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**The initial phase of cancer care -  
An action research project**

**Volume One**

**Ingrid Maria Ablett-Spence**

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**PhD Thesis  
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**2004**



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## **Abstract**

### Title

The initial phase of cancer care – an action research project

### Rationale for the study

Anecdotal evidence suggested that patients receiving treatment within a Cancer Unit were not receiving equitable care. Some patients reported being told their diagnosis in an empathetic manner, whilst others reported consultants being brutal and/or uninterested. In addition, it appeared that patients were given variable levels of support and information during their initial phase of cancer care.

### Aims of the study

The purpose of the study was to explore whether the information and support offered to cancer patients in the initial phase of care was sufficient and appropriate to their needs. It was further hoped that the findings of the study could be utilised to change services in a patient centred way.

### Methodology

A qualitative study divided into three stages. Firstly, eighteen non-participant observations of doctor/patient consultations were carried out at the time when patients were told they had a diagnosis of cancer and given information relating to their proposed treatment. The

purpose of this was to ascertain what actually happened in practice. The data resulting from this stage of the study enabled an understanding of the problem in context and facilitated the development of an interview schedule, which formed the basis of the second stage of fieldwork. Stage two consisted of thirty-three semi structured, tape recorded patient interviews. These were carried out 3-4 months following diagnosis. The third stage of the study consisted of interviews and focus groups with consultants, clinical nurse specialists and senior managers, the purpose of which was to explore their views regarding the results of the patient interviews and perceptions of the implementation of change in clinical practice. The approach taken to structure the data collection was based on grounded theory (Glaser and Strauss, 1967).

### Findings

Many of the issues raised in the patient interviews were consistent with the literature i.e. patients experience a wide variety of emotions when told they have cancer. The vast majority of patients hear little after the word "cancer", it is therefore important to repeat information and ensure patients have access to ongoing support. Patients also value being told the truth, continuity of information and doctors showing that they care. They appear more satisfied with their care where an effective multidisciplinary team exists. However, patients in the Cancer Unit where the study was conducted did not receive equitable care, particularly in relation to the amount and type of information and support offered to them in the initial phase of cancer care. The third stage of the study explored consultants', clinical nurse specialists' and senior managers' views relating to the findings from stages one and two of the study. The health care professionals did not exhibit surprise at any of the findings but were keen to explore them

further. Views relating to the implementation of change within cancer care were also explored in this stage of the study and their comments were largely consistent with the literature on change management.

### Innovations in practice

A number of changes have been made to clinical practice, including, improved multidisciplinary team working, developing multidisciplinary documentation and developing site specific cancer pathways which identify the patients journey from the point of referral through to follow up or palliation. These pathways help patients know what to expect at each stage of their disease journey and ensure patients receive equitable care, because the pathways act as guidelines for professionals outlining good practice at each stage of the journey. All of the developments initiated to date are aimed at improving the patient experience and staff satisfaction relating to the service they provide.

## **CHAPTER 1**

### **Introduction**

As a Clinical Nurse Specialist working with cancer patients on a daily basis it had become increasingly evident that individual patients recounted how they were told of their diagnosis in very different ways, which appeared to be dependant upon the communication skills of the consultant responsible for them. For example, some patients reportedly learnt their diagnosis almost by default because the consultant avoided using the word cancer and used terms such as wart, cyst, growth and tumour instead. In such instances the consultant rarely verified that the patient had understood that the diagnosis was cancer nor did he or she follow it up by saying something like "what I really mean is you've got cancer". Other patients were told that they had a cancer diagnosis in an empathetic and sensitive manner.

In addition to the different ways in which they were told they had a cancer, patients also received variable amounts of information from their doctors relating to their treatment and prognosis. The non medical support such as written information, access to Clinical Nurse Specialists, information about support groups and financial advice offered to patients also varied greatly and seemed to be dependant on whether the individual consultant chose to make this support available to his/her patients. In the current health care climate such inequities in service provision should not exist and patients should have "access to uniformly high quality of care"

(Calman and Hine, 1995).



The way in which patients are encouraged to discuss their diagnosis and treatment options also appears to vary greatly, with some patients feeling included and active participants in the discussions with their consultants and others feeling as though they were offered a “fait accompli” regarding their treatment options. The Calman and Hine (1995) report suggests that:

“Patients, families and their carers should be given information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards”

This was clearly not happening and there were a number of ethical concerns arising from existing practice identified by the Clinical Nurse Specialists, including:

- 1) The patients right to know their diagnosis
- 2) The issue of informed consent i.e. were the patients appropriately prepared, given all of the facts and opportunities to ask questions prior to them consenting to a particular form of treatment
- 3) Did the patients need an advocate and was the Clinical Nurse Specialist the appropriate professional to fulfil this role?

There was also an increasingly held view amongst the Clinical Nurse Specialists that there was a need to ensure more equitable practice throughout the Trust, it was thought that there were areas of good practice such as one colorectal cancer clinic. Bowel cancer patients were seen in this clinic by a consultant and given their diagnosis, the consultant was accompanied by a Clinical Nurse Specialist who could follow-up the patients at home if necessary and could continue to support them from diagnosis throughout their disease journey both in

hospital and at home. Patients attending this clinic were also given written information regarding their disease and treatments and were provided with contact numbers for further support. However, although the doctors and nurses utilising this model thought it was what patients wanted, this initiative had not been formally evaluated.

It was clear that the initial phase of cancer care varied greatly from patient to patient with some getting access to plenty of information and support whilst others were given the level of information which the doctor deemed it appropriate for them to know and were provided with limited information and support.

The purpose of the study was to explore what cancer patients were being told by their doctors in the initial stage of cancer care and to examine whether the information they were given and the support they were offered met their needs at that particular time in their disease journey. It was hoped that the study would highlight the importance of ensuring that newly diagnosed cancer patients were all provided with the same standard of care regardless of their primary site of cancer and the health care professionals responsible for their care. It was also envisaged that the results could be used as a starting point for discussions on the development of a multiprofessional core communication protocol. The existence of such a protocol could help ensure that patients received a more equitable service than currently seems to be the case. It was also envisaged that the results of the study would support the need to develop other areas of practice which enhance patient care such as promoting multiprofessional team working and utilising the Clinical Nurse Specialist's more effectively. Finally, the Macmillan Nurse Specialist team hoped to utilise the findings of the study when formulating and delivering training programmes aimed at the doctors and nurses working within the Trust,

particularly when focusing on the patients needs around the time of diagnosis during the initial phase of cancer care.

The word cancer instils fear into everyone, both health care professionals and the general public alike. It is estimated that at the moment one in three people will get the disease, with one in four dying from it, it has also been suggested that by 2005 this figure will have risen to one in two people developing the disease (Sikora, 1998). The incidence of cancer in the United Kingdom is high. However, although many people present late not all cancers are incurable. Some cancers such as Hodgkin's disease, Acute Leukaemia and Testicular cancers have a high survival rate. Complete cures are sometimes achieved with specialist treatments such as surgery, chemotherapy and irradiation, or a combination of all three. Where cure is not possible the same treatment modalities are often employed in order to improve quality of life for the patient by reducing symptoms or in some instances to also extend life span. In some cases none of the aforementioned treatment options are appropriate and in such instances the palliation or control of troublesome symptoms is the mainstay of management.

In 1995 the expert advisory group on cancer noted encouraging signs in the management of the disease. For example surgical and radiotherapeutic techniques have improved substantially, in addition the expert advisory group commented that in several common cancers the use of pharmacological interventions has been associated with a modest but significant increase in cure rates in some groups of patients, however they did not support this statement with statistical evidence. The group also went on to suggest that due to "advances in medical science the developments of new treatments may be a possibility in the foreseeable future". They also recognised the

significant advances in symptom management particularly pain control and the fact that the professions involved in cancer care have “sharpened their emphasis on maximising the quality of life for cancer patients” (Calman and Hine, 1995). However, despite such advances in the clinical management of cancer, there is a substantial body of evidence describing psychological morbidity associated with a diagnosis of cancer. (Calman and Hine, 1995; Ramirez et al, 1995; Derogatis et al, 1983; Greer, 1984; Carey and Burish, 1987; Fallowfield, 1988; De Walden-Galusko, 1995 and Lewis and Fallowfield, 1995). The individual consequences of a diagnosis of cancer for patients are far reaching and profound, as cancer is still regarded by the public as an especially threatening disease and one which to some extent remains a taboo subject (Calman and Hine, 1995). From the period of initial investigations through to treatment or palliation of symptoms the experience of cancer has a profound personal effect, not only as a disease but also as a personal and social experience. Patients are faced with a life threatening diagnosis which is associated with fear of the unknown , potentially unpleasant treatment and side-effects and an associated loss of psychological self. A diagnosis of cancer also has the ability to disrupt feelings, attitudes and relationships and is very often seen as a metaphor for death (Corner, 1993; Hanson, 1994; Burt, 1995; Barter et al ,1997). Even when cancer is diagnosed in the curative stages psychological morbidity remains an issue (Lovejoy and Matteis, 1996). As cancer treatments continue to improve and there is a corresponding increase in long term cancer survivors there is also potential for health care professionals to become increasingly involved with supporting patients with chronic psychological disorders directly due to their initial diagnosis if they are to prevent the development of long term problems in their patients such as depression and inability to deal with subsequent illness. However, it is currently thought that fifty percent of

those who present for medical help are already incurable and suitable for palliative management of their disease at the time of diagnosis. This places incredible psychological distress on both the patients and their carers, there are also the physical consequences of dying of cancer, the associated symptoms and the potential for a substantial financial burden being placed upon the family and carers resulting from disabilities and premature deaths of people often during their most productive middle years (Calman and Hine, 1995).

The Calman and Hine (1995) report attempted to address the variations in cancer treatments and associated outcomes, which existed at that time in the United Kingdom. The general principles which governed the provision of cancer care as advocated by the report and which are applicable to this study are as follows: -

- “All patients should have access to uniformly high quality of care in the community or hospital, wherever they may live to ensure the maximum possible cure rate and the best quality of life. Care should be provided as close to the patients’ home as compatible with high quality, safe and effective treatment.
- Patients, families and carers should be given clear information and assistance in a form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards.
- The development of cancer services should be patient centred and should take into account patients, family and carers views and preferences as well as those of professionals involved in cancer care. Individuals’ perceptions of their needs may differ from those of the professional. Good communication between professionals and patients is especially important.

- In recognition of the impact of screening, diagnosis and treatment of cancer have on patients, families and their carers, psychosocial aspects of cancer care should be considered at all stages”.

The report also recommended that cancer care be provided in three areas: -

- 1) Primary care
- 2) Cancer units
- 3) Cancer centres

Primary care refers to the point at which the patient enters the health care system i.e. their general practitioner and associated services. Cancer units are District General Hospitals which have been assessed regarding their ability to provide care for patients with common cancers such as lung, breast and colorectal cancers. Patients attending cancer units should expect to receive high quality care in close proximity to their own homes. Cancer centres are specialist units where patients can be given complex treatments such as toxic chemotherapy regimens or radiotherapy. In addition, the cancer centres have clinicians who have considerable expertise in treating the less common cancers. It is clear that all health care professionals have an obligation to ensure that patients not only receive the highest standard of physical care possible but also that their fears and concerns and those of their family and carers are also addressed in a sympathetic manner. Good communication skills are vital and should be seen as an integral part of providing appropriate care for cancer patients (Stedeford, 1994; Calman and Hine, 1995; Kaye, 1996). These skills are particularly appropriate at times such as when a patient has been given a diagnosis or information regarding treatment options and outcomes, if the patient fails to understand the

implications of what has been said to him or her, he or she will be unable to make informed decisions regarding the management of his or her disease. There is increasing evidence to suggest that counselling and other psychological techniques are a valuable method of improving patient outcomes, particularly those relating to psychological morbidity (Sikora, 1998; Ream and Richardson, 1996; Johnson, 1982).

Information and understanding or knowledge regarding a patient's own cancer can be seen as power by the patients themselves. Information allows patients to make appropriate decisions regarding their treatment and also enables them to have some control at a time that they may feel that their body is out of control and they can do nothing about it. Without accurate information regarding diagnosis, prognosis and expected effects of treatment, patients are unable to give informed consent, which is itself an ethical requirement. The importance of accurate information regarding treatment outcomes was emphasised by a study showing great variability with people with lung cancer in their choices of treatment options (Brundage, Davison and MacKillop, 1997). Whilst some patients placed value on the hope of increased survival time, others were much more concerned about the quality of their remaining life; these different values should imply different approaches to treatment (NHS Executive, 1998).

Evidence suggests that patients commonly misunderstand the information given regarding their disease (Quirt, MacKillop and Ginsburg, 1997). Patients often underestimate the extent of their disease and may overestimate the effectiveness of oncological treatments. Patients often believe that palliative treatment will be potentially curative. In addition many fail to recall information about side effects in instances where doctors have maintained that they

have provided this information. The doctors in Quirt, MacKillop and Ginsburgs study frequently believed that patients understood more than they actually did about their illness and treatment. Overestimating the benefits of treatment could potentially lead to patients opting for treatments that are not appropriate for them and may indeed have adverse affects leading to unnecessary side-effects and resulting in poor quality of life for whatever time they have left. Several studies support the idea that giving information to patients can reduce anxiety and in some instances even being the recipient of bad news is more reassuring than uncertainty and subsequent fear of the unknown (Johnson, 1982; Ream and Richardson, 1996; Grahn and Danielson, 1996). Specific information about what patients are likely to experience when they undergo treatment helps overcome anxiety and it appears that the benefit of information given before treatment begins can last throughout the treatment period (Rainey, 1985; Poroch, 1995). There is also some evidence to suggest that better informed patients may look after themselves more effectively (Ream and Richardson, 1996).

Quality communication between patients, doctors and other health care professionals not only improves patients and carers satisfaction with a service but it can also be seen as one determinant of the amount of accurate information patients receive, this in turn can influence patient compliance with poor control of side effects and ultimately, due to this, withdraw from treatment or advice (Ley, 1988). Those patients failing to get sufficient information regarding treatment toxicity may experience poor control of side effects and ultimately due to this withdraw from treatment (Ramirez, Richards, Rees et al, 1994).

Studies which have assessed the information giving process as part of a specialist palliative care service indicate that patients and their



families are more satisfied when they are given more information (Hinton, 1980; Hinton, 1986). In clinical practice it is evident those patients who are well informed regarding treatment options appear to be better adjusted to their decision than patients who are unable to access their options fully due to insufficient evidence.

Lack of information particularly relating to the time of the original diagnosis and when patients are given information about treatment options, and communication in advanced stages of illness is a major cause of dissatisfaction amongst cancer patients (Johnson, 1992; Cassileth, Zubkis, Sutton-Smith et al, 1980; National Cancer Alliance, 1996; McHugh, Lewis, Ford et al, 1995). Unfortunately there is some evidence to suggest that oncologists underestimate a patient's distress and do not appreciate the level of concern that patients have about their treatment and indeed about interacting with the doctor in the first instance (Goldberg, Guadagnoli and Silliman et al 1990).

It appears that the problems not only relate to face to face communication between patients and doctors or other health care professionals but also with written information. A survey of written information available in the United States shows that it constantly fails to deal with common symptoms of lung cancer and may not give clear guidance on the disease or its treatment. Most of the material also requires a level of reading skill that is higher than many patients with lung cancer are able to cope with (NHS Executive, 1998).

Some of the problems relating to communication with cancer patients may be due to a variety of reasons, it may be that health care professionals do not have the appropriate training particularly relating to the giving of bad news, they may feel ill equipped to deal with patients fears and anxieties or may find the giving of such news

difficult because they may feel they have failed. The issue of communicating with cancer patients is compounded by the ethical concept that "patients should be told as much of the truth as they want to know ". This stance relates to current teaching in oncology and palliative care in North America, Western Europe and the United Kingdom. However such a dichotomy exists as it is not universal practice to follow this recommendation, since carers still often tell relatives the news about their diagnosis and afterwards only consider whether the patient should be told. It is also naïve to assume that even if professionals did follow this principle all of the moral dilemmas surrounding truth telling in palliative care and oncology could be resolved (Randall and Downie, 1996).

Despite the ethical principle that all patients should be told the truth in palliative care or oncology there are still a number of questions that remain unanswered. Are there some choices the professional must make and for which he or she is morally responsible, such as how much of the truth to tell or how to tell it? Randall and Downie argue that there are two positions that minimise the moral choices that have to be made by the professional. Firstly, there is the position that patients must be given all the information that they can comprehend and secondly the position that the professionals task is limited to giving only that information which that patient states they require. They suggest that patients must be told as much of the "whole truth" as they can comprehend and there would be serious adverse consequences as a result of giving large amounts of bad news. Patients would be told all possible outcomes including the ways of dying. In reality many of these possible outcomes would never really happen to that particular patient and therefore there is potential for that patient to become unjustifiably distressed and psychologically damaged by such information, much of which would turn out to be irrelevant to their

particular circumstances. They also suggest that limitations of time and attention span render this proposal for information giving as being totally impractical. The second proposal suggests giving professional answers to patients questions truthfully but only and always literally. The suggestion is that the patient should be in control of the flow of information by being allowed to ask questions but also by being asked how much information they really want. This proposed method of information giving will enable patients to gain knowledge at a pace at which they can assimilate it and will also take into account their individual wishes. Randall and Downie suggest that it should not be done simply in an attempt to take moral responsibility for judging exactly what aspects of the truth should be told. However, although such a proposal seems initially attractive, it is an over simplification of the situation and that in some circumstances patients have indicated that further bad news is not wanted but health care professionals may feel that they should be told some more about their illness for their physical well being. An example of this may be a patient who is found to have bone metastasis in the cervical spine with a risk of spinal cord compression which could result in quadriplegia, that patient should be advised that they require radiotherapy in order to minimise the risks of quadriplegia and may need to take special precautions in the interim. In such a situation the patient has to be given the bad news of cervical metastasis in order for him to adjust his lifestyle pattern and minimise the risk of the very serious harm of quadriplegia. The circumstances may arise in which the professional becomes aware of major risks of serious adverse consequences which can be averted by informing the patient who can then choose to co operate to minimise those risks and subsequent consequences. In such a scenario the professional needs to consider how they should respond to this knowledge: -

- 1) Only tell the patient the information he/she requires and hope that no adverse events occur. (Clearly this response has ethical implications as it could result in a patient who is harmed due to medical inaction, fortunately this response is rarely seen in clinical practice in the United Kingdom).
- 2) Inform the patient of the bad news even though it may be unwanted in order that an adverse event may be avoided.
- 3) Suggest that if further bad news is unwanted then the patient may wish to pass the clinical decision making to the professional who may give advice about lifestyle or treatment, for example if the patient does not want further information the doctor may suggest that a particular course of treatment such as radiotherapy may help avert further problems.

It is apparent that in such a scenario when the professional decides how much of the truth to tell, he or she has to make a moral choice which involves a harm/risk assessment relating to the impact of the information on the patient. Such a calculation can be very difficult and getting it right is very much a part of the art of oncology/palliative care. It is clear that if the patients total good i.e. physical, psychological, spiritual and social well being, is the health care professionals prime aim and if their total good can only be achieved by professionals passing on to patients professional knowledge, the professionals should take moral responsibility for sharing the necessary aspect of that knowledge with them. A decision not to give any information, which has not been requested purely to avoid such responsibility, amounts to moral abandonment. Therefore sometimes health professionals are morally obliged to give more information than the patient requests based on a harm/benefit analysis, which is undertaken on the basis of professional knowledge and experience.

Cancer patients are cared for by a variety of health care professionals all of whom play an active part in the communication of information to their patients. The delivery of care can vary greatly from the professional working in isolation at one end of a continuum to professionals working together to provide a multiprofessional approach. Clearly where a multiprofessional approach is adopted, teamwork improves coordination and patient support. Studies suggest that a multiprofessional approach can improve patient and family satisfaction, increase the probability that patients are cared for where they desire and increase the likelihood of effective symptom control (Addington-Hall, 1992; Kane, 1984; Wakefield, 1993). There is fairly strong evidence that multiprofessional palliative care teams can improve the flow of information in so far as patients feel better informed and have better access to necessary services when a multiprofessional approach has been taken (Higginson, 1990; Viney, 1994; Greer, 1986; Parkes, 1994). Evidence suggests that where professionals work in isolation, patients miss out; they may not receive financial advice, advice about local sources of support or optimal symptom management (NHS Executive, 1998). A number of studies advocate a multiprofessional approach to cancer and palliative care (Harper, 1998; National Council for Hospice and Specialist Palliative Care services, 1995; Cancer Relief Macmillan Fund, 1994). The teams found to be most effective include nurses with specialist training in palliative care, a senior doctor e.g. a consultant with specialist training plus social work or psychology support. Palliative care and cancer expertise also appear to contribute to patient satisfaction and good symptom control (NHS Executive, 1998).

An increasing trend by oncology and palliative care teams is to appoint a Clinical Nurse Specialist. Some studies have attempted to evaluate the effectiveness of specialist nurses, particularly in areas such as

diabetic care, stoma and palliative care (Moyer, 1987; Wade, 1989; Doyle, 1982; Macdonald, 1989; Parkes, 1980). However the outcome measures used in these studies i.e. quality of life, the numbers of patients dying at home, and patient satisfaction ratings are in the main difficult to measure and their suitability as outcomes hard to assess (Haste and Macdonald, 1992). Godfrey (1996) highlights the fact that there is little continuity amongst specialist nurses and that the role of the Clinical Nurse Specialist is very much open to individual interpretation and this is a common criticism of the role. However, others suggest that Clinical Nurse Specialists do provide quality patient care, which is based on advanced nursing models with two important characteristics, clinical judgement and leadership (Spross and Baggerly, 1989). In order for Clinical Nurse Specialists to utilise clinical judgement for the benefit of their patients they remain within the realm of direct patient care (Kai-Cheung, 1997)

The term Clinical Nurse Specialist refers to a Registered Nurse who after a significant period of experience in a specialist field of nursing and with additional qualifications in that area is authorised to practice as a specialist with advanced expertise in that speciality. The role involves direct clinical practice, consultation, teaching and research (Tang, 1993). Expanded autonomy in direct patient care is an important aspect of the Clinical Nurse Specialist role because of their competency in advanced nursing practice (King, 1990). By being competent in managing patients with complex physiological or psychological needs (Spross and Baggerly, 1989). The clinical judgement of a Clinical Nurse Specialist can accelerate the nursing process and help them focus on the root problem experienced by the patient without wasting time on fruitless assessment (Benner, 1984). They meet more of patients needs than do basic registered practitioners (Storr, 1988). This is as a direct result of their

experiences as well as their post basic education within the area of their speciality (Kai-Cheung). In practice Clinical Nurse Specialists fulfil a number of important roles linked with developing nursing practice and providing quality patient care (Armstrong, 1999).

The research developed out of the involvement of a Clinical Nurse Specialist in supporting patients once they had been given a diagnosis of cancer and also from anecdotal evidence that the amount and quality of information given to patients with cancer varied tremendously. At the time that the study was commenced there were no pre-defined protocols for managing patients with specific cancers, which had been adopted, by all of the consultants across the cancer unit. This was despite recommendations that "all patients should have access to a uniformly high quality of

Care in the community or hospital wherever they may live to ensure the maximum possible cure rates and the best quality of life" (Calman and Hine, 1995). More recently, guidelines for good practice relating to the management of specific cancers have been widely circulated by the NHS Executive (Department of Health, 1998). However the provision of common standards and protocols remain patchy even at cancer unit level let alone regionally or nationally. The reality of the situation is that individual consultants interpret the guidelines (where they exist) in their own way. This phenomena results in patients with the same primary site of cancer being treated by different consultants in the same unit often receiving different information regarding their diagnosis, prognosis, treatment and support available to them. Some patients are offered specialist nurse support at the time of diagnosis, others during active treatment such as a course of chemotherapy or radiotherapy, whilst some patients are only offered support where treatment has failed or cannot be instigated in the first instance due to a poor prognosis at diagnosis. A similar scenario applied to the

patient's ability to access other specialist services such as dietetic support, physiotherapy and complimentary therapy practitioners. In some instances patients are not offered any further support from any agency at all. Such a situation was felt to be unsatisfactory, particularly as national guidance suggests:

"Patients, families and carers should be given clear information and assistance in the form they can understand about treatment options and outcomes available to them at all stages of treatment from diagnosis onwards ..... the development of cancer services should be patient centred and should take account of patients, families and carers views and preferences as well as those of the professionals and patients involved in cancer care. ... good communication between professionals and patients is especially important"

(Calman and Hine, 1995)

However, prior to the study being undertaken all evidence relating to inequality of care for cancer patients within the cancer unit was purely anecdotal.

The information and support needs of cancer patients is a topical area which evidently arouses great interest and in some instances a degree of anxiety both within the medical and nursing professions, particularly those newly qualified in their discipline. The majority of literature reviewed at the outset of this study related to the needs of patients diagnosed with specific cancers such as breast cancer (Luker et al, 1995; Smyth et al, 1995; Suominen et al, 1994) and gynaecological cancers (Corney et al, 1992; Anderson and Hacker, 1992). The focus of the published research tended to be the specialist aspects of information required by such patients, such as the psychological



impact of losing a breast or the loss of sexuality following radical breast or gynaecological surgery. Thus, at the commencement of the study there was a dearth of literature relating to the more general information needs of cancer patients. Of those studies which could be found relating to more general communication and information issues the general consensus was that most patients wanted to know their diagnosis, prognosis, treatment options and side-effects (Meredith et al, 1996; Cassileth et al, 1980; Fallowfield et al, 1994). However these studies have not explored issues such as the timing of information giving, the appropriateness of and the quality of support both written and practical which was offered and so on, all of which are areas which could be potential sources of inequity across the cancer unit where the study was conducted. There is a wealth of literature suggesting who should break bad news and advocating models which enable practitioners to deal with this stressful issue sympathetically and effectively (Webster, 1981; Selvin, 1987; Kaye, 1994). Yet despite such published guidance, evidence still suggests that breaking bad news and communicating with cancer patients are areas where health care professionals perform badly (Wilkinson, 1991; Doyle, 1991). These issues will be discussed in more depth throughout the body of this thesis.

The later part of the study will also explore implementing change within cancer care with particular reference to the cancer unit where the study was conducted.

## CHAPTER 2

### Literature Review

At the time that the study was initiated, there was limited published literature reporting studies carried out in the United Kingdom relating to the general cancer population, because of this the literature review includes studies carried out in the United States and Europe as well as the United Kingdom. Reviewing studies from an international perspective allows for comparisons and also identifies areas of 'good' and innovative practice; such examples can in some instances be integrated into local services.

This literature review includes studies relating to:

- The current medical practice relating to confirmation of a cancer diagnosis.
- The adequacy of the information given to cancer patients.
- Problems with the information giving process.
- Factors influencing the way in which doctors and nurses communicate with cancer patients.
- The nurses role in the information giving process.
- Improving communication with cancer patients.
- Support for the family.
- The need for ongoing support following the initial phase of cancer care.

### The current medical practice relating to confirmation of a cancer diagnosis.

Physicians and other health care professionals have been under increasing criticism since the late 1960's for allegedly failing to be

open and honest with patients who have a cancer diagnosis. Kubler-Ross, (1969) and Schultz and Aderman (1975) concluded that the majority of physicians adhered to a policy of not sharing their diagnosis with dying patients. Carey and Posavac (1978) carried out four parallel surveys comparing physicians with nurses, hospital chaplains and a non-health care professional sample of college students regarding their attitudes relating to informing terminally ill patients of their condition and towards active and passive euthanasia. The study supported the hypothesis that the apparent contradiction among reports of the attitudes of physicians may be due to a shift towards more openness with terminally ill patients on the part of the physicians over the previous decade. The nurse arm of the study reported that the proportion of physicians (87%) who felt that patients had an unqualified right to know the truth if they requested the information slightly but not significantly exceeded the numbers of affirmative answers in the comparative groups i.e. the physicians, chaplains and students. As for delegating their responsibility to others to inform the patient, the physicians were less willing to delegate responsibility than the nurses, chaplains or students were willing to have the physicians delegate this responsibility. None of the hospital personnel and only 4% of the college students said that they did not want anyone to tell them if they had a terminal illness. There was also consensus amongst all groups that they wanted a spouse or nearest relative to be the one to break the bad news. As for the factors that should ordinarily determine whether or not a patient is told, there was consensus among all groups that emotional stability as the most important factor to consider and that the depth of religious faith was the least important factor. Opinion was divided on the other factors. With respect to taking the initiative in telling the patient of his/her terminal condition 71% of physicians said they should do so, and even

a greater proportion of nurses (88%) felt that the physician should take the initiative to inform the patient.

