treatment) and continuing to derive satisfaction from those activities which were possible. Shades of Charmaz (1990) regarding minimising "loss of self" described in the section about loss, can be discerned in the ensuing citations.

This next quote then, is from Mary, who has been a long term volunteer for a local centre for the blind and partially sighted. After a period of absence, due to her own deterioration in health, she has returned to the centre, though it can be seen that she is not back to her previous state of health.

> *"Oh, I'm always raising funds, we have jumbles and bazaars ....* (the clients) *are very old actually, most of them are partially sighted, and when they all get together and are all rabbiting, that's the happiest part, you know. And erm, take them shopping and a walk in the park.. no, er, nothing's really changed at all, except I do really think sometimes I do get more tired, and I always used to stay up listening, watching television, until very late, and I don't do that now,I go to bed now, I drift off"*.

Will, a retired chef, explains the detrimental effects the cancer experience has had on him, as well as the enjoyment he still gains from life. A process of coming to terms with the situation appears to be illustrated, where seemingly contradictory remarks occur, e.g. "*...I can do most things..*" versus, "*I don't do anything outside that,* (ie.cooking) *I don't think there's anything* *else I could do at the moment..*". In other words, accepting losses but continuing to accentuate the good that has been retained.

> "*I can do most things really... I can get through a day's working quite well. If er I undertake to do something* (at home)*.. I think its best to get on with things. I-I don't want to dwell on anything that's there. I accept whatever is going to happen, is going to happen... I don't want it to become a part of* ***life,*** *if you see what I mean.. I mean if its in the family, its part of life.... I think its made me very introverted, I feel I don't want to get involved in things, anymore, you know, ... try and live out as calmly and as quietly as I can ..Oh, I do* (cooking for the family) *most of the time, just to keep me out of mischief! ..Yes, I enjoy it. I do all sorts of crazy things, if I'm in the mood!* (laughs) *No, I don't do anything else outside that, I don't think there's anything else I could do at the moment. I gave*

> *up work, because I realized that I had enough to carry on with... I have been for a long time, chairman of the scouts, erm well they want, they want me to come again, for various things, but I don't know whether I want to do it or not.... It's committing yourself to something, I mean its all very fine, today I feel fine, can do this and that, tomorrow, you er, and when you commit yourself to do something,it means you've got to drive yourself, and I don't feel like doing that, Hmm? Oh yes, I'm happy to think that I've got to the stage I am now, hope to continue!... Think I could hold my own with anybody my own age".*

Harry, George and Bill all had stationary caravans, where they went as often as possible, to relax with their wives. Here, Harry talks about his caravan and also the joy of being alive, though perhaps also living on "borrowed time."

> *"...And er.... I just carry on as normal. It's no good sitting around moaning, is*

> *it?..*(At the caravan) *I got to have a go at cuttin' the grass!.*(though mostly) *oh, I stop, down tools... Well, it makes you, there are, er things you just used to take for granted. You get up of a morning, and you say to yourself, 'well, God's good, I've got another day'.. and half the time, you know, you got to be careful, providing... well, if you're under the weather kind of thing, you know, which is, er as I say, you get it sorted and other than that you get on well, enjoy going down the* <u>*van*</u>*, little things you know you'd miss, if well..".* (fades)

Charlie (a widower of ten years) took a lot of pride and satisfaction in running the home he shared with his adult son. This included tending the garden too. (In fact at the end of the interview, he kindly presented me with a parcel of home-grown green beans from his freezer). These self-appointed jobs were becoming harder, but Charlie was prepared to devote himself to maintaining them.

> *"Yeah, I-I all I do, I like plenty a sleep, now well, er, go to* (bed) *eight O'clock, and I got up at five this*

morning, that's a long time to sleep for an old person, in't it you know, but er I keep going, I keep er keep going, because after all, I used to have an allotment, but I give that up, cause it was too much for me, and er, that's all it was, you know I do me own garden now, and that back, you know.... No, er, all I hope, I will live a little bit longer, well, I mean I'm only seventy-five, not bad really, but as I say, er I'm enjoying life, I'm er er if there's anything like, I'll go to the sea-side now and again, I ain't had a holiday for years, you know and that, but I'm quite happy with what I'm about to do er like the housework and so on, sewing and ironing and shopping (laughing) *and all that, I'm quite useful and all that you know,... only some men can't get on with that, some men can't do, wouldn't be bothered and they let themselves go, but I wouldn't let myself go, cause I know I lost me wife, I can't bring her back....* (my son) *goes all round English coastline* (as a lorry driver)*.. and he's home about six O'clock, and er I do him all his dinners... if I never had me boy,I*

> *wouldn't have no-one, and er I don't know how I'd have had with that, cause I turned round, I er, pulled me socks up, I thought well, I aint gonna be like that old boy down there* (neighbour) *.... frightened to do anything,.. I'm gonna pull myself together, and pull through it, you know, which I've done so far, you know, come through it".*

Maggie, talks about how much of her role as a housewife has been eroded by the physical consequences of her illness. Still, survival in any form was precious, as her cancer experience included an initial misperception that she would be unable to have any treatment, and death was imminent. So, she values the help of her husband and adapts to her new way of life.

> *"I um- I do dusting, and I do a bit of polishing, because as long as its not too much like hard work, but I cannot push the hoover, and so while I've still got him and he's capable, he does it, but um, I still do cooking and things like that..I love cooking, actually I always used to do a hell of a lot of cooking at one time, I don't do so much now, 'cos the family's grown-up*

> *and whatever, but um, oh I did, I used to love cooking and experimenting with things, you know. We don't do bad,* (now) *but er, you know, we don't do anything sort of exceptional".*

This final quote is taken from Barry's interview. He tried to adapt to the problems associated with his cancer experience as he related to problems at work. That was, to try to "*solve*" them, and if that was not possible on any given day, then it was best to leave them be, not worry and approach the issues again the next day. He talked about keeping life in perspective, and like Harry, simply tried to enjoy life. He died about six months later. His death was sudden, and though few details could be traced, it seems that it was not associated with his cancer. His words are particularly emotive.

> *"... you enjoy it more, you've come back from death's door, each day is a new day, its another day, be grateful and thankful... you're not inclined to take things to heart... does it really matter? ... life is what its all about .. for example, work, its a job, other problems will sort themselves out... make you aware of things.. you relish eggs and*

> *bacon for breakfast ... simple pleasures ... I wouldn't say happier, but more awareness of life, not taking things for granted, grateful life is continuing".*

In the spirit of Barry's words, Neil Fiore (1979) a psychologist who has suffered (and survived) testicular cancer; has suggested that despite many losses to bodily integrity, there are some "secondary gains" from having cancer. He described,

> "..increasing reports of patients with cancer, some of them well-known personalities, who have used their bout with cancer to improve their lives, reorder their priorities and make every moment count". (p 288)

This type of feeling is also implied in the section regarding gratitude for survival. Such allusions come close to insinuating that some cancer sufferers are glad to have experienced their illness, because it has meant the "secondary gain" of valuing life much more.

Although Barry talks vividly about his renewed love of life, this should be tempered by a later comment in his interview i.e., *"It's all been an experience, one which I could have done without, if you like, given a* *choice...*" (George also passed a similar remark). Any "secondary gains" of having cancer, however valuable, are apparently discovered through an experience not sought or desired.

To conclude, Guggenbuhl-Craig and Micklem (1988) counsel that "..each of us may, and even perhaps should, find 'meaning' in our illnesses"(p 141). But, they caution against a "..cult of meaning, which may shield its followers from a realisation of the inescapably tragic dimension to illness" (p 141).

In other words, one is not "chosen" to have an illness, and such an experience cannot be said to be fortunate, but, it can be helpful to draw something positive out of the tragedy.

CHAPTER EIGHT

DISCUSSION

INTRODUCTION

The purpose of this chapter, is to bring together the themes of the analysis. These concern the interplay of communication and the individual's experience of cancer.

The main issues to emerge were related to information about diagnosis, treatment options, prognosis and the side-effects of treatment. Additionally, data emerged about the general influence health professionals exert upon the self-esteem of cancer sufferers.

A proviso should be, that the data reflects the specific circumstances of the study's participants, although some wider concerns are implied. Accordingly, this chapter will explore the corollaries of the analysis, commencing with informational needs and moving through to the behaviour of health professionals.

Information regarding diagnosis

In this study, all the participants felt that they had wanted their diagnosis to be made explicit to them before their treatment was commenced. This replicates the results of previous research (Cassileth et al., 1980; Reynolds et al.1981).

Will stated, that you, "..can't ignore nothing". In other words, at some level of consciousness (depending on the individual) one has to be aware of the nature of the illness. Then, whatever your usual approach incorporates (e.g. avoidance, information-seeking) it is somehow more possible to cope.

