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The initial phase of cancer care -

An action research project

**Volume Two
(commences chapter 6)**

Ingrid Maria Ablett-Spence

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Contents

Acknowledgements		2
Abstract		3
Chapter 1	Introduction	6
Chapter 2	Literature Review	24
Chapter 3	Research Methodology	64
Chapter 4	Results	108
Chapter 5	Problems of communication in cancer care	170
Chapter 6	Communicating bad news	194
Chapter 7	What patients really want	247
Chapter 8	The evolving role of the Clinical Nurse Specialist in the multidisciplinary cancer team	262
Chapter 9	Implementing change in cancer care	301
Chapter 10	Innovations in cancer care	325
Chapter 11	Discussion and conclusion	338
Appendices		364
References		
Bibliography		

CHAPTER 6

Communicating Bad News

Communication is a vital component of any health care professional's role, particularly those who deal with cancer patients, because of all the taboos and misconceptions relating to cancer. Being given a diagnosis can have an extremely debilitating effect on the recipient of that news. The way a patient and his or her friends and relatives are given the news of a cancer diagnosis is tremendously important and the ability to break bad news in a sympathetic manner is a vital skill particularly for doctors as they are usually the ones to impart news of diagnosis. However, there is evidence to suggest that doctors and other health care professionals function poorly when trying to advise patients of a life threatening disease and they often find it very difficult to maintain a meaningful dialogue once the information has been imparted. This may be due to a variety of reasons including their fear of the emotions they may have unleashed in a patient, poor preparation or education in dealing with such scenarios and the fact that where the cure is not possible they may feel they have failed, (Wilkinson, 1991; Doyle, 1991; Buckman 1992; Kaye, 1996). There is a temptation to let "experts" who have specialist counselling skills pick up the pieces once the patient has been given the facts about their diagnosis, this would allow the doctor to then withdraw and not have to engage in difficult or uncomfortable dialogue. However, this is not the answer as it interferes with the subsequent doctor/patient relationship and hinders rapport with the patient. Good communication skills are needed by all doctors and health care professionals and a doctor possessing the skills to break bad news in a sensitive yet effective manner can make a real difference to the way in which a patient and his or her family deal with the news and the implications of it. The

evidence suggests that the patients want to be told diagnosis and treatment by a doctor, therefore specialist's counsellors are not the answer, particularly as these skills are easily taught and understood (Kaye, 1996). "Bad News" can be defined as any information that drastically alters a patient's view of their future for the worse; this is inevitable when a patient is initially given a diagnosis of cancer. Peter Kaye (1996) reminds us that the Ancient Greeks used to kill a messenger of bad news and that giving a patient bad news remains a risky business to this day. He uses the analogy that breaking bad news is similar to breaking an egg – "a certain amount of skill is needed otherwise you are liable to make a mess" The word 'breaking' implies that something gets broken and what gets broken when a person is given a diagnosis of cancer is their whole vision of the future, which is why breaking bad news is such a shock, this was verified throughout the patient interviews as part of this study.

"I couldn't speak.....I don't know how I got home I was just so confused".

(Patient No. 17)

"I was just so lost, you know, because when somebody tells you you've got cancer you know, it's well, I think it's the biggest thing that's ever going to happen in your life".

(Patient No. 17)

"You don't really absorb it all in at the moment because the initial shock takes over.....and I said oh my god I'm going to die".

(Patient No. 15)

“I was prepared (for a diagnosis of cancer) but even when you’re told you are still shattered.....still absolutely gutted”.

(Patient No. 6)

It is clear from the aforementioned examples that many patients are extremely shocked when they are given their diagnosis so it has to be done sensitively. Breaking bad news is important for the following reasons; firstly to maintain patients trust, the relationship between a patient and the doctor should be based on honesty and trust and being truthful about the disease allows the discussion of the appropriate methods of clinical management.

Mrs A. was a 54 year old lady with a brain tumour who had always refused to discuss her illness, she had struggled for a number of weeks to try and get walking again but she had gradually become weaker and was becoming increasingly frustrated and depressed, having placed a return to some mobility over all other considerations. One day she asked the doctor how much longer it would take for her to get mobile again. The doctor explained to her “things have changed; your legs simply do not have the strength left for you to walk anymore”. Her initial sadness at being given this news was very soon replaced with a feeling of relief that the unsuccessful battle to walk was over, this enabled her to have more realistic aims and begin to enjoy other things such as going out for walks with her husband pushing her wheelchair.

Clearly there are a number of issues which related to this case study; firstly should Mrs A. have had to ask the doctor how much longer it would take to get mobile again, or should the doctor have identified

the fact that she was gradually becoming weaker and more frustrated and subsequently depressed, due to her inability to regain some mobility. There are also a number of issues related to the psychology of being confined to bed, whose responsibility is it to address these issue, is it the doctor's? In reality it is often the nurses or untrained staff who are left to deal with these issues and very often they are inadequately trained for such purpose and therefore try to disassociate themselves from difficult conversations which may lead to the patient asking questions which they feel ill equipped to deal with. There is of course a counter agreement which would suggest that if the patient really wanted to know how the disease was progressing or whether she was actually improving then she would ask the appropriate questions, when she saw her doctor. However, in the case of Mrs A. the mere fact that she was told that her legs were not going to regain strength helped her to reassess her goals and not waste precious time becoming frustrated with something she could not influence.

Secondly, imparting bad news can reduce uncertainty and uncertainty can be one of the hardest emotions to bear. One common reaction to bad news is that it is better to know the truth then live in a state of fear of the unknown.

One patient who was interviewed reiterated this point stating:

“To be honest by the time I was given a diagnosis it was a bit of a relief because at least once they knew what it was, they could start sorting it out”

(Patient No. 33)

Clearly this patient felt as though the time waiting to be diagnosed was particular frightening and because there was no definitive diagnosis at

that stage he had no idea what to expect in terms of treatments or their outcomes. For him that fear of the unknown was much worse than actually knowing he had cancer, what was the most appropriate treatment for him and the expected outcomes of that treatment. Once he had that information, he felt that he could focus on getting through the various stages of his cancer journey.

Thirdly, to prevent inappropriate hope such as expecting a cure where there is none which can be a demoralising business. Watching a patient commit to expensive and/or useless treatments or spend their last weeks hoping to feel well again is distressing, particularly for their relatives and friends and cause a great deal of anxiety and guilt This is not to say that some degree of hope is appropriate for all patients, but it may be more appropriate to alter what is hoped for. For example, rather than hoping to see ones grandchild grow up, hoping to survive until the next family Christmas may be more appropriate.

Fourthly, to allow appropriate adjustment in both practical and emotional terms so that the patient can make informed decisions about their future.

Mr. B. was a 29-year-old man with bowel cancer which had spread to his liver. For a long time he had not wanted any details about his disease, only focusing on what treatment was going to happen next and what side-effects may be relate to it. He saw his doctor and what was the purpose of his next course of chemotherapy, would it lengthen his life, also was there any guarantee that it would improve his symptoms. The doctor responded advising Mr. B. there was no guarantee of either and that it may also have the drawback of giving him side-effects whilst he was undergoing treatment, he gave Mr. B. another option, that of not having anymore chemotherapy at that

particular time and going and doing the things that were important to him whilst he had a reasonable quality of life and was not being troubled by lots of distressing symptoms. Mr. B. pondered this information for a long time and ultimately decided to make practical plans to do something that he wanted to such as selling his horses (which he was finding difficult to look after anyway) and buying a sports car, which he could enjoy whilst he was well enough.

In this scenario Mr. B. had spent a lot of time focusing on the practicalities of the here and now. He did not appear to be addressing his emotional needs, it is clear by virtue of the fact that he actually asked the doctor what was the purpose of his next course of treatment, that he had begun to consider the possibility that any length in survival was not guaranteed, and that despite having treatment he may suffer from symptoms. The fact that the doctor responded honestly to Mr. B's questions and gave him another option which was appropriate to his situation, meant that Mr. B. could reconsider his circumstances and make an informed decision about his future i.e. to use his time to address practical issues in his every day life and also to ensure that he enjoyed himself rather than potentially submitting himself to distressing side effects or chemotherapy when there was no guaranteed outcome of the treatment. It is clear that Mr. B. could not have asked these questions of his doctor had he not had a rapport with him which was based on trust. In Mr. B's case it might also have been appropriate to refer him to a Clinical Nurse Specialist who could support him at home by being available to answer any questions about his disease, but also to give psychological support and support him in other more practical ways such as providing skilled symptom control which would enable him to have the best quality of life possible.

Finally, the need to break bad news effectively is essential if a conspiracy of silence is prevented, such conspiracies can destroy family communication and prevents the family supporting the patient and the patient from discussing his/her feelings with the people who can probably be the best support to him/her.