Most of the physicians included in the study (84%) said there were times when they should tell the patient against the wishes of the patient's spouse, the situation when the spouse's wishes would be ignored would be described as "when the patient asks" or "when the patient shows he is emotionally ready to cope with the knowledge". Nurses and chaplains agreed with physicians on dealing with a spouse who wanted to hide a terminal condition from a patient. The only comparison that approached a reported statistical significance (although a figure is not given in the literature) was between the physicians (84%) and students (71%) who deferred slightly more to the family. The study supported the hypothesis that there had been a shift towards more openness amongst physicians over the previous decade on informing terminal patient's of their conditions. The attitudes of the physicians in the study did not differ greatly from those of nurses, chaplains or students concerning how information should be disclosed to terminally ill patients. Of even greater importance was the deep concern and interest that the majority of physicians showed during the interviews regarding dealing with dying patients.

Some of the interviews carried out in Carey and Posavac's study took 20-30 minutes because the physicians wished to elaborate and clarify their thinking for the interview. Many staff physicians emphasised that they considered the manner in which they informed the patients to be the most important consideration however there were limitations to the study as it did not investigate whether a physician followed through on their convictions and actually informed the patients clearly without euphemisms. In addition the survey does not provide any clues as to why hospital personnel differ from the general public on some issues.

Although it has become generally accepted by the majority of health care professionals that cancer patients have the right to be adequately informed about diagnosis and treatment options it has been suggested that many physicians tacitly assume that patients are better kept in ignorance (Henriques et al, 1980). The majority of published studies regarding the information sharing process have been carried out in the United States where concern regarding the application of informed consent law and its impact on general practice has promoted several investigations. Overall the majority of US studies suggest that physician's attitudes are changing and most of them are now willing to tell cancer patients their diagnosis and inform them of possible therapeutic alternatives, (Novack et al, 1979; The Interdisciplinary Group for Cancer Care Evaluation, 1986). The studies carried out in Europe and indeed the United Kingdom are patchy, perhaps this is due to the lack of legal obligation requiring the individual physician to make the decision regarding whether or not to inform his or her patients. However as more and more dissatisfied patients in the United Kingdom seek recompense via the litigation process the studies carried out in the United States begin to have more relevance to those health care professionals sharing information with British cancer patients. There is a suggestion that the sharing of information between physicians and patients leads to a reduction in dissatisfied patients and that satisfaction with information can improve a patient's compliance with medical advice, it is ultimately the patient who has to take the final decision regarding what treatment option he or she feels comfortable with, and is it unfair for him/her to take that decision when information has been withheld from him? On the other hand, there are also sceptical views regarding the feasibility and utility of free exchange of information between patients and their doctors. There is for instance a wide spread belief amongst doctors that patients forget

or deny much of what they are told, or that they are often not able to understand information or indeed that a rational exchange of information could negatively affect patient's trust in physicians, thus undermining therapeutic effectiveness, (Tuckett and Williams, 1984).

Mystakidou et al (1996), highlighted the fact that societies in developed western countries such as Greece were debating a variety of issues concerning truth telling, informed consent, the individuals rights in healthcare decision making, and so on. It is clear that the image of the physician is changing rapidly, he or she is being asked to give reasons for what he does to patients and to justify those reasons, and in addition physicians are expected to give much more information and to make patients partners in their own care. Mystakidou et al (1996) suggest that the issue of whether, how and how much to tell cancer patients about their diagnosis and prognosis is still approached in considerably different ways in different countries.

Gastroenterologists who are often the first point of contact with the hospital for patients diagnosed with stomach or bowel cancers in all parts of Europe were asked to consider a case of colonic cancer and to state what they would tell the patient and the patient's spouse, (Thomsen et al, 1993). Replies were received from 260 gastroenterologists in Northern Europe with details regarding what they would usually reveal relating to diagnosis both to the patient and with the patient's permission to their spouse. They would sometimes embellish the truth if the cancer had metastasised. Gastroenterologists in southern and Eastern Europe would usually conceal the diagnosis and prognosis.

In Spain Centeno-Cortes and Nuntas-Olarte (1994) attempted to assess the degree of knowledge of the diagnosis and the attitude

towards that information in a group of terminally ill cancer patients. They assessed 97 patients by means of a semi-structured personal interview and a psycho-social needs questionnaire. The data collected showed that 68% of the patients had not been informed of their diagnosis, 60% of this group has a high degree of suspicion of their diagnosis but 42% of non-informed patients did now want to receive more information.

As part of an Italian survey, questionnaires were sent to 1,171 women after surgery for breast cancer they revealed that only 47% had been told their diagnosis, Mosconi et al (1991). Most doctors in Northern Europe and Anglo-Saxon countries believe that cancer patients should be told their diagnosis, (Brody, 1980; Cassileth et al, 1980; Jensen, 1981 and Reynolds et al, 1981). In the south and east of Europe, doctors often conceal the diagnosis from their patients, (Estape et al, 1992 and Pronzato, 1994). This dichotomy illustrates a recurring theme in the literature of social science; different cultures have different moral codes, what is thought right with one group maybe utterly abhorrent to the members of another group and vice-versa. Enlightened observers have been accustomed to the ideas that conceptions of right and wrong differ from culture to culture and indeed differ between subcultures.

In the cancer unit where this study was undertaken a number of sub-cultures exist, for example the moral codes and expectations of fairly isolated rural communities may differ from those of patients coming from mining villages or the larger towns where the populations are not static.

The opportunity for a full disclosure of diagnosis to cancer patients is the subject of debate. Undoubtedly the pattern of the doctor/patient

relationship varies in different countries and cultures and this should be taken into account when problems of truth telling and informed consent are discussed. It may be also worth considering whether sub cultures exist within countries and whether doctors in the same country change their approaches depending upon the type of patients they encounter. This seems particularly true for patients with advanced disease and a poor prognosis. In the treatment of terminally ill patients the question of whether or not to divulge the nature of the disease and its prognosis is a difficult one, a patient has a right to information concerning himself, on the other hand healthcare professionals have an obligation to preserve both the physical and emotional well-being of the patient. Many doctors (78%) doubt the wisdom of giving bad news to certain patients, in the belief that it may be harmful to them, (Mystakidou et al, 1996). The argument is that some patients will not be able to cope with the information, will give up hope which is necessary to their proper functioning and become depressed or otherwise disadvantaged (Lichter, 1989).

Not being told what is wrong with them is the most common complaint that patients make about the medical profession, (Fletcher, 1980). There is evidence that many doctors in Britain fail to tell patients if they have cancer. In 1984 a postal questionnaire of doctors showed that only 44% of Consultants and 25% of General Practitioners told cancer patients their true diagnosis, (Wilkes, 1984). Since then few comprehensive studies have been carried out to investigate the needs of cancer patients regarding information. A small survey of young patients in a medical oncology unit who were receiving radical chemotherapy for mainly uncommon tumours with relatively good prognoses indicated high desire for information, (Fallowfield and Lewis, 1994). This study population however was not representative of the general population of cancer patients.



Feilding, Ko and Wong (1995) interviewed 142 surgeons and radiotherapists who regularly cared for patients with cancer. The doctors were asked about their practices in disclosing information to cancer patients who were recently diagnosed. Significant discrepancies were identified between what doctors believed their patients understood about their disease and what kind of information the doctors themselves had discussed with their patients, almost all of the doctors interviewed (92%) stated that they informed patients of a diagnosis, 86% of those interviewed informed patients about their prognosis. The statistics contrasted markedly with claimed rates of diagnostic (68%) and prognostic (47%) disclosure. Perhaps more significantly the study revealed that the claimed rate reflects disclosure of only selected information such as the name of the disease but not the nature of the diagnosis. Other discrepancies were also noted in that 83% of the doctors interviewed thought that their patients understood their condition but only one third assessed the patients' diagnostic understanding and one quarter their prognostic understanding. Significantly only 31% of the doctors in the study referred to discussions they had with their patients the other doctors relying on informal methods of questionable validity. Feilding, Ko and Wong (1995) argue that a formal assessment of patients information requirements should be considered mandatory when caring for cancer patients and indeed other patients with incurable illnesses, whilst this is a worthwhile suggestion there seems to be no evidence of this in clinical practice in the United Kingdom. However it must be noted that their study was carried out in Hong Kong with all of the doctors being Chinese and practices in medical training particularly relating to communication skills and breaking bad news may differ significantly from practices in British medical schools.

Centeno-Cortés and Nùnez-Olarte (1994) conducted a study which attempted to assess the degree of knowledge of the diagnosis and the attitude towards that information in a group of terminally ill cancer patients. The study also tried to determine the influence of the knowledge of the diagnosis on other patient's psycho-social needs. In total, 97 patients (64 under the care of the oncologists, 33 being cared for by the palliative care physicians) were interviewed and asked to complete a psycho-social questionnaire. The data which was collected showed that 68% of the patients had not been informed of their diagnosis with 60% of this group having a high degree of suspicion of their diagnosis. The study did not explore whether the uncertainty related to suspicion of having a cancer diagnosis was actually worse than being told in a direct manner whereby they may be able to address their fears and as a result explore appropriate forms of treatment. 42% of those 23 patients who had not been informed actually did not want to receive more information relating to their diagnosis. The researchers concluded that those patients who did want details of their diagnosis providing information regarding management appeared to be beneficial in establishing satisfactory relationships and communication between patients, relatives and staff. The researchers were unable to discover any negative effect on the giving of such information, in particular patients perceived symptoms of anxiety, despair, sadness, depression, insomnia, fear etc. were no higher in the group of informed patients. The beneficial effects of information had been clearly demonstrated, 75% of informed patients shared their concerns about their illness and its consequences with their relatives. Whilst only 25% of those 23 patients who had not been informed of their diagnosis were able to do the same. Those patients who had been informed of their diagnosis and prognosis tended to identify better with the attending physician, had a more satisfactory

relationship with him or her and understood better what was explained. Perhaps most importantly, those patients that had been given information not only failed to lose hope, but actually had a higher confidence level in the treatment they received. They concluded that the percentage of informed patients in their study is still considerably lower than the figures quoted for patients in Anglo-Saxon cultures, although they do not quote figures nor do they suggest the reasons for this and this comment cannot be validated unless the same study was replicated in a country such as Britain. However, the fact that patients who are given information fail to lose hope and have a higher confidence in their treatment is pertinent to practice in the United Kingdom.

With regards to what patients themselves wish to know there is a substantial body of literature which suggests that many patients want to participate in treatment decision making and that providing support at this time could lead to improved patient outcomes, (Degner & Sloane, 1992; Morris & Royle, 1988; Fallowfield et al, 1990; Neufeld et al, 1993). In recent years there has been a shift from the paternalistic view that only physicians can make treatment decisions to the view that many patients when properly informed and supported are capable of participating in making treatment choices. However Neufeld et al (1993) pointed out that despite the prevalence of consumer orientated attitudes in health care, finding ways to provide practical and emotional support for people who wish to participate in treatment decision making remains a problem particularly as treatment decisions for cancer patients are often made at critical times such as diagnosis and relapse, and have a profound effect on an individual's survival and quality of life. It is clear that the nurse has a vital role in providing decisional support and that his or her skills in this area need to be developed and evaluated, (Neufeld et al, 1993).

### Adequacy of the information given to cancer patients

The Interdisciplinary Group for Cancer Care Evaluation in Italy noted that there were no large scale investigations that had been carried out in their country regarding whether cancer patients received adequate information and if so how they received that information. The group carried out a mail survey in 1983 with questionnaires being sent to a large group of breast cancer patients to assess whether they had been informed about diagnosis and treatment or whether the lack of this information caused dissatisfaction, (Liberati et al, 1985). The study showed that about a third (37%) of the patients received thorough information but only 18% complained of lack of communication, views of the remaining 45% were not reported. Gibio (1986) tried to address the same question from a different perspective and interviewed physicians treating breast cancer patients. The physicians were asked to report what they told the patients about diagnosis and treatment and how satisfactory they considered the information they had given. Analysis of what the doctors reportedly said to their patients indicated that a substantial proportion of the cases did not receive satisfactory information. Moreover, they found substantial evidence that physicians tend to overestimate the completeness of the information they give. The study was a large scale study that incorporated information which was collected by 62 participating hospitals. The data was collected by a medically qualified investigator using standard forms. In addition to the detailed clinical and demographic description the study protocol required a summary to be included in the notes of what doctors told patients and their relatives regarding diagnosis and surgical treatment. In addition the doctors were asked for their own personal judgement on the quality of the interaction from an information perspective between themselves and the patients rating it as (A). Satisfactory, (B) Partial, (C) Unsatisfactory. According

to the protocol, interviews were conducted during the patient's first admission with a lag-time between doctor/patient dialogue on interview ranging from 1-30 days. Summaries of the doctor/patient communication relative to diagnosis and treatment were centrally analysed by two of the researchers rating phrases reported in each patient's form according to a pre-defined explicit protocol already tested in a study where quality of information was explored by patients.

Quality was classified using a three level scale, thorough, partial information given and no information, based on the following criteria: - when physician's phrases included words like breast cancer, tumours, cancer, neoplasm, and malignant nodule the information was classed as thorough, when words such as benign, nodule, lesion, border line nature, benign tumour were reported information was classified as vague or partial. Finally, when nothing was reported in the questionnaire or content did not fall into either of the previous categories information was classified – no information. A similar format was used for assessing the quality of information regarding surgery. The study incorporated 1262 newly diagnosed breast cancer patients. When asked to evaluate their communication with patients, the physicians reported the interactions to be thorough in 62% of cases, partial in 30% of cases, unsatisfactory in 3% of cases and the data was missing for 5% of cases. Of the 994 patients (79%) had both physician's judgement and summary reports of the information by the doctors were available for analysis. Communication by doctors was deemed 'thorough' in 387 patients and by the explicit protocol in 477 cases (81%). Agreement on the category 'partial' was less frequent, 175 cases were defined as 'partial' by the physician and 433 by the protocol (40%). It was even less frequent for the category 'unsatisfactory', 10 cases by the physicians and 84 cases according to

protocol (12%). When the information was 'thorough' according to protocol physician's judgment had acceptable sensitivity (81%) however, both specificity and more importantly positive predictive value indicating the likelihood of the patient to receive 'thorough' information when the physician said so, were low. When information was 'partial' or 'unsatisfactory', respectively the positive predictive levels were even lower (55% and 45% respectively).

The Italian study highlights the fact that what some physicians see as thorough information may not be seen as such by other physicians, other health care professionals or the patients themselves, a factor which has international relevance. Indeed, terms such as tumour, neoplasm or malignant nodule all of which are deemed as thorough using Gibio's (1986) criteria are in reality often meaningless to patients unless further explanation has been given to clarify such language. In such instances it can not be deemed as a 'thorough' communication unless the patient's understanding of what they have been told has been verified by the physician. There were some limitations to this study for example for about 20% of patients the summary reports on diagnosis and treatment by the doctors were missing. As it is not unreasonable to suspect that when no data were reported poor information was given, the researchers tried to look at the association between missing data and patients and physician's characteristics, they concluded that by re-analysis of the results by classifying all missing data as no information, the patients treated at specialist cancer centres had an almost 70% chance of having thorough communication. However such a method of re-analysis makes an assumption that because summary reports were missing, the doctors omitting to complete them did so due to the fact that they did not give sufficient information to their patients. This method fails to explore other reasons why summaries were missed such as whether the

doctors were busy with clinical issues and simply forgot or whether they were not fully briefed regarding the requirements of the study. Because no information was collected on the characteristics of the individual treating physician such as age, speciality, number of patients etc. the study does not allow for exploration regarding how the specific doctor's characteristics may interact with setting dependent features. Furthermore, another potential limitation of the study stems from the uncertainty on how accurate the data collection was and whether the physician interviews were those in charge of the patients or whether they were junior doctors.

Nobuyuki et al (1996) surveyed patients; views on disease and treatment information which should be provided in hospital. An anonymous self-administered questionnaire was distributed to patients at the Aichi Cancer Centre Hospital. All eligible first visits to outpatient departments (97 patients) and to randomly selected revisit outpatients (99 patients), about 1:10 patients refused and all except 6 eligible inpatients in good condition at discharge (97 patients) responded. Out of the 293 patients 74% responded that they wanted to be informed of their diagnosis irrespective of circumstances; 20% said they would want to be informed only in certain circumstances though they did not specify those circumstances and 2% did not want to be informed at all. There were no significant differences in response amongst the three sources of patients. Inpatients wanted more (81%) explanation about recommended therapy than either first patient visits to outpatients (67%) or revisits to outpatients (67%). The majority considered that about a 30 minute explanation was needed using pamphlet like written materials or video.

Luker et al (1995) carried out a study placing emphasis on the content of information by taking the patients perspective and asking the

patients themselves what particular types of information they perceived as being important at a specific point in time. The aim of their study was to explore what particular types of information were important to women with newly diagnosed breast cancer, to enable nurses and other healthcare professionals to utilise their time as effectively as possible and provide a high quality service to individuals in their care. Women diagnosed with breast cancer were interviewed on average 2½ weeks after they had been told their diagnosis and asked to compare items of information. The items of information were presented in pairs and the women stated a preference for one item in that pair, 26 pairs were presented in total. The analysis involved the use of a Thurston scaling model which allowed rank orderings or profiles of information needs, to be developed, reflecting the perceived importance in each item. Information about the likelihood of cure, the spread of the disease and the treatment options were perceived as the most important items of information at the time of diagnosis. Other information needs in order of descending priority included information about the risk to family, side effects of treatment, impact on family, self care, effect on social and sexual attractiveness. Profiles of information needs were produced to take account of differences in age, level of education and social class. This was a UK study which consisted of a 150 women taken from consultants lists in a large University teaching hospital. A Sample of 200 women with benign breast disease was also recruited to provide a control group for the study.

Luker et al (1995) suggested that arguably, the three information needs rated most highly by women who were newly diagnosed with breast cancer, namely the likelihood of cure, spread of disease and treatment options, are not within the remit of the average ward nurse as far as information giving is concerned. However, they may fall within the scope of the specialist breastcare nurse. An assessment of



the information needs which are important to the patient is within the remit of every registered nurse's role and an awareness of the patients needs is vital for promoting high quality care. If indeed the top three items of information are considered a priority to a patient then the nurse could act as a facilitator, enabling the patients to gain access to the information by, for example, making medical colleagues aware of the patients information needs. This may, in some cases, lead to the development of protocols of guidelines for information giving. These findings have further implications for nursing practice. Information giving is often focused on the time of diagnosis and hospital admission and nurses play a lead role. A mastectomy or lumpectomy is a time of crisis, when retention and recall of information may be severely limited, (Cimprich, 1993) Given that the average length of hospital stay for women with breast cancer is 2/3 days following lumpectomy there is a need to provide information that is perceived as relevant.

Luker et al (1995) highlighted the importance of survival issues for women at the time of diagnosis and studies carried out in the USA and Canada have also found survival issues to be a major concern for women with breast cancer, (Northouse, 1989; Bilodeau, 1992). Overwhelming the patient with information which they perceive as being low priority for example, regarding sexual attractiveness and body image may not be prudent at this time, it is clearly important to understand when a woman's information needs may change, time lapse from diagnosis is probably an important variable and further work is being carried out in this area. Luker et al (1995) go on to suggest that as a clinical reference tool, their information needs profile could be employed in everyday nursing practice. They suggest that it could be presented to women either in the outpatients department at the time of diagnosis or perhaps more appropriately at the time of admission to the ward for surgery. By using this structured approach it

would be possible to provide the women with the information that they consider to be important during their hospital admission. While using a structured format it would be possible to present the information in a way that is tailored to individual patients needs. It is clear that in the light of these findings it is important to consider the role of each member of the multi-disciplinary team enabling women with breast cancer to access the information they need when they need it. Women's information needs extend beyond the hospital admission and in situations where hospital stays are short it is necessary to explore alternative ways of providing women with breast cancer with sources of information.

#### Problems with the information giving process

Smyth, McCaughan and Harrison (1995) provide an overview of selected literature on women's experiences with breast cancer. Their paper places particular emphasis on the perceptions of the information received by breast cancer sufferers about their disease, its treatments and their perceptions of the support available to them. The overview illustrates the problem of inadequacies in the information and support currently available to women with breast cancer.

Derdiarian (1986) highlighted that the patients need for information is vital to help them understand the positive and negative implications of cancer and its treatment. This study showed that although disease-related concerns were discussed at the time of cancer diagnosis many patients still required more information than they were actually given at this time, however Derdiarian did not expand upon what types of information patients required. Anderson (1988) carried out a comprehensive study on the views of women who had undergone mastectomies. She indicated that patients appeared to be satisfied with information given to them in relation to their illness however, only

19% of women felt they had been given adequate information on what to expect immediately post-operatively. For example, many women were unaware that they would have drainage tubes and bottles attached to their bodies or that they may develop lymphoedema as a result of surgery.

Wong and Bramwell (1992) studied uncertainty and anxiety after mastectomy, 59 interviews were carried out with women 1-2 days prior to discharge and 1-2 weeks after discharge from hospital. They found that although the women had been informed as to the extent of the breast cancer at the time of their first interview, many were unaware about the status of possible lymphatic spread, or if they required further treatment. The women felt that their lack of knowledge about breast cancer and limited understanding of further treatment caused anxiety and became more acute once they were discharged.

Hailey et al (1988) traced mastectomy patients' experiences from detection of a breast lump until complete recovery. In relation to information received, 52% of patients had not been informed of treatment options after an initial diagnostic examination. When asked if they had been informed by health professionals what to expect after mastectomy approximately 50% stated that they had been.

In an overview of the literature relating to women's perceptions of breast cancer Smyth et al (1995) concluded that there are many inadequacies in the information that is currently available to women with the disease:

"There appears to be a fundamental failure on the part of health care professionals to raise the awareness of breast cancer patients needs. Information given to patients with regard to their disease, treatment

and the impact of breast cancer on their lives, seems to be at best barely adequate”.

(Smyth et al, 1995).

Meredith et al (1996) conducted a study with the aim of assessing the information needs of all cancer patients in the west of Scotland. The study comprised of a cross-sectional survey of patients' views by means of semi-structured interview with questionnaire. 250 (93%) of 269 cancer patients being treated at a regional cancer centre and two University hospitals in the west of Scotland were invited to participate in the study. They were selected by age, sex, associated economic status and tumour site to be representative of cancer patients in West Scotland. The main outcome measures were the patients need to know whether they had cancer, the medical name for their illness, progress through treatment, how treatment works, side effects, and chances of cure and treatment options. 79% of patients wanted as much information as possible and 96% had an absolute need to know if they had cancer. Most patients also wanted to know the chance of cure (91%) and about the side effects of treatment (94%). When the replies were cross-tabulated with patients' age, sex, deprivation score and type of treatments there was a linear trend for patients from more affluent areas to want more information and those from deprived areas to want less. There is a strong preference for diagnosis of cancer to be given by a hospital doctor. Almost all patients wanted to know their diagnosis and most wanted to know about prognosis, treatment options and side effects. Interestingly, in this survey most of the elderly patients (aged over 65) and most of those receiving palliative treatment wanted to know about their diagnosis, this may be a relatively recent trend as about half of the group of patients with an inoperable cancer who were interviewed before 1981 did not ask for a

diagnosis when given the opportunity, (Jones, 1981). There was more diversity in answers to other specific questions particularly concerning the medical name of the illness.

Terms such as lymphoma, sarcoma, metastasis, small cell, adenocarcinoma and so on may be meaningful to health care professionals but in reality are at best meaningless at worst confusing for patient and it is the word cancer which is actually understood. Only 30% of the patients said that they had an absolute need to know the medical term for their cancer. This suggests that cancer is seen as the same illness regardless of the site of origin and the patients did not appreciate that their diagnosis could vary greatly depending upon the site and type of tumour.

Meredith et al (1996) suggest that a substantial minority of British doctors avoid telling patients that they have cancer; this is a well intentioned omission and is due to the doctors feeling that knowledge of the diagnosis will depress and alarm patients and will impair their quality life. Using the word "cancer" with all its implied connotations is stressful for both doctors and patients and there may be many reasons why doctors avoid communicating news which may be perceived to be bad. Some think that telling patients about their diagnosis and prognosis would only precipitate a state of depression, (Slevin, 1987). Doctors have only limited time with each patient and communication may often have a lower priority than medical treatment. In addition, many doctors feel ill at ease discussing serious illness and dying, and resort to euphemisms such as "tumour", "growth", "cysts", or "lesions", (Holland et al, 1987). The majority of patients in Meredith et al's (1996) study not only wanted to know their diagnosis but they also wanted to be told plainly if they had a cancer. Protecting patients from the truth may be counter productive; lack of

information can increase uncertainty, anxiety, distress and dissatisfaction, (Audit Commission, 1993). There is also evidence that the level of psychological distress in patients with serious illness is less when they think they have received adequate information, (Fallowfield, McGuire and Baum, 1993). In Meredith et al's (1996) study, 60% of the patients wanted to be told about their cancer by a hospital specialist. Despite the increasing use of specialist nurses and counsellors, patients want their doctors to support and inform them about their cancer and its treatment. In order to achieve optimum benefit for patients, doctors need sufficient and appropriate surroundings as well as the knowledge, understanding and good clinical skills.

Turner et al (1996) questioned a total of 165 adult patients with Hodgkin's Disease. The patients were questioned following treatment to examine their perceptions of actual and desired involvement and provision on information in the treatment decision making process. Irrespective of the degree to which patients felt they had been involved in the decision making process and of the outcome of their particular treatment, patients who felt satisfied with the adequacy of the information given were significantly more likely to feel happy with their level of participation in the overall process of decision making. As part of the strategy investigating patient priorities, patients were asked to rank a series of possible acute and late treatment related morbidity's. Counter intuitively, the majority of the long term survivors felt early short-term side effects were more, or equally, as important as morbidity with respect to influence in choice of therapy. Unpredictable importance was placed by patients on side effects such as weight gain and fatigue in relation to other complications such as infertility and risk of relapse. The study highlighted the fact that patients do not necessarily share doctors' priorities in decision making or place the

same emphasis on different types of morbidity. Many patients cope by focusing on the here and now and place emphasis on issues such as hair loss rather than the larger issues of whether they will be alive in the long term. This often differs from physicians who may take the view that hair loss in the short term is worth a greater likelihood of long term survival. This study focused only on patients with Hodgkin's Disease whose ten year survival rates for Stage 1 and Stage 2 Hodgkin's Disease are now as high as 90% or greater; therefore they may have different priorities to the large cancer population.

#### Factors influencing the way in which doctors and nurses communicate with cancer patients

Cull (1990) in a review of literature on psychological aspects of cancer and chemotherapy, indicates that recent studies underline the need for an improvement in the communication skills of doctors and nurses during their interactions with cancer patients. The review suggested that this would facilitate early detection of psychological problems which individuals with cancer may be susceptible to, and would enhance the support offered by healthcare professionals (Cull 1990).

Wilkinson (1991) showed that many nurses used blocking techniques in the course of their conversations with cancer patients. She proposed that if nurses felt uncomfortable about a patient's prognosis, they preferred to keep conversations to a superficial level. In a definitive discussion, McLoud-Clarke (1981) used tape extracts of nurses conversations with patients to demonstrate that this evasive communication technique is used frequently by nurses in their interactions with cancer patients. Funch and Mettlin (1982) in a study of 151 breast cancer patients during their 3-12 month post-operative period concluded that if there was adequate communication on

information between the patient and the healthcare professional, then patients reported adjusting more successfully to the disease.

Wilkinson (1991) conducted a study which examined how nurses communicate with cancer patients; using a combination of qualitative and quantitative techniques she adopted a multi-method approach of questionnaires, observations and interviews. The subjects of her study were all nurses working in a general hospital and specialist cancer hospital. She found the ward environment was an influential factor as to how nurses communicate with cancer patients, with the nurse in charge having the greatest influence on the ward environment. This influence was directly linked to the nurse in charge's management style. Where these nurses adopted a democratic style of leadership, their communication skills appeared to be effective. Conversely where their leadership style was autocratic there was no commitment to open communication and nurses frequently blocked patients' questions. She also noted that the democratic nurses were more likely to involve specialist nurses in patients care than their autocratic counterparts. Wilkinson also suggested that education in cancer appears to influence the ability of nurses to communicate effectively since those nurses who had successfully completed relevant oncology courses such as the English National Board Course, were better able to communicate with cancer patients than those who had not. Interestingly, the completion of a communication skills course did not appear to significantly influence how well nurses communicated and that knowledge in the field on oncology seemed to have a more positive benefit in terms of patient care.