Lazarus (1966, p80) seems to refer to this type of coping, when he proposes that, "what may be appraised..is that aspect of the stimulus which has a harmful impact upon the individual; other aspects may be ignored or may be only dimly perceived". For instance, the cancer sufferers needed to understand that they had a serious illness requiring lengthy and demanding treatment. Nevertheless, once completed, some of the subjects seemed to opt for remaining "dimly" aware of the prognosis (to be explored in the next section).

Alternatively for some, despite prevarications along the way (e.g. Harry not following up his chest x-ray results), practising avoidance becomes unnecessary once it has provided the breathing space to acclimatise to the situation (Benner and Wrubel, 1989).Buckman (1992) also reflected on this type of phenomenon, concluding that for some patients, "..denial and disbelief shade into each other.." but the denial does not "go all the way down", at some deeper level they accept the diagnosis.

Consequently, the message appears to be, that cancer sufferers appreciate the modern trend of openness regarding diagnosis. Those who need time to adjust may experience denial, but generally reach a point of acceptance. In the light of this, the issues seems to be how much information is desired about the impact of treatment and the expected outlook or "prognosis".

Information about treatment options and prognostic outlook

In this area of communication, the subjects expressed differing preferences. Some would have liked more information than they felt they received, though notably they had not verbalised this at the time. Others wished to have only the minimum amount of information, content to allow the doctors to decide the best treatment and when to give guidance about outcomes. In fact, there was a sense that those taking a passive line, would have found more information (and consequent pressure to make treatment decisions) an extra source of worry.

In addition, desire for information can change over time. For instance, the satisfaction with openness about diagnosis did not necessarily transfer to a desire for a similar openness about cure rates after a recurrence.

Difficulties such as these, seem inevitable in such portentous areas of communication, bound-up as they are, with the possibilities of mortality, future suffering and disability. The challenge, once this premise is understood, is how health professionals address individual needs.

This research study has indicated that current practice is not adequately meeting such individual preferences for information. Therefore it would appear to be vital to raise the profile of strategies (like that of Luker et al 1995) in order to improve communication in this area.

Information about tests during follow-up visits

Related to the issue of information about treatment and cure, is the issue of test results. Both Maggie and Mary were frustrated by the lack of feed-back and apparent non-urgent manner in which some of their test results were handled. It seemed illogical to them that if such tests were necessary, they were not reviewed promptly. This sends signals of doubt about the competency of the health care team. Why ask for them if they were not necessary?

Most of all, some of these tests were carried out to find out if the cancer had been cured or had progressed. As such, they held great significance for the cancer sufferers.

This seemingly cavalier approach to the results, e.g. Maggie having to wait another three months to see the doctor following her tests, seems distinctly lacking in an appreciation of the value placed on them to indicate the chances of survival. There seems a particular danger of this, when tests are required for the purposes of research projects but are deemed to be unimportant to the participants themselves.

The clear message is, cancer sufferers feel tests are significant.

Information regarding the side-effects of treatment

In contrast to the difficulties about treatment options and prognosis, there seemed to be a relatively clear-cut desire for full information about the side-effects of treatment. When communication of this nature was inadequate or inaccurate, anxiety levels seemed to be increased (examples of this will be discussed in the following sections).

This finding could be difficult for some health professionals to accept, as sometimes there is an inclination to "spare the patient" and lessen the worry of treatment, by moderating graphic descriptions. The rationale being that not all patients will suffer the worst effects.

This study has suggested that it is much more damaging for something unforeseen to occur, than for the sufferers to be concerned a priori about the difficulties of treatment. In fact, the cancer sufferers conveyed an awareness that most cancer treatments are harsh and exacting. (For instance, by their terror of the Cancer Specialist Hospital). So, information about the specifics of treatment are unlikely to be any worse than the expectations already formed in their "mind's-eye".

Cassileth et al. (1980) have suggested comparable reasoning, saying that the fears associated with uncertainty were, "worse than knowing the facts". The implication being that "becoming well informed may enable patients to maintain hope by freeing them from anxiety and fear" (Cassileth et al. 1980, p835). The consequences of inadequate information about the side-effects of treatment will now follow.

Inadequacy of information for those with head and neck cancer

This concerned the possibility of extremely copious, foul and sticky saliva for "at risk" head and neck cancer sufferers. Subjects experiencing this problem appeared un-complaining about the ill-effect itself, which they accepted. What was distressing for them, was that they had not been forewarned.

Health workers may underestimate this particular side-effect's impact, due to its temporary status. For example, in comparison, all the sufferers who were experiencing a permanently dry mouth due to the consequences of radiotherapy, recalled being forewarned (and perhaps fore-armed) about the problem.

In comparison, an unexpected outcome can leave a lasting impression of being, as Mary termed it, "unique". The implications being that it is perceived that the treatment is not going to plan or that their cancer is progressing.

Inadequacy of information about treatment for lung cancer sufferers

It emerged that in the case of lung cancer sufferers, health professionals seemed reluctant to indicate that subjects were likely to experience a deterioration in physical ability. In fact, this discussion was only recalled by one out of the five lung cancer sufferers. Maggie had remembered being warned that her breathlessness may not be helped by the treatment. So afterwards, despite her disappointment that her breathing had not improved, she was pleased that at least she was still alive.

But, just as Maggie made it clear that she appreciated the candour of her radiotherapist, those with inadequate information, found it more difficult to comprehend. In such cases there is a danger of attributing feelings of exhaustion to other causes. Such misperceptions may yet again be the cause of further anxiety, like the difficulties of George, who felt he might be radioactive.

Continuing with this example of perceived "radioactivity", the consequences could be fear about the ongoing damage to oneself, as well as possibly being hazardous to others with whom one has contact (e.g. grand-children). I suggest that a possible explanation of this misconception is a phrase commonly used by the doctors in clinic. Namely that, "..the radiotherapy goes on working after the treatment has finished".

The doctors usually say this to explain why patients are still experiencing soreness in the first few weeks after completion of treatment. Or alternatively, why it is too early to assess if the cancer growth has been eradicated. Thus it is meant to convey that the cancer cells may still be reducing and that normal tissue within the radiotherapy field will still be healing. Unfortunately, this is not the message that all radiotherapy patients are receiving.

Information about survival and the "costs" of treatment

In this area of life and death, though all of the subjects perceived the life-threatening aspect of their cancer, the lung cancer sufferers seemed particularly mindful of it.

In the hierarchy of cancers, lung cancer is the commonest in the United Kingdom. This large lung cancer population makes it more likely that the subjects (and the general population) would have knowledge of the impact of this particular diagnosis. Whereas head and neck cancer, which although affecting a sizeable number of people, e.g. 2000 new oral cancer patients each year, (Cancer Research Campaign fact sheet, 14, 1 1993) is proportionately much less common.

Such a likelihood of personal experience of others with lung cancer, may account for why the lung cancer sufferers in my study appeared to weigh-up the costs of treatment against the poor odds of surviving at all. Thus, they were ready to accept breathlessness after treatment and to compensate, they endeavoured to cherish the simple but nonetheless important activities they were still able to do.

Evidence of a similar attitude to survival also existed in the head and neck cancer sufferers, but it seemed to be less common. For instance, Bill and Tom thought that whatever happened, they did not want to lose their ability to speak.

The point seems to be, that the cancer sufferers often want more information about the long-term ill effects of treatment. They need this to help them decide whether to have any treatment at all, or which treatment option to choose. They also require such information to facilitate future coping with a diminished quality of life. It could also alleviate unnecessary worries, e.g. of being radio-active.

The influence of health worker's demeanour on the self-esteem of cancer sufferers

The participants in this study may have had particular reason to feel devalued. Cancer of the lung and head and neck regions, is strongly associated with smoking.

Additionally, excessive alcohol intake is implicated in causing head and neck cancer. (Cancer Research Campaign Factsheets). Such "social habits" could be viewed as contributing to a self-inflicted illness, with those who do not smoke or drink heavily (in this context, perhaps some of the health professionals themselves) in danger of appearing judgemental.

This was a less tangible area of communication, but as the data accumulated, it emerged that there were signals the subjects were receiving, regarding their value as a fellow human being. For, in a world which uses cancer as a metaphor for other social ills e.g. poverty growing like a cancer, (Sontag 1983) it is clear that such a diagnosis is still a cause for feeling stigmatised. Thus, the whole demeanour of health workers can boost self-esteem, or as Charmaz (1983) phrases it, counteract a "loss of self" or it can increase this loss.

So, when the cancer sufferers recalled small acts of kindness, a "good morning", sharing a joke or a smile, they were remembering being made to feel worthwhile.

Conversely, when they remembered hurried and unsatisfactory consultations, e.g. Tom citing going "cap-in-hand", they were indicating a feeling of gross inequality with the staff. (This feeling may be exacerbated by the architecture of the hospital, which does little to promote privacy).