It is clear that breaking bad news and engaging in dialogue where patients ask difficult questions is not a pleasant experience. Doctors often dislike explaining bad news even though it is a very important part of their job and there are several possible reasons for their discomfort:

1. Feeling incompetent in communication skills (“what if I do some harm”).
2. Getting blamed either by the patient or relatives for the illness (transferred anger) or in some instances by colleagues for upsetting the patient or making them cry).
3. Unleashing a reaction – doctors may feel uncomfortable about what to do if the patient cries uncontrollably.
4. Failing the patient by not curing them (although in reality patients usually hope for kindness more than miracles and this was reflected throughout the patient’s interviews).
5. Wanting to shield the patient from distress by saying things like “I’m sure all is well”. (This can seem an easy option, because it is what the patient wants to hear) but unrealistic optimism on the part of the patient will eventually destroy trust and cause resentment and has potential for facilitating psychological morbidity in the patient.
6. Feeling awkward about showing sympathy as a professional. Many doctors and indeed other health care professionals are under the impression they need to control their emotions in order to stay in role and function efficiently, saying “I’m sorry you have this illness” can feel

- unprofessional to some doctors and yet not saying it feels unkind, because we would say it in other circumstances e.g. to a neighbour.
7. Being powerless to control emotional distress can be difficult for doctors who are used to having the power to change things.
 8. Feeling embarrassed about how to behave when someone is very upset and uncertain about whether a doctor should comfort a patient in this situation.
 9. Many doctors feel that they do not have enough time to break bad news in a sympathetic matter (although patient satisfaction depends less on time spent than the quality of the interaction and this was made very clear by the patients themselves when they were interviewed).
 10. Being reminded of human vulnerability to illness is often difficult for doctors and other health care professionals to deal with and the hidden agenda of our own personal mortality can block the conversation.

Medico-legal factors can also compound this problem, because the medico-legal atmosphere is changing in all countries and it is becoming easier, particularly in the United States to attach the blame for any medical deterioration to a doctor or nurses, this can contribute to or as Beckman, (1992) states, perhaps reflects society's view that all patients have a right to be cured of any condition and if they are unable to achieve that objective it must be ultimately be due to the fault of the medical establishment, this being the case there must then be some sort of legal and financial recourse for the person who believes that he or she is a victim. Where such attitudes prevail it means that it can become increasingly difficult for patients and their doctor to face facts calmly when they included inevitable deterioration or death.

Buckman (1992) suggests that doctors fear breaking bad news if they have not been adequately trained. During their professional training they learn to do 'a task properly' which generally means following conventional procedures, if they deviate from conventional guidelines they expect to have problems and usually do, thus 'they are trained and programmed to avoid deviations from standard practice'. Doctors can therefore feel uncomfortable when they meet a scenario where they have been given no guidelines such as in the case of breaking bad news; they can naturally feel ill at ease and will show a tendency to avoid the subject entirely. No one enjoys doing something that they feel uncomfortable with and which they know they have not been taught to do properly (Buckman, 1992). It has also been suggested that this tendency becomes worse as other clinical skills are increased. The more competent doctors become at reading ECG's or interpreting chest x-rays, the more difficult it becomes for them to face up to the fact that they do not know how to do the apparently simple task of sitting down and talking to a patient. This being the case it is essential for health care professionals and particularly doctors to be as thoroughly trained in patient communication skills as they are in other clinical skills. Furthermore, if these skills become a compulsory part of the curriculum in medical schools, nursing courses and part of the pre-registration training of the professions allied to medicine then they will also be perceived as being an essential component of clinical management. On the other hand if they are excluded they will be regarded as optional and clinicians will feel more and more uneasy about their own interviewing skills later on in their careers. Current evidence suggests that "communication" is part of the curricular for all medical students and pre registration health care professionals' courses. However, it is uncertain as to how much of the focus is on specifics like breaking bad news. In reality junior doctors who have probably had appropriate training are very rarely asked to give a

patient a diagnosis of cancer and by the time they become responsible for doing so they often forgotten such training or at best have not practised such skills. It is often the Consultants or Senior Registrars who impart such information and where they have qualified some time ago they may not have had the opportunity to be the recipient of such education, they have often learnt by trial and error and many have acquired poor habits overtime. There are more and more resources available including books, videos, distance learning and residential courses all aimed at equipping health care professionals with the skills to break bad news effectively, the challenge is to ensure all professionals utilise such resources. However, as Calman (2000) pointed out attending one course does not automatically make a doctor a good communicator, and as with any skill one only develops competence and confidence with practise.

Though it can be initially threatening and uncomfortable to acknowledge and deal with professional deficits, it can also be satisfying to develop competence in dealing with the emotional elements of illness (Kaye, 1996). It is therefore necessary to encourage doctors to develop and practice such skills and not allow them to defer to other professionals such as Macmillan Nurses just because they may feel uncomfortable.

Unfortunately, in reality patients and their relatives report numerous examples of doctors not breaking bad news well; ranging from doctors not being prepared, to use euphemism or simply being blunt and some examples were given during the interview:

“And he said you’ve got a cancerous growth which we can either treat with chemotherapy or operate on it”.

(Patient No. 12)

“He told me I had a wart, a tumour”.

(Patient No. 4)

“It was a young Doctor.....he seemed to be a bit reluctant to say too much about anything to me and I had to ask him what, if he’s got the result of the biopsy.....he took a long time going through the file and eventually just looked up and in a very low voice said I think it’s cancer”.

(Patient No. 12)

Peter Kaye (1996) suggests that there are a number of classic ways in which doctors exhibit how not to break bad news. Firstly, there is what he describes as “velvet covered hand grenade approach” this is where the doctor sounds and feels concerned but uses jargon or euphemisms such as a ‘wart, lesion, tumour’ to distance himself from the patient and avoids open discussion of the issue in case it upsets the patient. Where the doctor uses such terminology it is not uncommon for patients to be misled regarding their diagnosis and it’s potential consequences. In these instances the doctor gives the bad news in a disguised form. For example, if the patient asks whether it would be alright to go on holiday in the summer the doctor may respond by saying “it would probably be best to stay nearer to home just in case”. When a doctor uses this type of approach he/she is trying to be kind but such an approach inevitably causes confusion and resentment on behalf of the patient. The second approach described by Kaye (1996) is what he calls the “hit and run approach”. It can come in varying forms and can sometimes be inadvertent such as when a patient is being discharged and is told the diagnosis procedure. In this instance the patient is often told at a time that suits the professional with the patient having no say in the way that they are

told or choice regarding who is with them at the time, there is also no negotiation about how much information would be helpful at this stage. It is simply a case of "do you know your diagnosis oh well have you got cancer and we have arranged for you to see an oncologist.....". Another example of this 'hit and run approach' is when the patient asks "is it cancer?" and the doctor responds "well, yes it is". It can be tempting to give a straight answer to a straight question especially if the patient seems to be calm and intelligent but it is always best to find out more about what the patient really wants to know.

This sort of approach was described by a number of patients interviewed, although non stated they had been given the diagnosis as part of the discharge procedure. In reality it is often junior nurses that are suddenly confronted with questions like this as they often seem less threatening and more approachable and in an intimate moment such as during a bath the patient may ask difficult questions: "Am I dying?" or "Do you think it is cancer?"

There are simple ways of dealing with difficult questions and Kaye, (1996) proposes the following approach:

1. Ask questions about the question (this is known as a reflective listening), for example saying to the patient "What makes you ask that question?"
2. Ask questions about the need for more information for example "What do you already know about you illness?" or "Would it help you to know more about your illness?"

It is clear from these examples that is possible for health care professionals to explore the patient's real concerns without giving

further information and potentially overloading them with that information or giving them information that they are not ready to deal with. The way in which patients react to being given bad news varies tremendously and their responses can be a result of previous experience of the situation. For example, if they have had a friend or family member diagnosed with a cancer, inevitably the outcome for that person will have influenced the way in which they respond to being given a similar diagnosis. Patients who have had a warning that this may not be good news may deal differently to those patients who have no inkling that this maybe a serious problem for which they had been investigated. Also people with different religious and cultural backgrounds can react in different ways, some people do not wish to exhibit their feelings in public and prefer to do it in private with friends and family, others feel the need to express their feelings in a very overt manner, these different reactions were described by a number of those interviewed during the study:

“I’m a bit of a stoical person I think and I don’t show my feelings very well”.

(Patient No. 10)

“I said I can’t believe you’re talking about me”.

(Patient No. 15)

“I said Oh God I’m going to die”.

“He was so blunt, just came out with it and I thought you ignorant pig”.

However an individual responds to a diagnosis of cancer, it is important that the health care professionals react appropriately and regardless of any anger or animosity which may be directed at them, that they ensure a patient and his or her relatives are offered on going support and not just left to "God and providence".

One patient commented how once she had been bad given the "bad news" regarding her diagnosis she felt that the consultant did not respond to her anxieties nor did she feel he wanted to provide further support:

"he didn't put me at ease, you know he didn't do anything to try and make things easier for me you know, and it was a case of like I've told you now, bye".