In the past, a number of authors have suggested that the time nurses actually spend communicating with patients is minimal and that conversations are often superficial and rarely related to diagnosis or



prognosis (Reynolds, 1978; Macleod-Clark, 1982). The view being that nurses tend to interact with patients only when physical tasks are required to be carried out (Seers, 1986). It has also been observed that physical aspects rather than psychological aspects of care appear to dominate most nurse/patient communication (Faulkner, 1985). Nurses have admitted to difficulties in communicating with cancer patients (Wilkinson, 1986). Problems relating to the way in which nurses and other health care professionals communicate with cancer patients still exist despite the emphasis on specialist training and the high profile that cancer and palliative care services have had in the United Kingdom particularly in the last ten years. As a result there have been a wide variety of publications describing good practice in term of communication with patients and describing communication and information needs of cancer patients (Ford, Fallowfield, Lewis, 1994; Coalman Hone, 1995; Harper, 1998; National Cancer Alliance, 1996; Ramirez, Richards, Rees, 1994).

The need for improved professional education and training in communication particularly relating to cancer and palliative care patients has long been recognised and acknowledged. In 1982 a study was carried out which revealed gross inadequacies in medical under-graduate and post-graduate palliative care/communication education as perceived by the doctors themselves (Doyle, 1982). Many respondents showed an interest in further training specifically in the areas of physical and emotional problems whilst others requested training in bereavement counselling. Since that time palliative care/communication education for doctors has improved dramatically and by 1991 all but one medical school in the United Kingdom included palliative care and communication in its curriculum (Doyle, 1991). Unfortunately, many of the doctors who are now working as consultants trained prior to large scale communication programmes in

medical schools and have had to either 'learn on the job' or seek post-graduate education.

#### The nurses role in the information giving process

Suominen (1993) focused on assessing how nurses assess the information received by breast cancer patients. The aim of this study was to identify how nurses assess the information targeted at breast cancer patients before, during and after hospitalisation. The sample group consisted of 176 nurses from surgical and radiological wards and clinics in South West Finland. The nurses assessment of the information received by breast cancer patients was analysed by a questionnaire containing multiple choice questions according to the five point Likert Scale and also open ended questions. The nurses reported that breast cancer patients do not receive sufficient information on their illness before they are actually admitted to the hospital for treatment. Although this aspect was considered throughout the statistical analysis it is worth noting that no statistically significant differences occurred between those nurses working in wards and those working at the clinics. 96% of nurses who completed the questionnaires presumed that patients liked to receive information of their disease. However dissemination of information was largely regarded and doctor's duty. Only 58% of the nurses reported that nurses provide information. The nurses thought that patients do not receive sufficient information and they identified cumulative effects in the sense that those patients knowing very little about their illness and treatment were also considered to know very little about operation possibilities and prosthesis. 10% of the nurses assumed that a breast cancer patient admitted to hospital knows hardly anything about her situation. Only 5% of the nurses considered that patients know enough. However 38% assumed that patients know about the lump in the breast or cancer or about the possible operation.

The nurses evaluation of patients hospital stays were detailed, several nurses assumed that the patients received sufficient information, on the other hand, according to nurses' reports, more patients seemed to be more insufficiently informed during hospitalisation than before it. The nurses themselves were uncertain about their role in meeting patient's information needs. The answers to an open ended question revealed of the three groups of nurses, one group of nurses felt that information was somebody else's duty, the second group who reported that they provided information when asked and finally there were those nurses who felt they had provided information for breast cancer patients regarding care and treatment and the total illness situation. The nurses do comment that there were some patients who do not want to ask questions about their diagnosis or prognosis. However there are others who want to know about their disease, recovery and potential side-effects.

Unfortunately some nurses in the study considered that there was no room in the health care system for patients' questions. Surprisingly 13% of the nurses expected that the information they provided would not benefit the patients with only 10% of the nurses considering that their information would be highly beneficial for patients. However, it was not reported whether the reasons why the nurses thought the information they provided would not benefit patients were explored. One difference could be seen between ward and clinical nurses in that the ward nurses assumed that the information that they provided for patients would give them comfort and a feeling of security whilst the information given at clinic was regarded as highly encouraging and reassuring. The time after hospital discharge received less attention from the nurses with some reporting that information should be provided only if the patient shows signs of wanting it. Some nurses

stressed how important it was for the patient to know about her present situation and possible later developments, but 11% of nurses pointed out that breast cancer patients hardly receive any new information after discharge from the hospital during their contacts with the health care system, check ups and treatments. 39% of the nurses considered that after hospitalisation patients should be given information by both doctors and nurses however 21% of nurses assumed that it was the exclusive right of doctors to provide information to patients.

The data from this study is an interesting indicator of some Finnish nurses' attitudes to providing information, however due to the existence of specialist breast care nurses in the UK whose role it is specifically to address these issues it would be unlikely for this study to show the same results if it was to be replicated in the UK. Certainly breast care support nurses and Clinical Nurse Specialists involved in breast cancer would see themselves as autonomous practitioners and would be happy to provide patients with any information regarding their disease, prognosis and treatment options and so on. However the results relating to the nurses working on surgical and radiotherapy ward may be reflected if the study was to be replicated in those areas in the United Kingdom.

Suominen and Laippala (1994) carried out a study to determine which nursing care activities in informing breast cancer patients were considered important by the patients themselves and by their nurses. 109 women who had had surgical intervention for breast cancer and 125 nurses participated in the study. All of the patients had contracted breast cancer in the previous three years but not within the previous 3 months. Ward and clinical nurses from one University and six area hospitals were contacted. Two questionnaires were developed

separately for nurses and patients and pre-tested on patients as well as ward clinical nurses. The questionnaires were largely identical, the first section assessed patients' readiness and resources for participation and in the second section patients were asked to report how they perceived that information and the support and guidance that they had received. The care of breast cancer patients was carefully examined in the part of the study that focused on nurses.

Statistical analysis of the data was based on presented distribution, correlations and cross tabulations. The samples were analysed using log linear models. The method has been previously described in greater detail by Agresti (1990). The comparison of the two sets of data was made at a content level and statistical analysis was used as a formal tool to support the conceptual content of the comparison of the problem. The patients perspectives were dissimilar to that of the nurses, thus statistical analysis of two such different groups was not considered conceptually reasonable. However, comparison of the models developed was possible at content level. It was possible to identify those issues that were important for patients and nurses as far as the breast cancer patients knowledge of her own situation was concerned. Only a few patients and nurses considered that breast cancer patients were sufficiently informed on admission to hospital regarding their treatments. The patients did not consider themselves well informed about their illness situation in hospital and most nurses agreed on this. However, nurses reported that patients were well informed about their disease and treatments. They also reported that they gave patients information on external prosthesis. Patients and nurses were asked the same questions about illness related knowledge held by the patients, breast cancer patients and nurses stressed different parts of the informational area. However, all study variables measured the same content area. When the nurses caring

from breast cancer patients assumed that the patient had received a lot of information from varying sources before hospitalisation, they were also better aware of the patient's knowledge level during hospitalisation. For patients the variable information received about examination seemed to have central position among information received variables. When breast cancer patients reported that they were sufficiently informed about examinations their knowledge about different factors involving breast cancer would increase and they would thus have better opportunity to formulate enough questions. A patient who has been well prepared and has insight into her own situation prior to hospitalisation also had an improved chance of receiving information about examinations. Hospital nurses who were aware that areas where breast cancer patients had sufficient knowledge tended to think that the patients were well informed by doctors and nurses about their own situation even before hospitalisation. Furthermore, if breast cancer patients were not informed about the purpose of examinations they felt that they missed information during their hospitalisation. When patients were informed about examinations they also felt that they had received information about the illness itself, possible treatment and economic support available. Nurses reported that they informed the patients about single issues such as economic support and prostheses, although they were not willing to define the areas where patients had insufficient knowledge. However, most nurses reported that they explained to patients about examinations, gave information and also tried to find out what matters patients expected to receive more information about. The results were in many ways similar to other findings regarding this subject. It is clear that if breast cancer patients had received information, their recovery also seemed to be better; this finding is also in agreement with the results of previous studies (Lazarus and Folkman, 1984). However, if patients felt that they were

not well informed before hospitalisation they were not well equipped to ask questions about their situation in the hospital either. It is therefore crucial for health care professionals to ensure that patients are given plenty of information from the time at which doctors suspect a cancer diagnosis may apply. This allows patients time to absorb the information given to them and formulate questions appropriate to their needs. The role of the nurse in informing patients seemed to be important even before hospitalisation. Breast cancer patients expected information both from nurses and doctors during their illness experience. Those nurses in the study who were interested in evaluating how much patients knew about their situation were also willing to inform their patients. Nurses should try to identify those patients who were not well informed because information seems to promote recovery in cancer patients, (Larson, 1984). In addition when asked which nursing care activities cancer patients consider most important Larson (1984) found that patients with cancer rank information highly and considered other activities such as developing trusting relationships as less important. It is clear that there are many organisational practices within the healthcare system which may encourage or discourage nurses as effective patient educators and perhaps more research needs to focus on these areas of clinical practice.

A study of cancer patients perceptions of caring behaviour exhibited by nurses showed that patients rated competent clinical know-how as the most important caring behaviour. Talking and listening, the particular psycho-social skills thought to be highly valued by nurses appeared to be of secondary importance to cancer patients at least until their basic recovery needs were met. The author also highlights the importance for cancer nurses to realise that their perception of

caring may not be the same as that held by the patients, (Larson, 1994).

#### Improving communication with cancer patients

The need for information is one of the most frequently cited self perceived needs recited by cancer patients and their families, (Mor et al, 1987; Hots et al, 1988; and the Canadian Cancer Society, 1992). Randomised trials have demonstrated that treatment and disease specific information provided to patients during the course of treatment or in the advanced/terminal stages of illness increases patient knowledge and several trials have shown an increase in patient satisfaction and a decrease in emotional distress, (Morrow et al, 1978; Dodd & Mood, 1981; Johnson, 1988 and Dunn et al, 1993). However, limited data regarding the effect of providing procedural information to newly diagnosed patients of cancer at the point of entry to a cancer specific health care system exists.

Mohide et al (1996) developed an information package to provide newly diagnosed cancer patients attending a regional cancer centre in Canada with information regarding the centre and the process of delivery of care, the aim was for the package to be mailed to patients before their first appointment at the regional cancer centre and a randomised trial was designed to assess the extent to which the new information package or a mini version of the same package reduced the psychological distress and met the information needs of these cancer patients. The patients studied were those with newly diagnosed breast, gynaecological, lung and prostate cancer, the eligible patients were randomised into one of three groups a new patient information package group, those patients receiving a mini



version of the new patient information package and a third group where the patient received no information at all.

When patients arrived at the cancer centre approximately 30 minutes before their appointment they were approached regarding the study, those patients willing to be included in the study were interviewed and patients were asked to complete a questionnaire consisting of items developed during the feasibility study. These items included patients' expectations of care and fear regarding the initial appointment, preferences for information in general and by which methods, the understanding and usefulness of the information package sent and so on. During the administration of the patients questionnaire relatives who had received an information package were interviewed as to whether they had read the information package their understanding and usefulness of that package. Patients and relatives in the control group who were not mailed any information were not asked any specific questions regarding the information package but were given a comprehensive package following the interview relating to psychological state. A total of 465 patients were randomised in this study, there were 53 patients excluded post randomisation in the new patients information package group, 46 patients mini package information group and 62 in the control group, thus 100 patients in the new information group, 102 in the mini new patients information package group and 102 patients in the control group completed the interviews and contributed data to the analysis. Overall 98% of the patients preferred to receive information and there was no difference between groups, over 83% of patients preferred to receive information before the first appointment, 6% after the first visit, 4% upon arrival at the hospital and 4% had no preference. Patients who had received the package were more likely to prefer to receive the information before they arrived (94% versus 62%). Patients were also asked

about the method by which they preferred to receive the information, 79% preferred to receive the information in the mail, 7% by telephone contact, 5% by pamphlet available at the doctors office, 1% a pre-recorded telephone message and 8% of patients had no preference or expressed an alternative source, the patients who had received the information packages were more likely to prefer receiving information by mail than those who had not received the packages. Overall 49% of patients expressed dread or fear regarding their initial appointment and 89% expected to receive good quality care at the centre. No difference was demonstrated between groups.

Eleven patients in the new patient information package group and three patients in the mini new patient information package group did not read the packages, however, overall 88% of patients found the information packages easy to understand and a greater percentage of the patients found the mini new patient information packages extremely easy to understand (73% versus 55%) a total of 89% of patients found the information packages useful and again a trend was noticed where a greater percentage of patients found the mini new patient information package very useful (61% versus 49%).

Patient understanding and usefulness was affected by the level of education and when this was adjusted by logistic regression, the differences between information packages were no longer evident, all topics within the respected packages were found to be useful ranging from 72% of patients reporting information regarding the administrative structure of the clinic as useful, to 88% reporting information concerning what to expect at their first visit as being useful. In all 50% used the question and answer sheet that was included in the packages and there was no difference in information packages. Mohide et al (1996) conclude that the provision of health related

information to patients with cancer may have many effects including increasing knowledge, increasing satisfaction, enhancing self care and compliance thus leading to better health outcomes, increasing involvement in decision making, and reducing anxiety and distress this is confirmed by Fernfeler & Cannon (1991) the researchers did acknowledge that most previous studies have evaluated the provision of information on emotional distress and have shown a reduction of anxiety and depression. The fact that the provision of information was not shown to reduce the psychological distress in this study may have occurred as a result of several different factors. The information presented was procedural and general in context rather than specific information for patients regarding their disease, prognosis and available treatments. Derdiarian (1989) found that patients newly diagnosed with cancer attached to highest importance to information pertaining to their disease and its consequences and much less important to a social and practical nature. Thus it may be that although the type of information provided in Mohide et al's study may be useful to patients it does not have a marked effect on psychological distress. Another possibility is the information truly reduces distress to some modest degree but attending the cancer centre for the first time was relatively stressful and any effect of the information package was not evident at that particular time.

#### Support for the family

Cancer is a chronic illness with the fundamental characteristics of being long-term and having a profound affect on the life of the sufferer, (Lockyear, 1991). Literature on the concept of support in relation to coping with serious illnesses emphasises the importance of social support. This has been described as tangible and psychological support available from a network of personal ties such as a family, spouse, friends, healthcare professionals and support groups,

(Rearden Aydin, 1993). Social support of this type can assist patients in muting the stress effects of serious illness such as cancer, (Taylor et al, 1996). However in order to support the cancer patient, friends and family need additional support themselves from health care professionals to enable them to deal effectively with this additional burden at a time when they are coming to terms with their own emotions in relation to a cancer diagnosis.

Thorne (1995) and Lewis (1986) highlight how a diagnosis of cancer can produce a crisis within the patient's family and that such a diagnosis has a long term impact on the lives of the families and significant others. Hinds (1985) also identified that patient's families have specific needs; these needs have been identified as being physical, social and psychological and she divides the social needs into financial, affective and respite needs. Hardwick and Lawson (1995) suggest that the need which has not been mentioned but which has featured extensively in the work of others such as Grant and Johnson (1997) is the need for information, studies suggest that patients who receive minimal support from their family, experience a difficult adjustment to the diagnosis of cancer, (Northhouse, 1984). A well adjusted and well supported family can in turn often support the patient during their illness and adjustment will be made easier for all individuals involved. It can therefore be seen as important to assess the needs of the care-giver and to attempt to support the care-giver in promoting the patients well being. Hardwick and Lawson (1995) suggest that the family needs are dynamic through the cancer journey and that the family or significant others can be the patient's most important resource in assisting them to come to terms with cancer. Jassak (1992) suggests that different coping mechanisms are adopted by individual members of individual families and these mechanisms will affect the patient's own ability to cope. Differences in need and in

the understanding of each others needs must be identified through open communication if people are to support each other effectively. Hardwick and Lawson (1995) suggest that the nurse is in an ideal position to facilitate this process by assessing the level of communication between the family and the patient and encouraging the discussion of feelings.

Hill and Hanson (1964) identified four main factors that influence family's ability to cope with chronic illness which cancer can become. (1). The illness characteristics/the family's perception of illness. (2). The perceived threat to the family unit. (3). Available resources financial/social support. (4). The family's previous experience with similar situations. An assessment of such factors can help in developing interventions which facilitate care givers to cope. Lewis (1986) recognises that the carer of a patient with cancer may experience emotional strain however if the care givers needs are met then the main outcome of the care giving experience could be one of rewards. Hilman and Lackey (1990) demonstrated that care givers had a considerable need for information, Write and Deck (1984) showed that the need to be informed of the patient's condition was a primary need recognised by the care-giving family. Nathanson and Monaco (1984) found that the most important information needs as identified by the care-givers were to do with information regarding the disease process and the delivering of home care, i.e. what support was available to them. Hilman and Lackey (1990) also identified that the ability of the patient to ingest food, selection, preparation and serving, and the patients' weight became an important criteria in cancer management. Johnson and Jackson (1989) highlighted that care-givers often needed information about body function, health promotion, medications and specific side effects related to them and community resources and financial support which may be available.

Grobe et al (1982) found that care-giving families were often unaware of the availability of services for support and counselling despite this information being given to them by health care professionals. Two possible reasons have been suggested for this, one, that it was felt that family members were not ready to hear about the resources when told. Two, that they forgot about the services that had been described to them because at the time of telling they perceived themselves to be coping well and not in need of such support. They also suggested that the way around this was to provide multiple cycles of information, identifying the resources for the family might help to meet the information needs of the family at the appropriate and relevant time. Lewandowski and Jones (1988) highlighted the fact that the information needs of care-giving families not only varied from family to family but also varied at different times throughout the cancer journey. This study showed that the primary need of the care-givers was for information which was seen to be highly desirable in all phases of the disease and that care-givers wanted information to be realistic and honestly given. Information giving is important.

Weisman (1979) described how information seeking is one of the general coping strategies used by individuals. Tringali (1986) suggested that knowledge about an unfamiliar subject decreases anxiety and increases a sense of control. Thorne (1985) described how the care givers need to demystify cancer and to understand it better by seeking information. This can produce emotional acceptance and such acceptance is necessary in order to "fight back". Hardwick and Lawson (1995) suggest that fighting and acceptance although contradictory are seen as the cancer families way of implying hope. Wright and Dyck (1984) found that one concern identified by care-givers was difficulty in getting information, almost half of their sample

of 45 families felt that the doctors were controlling the information given to them and the nurses were expected to co-operate with this attempt to control information. If this study was replicated today the results may differ slightly due to more doctors professing a willingness to be open and honest about diagnosis and prognosis. Meissner et al (1990) argued that patients and care givers may be reluctant to ask questions because they think the doctors and nurses are too busy, or that they do not wish to be seen as complaining or that they simply do not know what questions to ask. This may make health care professionals believe that their families are satisfied with the information they have been given because they are not asking further questions and so a vicious circle ensues perpetuating the lack of information. Jassak (1992) suggests that a lack of communication between health care professionals and care givers/patients could be due to the fact that information had not been received, processed, interpreted correctly or retained accurately and that health care professionals should be advised that they should verify with the care giver/patients that the information discussed has been understood. Evans and Clark (1983) highlighted the need for examining the way in which information is given, stating that "given the different types of cancers and treatment options and the dynamic nature of information that is necessary for coping with the different phases of the disease, static channels of, for example pamphlets, or the traditional approaches to care giver/patents education, for example meeting with the staff are not likely to satisfy the changing information requirements of the cancer patients or his family." An example of a more dynamic approach to the giving of information can be found in the UK in the form of BACUP who have set up a free telephone information service. Other telephone services such as those provided by Cancer Link in the UK and The Cancer Information Service in the USA are seen as being invaluable to the care giving family because they provide a way

of finding the relevant information the family feel that they need at a time when they need it, Hardwick and Lawson (1995). Family dynamics are also important and any health care professional trying to facilitate the information process needs to be aware of this.

Wong and Bramwell (1988) note that support offered by healthcare professionals needs to progress beyond the hospital recovery phase. During their interviews with breast cancer patients 1-2 weeks after discharge they discovered patients had many questions that had been left unanswered in relation to their disease, its treatment and the effect of breast cancer on their lifestyle. They concluded that one of the most important findings of their study was that nurses should develop strategies to ensure that a supportive follow-up programme is available for the patients when they are receiving treatment and after discharge.

The need for ongoing support following the initial phase of cancer care  
Neuling and Winefield (1988) researched patient satisfaction with various supportive behaviour patterns during recovery after mastectomy. They showed that family members provided patients with more support of an empathetic nature than any other kind of social support network. This type of support was greatest just prior to surgery but decreased when measured at 1 and 3 months post surgery. They concluded that patient satisfaction with support from family members was of the utmost importance for psychological adjustment during the initial stages of the disease i.e. diagnosis and surgery. Wong and Bramwell (1992) reported similar findings. Their subjects highlighted family support as being essential in helping them cope with the uncertainty of breast cancer. Nurses need to understand how the family unit can help the patient make some sense of her illness and its treatment. The importance of encouraging husbands to participate in



their wife's experiences throughout the process of breast cancer has also been highlighted, (Wong and Bramwell, 1992).

Neuling and Winefield (1988) pointed out that patients who have undergone mastectomy for cancer require different sources of support at different stages of their disease. It is therefore necessary for health care professionals to ensure that patients have access to ongoing support and advice throughout their disease journey and not just the time of diagnosis and initial treatment. In their study, the patients' need for support switched to their surgeon after they had undergone a mastectomy when previously they had relied upon the family network as a source of support. Surgeons provided informational rather than empathetic support but this decreased as the recovery period progressed. Patients were more dissatisfied with support received from surgeons than that received from family and friends. A possible reason for this dissatisfaction was not evasion or refusal to give information on the part of the surgeon, but was due to the patients own reluctance to ask questions that might have worrying responses. Neuling and Winefield (1988) concluded that patients needed a greater degree of empathetic and emotional support from health professionals for at least three months post-operatively.

The literature review was particularly useful in helping form a wider understanding of the needs of cancer patients in the initial phase of cancer care and it also provided empirical evidence regarding nursing and medical practice. In addition the issues highlighted by the literature review process helped in the development of the interview schedule which was used during the data collection stage of the study.

## CHAPTER 3

### Research Methodology

The purpose of this study was to explore what cancer patients were being told by their doctors in the initial stage of cancer care and to examine whether the information they were given and the support that they were offered at that time met their own individual needs. It was intended to be an action research project, whereby the findings would influence changes to clinical practice in order to improve/enhance the care of patients during their initial phase of cancer care.

Having identified the research problem it was necessary to examine the research methods available and to make a decision regarding which type of methodology is most likely to produce the information required. There are basically two styles of enquiry, quantitative and qualitative, each of which have their own merits and disadvantages. Bryman (1988) suggests that quantitative research is associated with a number of different approaches to data collection. In sociology in particular, the social survey is one of the main methods of data collection which embodies the main features of quantitative research. A survey is particularly useful for generating quantifiable data on large numbers of people who are known to be representative of a wider population, in order to test theories or hypotheses. Most survey research is based on an underlying research design which is cross-sectional, meaning that the data collected is on a cross-section of people at a single point in time in order to discover the ways and degrees to which variables relate to each other.

The social survey approach differs from experimental designs which constitutes the main approach to data collection within the tradition of

quantitative research in social psychology. In an experiment there are at least two groups to which subjects have been randomly allocated, an experimental group and a control group. The logic of the experimental design is that the experimental group is exposed to some sort of stimulus whilst the control group is not. Any differences which are observed between the two groups is then deemed to be due to the experimental stimulus (the independent variable) alone, because the two groups are identical in all other aspects.

Bryman (1988) suggests that surveys and experiments are probably the main vehicles of quantitative research, there are also other ways of collecting quantitative data. The analysis of previously collected data like statistics on morbidity or mortality following cancer treatment can be subsumed within the tradition of quantitative research. Structured observation, where a researcher records observations in accordance with a pre-determined schedule and quantifies the resulting data, also displays many of the characteristics of quantitative research and such methodology is often used in the examination of patterns of interaction.

Quantitative research allows the researcher to acquire large amounts of data regarding their area of research, it seeks causes and facts from the etic or "would-view" perspective, therefore the researcher is able to generalize from the results (Osbourne, 1977). However in the case of quantitative research the findings are based on the researchers own interpretations of the observed phenomena rather than on the subjects interpretation of the events. Surveys do not allow the researcher to probe into the answers provided by the respondents and clearly designing an experiment to explore what cancer patients were being told by their doctors in the initial stage of cancer care and to examine whether the information met their needs was inappropriate.

In contrast, qualitative methods are particularly useful when describing a phenomena from the emic perspective that is the perspective of the problem from the “natives” point of view, (Harris, 1968). In the case of this study the emic perspective is that of the cancer patients in the initial phase of cancer care. There are a number of methods of data collection with which qualitative research is associated; this includes participant observation, whereby the researcher immerses him or herself amongst those whom he or she seeks to study with a view to generating a rounded in-depth account of the group or organisation. Interviewing subjects is another method of data collection with which qualitative research is most closely associated, interviews can range from the semi-structured, whereby the research has some prompts to unstructured interviewing in which the researcher provides minimal guidance and allows considerable latitude for interviewees. The aims of such interviewing are quite different from the familiar survey approach whilst some qualitative researchers make use of an interview schedule; others operate with a loose collection of themes which they want to cover. In both instances the subject is given a much freer rein than in the survey type interview. Unstructured interviewing in qualitative research departs from survey interviewing not only in terms of format, but also in terms of its concern for the perspective of those being investigated.

Other qualitative methods include the life history method, which is often depicted as a major method of qualitative research (Bryman, 1988). This method entails the reconstruction of the lives of one or more individuals. The data sources can be varied but include diaries and autobiographies which are used as a basis for generating life histories. Such materials may already be in existence for the qualitative researcher, or in some instances the researcher may need

to solicit them. When the researcher needs to gain the life history of an individual this can become a highly protracted unstructured interview in which the researcher encourages the subject to reflect at length on his or her life and the changes and processes that underpin his or her experiences. Clearly such an approach is very lengthy and not appropriate for looking at a population of cancer patients all be it a small one.

The group discussion method is another approach, which can be used by qualitative researchers. Essentially it is a form of unstructured interview but with more than one subject, such discussions have the advantage of bringing to the surface the differences among the participants and the contradictions within and between their replies. However such an approach needs to be handled in a skilled manner and there may be group members who would feel intimidated by their peers or many have issues which are extremely important to them, but they do not feel comfortable or able to share with others in the group setting. Bryman (1988) suggests that when used by a qualitative researcher the group technique is almost always one among a number of methods of data collection.

Recently it has been suggested that qualitative research methodologies present a means of conducting rigorous and ethically sensitive research in cancer and palliative care (Clark, 1997; Seymour and Clark, 1988). Such a view may reflect a broader assumption that qualitative methods are by their "lifelike" nature, inherently less potentially harmful than other forms of research conducted in health care settings (Faulkner, 1980; Field, 1989). Such assumptions can lead to under examination of the problems which may emerge as a result of intense face-to-face contact and tenuous relationships necessarily sustained during fieldwork. Seymour and Ingleton (1999)

argues that intense fact-to-face contact where tenuous relationships exist may present problems that are difficult to resolve and damaging to both the research participant and the researcher him or herself. They argue that such problems are likely to be of pressing concern in research within settings such as palliative care or cancer, where patients and their informal carers are in a particularly vulnerable and anxious state and that staff working in these areas may already be experiencing stress because of their close contact with death and dying.

Seymour and Ingleton (1999) suggest that research ethics committees who are often more use to the biomedical model of research may not recognize the extent of such difficulties. Unlike biomedical research, qualitative research has an unfolding and unknown quality, the ethical implications of which cannot always be seen fully at the outset of the research process. They suggest that the researcher undertaking such work assumes a special responsibility for ensuring that the research participants rights of autonomous choice and informed consent, lack of harm confidentiality and anonymity, and respect and dignity, are protected throughout the course of the study. Such principles are central to all codes of research conduct (Royal College of Nursing, 1977). Seymour and Ingleton (1999) suggest that researchers need to maintain a vigilant and reflexive stance throughout their research. It is clear that in order to carry out rigorous and ethically designed research a number of factors require consideration, including: the process of gaining access to research settings and consent from individual research participants; the management of the researchers role during fieldwork; and the dilemmas associated with preserving anonymity when "writing up" the research report. How these areas were incorporated into the research process will be discussed later in this chapter.