Tightly interwoven with this issue of feeling valued, was the feeling of trust in the air of confidence exuded by the staff, which helped to maintain "hope". The staff appeared efficient and knowledgeable enabling patients to feel satisfied with their care. The fact that most seemed genuinely appreciative of the care that they received is reassuring for hospital staff.

Nevertheless, more needs to be done in this important area of communication. For instance, more efforts at providing privacy and as highlighted in the next section, further efforts can be made to boost patient's self-esteem.

Verbal acknowledgement by staff, of the difficulties of treatment

Finally, this study's perhaps unique contribution is in its characterisation of the subjects desire that staff acknowledge the "mountain they have had to climb" in accepting their debilitating treatment.

Some of the cancer sufferers demonstrated that understanding of this nature can be absent. For instance Tom vividly described how the doctors had discussed his case, whilst excluding any contribution from him (despite the fact that it was surgery which would remove his ability to speak). Ivy noted the off-hand manner of the consultant at a follow-up visit and Charlie appeared to have an unsatisfied need for praise regarding the endurance that had been required of him in completing his radiotherapy treatment.

CONCLUSION

Where communication of an empathetic nature is lacking, health professionals fail to show that they appreciate the difficulties inherent in the experience of having cancer. These experiences include the devastating news of the cancer diagnosis, understanding and enduring treatment, and coming to terms with the uncertainties of prognosis.

CHAPTER NINE

CONCLUSION

INTRODUCTION

The aims of this study were to elicit a patient-led understanding about the impact of a cancer diagnosis and to draw out cancer sufferers' perceptions of how health professionals influence the illness experience, especially in regard to information-giving. These aims appear to have been achieved with the respondents giving important and vivid insights into what it's like to be a cancer sufferer.

The main findings

In the past, those involved in cancer care have debated over the issue of whether to "tell or not to tell" patients their cancer diagnosis. This research project confirmed that the current practice of revealing the diagnosis is well accepted by patients. Having moved forward in this respect, the concern now is how much individual patients desire to know about treatment options and prognosis.

Following the decision about treatment, there appeared to be a lack of explanation and fore-warning about the degree and breadth of side-effects. Again, this was a source of concern for some patients. They considered themselves to be unique in their suffering, concluding that something had gone wrong either with their treatment or their disease. Consequently, it appears that the participants would have preferred full information regarding the side-effects of treatment. This needs to be approached sensitively but avoidance of this task by health professionals, even in order to shield the sufferer from more bad news, does not seem constructive. Conversely, it seems to cause the patient to cast around for their own uninformed explanations, which often do little to ease the burden. For instance, there seemed to be a danger of some patients thinking themselves radio-active after treatment with radiotherapy. This was a misconception and perhaps stemmed from communication difficulties in the clinics.

It was also evident that patients perceive all test results as important (and do not differentiate between tests) a fact that was not always acknowledged in the clinics. When tests were carried out, even though it may have been for research purposes, lack of feed-back caused concern.

Further, the study highlighted that the manner of health professionals in their daily work can influence the self-esteem of cancer sufferers. This was tightly interwoven with feelings of trust in the health care team. Thus being given time, privacy and even the exchange of everyday pleasantries, was perceived by the patients that they were valued.

Tied-up with this issue is how health professionals can counteract at least a little of the pain of loss. The cancer experience can be seen to be a great personal challenge and in acknowledging this, health professionals could reassure patients that their carers do appreciate the significance of all they have had to endure. It would be a simple act to provide this kind of acknowledgement and if it did combat feelings of a "diminished self", it could prove an invaluable communication skill.

To recapitulate, a great deal of general satisfaction with care was demonstrated by the respondents. However, this study has highlighted some areas where health professionals need to continue to listen attentively to the needs of cancer sufferers so that feelings of trust can be maintained and demonstrations of empathy nurtured.

Limitations of the study - methodological issues

The study was limited by the practical constraints of time and money. Home visits were funded independently and fitted around a full-time research nurse post. Therefore, the number of subjects was limited in the main study to fifteen, which detracts somewhat from the ability to generalise conclusions to a larger population (external validity).

In addition, the single interview technique may have influenced the data itself, whereby the opportunity to explore further changes over time and re-examine the cancer sufferers' perceptions were lost. Thus, the reliability and consistency (internal validity) is more difficult to demonstrate. Though, in this respect it may be worth noting that many of the lung cancer sufferers deteriorated rapidly and may not have been well enough to be interviewed repeatedly.

There was also a lack of comparative data from another group of cancer sufferers, who were receiving radiotherapy out-side a medical research project like "CHART". This type of group would have perhaps provided information about any differences in "information-giving".

There may have been an added difficulty in the venue of the interviews, i.e. the patients' own homes. As the researcher I was an "out-sider" and this may have influenced both my behaviour and the interviewees. On balance, it seems likely that the interviewees felt more in their own homes than with interviews at the hospital.

Finally, in interviews of this nature, there is the perennial problem of whether or not the subjects were telling the truth, or at least the truth as they perceived it to be. This may have been exacerbated by my dual roles of "research nurse" and "social researcher". The subjects were unlikely to have perceived any difference in the roles and shaped their responses as in reply to someone intricately tied to the institution on which they relied for their treatment.

It is not possible to remove all doubt that a true reflection of the subjects' perceptions was obtained. However, it can be seen that strong feelings emerged from the interviews, including anger and fear, as well as philosophical thoughts about life itself. These kinds of responses would seem difficult to falsify.

Recommendations for practice

(i) Research (e.g. Luker, et al. 1995) which raises the profile of addressing individual information needs (especially regarding treatment options and prognosis) should be carefully examined and incorporated into the everyday work of health professionals.

(ii) Related to this problem, communication skills should be given more attention in the training of health professionals. This is confirmed by Simpson et al. (1991) who in a "consensus statement" feel there is a "clear and urgent need" to prioritise communication skills in medical training so that interactions between doctor's and patient's may undergo a "material improvement".

Improvements in training for nurses (for instance in specialist oncology courses) may assist by providing skilled practitioners who can then act as good role models for other nurses. This seems especially important in relation to facilitating cancer sufferers to air distressing feelings about their experiences.

(iii) Health professionals should offer prompt feed-back on test results, unless the patient has requested otherwise. This is true even where tests are primarily performed for research or "routine" purposes.

(iv) There should be more information given regarding the side-effects of treatment. This should include the degree of severity as well as the range of ill-effects. For, in this particular area of information-giving, unforeseen occurrences caused distress.

(v) Radiotherapy treatment seemed to produce a fear of becoming radio-active for some patients. This was a misconception and a clear statement from health professionals explaining this, would be helpful in anticipating and allaying anxieties.

(vi) Being polite, providing time and privacy seem almost too obvious to mention as a recommendation for health professionals. Nonetheless, it may be worth repeating because on the one hand hospitals are often old buildings where the architecture makes it difficult to provide privacy; on the other hand more high-technology equipment is included in the care of patients (e.g. sophisticated x-rays, the radiotherapy machinery). This may make it all too easy to lose sight of allowing time for explanations and the reassurance of sympathetic human contact.

(vii) I suggest that a tangible, verbal acknowledgement from health professionals, that they appreciate the adversity inherent in the cancer experience, would be valued by cancer sufferers. This could perhaps take the form of, "I know this has been very difficult for you, but you are getting through despite all of these difficulties" or, "I know how hard it has been for you to endure this treatment, but you have persevered and completed it".

Recommendations for further research

The pressing need seems to be for further research into assessing and meeting individual requirements for information, particularly in relation to decision-making for treatment and giving prognoses. This could take the form of further development of the approach by Luker et al (1995) with breast cancer sufferers. The emphasis should be on how and when to elicit these needs that both suit the patients and fit into busy clinics. In other words, how to make them part of everyday practice as smoothly as possible.

Another research project could be the exploration of more focused information sheets detailing the short and long-term effects of radiotherapy for specific areas of the body. These could be supplementary to any existing general radiotherapy booklet (perhaps folded into a pocket at the back of the book).

Finally in closing, further research in the spirit of this study which elicits patients' own perceptions about their experiences is important. For instance, extracts of subjects' descriptions of enduring the side-effects of treatment could be included in information packages for other patients and text books for health professionals. In this way such research could contribute to paving the way for improvements in communication by a "sharing of experiences" (Kestenbaum, 1982). In turn, this could facilitate an atmosphere of understanding and insight for both health professionals as well as those undergoing demanding cancer treatments.

APPENDICES

Contents

REFERENCES

Appendix 1

EXTRACTS FROM THE "CHART" PROTOCOLS REGARDING THE TREATMENT OF HEAD AND NECK OR NON-SMALL CELL LUNG CANCER

Aims of the study

The aim of the study is to compare radical fractionated radiotherapy given daily over six weeks with CHART given over 12 days, with respect to survival, local tumour control and morbidity.