(Patient No. 21)

A number of guides now exist to help equip health care professionals in the skills they need to effectively break bad news (Buckman, 1992; Faulkner & Maguire, 1994; Kaye, 1996). They all offer similar advice and provide a staged approach to braking bad news. However, for the purpose of this thesis Buckman's 6 step protocol will be focused upon. Buckman, (1992), suggests that whoever it is that takes responsibility for breaking bad news to the patient, all other health care professionals involved in the patient's care still have a role in supporting the patient after he or she has been given that news; indeed if continuity of care is to be assured this sort of approach is essential. Supporting the patient involves time spent listening, hearing and acknowledging the emotions that the patient is experiencing and also involves advocacy on the patients behalf. The word advocacy literally means "speaking for" and whatever an individual health professional's relationship is with the patient or whatever their role in

the health care team, it is always possible to assist the patient in framing his or her main fears and anxieties and to help the patient obtain information regarding questions that can not be answered by that individual health care professional may not be able to answer. It is appropriate therefore to accept them as problems central to the patient's view of the situation and to take them to a potential source of answers. This act of advocacy is an extremely valuable service for the patient. An example of this is when a patient may ask a nurse what experimental chemotherapy drugs may be used in his or her case, the nurse may not be able to answer this question but, it would be appropriate for her to facilitate a meeting between the patient and his or her consultant who would be able to answer such questions.

Buckman's (1992) guide is primarily aimed at Doctors but the principles underpinning it are applicable to all health care professionals who have to deal with patients who are the recipient of bad news.

The six basic steps of the protocol will be described and where appropriate will be illustrated with case studies from clinical practice and from patient quotes taken from the transcripts of the patient interviews carried out as part of this study:

Step 1 – Getting Started

Getting the physical context right is important, this involves ensuring that a suitable environment is available which will be free from interruptions and distractions and provides privacy.

Interestingly, during this short study when patients were asked about the environment in which they were given their bad news non felt that

it was significant, regardless of the setting, even those who were told in the middle of a nightingale ward with only the curtains surrounding the bed providing an illusion of privacy did not find this objectionable. From this study it is clear that it is not where you tell the patient that matters rather, how you do it.

At this stage in the process the doctor should ensure that he or she is fully equipped with all the available information, there is nothing worse than a doctor not being aware of what the patient has been through or what tests have been ordered, their results and so on. Patients lack confidence in Doctors whom they feel are ill prepared, and those who commented on Doctors not knowing about them or their results were less than happy about this. Whilst some patient commented on such incidents, such lack of preparation was not in any of the non-participant observations.

It is also worth considering who should be with the patient and it may be prudent to suggest prior to the interview that they may be given lots of information and might like to consider having someone such as a close friend or relative with them to be "another pair of ears". Most patients, particularly those attending clinics to hear bad news brought friends or relatives with them who are included in the interview. Those who did not bring someone with them either did so by choice, sometimes because they were trying to protect others or because they were unprepared for the news:

"I didn't take her (his wife) with me because there was no point in worrying her, she's had enough on her plate lately".

(Patient No. 1)

It is important for the Doctor to attend to normal courtesies such as introducing his/herself, ensuring the patient is comfortable and not exposing him/herself whilst awaiting a physical examination keeping a comfortable distance from the patient is important and ideally the Doctor will sit facing the patient at the same level. In reality due to cramped treatment rooms with inadequate seating arrangements in the majority of instances (observed during the non-participant observations) the consultants ended up sitting on an examination couch looking down at the patient. However, no patients commented on this as an issue during the interviews and the Doctors observed invariably responded when the patient became distressed putting their arms around patients, moving to the patients side, patting the patient's hand, crouching down next to them and so on.

Touch from the doctor was valued by a number of patients, one person commented:

“He was so nice and held my hand and everything.....”.

(Patient No. 21)

Early during the interview it is also helpful if the doctor ascertains that the patient feels up to discuss. A patient who is in pain or nauseated requires these things addressing first if they are able to concentrate on what the doctor has to say.

Starting an interview by asking how the patient is has a number of useful purposes:

- a). It gives the patient the idea that the doctor is interested in him/her.
- b). It makes the patient aware that the interview is a two way process.

- c). It encourages the patient to talk.
- d). It allows the doctor to assess the patient's current medical symptoms, mental state and vocabulary. All of which are important particularly if the doctor-patient relationship is in its infancy.

Step 2 – Finding out how much the patient knows

It is important to obtain from the patient an impression of what he or she already knows about the illness. In particular how serious he or she thinks it is and or how much it will affect his/her future. Initially many patients often deny having much knowledge or insight into their situation, and many of those who have a good understanding will claim to know nothing at first, it is therefore a good idea to encourage the patient to tell the doctor/health care professional as much as he/she knows before starting to explain. The best way to do this is to encourage the patient to give a narrative of events ask "How did it all start?" (The same sort of approach was used to open the dialogue during the interview phase of the study). With a little prompting (What happened next?) they will go through the story. However, such an approach will only provide the appropriate information if the patient has a reasonable memory and is not mentally impaired in some way. Buckman does not suggest how to deal with patients who have some form of mental impairment or who are distressed about their circumstances that it hinders meaningful communication. As the patient talks, the doctor can gain information not only about his/her understanding of the medical details but perhaps more importantly he/she can start to understand the experience from the patient's perspective. A useful phrase maybe "What has been the most difficult part of the whole thing for you?" The doctor can also hear the words they use and begin to develop an idea of what is understood. The

same events could be described in a million ways and the way in which a patient chooses to describe what has happened to him or her can give very useful information regarding his/her concerns and about how much information might be helpful. It is essential to listen carefully to the words the patient uses, in order to give meaningful explanations and have a therapeutic dialogue between doctor and patient a common language is needed between the two. It is not uncommon for patients to leave out bits of the story for example previous medical explanations so they don't use the word cancer, because they are too painful to discuss or remember. It is important to have as much information as possible from other sources and it maybe appropriate for the doctor to press a patient gently to tell him or her what is already arranged or known.

Patients come with very different interpretations and knowledge bases. For example, a patient who says "The surgeon said it was a breast lesion and I was so relieved it wasn't a tumour or even worse cancer", needs a different approach and will need very different management from the patient who states; "My GP was very good he told me that the shadow on my x-ray was most probably cancer".

Buckman (1992) advises health care professionals to disregard the patient's profession when making an assessment of their ability to understand what they have been told stating "This is particularly true if your patient is a member of a health care profession – for instance another doctor or nurse". Far too often you will find yourself making assumptions. Even physicians when they are patients may not be experts in their own disease and may not understand something like "it's only a stage 2 but I don't like the mitotic index", when they are hearing it as a patient. In such instances he recommends saying "I know you are a nurse/doctor, but I hope you won't mind if I treat you

as a human being – we will start at the beginning and if I'm covering old ground tell me.....". Whilst no health care professionals were interviewed during this study, in clinical practice it is not uncommon to find health care professionals who are patients to be completely lacking in any insight relating to their disease.

It has been suggested that the emotional state of the patient can be assessed by the health care professionals considering the patient's verbal and non-verbal responses. From a verbal perspective it is not only what the patient is actually saying but some assessment is also required regarding what the words imply i.e. reading between the lines for hidden meanings. A patient's body language can give a health care professional a number of clues to what they are feeling, sitting back away from the doctor, hunched forward, crying, hand wringing and so on can all be indicative of how a patient feels. However, it is also important to look for discordance between verbal and non-verbal communication. For example, if a patient is wringing his or her hands (which may be a sign of anxiety) and the words they are speaking project calmness or bravery the health care professionals must take note, there is probably a major anxiety that exists which is being suppressed by the patient. This discordance between verbal and non-verbal communication was clearly witnessed during the non-participant observation phase of this study, and the doctors observed invariably modified their behaviour accordingly.

It is important to note that the health care professionals are not required to and should not make valuable judgements about the responses of individual patients, it is not necessary for the professional to decide whether they are normal or abnormal responses because they are not usually privy to knowing how that individual patient reacts under "normal" circumstances, the patient's

responses are simply clues to their emotional state. However, although not suggested in Buckman's model, there is no reason why health care professionals shouldn't ask questions like "How do you normally react to times of stress?" as the response might give some indication as to what support maybe appropriate for that individual patient.

Before stage 3 of the breaking bad news protocol is undertaken, health care professionals should have attempted to minimise the psychological discomfort experienced by themselves and their patients as far as possible. They should let the patient know that they are trying to listen and that they are interested in what he or she thinks is going on. The third stage of the protocol is crucial to the way in which the health care professional responds and it is the stage in which the course of the interview and to a certain extent the future course of the doctor/patient relationship will be determined.

Step 3 –Finding out how much the patient wants to know.

This stage may be the most crucial part of the whole interview as it is the point at which it is established overtly whether or not the patient wishes to know what is going on. Omitting this stage in the interview process can cause confusion, with patients and doctors being unsure about what exactly the patient wants to know, how much information they should be given and so on. Without a clear invitation or declination from the patient to share information health care professionals will feel unsure whether they are to give the patient a lot of information or only a little. Kaye, (1990) suggests that at this stage it maybe appropriate to ask the patient "Would you like me to tell you anything else about your illness?" He suggests that this stage could be called "testing the waters" and it is important because most patients

are frightened about having more information, despite the fact that they value truth-telling and honesty on the doctor's part (patients interviewed in this study suggested that truth-telling was important). Patients experience a conflict between the discomfort of uncertainty, which can be reduced by information, and the discomfort of fear, which can be reduced by them "being an ostrich".