The development of research designs for the examination of cancer and palliative care related issues is particularly challenging. Some commentators have gone so far as to argue that “dying” places a special frame of reference around people that should exclude them from research (De Raeve, 1994). The counter argument to this stance is that there is a moral imperative to conduct research with potentially dying people and their carers as that is the only way in which areas of unmet need can be identified and addressed (Mount et al, 1995). If Mount et al’s (1995) argument is accepted then researchers need to ensure that the design and practice of research “fits” with the ethical principles of cancer and palliative care as a discipline.

As already stated the purposes of the study was for cancer patients in the initial stage of cancer care, to tell the researcher their own story about how they were told of their cancer diagnosis. The researcher aimed to explore their experiences in context and to examine whether the information and support they had received met their needs at that particular time of their disease journey. The approach taken to structure the data collection and analysis is based on grounded theory (Glaser and Strauss, 1967). Thus interpretation and analysis could begin from what was emerging from the data rather than from any pre-conceived idea, theory or hypothesis. Ground theory will be discussed in more depth later in this chapter. It was decided that interviews would be the most appropriate way of exploring the experiences of cancer patients in the initial stage of cancer care as such a qualitative approach was well suited to exploring a person’s “experiences and interactional relationships”; (Strauss and Corbin, 1990). The purpose of using such a method was to uncover and understand what lies behind things and to provide new angles on seemingly well known areas.

Data collection was carried out in two ways, firstly by means of ethnographic type of enquiry in the form of non-participant observation in order to ascertain what actually happened in practice during medical consultations. It was hoped that the data obtained from the non-participant observations would enable an understanding of the problem in context and allow the subsequent development of an interview schedule, which would form the basis of the next part of the proposed fieldwork i.e. interviewing patients.

Nisbet (1977) reminds us that observation is not a natural gift, but a highly skilled activity for which an extensive background knowledge and understanding is required and also a capacity for original thinking and the ability to spot significant events. Carrying out non-participant observations of doctor/patient consultations required careful planning and therefore a pilot was carried out. Initially, during the pilot, detailed notes were taken throughout the observation of what was being said and by whom, in addition to this; notes were made of the non-verbal cues which were witnessed during the consultation. However, when it came to reviewing the material obtained from the pilot it became very obvious that a number of potentially important non-verbal cues had probably been missed due to the researcher trying to write down everything that was happening at the time it was happening. A second pilot was carried out, whereby the researcher tried using a grid, which could be ticked each time a particular action was witnessed or particular issues were raised during the consultation. However when reviewing the results of this pilot it was felt that the data captured this way was not particularly meaningful and that the qualitative qualities of the interaction were not being effectively captured. The third and final pilot consisted of the researcher making brief notes in a self invented form of shorthand and then immediately



after the interview expanding these notes, so that the main issues raised during the consultation could be captured on paper for subsequent analysis. Clearly this method meant there was still some things that would be missed by the researcher, but it was felt that the only way to prevent this was by video taping the interactions and apart from the resource implications, i.e. not having access to a video recorder, the consultants were not keen to participate if this mode of technology was employed. They felt that it would make the patient feel uncomfortable and perhaps adversely affect the way in which they communicated with patients. It was felt that the third pilot was the most appropriate and that was the technique employed for the subsequent eighteen non-participant observations, which were carried out.

Interestingly, at the outset of the research it was felt that a number of patients may actually object to being observed whilst they were talking to their consultant. Prior to the researcher carrying out each non-participant observation the patients were given an information leaflet explaining the purpose of the study and were asked if they would like to participate in it. Non one who was approached refused to participate. Having agreed to take part in this stage of the study the patients were asked to sign a consent form and reassured that when the observation was written up that the anonymity would be assured and confidentiality maintained. Once the patients were actually seated in the consultation room, waiting for the consultant to come in, the patients were again asked if they were happy about having a observer in the room, and given the opportunity to withdraw from the study if they should wish, no patients wanted to do so.

As previously stated eighteen non-participant observations were carried out. In the first part of this study these involved observing face

to face consultations between patients and their consultants, at the time that the patients were being given a cancer diagnosis and information regarding the initial phase of their cancer care. In some instances there was a Clinical Nurse Specialist also available in the room at the time of the consultation, although she did not take an active part of the conversation until after the consultant had left. Three consultants were observed talking to six patients each. The consultants were observed in more than one clinic on different days at different times in order to ensure that they were not being observed on a particularly "good" or "bad" day.

It was decided to analyse the notes made from the non-participant observations (see appendix 1 for an example of field notes) by constantly comparing each section of the data with every other throughout that stage of the study looking for similarities and difference i.e. method of content analysis. The finding from this stage of the study, added to some of the issues raised during the literature review, formed the basis of the interview schedule to be used as a prompt during the patient interviews (see appendix 2).

In the planning stages of the study, it was proposed that where patients had reported having relatives present at the time they were told of their cancer diagnosis and subject to that individual patients consent, those relatives would be approached and would be interviewed using a modified format of the interview schedule used on the patients themselves. However a pilot was carried out on three relatives, where they were interviewed as per the initial proposal and the data retrieved from their interview transcripts simply echoed the data provided by the patients themselves. This was despite the fact that they has been interviewed separately. It was therefore decided that this was a time consuming course of action and was unlikely to

provide any more useful data for the purpose of the study, and was discontinued. It was decided that the next stage of the study would focus purely on semi-structured interviews of the patients themselves.

Burgess (1984) suggests that interviews have been perceived as "conversations with a purpose". A major advantage of the interview is its adaptability, a skillful interviewer can explore ideas, probe responses and investigate motives and feelings, which questionnaires can never do (Bell, 1993). The way in which a response is emphasized by the tone of the informants voice or/and their facial expression can also provide valuable information, which would be concealed by a written response. However Bell (1993) also introduces a note of caution regarding the use of interviews stating:

"It is a highly subjective technique and therefore there is always a danger of bias. Analysing responses can present problems and wording the questions is almost as demanding for interviews as it is for questionnaires. Even so, the interview can yield rich materials".

Having decided that interviews were the most appropriate method of eliciting information from the subjects in this study, the type of interview had to be decided upon. Grenbenik and Moser (1962) see the alternative types as ranging from somewhere in what they call "A continuum of formality". At one end of the continuum is the formalised interview where the interviewer "behaves as much like a machine as possible", perhaps utilizing a questionnaire or check list. The more standardized the interview, the easier it is to aggregate and quantify the results (Bell, 1993). At the other end of the continuum is the completely informal unstructured interviews, in which the shape is determined by the individual informants themselves. Completely informal or unstructured interviews can provide a wealth of valuable

data if conducted by an experienced researcher, but such interviews require skill and a substantial amount of time for analysis. Conversation regarding a particular topic may provide some insights into the problem and would undoubtedly be interesting to the searcher, but it should be more than just an interesting conversation, the interview should provide information. In order to ensure that the appropriate information is obtained one needs to consider how this needs to occur, for the purposes of this study it was decided to use semi-structured interviews. Not only did this seem to be the most appropriate method of gaining the information that was required, but due to interviewing inexperience the use of an unstructured approach might present difficulties in controlling the interview itself and also later when trying to analyse the data. Semi-structured interviewing is a useful technique because, an aide memoire or interview schedule ensures that the researcher will obtain all of the information required (without forgetting to ask appropriate questions) whilst still allowing the informant freedom of responses and description to illustrate concepts.

It must be recognized that there is always a danger of bias creeping into interviews, largely because, as Selletiz et al (1962) stated "interviewers are human beings, not machines" and their manner may have an affect on the respondents. In a study of this kind where there is only one researcher conducting all of the interviews it must be noted that any bias may be consistent. Borg (1981) suggests a few problems that may occur relating to bias:

"Eagerness of the respondent to please the interviewer, a vague antagonism that sometimes arises between interviewer and respondent, or the tendency of the interviewer to seek out the answers that support his preconceived notions are but a few of the factors that might contribute to biasing of data obtained from the interview".

In many ways it is easier to acknowledge that bias can creep in, than to eliminate it all together.

In total thirty three patient interviews were carried out. The sample consisted of English speaking adults, who has been diagnosed with cancer approximately three to four months prior to the interview taking place. The patients were aged between 23 and 70 years of age, although the study criteria stated anybody over 18 years of age, who was mentally competent and English speaking. The entire sample was Caucasian, however this is representative of the local community, which has extremely low numbers of ethnic minorities. Seventeen of those patients recruited into the study were female and sixteen were male. The sample included patients with a wide variety of primary cancer sites (see table 1)

Table 1

Number of Patients	Site of Primary Cancer
13	Bowel
5	Lung
4	Breast
3	Oesophagus
2	Testes
1	Stomach
1	Prostate
1	Liver
1	Ovary
1	Pancreas
1	Skin (Melanoma)

The high number of bowel, lung and breast cancer patients recruited into the study is not particularly unusual as these are most common

cancers in the United Kingdom and reflect the national trend. However it must be noted that the number of lung cancer patients recruited into the study would have been higher, reflecting the local population, had not patients with a shorter prognosis been excluded from the study, this was a requirement of the local medical research ethics committee. In order to gain ethical committee approval patients with an expected prognosis of less than eleven months were to be excluded from the study. It was decided that the consultant responsible for the individual patient's care would be the one to identify whether or not the patient has a prognosis of less than eleven months thus excluding them from the study.

Informants were chosen who had specific characteristics or knowledge, which would enhance the researchers understanding of the setting and help develop emerging theory, in grounded theory this type of sampling is known as theoretical sampling (Glaser and Strauss, 1967). The informants were identified by a number of sources, the consultants themselves, the chemotherapy day unit and other Clinical Nurse Specialists. Patients names were forwarded to the researcher, in order that they could be contacted and approached regarding their involvement in the study. Each patient was contacted by telephone and the study was explained in detail to them, they were then asked if they would like to participate in the study. Informants were advised that subject to their agreement they would be required to sign a consent form, verifying their willingness to participate in the study. They were reassured that their confidentiality would be maintained and anonymity would be assured when the findings of the study were written up. Informants were also given a patient information leaflet with contact number and details regarding the purpose of the study. They were asked if they would consent to the interview being tape recorded. Again all of the patients agreed to this,

knowing that the tape recordings would then be transcribed verbatim in order that the interviews could then be analysed. All of the informants were reassured that they would remain anonymous in the transcripts. Suitable times and places for the interviews to take place were agreed during this telephone conversation, some of the patients were happy for the interviews to take place in their own homes at a time convenient to them, whilst others preferred to be interviewed when they were coming to the hospital for treatment purposes. The day prior to the allotted appointment time the patients were contacted again to ensure that they were still happy about participating in the study, again no patients had changed their minds. At the time that the interviews were carried out it was made clear to the patients what would happen to the information and they were advised that any quotes which may be used in the writing up of the study and the transcripts of the interviews would remain anonymous. At the outset of the study it was anticipated that the interviews would take 30-45 minutes and, in the majority of instances, this was the case although a couple of interviews were almost an hour long and some were a lot shorter.

One pilot interview was carried out; all of the areas identified on the interview schedule appeared to be appropriate to the patient. However, when reviewing the transcript of the pilot interview it was noted that the interview technique could be improved upon, with the use of more open ended questions. It also became obvious that a verbatim transcript of a tape recorded interview did not take into account any non-verbal cues which were exhibited by the respondent during the interview, nor did it convey other important issues such as the tone of voice used by the respondent. It was therefore decided that immediately following the subsequent interviews, notes would be

made regarding the aforementioned issues, and that the interviews would be transcribed as soon as possible following the event.

Since the stated aim of the study was for patients to tell the researcher their own story about how they were diagnosed with cancer and to explore whether the information and the support they had been given met their individual needs in their disease journey, the research was designed to explore these experiences in context. The approach taken to structure the data collection and analysis was based on grounded theory (Glaser and Strauss, 1967).

Grounded theory described by Glaser and Strauss (1967) is one approach to the development of inductive theory, although both inductive and deductive thinking are used in the process. Although grounded theory has its origins in sociology it can be used in any field of study and for any type of unstructured material such as interviews, transcripts, observations or documents. Glaser (1992) claims that grounded theory methods are not specific to a particular discipline or type of data collection, however he suggests it seems to be particularly useful for health professionals as it is systematic and detailed. Strauss (1987) maintains that grounded theory is not a particular technique but a style of carrying out qualitative research with distinct characteristics.

The theoretical framework for grounded theory is derived from insights of symbolic interactionism which focuses on the processes of interaction between people and explores human behaviour and social roles. Symbolic interactionism explains how individuals attempt to fit their lines of action to others, take account of each others acts, interpret them and reorganize their own behaviour, (Blumer 1971).



Mead (1934) sees the self as a social rather than a psychosociological phenomenon. Members of society affect the development of a person's social self by their expectations and influence. Initially individuals model their roles on the important people in their lives, they learn to act according to other expectations which ultimately shapes their behaviour. Eventually individuals can play a number of social roles and can organize the roles taken from the community. Mead compares this to a team game where members of the team anticipate the behaviour of other players and can therefore play their own role. The observation of these interacting roles is a source of data in ground theory. The model of the person in symbolic interactionism is active and creative rather than passive. Individuals have the ability to plan, project, create and revise actions, they do this by interpreting each others behaviour and chose appropriately from a variety of social roles. Individuals are seen as sharing the attitudes and responses to particular situations with members of their own group, hence members of a cultural or community analyse the language, appearance and gestures of others and act in accordance with their interpretations. On these perceptions they base their justification for conduct which can only be understood in context. Grounded theory therefore stresses the important of the context in which people function.

Symbolic interactionism focuses on actions and perceptions of individuals and their ideas and intentions. Thomas (1972) states "if men define situations as real, they are real in their consequences" this infers that the individual definition of reality shapes perceptions and actions. He also suggest that participant observation and interviewing trace this process of definition of the situation. Denzin (1989) links symbolic interactionism to naturalistic, qualitative research methods by stating that researchers must enter the world of their subjects in order to understand them. Taking this approach researchers see the

situation from the perspective of the participants rather than their own, this perspective can be uncovered by interviews and diaries. Qualitative methods clearly suit the theoretical assumptions of symbolic interactionism. As human beings are seen as active and creative they can be particularly with significant others. Researchers use grounded theory to research these interactions, behaviours and experiences as well as individuals thoughts and perceptions of them.

One of the main features of grounded theory is the generation of theory from the data although existing theories can be modified or extended through this method. This approach emphasizes the development of ideas from the data, grounded theory researchers start with an area of interest, collect the data and allow the relevant ideas to develop, whilst quantitative research begins with preconceived ideas, theories, hypothesis which are then tested for confirmation. Wiener & Wysmans (1990) maintained that the concept of grounded theory is not always understood and suggest that this approach means "identifying the relationship between and among concepts as presenting a systematic view of the phenomena being examined in order to explain what is going on". According to Strauss and Corbin (1990) a good grounded theory has four main criteria; a fit, understanding, generally reliability and control. It should be true to real life and it should be clearly understandable to the participants and the professionals who are linked to the area of study. They demand that it be applicable to a variety of similar settings and context. Glaser and Strauss (1967) advise that rigid preconceived ideas prevent development of the research and imposing a framework may block the awareness of major concepts that may emerge from the data. Grounded theory helps health professionals to give up their own model of patient care and disease management in order to adopt an alternative perspective based on the perceptions and beliefs of

patients. For such an approach researchers need to be flexible and have open minds, qualities which could be said to be related to the processes involved in nursing, which demand an open and flexible approach.

Grounded theory uses constant comparison, comparing each section of the data with every other throughout the study for similarities and differences. Included in the process are the themes and categories and identified on the literature. In this study all of the data was coded and categorized and from this process major concepts and constructs were formed. Major themes were identified which linked ideas to find a "storyline" for the study. This approach is both inductive and deductive. Strauss (1987) sees the process of induction, deduction and verification as essential in grounded theory. Grounded theory does not start with a hypothesis, after collecting the initial data relationships are established and provisional hypothesis introduced. These are then verified by checking them out against further data. Corbin (1986) reminds the analysts that this process of grounded theory is very similar to the nursing process and should therefore be easy for nurses to use. Strauss and Corbin (1990) acknowledge that grounded theory has similarities with other qualitative methods of data sources and emphasis. Grounded theorists accept their role as interpreters of the data and do not stop at merely reporting them. The method does however differ in that researchers search for relationships between concepts while other forms of qualitative data often generate major themes but do not always uncover patterns and links between categories or develop theories.

Data can be collected through field observations and interviews, as in this study. But diaries and other documents like letters or even newspapers could have also been used. Researchers tend to use

interviews and observations more often than other data sources, these sources are supplemented through literature searches. Indeed the literature review becomes part of the data that is analysed. Everything, even the experiences of the researcher, can become sources of data. Glaser and Strauss (1967) suggest that the researcher does not approach the study with an empty mind, in fact most research is based on prior interest and problems, which the researcher has experienced and reflected upon even when there is no hypothesis at the start of the research, this scenario was clearly the case for this study.

The data collection and analysis are linked from the beginning of the research and proceed in parallel and interact continuously. The analysis starts after the first few steps of data collection have been taken, the emerging ideas guide the analysis. The gathering of data does not finish until the end of the research because ideas, concepts and new questions continually arise which guide the researcher to new data sources. Researchers collect data from initial interviews and observations and take their cues from the first emerging ideas to develop further interviews and observations. This means that the collection of data becomes more focused and specific as the process develops. This happened during this study with some of the most valuable data coming towards the end of the fieldwork as the interviews became more focused. Whilst observing and interviewing, the researcher wrote field notes from the beginning of the data collection throughout the project. Certain occurrences in the setting or ideas from the participants that seemed of interest were recorded either during or immediately after data collection as they reminded the researcher of the events, actions and interactions and triggering thinking processes.

According to Glaser (1978) the following are necessary for grounded theory:

- Theoretical sensitivity
- Theoretical sampling
- Coding and categorizing
- Constant comparison
- The use of the literature as data
- Integration of theory
- Writing memos and field notes

Strauss and Corbin (1990) state that:

“theoretical sensitivity refers to the attitude of having insight, the ability to give meaning to the data, the capacity to understand and the capability to separate the pertinent from what isn’t”.

Theoretical sensitivity enables the researcher to be aware of the significance of the data, there are a variety of sources for theoretical sensitivity, it is built up over time from reading and experience, all of which guide the researcher to examine the data from different angles. Professional experience can be one source of awareness and personal experience too can help make the research sensitive. In this case the researcher was actually a health care professional involved in caring for cancer patients. The literature can also help add to theoretical sensitivity in that documents, research studies or autobiographies can create awareness of relative and significant elements in the data. Strauss and Corbin (1990) believe that theoretical sensitivity increases gradually when the researchers interact with their data.

As previously stated sampling guided by ideas which have significance for the emerging theory is called theoretical sampling. One of the main differences between this and other types of sampling is time and continuance. Unlike other sampling which is planned beforehand, theoretical sampling in grounded theory continues throughout the study and is not planned before the study starts. At the commencement of a project the researcher makes initial sampling decisions, deciding on a setting and on individuals or groups of people able to give information on the topic to be researched, such as English speaking, cancer patients in the initial phase of cancer care who were being seen in a District General Hospital. Once the researcher has started and the initial data analysed and examined, new concepts arise and events and people are chosen who can further illuminate the problem. Theoretical sampling continues until the point where saturation has, when a concept is mentioned frequently or is described in a similar way by a number of people or when the same ideas arrive over and over again. Morse (1995) suggests that researchers can recognize when saturation has been achieved by the quality of the theory that has been developed; "saturated data are rich, full and complete". Saturation occurs at a different stage in each research project and cannot be predicted.

Coding and categorising data goes on throughout the research. From the start of the study data was coded. Coding in grounded theory is the process by which concepts or themes are identified and named during the analysis. Data are transformed and reduced to build categories. Through the emergence of these categories theories can be evolved and integrated. In grounded theory all the data are coded with initial codes tending to be provisional and to be modified and transformed over the period of analysis. The researcher groups concepts together and develops categories, at the start a large

number of labels are used and after initial coding the researcher attempts to condense codes into groups of concepts with similar traits which are categories. These categories can be abstract than the initial codes and are generally formulated by the researcher. The broken down data must be linked together again in a new form, the main features and dimensions of these categories are identified. Constructs are major categories which, although generated from the data and based in them, are formulated by the researcher and routed in the researchers professional and academic knowledge. Such constructs contain developing theoretical ideas and themes, and through building these constructs the researcher reassembles the data. Categories are linked to sub-categories, this process of reassembling the data is called axial-coding.

Although there is a lack of an initial hypothesis in grounded theory, during the course of the research a working hypothesis or hypotheses are generated. These are based in and indicated by the data. The process of testing and verification for these hypothesis which link the categories goes on throughout the research. This includes the search for deviant cases which do not support a particular hypothesis. In grounded theory the process of coding and categorizing ceases when:

- 1) No new information can be found in spite of the attempt to collect more data from a variety of sources.
- 2) The category has been described with all its properties, variations and processes.
- 3) Links between categories are firmly established.

(Strauss & Corbin, 1994)

It is essential for the researcher to discover the core category. In grounded theory the major category which links all others is called the

core category or core variable. In the case of this study the core category was communication. Throughout, the category should be woven into the whole of the study and provide the storyline. The linking of all categories around a core is called selective coding. This means that the researcher uncovers the essence of the study and integrates all the elements of the emergent theory. Strauss (1987) claims that some major characteristics for the core theory are:

- 1) It must be the central element of the research related to other categories and explain variations in behaviour.
- 2) It must recur often in the data and develop as a pattern.
- 3) It is connected with other categories without a major effort by the researcher.
- 4) In the process of identifying, describing and conceptualising the core category, the general theory of the study develops more fully.
- 5) The core category is usually found towards the end of research.

To be credible, the theory must have explanatory power linkages between categories and specificity. Categories should be connected with each other and tightly linked to the data. Researchers do not just describe the static situations but take into account processes which occur. Glaser and Strauss (1967) state that two types of theory are produced; substantive and formal. Substantive theory emerges from the study of one particular context such as the nursing care on a ward of patients with cancer or nurse education, this type of theory is useful to nurses since it has specificity and applies to the setting and situation studied but, this means that it is limited. Formal theory is generated from many different situations and settings and is conceptual in nature. It may be a theory about vocational education or general experiences of suffering. Layder (1993) demonstrates the links between substantive and formal theory, the career of dying



patients in hospital, the stages through which they precede, is substantive theory when this is linked to the concept of status passage, which can be applied to many situations it becomes formal theory. This type of theory has general applicability, that is, that findings can be applicable to other settings and situations.

The literature becomes the source of the data. When categories are being found researchers trawl the literature for confirmation or refutation of these categories. The researcher tries to discover what other researchers have found and whether there are any links to existing theories. Hence, the literature becomes part of the data. Strauss and Corbin (1990) make the following points about the use of literature:

- 1) Literature can stimulate theoretical sensitivity it can make the analyst aware of ideas which they can check against the data.
- 2) The literature becomes part of the data.
- 3) The literature can generate questions and problems. Interviews or observations might be illuminated by the literature in which similar or different ideas are discovered. Researchers have to consider why the literature confirms or refutes their ideas.
- 4) The literature can guide theoretical sampling. It can help decide where to go next. Ideas might arise which increase the chance of developing further the emerging theory.
- 5) The literature can be used to validate the researchers categories. Concepts in the literature may confirm the findings of the researcher. They may however, contradict the theory in which case the researcher tries to discover the reason for this conflict.

As previously stated throughout the study field notes and memos were written. The purpose of memos or field notes are to remind the

researcher of events, actions and inter-actions and trigger thinking processes. Certain occurrences or sentences seem vital and were recorded either during or after data collection. Every grounded theory researcher should write memos as they are meant to help in the development and formulation of theory. Strauss (1987) gives a number of different types of memos some are preliminary, others are memos on new categories or initial discovery memos. He also suggest that memos are the written version of an internal dialogue which goes on during the research. Memos and diagrams provide density for the research and guide the researcher away from the data to abstract thinking then in returning to the data to ground these abstractions in reality, (Strauss & Corbin 1990). This process was adhered to throughout data collection and analysis of this study.

Once all of the data had been analysed from the interviews, two Clinical Nurse Specialists were asked to review the transcripts and verify the themes which had been identified during analysis, fortunately they concurred with those already identified.

Following the semi-structured interviews, which were conducted with cancer patients in the initial phase of cancer care, informal discussions were carried out with the Clinical Nurse Specialists who had been present during the non-participant observations or whom the patients had identified during their interviews when the consultant gave them their diagnosis of cancer. The purpose of these discussions were to further clarify some of the issues raised by the patients themselves and also to get another health care professional perspective on the doctor/patient consultation and the sorts of support subsequently offered to patients.

It was evident that for many patients the opportunity to “tell their story” was very valuable and therapeutic in itself. Some patients commented that it was the first time that they had really had chance to tell their story in their own way and a number of patients made comments at the end of the interview such as:

“thank you for listening, it was really helpful just to have somebody to listen to it all again, it put everything into perspective for me”.

The third and final stage consisted of a series of focus group discussions to explore the findings of the study to date and discuss issues such as implementing change in the NHS and more specifically within the field of cancer care today.

Rubin and Rubin (1995) suggest that focus group interviews are a form of evaluation in which groups of people are brought together to discuss potential changes or shared impressions. They suggest that matters discussed within focus group interviews can range from the narrow and specific, such as how people react to a new type of seating in an Outpatients Department, to broader concerns of particular groups as they share their hopes and concerns relating to a particular issue such as implementing change within the NHS.

There are pitfalls with focus groups, the main one being that because a focus group interview occurs between a number of people, some of whom may not know each other very well if at all, there may be considerable effort to portray a particular persona in these situations. For example, nurses may be unwilling to indicate that they are uncomfortable talking to cancer patients in case they are perceived as being unprofessional or insensitive by both their colleagues who also

make up the focus group, and by the researcher. Frey and Fontana, (1991), Goldman and McDonald, (1987) and Morgan, (1988) all cite this as something which needs to be taken into consideration when carrying out focus group work.

Rubin and Rubin (1995) state that focus group interviews can be divided into two categories, cultural interviews which focus on the norms, values, understandings and taken for granted rules of behaviour of a group of society, and topical interviews which are more narrowly focused on a particular event or process and are more concerned with what happened, when and why.

Cultural interviews look at the special and shared meanings that members of a group develop. Within a cultural interview, an interviewer learns about the culture of that particular group by eliciting examples and stories that reveal how people understand their world in such instances, the researcher also hears the values that underline both fronts and accounts. The researcher asks for examples that show how particular words and phrases are used and deduces the meaning from such examples. Generally the style of questioning within cultural interviews is relaxed with no pre-set agenda of issues to cover, in such interviews there is no reason to rush through material or to steer the interviewee in a particular direction. With adequate time and many conversational partners who can provide similar information, the researcher can hold back questions that seem sensitive or ask them only to the interviewees who appear most willing to respond. Most cultural interviews usually involve re-interviewing the same people several times so ideas and themes that emerge in early interviews can be pursued in greater detail during later interviews. Rubin and Rubin (1995) suggest that a cultural interview involves more active listening than aggressive questioning. The researcher

asks the interviewee to describe a typical day or occurrence allowing the conversational partner to define what is important. In such interviews the interviewer asks for examples of cultural premises, norms and behaviours and it is suggested that the factual truth of an example is less important than how well it illustrates the premises and norms of that group. Culture is often communicated through stories, so the interviewer listens at length to sometimes protracted tales through which cultural lessons are shared (Hummel, 1991; McCall, 1990). Stories are important because they convey the values and themes of a particular group.

In contrast to cultural interviews, topical interviews seek out explanations of events and descriptions of processes. The researcher is generally looking for detailed factual information. During topical interviews the interviewer tends to be more active in directing the questioning and in keeping the conversation on a specific topic. Topical interviews deal with more precisely defined subjects such as what happens at ward level when nurses are asked to implement a change by a manager.

Although cultural interviews are frequently repeated with the same interviewees in topical interviews the researcher may only have one opportunity at getting the required information. As a result, the interviewer may adopt a more focused style of interviewing, developing a list of specific questions and pursuing them until he or she gets some kind of satisfactory answer. Rubin and Rubin (1995) suggest that topical interviewing is often considerably more directive than cultural interviewing.

Rubin and Rubin suggest that cultural and topical interviews also differ in the ownership of the resulting report. In a cultural study the

researchers report ideas, expressions and understandings that they heard in the interviewing as belonging to the conversational partners. They suggest:-

“in preparing a cultural report, the researcher is like a photographer, making choices about what to frame within the picture, but reproducing exactly what is there....”

In contrast a topical study is often based on the interpretations of the researchers, with the researchers sorting out and balancing what different people say, especially if there are contending interpretations of the same events.

“Rather than being a photographer, the topical researcher is more like a skilled painter. The events portrayed did occur and were learnt about through the interviews; the information is still grounded in the interviewee’s lives and stories. But the narrative is the truth as heard and interpreted by the researcher. It is an artist’s rendition...”