Background

In a course of radiotherapy, if cure is to be achieved, the dose given must be adequate to destroy all tumour cells present at the time of initiation of treatment. An additional dose, however, may be required to eradicate those cells resulting from divisions which occur during the period of treatment. Until recently oncologists have not considered growth during treatment to be of major importance. There is now laboratory and clinical evidence to suggest the contrary (1,2,3,4).

Alongside this evidence concerning tumour control, laboratory and clinical research has shown that the giving of radiotherapy in many small doses leads to a relative sparing of late radiation damage (1,5) when compared to the same dose given in larger fractions.

Therefore, Saunders and Dische (3) proposed that treatment should be:

1. **continuous** - without interruption even for the weekend.
2. **hyperfractionated** - giving three treatments per day with a six hour interval between each so as to give 36 small radiation doses during the

course.

3. **accelerated** - being given during a period of 12 days and finished before acute reactions might prevent its completion.

By commencing on a Monday morning, the 12 day regime was concluded in the evening of the Friday of the following week, treatment being given as 8am, 2pm, and 8pm on each of the 12 days.

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5. Withers H.R., Thames H.D., Peters, L.J., "Differences in fractionation response of acutely and late responding tissues. In: Karcher K.H., Kogelnick H.D., Reinartz (eds) Progress in Radio-oncology vol. 3, 287-296 (Raven Press, New York, 1982)

Appendix 2

INFORMATION SHEET

Dear

I am a Research Nurse, hoping to find out what patients think about their disease and treatment.

In order to find out about your own feelings, I would like to interview you, in your own home about six months after you have completed your radiotherapy treatment.

Participation in the study is completely voluntary, and you may refuse to take part without any effect upon your treatment and without any reasons having to be given for your refusal.

If you are willing to take part, the interview will be taped, so that I can record your views accurately and we will not have to stop whilst I write notes.

There are no right or wrong answers and your views will be treated confidentially. However, with your permission, I may wish to use part of the tape recordings at research presentations.

Please use the enclosed form to indicate if you are/are not willing to take part in the project. (Nearer the interview you will also have to complete a "Hospital Written Consent" form if you are taking part).

If you would like more information on this project please do not hesitate to contact me on the above telephone number.

Thank you for your consideration.

Yours sincerely,

Karen Gamble
Research Nurse,
Head and Neck Unit.

enc. Reply form and stamped addressed envelope.

Appendix 3

"Aide-memoir" - Interview themes/questions

General idea at present is to try to get the patient to reflect back, starting with what led them to the doctor (i.e. worries, symptoms) and when/how they were given their diagnosis.

DIAGNOSIS

- how long did this take from their first presentation
- who told them, GP, consultant, registrar, nurses, other person?
-did they suspect their diagnosis and if so, why?
-did they want to be told outright their diagnosis or were they unsure of what they wanted to know at that point.
-did someone tell them directly, i.e. that they had cancer or did they use phrases like a "growth" "tumour" and were such phrases acceptable to them.
-what sort of environment were they in when they were told, e.g. doctors office, clinic room, were they in private, was someone (friend, relative) with them
-were they given the chance to ask questions and in fact, at that time, did they have any questions
-were any questions that they asked answered, and were those answers understandable to them
-did anyone offer future opportunity for asking questions, perhaps saying that they were willing to speak again about the disease when the patient had chance to think about it themselves, or if relatives wished to contact them, that it would be o.k.
-was there anything about the time when they first learned of their diagnosis, that they wished to add
-did they do any reading about their condition, e.g. hospital information or did they buy any books

INFORMATION ABOUT DISEASE AND TREATMENT

-what treatment(s) were offered, e.g. surgery or radiotherapy
-if surgery was offered first, why was it not given e.g. in some lung patients, after investigation the tumour is involving major blood vessels and inoperable, or they might have some other long-standing lung complaint prohibiting

anaesthesia, or in head and neck patients, sometimes surgery is refused due to its impact on quality of life. How do the patients feel about not having surgery? Do they see radiotherapy as different but equally effective?
-what were they told about how radiotherapy works, and did they understand to their satisfaction what they were told, or were they not told anything more than that is what they should have?
-did they feel that they had all the information that they wanted about radiotherapy?
-did they feel that they were given sufficient information about CHART
-did they feel happy about consenting to go into a study
-were they unhappy with the treatment they had drawn
-if happy/unhappy why?
-how did they feel about clinic visits
-who did they feel supported them
-who did they see in clinics
-what were they expecting at clinics
-were they given information about side-effect
-who gave them information
-was the information sufficient, did anything happen that they feel was covered/not covered in the information about side-effects
-did they <u>want</u> to know about side-effects
-was the information satisfactory to the, or was it too much, too little, too technical
-was information repeated, and if so was this helpful
-was information about side-effects off-putting about having treatment
-were their experiences about having radiotherapy as they had expected
-were they give any contact number/persons to seek if they were concerned about side-effects
-were they seen regularly in clinic and if so, was this helpful
-at clinic visits, did they see the same people e.g. regular doctors and nurses, and if so, was this helpful. If not, did they mind new people.
-how long did the side-effects last, and when can they remember feeling better -were they prepared for the duration of symptoms
-how did they feel after the completion of treatment

PRESENT TIME

-do they feel the treatment was a success, and why/why not
-are they satisfied with the radiotherapy
-how are they feeling now, are their lives

different to before their disease, and if so, in what ways
-how do they feel about going to the hospital for check-ups
-do they have any other comments that they would like to add

Appendix 4

Reflexive Account

Charlie (aged 74, retired, lives with only son)

PREPARATION BEFORE VISIT

Sent letter approved by ethics committee. When acceptance arrived, I telephoned Charlie to arrange day and time. The day was my suggestion, the time was Charlie's.

The day of the interview, checked route and readied hospital consent form - wanted to appear organised! Put tape in recorder with his name on, so that I wouldn't have to fiddle too much before the interview.

Thought about clothes, I wanted to look smart (i.e. professional) but not so "dressed-up" as to be possibly unapproachable. Chose smart trousers and a sweater.

Thought over questions/areas of diagnosis and information I wanted to explore (again, trying to be prepared and able to lead way into interview).

INTERVIEW

Arrived 11.25 am, five minutes early

Greeted warmly, and brought into sitting-room. This was a cosy room, fairly tidy and with old-fashioned furniture. The t.v. was on, but was quite quickly switched off. Charlie said, "Not bad housekeeping for a man - eh?" and laughed.

I agreed, and was immediately offered coffee, whilst I "set-up" (as he put it) for the interview.

Whilst he was in the kitchen, I got out the tape-recorder. He produced a long cable (which he used for the lawn-mower) to let me place the tape-recorder a convenient spot.

He told me "We'll start when you've had that", pointing to the coffee - I'd intended to start sooner. But, thought he was probably right, we ought to socialise first.

He told me he knew I'd just got married, as he'd telephoned my office when I was on honeymoon. He asked if I liked married life and got to talking about his wife. He told me about how she'd died, in an accident 10 years before.

His account was very vivid and obviously still painful. Eventually, he started to talk about his own illness - and so I said, that this was the sort of thing I was going to ask him about, so did he mind if I started the tape. (about 11.55)

Overall, I felt it was difficult for me to channel the patient onto his feelings about the diagnosis. At first, I felt completely out of control of the interview, when he seemed to start a monologue of events. It was difficult to interrupt without seeming rude or abrupt. I decided to let him go on and at a natural stop, perhaps bring him back to something he'd said.

I tried to make my questions diagnosis/feelings/information/side-effects related. Sometimes I had to repeat myself, as they were not clearly phrased.

My first impressions were of some useful information, (e.g. his comments about the x-ray, counting his tests as "treatment" and feeling the doctors had been usefully frank about treatment). Although I did wonder if I had pushed him too far about the x-ray results.

He seemed to view my visit like a social call - coffee, showing me the garden and framed certificates for safe driving - he reminded me of the kinds of things my own father (who is about the same age) does for visitors.

He revealed that he wanted to do the interview as he felt that the hospital staff worked very hard, and he wanted to help them.

After about one hour ten minutes, he seemed to be getting a bit tired, and winding down, "don't know what else to say" - shortly after, I switched off the tape-recorder. (about 1.05pm).

Afterwards, he gave me another coffee, chocolate, sweets and garden beans to take home! Also, a pen set he had once won.

I left about 1.30pm

I feel for the future interviews, I need to make my questions clearer and be prepared to take time to "socialise" before the interview. Also, the concept of tests being perceived as "treatments" may be interesting to watch out for. Charlie seems to describe his radiotherapy as a "coping strategy", which could also be interesting.