A number of patients observed and interviewed as part of this study indicated that they did not wish to have too much information at the time of diagnosis, this wish was universally adhered to by the doctors, fortunately in each instance the patients were offered recourse to come back for further discussion at any time should they change their minds. One lady described how she later returned to see the consultant following a visit from a Clinical Nurse Specialist during which she started to explore some of her concerns, which had recently developed. Such support offered to all patients could enable those patients who did not want too much information initially to either address their concerns/fears at a time of their choosing with the Clinical Nurse Specialist, or alternatively he/she could act as an advocate and facilitate a further doctor/patient consultation if and when the individual patient required it.

The current trend advocating that doctors should tell patients everything relating to diagnosis and prognosis can occasionally cause uncertainty and discomfort for doctors particularly when patients make it clear that they don't want more information and consent is being sought for treatment. Many doctors will argue that ethically patients cannot consent to treatment if they have not had a full explanation relating to what the treatment involves, risks associated with it, side-effects and so on.

Buckman, (1992), states that the way in which doctors actually ask patients whether they require more information is largely a matter of their own individual style. Examples of other ways of asking the patient how much they would like to know are as follows: -

- “If this condition turns out to be something serious are you the kind of person who likes to know exactly what is going on?”
- “Would you like me to tell you the full details of the diagnosis?”
- “Are you the kind of person who likes the full details of what’s wrong or would you prefer just to hear about treatment plan?”
- “Do you like to know exactly what’s going on or would you prefer me to give you the outline only?”
- “If your condition is serious, how much would you like to know about it?”
- “Would you like me to tell you the full details of your condition or is there somebody else you would like me to talk to?”

However, you could argue that the use of such a question could alert the patient that their condition was serious simply because the question was being asked and those not wanting more information may become frightened of the unknown and psychologically damaged.

In practice (and reflected in the interviews) there is not much evidence that this actually happens, instead patients report being happy that they were asked.

Buckman (1992) reports that many students express initial reservations about asking patients directly what they want to know, they think that it’s “giving the game away” and that in making this enquiry doctors are telling the patient that he or she does have something serious and therefore the doctor is not “playing fair”. Their

reservations arise from two sources, firstly, that the question is a false one since by the act of asking the question you are removing from the patient one of the choices that you seem to be offering i.e. the option not to discuss the situation. Secondly, that asking the patient's views will cause distress to the patient, which might be avoidable. Both of these difficulties arise from a misunderstanding regarding the function of the patient's denial, (Buckman, 1992)

In any conversation about bad news the issue is not really do you want to know, but more in how much depth do you want to know what's going on? Despite common illusions to the contrary it is not only the doctor's statements, which provide a source of information to patients. Patients themselves know how they feel, they know that they have undergone tests or surgery and they know what other patients say about what they have experienced. They also pick up on things that other members of staff say and if doctors avoid them or say nothing, patients are very astute and know that the news may not be good or may not be a simple reassuring diagnosis. If however the patient is using denial, he or she is able insulate him or herself against the impact of all of this and will do the same against the impact of the question "what do you want to know?" Evidence suggests that at some level every patient knows when things are not going well and in asking the patient about how much information they want, doctors are simply finding out whether or not the patient wants the information discussed overtly and in full view or not. Throughout the patient interviews a number of patients expressed their wish to having minimal information, usually relating to the clinical decision making i.e. patients wanted the doctor to sort through the information and conclude the best form of management for the patient having to make that decision for him or herself, one patient encapsulated the problem stating:

“..... it was really confusing to try to sort through the amount of information and the technical terminology.....I just wanted to be told what was best for me and I would have gone along with that.....”.

Although some of those interviewed as part of the study stated that they really didn't want to know their diagnosis, none of them actually reported advising the consultant of this.

Where a patient expresses the view that they do not wish to hear the full details of their diagnosis or prognosis it is essential that the doctor says overtly that he or she will maintain contact and communication (for example concerning the treatment plan) but not about the details of the disease. Saying “are you the kind of person who” can be helpful because it suggests to the patients that they are not unique and that there are many other patients who feel like this, and that if he or she prefers not to discuss the information that is okay and that does not mean that he or she perceived as being feeble or weak. Patients who feel as though the consultant's have washed their hands of them for whatever reason feel anger and resentment and this was clearly illustrated during some of the interviews.

The purpose of phase three of this protocol is to gain an invitation if that is what the patient wishes to share information, if the patient expresses a preference not to discuss that information then it is essential to ensure that the patient feels they still have a access to the doctor in the future. For example, “.....that's fine however if you change your mind or want any questions answered at any time just

ask me, I will wait for you to ask and I won't push information at you if you don't want it".

In reality many patients express a wish not to be given full information and in this study a number did not want to know too many details regarding treatment options instead they wanted the consultant to focus on what was best for them (in his professional judgement) and this does not necessarily compromise their treatment, for example:

Miss. C. was a very anxious 40-year-old lady. The letter from her GP said "she will simply not allow me to tell her what is going on and I am concerned that you may not be able to offer her treatment". When the oncologist first met her she said "if it is cancer, I don't want you to tell me", the oncologist assured her that he would not, and asked her about her fears relating to cancer and she told him about five members who had died of cancer and who had all suffered in the extreme. Her main fears were related to the thought of suffering. The oncologist then described the treatment and side-effects in detail which he thought might be most appropriate for her and mentioned the various support services, which could be offered. When she heard about the treatment she recognised it as chemotherapy. When the oncologist confirmed this was the case and recommended it she smiled and said, "I knew it was cancer anyway".

In clinical practice, many patients adopt this sort of approach, stating that they don't want to know what their diagnosis is, but they are willing to listen to what the consultant thinks is the most appropriate treatment. Very often when this information has been provided, they confirm that they knew that the diagnosis was cancer all along. In the case of Miss. C. the oncologist acknowledge her concerns and asked her about her fears relating to the word 'cancer' this enabled him to

address those fears and reassure her that the proposed treatment for her illness might prevent those fears from becoming a reality. He also went on to discuss the various support services, which could be offered to her, in order to ensure that she did not become isolated and that her psychological needs could be addressed. In discussing treatment and its side effects, he allowed the discussion to open up, allowing Miss. C. to confirm that she knew that she had a diagnosis of cancer anyway. Once she acknowledged this diagnosis the consultant could then confirm this for her, and address her fears in a more direct manner.

Many patients interviewed seem to cope with their diagnosis by "denial" initially but for all of those interviewed for this study it was reported as transient and no one exhibited signs of denial during interviews. Some authorities believe that all denial is intrinsically wrong and obstructive to the patient's progress. However, for some patients denial serves a purpose, as they need denial to acclimatise themselves to their condition. Others use it as a buffer against distress (Buckman, 1992). Provided that denial is helping the patient adapt to his or her circumstances and that it is not preventing adaptation or adding to distress then there seems to be no benefit to the patient in confronting the condition. Kaye (1996) suggests that denial is a way of coping with fear and that it should be respected as a coping strategy especially if the patient is coping. If the patient changes the subject then he or she sends a very clear message that further information is not wanted at that particular moment in time and Kaye advocates that clinics should never give un-requested information as this can cause anxiety or anger. Few patients adopt a stance of denial permanently, most to start to ask for more information once they feel more secure, and that progression was reported in a

number of interviews. Many patients experience relief once they are able to discuss some of their fears.

Step 4: Sharing the information (aligning and education)

Any interview in which bad news is discussed is an unequal one, that is to say the doctor has information to give the patient and the patient is not yet in possession of that information. The patient's responses are the most crucial part of the interview. An interview can be identified as having two components. One, the divulging of information, by which the professional imparts information to the patient. Two, therapeutic dialogue by which the professional listens to, hears and responds to the patient's reaction to the information. Clearly both the transactions go on simultaneously but for the purpose of the thesis it might be worth considering each component separately.

The Divulging of Information

Most "experts" suggest that even before the start of the interview the doctor should have some idea of what he or she is trying to achieve. Obviously this depends partly on the patient's disease status and partly on their role in relation to patient care. It is clear where a health care professional is not the doctor their role may differ slightly and it may not be their brief to explain the treatment plan etc. Although they still act as an advocate for the patient and how to find out how much the patient understands the illness what his or her main concerns are. In any case it is essential to have some form of objective in mind, without it the interview could get confusing for both the health care professional and the patient. Buckman (1992) suggests four crucial headings for structuring the agenda:

1. Diagnosis
2. Treatment Plan
3. Prognosis
4. Support

During the non-participant observations certainly the first three headings were adhered to but the area of support was discussed on an adhoc basis by all three of the consultants who were observed. Obviously the amount of information to be shared on each of these points depends upon the disease, the treatment options, the patient's preferences, his or her reactions and so on. It may be easiest to state the rough outline of the interview before beginning this part perhaps with a comment such as "I'll start off by telling you about your illness and then what treatment we can offer for it, we could then discuss the future and any other concerns you may have".

A doctor's agenda may not be the same as the patient's. However, from the beginning it is essential to accept that a mentally competent and informed patient has the right to accept or reject any treatment offered and to react to the news and express his or her own feelings in any way which he or she chooses. Whilst this seems obvious many interviews end in frustration because the doctor or health care professional feels that the patient has to accept the proper treatment or has to react in a certain way.