(Rubin & Rubin 1995)

Rubin and Rubin (1995) suggest that the cultural report is credible because it is a story which is told by the experts i.e. the members of the culture in their own words. However, because the topical researcher reports more of his or her interpretation of what he or she has heard, their report must show that the interpretation did not go far from the evidence and it must also show the reasoning and evidence that lead from the interviews to the conclusion. To the extent that the topical researcher combines different points of view to form a single narrative, almost every piece of information has to be confirmed. The topical researcher must solicit information that can be checked against other sources such as minutes of meetings and the interviewees must

be chosen because they are knowledgeable about distinct parts of an event or have different perspectives on what occurred.

The reality is that in practice, cultural and topical styles are often mixed in a single interview. In such situations, the researcher may alternate between listening for new cultural meanings and asking about events. You can mix topical and cultural interviews because they share the underlining assumptions which guide all qualitative interviewing (Rubin and Rubin, 1995).

In a focus group, the researcher calls together several people to talk about a concern held by the researcher or clients of the researcher. The members of the focus group might be consumers of a product or service, such as patients, or they may be persons who have weathered some sort of event together, such as being required to implement change within their clinical area. An increasingly common use of focus groups is to bring together a group of people who have experienced the same problem. However, although this seems a good way of exploring the same issue with a number of people, focus groups do present their own particular set of problems. Firstly because people have been pulled together for the sole purpose of a focus group which may last for about an hour, the situation can seem rather false and it is certainly one that lacks the opportunity for the researcher to build a rapport with the members of the group (Morgan, 1998).

In a focus group the interviewer becomes a group leader who facilitates the discussion asking questions and listening to the answers of the whole group. In most qualitative interviewing, the purpose is to obtain depth and detail from individuals. In focus groups the goal is different and it is to let people "spark off one another", providing

different perspectives of the original problem that anyone individual might not have thought of (Rubin and Rubin, 1995). In some instances a totally different understanding of a problem emerges from the group discussion. In focus groups it is impossible for the researcher to build a deep relationship with the subjects, focus group meetings involving typically 6 – 12 people usually run for about an hour or two and therefore there isn't time to get to know anyone or build trust slowly. Instead the researcher has to try and create a comfortable atmosphere so that all of the participants are willing to talk in front of each other. This can be equally difficult for people who are complete strangers to each other as it is for people who know each other and are part of the same professional group or organisation (here there may be issues of professional pride at stake).

Rubin and Rubin, (1995) suggest that the interviewer can allow time for individuals to greet each other, have coffee and have a social break in the middle. They also state that people in a group interview situation are most comfortable when they feel they are contributing to a professional project and that a professional is in charge. They suggest that the researcher gives overall direction while communicating the expectation that the focus group members will do most of the talking.

Rather than the researcher trying to develop a personal relationship with each member of the group, he or she needs to convey through his or her manner that it is a professional environment and that group members are the experts in that particular topic. Rubin and Rubin suggest that the researcher labels him or herself as a moderator who is the person who is going to guide the conversation of others. During the conversation the moderator plays close attention to the relationships between members of the group to ensure that people



don't "step all over each other". Some people can be frightened to speak in front of those who they don't know very well and whom they perceive have a higher professional status than themselves and are willing to let others talk and in such instances the moderator may have to take special measures to get their opinions, such as asking them directly whether they have experienced such an issue. Thus removing the focus away from an overly talkative person and highlighting the experiences and hints competence of the person whom he or she is soliciting.

Prior to conducting the focus group interviews analysis of the non-participant observations, and the patient interviews had identified a number of issues which appeared to influence the quality of care provided, to patients during the initial stage of cancer care. These issues included the need to improve communication skills for all health care professionals and in particular for doctors, also the need for health care professionals to exhibit a "caring" attitude towards their patients. The need for patients to experience effective multidisciplinary care and to have access to the right professionals at appropriate times in the patients disease journey had also been identified. Another issue which had been identified was the pivotal role held by the Clinical Nurse Specialist in improving communication and the quality of care as perceived by the patients themselves.

Also by this stage in the study a number of changes had been made to clinical practice including altering the working patterns of Clinical Nurse Specialists, namely having them there at the time a patient was diagnosed so they could support a patient through the whole cancer disease journey and particularly in the initial stage of that journey. The development of patient pathways to ensure equitable care and the development of protocols to support those pathways also appeared to

have been effective in ensuring that patients got the same standard of care regardless of which consultant was responsible for that care. Anecdotally some of the initiatives which had been implemented to improved multidisciplinary team working also appeared to have been beneficial, although these had not been formally evaluated at this stage.

It therefore seemed appropriate to carry out a number of focus groups with health care professionals responsible for delivery of the initial stage of cancer care. It was thought that it might be useful to explore professional views regarding some of the issues identified by the patients themselves and some of the changes that were subsequently introduced to practice as a result of this. As this was an action research project and change was a key component of the project it was also thought that there would be some mileage in exploring the concept of change within today's NHS and implementing change in practice with those health care professionals who are responsible for delivering care on a daily basis to cancer patients.

It was initially anticipated that five focus groups interviews would be carried out with the following groups of staff:-

- Clinical Nurse Specialists
- Service Managers
- Ward Nurses
- Consultants
- Community Nurses

Recruitment into the Clinical Nurse Specialist, Consultant and Service Manager Group was not a problem and everybody who was approached agreed to participate. However, when the ward nurses

were approached they felt that they would have little to offer to a focus group particularly if the Clinical Nurse Specialists were having a group of their own, the ward nurses explained this by saying that all of the Clinical Nurse Specialists had previously worked on the wards at some stage earlier in their careers and that they were aware of the issues relating to them. The ward nurses also felt that a focus group with them would be overkill if the Clinical Nurse Specialists, service managers and consultants were also being consulted. Rather than lose their perspective completely, the researcher asked the Clinical Nurse Specialists to discuss the key findings of the study with their ward nurse colleagues and also to discuss issues around implementing changes at ward level with the ward nurses prior to the focus group so that their issues could be fed into that focus group. Both the ward nurses and Clinical Nurse Specialists agreed to do this. It was also planned to do a focus group with community nurses in order to get a community perspective but the researcher was advised that this group of staff did not wish to participate as the initial phase of cancer care was perceived as being the remit of the hospital. This is particularly concerning bearing in mind that Calman and Hine (1995) state the importance of primary care in the cancer journey and given the fact that the majority of patients present to the general practitioner in the first instance, and indeed, after a diagnosis often return to their own home in a vulnerable state with minimal, if any support from the hospital.

The focus group with the Clinical Nurse Specialists comprised of 10 specialist nurses from the following specialities:-

- Colorectal Nurses x 2
- Lung Nurse x 1

- MacMillan (Palliative Care Nurses x 3)
- Chemotherapy x 1
- Haematology x 1
- Breast Care x 2

This group was very animated and needed no encouragement to participate in the discussion. There were no members of the group who did not participate equally, perhaps that is because they were all experienced Clinical Nurse Specialists who were used to articulating their needs and concerns relating to their area of clinical practice. This discussion was scheduled to last an hour but because of the issues that were generated actually went on for much longer and was only drawn to a close because it was carried out over a lunch time and people needed to go back to their clinical areas.

As part of the process of carrying out the focus group interviews, the researcher enlisted the assistance of a colleague who had had experience of focus groups previously. This colleague came along to observe the process with a view to advising the researcher if it looked as though certain individuals were not getting the opportunity to articulate their views or if it looked as though other personalities were actually taking over and controlling the direction of the discussion. This colleague also made notes about what she witnessed particularly around the non-verbal cues exhibited by both the researcher and focus group participants. Fortunately within this interview the colleague did not have to intervene and her post interview comments echoed the perceptions of the researcher.

The focus group interviews, which were carried out during this stage of the study, were all tape recorded and transcribed in the manner previously described when referring to the individual patient

interviews. Staff were assured of anonymity and confidentiality when writing up the study. They were also given the opportunity to read the transcripts of their own particular focus group.

The focus group carried out with the service managers consisted of six senior service managers responsible for running 6 separate clinical areas. In the Trust where the study was carried out all service managers also have an additional professional qualification for example; nursing or radiology qualifications. The service managers group came from a variety of clinical areas and the rationale for this was because cancer patients receive care from throughout the hospital, they are not just based on cancer only wards. The six clinical areas for which they were responsible are outlined below:-

- General surgery
- Gynae Oncology
- Outpatients
- General Medicine
- Orthopaedics
- Ear, Nose and Throat

Again the service managers were an articulate group who participated openly in the discussions, thus making it easier for the researcher to elicit information regarding the issues identified by the patients as important, and also, regarding implementing change in the NHS today and more specifically in areas caring for cancer patients in their initial phase of care.

The other focus group which was planned at this stage of the study was with consultants and although all six of the consultants approached had agreed to participate in a focus group, due to their

workloads it proved impossible to get them together at the same time. In an attempt to ensure that their views were still captured it was decided to carry out some short focused interviews.

Six consultant interviews were conducted in total and these interviews were conducted with the following specialists:-

- Breast Surgeon x 1
- Colorectal Surgeon x 1
- Clinical Oncologist x 1
- Palliative Medicine x 2
- Respiratory Physician x 1

Both the one to one interviews carried out with the consultants and the focus group discussions with the service managers and Clinical Nurse Specialists covered largely the same topic areas, namely the need for health care professionals to have good communication skills particularly at a time when they are giving a patient a diagnosis of cancer. All groups/individuals were asked whether they thought that this was an issue and, if so, how we could improve those skills for all staff involved in the initial phase of cancer care. The concept of presenting a “caring” persona to patients and whether or not this was perceived as important by the health care professionals themselves was also discussed with everyone, as was the idea which was raised by some patients that professionals, and in particular consultants, can appear to be too “professional”. In this case the term professional being associated with “coldness” and “clinicalness”, with the consultant providing facts and not offering support or exhibiting he or she “cared”.

Other issues forming the basis of the focus groups/consultant interviews included discussions regarding how to ensure all patients entering the Trust received an equitable service regardless which professionals were involved in their care. This in turn led to discussions about how to ensure there was continuity of care for patients and continuity of advice and information. The role of the Clinical Nurse Specialists was also discussed at length and with the Clinical Nurse Specialist focus group this discussion was extended somewhat with the nurses themselves looking at how they could expand their roles and what additional things they could bring to enhance the care of patients in the initial phase of cancer care. The role of the multidisciplinary team was also explored in each of the groups as was leadership within those multidisciplinary teams. The final area for discussion in the focus groups and consultant interviews was the concept of change within the NHS and how individuals and departments could implement change in clinical practice effectively.

Prior to the interviews all of the participants were given an information sheet outlining the purpose of the focus group, this also detailed some of the findings of the study up to that point and in particular those issues which appeared to be important to those patients who were interviewed in an earlier stage of the study.

At the commencement of the focus groups/interviews the participants were again given the opportunity to withdraw although nobody expressed a wish to do so. They were also given the chance to ask further questions regarding the results which had already been presented to them. The participants were reassured about confidentiality in anonymity. They were also reminded that the focus group/interview would be tape recorded and later transcribed. It was anticipated that the focus groups would last approximately an hour,



the one with the service managers did last about that length of time, however, the one with the Clinical Nurse Specialists ran over substantially. That was probably because it was a large group and also there were some specific questions actually relating to the Clinical Nurse Specialist role which formed part of the discussion. It was thought that the consultant interviews would last about 30 minutes because they were meant to be quite focused and were not intended to include as many issues however, they tended to more like 45 minutes to an hour. The interview schedule was as highlighted in the previous chapter and this formed the basis of the subsequent discussions.

The data from the focus groups and consultant interviews was analysed in the same manner as the patient interviews which have been described previously within this chapter.

The results of the analysis are to be discussed later in this thesis.

The results of the study will be discussed in detail in the following chapter. However, before focusing on the results it is necessary to consider research carried out on sensitive topics such as cancer. One difficulty in talking about "sensitive topics" is that the phrase is often used in the literature as if it was self-explanatory. Lee & Renzetti (1990) suggest that the term is treated in a common sense way without actually being defined. Farberow (1963) equates sensitive topics to those areas of social life surrounded by taboo, cancer should therefore be defined as one of those sensitive topics. Farberow's discussion is based in a rather eclectic way on a range of anthropologic and psycho-analytical sources. On the basis of this material Farberow regards taboo topics as those that are laden with emotion or inspire feelings of awe or dread, it is clear that he views



matters relating to sex or death as "sensitive". The problem with this approach is that it is much too narrow as it does not allow for the possibility that research might have a sensitive character for situational reasons, (Brewer, 1990). Or because it is located within a particular socio-political context (Rostocki 1986). An alternative approach would be to start from the observation that in so far as there is a common thread in the literature it lies in the implicit assumption that some kinds of topics potentially involve a level of threat or risk to those studied which makes data collection difficult, and/or decemination of research findings, (Lee and Renzetti 1990). A simple definition of sensitive research would therefore be research that potentially poses a substantial threat to those who are or have been involved with it.

From the scant literature on sensitive topics one would most expect research to be threatening within three broad areas, (Lee, 1993). The first is where research poses an intrusive threat, dealing with matters which are private, stressful or sacred. The second relates to the study of deviance and social control and involves the possibility that information may be revealed which is stigmatising or incriminating in some ways. Finally, research is often problematic when it impinges on political alignments, if "political" is taken in it widest sense to refer to the bested interests of powerful persons or institutions or the exercise of coercion or domination in these situations, researchers often trespass into areas which are controversial or involve social conflict. Lee suggests that a further important point is, while the threat posed by research most obviously affects the research participants it may also have an impact on others, these include the researcher, but also the family members and associates of those studied, the social groups to which they belong, the wider community, research institutions and society at large. Research which intrudes into the private sphere may

be deemed as having a sensitive character however, this is not inevitably the case. Day (1985) concluded that there is no fixed private sphere, topics and activities regarded as private vary cross culturally and situationally. None the less any study which involves asking individuals about their experiences surrounding being given a diagnosis of cancer has to be handled with sensitivity. Areas of person experience such as feelings about a diagnosis or bereavement are not so much private as emotionally charged. Lee (1993) suggests that research into such areas may be threatening to those being studied because of the levels of stress that may be induced. He also states that there is an additional problem that affects research into the private sphere which is about the subject being able to maintain an appropriate demeanour in face-to-face contact with the researcher. Although it may be difficult to remain composed in trying circumstances the ability to do so is socially prized, (Goffman, 1957 and Scheff, 1998). Doubts that the individuals can maintain proper standards of poise when asked sensitive matters may therefore make the prospect of such research even more threatening. Lee (1993) also points out that feelings of discomfort may apply to the researcher as well, as he or she might have to share with those researched feelings of unease, discomfort or emotional pain. It is clear that in order to glean information on issues that may be sensitive to the individual such as their feelings about being diagnosed with having cancer, the researcher needs to have excellent communication skills. The role of trust in the data collection process is pivotal, the research participants needs to be able to trust the researcher and feel comfortable disclosing to them, if mechanisms or procedures are in place to block possible negative repercussions from involvement in the research. The establishment of trustful relations depends on the quality of the interpersonal engagement between the researcher and the individuals being researched and the building of a rapport throughout the

research relationship, increasing levels of fellowship, mutual self disclosure and reciprocity (Lee, 1993). During this study the research participants seemed quite comfortable, although a number did exhibit strong emotions such as tears whilst "telling their stories". Perhaps the establishment of trustful relations was "taken as read" simply because the researcher was known as a health care professional dealing with cancer patients.

Research can also be seen as a political threat (Lee, 1993). Since research settings exist inside a wider social, economic and political environment, that context may have repercussions inside the setting. Even in situations which are not overtly conflictual, research which seems to threaten the alignments or interest of those being studied is frequently seen as having a sensitive character. This is particularly so when a study touches on the exercise of power or extremes of wealth and status. Beynon (1988) states that "historically the rich and powerful have encouraged hagiography not critical investigation". As a result there has been a tendency for social scientists to study "down" rather than "up" with researchers directing attention towards the relatively powerless rather than at elites. To some extent the difficulties involved in studying elites may be exaggerated. Elite groups may share values with researchers concerning the importance of the research as Moyser and Wagstaffe (1987) point out, they may also presume that a study will be objective, unbiased and useful for the formulation of policy. It has been noted that an essential feature of elite psychology that was particularly helpful, was the desire to know how one individual stood in relation to others. (Winckler, 1987). Some of those he studies allowed him access because they were curious to know "what it was like for the others and how they rated alongside the famous". Certainly in the case of this study there was tremendous support from the doctors who may be seen as "elites" who

had been approached to participate in the study. On the other hand Punch (1986) highlighted the difficulties of studying "literate, articulate, self-conscious people with the power, resources and expertise to protect their reputation". Elites may in some cases actually feel demeaned whilst being studied by those of a lower status (Cassell, 1988). In the case of this study there were no problems encountered gaining access to doctors who may be perceived as elites but perhaps this was due to the fact that the researcher was professionally known to the individuals who were approached to participate in the study and perceived as a colleague and team member by some of the doctors approached. Problems were however encountered when the researcher was trying to gain local ethical research committee approval as her initial proposal was rejected without any explanation for their rejection. The committee was then approached for a personal hearing and at that subsequent meeting they revealed that they wanted a couple of changes to the protocol. Firstly that the time which had elapsed post diagnosis when proposed interviews should occur should be written into the protocol (this was a simple omission on the part of the researcher). Secondly, that the patients be defined as having a prognosis of a minimum of 11 months, the prognosis being defined by the consultant in charge of that patient's care. Subject to these two amendments the committee agreed that the research could go ahead. In subsequent discussions with other interested parties it was felt that although these requests were appropriate they were not a basis for denying approval for the study on ethical grounds. It has since been suggested that the reason the study may have been refused ethical approval in the first instance was that some of the medical practitioners on the committee may have felt threatened by the idea of a nurse observing and attempting to analyse doctor/patients interactions. This view is supported by others who state that collaborative working and research is fraught with

issues arriving from the “politics of collaboration” and that such politics operate at individual and institutional levels and can have debilitating affects on the research enterprise if not dealt with (Beattie et al 1996).

The results of the non participant observations, patient interviews, focus groups with Clinical Nurse Specialists and Senior Managers and the Consultant interviews will be discussed in the next chapter of this thesis.

## **CHAPTER 4**

### **Results**

#### **Results of non participant observations**

During the non-participant observation phase of this study doctor/patient interactions were observed at a time when patients were being given bad news i.e. a diagnosis or a confirmation of a diagnosis of cancer and/or information regarding treatment options, which in some instances were palliative not curative options. A total of 18 doctor/patient interactions were observed (3 Consultants were observed talking to 6 separate patients each). "Normal pleasantries" were exchanged during all of the observed interactions, in every interaction that was observed the doctors introduced themselves on entering the room if they were unknown to the patients and relatives, after checking out that they had got the correct patient and in those instances where the patient was known to them and was coming back for a confirmation of a diagnosis or treatment information usual language related pleasantries were exchanged such as "hello" "how are you".

12 of the 18 interactions were carried out in a hospital examination room, the layout of which was not conducive to informal or relaxed discussion. The examination room was very small and the furnishings consisted of an examination couch along one wall, a sink on the adjacent wall and a door in which the doctors entered on the same wall, the wall opposite the examination couch had two hard-backed chairs without arms, both of which were placed against the wall. There was also a door on that wall by which the patients and relatives entered into the room from the waiting area. The wall adjacent to that

in a clockwise direction had nothing on it except a metal examination trolley. The walls of the room were a magnolia colour and there were no fixtures or posters on them. The only windows were at the top of the wall on which the examination couch was situated and it was impossible to open them, this meant that when there were a number of relatives in addition to the patient and health care professionals in the room, the room temperature could become uncomfortable. Indeed the temperature of the room was comfortable if wearing indoor clothing but for patients who entered still wearing their outdoor wear it could become extremely warm and uncomfortable (6 patients showed discomfort via their body language). Due to the cramped conditions of this room it meant that it was difficult for the doctors to sit next to the patient because invariably the patients were brought into the room (prior to the doctor entering) by a clinic nurse and in every observed interaction that took place in that room, the patients and their relatives sat on the chairs, where there were additional relatives they tended to stand on either side of the chairs, as a consequence of this the doctors had to stand or sit on the examination couch, invariably they chose to sit on the examination couch. The problem was this was the fact that even at its lowest height the examination couch was slightly higher than the patient's chair; this meant that the doctor was looking down on the patients and his or her relatives. This positioning in itself is not conducive to open and equally weighted conversations. On five separate occasions patients became particularly distressed and all three of the doctors who were observed, responded to this by getting off the examination couch and walking over to the patients and responding by either putting their arms around the patient, touching the patient or crouching down next to them.

Three of the non-participant observations actually occurred in a slightly different environment which comprised of a fairly large

consultation room with no windows. The room had one door by which both the patient and the doctor entered into the room and opposite the door was a desk; there was one chair behind the desk and two chairs in front of it. To the right of the desk was a long wall with an examination couch next to it and a trolley at the foot of the examination couch. Again the walls of this room were a magnolia colour and there were no fixtures or pictures on them. The doctor who was observed in this environment also entered the room after the patients and their relatives had been seated on the chairs in front of the desk. In one instance the doctor sat on the examination couch which again was slightly higher than the patients and the patient's relatives, this resulted in her looking down at the patient in order to make eye contact, on a second occasion the doctor physically moved the chair from the other side of the desk so that it was adjacent to the patient and the relatives themselves and she was looking at them on the same level.

In 13 of the non-participant observations that were observed there was a Clinical Nurse Specialist also present in the room, this Clinical Nurse Specialist was either a stoma nurse who was available for those patients with bowel cancer or a Macmillan Clinical Nurse Specialist. These nurses altered their seating position depending upon how many people were in the room and the available seating space, so if the seat next to a patient was available by and large they would occupy that seat after moving it slightly away from the patient so that they were not invading the patient's personal space. Alternatively if that seating was not available they either perched on the end of the examination couch which the doctor was occupying or stood up in a corner of the room usually leaning against a sink or a trolley. Where there was a Clinical Nurse Specialist present they were largely ignored by the patient and doctor during the initial part of the interaction. However, they were



introduced by the doctors and acknowledged by the patients when they entered the room but most of the other verbal and non-verbal communication which was observed occurred between the doctors and the patient and to a lesser extent the relatives themselves who were present.

A further three interactions were observed at the patient's bedside as they were in-patients on old fashioned "Nightingale" wards. These wards had no facilities available for private discussion. Two of the observed doctors saw patients on the ward, the same responses and interactions were witnessed as previously discussed, however when these patients were seen they had no privacy just the illusion of it, made by pulling the curtains around the bed, interestingly this did not seem to bother them at all. Both doctors made an effort to sit either next to the patient or on the bed prior to commencing the interview having to move things off the bed or rearrange chairs to enable this to happen, all 3 patients visibly relaxed in response to this gesture. When the interviews in the ward setting had concluded both of the consultants gave the patients the opportunity of leaving the curtains around the bed area in order to give them some privacy/time to compose themselves, all 3 patients confirmed they would like this.

Obviously, a large proportion of verbal communication was observed during the interactions and on the whole the patients and their doctors appeared to understand each other. That assumption, made by the non-participant observer, is based on the fact that the non-verbal aspects of communication which indicate understanding such as eye contact, head nods and facial expression seemed to indicate understanding. Where the patient or relatives body language indicated distress or confusion without exception the doctors picked up on this and either gave the patients time to think about what had been said,

tested out their understanding by asking patients what they understood by the term tumour of cancer etc. (although this was not done routinely) or they rephrased what they had just said. All of the doctors appeared comfortable with silence and did not rush the patients. Interestingly some of the interactions were quite short only lasting 12 or 15 minutes, which is not a long time if a patient is actually being given a diagnosis and some discussion about potential treatments, but there seemed to be an illusion that the doctors had all the time in the world and that they were in no real hurry. This illusion was reinforced by the fact that the doctors all asked the patients whether they understood what was being said, whether they had any questions and all of the doctors observed included the relatives who were present as well.

Both the patients and relatives posture was a useful cue for the doctors in terms of assessing patient's distress. When patients slumped in their chairs, started looking at the floor and so on, the doctors appeared to use that as an indicator that patients were distressed or required more time or a different approach and they altered their response accordingly. Where patient started avoiding eye contact with the doctors, shifting their position, or fidgeting, the doctors appeared to take this as an indication they were distressed with the news that they had been given or that they had become saturated with information and could not cope with anymore, or alternatively, that they did not understand what had been said to them. This sort of behaviour usually signaled a change in the course of the interaction and quite often resulted in the patient being given the opportunity to come back in one weeks time for further discussion/information.

When reviewing the detailed notes that were taken at the time of the non-participant observations it became very clear that all of the doctors used a lot of medical terminology, terms such as “fractions of radiotherapy”, “randomized clinical trials”, “tumour markers” and “Dukes staging” were all used without the doctors actually explaining what these terms meant. In the majority of cases neither the patients nor their relatives actually questioned the doctors regarding the meanings of such terminology. Whether that was because the terms were indeed understood by the relatives and patients or, whether the patients or relatives asked the nurse specialist after the doctors had left the room, or they chose to remain ignorant is open to conjecture.

Perhaps the other issue, which was a reoccurring aspect of verbal communication throughout the non-participant observations, was the need for patients and their relatives to focus on practitioners once they had been given a diagnosis or prognosis. 12 patients and their relatives focused on issues about how they could actually get to the hospital for treatment, how long the treatment would take and so on rather than issues regarding treatment outcomes and potential life span left to them and so on.

It is important to note that although these interactions were by and large unhappy and distressing events to the recipients of the information not everybody reacted with overt distress. Some patients were very stoical in their attitude to the news they had been given whilst others even exhibited humour and the doctors were also comfortable and where appropriate introduced humour to lighten up the consultations, where this did occur the patients did not appear uncomfortable with this.

From the observer's point of view the doctors had an understanding of the complexities and nuances related to non-verbal communication. This was evidenced by the fact they altered the course of the conversation if they witnessed someone's non verbal cues indicating anxiety, distress or confusion in order to address the patient's reaction. However, none of the doctors included in this phase of the study reported having ever had any formal communication training. However, it is also clear that on a number of occasions there are no problems surrounding the verbal communication which takes place during a doctor/patient interaction. The majority of patients start to look confused once medical terminology had been introduced into a conversation and indeed that confusion worsens dramatically when doctors provide complex information, such as when they are trying to recruit patients into randomized clinical trials. For example, when a patient is told that he/she has cancer for which a trial exists, the trial has three arms all of which have different intervention, different side-effects and so on, this information easily becomes confusing and this can be exacerbated by the use of medical terminology and the names of drugs etc.

What also became clear from the eighteen non-participant observations was the variety of support offered to patient at a time when they had been given their diagnosis/prognosis/treatment options. Support not only varied from doctor to doctor but also varied between individual patients, the patients of one doctor may be given written materials (to reinforce what had been said), on one occasion but not on another, sometimes they were offered Clinical Nurse Specialist support, other times they were not. On those occasions when a Clinical Nurse Specialist was present during a doctor/patient interview he/she offered support when the doctor omitted to do so. These inequalities existed despite the knowledge that patients require

ongoing support and the availability of support material in the clinics at the time of consultations. Whether a doctor had made some sort of assessment as to whether the patient needed either psychological support of a Clinical Nurse Specialist or written materials to reinforce what had been said or if he/she simply remembered on some occasions and forgot on others is open to conjecture. The only exception where patients were routinely given written materials to support what had been said verbally was in the case of those patients who were being asked to consider recruitment into randomized clinical trials (this was a requirement of the recruitment process).

It was clear from observation that all of the doctors involved at this stage of the study had some skills in identifying and interpreting the non-verbal cues exhibited by the patients and their relatives and in most cases their responses appeared to be very appropriate. For example when a patient started to fidget and look at the ceiling the doctor recognized that he had ceased to listen and stopped talking as it was inappropriate to give more information at that stage of the consultation. However the areas where there seemed to be more confusion was in relation to pitching the verbal information given at the right level. In all of the instances observed, patients were given information regarding when they would be followed up, where that follow up would be and by whom.

The purpose of non-participant observations of doctor/patient consultations was to ascertain what actually happened in practice during medical consultations. The data obtained from the non-participant observations enabled an understanding of the problem in context. The themes identified during analysis of the field notes of the non-participant observations assisted in the development of the

interview schedule which was to form the basis for the next part of the fieldwork i.e. semi-structured interviews with cancer patients.