Appendix 5

An Interview Transcript - "Harry"

kg As I was saying, we, we could start with what took you to the doctors originally? When you first went, whether it was the GP, or whoever.

h Well, the first one I went to was the GP.

kg Hmm mm.

h And erm, I thought it might, I saw some blood in my cough, and he said, it probably may be strain, cause I used to be a heavy smoker.

kg Hmm mm

h And I packed up smoking four and a half years ago.

kg Hmm mm

h And then, this was the beginning of this year wasn't it, I went to the doctors, yes, it must have been about February-

kg Hmm mm

h- So, he said to me, "Well-" I went back again, where was I - oh, and he said, "best thing to do" he says, "there, you might aswell go and have an X-ray". The next day I went, to St. Heliers, for an X-ray-

kg Yeah

h - I didn't trouble to go back to the doctor, I thought to meself, if he wants me, he'll find, soon find me, you know?

kg Hmm mm

h Hoping, I felt alright, that everything'd be alright.

kg Yes.

h Cause it was spasmodic, the bits of blood.

kg Yes, yes.

h Anyway, erm, I got a letter about ten days afterwards, and me GP sent for me to have a chat, and I thought to meself, there's something wrong.

kg Right

h And he told me, me lungs were o.k., and er he'd like me to have a bronchial er

kg Bronchoscopy?

h Bronchoscopy.

kg Hmm mm

h He said, there isn't nothing in it- (quietly)

kg Hmmm (disbelieving, as bronchoscopies are difficult)

h Anyway I wasn't ?????? And they did the job ??? And he laid you down, said, that's ok. and he went in this side, and found what they did find.

kg Right.

h So, he sa-, I was naturally, I was, <u>choked</u>, naturally, anybody would be-

kg Hmm, hmmm.

h- so, he said to me, "look positive", which I have done-

kg Aha

h he said, "and leave it to me, you wait and see", and the next thing, I think I went up, couple of days afterwards, I wasn't quite sure how long a period, to see somebody from Marsden-

kg Yes

h Chap like ??, well I said, "I know this", and erm, another young girl came in eventually, after I'd sat there for about an hour, she took me into the room, and, told me they'd found a small tumour, tumour. Would they, would I like to, er, have the 12 day <u>if</u> things turned out, same as what you gave me-

kg Yes

h- in Fulham. Well, anyway, the erm, they sent, it was the day after the, <u>easter monday</u>, I think it was, yes, they sent the car for me to go to your place, Sutton, and I said to the driver, "No, I've got to go to

Fulham!", he said "No", cause they messed it up, the transport department, they take me all the way there, she can't come with me (pointing to wife)-

kg Yes

h - cause he's picking other people up, so, we go there, then they get another car to fetch me to you, and that was on that Tuesday when-

kg Yes, I remember-

h- when you first saw me with, erm, -

kg Dr Cornes

h - Dr Cornes. Anyway, they, had to spend a whole day that time-

kg Hmmm Hmmm

h- And then I went back again on the Thurday, he said, "No, the blood tests are o.k., this end, well you 'phoned me to tell me to come on the Thursday, -

kg Yes

h- to be planned, and then you had me in on the Sunday.

kg Yes. It was quick.

h It was quick, because the cycle started on the following Monday, didn't it, so you- (fades)

kg Because I think I can remember asking you, if you were upset because, it was all happening very quickly.

h Oh I didn't mind that (pauses a second) can't say how long you're gonna live, or anything, no-one knows it, er, I mean I think they're pretty good today, contrary to what it was a few years ago, with this treatment, its much better.

kg Hmm Mmm. So, when, when you went back to the GP, when the GP sent the <u>letter</u>, and he said, come and have a chat,-

h That was, when he sent me for the bronch-

kg (talking together) That was right at the beginning, yeah, how did you feel going then? I think you said to me, that it did worry you?

h Oh, it worried me a bit-kg What did you think it was?

h Well, I guessed it was something-

kg Hmmm.

h - And I didn't actually know, not being a medical person, its obvious, but you're hoping that it isn't, bad, you see, cause when I did see him afterwards, oh, I went back with this tickle, you know-

kg Aha

h - and he gave me the seven day treatment for the, well, antibiotics. And I went back, well when I first went back to see him, I said, "it was a bit of a shock, wan't it?", he said, "to you it was", (smiling), I said "Gee"-

kg Hmm, yes

h - Well, he must have known something,-

kg Yeah

h Anyway, he said, "Its no good giving you any more medication for this" he said, " They'll probably they, the treatment they've given you has caused the, irritations-

kg Yes

h -and given you this cough", but I'm still gettin' a lot of mucus-

kg Yes

h- It's only white, you know-

kg Hmm

h - so, its similar to when they first started givin' it to me, they used to do the same, so I asume its, (laughing) I'm still walkin' about ain't I?

kg Yep! (pauses a second) So, you went off to see Dr Cook, to have the bronchoscopy, erm, how did you feel about having that test?

h What the bronchoscopy?

kg Yeah, the bronchoscopy, what did they explain to you about that?

h Well, I, I, (quietly) I just take it. I went there, and when I saw him, he said to me, "We'll have a-", oh, he just had a chat with me first, and he said, "With er-" , I was given a day to go, couple a more days afterwards, had it. Oh! I got a letter actually, it says, you come down at half eight, eight -thirty, and you'll be there till probably two, have somebody pick you up, at two O'clock, -

kg Hmm mm

h -Or, you'll have to get a cab, because we don't do transport-

kg Yes

h- and erm, course, that was that, I can- , there was six people in the ward, three ladies and three men.

kg Hmm mm

h But when I go down, I chat to the porter, not a care in the world!-

kg Hmm mm

h - to be honest, I (pauses)

kg Yes.

h Anyway, got down there, I, well (quietly) I don't make no fuss of it.

kg Hmm mm

h And then when they were, s-stood waiting, this charming little sister, very charming-

kg Hmm

h - I might be tired, but I would never give in-

kg Hmmm

h -she was saying, (quietly) "Are you alright?", and you know, and they made me bleed afterwards, I recall this,
anyway, they took me back, and I got some swabs, and it stopped eventually, and er, then, after about an hour, they came and they told me, as soon as they could.

kg Can you remember what they said to you?

h He just sort of ???, "Harry, I'm sorry", he said, "You've-"
,I said, "Leave it out", and I said, "Well, how long have I got?", just like that, he says, "Don't be like

that, leave it to me and I'll get things moving". And this was how it transported to come to you, at Fulham.

kg Yes.

h And, I must say that everybody I've seen, at Fulham, and the Dr Henk, and his team, you included, the therapy girls, radiotherapy girls, and the staff and the nurses in the Royal Mar-, you can't find a fault, everything, everybody was wonderful! And it gives you the greatest confidence in the world! I mean, so er (fades out)

kg What, can you remember what we told you then, when you came up, that by that point you knew, your diagnosis-

h That I had a tumour, a small tumour-

kg Tumour, hmm mm

h That was hidden behind the gullets.

kg Hmm mm

h And erm, then he told me, if, that's Dr Cornes (quietly) you were there at the time-

kg Yes, yes

h- that if the blood tests are satisfactory, we'll get you in on a Monday, and would you have the six week treatment or the twelve day? I said, I'll have the twelve day.

kg Hmm mm

h He said, "You'll be admitted" , this was Raven Ward, and er, you go out after your treatment, eight, eight o'clock, between p.m. and eight p.m.

kg Yes

h And in between time, you could just go out whatever you wanted to do, aslong as you were there, on time for the treatment.

kg Can you remember if we told you anything about side-effects?

h Oh yes, (coughs) you told me that, some people may, after the treatments stopped there for a day or two, because, but I felt so good. In fact, I was coming home, and my first time on the following Friday, I had to, you transferred me to Sutton, cause of me living on top of there-kg Yes

h And I happened to, you won't remember, I said to the doctor, he said, "You eatin'", I said "yeah, I had a lovely toast this morning". He said, "Hark at him, toast!".

kg Hmm

h The next day, it took the smile off me face! Then it started. For three weeks, I was having a glass of beer pouring out and leavin' it. Food, I'd never, I could hardly eat it, after it affected me real bad.

kg Hmm. And do you feel, had we prepared you for that?

h Oh, yeah! Yes, I because erm, I remember everything they said, and other patients that were there, when we sat in the dining room, having our meals, erm, you get people that have been there before, and they tell you, and one chap went up to Birmingham, ????, on that day, later I think it was, over the holiday, he said, "You won't get no treatment", well, we had treatment all the time.

kg Yes

h Mrs Duncan, myself and that, that Barry, three of us.

kg Hmmm mmm

h All over the holiday and er, he came back on the Tuesday, and he said, it played him up, no end, he was in terrible pain. He said he couldn't eat his food-

kg Yeah?

h- and I was there at the same time, so as soon as it started, I was well prepared for it, as soon as I started gettin' it, I remember what they told me, you know?

kg Yeah. Are you, how do you feel about us saying, you know, about the side-effects of the treatment, are you glad that you knew what to expect, or would you rather have not known-?

h Oh yes! It's best to know! It's best to know because, some people might be, a nervous disposition, and it might come as a bigger shock to them, and then anything else, it might be, for what its worth, you know what I mean?