It is recommended that the doctor starts from the patient's starting point (aligning), it is therefore essential to have heard from the patient how much he or she knows about the situation and the vocabulary in which this knowledge is expressed. The doctor should reinforce those parts of what the patient has said which are correct using the patient's words if possible and continue from there. This gives the patient

confidence in himself or herself to realise that his/ her point of view of the situation has been heard and is being taken seriously, even in those instances where it has been modified or corrected. Maynard (1989) described this process as aligning, that is to say the process by which a doctor lines up the information he or she wishes to impart to the base line as it were, of the patient's knowledge.

The next phase of the interview is educating the patient, that is the way in which health care professional helps the patient understand their medical situation. In order to do this effectively it is important to assess the magnitude of the divergence between what the patient understands and the medical facts. Then the process of education begins, changing the patient's understanding in small easily understandable steps observing the way in which a patient responds to each new bit of information. During this process the doctor should reinforce those responses from the patient and emphasise the relevant medical information if it becomes apparent that the patient is moving away for accurate understanding. In order to get this stage right it is essential for the doctor to carefully observe the patient and continually guide them in the direction of the interview rather than moving them too quickly or giving them too much information (both of which were observed during some of the non-participant observations) for them to comprehend at one time. It is therefore important to remember the following points:

- Give information in small amounts.
- Medical information is hard for patients to understand.
- The evidence suggested that most patients' fail to retain up to 50% of the information given and when a diagnosis is serious the information loss may be greater. This was reinforced by many of the patients interviewed for this study:

“I switched off as soon as I heard the word cancer even though I’d prepared myself for it, I just thought oh God I’m going to die”.

“.....You don’t really absorb it all in at that moment and because the initial shock takes over the rest of what they say to you.....”

(Patient No. 15)

It is therefore important to give the information in small easily understandable amounts. One useful technique advocated by Buckman (1992) and Kaye (1996) is using the “warning shot”. If there appears to be a large gap between the patient’s expectations and the reality of the situation, doctors can facilitate the patient’s understanding by giving them a warning shot. Things like “the situation does appear to be more serious than we first anticipated”. Following the warning shot a narrative of events can be an extremely useful technique. This helps the patient understand what has been happening and can provide a logical and intelligible approach to difficult issues saying things like “when you had those bruises, your blood test showed that you weren’t making some components in the blood called platelets they are made in the bone marrow and that’s why your doctor wanted a bone marrow test to see what was wrong. It was that test that showed the problem.....” This approach is not only easy to follow and remember but also helps the patient to frame his or her questions as the story continues.

Using English not medical terminology or jargon is essential for patients understanding. A substantial amount of medical terminology

such as 'staging', 'lymph nodes', 'clinical trial' were all witnessed during the non-participant observations. The languages used by health care professionals are highly efficient and precise and they are capable of transferring a large amount of data about a patient from professional to professional in a short space of time. However, they are only intelligible to the initiated and if the patient does not understand them he or she is effectively excluded from the conversation. It is important to give the patient an understanding of the medical situation, but it is necessary to translate it from medical terminology into English. The use of terminology by health care professionals can be comforting when entering difficult situations such as breaking bad news. Using it to explain something to a patient can make it less likely that the patient will be able to ask difficult questions and it does comfort and reassure the professional who uses it, this in turn isolates and alienates the patient who finds it unfamiliar. It is therefore clear that during a bad news interview it is extremely important to ensure that health care professionals use vocabulary that is intelligible to the patient. A number of patients in this study commented on the language used by health care professionals:

“Dr. B. gave me the scan results which were normal and then went on to tell me that I had a stage 1 seminoma.....”.

(Patient No. 31)

“They couldn't find the primary, that's where it started from”.

(Patient No. 21)

Terms like benign, malignant, colostomy, radiotherapy and chemotherapy were all regularly used without doctors checking the

patients understanding of such terminology and were witnessed frequently during the non-participant observations, invariably the patients observed did not ask the doctor to explain such terminology. It is also important to check that the patient and his or her relatives are receiving the message that health care professionals are giving. This is a vital part of the professional's communication skills and should be done frequently during an interview, breaking up the transmitted information into smaller intelligible sections and then checking out the patients understanding of each section of information. Whilst few patients commented on the amount of information they were given as being too much, during the non-participant observation place of this study, the observer noted a number of interviews where patients were being deluged with vast amounts of information, during these interviews patients became very confused and unable to make appropriate treatment decisions. This occurred most frequently when the consultants were trying to recruit patients into randomised clinical trials.

Buckman (1992), suggests that many different phrases can be used to break up a monologue but the following maybe useful:

- Am I making sense?
- Do you follow what I am saying?
- Does this all seem sensible to you?
- This must be a bit bewildering but do you follow roughly what I am saying?
- Do you see what I mean?

It is helpful to ask patients whether they have understood. However, when you look at the above phrases in black and white they can appear to be quite condescending, but when such an approach was witnessed during the non-participant observations the patients did not

exhibit offence and it seemed appropriate. Buckman does not suggest getting the patient to paraphrase what has been said and this can be helpful as it can assist the health care professional in assessing how much the patient has really understood.

Such interjections serve a number of important functions:

1. They demonstrate that it matters to the health care professional if the patient doesn't understand.
2. They give the patient the opportunity to speak.
3. They allow the patient to feel an element of control over the interview.
4. They validate the patient's feelings. (i.e. make those feelings legitimate subjects for discussion between doctor and patient).

It is essential to reinforce the information frequently and to clarify what has been said throughout the whole duration of the interview. In order to clarify points it is important to repeat important points and to use diagrams and written messages where appropriate. One patient interview specifically commented on the value of using diagrams to explain her surgery.

All of the patients were asked whether they were given written information to support what had been said verbally to them. Some were given information and didn't think it was particularly helpful:

“.....the ones (Bacup booklets) on radiotherapy and chemotherapy are a bit broad and a lot of it didn't apply to my particular circumstances”.

(Patient No. 32)

Some patients, weren't given written information and would have liked it:

"I never got any leaflets or anything, I would have liked them, just to look at for reassurance like".

(Patient No. 20)

Others were given information and found it helpful:

"The booklet (Bacup) on breast cancer was really helpful it explained everything in language I could understand".

(Patient No. 22)

The Bacup booklets are a nationally produced booklet which covers all aspects of site specific disease management without resorting to medical terminology or where such terminology has to be used such as chemotherapy or radiotherapy full explanations for the terms are provided. For example, the breast cancer booklet discusses signs and symptoms of the disease, investigations, treatments, support available, diet, sexuality and so on. The major criticism of the Bacup booklets by health care professionals and patients centres on the fact that they cover all investigations and treatments, some of which may not apply to the individual patient. It is therefore helpful if those that are highlighted at the outset. Some weren't offered information but wouldn't have wanted it either, taking the view:

".....the least I know about things the better".

(Patient no. 3)

This patient felt that too much information might cause confusion or raise fears which he had previously not considered.

None of the patients involved in the study, or the Consultants observed for the non-participant observations used tape recordings of the interview (which can be given to the patient to take home) to reinforce what had been said during the interview. This method is feasible and has been shown to reinforce the interview, but many professionals find it a little too fussy and others feel insecure about having their interviews recorded in the light of increasing litigation against health care professionals. A criticism against taping doctor/patient interviews is that it can make the atmosphere a little forced and unnatural. However, those patients who had their interviews tape-recorded (all 33) for the purpose of the study did not appear to find it a problem and the interviewees did not feel it hindered meaningful discussions. As the interview progresses the health care professional should be conscious of the level at which they are talking to the patient. It is easy to talk down to the patient and appear to be patronising or conversely to assume the patient has a basic understanding at the outset and over estimate their ability to comprehend technical terminology. In order to avoid this it is necessary to check how the information given is being received on a frequent basis and to listen to the language in which the patient replies. If the patient replies using a different vocabulary then it is advocated that the health care professional tries to adapt his or hers to this.

Taking a transactional analysis approach, ideally all doctors and adult patients would communicate adult to adult. However, some patients occasionally may elect for a more parental adult/child pattern of communication, this can be identified by their responses such as when

patients are unable to make a decision and defer to the doctor or relatives to make it on their behalf, health care professionals should accept this initially as part of the patient's coping strategy.

It is important for the health care professional to listen to the patient's agenda and address the issues which are important to the patient and not to the health care professional him/herself. There can often be a divergence between important issues to the health care professional and those issues which are important to the patient. Where the doctor follows his or her own agenda and not that of the patient resentment and anxiety can follow and a trustful relationship will not ensure. Such an example was described by:

Mrs. S. who was concerned about hair loss during chemotherapy, this was a major psychological issue for her and she was very angry when the oncologist dismissed her concerns saying she could always get a wig and steering conversation towards other side-effects which she may encounter.