The following areas were identified using thematic content analysis of the detailed notes taken throughout the non-participant observations:-

- Approachability of the doctor
- Amount of time given to the “breaking bad news” interview
- The manner in which the “bad news” was given
- Opportunity for the patient and/or relatives to ask questions
- Patients perceived understanding of the language used by the doctor
- Suitability of the environment for the interview
- Availability/suitability of written materials (To support verbal information)
- Whether treatment options were discussed
- Whether the patient was offered ongoing support
- Whether relatives (where appropriate) were included in the process
- Amount of information given – was it appropriate
- Suggestions for improving that process

The notes of the non-participant observations were also reviewed by two colleagues (one a Macmillan Clinical Nurse Specialist practicing in another Trust, the other a Health Visitor with experience of the research process but minimal knowledge and insight into cancer services) with a view to trying to ensure some accuracy interpretation. Both reviewers concurred with the themes identified at this stage of the study. Other topic areas discussed during the interview phase of the study were introduced as a direct result of the interviews themselves or as a result of the ongoing literature review.

### Results of the Patient Interviews

Thirty three patient interviews were conducted as part of this study. Patients were given the choice of where they would like to be interviewed i.e. their own home, a private room in the hospital or a private room in the Chemotherapy Day Unit. Most patients opted for their own home. Appointments were made at a time convenient for the patient and the day before the interview the patient was telephoned in order to confirm that they still wished to participate in the study and that the time remained convenient from them. No patients opted out of the study at this stage.

On the day of the interviews commencing all of the patients were again given the opportunity to change their minds and they were asked to read an information sheet outlining the purpose of the study. They were then given the opportunity to ask further questions and once they felt fully informed were asked to sign a consent form agreeing to participate in the study. The patients were reassured about confidentiality and anonymity. All of the patients were tape recorded and none of the patients appeared to be adversely effected by this, although two patients provided information once the tape recorder had been switched off as this information was deemed relevant by the researcher the patients were asked if it could be used in the study, they both agreed to this. It was anticipated that the interviews would take approximately 30-40 minutes (based on the pilot interviews) they actually varied between 20 and 50 minutes in duration. The interview schedule previously discussed in this chapter formed the basis for the subsequent interviews.

The patients who were interviewed were all aged between 23-70 years of age. All were English speaking Caucasians (representative of the local community which has low numbers of ethnic minorities).

17 of the patients were female, 16 male. Table 1 shows the cancers that the informants had been diagnosed with:-

Table 1

Number of Patients	Site of Primary Cancer
13	Bowel
5	Lung
4	Breast
3	Oesophagus
2	Testes
1	Stomach
1	Prostate
1	Liver
1	Ovary
1	Pancreas
1	Skin (Melanoma)

The high number of bowel, lung and breast cancers follows the national trend, however the number of lung cancer would have been higher (reflecting the local population) had not patients with a short prognosis been excluded from the study.

All of the patients were asked for their comments relating to the environment in which they were told their diagnosis. Only three patients had any comment to make and these related to the



examination room being too hot and cramped and the waiting areas being busy and therefore not relaxing. Those told in a ward setting with little privacy except for a curtain around the bed did not make any comments about where they were told.

All of the patients were asked to describe the story of how they were told their diagnosis. 19 different words were used to describe their feelings on hearing the news that they had a diagnosis of cancer, with some patients using more than one word to describe their initial feelings.

Table 2

Words used to describe initial feelings/reactions regarding a cancer diagnosis	Number of Patients using descriptor
Shock	13
Isolated	3
Switched off	3
Numb	2
Death sentence	2
Angry	1
Frightened of the unknown	1
Loss of individuality	1
Drained	1
Wanted to escape the hospital	1
In limbo	1
Withdrawn	1
Shattered	1

Traumatised	1
Anxious	1
Lost	1
Huge psychological impact	1
Vulnerable	1
The biggest things that's ever going to happen in your life	

NB. 19 different words were used; some patients used more than one word.

Thirteen patients stated that they experienced shock on hearing a diagnosis of cancer, despite the fact that many of them had considered that it may have been their eventual diagnosis; this is consistent with the view held by some that cancer is something that happens to other people. Indeed to a certain extent for some patients denying the possibility of a cancer diagnosis enables them to function as they would normally do so in the short term, thus giving them some degree of psychological protection. However when a doctor challenges this denial by advising them of a cancer diagnosis many patients experience genuine shock.

Three patients reported feeling isolated on hearing their diagnosis, these patients were not patients who had been offering ongoing Clinical Nurse Specialist support and they may have benefited from this type of support from the time of their diagnosis as it may have reduced their feelings of isolation.

Three patients reported "switching off" when they heard they had cancer, this response is documented in the literature relating to communicating a cancer diagnosis (Kaye, 1996; Buckman, 1984 and Stedeford 1994). This response seems to provide one main function, it protects the patients from hearing more potentially distressing news which they are unable to cope with at that particular moment in time, in effect it gives the patient time to assimilate the news of a cancer diagnosis at their pace not the doctors. However in practice this only works when the doctor is a skilled communicator and is:

- a) able to identify what is happening to the patient
- b) able to see them again to give more information at a gradual pace which is led by the patient.

Two patients automatically thought that a diagnosis of cancer was a death sentence despite the fact that publicity reports that treatments are becoming more effective and there are increasing numbers of long-term cancer survivors. Interestingly one lady deemed her diagnosis a death sentence had breast cancer which was detected via screening (her breast lump was not large enough to be felt on examination) and she was deemed to have a quite a good chance of being disease free following treatment.

Many of the feelings identified by patients such as anger, anxiety, vulnerability, fear of the unknown and feelings of loss are all common experiences of patients who have been diagnosed with life threatening diseases and such emotions are well documented in the literature (Kübler-Ross, 1970' Kaye, 1996; Buckman, 1984; Ford et al, 1994 and Goldberg et al, 1990).

Many of these feelings can be alleviated to some degree of ensuring that they are acknowledged by the doctor and where possible addressed as soon as possible. For example a patient frightened of the unknown may have his or her anxieties reduced substantially by being given full explanations of what to expect both from a treatment perspective but also regarding the predicted pattern of the disease. In addition the offer of ongoing support may also assist in the reduction of such anxieties. Even when patients do not access the support of a Clinical Nurse Specialist some report feeling reassured by the knowledge that such support was available to them should they wish to access it.

Some emotive terms were used to describe how patients felt at the time when they were given a diagnosis of cancer words like “shattered” and “traumatized” reflecting the psychological pain that accompanies a diagnosis of cancer. The use of such terminology by patients is not uncommon and should remind health care professionals of the impact of their choice of words when telling a patient he or she has cancer.

One patient explored his response to his diagnosis further stating that he felt that it was a “huge psychological impact” whilst another patient alluded to the way in which a cancer diagnosis affects all aspects of a patients life, he described being told as:

**“the biggest thing that’s ever going to happen to you in your life”**

(Patient No. 17)

Not all patients used emotive language and/or exhibited distress on hearing they had cancer indeed three patients appeared stoical in their response to a cancer diagnosis, stating things such as:

**“You just have to get over it and try to hope that you will be cured”**

(Patient No. 2)

**“It hasn’t worried me at all, it err, no good worrying about it”**

(Patient No. 12)

Once insightful patient commented on how he felt when he was told he had cancer and how he felt, his reaction may have been misinterpreted by the doctor:

**“..... so while I had begun to think there might be a growth there, I’d never thought about it being cancer really and of course it was quite a shock, but I’m a bit of a stoical person I think and don’t maybe show my feelings very well, and I think Mr. S. imagined that it might not have sunk in because I can remember him saying to me, you know what I’m saying? You understand what I’m telling you?”**

(Patient No. 10)

Eleven of the patients interviewed went onto describe how they never heard anything of the subsequent conversation after they had been told they had cancer:

**“When you first hear it you can’t take it in .... You just blank”**

(Patient No. 4)

**“You don’t really absorb it all in at that moment and emm, because the initial shock takes over”.**

(Patient No. 15)

**“I just went numb and I never heard anything after that”.**

(Patient No. 21)

These statements support the need for health care professionals and doctors in particular to give information gradually to a patient, ensuring that they have understood and assimilated each piece of information before more is given.

Nine patients also described euphemisms for cancer, two referred to “growths” two the “Big C”, one a “shadow”, one “suspicious”, one an “ulcer” and a further two patients included more than one euphemism in their diagnosis:

**“they found a growth you know, a tumour whatever, it’s the same thing I believe”.**

(Patient No. 4)

**“Well, he just said that it was an ulcer first and he wasn’t sure whether it was an ulcer or a tumour”.**

(Patient No. 2)

Patient Number 4 continued to use euphemisms such as “seeds” when describing the story of diagnosis and initial phase of treatment although at no stage did he refer to his disease as “cancer”. He did however appear to the interviewer to be fully aware of the diagnosis as he described his chemotherapy treatment and the initial shock on hearing his diagnosis, in addition he discussed the merits of the information leaflets he had been given which certainly used the word cancer, the reasons he did not articulate the word cancer are open to conjecture but it may be that he found using the word too painful and a reminder of what he had had to endure.

Whilst also using euphemisms to describe advanced warning that they may be the recipient of bad news, however those patients who had been given some indication to expect a cancer diagnosis appeared to appreciate the warning and deal with the news in a less emotional manner, probably because they had time to adjust to the potentially “bad news”. Such “warning shots” where they occur seems to fall into three main categories, firstly, where the GP has warned the patient that their symptoms are suspicious of cancer, secondly, where the patient has informed him or herself via books etc. and thirdly, where the consultants informs the patients that his/her symptoms maybe due to cancer at the time investigations are being undertaken:

**“Well the GP did an X-Ray cos I was breathless and I’d coughed up a bit of blood and stuff, so he got me to see a specialist at the hospital. He put a camera down into my lungs and then when the results came back he told me it definitely was cancer. I wasn’t at all surprised because the GP told me the shadow on the x-ray could be cancer so I’d had some preparation”.**

(Patient No. 23)

**“Well I’d had prostatic cancer about eight years ago and I’d had no problems at all, then I started to get pain in my shoulder so I was referred back for an x-ray and then to Dr B the oncologist, so I went to the Oncology Clinic for the results of this x-ray and I knew that the cancer could have spread, because my wife and I had read all the books when I was initially diagnosed....”**

**(Patient No.22)**

When asked whether the doctors gave them sufficient time the majority of the patients felt they had, the exception to this was one patient who felt that once the diagnosis had been given the surgeon wanted to end the consultation:

**“He (the surgeon) said well it means I can cut it out but it won’t need any further treatment, or we don’t it will and, err. he was quite pleasant, you know he didn’t put me at my ease, you know he didn’t do anything to try and make things easier for me .... It was a case of like I’ve told you now, bye”.**

**(Patient No. 17)**

This patient also had to ask for time to consider treatment options and the interviewer felt that the patient harboured a lot of anger towards the consultant who gave him the diagnosis.

One patient expressed concern over him/her taking up too much of the doctor’s time:



**“you think that time is money for them (the doctors) .... I think the patient is aware that you’ve got to hurry up and get through it as quickly as possible which isn’t always to the good”.**

(Patient No. 6)

However, the patient did not offer any explanation as to why she felt that way, indeed although she felt that she did not want to take up too much of the doctors time she commented throughout the interview about how caring the doctors and nurses in the clinic setting were:

**“It was a very caring atmosphere when I was actually interviewed ... she (the nurse) was very supportive ..... I thought they were very professional, I couldn’t really fault them, I felt that atmosphere was very caring”**

(Patient No. 6)

Patients attending out-patients were all given the choice regarding whether they had relatives present and where those relatives were in attendance they were included in the discussion which ensued. Six of the patients did not have relatives present when they were given a diagnosis, either because they were unaware that they were getting a diagnosis, or because they were seen on the ward by the consultant and therefore not given a specific appointment time (and so did not know what time to ask their relative to be present). Four patients did not want relatives present primarily because they were trying to protect them.

One patient described how when things went wrong for her, in the post-operative period, her husband had difficulty in arranging a formal interview where he could be told “what was going on”:

“They did a little drawing and everything to say what the operation was going to consist of and originally it was, err, key hole surgery, pretty straight forward as far as they were concerned and that was it really. They gave me a date to go in and I went in and had the operation and instead of the hour to an hour and a half you’re in surgery for key hole, I was in for nearly four hours because the cancer had spread into the lymph nodes so he (the surgeon) had to take away a lot more than he’d originally thought. The next day I spoke to the Mr. M. (the surgeon) and, I presume, his registrar, I was still quite groggy so obviously I couldn’t take in what he was saying. I could hear certain words just because I felt really ill, very ill, err, and really the only thing I remember about that is, oh, you’ll feel better in a few days time but we think we are going to have to give you chemotherapy followed by radiotherapy, umm, and I just couldn’t really take it in, I was feeling that bad at the time ..... but after the operation the most upsetting thing was for K (her husband) because he had to chase them (the doctors) about for three days before he could get any information out of them”.

(Patient No. 14)

The scenario described by patient no. 14 highlights a number of important issues in relation to communicating with cancer patients in the initial stage of their care. Firstly the timing of the information giving is critical i.e. it should be given at a time when the patient is lucid and can understand what is being said to him or her. Secondly, the health care professionals responsible for imparting such information should try to ascertain whether the patient would like someone to be present at this time, this is much easier to facilitate if the patient is an inpatient following investigations or treatment as in the case cited. Thirdly the health care professionals and, in particular, the doctors should make

themselves available to speak to relatives (with the patients permission) and be available to reinforce information for patients at a time when patients are able to understand the implications of what has been said.

The impact of poor communication can have lasting effects on patients and their relatives and patient no. 14 alluded to her discontent relating to the problem she had described and other communication issues such as lack of information about her chemotherapy throughout the remainder of the interview:

**“Yeah, we were very disappointed after the operation ..... I know they were understaffed and they were extremely busy but I think they could have done a bit more ..... and they weren’t bothered about what I felt ..... they could have done a bit more explaining but they didn’t”.**

(Patient No. 14)

The patients were asked about the amount and quality of information they were given (i.e. were they given enough/too much information and could they understand it, were they given plenty of opportunity to ask questions). The vast majority felt they were given simple information relating to their diagnosis and given an opportunity to ask questions. However, 9 patients felt they needed more information not relating to their diagnosis but to their proposed treatment and side-effects and lifestyle changes.

Four patients expressed the view they had been given too much information, three of those were being approach to consider entry into randomized clinical trials and found the concept of being requested to participate in a randomized clinical trial difficult to grasp, in addition the

amount of information also made it harder for them to give informed consent. This was well illustrated by one patient:

**"I had Stage 1 seminoma which was a cancer of the testes. He (the oncologist) said for such a tumour they normally recommend radiotherapy for 3 weeks as a standard treatment but the alternative was to enter a clinical trial, that's when it got really confusing because there were other treatment regimes but I couldn't choose, ..... It was really confusing to try to sort through the amount of information and the technical terminology".**

(Patient No. 31)

Two patients described how they did not want much information, "wanting to bury their heads in the sand" and how the doctors adapted the interview to accommodate their wishes.

Whilst the vast majority of patients were afforded the opportunity to ask questions, should they so wish, one patient commented that he/she was too overwhelmed to respond to the offer of asking questions:

**"I didn't get him to explain things to my satisfaction despite the fact that he kept asking me if I had questions and if I'd understood. To be honest I just switched off, I was just overwhelmed by the choices".**

(Patient No. 31)

Another patient commented that he/she was there to see the "expert" and didn't know what to ask:

**“The thing is you don’t know what to ask, do you, I mean they’re the experts aren’t they”.**

(Patient No.22)

The way in which the consultant opened and conducted the interview was significant in affecting the way in which the patient perceived the quality of that information and indeed in their ability to establish a trusting relationship with the consultant:

**“He was fairly brutal, said that the news was not so good, you have a “carcinoma” and that’s a cancer ..... It’s serious and I think any treatment we can give you is purely palliative ..... The way in which the information was given was very clinical”.**

(Patient No.11)

**“If I don’t have the operation, he said well you die”.**

(Patient No.16)

Both of the above patients sought further information and support from other agencies such as books, advice centres and Clinical Nurse Specialists and tried to avoid the consultant.

One patient highlighted that information cannot be absorbed if the timing of the interview is not appropriate, such as in the immediate post-operative period when a patient is still under the influence of an anaesthetic.

Eighteen patients were offered Clinical Nurse Specialist support, though they were offered this support at different stages in their disease journey, at the time of diagnosis, on discharge, on

commencement of treatment or sometimes long after that. Not all patient who were offered Clinical Nurse Specialist support utilized it and some were offered the support from more than one Clinical Nurse Specialist, e.g. from a breast care nurse and a Macmillan nurse, thus duplicating and perhaps diluting the support offered. Of those patients who did not utilize the support offered by the Clinical Nurse Specialist, five commented that although they didn't use it, it was reassuring to have a contact number for support.

The patients were asked about whether they had been given written information to reinforce what had been said verbally, eight patients reported having been given no literature initially, though two of those were given some literature later on during their disease journey, of the remaining six patients, two commented that they would have liked to receive some written information.

Table 3

<b><u>Descriptors used relating to the quality of written information given to patients</u></b>	
Helpful/Good	8
Okay	2
Adequate	1
Unhelpful	2

Thirteen patients reported having been given some information, Table 3 represents patient's views of the written information they received. The remaining patients (12 in total) were not sure if they had received written information or not. The source of the literature appeared to vary, ranging from local hospital publications to "Bacup" booklets and

leaflets published by specific groups such as the "Oesophagectomy Association". Three patients felt that the (cancer) site specific literature they were given was particularly helpful but that the literature relating to treatments such as chemotherapy and radiotherapy were "too broad" and directly applicable to them. One patient who found the content of the literature useful, unfortunately couldn't read it herself due to cataracts!

Patient No. 1 commented:

**"..... The least I know about things the better ..... I'm prepared to leave it to the people that know".**

(Patient No. 1)

The doctors must have adapted to his particular needs because he went on to report that the amount of information he had been given was "about right really".

Patient No. 4 when asked whether he wanted to know what was happening also reflected that:

**"..... In one sense yes, and another I didn't want to know. You know the less I hear about it the better you know what I mean? But I know I want to be educated a little bit about it but not right into the details".**

(Patient No. 4)

He went on to suggest:

**"They didn't chuck too much (information) on to use I don't think, no, no, sufficient, not overboard like".**

(Patient No. 4)

The first few patients were not asked about the lifestyle information that they were given as this was an issue which was introduced by a patient during an interview who commented on the need to know about changes to diet or exercise as a result of a cancer diagnosis. Five patients said that they had been given such information but did not elaborate regarding the format, two of those five said they would have liked more. One patient would have liked it earlier, four patients were given information verbally, one would have liked some written information to support the verbal. Two patients commented that they would have liked such information but didn't get it and utilized the library and the INTERNET as a resource.

When asked whether the doctors checked with the patient to ensure he/she had understood the information he/she had been given, five patients said that the doctor did check out their understanding, one was clear that the doctor had not, the remainder were unsure or did not comment about it. This reflects what was seen during the non-participant observations carried out in the first part of the study, in some instances particularly if a patients non verbal cues indicated confusion or distress the doctor did verify the patients understanding of what had been said. However, on other occasions, particularly when the patient was nodding his or her head as if to indicate understanding the doctor often failed to check out understanding. All of the patients were asked whether treatment options had been fully discussed. Eight patients could not remember, twenty five patients, had had their proposed management discussed with them, though fourteen patients felt that they had a limited choice and were being encouraged to consent to a particular treatment modality with minimal or no discussion of other treatments taking place.



A number of patients raised the issue of "control" during the interviews. This concept appears to be divided into two diverse categories, firstly those patients who wanted the Consultant to take "control" making treatment decisions etc.:

**"I just wanted them (the doctors) to tell me what was best for me and I just wanted it over and soon ....."**

(Patient No.19)

**"I'm prepared to leave it to the people that know".**

The patients in this category felt that having a cancer diagnosis was outside anything they had previously experienced and as such felt unable to make appropriate decisions regarding their management. Instead they preferred to leave the major decision making to the doctors whom they deemed to be experts in the cancer area and in whom they had placed their trust.

The other group of patients who raised the issue of control was in the context of them losing control of their process, with that control passing to the health care professionals in some instances simply being a "fait accompli" in response to proposed treatment:

**"Well you know you've got cancer and I want to cut it out for you" "..... allowed to go home".**

(Patient No. 14)

In clinical practice as well as throughout the interviews it is not uncommon for patients to reflect that the doctors tell them what treatment is best for them, with many doctors adopting a paternalistic

approach to the management of their patients. Interestingly, patients do not seem to be unhappy with such an approach and accept it as the natural "role" of the doctor.

One patient talked about "fighting the disease" in the context of the taking back control. The concept of a patient's body being "out of his or her control" when he/she has cancer is not uncommon, therefore the idea of "fighting the disease" gives the patient something to focus his/her energies on and allows them to take back some of the control they perceive they have lost.

The fact that they were visited by an entourage of doctors made two patients feel very intimidated.

Patients were asked whether they found the process of being given bad news/a cancer diagnosis stressful. Six patients commented on having to wait in busy hospital out patients departments as being a major stressor to them. Delays in gaining a diagnosis, result of tests and delays in gaining admissions to hospital for treatment were also cited as major stressors by a further four patients interviewed.

The non-verbal cues employed by the doctors were directly commented upon by 3 patients, comments related to the consultant being "comfortable with silence", using "touch" and from a negative perspective "avoiding eye contact".

Two patients made assumptions regarding the news being "ominous" due to the actions or inaction of health care professionals, one patient thought the news was "bad", "because of the long wait" another regarded "pulling curtains around the bed" as ominous.

Twelve patients discussed the professional attributes of the doctors and other health care professionals with whom they had come into contact and nine of them used descriptors such as “nice”, “kind”, “caring” and “patient” as attributes which they valued. During the non-participant observation stage of the study the doctors gave the impression to the observer that they did indeed “care”, this impression was based on the non-verbal cues witnessed. Interestingly three patients used the term “professional” in a negative manner, implying if doctors were professional then they didn’t have the “personal touch” and were “less caring”.

Truth telling and the need for doctors to be honest was raised by five patients.

Four patients were particularly concerned about what impact a cancer diagnosis would have on their significant others and actively sort to protect their loved ones for a variety of reasons, including feeling that they themselves already had enough problems and not wanting to cause them distress:

**“Well my wife – she’s got medical treatment, she’s a diabetic and I think she’s got enough to cope with without being involved in my troubles you know, so I just said I’ll get on with it”.**

(Patient No. 1)

**“I was so worried about how to tell my sister”.**

(Patient No. 21)

Five patients commented on lack of continuity relating to the information they were given and also lack of continuity in relation to the health care professionals involved in clinical practice. These sorts

of problems are described by both health care professionals and patients on a regular basis, one patient described how she saw a number of professionals, with which she was dissatisfied:

**“I didn’t think she (the Breast Care Nurse) was much good at all, she said she would be there for me ..... she wasn’t, you see the continuity wasn’t there, because I never saw Prof. L again, the next time I went I saw someone else”.**

(Patient No. 15)

Others stressed the need for continuity and one patient described how a Macmillan Clinical Nurse Specialist was in both a surgical and oncology clinical and he or she saw this as being reassuring:

**“Well I saw Dr B in the clinic and the same Macmillan Nurse was with him, we found that reassuring”.**

It is clear from these sort of responses that there are areas where continuity and communication between health care professionals is good and patients feel reassured by this. However, there are also patients who experience lack of continuity and therefore feel unsupported throughout their disease journey, which could in turn adversely affect their psychological well being. It is therefore necessary for health care professionals to review current practice in order to perhaps develop a protocol which would include guidance for giving bad news, discussing treatments and ensuring that support is offered to patients throughout their disease journey and so on.

Two patients commented how humour helped with the interview:

**“Even though we talked about a serious subject the little cancer doctor and I even managed to have a bit of a laugh”.**

(Patient No. 28)

**“It was lovely talking to them, I felt so much better and even went out laughing”.**

(Patient No.30)

Comments such as these reinforce that idea that humour can be therapeutic and can therefore help patients to cope with difficult situations.

A further two patients described the need to retain some hope.

**“He’s (the consultant) has managed to give us hope and everyone needs hope don’t they?”**

(Patient No.32)

The concept of hope is important for cancer patients but the reality of clinical practice is that many doctors find it difficult to strike a balance between telling the truth in its entirety and allowing the patient to retain some hope. For some patients lack of hope means that they have no reason to continue living.

Three patients identified coping mechanisms which they had employed to assist them in dealing with the news of their diagnosis, two used alcohol to help them “forget” and one suggested focusing on “the here and now” as helpful.

Feelings of anger, isolation, looking for someone to blame, fear, frustration, denial were articulated in some degree in twenty three interviews. Most of these emotions were transient and did not stay with the patients. However five patients retained some degree of anger relating to specific incidents such as the GP not making the diagnosis sooner or lack of in depth follow up. Two patients felt as though the hospital had “dumped” or “washed its hands of them” because active treatment could not be offered following palliative surgery:

**“I went for my check up, and again, at the check up, it was a case of lets have a look at your tummy, you know two minutes and you were out. There was absolutely no sense of anybody bothering”.**

(Patient No.17)

One patient was primarily concerned about the junior doctor who gave him/her the diagnosis because he was:

**“so young and inexperienced”**

Other criticisms of the process were identified by a number of patients including, doctors being ill prepared, for example, not having notes, not liking to travel to another hospital from the one at which they had been diagnosed for treatment (radiotherapy), doctors not understanding emotions such as anger when delays in receiving diagnosis occurred, communication seemed to breakdown when unplanned for variances occurred.

**“After the actual operation nobody really said a lot to K (the husband), he was really upset about it, he had to keep chasing the registrars and nurses (to gain information)”.**

(Patient No. 14)

A number of frustrations were also noted, ten patients described delays in waiting for diagnosis, waiting to see the doctor, waiting for test results and busy clinics as major stressors, at a time when they are already extremely anxious. It would therefore seem if investigations could be streamlined and patients be seen in less busy designated cancer clinics, patient satisfaction may improve.

There were also comments relating to valued and helpful practices, such as providing a multi-professional approach and arranging immediate follow up.

Those patients who had been offered it valued the accessibility of the Clinical Nurse Specialists for support, even where patients did not access it they were reassured to know it was available in case they needed it. Regarding the way in which they were given their diagnosis all patients wanted the doctor to tell them the truth although in a few patients this was tempered by the fact that they didn't want “too much information”.

#### Results of Focus Groups Interviews with Clinical Nurse Specialist and Service Managers/ Consultant Interviews

The service managers who were interviewed were aged between 36-56 years of age, 4 of them were female and 2 were male, 5 were nurses by professional training and one a radiographer, they had all been in senior management positions within the NHS for a number of

years, the least senior management experience being 3 years, the most being 20 years.

The Clinical Nurse Specialists were aged between 30-53 years of age. 9 were female and one was male. They had all worked as senior nurses i.e. Grade F or above at ward or community level before being appointed to Clinical Nurse Specialist posts, the most junior Clinical Nurse Specialist had been in post for approximately 2 years and the most experienced in that role had been in post for about 16 years.

The consultants were aged between 39-55 years of age. 5 males were interviewed and 1 female. The most junior had been in post for approximately 4 years and the most senior for approximately 21 years.

Both of the focus groups (see appendix iv for a sample transcript) were held in large comfortable airy meeting rooms on Trust premises and there was tea and coffee available for participants throughout the session. The interviews with the consultant took place in a variety of settings ranging from meeting rooms to consultants offices, the venue and times for the consultant interviews were decided by consultant preference and availability (see appendix v for a sample transcript).

The first part of the focus groups/interviews consisted of the researcher re-capping on those issues which the patients had highlighted as being important, the participants were given an opportunity to ask more questions about these issues if they so wished. With respect to the importance of communication skills, all healthcare professionals who participated in the interviews or the focus groups agreed that communication skills were vitally important but views were mixed as to whether some people were "just naturally good communicators" and others were not, or whether it was actually



a skill that could be taught. The general consensus was that you could teach skills which could improve the process but perhaps it would be difficult to make somebody who wasn't a natural communicator into an excellent one by just giving them skills.