kg Yeah. Yes. So, so, so you were pleased that we'd talked about-h Oh yeah, yeah

kg - the side-effects.

h That's right, yes, well, it's just like being told what you got, you got to either accept it or, go and chuck yourseld under a train! (Then quietly) In a figure of speech.

kg Yes, yes.

kg Which obviously, you wouldn't do that, not in this day and age, now, because I think you have got a (fades out)

kg So, just thinking about that, when you say, when they tell you "what you've got", and , Dr.Cook said, did he say "You've got a tumour" or did he say it in some other way?

h Er, (pauses a second) Well, the way he told me, I think, I assumed it was a cancer.

kg Hmmm mmm

h And, er cause it was Dr Cornes, oh no, then this nurse, that was with the team from Marsden, er, came and told me eventually, was sitting there for hours, there was a load of people waiting, it was on the Tuesday, and I usually go up there after, to have a check, I've got to go next <u>month</u>, I got to go up there regularly, and er, she said "I'm sorry to keep you waitin'", she took me in the room, she said, "We're ever so busy, you can't see the doctor," so she told me.

kg Right. Right, and what did -

h I mean it was a small tumour.

kg Right. That's what she said?

h Yep. And er, and then, I said "Can't they operate?", and she said "No, no chance, because it's under the gullet", and then she told me as I stated earlier, like, that erm, I could have this six weeks, if everything's satisfactory, or er, I could have the twelve day treatment, and she gave me the outline of what they do.

kg Hmm mm.
(short pause whilst his wife asked me if I wanted more tea)

kg Erm, so, (pauses a second) You've said that, you were, obviously you were choked, you said you were choked when you were told-

h When I first found out, oh yeah.

kg And that was, from that nurse, or from Dr Cook?

h Well, when Dr Cook told me.

kg Dr Cook told you.

h Then he had a ssss- , one of my sisters came with me, early about half-past-one. And they told me.

kg Hmm Hmmm

h And, I was down in the dumps! not, you know, you know what I mean, I was really choked.

kg And this little sister, she was really a charming woman, she come and said, "Harry, don't despair!" she said, "Think positive!", and then Dr Cook had us in, had us in his office, and he told us more or less the same, he said "I told you didn't I, we can't cure it" he said, "but, we can prolong it" he said, and er he said, "I told you what I was gonna do", now get on with it, you know? He's a good chap, do you know him, do you?

h Well I've heard quite a bit about him, but I've never actually-

h Little guy with glasses on, dives about, he's a character, but he's a charming chap. Charming bloke, funny wasn't he (to wife, who agreed)

kg So, how, so you were pleased that he'd told you, even though, it obviously wasn't good news?

h Oh yes, he was er pullin' no punches, you know?

kg Yes.

h He just, he just told me straight. And er, then the next stage was when I came to Fulham.

kg Right. You've told me what we told you, a little bit about the treatment, did anybody actually, can you remember if anybody sat down and told you, what the experience might be like when you actually go and have the treatment, you know, like the machinery or anything like that?

h No, I didn't know. I was down in the dumps on the Sunday, when I arrived, cause I had to go on me own, she couldn't come in the ambulance, they sent a paramedic, and I got there just after four, and a young doctor come on the ward, to ask me questions. Run the rule over me, and I was down in the dumps in that room, it's a bad room that was cause two of us sharing, oh there was two old beds-

kt Yes

h Anyway, with, Tuesday, on the Monday morning, right as nine-pence, went down for the treatment, just went in, and just got under the big machine and that was it-

kg Aha

h - the only thing is, thought to meself, I got another 35 to go.

kg Yes

h See, thirty-six. Anyway, soon as ????? and got the holiday over, ???? with Mrs Duncan and Barry-

kg Yes

h -have you seen him? Is he still in there?
(no reply)

h Barry G....?

kg Right, I, I tell you why I'm always confused, because I know him as William G.....-

h Oh, I see

kg That's his, I think that must be his nick-name, or his middle name, or something-

h Oh right-

kg Yes, he's alright, I think he's been away on holiday. Hmm hmm.

h Give him my regards when you see him, I rang him, when they asked if they could have him back, when I left,I rang him and er, he thanked me, and I said, "Well, I was a bit worried, when they said for you to come back".

kg Right

h I'm glad that- and Mrs D...?

kg Wha-

h That's the old lady. She lives at Putney in a home.

kg Oh! I know who you mean.

h Yes, she had-

kg Was she the very, very old lady?

h Yes, ninety-two I think-

kg Yes

h she used to sit with me in the dining-room

kg Yes. She's, she's alright, erm, but, her erm, it did knock the stuffing out of her a bit, having treatment,but she's doing alright-

h Ahh, she was a brave woman, er, her grandson came up, he's called, I don't know what it was, and er and he said, "She's as tough as old boots!". She was, she was a character. I enjoyed every minute of it, she was a comic, and I said to you, she was the only one who eat her meals with us, cause all the other women, cause she used to say, can I come and sit with you? Course, she was an educated woman-

kg Oh yes, she was very interesting.

h Educated woman, she was.

kg Yes. So when you said, you felt like, "oh another 35 to go", how, what did that make you feel like? You'd had one, and you knew you had a lot more to do.

h Well, it it made no difference. You see, when you went down and had the treatment, -

kg Hmm mm

h - and you feel nothing obviously, you hear the buzz of the machine going around, you feel no pain nor nothing, and its only a matter of seconds, then they take you to get planned er it was nothing to it at all! You see the machines, its exactly, you have an idea what they're like you know, by other people when they spoke. But er, nothing to be frightened of, the radiotherapy department, nothing at all. Only thing is, to see if its done any good.

kg Yes. And when you got side-effects, how long before you felt any better?

h Oh, a good three weeks.

kg Hmm mm

h Good three weeks long. But erm, as I say, I expected it, from what I was told, and,she knows, I would pour a pint of beer out, she knows I never leave a beer (signalling to wife) -

kg HMmm mm

h - and I had to throw it away, cause I used to drink scotch, I was a scotch drinker, and Dr Henk told me to give it up, no scotch, am I allowed gin?

kg Well, it, it all really when the side-effects are there, but probably now if you had them watered down, you could -

h Oh yeah, I have the tonic type of thing, but I used to have scotch, scotch and water. Doctors drink that themselves.

kg Hmmm

h They love it

kg Yes.

H??

kg And, you were telling me a bit, when I came in, how you're feeling now. T-tell me how you feel now.

h Well, it's irritating, this it's,it's better than what it was, it used to keep me awake all night-

kg Hmm mm

h When I first went to the doctors, but I've had it all the time, and they gave me, a sort of, like a, the red tablets, take 4 in the morning, and er, what were they for?

kg The- ?

h (coughing) See, I'm congested aswell at times.

kg I'd have to, I'd have to check that, I can't think to be honest what they were.

h They were very small.

kg Aha

h It was about the first week, I took four, the second week-

kg Oh I know! They were the steroids weren't they, to reduce the inflammation. That's right.

h Oh that's it, cause it was a bit inflamed, see, you remember when you came outside with me?

kg I do remember now.

h I was inflamed. I said "Well, that's it" (smiles) I took no notice.

kg Yes

h Didn't worry.

kg And what sort of things can you do now, or that you can't do?

h Oh, the only thing is, I get short of breath.

kg Hmm.

h Other than that, I just carry on as I have been. I eat everyday alright.

kg Yes. What, how do you feel now when you come up and have to have checks at the hospital, how do you feel about coming back to the hospital?

h Well, to be honest, you're on edge, because you wonder what the results are gonna be.

kg Yes.

h Will they let you know that everything's alright?

kg Yes.

h Last time I went, o.k., I had an x-ray, you was in that other room, because you, you were so busy because you had a double lot that week, didn't you?

kg Yes

h You were-

kg It was a bank holiday.

h And er, well, I didn't get out of there till half-past-five, time I waited at the, pharmacist, I didn't come out of the x-ray till ten to five, -

kg Right

h- that's when you came out and you told me, they were really pleased, and gave me these tablets, and then when you were there, I mean I don't know, I don't care, I mean, when I look around at the amount of people that's there, it surprises you, and that's only one hospital!

kg Hmmm

h And there's hundreds there, ain't they?

kg Yes.

h And er, then when you come in, all you pray for, is hope you get a good result!

kg Aha, hmm mmm

h So I mean what everybody goes through, I mean, if you had to go through it again, same treatment, well you'd have it, but not that you want it, as I say, you like to have a good bit of news.

kg Yes. (pauses a second) Do you feel when you come up there's enough time to ask questions and ??, you were saying that that day it was very busy, very packed-

h Oh yes! Well, you, there's so many people there, its nice to go in, see the doctor, ask you how you are, so and so, so and so, and its nice.

kg Yes

h Get dressed, and tata, see you in 6 weeks time.