Whilst Mrs. S. probably needed to know potential side-effects which could affect her due to her chemotherapy, clearly at the time the interview with the consultant occurred, the side-effects were not her priority, but the hair loss was, had the doctor spent time addressing fear relating to hair loss and allowing her to discuss her anxieties and indeed acknowledge that this was a big thing to happen to a woman, then he may have still been able to steer the conversation towards side effects after having addressed the issue that was important to Mrs. S. Instead what actually happened was Mrs. S. did not listen to the rest of the conversation and became very angry that the consultant did not acknowledge things that were important to her. Not only did this interview upset the patient but also it went on to harm the

subsequent relationship with the consultant, because Mrs. S. continued to harbour a lot of anger and resentment towards the oncologist.

A couple of patients interviewed for the study indicated that they were more worried about how they would cope with a stoma than a diagnosis of cancer. It is easy for health care professionals to assume that having cancer would be the primary concern of most patients, clearly this is not always the case and such an example illustrates the importance of eliciting the patients main concerns, where possible addressing them as soon as practicable.

It can be quite helpful to elicit a list of concerns with the most pressing concern at the top of the list and having received the list from the patient it is important to address the most pressing needs first regardless of the health care professional's own agenda. For example a patient maybe more concerned about the effects of a colostomy on his or her sex-life than the side-effects of adjuvant chemotherapy. Some patients such as Mrs. S. are also more worried about hair loss during chemotherapy than the potential risk of their primary disease. It may not be possible to address the patient's primary concerns for a number of reasons. However, in such instances the health care professional should acknowledge them and agree to return to these concerns at a later date, it is essential not to ignore what the patient is saying.

Buckman (1992) describes "buried questions" he suggest that many patients have deep personal worries which do not emerge easily, but sometimes a patient asks questions whilst the health care professional is talking. These question, "buried questions" are often highly significant to the patient. He suggests that when this scenario occurs

the health care professional should finish his/her own sentence and then ask the patient what he or she was saying. However the health care professional needs to be prepared to follow that train of thought from the patient and to acknowledge that it is likely to be an important one.

It is not uncommon for health care professionals to draw an interview to a close and then find that a patient wants to start part of it again. It is important to remember that this is not simply contrary behaviour on the part of the patient but it often stems from fear or insecurity and that by restarting the interview the patient is exerting some measure of control over the consultation. This scenario was evidenced in a number of the non-participant observations where the Consultant was preparing to leave the interview room and the patients started to ask very important questions sometimes even relating to prognosis. For example one patient waited for the conversation to close and the doctor to stand up in preparation to leave the room before he asked, "how long have I got then doctor?" This scenario also happened during a number of the patient interviews conducted as part of this study. Those patients, who re-commenced the conversation once the tape-recorder was turned off, often had very significant things to say. When such incidences occurred the patients were asked whether this information could be utilised and reproduced for the study, they are thus included throughout this paper with the individual patient's agreement.

Mr P recounted his anger when he was a post-operative patient. In an intensive care unit, he was in pain and suffering a lot of psychological distress, finding it hard to come to terms with his diagnosis. He was very angry with the nursing staff because they were laughing amongst themselves, he knew they were not laughing at him but resented the

fact that they were not sympathetic towards his own acute distress. He wanted them to be made aware of how isolated he felt laid in an intensive care bed knowing he had cancer and how insensitive their laughter was at a time when he felt so vulnerable, he really just wanted someone to recognise his distress and felt very concerned that in the future other patients may feel this way too.

He was happy for this information to be included in the study but chose to address his agenda and take control once the tape recorder had been turned off.

Beckman (1992) also advocates trying to blend the health care professionals' agenda with that of the patients. He suggests doing this by obtaining a shopping list from the patient, acknowledging the items on it and trying to include them in the topics that the health care professional intends to cover in that conversation. He suggests that doctors can often state this blending quite overtly, for example, "I know that you are worried about hair loss and I will come to that in a moment, but first can I cover the reasons that we recommend chemotherapy in this situation?"

Step 5: Responding to the patient's feelings

Success or failure in breaking bad news ultimately depends on how the patient reacts to that news and how the health care professional responds to the individual patient's reactions and feelings. Patients will react in many different ways to being given bad news and their feelings are also extremely diverse, however many of the patients interviewed described their reactions/feelings in similar ways:

"I mean it was a shock at first when he told us it was cancer but it was something that you just have to get over and try and hope that you'll be cured".

(Patient No. 2)

"Of course, it was a shock you know, I just drained, I didn't really think it was anything like that you know".

(Patient No. 4)

"I was prepared but even when you're told you are still shattered".

(Patient No. 6)

"You don't really absorb it (the information relating to the diagnosis)"

(Patient No. 15)

"I was just numb, absolutely numb".

(Patient No. 7)

The full range of feelings described by patients during the interviews has been highlighted in the results chapter of this thesis. It is clear that doctors need to respond appropriately to the different feelings and subsequent reactions exhibited by patients when they are given a diagnosis of cancer. As already stated these can range from shock, denial, isolation, numbness and so on, and each reaction requires a

different response from the doctor. It is important for the doctor not to make a value judgement about the way an individual reacts, as he or she is unlikely to know whether this particular reaction is normal in times of stress for that individual patient. Also, any reactions exhibited by that patient will be influenced by their previous experiences of cancer, for example a patient who has had a loved one who has had a cancer diagnosis and subsequently recovered may be more positive and appear to be less distressed than a patient who has known somebody who has had cancer who has subsequently deteriorated quickly and experienced lots of side effects from treatment, or distressing symptoms at the end stages of their disease. Whatever the reactions exhibited by patients it is important for the doctor to acknowledge these reactions and where fears or anxieties are raised to address them.

Step 6: Planning and follow through

After being given the diagnosis of cancer many patients will feel bewildered, dispirited and disorganised. Whilst it is important to be sensitive to those emotions and to display empathy, it is not enough to simply reflect the patient's emotions. The patient looks to health care professionals to make sense of any confusion and offer plans for the future and indeed it is the ability to clarify the situation and plan for the future that distinguishes the professional from a friend or well-wisher. It is therefore essential to have some sort of management plan to offer the patient. Such a plan should offer the clinical perspective and guidance but should also fit in with the patient's own agenda. It is at this stage of the interview that the patient really perceives the doctor/nurse/other health care worker as a "Professional". This stage of the interview can be broken down into five basic steps where the health care professional needs to:

1. Demonstrate an understanding of the patient's problem.
2. Indicate that he/she can distinguish the fixable from the unfixable.
3. Devise a clinical management strategy.
4. Prepare for the worst whilst hoping for the best.
5. Identify the individual patient's coping strategies.
6. Identify sources of support.

The stages will be discussed in more detail in the following chapter.

The final part of the consultation should consist of a summary of what has happened. This serves to reinforce the information given throughout the interview and the patient should be given a further opportunity to ask questions, following this there should be some sort of contract for the future for example "I'll give you a few days to think about what I have said and to decide what treatment, if any, you would like to try and perhaps you could come back on Wednesday to discuss your wishes with me further." The difference between a skilled and unskilled health care professional when breaking bad news is most clearly seen in the abilities and techniques used in coping with patient's reactions. The information divulging component of breaking bad news is relatively simple and can be improved with a judicious choice of words and a few general rules. The difficult component of the interview occurs as a patient reacts to the news they have been given and this reaction can often begin prior to the health care professional entering the room, whether the doctor or the patient realises it or not. This was highlighted during the patient interviews when one patient described how he/she knew that the news was 'bad' because he/she had been kept waiting in the consultation room for a long time.

The range of normal reactions is very wide and it is all too easy to make a diagnosis of "abnormal reaction" in an individual case, therefore ignoring or isolating the patient. The sensation of being cut off or ignored by health care professionals as the result of an implicit judgement of behaviour or response is a common and major cause of patient's dissatisfaction with health care staff. This is not to say that in responding to a patient's behaviour health care professionals are under an obligation to accept that "anything goes" and that any form of behaviour by a patient or relative should be accepted and accommodated i.e. violence against health care professionals should never be condoned, and it is not an excuse to say that violence is acceptable because somebody was angry/upset because of the news that they had been given.

Health care professionals need to be able to assess a patient's reactions and then respond to them Buckman (1992) suggests using the following criteria:

- Social acceptability, a reaction needs to be within the boundaries or cultural norms and rules, for example crying on being told of the diagnosis of cancer are almost universally acceptable, however running wild in a clinic is not.

- Adaptability, the health care professional needs to assess whether the reaction increases or decreases the patient's distress at his or her situation and respond accordingly.

- Fixability, if the reaction is actually increasing the patient's distress then the health care professional needs to determine whether any intervention might redress that balance.

◦ When looking at the reactions patients might exhibit at a time when they are told that they have a potentially life threatening disease such as cancer, it is essential to remember that health care professionals should not be judgmental about the reactions that they are seeing and in most instances they are not appropriately qualified to decide what is “normal behaviour for that individual patient”. However a number of reactions can be seen fairly regularly and it is useful if health care professionals know how to deal with them in a appropriate and sympathetic manner.

Early on in the chapter denial has been discussed, it can be seen as part of the way in which most human beings take on board information that threatens to overwhelm them. It can therefore be viewed as adaptive in the early stages of taking in bad news when it may allow the patient to cope with that bad news one step at a time. However, if denial is prolonged and later stops the patient from making rational decisions then it becomes maladaptive.