Consultant No. 1 commented:-

**“Often the people who want to get better (at communication) are already those who are good, I think people who have difficulties and fit the cold end of the scale, I think some would be quite resistant to training but they may be willing to listen to guidelines of how to do it, the quite mechanistic aspects really but I don't think that they would get into introspection really”.**

The same consultant also had views about at what stage during training and post qualification communication skills ought to be addressed:-

**“I guess a good time to get people would be in the middle of their training when they are not yet fixed in their ways.... Perhaps communication could come into appraisals, I think this probably happens at the moment if there are problems but perhaps it should happen routinely in everybody's appraisals”.**

(Consultant No. 1)

Another Consultant highlighted that it was not just junior staff who required such training:-

**“I think every clinician approaches breaking bad news in a slightly different way, some may appear more caring than others but I do think there are a series of skills which can be taught and**

**indeed should be taught and should be compulsory. I know you have got breaking bad news on the post graduate medical training programme but that doesn't catch the senior medical staff like consultants and perhaps that should be a compulsory part of their continuing professional development".**

**(Consultant No. 5)**

The general consensus from the manager's focus group was that communication skills needed to be taught at an early stage in medical training and that it was something that should reinforced through the post graduate education programme within the Trust on a regular basis:

**"I do think communication skills can be taught and although you can't teach kindness I think there are techniques that can be taught to encourage people to be better communicators and therefore appear that they are at least interested in the patient, I think all healthcare professionals should have at least some in house training which covers communication skills such as breaking bad news"**

**(Manager No. 1)**

Manager No. 2 agreed with this sentiment but felt that communication skills training needed to be addressed in everybody's pre-registration training so that it was ingrained at an early stage.

The Clinical Nurse Specialists also echoed the view that some people were naturally better communicators than others but that they could be

taught skills to enhance their performance, when they were asked whether it was worth actually providing education relating to these skills one commented:-

**"I think you give people pointers of how to do things".**

(Respondent 2)

The following discussion then ensued around this topic:-

**Respondent 6:** "Yes but you can't change someone's basic personality, yes you can educate them but how much you can really change their basic makeup, I don't know".

**Interviewer:** "I am just curious to explore whether we should try to address this through education programme?".

**Respondent 1:** "Well if you believe education encourages people to reflect on their practice, then yes it is worth trying".

**Respondent 5:** "You know the Sheila Cassidy video? Well there are some good pointers in there".

This sort of discussion was not uncommon in the Clinical Nurse Specialist focus group and very often the specialist nurses started problem solving as part of the discussion process.

The concept that there was a continuum of caring, at one end of which were those professionals who were very "kind and caring" and at the other end those professionals who were deemed as "cold, clinical and professional" (in a derogatory sense of the word) was one that particularly interested the researcher. She was therefore keen to

explore this with the healthcare professionals. The idea that some patients may perceive that there is this sort of continuum also provoked a lot of interest amongst the healthcare professionals and stimulated much debate. This was amongst all of the groups who were interviewed although the Clinical Nurse Specialists and consultants had more to say regarding this phenomena than the service managers.

All of the healthcare professionals who were interviewed felt that it was important to appear to be kind and caring to patients but that this also needed to be supported with clinical skills and knowledge, the importance of caring was illustrated in a number of statements:-

**"I think it is important to highlight to medical students the importance of being kind and almost giving a bit of themselves to patients, this is particularly important with cancer patients because they are going through a myriad of emotions and are often particularly vulnerable".**

(Consultant No. 4)

**"I have always thought that the ever increasing grades required at 'A' level to define whether someone should be a doctor or not is completely wrong – most of the people that I know barely scraped in ordinary grades and are the best doctors around because they have the ability to communicate and the ability to give".**

(Consultant No. 3)

**"Attitudes will only change if you feel the emotion".**

(Consultant No. 2)

Two of the managers provided anecdotal evidence of consultants in their clinical areas who were excellent clinicians but were sometimes seen as cold by nursing staff and occasionally by patients. The managers working with these consultants were concerned about such reports and did feel that such individuals needed communication skills training, but were dubious as to how effective such training was likely to be, in view of the fact that the consultants were well established and were perhaps unlikely to change at this stage of their careers. Interestingly both of the managers felt that they would rather have somebody who was clinically expert and lacked in communication skills as apposed to somebody who had good communication skills but was clinically inept. They did however acknowledge that ideally they would like somebody with both attributes.

When asked about the “professional/cold clinical” end of this proposed caring continuum, the following comments were made:-

**“There is a myth that professionalism is about the white coat that you put on or the three piece suit that you wear. Professionalism in my book is where you put in whatever is necessary to do the job irrespective of the effort involved. The people who are seen as clinical and cold by and large cannot cope with bad news and have to put on some form of front. On the other hand, if you wish to deliver services that involve a great emotional distress to those concerned then you have to give some of yourself, you have to allow patients to see that you are human, and that sometimes has major disadvantages in that you go home and you can’t disassociate yourself. I think that, if as a professional,**

**you can't remember the names of patients with some of the most horrible cancer processes then you are exactly the clinical cold type. On the other hand going home and reliving every patient isn't healthy either – there has got to be a balance”.**

**(Consultant No. 3)**

**“The patient has got to feel you are a human being, but they have also got to feel that you are able to take a dispassionate view objectively about their condition”.**

**(Consultant No. 3)**

This latter comment was also echoed in another consultant interview:-

**“The hospice motto is competence with compassion. You have to be good at what you are doing, there is no point in prescribing the wrong chemotherapy and being awfully nice with it, you have to be able to prescribe the right chemotherapy but be understanding and empathetic with it at the same time. I always feel you are more likely to be blamed by a patient for not listening, not understanding or not attempting to understand than you are for getting the diagnosis wrong. People do accept the uncertainties of medicine where as they will not forgive our human failings as easily as they will forgive our professional failings”.**

**(Consultant No. 2)**

A number of specialist nurses, service managers and consultants all felt that the reason people appeared very professional and cold was very often to protect themselves, this was illustrated particularly well in some of the consultant interviews:-

**"With regards more established medical staff like consultants I think you get a range from those who do appear to be kind and caring and those who are cold. I think those who are cold and who patients think are uncaring or clinical are often those who are presenting some sort of professional front and they do so because they cannot cope with giving a bit of themselves and sharing a patients distress. I do not know if you can change those people but sometimes I suspect some of them don't even know that they are doing it".**

**(Consultant No. 4)**

Consultant No. 2 described the thought process that he thought consultants who were defined by others as being cold and uncaring were working though:-

**".... I don't know what to do when people break down in front of me therefore I must avoid it at all costs."**

The same consultant went onto suggest that:-

**"People can learn that in fact it doesn't feel that bad and I am sure that you can learn all these things... People need to be prepared to look for cues and respond to them, but it is also an attitude change that is required and professionals need to be aware that it is okay to care about patients and it is okay to get upset about what is happening to these people".**

**(Consultant No. 2)**

During the interview with Consultant 3 he also presented suggestions of how to address this problem:-

**"I teach the medical students that medicine is to some degree an act, it's a performance, I look through the notes prior to seeing a review patient in the clinic and I look for something that I can remember as being different or that identifies them as being an individual and I make reference to that..... It is an act, it is a performance but one that is necessary to win that patients confidence."**

Interestingly both the specialist nurse focus group and the managers focus group felt that there were less consultants who lacked communication skills or who were willing to engage emotionally with cancer patients than there used to be, this was illustrated by the direction of conversation in the managers group:-

**Manager 2: "Yes I think there are some clinicians who do innately care and that is evident when you see them with patients, others have developed skills which help them communicate and show kindness to patients but on the whole I think there are less doctors who are so clinical that patients don't think they care at all. I do not think having that sort of manner is acceptable anymore"**

**Manager 4: "Mmmm, I think those who do portray an unsympathetic manner are more likely to be challenged these days, if not by medical colleagues then by specialist nurses, ward nurses and patients and relatives themselves".**

**Manager 2: "I know I am certainly more happy to challenge consultants who behave inappropriately with patients than perhaps I was a few**



**years ago, I think that is about us being more aware of the need to be a patients advocate”.**

Specialist nurses also thought that they were in a position to challenge and influence consultants who did not communicate well with their patients and interestingly one of the consultants felt that the Clinical Nurse Specialists had an important role in feeding back to him the effectiveness of his consultations with patients:-

**“Getting feedback from specialist nurses at the end of consultation can be particularly useful for clinicians if they are willing to accept constructive criticism from nurses”.**

(Consultant No. 2)

It was clear from the patient interviews that patients within the same Trust were often receiving different types and quality of support through the initial phase of their cancer care and also that there was a distinct lack of continuity in terms of the care that they were being offered but also in terms of the advice and support, this issue was therefore explored with the Clinical Nurse Specialists, managers and consultants. Continuity was identified in the interviews and the focus groups as being an important issue:-

**“Continuity is fundamental. I think we are at risk of loosing that, unless we accept that it doesn’t matter who gives the message so long as the message is all the same and therefore the key to this is the multidisciplinary team that works things though, that speaks to each other and has the same message to give from whatever origin, be it nursing, radiography, technical or medical,**

**as long as it is the same message whereby what we have to have if full and frank discussions between all parties”.**

**(Consultant No. 3)**

**“Continuity is extremely important and I think specialist nurses can be the lynch pin to this, especially those that are not restricted to working either solely in the hospital or solely in the community. Those who can go where ever the patient does, provide a valuable source of information to other health professionals regarding what is happening to the patient. The specialist nurse also provides continuity to the patient, that is continuity of information but also, the same person to build a rapport with and to relate to. The specialist nurse can also cut down on red tape for the patient, for example, by liaising directly with the consultant to get an early clinic slot if problems occur and so on. So yes, continuity is important and I think when you have got a good specialist nurse who is a skilled communicator she is the key to this, otherwise care can tend to become compartmentalised and fragmented”.**

**(Consultant No. 4)**

As part of the action research, some care pathways were developed with a dual purpose, firstly to map the patient journey in diagrammatical form from the point that they enter the hospital system to the point at which they were discharged. This helped the healthcare professionals involved in the care of patients in the initial phase of cancer care to identify everything which a patient might routinely be expected to experience. It also provided healthcare professionals with the opportunity to meet together and discuss areas where care needed to be altered or services needed to be enhanced. One example of this was that when the care pathways had been

mapped it was decided that it would be appropriate to have a specialist nurse involved in the clinic at the time that the patient was given their diagnosis. The purpose of this was that the specialist nurse would be able to provide them with support both at that time and throughout their cancer journey. The second purpose in developing the pathways was to provide the patients with some documentation which should effectively outline the care which they could expect to get and which would also highlight when they would get it (see diagram 1, Chapter 10 "Innovations in Cancer Care").

All of the service managers felt that developing patient pathways was a good idea but that the pathways needed to be clinician owned if they were to be more than a bit of paper that was consigned to shelf in order to gather dust.

One clinician thought that care pathways might be helpful but that they would not automatically ensure equity of care and continuity for the individual patient:-

**"Care pathways are important ..... I think there are skills involved ..... I do not think a pathway on its own ensures things happen but it may make it more likely that it happens".**

(Consultant No. 2)

Other consultants commented on the value of care pathways:-

**"I think it is useful to map patients' journeys so that you can really identify what is happening to them, and where the service is provided by more than one consultant it can be useful to agree what is the most appropriate journey and develop a pathway around that. We have done this by negotiating with neighbouring**

**trusts with the help of the cancer services collaborative so that all the lung cancer patients presenting in our area regardless of the hospital should receive an equitable service”.**

**(Consultant No. 6)**

**“Pathways are excellent as part of our patient education, I think this idea of them coming and being exposed to a system over which they have absolutely no idea of what is going to be happening to them is wrong. I think it is very much like you go and buy a new car, you see in the back of the brochure what you will expect from the car dealer. You get a list of what you will get every time you have your car serviced. I am not suggesting that we treat patients the same as cars, but I think giving them the sort of information that allows them to see how their progress is measured and how it comes up against the yard sticks for measurement is entirely appropriate ..... We need to de-mystify medicine by all means”.**

**(Consultant No. 3)**

Not all of the consultants were familiar with patient pathways but interestingly those that had not had experience of the positives related to them were not adverse to them in principle:-

**“I don’t have much experience of patient pathways but I imagine it would be useful for people to have an outline of what to expect next”.**

**(Consultant No. 1)**

It became evident from the patient interviews that the Clinical Nurse Specialists had the ability to greatly enhance the initial phase of

cancer care. Where patients had access to a Clinical Nurse Specialist, even when they chose not to contact him/her, they valued the fact that they had been offered access. As already discussed in this chapter patients gave examples of where a Clinical Nurse Specialist enhanced care by explaining things or by being the patient advocate and by communicating with other healthcare professionals on the patients behalf. This information was fed back to the focus groups and at the consultant interviews. The service managers thought that the Clinical Nurse Specialists and nurse practitioners were useful, stating:-

**"I think Clinical Nurse Specialists and nurse practitioners are particularly useful, especially in cancer care as they can streamline the process for patients and provide expertise relating to their speciality. They can also provide continuity of care for these patients".**

(Manager No. 5)

**"They can provide expertise and continuity which they (the patients) wouldn't get from junior medical staff. I am not advocating that they simply replace junior doctors because they are much more versatile than that, offering a more holistic service to patients".**

(Manager No. 2)

One manager although acknowledging that Clinical Nurse Specialists may have special skills and special expertise made the following comment:-

**"They do have special skills and special expertise, but very often that is by virtue of the fact that they have worked in that**

**specialist area for a long period of time and what we must not forget is that they are a costly resource and that's okay if they are working in a speciality where you have got a lot of cancer patients coming through, but if you work in a speciality like mine, then it would not be cost effective to appoint a specialist nurse because we wouldn't have enough newly diagnosed cancer patients going through per week and it would be an expensive resource that would be getting wasted. In such instances I would much sooner prefer to use the money to provide education to the ward based nurses or the clinic nurses and try and give them extra skills and knowledge that would enhance the care of all patients and particularly those cancer patients who have come through the system".**

(Manager No. 3)

The consultants were all without exception supportive and effusive regarding the value of specialist nurses, some examples are cited below:-

**"In terms of continuity the specialist nurses are really useful in providing me with information which is patient focused, that is not always the same with the junior doctors.... They (specialist nurses) have a level of expertise and experience above and beyond (the generic nurse) and they have their own networks which can be accessed".**

(Consultant No. 1)

Consultant No. 1 also made the following statement regarding specialist nurses:-

**“Specialist nurses are mature clinicians and they provide a level of maturity to patient care ..... I suppose that helps them be objective and provide advocacy for patients”.**

Other consultants also saw the role of the specialist nurse as being key to providing good quality cancer care:-

**“I think specialist nurses are key to providing high quality care to cancer patients, they offer much more than ward nurses in terms of knowledge, skills and time. That is no disrespect to the ward nurses but they do not have the time and the opportunity to access the same level of training. The other thing is they compliment the service provided by other members of the multidisciplinary team.”**

(Consultant No. 3)

**“They are very good at co-ordinating ... sometimes they get things done, sometimes it is about information”.**

(Consultant No. 1)

**“My service could not function without the Clinical Nurse Specialist. She is the organiser, the link with the patients and often other clinicians, she is also a specialist in her own right who enhances the medical care and knowledge that I bring to the service.”**

(Consultant No. 6)

**“I am sure specialist nurses who are key players particularly in the clinic situations or wards where people have been given**

**information and there is a need for people to reflect and ask more questions directed towards more information or services.”**

**(Consultant No. 2)**

**“I see the role of the specialist nurse as being the lubricant between the various bits of the machinery and without it the machinery may well not work ..... they have the ability to discuss with all the different disciplines in a manner which is not threatening, is supportive but also carries with it its own expertise and professionalism. So I think that the ability for nurses to speak to patients is well described, the ability for nurses to speak to clinicians with whom they have built a rapport..... and for the nurse to have the confidence to articulate her opinion is so beneficial.”**

**(Consultant No. 4)**

When the consultants were asked whether the specialist nurses had something to offer, above and beyond that which could be offered by the generic ward nurses the response was positive:-

**“If you speak to a generic ward nurse about what the role of the Clinical Nurse Specialist is you will get a very different idea from what happens in reality. If you realise that these nurses (specialist nurses) often work independently, if you realise the depths of the discussions that take place and very few realise the extra work involved in training and education that these nurses have gone through to be able to function in the way that they currently do”.**

**(Consultant No. 3)**



**“Specialist nurses have a greater understanding and a greater knowledge.... they have the time, listening skills and can cross the boundaries to provide continuity of support and information.”**

(Consultant No. 2)

The Clinical Nurse Specialists all felt that they had something extra to offer above and beyond generic ward nurses and which complimented the skills of their medical colleagues. All of the Clinical Nurse Specialists felt that they provided a more holistic approach to patient care than either their medical colleagues or their ward or community based nursing counterparts. They also thought that advocacy was a key component of their role as well as their in-depth knowledge in their area of expertise:-

**“I think we offer more or less the same to patients, I mean we have an overview of their whole disease journey, we are their advocate – we also have core skills common to all of us such as communication skills. Then the bit that makes us different and probably specialist is the specific knowledge relating to the disease, so I know all about breast cancer where C knows all about colorectal cancer, G knows all about chemotherapy and so on”.**

(Clinical Nurse Specialist 3)

An interesting discussion around role boundaries as specialist nurses and also about the development of specialist nurses also took place within this focus group and this will be discussed in more detail in the Chapter relating to the evolving role of the Clinical Nurse Specialist in the multi-disciplinary team.

When the patients were interviewed it was somewhat surprising to note that many of them were not aware that a multidisciplinary team had actually discussed their case and a team decision had been made regarding the most appropriate management for them as an individual. Those patients who were aware of it seemed to have been made aware of it by the Clinical Nurse Specialists involved in their care and these patients seem to value a team approach to their care. This was somewhat surprising to the researcher because since 1995 and the publication of the Calman and Hine (1995) report, the development of multidisciplinary teams have been encouraged. All of the healthcare professionals were asked whether they thought it was useful to let patients know that a multidisciplinary team was involved in their care. The response to this was generally positive with the following reasons being articulated:-

**“I think it is really useful to let patients know that their treatment is discussed by a variety of professionals at a weekly meeting and that these people are experts in their own fields, all contributing to deciding the most appropriate and effective course of action for them.”**

(Consultant No. 6)

**“I think the MDTs (Multidisciplinary Team Meetings) are a really valuable forum for clinicians to challenge each other and to ensure that a patient is looked at from a holistic perspective – I think in the past what has happened is that clinicians have made a decision regarding what treatment they think is appropriate for that person and that is all that has been offered a patient. But where you have got a team that consists of specialist nurses, oncologists, radiographers, radiologists, surgeons – where in the past a surgeon may have thought surgery has been the only**

option, an oncologist might actually challenge that and say we could probably preserve this patients whatever bit of the body it may be and still give them as effective treatment by giving them radiotherapy. I haven't explained that very well but in terms of the outcome for the patient may be the same whether he or she has radiotherapy or surgery so I think it is healthy for these discussions to occur and also for patients to be advised that they will occur."

(Manager No. 5)

"I think patients feel reassured in clinic when I tell them that I am going to discuss their case at the next Multidisciplinary Team Meeting with the collection of experts in their field, and that at the end of that meeting we will be able to decide on what is the most appropriate and effective care for that patient. I have had very few patients say that they are not happy with this sort of system and I think they actually feel reassured of the fact that the decision is being made by a group of specialists and not just one person"

(Consultant No. 4)

Although the specialist nurses all felt that multidisciplinary team discussions were very important in planning an individual patients care, they did comment that sometimes they had to explain a delay in commencing treatment to patients on the grounds that their case needed to be discussed by a wider group of specialists before treatment could be commenced. They did also say that most patients actually accepted this and felt comfortable with this once it was

explained, but sometimes they were not explained about this delay at the outset of their journey.

This pressure reportedly experienced by some patients was also raised in the managers focus group:-

**“It can be difficult when patients want to start treatment straight away and they are not allowed to because their case has to go back to the multidisciplinary team for further discussion and I think this can cause a lot of frustration, although I have to say, I have never had any complaints about it but I think the specialist nurses sometimes kind of deal with that sort of frustration when it occurs. I suppose the reason I am raising it here is that I have recently been on the other end of it as a relative of somebody who had to wait until their loved one was being discussed at a multidisciplinary team, and I know I work in the health service and I know the reason for it and I know how important it is to get everybody’s perspective, but actually when you are on the receiving end of that and you want to know what people are going to do for the person you care about it can be particularly frustrating and distressing as well, so I suppose that is the time when the Clinical Nurse Specialist can be particularly effective in providing additional support to patients”.**

(Manager No. 2)

From a professional perspective the practicalities of who chaired the multidisciplinary team was also discussed with the general consensus from all groups being that it did not have to be a surgeon or the consultant in charge of the patient who chaired the meeting – anybody who was a skilled chair could do it, that could be any professional from

any discipline but that it should be the consultant in charge of the care who actually reported on the individual cases prior to the treatment decisions being made. One consultant differed slightly in his perspective:-

**“We also need someone to be putting the agenda down as the patient might see it, we need to be seeing the patient at the centre of that discussion rather than the pathology of the disease. What sometimes happens is that a decision is made that up to Grade 3 we need to go for this treatment when what we should actually be doing is asking what is Mrs. so and so going through at the moment and what is she going to be able to cope with in terms of the treatment options that we can offer and I think it requires the person who can tune into that particular patient who will not be the same person for each patient”.**

(Consultant No. 2)

A similar point was also made by another consultant:-

**“Yes I think multidisciplinary working is key to providing excellent care for patients, it is the most effective way of ensuring that a holistic approach is taken. For example specialist nurses can raise issues which may affect the treatment decision, they might be more aware that a patient is needle-phobic or has a dependent relative and therefore will not attend for the treatment on a daily basis”.**

(Consultant No. 3)

By the time the professional focus groups/interviews were undertaken there appeared to have been a change in culture with more people feeling they were equal partners in multidisciplinary teams.

The researcher witnessed a subtle shift in power over the period of time that the study was carried initially at the beginning of the study the power based seemed very much with senior managers and doctors with nurses having little authority and autonomy however this does seem to be changing slowly, this was evidenced by a statement from one of the consultant interviews:-

**“It has always been seen hither to whether we say it openly or otherwise the nurses role is subsidiary to medicine. May be it is time to re-evaluate all of those things. Maybe we should stop and think, it is not a particularly fruitful argument of whether one is better than the other or is subservient, I think one ought to be saying how can we get them to better compliment each other rather than anything else”.**

(Consultant No. 3)

The Clinical Nurse Specialists also identified a subtle change in the way that they worked with other health care professionals and particularly medical staff:-

**“Certainly within the team in which I work in I feel I can discuss patients freely and that my opinion is listened to and valued. In fact I think the nurse is in a unique position being able to present a holistic perspective, you know background about family dynamics the patients fears and anxieties and so on. It is often the nurses who have this overview and within that there may be some important information which could influence the most**

appropriate decision for the patient. For example a needle phobic patient may require special support if she were to require chemotherapy as first line treatment so I do feel we have an important role to play in supporting patients and on some occasions being their advocate”.

(Clinical Nurse Specialist No. 1)

There was lots of consensus around this statement and many of the Clinical Nurse Specialists felt that it was their communication skills and the time that they had available to spend with the patient that would encourage a patient to disclose such fears, they felt that without their input consultants may be unaware of such issues until a patient actually presented at the Chemotherapy Day Unit and refused treatment, or didn't turn up for treatment at all.

All of the Clinical Nurse Specialists who were interviewed in the focus group felt that they were part of the multidisciplinary team and had an equal although different role to play from their medical colleagues. The researcher asked the Clinical Nurse Specialists whether they felt that they brought added value to the multidisciplinary team, and everyone present responded in a positive manner. The Clinical Nurse Specialists also raised the fact that they thought education and empowerment of other nurses and junior medical staff was an important component of their roles as was the ability to lead and implement change which would ultimately benefit patient care.

The fact that more than one multidisciplinary team meeting occurs was also highlighted and it was pointed out that another type of multidisciplinary meeting exists which is one based on service

developments which aims to improve/enhance patient care. The general consensus of everybody interviewed was that it didn't really matter who chaired these meetings as long as it was somebody who had chairing skills and an in-depth knowledge of that particular service. Examples were given to the focus groups and consultants relating to the work that had been carried out to date using Belbins work (which is discussed in more detail in Chapter 10 "Innovations in Cancer Care") and the idea that this might be a useful tool for other multidisciplinary teams to employ was embraced unanimously by all staff groups with which this issue was discussed.

Because this was an action research project, and involved implementing change in a number of areas, the researcher thought that the focus groups and consultant interviews were an ideal opportunity to explore with them their attitudes to change. The following is an extract from the focus group with the service managers:-

**Manager 3: "I think most people are receptive to change, in this organisation at any rate. I think partly the reason is because from an organisational perspective we try to get them (the staff) to have ownership of the change. By and large people understand why we are trying to implement change and are happy to go along with it".**

**Manager 1: "I think we are fortunate here because the Trust see modernisation of services as a high priority and that is demonstrated by the fact that we have a modernisation team, providing a number of in-house courses on modernisation and change issues and also by the fact that the Chief Executive has recently been seconded to a modernisation agency – I just think**



**that sends out a message that change is good and is seen as important by senior people within the organisation”.**

**Manager 6: “Whilst I agree with you on a personal level, there are people in this organisation who do not like change even when you involve them at every opportunity and they are at every level of the organisation”.**

**Manager 1: “But you get people like that everywhere and I am not sure you can do anything about them – it is often just a case of hoping they are just laggards and accept the change once they have witnessed the benefits of it”.**

The discussion with the Service Managers went on to focus on how some people were constantly having to deal with one change after another and sometimes some of these changes were perceived as change for change sake and in such instances the general consensus was that it was not surprising that people got quite cynical and jaded. The managers then tried to address how such cynicism could be avoided:-

**Manager 2: “That is why it is so important for people to understand why a change is required, particularly if it is a change which has been externally imposed”.**

The fact that not all change is better than existing practice was discussed at length and the group decided that if the change was detrimental to patient care then clearly it should not be implemented, that it was the manager’s responsibility to feed that back to whoever wanted the change in the first place and that applied to whether the change was imposed by a service manager, a director, the chief

executive or the Department of Health. One manager also commented on the fact that if change is to be implemented successfully then people needed to be equipped with certain skills:-

Manager 1: **“If we want to change services dramatically or to use the current buzz word “to modernise services” then we need to have more people with the skills out there working in clinical practice. By that I mean skills such as process mapping, redesign, understanding of plan, do, study, act cycles and project management. These are all crucial if we are to continue to change and perhaps most importantly to facilitate staff to sustain change in their own areas”.**

All of the consultants accepted that change was an inevitable part of the NHS today but they had mixed views about who should lead change and how to implement it:-

**“I think we need to devise a hypothesis and test it and put into practice if successful”.**

(Consultant No. 4)

The same consultant had concerns about a number of committees that were formed to generate a change:-

**“We have spawned immense numbers of cancer committees none of whom have any mandate that I can see to impose cancer care, none of whom have any remit other than to keep themselves going”.**

(Consultant No. 3)

The same consultant did however suggest some practical ways of approaching the implementation of change within clinical areas:-

**“By demonstrating the benefits other people come along with you, leadership is the key to this. If you expect instant change you are going to have a very disappointing career. If however you expect things to evolve and you are prepared to take the time and effort you will be rewarded”.**

(Consultant No. 3)

Another consultant felt it was useful to have somebody else driving the change allowing the consultant to focus on clinical access issues.

It appears from the results of this study that health care professionals acknowledge and are concerned that cancer patients often receive variable standards of care. Indeed, the thirty three patients interviewed reported receiving very different standards of care, some feeling completely unsupported at one end of the continuum and others satisfied with all aspects of their initial phase of cancer care. Clearly there are a number of areas which need to be explored if patients are to receive an improved service in the initial stage of cancer care. These include exploring the ethics of cancer care, the psychology of communication, multidisciplinary team working, communicating with cancer patients and the concept of caring. These issues need to be considered in order to devise appropriate strategies aimed at improving the experience of patients in the initial phase of cancer care. Implementing change in the NHS and methodologies for effective change management also need to be considered if any recommendations are to be implemented and any changes to be sustained and integrated into mainstream practice. These concepts will be explored in more detail in the following chapters.

## CHAPTER 5

### Problems of Communication in Cancer Care

Cancer is regarded by many individuals as an especially threatening disease and a patient being told that he or she has got cancer may experience a number of emotions including fear, anxiety, despair, anger and disbelief. Similar emotions may also be experienced by relatives and friends of cancer patients. Health care professionals and particularly the doctors who are responsible for giving a diagnosis to patients need to have an understanding of the way in which individuals communicate with each other in order to be able to give information appropriately and to respond to the patient in a sensitive manner. However, this is not as simple as it appears because many doctors themselves feel uncomfortable telling a patient that he or she has a diagnosis of cancer. Such discomfort could be due to a variety of reasons: it could be that doctors (who enter the profession to 'cure' people) feel they have failed if they cannot offer a cure for a particular cancer. They may be frightened of the response they will receive from the patient and his or her relatives and be worried in case they cannot deal with the reactions of the patient and relatives. Doctors could also feel uncomfortable giving bad news to a patient because they have not had adequate training and practice. A Doctor's previous experience of the way people have responded to the news of a cancer diagnosis will affect the way he/she deals with subsequent patients and where a doctor has had personal experience of cancer he or she will be influenced by that.