kg Hmm Hmm

h I mean its no good sitting there, having a chat if there's nothing, part from this, a' course, beneficial probably to somebody, make it easier, you know, but er, well the sooner you get out of there, the better of course, obviously.

kg But if you have got something on your mind, that you want to ask, do you feel happy about asking it?

h Well, not particular,because I've got nothing on there at the moment, you know, while I'm getting results, please God, a good result, I, I know what I've got and that's it, you know.

kg Hmmm

h But erm, as I say, I don't moan about it, always luckier than other people, I'm still breathing.

kg Yes, you were saying about looking at other people when you came up to the hospital-

h Oh there's plenty worse, that's the way I look at it.

kg Right

h Plenty worse off than me. And I've never been a one to make a fuss of anything.

kg Hmm mm

h I've learn't meself, do your nut, but I mean I've had some, ??some stick, because there's plenty of things take just as much, but its all for the good!

kg Do you feel, you know when you came back, for the <u>scan</u>, how did you feel about having the scan?

h Oh I didn't mind, I've had, she said to me, "You been scanned before?", I said, "Yes, at St Heliers", that's when Dr Cook sent me for a scan, and then I, I had the bronchoscope after that, didn't I (to wife) and that's it, because he seemed unsure about the scan-

kg Right

h But he was, he put that thing through here (pointing to nose) and you can keep that anytime! (smiling)

kg Right, the bronchoscopy wasn't very nice, was it?

h Well, I took it, I took it-

kg Oh yes

h -but er, its not a thing, if I had to have it again, I'd have to have it, but I wouldn't like to volunteer!

kg No (laughs) Right. So, you don't mind coming back for check-ups?

h No, oh no. It's, it's nice to know they're keeing their eye on you!

kg Hmmm. And when you look back on the whole thing, is there anything that sticks out in your mind, that was particularly a landmark? Or that <u>sticks out?</u>

h Best thing is when I saw you on the Thursday, and you said you can go Saturday, and I said, "Well I'm going Friday!"

kg (laughs)

h Can you remember? That's when old Donald came up to see me (to wife) chap downstairs, he's eighty some, very good man, and he was standing there when we came out. But er, other than that,I was happy in there, no qualms, lovely staff in the Raven Ward, and as I say, the, er the super on the radio- the radiotherapy girls and men, beautiful people-

kg Hmm hmm

h Made you feel comfortable, can't say a bad word against any of them.

kg Hmm mm Hmm mm, when you say, they were all good, what, what sort of things have we done then, that make you feel, that have been helpful?

h Well it's, the confidence you get! By the doctors, you nurses, staff, and the company of others, that's in the same boat as you, you, you don't see 'em laying about, well, I didn't, moanin', any, there was a chap, I gave him me phone number, he hasn't rung (quietly) he's very ill, he's sixty ??? his name was, and I was hoping to hear from him, but he was, he was in a ??? needed transfusions, oh he was very ill, and when I look back at those poor devils, and he'd always have a smile on his face. We'd be sittin' down with Mrs D..., and we'd be having a laugh, and she'd be saying, "I'm getting a bit old for this", and he'd turn round and say "oi, leave my girl alone!"-

kg Yeah, yeah

ht Things like that, I'm happy, you know, made the day go. But erm as I say, its a funny thing, a funny experience really, especially if you were going in to have surgery, which I'd rather have had really, once you wake up, you know its done and no worries, but this is a different kettle of fish!

kg Hmmm. Tell me why you think its different?

h Well, for all you knew, up to before this treatment, the failure of radium, but I think now they give you this radiotherapy-

kg Aha

h It's a new thing that's been on for about 5 years, hasn't it, er, and that's the experiment, but knowing the confidence I've got in you people, well I'll be ?????- you don't want anymore do you? (referring to tea)

kg Aha

h And er, other than that, I just er carry on as normal. It's no good sitting around moaning is it?

kg I think you said at the beginning, it might have been Dr Cook, that took you into his office, with your wife was it, and -

h Well, he said, er "Harry, I've told you what I'm gonna do", there was the little sister, sitting there in the corner, "Told you to think positive, and I'm gonna start moving", and when we came out, the sister said, "I told you, he won't let you down, he'll get the ball rolling right away".

kg Hmm mm

h And things like that really, and when I thought after a while, well, its no good moaning about it. I'll just er carry on and do your best!

kg Did you talk about it at home at all?

h No. Only one or two people have asked me, and I say "Cor, leave it out", "how'd you get on?", I say "leave it out".

kg Hmmmmm

h I'm unstuck, kind of thing, you know.

kg Right

h And after that, I just, took everything in me stride.

kg Did, did you get chance to talk about with your wife?

h Oh yes, I know she's disappointed (laughs with wife) - only joking, cause we generally go away in the caravan, and then we'..

wife We've always been positive.

kg But, if er, now that you've had the treatment and you're sort of about 6 months from it, do you think there's been any benefits from it? What do you feel has happened from it?

h Well, I should imagine so, cause it used to be

- they've dispensed with that at least.

kg Hmm mm

h But, as I say, I can't say no more, until, providing I'm getting the, the clear bill of health each time we go up for the check. I've never had so many x-rays!

kg Hmm mm

h I don't mind having them, you expect it, you know.

kg Yes, yes. What erm, when, when it was first put to you, about the treatment, they said to you, surgery wasn't possible, that's right didn't they?

h That's right.

kg And that it would have to have radiotherapy, how did that make you feel?

h Well, I was with my son-in-law, I says "I've got to go to the Marsden", he says "Oh blimey", just like that, I said, "oh its o.k.", and I-I came home and, - oh, the only thing is The Marsden, everbody feared the name of that place-

kg Right.

h But erm, the day they took me up there by mistake, and then they had to transfer me back to you, plus the chap was taking me for a tour of London, the driver, oh, a nutter there, and I didn't know what I was coming in to, I was right in the dumps!

kg Yes

h Right down in the dumps. And when you come in that back entrance, where the ambulances pull, well, "Good Lord, what's this?", till you go in to find the hospital, then you find what a lovely entrance there is. I go in the office, to answer the questions, to this young girl that was there, a nice kiddie! Asking a lot of questions, then they sent me, round, and I was waiting.

kg When you first thought you were going to the Marsden, and you said a few people, you said it was your son-in-law, was sort of taken-aback, why do you say it strikes you with fear?

h Well, knowing what you got. What the hospital, er what the hospital er treats, treatment is.

kg Yes

h Cause when I, I lost my old mother, years ago, God rest her soul, in St Heliers, and we came out, and went to see her, before she died, and some family came out crying, this was quite a few years ago, and I heard him say, "Oh, it can't be long, she's got to go to the Marsden".

kg Right

h See, and that sticks in me mind, but I wasn't concerned with it, I was just thinking of number one, to go up there and get it seen to, you know. But er as I say, I just got to go up there now, and I'm not the only one, when I look round there, there's thousands, and there's people walking round there, don't even know they got it themselves, do they, you see?

kg Yes, yes.

h As I say, while they're trying these new things and that, it gives you half-a -chance, (pauses for a second), well I won't give in, if I can help it, no way.

kg HMmm

h But er, as I say, the treatment, well, you can always go back to that aswell, can't you?

kg For more radiotherapy?

h Oh yeah, that's it. Cause I said to the doctor, "Can you go back to this again?", and he said, "oh yes".

kg Not on the same spot though?

h Oh no, no, no. No, not on the same footing.

kg Not on the same part of the, you can't -

h Oh no, I'm with you, yeah that's right.

kg Hmmm

h I know you said I should wear a shirt, but I don't sit in the sun.

kg No.

h No way. I used to, but not since I've had this.

kg Yes.

h Cause the super' told me, she said, that was radiotherapy at all, cause she says if you do, she says, I can't sit out-side me caravan now, and she says "Well, you can, providing you got a vest on or, you keep it covered", but I don't try it, the only thing is, I got burnt on me head, well now me hairs gone, I couldn't even touch it, ahhhhh! I didn't have me Billy Bean hat on!

kg Yes? (laughing)

h To keep the sun off, to protect it. Oh it was a beast.
I've always been red there haven't I? (to wife)

kg Was there anything that happened along the way, either at the hospital, or by your own doctor, or wherever, that, was unexpected, that, you know, perhaps related to the treatment, but things, did anything happen that you hadn't expected, that you got a bit of a surprise?

h Well, I didn't think, I didn't think that I would get anything like it, you know, I didn't think I was going to get this at all.

kg Yes. The actual-?

h The actual complaint.

kg Hmm mmm

h But as I say, as the, once you get over the initial shock, you then, you got to take it, you got to get it into perspective. It's no good saying sittin' around mopin' is it? I mean, once or twice, she says to me "Pull yourself together"
but, I was really in the dumps when they ? me up, and you know, with other people,and the, they made me swallow or try to, oh, it was a bit of a beast.

kg Hmm

h But as I say, the, you're looking all the time and you know its gonna wear off. They say two to three weeks, and then when it wears off, you go out and get drunk!