Similarly, a patient crying when told they have cancer may be part of the way that individual copes with bad news but prolonged tearfulness (say over several interviews over many days or weeks) is part of a more severe problem and needs to be addressed. Buckman (1992) suggests the following main reactions and categorises them as either adaptive or maladaptive:

Adaptive Reactions

Humour

Denial

Abstract anger

Crying

Fear

Maladaptive Reactions

Guilt

Pathological denial

Anger against helpers

Collapse

Anxiety

Fulfilling an ambition	The impossible quest
Realistic hope	Unrealistic hope
Sexual drive	Despair
Bargaining	Manipulation

It is clear from the results section of this thesis that the patients interviewed exhibited a number of the reactions cited above particularly fear, anger against disease, abstract anger and also crying was noted during the non-participant observations and some patients cried at the time that they were actually being interviewed.

It is important to remember that some of these reactions will give the patient an immediate short term decrease in distress but if they persist may lead to long term problems. Denial provides a useful example; if a form of chemotherapy has a low chance of success a patient might say something like "Well I can't even contemplate it not working". This might decrease the patient's distress temporarily but if this viewpoint prevails and the treatment does fail there will come a time when the patient may have to face that outcome. In such instances the patients then find it much more difficult to make realistic plans when they are suffering deep disappointment and perhaps even despair.

It is therefore important that health care professionals need to consider what may potentially happen next to the patient if they continue with that particular reaction. It is important to try and assess whether the reaction will continue as the disease progresses because it has implications for the sort of support a patient may subsequently require.

As already stated, the first criterion in assessing the patient's reactions is social acceptability, the second is adaptation, that is to say, helping

the patient to adapt to the circumstances or not, the third criterion relates to maladaptive responses and that is fixability, if this particular response isn't helping the patient then is it appropriate to intervene to reduce the distress or not? If health care professionals cannot intervene successfully are there other professionals who could improve the situation? In some instances it is necessary to acknowledge that some distress is unfixable, this is often hard for members of the caring professions to accept particularly when they are dealing with patients who cannot be cured and may feel that they have already failed that patient once.

It may be worth using Buckman's criteria as part of the caring strategy i.e. using it as part of a psychological inventory which could be carried out prior to treatment as it would provide the health care professionals with clues regarding the type of support subsequently required by individual patients.

Conflicts between doctors, their patients and or families are not uncommon, particularly when a patient has been recently diagnosed, or is not responding to treatment, or the future looks bleak. In reality it is not uncommon for tempers to become frayed where patients are frightened and professionals see themselves as being challenged. It is clear that in such instances all parties apparently share the same objective i.e. the very best for the patient but there often seems to be disagreements about what is actually best for the patient. It is clear that no health care professional likes conflict between themselves and patients or relatives and though it seems obvious to state this it is essential for the health care professional to remain calm during a health care professional/patient conflict. Buckman (1992) suggests that the most important guideline relating to this is don't forget the basic rules, the greater the conflict the more important it is to stick to

the basic rules of interviewing (prepare – question – listen – hear – respond) and the six steps of breaking bad news which have been discussed in this chapter. During the non participant observation part of the study a couple of examples of potential conflict were noted particularly in one instance where the relatives of a patient were particularly aggressive towards the doctor mainly due to their frustration and anger around the fact that it had taken a long time for the patient to be referred to the oncologist by a previous medical practitioner. The doctor remained calm and refused to be drawn in to a discussion denigrating her colleague. She moved the conversation on by acknowledging their frustration and anger and trying to address their major concerns, which centred on their wish for their mother to be treated as soon as possible. The doctor focused on this priority rather than allowing herself to get into a discussion regarding her colleague. Ultimately it appeared to the observer that she managed to steer the conversation towards the family's real concern and priorities whilst remaining professional and not being side tracked into a discussion about her colleague. Other examples of conflict between health care professionals and relatives were described by patients throughout the interviews and these tended to be related to frustrations around a patient being given a diagnosis:

“While D. (her son) came in, took one look at me and phoned the doctor immediately, it was the stand-in service and then the doctor spoke to my son for quite a while, he said he would arrange for an ambulance to take me into hospital. My son got a bit angry about that, not because the doctor wanted me to go into hospital, but because he couldn't see the point in coming out to examine me..... The ambulance came about two hours later, by that time D. was full of hell, because he could have got me there earlier himself and I was in agony because of the pain and D. was

furious because of the stand-in doctor and the wait..... They put me in a bed and left me for another hour and a half before they got a doctor to see me and I hate to say D. was a bit rude to the nursing staff but that was because he was really worried about me”.

(Patient No. 24)

When such incidences do occur it is important for health care professionals to take “one step back”, this involves trying to assess the patient’s own emotional stance and not focusing on the health care professionals own point of view. As part of the same process it is helpful if the health care professional could try to understand what emotions they are actually feeling and describe it to the other party instead of displaying it. So instead of the doctor saying something like “look I have already told you there is not a shred of evidence that a diet makes any difference, just forget about it and eat what you like”. It may have been more helpful if the doctor had responded in a different way, for example, “I am sorry if I am sounding impatient but I have told you the facts as we know them today, having a special diet and vitamins won’t affect the outcome of breast cancer, no matter how many times I say this it won’t change the situation and those are the facts.”

Being calm and rationalising emotions will certainly improve the chance of resolving any conflict without bad feelings on both sides.

It is also helpful to achieve some sort of mutual definition surrounding the area of conflict in some instances where agreement cannot be achieved it may be appropriate to agree to disagree. This might be important in terms of the relationship between a health care

professional and his or her patient and may be the only way of resolving conflict and maintaining a "workable relationship". The objective should be to define as precisely as possible the area of disagreement so that both parties can agree the boundaries surrounding that area.

It is essential that where conflict occurs, health care professionals try not to be pushed too far from the truth of the situation. For example it is easy to respond to an over anxious patient with over reassurance and over optimism, and whilst hope is important to all patients there is ultimately a risk of the patient becoming distressed and the doctor/patient relationship being ruined when such promises fail to materialise. Another common reaction exhibited by patients when they are told of the diagnosis of cancer is that of disbelief, patients use phrases like "I don't believe it" and "I can't believe you are talking about me". Patients do express disbelief quite frequently and their intention is not to provoke an argument with the doctor but merely to register the fact that they are having difficulty taking the news in. Very often acceptance of the news can be demonstrated in the way that they react or by statements that they make. The combination of stated disbelief combined with actions and plans which show acceptance is quite common, for example a patient may say "I can't believe you are talking about me" but then plan to write a will or teach their husband to cook so that he will be able to cope should the worst happen.

It is necessary to move the patient and the conversation forward after divulging a diagnosis of cancer and not to get stuck at the point where they have difficulty in accepting the news. For example a 49 year old lady who exercises regularly who has never smoked and who develops lung cancer, which is picked up on a routine chest x-ray may find it difficult when a doctor says "the x-ray shows a tumour in your

lung which is cancerous" the patient may respond by saying "but I can't have lung cancer, I've never smoked and I keep fit". It may be appropriate for the doctor to respond by using an emphatic response such as "it must be very hard to accept a serious illness when you feel so fit". Such a response identifies the cause of the difficulty but it also allows the doctor to confirm the accuracy of what he or she has already said.

Shock is an extremely common reaction to a diagnosis of cancer and was discussed by many patients during the interviews. It may be caused by many different emotions such as fear, anger or sadness as well as by the bad news itself. It is useful to think of shock not as an emotion in itself but as a behaviour indicating a degree or intensity of emotion with which the patient is unable to cope. A diagnosis of cancer may be too much for the patient to come to terms with whilst still operating normally and shock is therefore a measure of the severity or depth of the emotion rather than a separate emotion itself.

Shock manifests itself in many different ways. Some patients use very dramatic gestures. Other patients may hug themselves and rock in the chair, but perhaps the most common symptom of shock is silence, where the patient is simply unable to speak or respond to what is being said. When patients exhibit such a response a number of reactions may be appropriate. Firstly, it may be appropriate to use an open question such as asking the patient "what are you thinking about right now" this open question is the text book psychotherapeutic response to a significant silence and when doctors use this approach they are indicating that they are prepared to listen to what comes next. An empathetic response may also be appropriate, an example of this would be the doctor saying "this must be overwhelming for you" with this sort of response the doctor is indicating to the patient that it is

okay to feel overwhelmed by bad news and this feeling is not unexpected nor is it abnormal. Buckman (1992) suggests that this sort of response can be very useful when a patient seems stunned into silence.

Another way of responding would be to use attentive silence, this is when the doctor indicates by body language and non-verbal cues their willingness to listen, without actually saying anything verbally, such an approach may allow the patient to express a deep seated concern. Indeed this seemed to be the approach favoured by the Consultants who were observed during the non-participant observations as they all appeared comfortable with silence and their body language remained open and receptive towards the patient.

This chapter has covered the theory of communicating bad news using Buckman's (1992) six step protocol which aims to tell health care professionals 'how to do it' it divides breaking bad news into the following stages:

1. Getting started
2. Finding out how much the patient knows
3. Finding out how much the patient wants to know
4. Sharing the information
5. Responding to the patient's feelings
6. Planning and follow through

The relevance of the model to health care professionals working with cancer patients awaiting a diagnosis has been discussed and examples have been given regarding how health care professionals can utilise this protocol. The data from the non-participant

observations and patient interviews has been used to support and illustrate the theory presented.