To explore the issues pertinent to communicating with cancer patients and the problems encountered one needs to understand how individuals interact and communicate with each other. This chapter

has been divided into a description of how individuals react during times of stress such as when a patient is given a diagnosis of cancer.

### Communication in Action

When two or more people are engaged in interaction/communication each one emits a variety of visual and audible signs, for example – making eye contact, head nods and audible signals such as 'Mms', some of these signals are intentional others are not, and these signals have the ability to affect other individuals who are present. This statement applies where the interaction is primarily verbal as in conversation or where it is mainly non-verbal as when people are dancing, playing or working together at a manual task.

Psychologists suggest that the main components of communication in humans are: -

1. Non verbal (tactile and visual).
2. Verbal (speech). (Verbal communication will be focused upon primarily in the chapter relating to "Communication with Cancer Patients").

Non-verbal communication is the most basic type of social behaviour. Bodily contact can occur in a wide variety of ways and can differ from culture to culture. The body can be touched in many different ways, but the main ways of touching another person can be divided into the following areas: -

- Greeting and farewells may involve shaking of hands, kissing or more elaborate processes of striking or stroking based on culture. The way in which a doctor greets a patient and relatives is particularly important because in many instances this is the first impression they get of the doctor. If he or she does not shake hands and introduce him/herself patients are left wondering whom they are talking to and questioning his or her credibility particularly if the doctor goes on to give them “bad news” such as a diagnosis of cancer, politeness such as asking a patient how he or she feels also takes on extra significance because it reaffirms the doctor’s interest in the patient as an individual. It also allows the doctor to assess whether the patient is ready to be given further information, for example if a patient says they are distressed or in pain, clearly those issues take priority and need addressing before the rest of the consultation occurs.
- Guiding the movements of others may entail leading by the hand, steering by the elbow, or be combined with aggression as in pushing or pulling. Touch is used to guide skilled motor responses and bodily contact with another and is important in teaching specific motor skills, (Frank 1957).
- Touch can also be reassuring and whilst in British culture many would deem it inappropriate to touch someone whom they did not know well in some circumstances such as when a patient becomes distressed touch from the doctor can be interpreted as a reassuring and appropriate gesture. Certainly touch between doctor and patient was witnessed during the non-participant observation and in each instance the doctor must have assessed the patient correctly because no patient objected or drew away from such a gesture.

- Holding can be used for communication and companionship, as when two people remain in bodily contact during a whole period of interaction, by holding hands, keeping a hand on a knee and so on. The context in which non-verbal communication is used is important, for example somebody keeping a hand on another's knee may seem a very intimate form of touch, but in the right context a pat on the knee of a distressed patient by a doctor can be reassuring and not out of context at all. The same applies to hand holding for example in the non-participant observation number five – the patient started to sob and in response the consultant got down off the examination couch where he was seated and crouched next to the patient holding her hand, the remainder of the interview between the consultant and the patient was actually witnessed with the consultant staying in a crouched position and holding the patients hand, he was also noted to squeeze her hand gently throughout the interview. The patient appeared to be reassured by this fairly intimate form of touch and in those circumstances it did not seem at all inappropriate to the observer. During the non-participant observation number one hand holding appeared to convey something different, for example the doctor suggested that the appropriate treatment for this patient needed to be carried out at the Regional Cancer Centre, the patient frowned at the suggestion, looked at her daughter and held her daughters hand, it appeared to the observer that this holding of her daughters hand made her feel stronger and enables her to ask questions of the doctor. During this observation other forms of contact between mother and daughter were also witnessed such as the daughter cuddling her mother in an affectionate yet protective manner. When the daughter stopped cuddling her mother, she removed her arm from around her mother and went back to holding her hand. This hand holding only ceased when the patient became distressed and started wringing her hands. The patient also started to cry and again

her daughter reverted to cuddling her. It was clear to the observer that touch was an extremely important supportive action in this observation and obviously both mother and daughter felt comfortable with it and it was therefore appropriate for them. However, in situations where people do not readily show their feelings or exhibit them in a non-verbal manner, to use touch in such a way could be interpreted as invasive and inappropriate. It has appropriately suggested that bodily contact is a language in itself, although obviously not as elaborate as verbal languages (Frank 1957). Different degrees of pressure and different points of contact can also signal emotional states, such as fear for example, the anxious patient who is frightened of what he or she is to be told may exhibit this by holding tightly the hand of a relative or occasionally a health care professional. When two people are in contact there is a two-way system of interaction, because the recipient of the contact can choose to respond or withdraw in order to keep the interaction as he or she wants it. It is important for doctors and nurses to respond to such types of contact appropriately if they are to maintain a meaningful dialogue with the patient.

- Stroking, caressing or holding can occur in a paternal/maternal manner and can often be witnessed between patients and their families and sometimes between patients and health care professionals. Stroking can often be interpreted by the recipient as a reassuring gesture.
- Hitting another person as in an act of aggression is usually done in a way defined by culture, for example, punching a person in the jaw. This sort of communication is seldom seen in the context of a cancer clinic, but occasionally patients and relatives display this sort of behaviour toward inanimate objects as a way of venting anger/frustration, and it is important for health care professionals to be



able to recognise that when such behaviour occurs it is not usually aimed at them but it is the individuals way of expressing strong emotions such as anger and frustration. To prevent such behaviour may lead to the individual internalising their emotions and subsequently exhibit more psychological distress than they may otherwise have done. The extent to which bodily contact occurs between people depends very much on their age and the relationship between them. Contact can be fairly extensive between husband and wives but otherwise there is visually a taboo in our society on bodily contact apart from greetings and farewells. There are however great cultural variations in the extent of bodily contact, which occurs between individuals and indeed the forms in which that contact occurs. The common element running through most kinds of bodily contact is an increased intensity of involvement with the other person, often in the cancer clinic setting of affiliative. However, increasingly health care professionals are being expected to display empathy in a variety of ways, including non-verbally. The need to 'read' the situation and interpret the patients non-verbal ones in order to respond in an appropriate manner is crucial, for example during observations number five a distressed patient appeared comforted by a consultant holding her hand, however, in a non-participant observation two, both the patient and her relatives exhibited anger and frustration, clearly in this instance the doctor attempting to hold in order to reassure her would have been inappropriate and probably would have provoked further anger.

Proximity or personal space is another component of non-verbal communication. Whatever two people engage in a social encounter they must choose some degree of physical proximity. It has been suggested that proximity can be classified as one of four degrees: -

- Intimate.
- Casual/personal.
- Social/consultative.
- Public.

Each of these differs from the others in that different sets of sense predominate. At the casual/personal (about 5 feet) vision and hearing are used but in the intimate range, smell, touch and taste play a part and vision becomes less useful, (Hall, 1963). What determines how close the person will come to another? Factors of sight, sound, smell etc. are all clearly important, greater proximity will be sought by a person whose senses are in some ways impaired i.e. a person who is deaf or short-sighted. Proximity is also influenced by cultural factors such as whether smell is sought or avoided. In the cancer clinic setting other factors may influence how close a patient may get to the doctor, for example, in the non-participant observation number two, two of the relatives positioned themselves standing, leaning against the walls close to the door by which they had entered the consultation room, a third relative seated herself next to her mother on the chair closest to that door, to the observer it was almost as though they either didn't want to hear what the doctor was going to say to them and their mother and wanted to get out as quickly as possible, thus escaping from the situation or they didn't think the doctor would be able to offer them anything and therefore they wanted to remove themselves from the situation as soon as possible.

Proximity can be considered in conjunction with another element – orientation. When there are more than two people a person tends to position him or herself opposite to those to whom he or she will talk to most. During the non-participant observations carried out as part of this study the observer witnessed the consultants position themselves

opposite the patient in every instance (a total of 18 observations) regardless of where the interaction between doctor and patient occurred, this can also denote a position of authority as the doctor orientates him or herself in order to face primarily the patient but also as many other people such as relatives, as possible (Sommer, 1961). In many instances during the non-participant observations the observer noted that the doctor sat on the examination couch opposite the patient and his or her relatives, this presents another issue relating to who takes control of an interaction and is seen in authority. The examination couch was slightly higher than the chairs which meant that the doctor was looking down on the patient and the relatives, which in turn re-inforces the idea that they are the person in authority and that the patient and his or her relatives are somehow sub-servient. It must be noted that the doctors did not appear to choose to do this consciously and did so more because that is where seating availability was left in the room once they entered and the alternative would be to crouch down for the whole of the conversation or stand over the patient which would be even worse. In general, relationships between people are reflected in the way in which they are positioned and orientated.

Posture is another important component of non-verbal communication it can be classified into several main areas including standing, sitting, lying facedown or on the back, kneeling and so on. Each of these can be further sub-divided according to the manner in which it is done, for example how relaxed different parts of the body are, whether arms or legs are crossed and so on. The posture a person will adopt is partly a matter of cultural conventions governing a given situation. However, posture can reflect status or the dominant roles of health care professionals such as doctors and nurses, or rather the way a person perceives his or her status in a given situation and in relation to the

others present at that time. Posture is also a vital clue in reflecting a person's emotional state. During the non-participant observations carried out as part of this study the observer noticed the importance of posture during many interactions for example, during non-participant observation number six, the doctor discusses the different stages of bowel cancer with patient and continues to suggest:

**“It could be that leaving you alone would be the best and even if we didn't do anything you would never develop further problems.....The simple answer is that we really do not know, but for your stage there is a big trial looking at chemotherapy, that is to say do people do better with chemotherapy or not, that is what we are trying to find out in the trials”.**

(Non-participant observation 6)

In response the patient nods but starts to look somewhat perplexed the patient responds:

**“But I understood from Mr. S. that it was cut out and that there was no tumour left”.**

(Non-participant observation 6)

As the patient says this he moves his hands from a very relaxed position on his knees and holds them tightly across his chest as if to protect himself from what is being said. This change in posture is a clear indication of the patient's vulnerable position and it is necessary for a doctor to identify this and respond accordingly. Another example of when a change in posture indicates patient's distress was noted during non-participant observation number three, when the doctor stated:

**“Well, basically you have had a growth in your back-passage and that is what Mr. S. found when he did the surgery. We would like to treat you with some extra treatment up at the Cancer Centre”.**

(Non-participant observation 3)

In response the patient became very agitated, fidgeted in the chair and then began to cry, the doctor did respond to this behaviour by standing up and putting her arm around the patient. Such fidgeting, shuffling and changing position in a seat and looking at the floor was witnessed in a number of the non-participant observations and in all of the instances where it was witnessed the observer attributed it to the patient not wanting to hear what the doctor had to say to them or alternatively they simply couldn't deal with the information that was being given to them at that particular moment in time. Posture can indicate many things to the observer it can reinforce what the patient is actually saying verbally or alternatively it can be in opposition to the verbal information for example when a patient tells the doctor that they had suspected it was cancer and "you have to die of something anyway" but their posture does not reflect their stoical stance and they are slumped in the chair or bent over with their head in their hands. It is therefore important for health care professionals to be aware that these dichotomies exist and to respond accordingly. Often it is the non-verbal cues that may be the real indicator of how a person is feeling because they have thought about what they are going to say before they actually speak, the same thought does not always go into an individuals use of non-verbal communication particularly during times of stress. Posture can also be regarded as an aspect of personality since individuals have characteristic styles of expressive

movement. When a health care professional knows a patient well a change in their characteristic style of movement may indicate problems such as depression, but in most instances the doctor/patient relationship is relatively new during the initial phase of cancer care. Style is deliberately chosen and reflects a person's self image and shows the cultural models to which he or she aspires. The way in which individuals stand, sit or move about is partly a matter of cultural conventions and also reflects status of those concerned (Burns, 1964).

One of the ways in which one individual can impinge on another is his or her physical appearance; in our culture clothes hide most of the body. So clothes themselves become a major element in appearance. They are entirely a matter of a personal choice and can be regarded as a piece of social behaviour. However, clothes are only meaningful within a cultural setting; they can be in fashion, associated with a particular social group, such as students, country gentlemen, farmer's etc. To this extent clothing can resemble uniform showing the social group and rank of the wearer. Changes in the condition of an individual's clothing may also be indicative of more deep-seated problems such as clinical depression, something which is exhibited by a number of newly diagnosed cancer patients, the problem for the doctor is trying to assess whether a patient is wearing his usual clothing, cared for in a way that is normal to him or her or whether he or she is behaving differently. This assessment is difficult to make when the doctor has little previous knowledge of the individual patient, for example, an unkempt patient may have always been like that or alternatively he or she maybe "letting themselves go" due to depression. The real skill for the doctor is being able to elicit that information from the patient without causing offence and subsequently damaging their professional relationship.

An individual's face is extremely important with regards non-verbal communication as it is a person's face that somebody looks at during most interactions. Some aspects of the face are not under voluntary control at all, though they maybe the basis of another's reaction e.g. the distance between somebody's eyes, shape and length of their nose. However there are aspects of the face, which are almost completely under voluntary control and can therefore be regarded as elements of social behaviour.

Facial and gestural movements are vital components of non-verbal communication. One of the most expressive areas of the body is the face; the face is the area which is most closely observed during social interactions, and it signals inter-personal attitudes and comments on utterances, such as puzzlement or surprise. The key messages relating to an individuals state of mind can be reflected in the face, for example, happiness, surprise, sadness, fear, anger, disgust, contempt and interest. It has been suggested that responses to facial expressions can be divided into three dimensions: 1) Pleasantness 2) Activation 3) Control (Osgood, 1966). Facial expression plays several roles in human social interaction it shows the emotional state of an interactor although he or she may actively try to conceal this. It also provides continuous feedback on whether an individual understands, is surprised or agrees with what is being said. Facial expression is the main non-verbal cue to support speech. Facial expression can indicate attitudes to others and it can communicate modifier or comment on what is said or done at any particular time.

Next to the face the hands are the most visible and expressive part of the body, although they are attended to much less than the face is. Hand movements play a different role from facial expression during social interactions. Their principal function is as illustrators,

accompanying and reinforcing speech when verbal skills are inadequate. Hand gestures can replace speech in such instances such as with sign language. Unfortunately in reality cancer clinics and the health service in general are often ill equipped to deal with individuals who have special communication needs, it is actually much easier to get an interpreter for somebody speaking in a foreign language than to get a sign language interpreter. This can lead to all sorts of confusion when a doctor is trying to give specific information about a diagnosis or treatment to someone who cannot hear or cannot speak in the conventional manner and apart from raising practical problems it also presents a number of ethical dilemmas. If an independent interpreter is not available to interpret for the patient and consultant and there are relatives available how does the consultant know that the information being given to the patient is actually as he or she has stated it, how does the consultant know the patient has understood it and indeed is it right that the patient gets the information from a relative when it is his or her information and he or she may not want that relative to know of the diagnosis. Other problems occur for this group of patients later on in the initial phase of cancer care particularly if they need counselling as this can not be achieved without having an independent sign language interpreter available, in such instances the counsellor may feel uncomfortable and may have difficulty in establishing a relationship with the patient because they have to go through a third person. Hand movements can show emotional states as well, although this is usually unintentional. Many hand movements are related to self-grooming, scratching etc. These movements are usually restrained during most social encounters, and certainly were not witnessed much during the non-participant observations.



The position and the movements of an individual's head are highly visible during any social interaction; however the amount of information these actions convey is rather limited. The head can be raised or lowered and can be turned into a frontal or sideways position, it may be nodded or shaken which indicates different things in different cultures and the meanings of these actions must be learnt by those wishing to interpret them. Head nods play a distinctive and important part in verbal interaction as the head nod gives another person permission to continue speaking and can act as a reinforcer. Head shaking has the reverse effect. It has been observed that individuals seeking approval were observed to nod more than those who avoided approval do, (Rosenfeld, 1966). However, it must be noted that if a patient nods frequently this does not necessarily mean they have understood everything, which has been said, and it is therefore necessary for health care professionals to check out a patient verbal understanding of what they have been told. During the non-participant observations much head nodding by the patients was noted, even when they clearly had not understood what the doctor had said, perhaps this supports Rosenfelds work and suggests that such a response was indicative of their need for approval from the doctor.

Eye contact can be an important component of non-verbal communication, indeed many social interactions are often commenced by a period of eye contact, which seems to signal that each individual is ready to interact with the other, once an interaction has commenced each individual looks at the other in the region of the eyes, on an intermittent basis in the form of glances of varying length, usually between 1-10 seconds. The proportion of time each person spends making eye contact with another may vary from 0-100% however, more typically it lies between 25% and 75% of time during any given interaction (Goffman, 19630). Usually the person listening gives

longer glances than the person who is talking does. Eye contact can be used combined with different facial expressions to establish dominance, disapproval, feedback, approval and so on. People have been noted to make more eye contact when what they see is rewarding. However too much eye contact can create anxiety in the recipient of that contact. In the cancer arena evasion of eye contact is not uncommon when patients or relatives don't want to hear what they are being told i.e. the diagnosis is cancer, or when the doctor is having problems relating the information to the patient perhaps due to the doctor's inexperience or lack of preparation. In clinical practice, during those consultations which were observed the doctors made more eye contact than the patients even when they were the ones who were talking, to the observer it seemed to convey two things, firstly their interest in the individual and the secondly the fact that they were watching closely in order to identify and respond to the patients reactions to a cancer diagnosis.

There are non-verbal aspects to speech, that is to say much of the communication involved in speech goes on at a non-verbal level, how it is said rather than what is actually said. Laugh, pitch, silences, length of pauses, tone are all non-verbal aspects of speech and can sometimes indicate embarrassment, lengthy pauses and silences maybe due to people not knowing what to say or how to say it. The timing of speech is also to some extent a function of personality; some people talk more than others do and this correlates with extrovert tendencies. Clearly the doctors spoke more than the patients during the consultation which were observed, however, that was primarily due to the fact that they wanted to give information to the patient rather than it being a reflection of extrovert tendencies. Others speak little and give long pauses before replying. Most individuals vary their speech patterns, such as timing, depending upon the different

situations and the different people with whom they are required to interact. Tone, pitch and loudness may all be indicators of the individuals' emotional state, for example, people tend to speak in a higher pitch when they become distressed. Though most people vary greatly in their ability to express different emotions by the quality of their speech.

When an individual speaks to another he or she emits non-verbal signals as well. In general, the non-verbal elements of communication should be supportive of the verbal. The verbal elements of speech are much easier to control rather than the non-verbal ones although practise can make people fairly adept in controlling the non-verbal cues they exhibit (Argyle, 1965).

In Britain accents can reflect social class as well as the region the person originates from and an accent has the potential to reflect educational or occupational background as well. However, more recently some of these class, educational and occupational distinctions have become more blurred as regional accents have become more acceptable and in some cases even 'trendy'. It is important for health care professionals not to make judgements on a person's class or education and therefore potential ability to understand what the doctor or nurse saying based on accent, as this is clearly an unreliable measure of intellect.

The social behaviour that humans exhibit resembles closely that of the non-human primates in a number of ways. However, the main difference is that humans are able to communicate by means of language. This verbal behaviour is known as speech. Speech can be used to impart information, pose questions, which can be closed or open, ended, establish relationships, sustain and maintain

relationships as well as being used to reward or punish individuals. The conversation may be interesting to the recipient of that information or they may be uninteresting, embarrassing, and displeasing, influencing whether he or she wants to respond. During specific types of interaction (such as between doctor and patient) particular kinds of language may be important.

### The Psychology of Communication with Cancer Patients

Trust is an essential component in any doctor/patient relationship. Adults in general know more about themselves than anyone else does and they tend to ensure that they remain in control of personal information deciding what others may or may not be allowed to know about them and what has to remain their secret. When a patient consults a doctor and following investigations is told that he or she has a serious illness that level of control is lost. The information is about the patient but the doctor is the person in control (Stedeford, 1994). Not only does receiving bad news create fear and anxiety it is also the beginning of a range of feelings and situations beyond their control which will ultimately change the patient's life.

The experience of confronting the idea that one may have a terminal illness, which is often an integral part of being diagnosed with cancer, can be far-reaching and profound for the patient. Cancer is still regarded by the majority of the public as an especially threatening disease and one, which remains a taboo subject (Calman and Hine, 1995). Fear of the unknown is debilitating and affects each individual differently. Fear can be directly responsible for producing a variety of symptoms such as increased pulse rate, breathing difficulties, tremors and perspiration. Some patients experience headaches, feel nauseous, dizzy and loose concentration. When these reactions

occur particularly in the presence of others, patients often feel ashamed and they think they maybe perceived as being weak (Rowe, 1988). Such patients often have a tendency to apologise for everything they do and say.

Patients need to be aware that the doctor understands their condition and there is an expectation that the doctor will take the best possible care of him/her. This assumption includes the idea that the care will extend to the patient's psychological well being as well as their physical well being. There is an expectation that the doctor will tell the truth and will also take care for the whole person. The dilemma is that until the patient knows what the information is and feels its impact on him or herself, he or she is unable to anticipate what he or she would have wanted to be told or not. Occasionally there are individuals who make it clear before hand how they think they will want information to be given to them should they become seriously ill, but mostly the doctor is not so lucky and has to make some value judgement about how to impart such information. There are some patients who wish to know the diagnosis and all its implications and there are others who maybe in denial, some do not ask questions and wish to leave their clinical management in the hands of the individual doctor, because he or she knows best.

When a diagnosis of malignant cancer is made the patient is likely to be distressed and frightened. However, the decision about how best to impart that news and at what rate is usually left to the individual physician. As has already been discussed in an earlier chapter it is rarely justified to withhold information from a patient on the grounds that he or she may be spared anxiety. In general, knowledge instead of uncertainty about an individual's condition may actually achieve a better result. All of the patients interviewed stated they wanted to

know diagnosis although not everyone wanted a in depth discussion relating to disease progression, prognosis and treatment. As a general rule it is appropriate to let the patient control the flow of information. However, it has been suggested that there may be situations where this would not be in the patient's best interest.

Occasionally the patient might not ask about prognosis because the possibility of death has not occurred to him or her and it has been argued that if he or she is not told that this is a possibility until they are critically ill then there may be issues which he or she may regret not having had time to resolve, such as putting their finances in order, planning for a funeral or teaching a husband to cook so that he may be able to cope following his wife's death and so on. The ability for some individuals to plan for their imminent death at a time when they are reasonably well can promote the process of acceptance (Stedeford, 1994). Some patients have considered that death is a possibility but don't want to want to know more because they are afraid of the reality, this sort of denial may not be harmful in the short term, but in the long term may also result in the patient not addressing both practical and spiritual issues which maybe important to him or her and such avoidance may mean that they remain unaccepting and potentially in turmoil until death. Information regarding the disease, treatment options, possible side effects and treatment outcomes are essential to the patient, family and carers. Patient's need to be able to make informed decisions on the basis of the information given to them. It is important to explore the patient's awareness and reactions to their diagnosis and prognosis in order for health care professionals to assess their further information needs and their need for support. Research has shown that patients often know they have a serious illness even when they have not been explicitly told of this (Stedeford, 1994).

Individuals differ greatly and some patients require lots of information whilst others are content with the minimum level required to enable them to cope. In the face of adversity patients exhibit a range of responses and behaviours which help them to cope. Defensiveness can be a necessary and even helpful response in patients and relatives because it may help to maintain a degree of hopefulness for the future and gives patients the opportunity to take the lead in asking for information.

Coping styles of individuals need to be identified to enable carers to assess the possible consequences of giving information. For example, denial of the seriousness of diagnosis or prognosis maybe helpful to patients in the early stages of their illness because it enables them to cope with surgery or unpleasant chemotherapy regimens and fosters hope which is central to everybody. However, it can be argued that if denial continues it may mean that communication within the family is blocked and family members can be left unsupported in their anxiety. Kubler-Ross, (1970) describes five reactions to impending loss, denial, anger, bargaining, depression and finally acceptance. Anxiety is an emotion experienced by most patients at different stages of their disease journey. Denial as a means of coping discourages others from giving information about the patient's illness because he or she wishes to make their situation appear less frightening to him or herself. When the patient's condition deteriorates it becomes more difficult to deny the reality of the situation. Whilst denial might be a useful short term coping mechanism it rarely extends throughout the whole of the disease journey and the other emotions are usually experienced. Where individuals exhibit denial there is a potential that problems will not be addressed and therefore anxieties will increase. It is important for health care professionals to accurately assess any

sources of anxiety and to try and address them; methods of doing this are discussed in the next chapter.

Anger or aggression may be shown by patients receiving a diagnosis or prognosis or by patients who are seriously ill. Relatives also experience the same emotions as patients as they are also subjected to an impending loss. Usually where anger or aggression is exhibited this disguises underlying fears and anxieties. If a patient's anger is directed at carers and health care professional it may discourage the professionals from trying to help thus leaving the patient more lonely, isolated and frightened.

Bargaining with medical staff or with God for a cure or a remission is a stage, which can be experienced by patients with a diagnosis of cancer and their relatives, particularly when they realise that the condition may be very serious. During this stage the patient may look for alternative treatments to traditional medicine, healing through prayer and so on. This should not be discouraged unless the patient is embarking upon harmful course of action for him or herself as these sort of actions give the patient some control and again foster hope, (Calman, 2000). Not taking control and the ability to make decisions about him or herself away from seriously ill patients is very important because they maybe struggling to maintain some sort of control over their lives and are often all too conscious that independence is slipping away from them, being dependent on others particularly health care professionals with whom patients have no real tangible relationship can often be a very difficult concept for them to come to terms with. In order for patients to retain some degree of control health care professionals need to ensure that patients are given enough information to make informed decisions about themselves. In addition they need to access support; perhaps in the form of a specialist nurse



who can be their advocate ensuring that their wishes remain paramount.

Depression is often associated with actual or anticipated loss in both patients and their carers. There may be many kinds of loss involved in diagnosis of cancer and the potential for dying, these include a loss of independence, a loss of physical attractiveness, loss of role and relationships and ultimately the loss of life itself (Speck, 1978). Sadness that life could end does not seem to account for all of the depression seen in patients with a diagnosis of cancer. There has been a link established between an increase in depression correlating with the length of a terminal illness and the presence of physical distress (Hinton, 1972). Anxiety and depression is usually the result of a failure to cope with difficulties, which are a direct result of the illness and treatment, a change in lifestyle, unsatisfactory communication or pre-existing marital and family problems (Stedeford, 1981). It is clear therefore that depression should not be accepted as an inevitable part of the dying process but the causes need to be explored and health care professionals with inadequate communications skills cannot do this. However, despite this evidence, in practice many health care professionals subscribe to the view that "of course you're depressed, you've got good right to be, you've got cancer". There is also an increasing trend of commencing cancer patients almost routinely on antidepressants to help them 'cope' rather than really trying to identify and manage the real issues contributing to depressions in many instances this process can be started by a health care professional who is a skilled communicator, unafraid to address difficult topic areas. This could be due to lack of time required to deal with such complex psychological issues, the unwillingness of doctors to refer on to other agencies such as Macmillan Clinical Nurse Specialists, Counsellors or Psychologists who may have more time and or communication skills,

or the fact that doctors are simply not up to date on cancer related studies.

Most seriously ill patients and their relatives exhibit some anxiety, particularly anxiety regarding the future. A proportion of patients and relatives will experience extreme anxiety and distress. Patients maybe anxious about frightening symptoms such as pain, breathlessness or about becoming confused or losing control of bowels or bladder experiencing a resulting loss in their dignity. There are some patients who are afraid of death and may be unable to sleep because of fear of dying. Two of the patients interviewed viewed their diagnosis as a death sentence. The fear of experiencing distressing symptoms can cause the patient to feel unsafe at home and this can result in the patient being admitted to a hospice or hospital even when no physical symptoms are present. The most helpful factor in alleviating anxiety in patients and their relatives is a professional who is well known and trusted to them and whose judgement is respected. The role of providing thorough and clear explanations and subsequent psychological support has been well documented in alleviating patients and relatives anxiety and in ultimately reducing psychological morbidity in cancer patients. Indeed research has shown that long term cancer survivors can present with chronic psychological disorders which are directly due to their initial diagnosis of cancer, consequently it is crucial to give the appropriate psychological support from that time at which patients are diagnosed, (Lovejoy and Matteis, 1996; Ramirez et al, 1995; Derogatis et al, 1993; Greer, 1984; Ford, Lewis and Fallowfield, 1995).

The following chapter on communicating bad news makes suggestions on how to communicate with cancer patients in the initial

stage of cancer care and will explore to what extent health care professionals have been able to integrate theory and practice.