kg Right (laughing with patient)
Is there anything we didn't tell you about that happened? That we hadn't warned you about?

h No, I don't think so. Is it contrary to what I'm telling you?

kg No, no!

h I mean like is it- is it any different, or is there any more that I should know?

kg No, no, no, I don't mind that. I was just wondering what had happened in the, you know, as it went along. You thought that the information you got, was the information that you needed?

h Well, it was coughing really, cause there was nights, oh, I'd cough all night long! Wouldn't stop. Couldn't stop. But now, you get it spasmodic, you get just that little tickle, and, then, of course, you're still congested at times, you hear a wheaze, and now and again it'll clear. If you breath in deep. Wheaze sort of.

kg Hmmm

h Well, in fact I don't smoke, I used to smoke about forty cigars, about forty quids worth of cigars I think!

kg Right

h And er, I-I'd sooner go without food, as long as I could smoke. I'd have one all day long, last thing at night, first thing in the morning, when I got up. But now, I can't stand the smell of it!

kg When did you give them up?

h Erm, it was four years ago, last April, so gettin' on for five years sort of thing.

kg And what made you give them up?

h Well through, when I had this,(pointing to leg) you see, they came, they said, "we're sending you in", Sutton General. And, through the smoke, you see, ordinary ?? everything'll go through your veins, arteries, its fantastic! But then I found, sittin' there, thinking, after me meals, I'd think, I'll have a smoke, I hadn't got none, and it went on like that, because, you could win a million pound, I'd never turn it in, anyway er, then I was thinking, the nicotine through the smoking, her nets, and the cielings, used to be yellow, and then I realised, then, that nicotine, if it sticks to curtains, it sticks to the arteries, and then I did see part of the arteries, and I seen what operations was on there (pointing to t.v.) Jimmy's, and there was an Ambulance chap lost his leg over it, cause he carried on smoking. After he'd had the treatment-

kg Yeah

h- and I-I it just went! I came home and there was nobody, I was in there, nearly a month, cause I, infected, got a bit of infection, and erm, then they didn't want to let me out, and I said, "well can I have a district nurse?", I wanted to get out, obviously, they sent a district nurse in, and it cleared up in a week, and er I've never, never put one to me lips, and I don't want to and I can't stand the smell of them.

kg hmm mm

h Can't stand the smell of them. Er, they say its a good thing in that respect, <u>but</u> bit late in the day now, ? worry used to smoke, <u>if</u> it causes it, which they reckon it do.

kg Aha

h Cause there was another young doctor, that did the treatment, Dr ? , were standing back, having a laugh, you know, and this young chap come, and he said, "Oh, here's the smoker", I said, "I don't smoke, for over four years", and that was the length of it.

kg That you had-

h Well, he er, er well, must have done.But, the thing is, I often wonder, I was driving the 37, and the 37's in them days, were in the smog, and , it was 1950, and I don't think that helped.

kg Hmm mm

h Because as you was driving along, you were just breathing it in, everything was black, that come up, you know what I mean, and
smog and diesel. It used to be laying on the ground, used to have to follow the tram lines, plus looking out-side, sliding the window back, and trying, one eye trying to see if there was a light in front and keeping your eye on the tram lines!
If you ran off a them, you'd be in trouble.

kg Right

h We used to do it like. I often wonder if that didn't help us. And you know I was playing football till I was forty. Still running about full of (fades out)

kg Yes. Yes.

h It was recently, before, I found out, before I went to Dr ?, I had to, worn out, I had to stand against the wall carrying a couple of bags, course I can't now, fighting for me breath, and I said to you, there's something wrong, didn't I, there's something wrong here.

kg And this was right at the beginning?

h At, before I went to the doctor's, yeah.

kg And when you thought there was something wrong, what was crossing your mind? Did you-

h Well, with the blood showing occassionally, I thought, there's got to be something wrong. You'd never think of that, cancer, but, you know there's got to be something wrong! Because you er, well somethings not going to be right. Till you go up for the examination, you don't know.

kg Do you think that the doctor's could have told you in any better way than they did, that it was cancer?

h Oh no. He came out with it, he didn't have a smile on his face, and I knew there was something wrong, because, he was a jolly sort of a chap, and I knew by, when he came, when he saw where I was, just started out, he says, "Harry, I'm sorry", I knew, I knew. And there was a young woman, she says I'm only smoking 5 a day, and next thing, she's told she's got the same thing. You get on your feet, you know, you get back-up, you want to enjoy your life and then, you got a nice family, and this happens. And she says, and next thing, he went over and told her, and she burst into tears. And I tried to comfort her, you know, and I said to meself, well, that's it , you know, there's nothing else to do. And erm, next thing I went up for , I went up, I can't remember the name, I went up to have a scan, and as I walked in with me son-in-law, she was sitting there. She'd been in, and they'd told her, she isn't too bad and she was gonna have, to have the therapy in Sutton. Then I went up and had me sc-scan, and er and that was it. Next one, they come and told me, I was going into er whats-it- er, sutton, only it was your place. And that's it.

kg You were saying about your son-in-law, went with you?

h Oh he came with me yeah.

kg Aha. And,were the family sort of aware of everything?

h Oh yeah, they were like me they just, well they know I'm not worried about it.

kg Aha

h They know me. Well, this, my daughters friend, she was over, for six weeks, she used to come over every morning. Used to drive her over from Carshalton to Fulham, used to run out feeding meters.

kg Yeah

h And she had it in her- where'd she have it? (to wife) And she's gettin' on alright, you know, they still keep an eye on- as much as you're keepin' an eye on my, my cousins daughter, at er that's Ediths er, and she 'phoned me up at the hospital when she heard, when my sister obviously- and she said, don't worry, what they do, I'm still comin' all the way from Herfordshire, every so often she comes here to have a check-up. But other than that, we ? used to have a laugh in there, I used to enjoy meself in there!

kg Yes, yes.

(wife) He didn't want to come home!

(all laughing)

h Much!

kg Yes, I know, you were all set to go off, weren't you, Friday night!

h Oh, Friday night, I was out-side the main gate, waiting for one of me grandsons to come up, with me daughter, and I put the case in. (coughs)

kg So, are you going off, well, you're probably not going off to the caravan now, -

h Oh! the sea was-

(wife) -it was trechorous-

h -the waves was high as this building, they were coming up, all the roadways, peoples caravans, cause we're farther back, Chelsea Beale, and it was like that! (indicating how high)

kg Yeah?

h See, don't want to get blown over.

kg So, when you do go to the caravan, can you do the sorts of things you like to do there?

h Oh yeah, I got to have a go at cuttin' the grass!

(wife laughs)

kg hmmm

(wife) No, we just sit around there and enjoy ourselves.

h Oh I stop, just down tools.

(wife) Often go for a ride, Chichester and walking round.

h Well, I say you look at these things, well, all got to go, I know that, but I don't want to go before me turn-

kg Yeah

h- everybody, I mean, providing you've got your faculties, everybody wants to live on. If you're a cabbage, you don't want to know.

kg Yeah.

h Cause life is so sweet!

kg Yes.

h Looking at a man next-door, he was, cremated last Thursday week, niney-three, he was a wonderful old gentleman, wonderful! His mind just started to go, well, then, its a blessing, cause you don't know nothing then-

kg Yeah

h- charming people though.(fades out)

kg Is there anything, you know, we've been talking about it for a while now, the whole experience, is there anything else you feel like you'd like to tell me about? Has it brought anything else to mind?

h (pauses a second) Well it makes you, there are, er, things you just used to take for granted. You get up of a morning, and you say to yourself, well, God's good, I've got another day-

kg Aha

h -knowing, and that, that as I say, you know when you go back to the hospital, you don't relish it, you-you know even though its just for a check.

kg Yes.

h- You take it into your stride, and once its done, you're given the all-clear, as he told me that time, Dr Henk says, er the first x-ray after the, after so many weeks, he said, well, it gone, its cleared up, and now, as far as you're concerned its finished!

kg Hmm mm, Hmm mmm

h And half the time, you know, you got to be careful, providing ? , and erm, I say you've had your, erm, little things that you used to just take for granted, you realize, well sometimes you get the hump, argumentative, you know, if you, if you're under the weather kind of thing, you know, which is, er as I say, you get it sorted, and other than that you get on well, enjoy going down the van, -

kg Aha

h- little things like that you know, you'd miss, if, well, its there you know, its like you trying to buy your own house, its lovely, then you start thinking, oh, whats behind it, you see, it isn't so easy as it looks!

kg Aha

h And when I was a young fella, and at your age, things were very hard. And we used to have to work hard. I was driving a double-decker all around the West End, for six quid a week! Six pounds a week. It was all different shifts. Shift works no good to anybody really. The time goes so quick. Do you want to stop? (pointing to tape, and seems tired)

kg Well, I'll stop the tape there.