The following chapter aims to explore what the patients really want from the health care professionals at the time they are told that they have cancer and in the initial stage of their cancer care.

CHAPTER 7

What the Patients Really Want

The purpose of this chapter is to explore those issues, which are important to the patients themselves, and which may improve or enhance the way patients are given bad news.

A number of issues were raised by the patients during the interviews carried out as part of this study, one key issue is the fact that many patients wanted the doctor to acknowledge how they were feeling and perhaps most importantly tell them what he or she was going to do from a clinical perspective in order to manage their disease:

“I just wanted them (the doctors) to tell me what was best for me and I just wanted it all over”

(Patient No. 19)

One patient who had an idea of his diagnosis did not appear to be unduly distressed where his fears were concerned but he saw the fact that the doctor had something to offer him as being very helpful and positive:

“That the good news was that he could give me some tablets that would help now and he got the Macmillan Nurse in to advise about them and arrange follow up whilst I was waiting for radiotherapy which would hopefully keep the cancer under control and stop the pain. I told him I was concerned that it may have spread to other parts of my bone and he was very good and

said prior to the radiotherapy he would arrange for a bone scan so that we could check if it was elsewhere”.

(Patient No. 20)

Clearly those patients who were given a straight forward explanation of what was the most appropriate treatment for them valued this sort of approach, but for some patients there are more than one treatment which may be appropriate and the doctor needs to advise the patients of the options that are available to them, however, many of the patients who had experienced being given a number of choices found this confusing. One patient encapsulated the view of many:

“Perhaps not to have given me too many choices, I just wanted to be told what was best for me and I would have gone along with that, however I appreciate in these times of informed consent and patient’s rights doctors can’t function like that anymore”.

(Patient No. 31)

It is clear from this and other interviews that there is a fine balance between ensuring that the patient is aware of the different options available to them and overloading them with information to the point where they feel they cannot make an appropriate decision. In such instances it may be helpful for the doctor to give written information to support what has been said verbally and invite the patient back in a few days time or the following week to discuss things in more detail or alternatively it may be helpful to have a Clinical Nurse Specialist available at that consultation so that he or she can hear what the doctor has actually said to the patient and then offer support at home where they may feel more relaxed when they have had time to think things over, he or she could then go over the details again and

address any questions the patient may have before they reach their final treatment decision.

All patients need to have some sort of plan or strategy regarding their subsequent management. Where this has not been given patients feel as though they have been let down by the health service, even when they know they are being referred on to another health care professional which happens fairly frequently or when they have been given someone as a point of contact.

If we consider Buckman's six stage protocol, stage 6 focuses on planning a patient's care and follow through, he suggests that this stage of the interview can be broken down into five basic steps where health care professionals need to:

1. Demonstrate an understanding of the patient's problems in the order in which the patient acknowledges them.
2. Indicate that he/she can distinguish the fixable from the unfixable with both medical problems and psychosocial problems, some problems are fixable whilst other are not and it is unhelpful to dwell on those that can not be changed.
3. Make a plan or a strategy and explain it, it is quite permissible for that plan to include many uncertainties, don't knows and choices. For example the doctor may tell a patient "we hope that if we give you chemotherapy at this stage then the cancer won't come back, however we can't give you any guarantees of this, the alternative is to do nothing and to monitor you closely and if you get any problems consider giving you chemotherapy at a later stage." Making a plan or strategy defines the immediate future for the patient and defines the course of the doctor/patient relationship. It also reinforces the individuality of the patient and what the doctor is going to do for him or her.

4. Preparing for the worst and hoping for the best. With contemporary emphasis on positive attitudes there are still a number of health care professionals who resist and criticise those who help patients to make plans for the worse scenarios (which are deterioration and death). But it is important in the management of cancer patients that they are not given false hope and where appropriate do have the opportunity to make plans in event of their death. It may not be inappropriate to suggest that a patient draws up a will, because drawing up a will does not cause instant death nor will it rob the person of his or her will to live (Lovestone & Fahy, 1991). It is normal to constantly make plans and then live as if those plans would not be needed, in helping patients to adjust to the future it is often worth stressing such a point very clearly. Buckman (1992) suggests a useful phrase is something like "preparing for the worst doesn't stop us hoping for the best" and this also allows health care professionals to reinforce the fact that this is a normal way of functioning.

Whilst such recommendations seem cold when printed in black and white in practice most patients appear unperturbed when the discussion follows such a course.

5. Identifying the coping strategies of the patient and reinforcing them. It is essential that the patient helps him or herself and it is counter-productive not to assess and assemble the coping strategies and support systems that are available to the patient. Health care professionals should begin to look at the psychological resources and resourcefulness available to the patient and begin helping the patient evaluate what he or she can do for him or herself.

As stated in the previous chapter it may be helpful to carry out a psychological inventory on each patient prior to commencing treatment, as it will identify areas where the patient requires support.

One way of helping a patient cope is by putting him/her in touch with a Clinical Nurse Specialist who can provide him/her with support once they leave the hospital setting. A number of patients interviewed were offered Clinical Nurse Specialist support and contact number and utilised it:

“The person who explained all about the operation..... Was the Stoma Nurse BH..... (she) cleared up any little worries I had.....”.

(Patient No. 16)

She was excellent.....she was very supportive”.

(Patient No. 5)

“I’ve said to everyone I wouldn’t have got through it if it hadn’t been for Nurse I”.

(Patient No. 15)

Others were offered Clinical Nurse Specialist support and a contact number and did not utilise it:

“Yes well I thought if I ever needed anybody, it was nice to know that there was somebody out there”.

(Patient No. 30)

This patient found the offer of support reassuring but due to her own coping strategies and existing support networks did not feel the need to use it.

“The Macmillan Nurse gave me her name and telephone number well read it and you push it to one side because you don’t want to know”.

(Patient No. 3)

This patient felt that contacting a Clinical Nurse Specialist might raise painful issues and would rather cope by “pretending life was normal”.

Some were not offered Clinical Nurse Specialist support and a contact number and felt it would have been helpful:

“No I got no support at that time. I was just left to go home and get on with it, and yes it would have been really nice if someone could have come out to see me at home to go over things again in those early days”.

(Patient No. 29)

This view was echoed by a number of patients and there seemed to be a view that repetition of information would have helped them adjust and it would have been particularly useful if it could have occurred in an environment where they felt safe such as their own homes. Also some patients viewed Clinical Nurse Specialists as “less threatening” and more likely to use language they would understand. Others were not offered Clinical Nurse Specialist support and, had they, would not have used it and would probably not have found it helpful:

“No I wasn’t given any contact numbers for support but to be honest I just didn’t want to know at that time”.

(Patient No. 9)

It is clear that all patients cope in very different ways and use different mechanisms to assist them in this process, however it would be useful if patients were all offered the same resources and then at least they could make a meaningful choice as to whether such resources were helpful or not, it would also assist practitioners in assessing what is a meaningful intervention for audit purposes.

6. Identify other sources of support for the patient and incorporate them. There may be a number of people who are “non-professionals” who can assist patients as many patients have at least one or two friends or relatives with whom they are very close and from whom they can gain additional support. For those patients who have no social support of their own it may help them to have access to whatever social service, voluntary or hospice support may be available in their neighbourhood.

During the interviews a couple of patients alluded to the need for hope to help them cope with their diagnosis. What is quite clear is that the health care professionals should not take away all hope from patients. Sometimes this might seem quite difficult to do, particularly when a patient’s prognosis is poor and it may be about “altering the goalposts” for example giving them hope relating to a good quality of life to enable them to do the things that they wish to with the time that they have got left as opposed to falsely giving them hope for a potential cure.

Humour can be seen as an important behavioural mechanism by which some people cope with the world, and put into perspective certain threatening events that might otherwise seem overwhelming. Indeed two of the patients interviewed commented on humour as being valuable to them:

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

(Patient No. 28)

“I felt so much better and even went out laughing”.

(Patient No. 30)

Humour is important for some people and vital to their coping mechanisms, but it is important to remember that it is not part of every individual's armoury and humour is a very subjective thing, what will lighten the mood for one patient may be deemed as frivolous and inappropriate by another patient. It is therefore vital to take your cues from the patient and if a patient makes a joke first then he or she is showing a desire to be distanced from his or her suffering and is rising above it. It is essential for the health care professional to respond to that humour, encourage the process and reinforce the patient's coping mechanism. It is evident that when it comes to humour the health care professionals need to respond to the patient's humour and take the lead from the patient rather than inflicting their own humour upon the patient. Such a pre-emptive strike has the potential to go badly wrong.

There is a school of thought that suggests that laughter can influence the outcome of serious diseases and therefore should be seen as therapeutic. However not all laughter is humour and some patients laugh when they are tense and their laughter can be misread as an indication of ease. Not only can laughter be a false signal but some patients use jokes as a substitute for coming to terms with the situation. In such instances the health care professional needs to tread very carefully and may need some specialist advice or help in dealing with the patient who uses humour as an escape instead of a coping mechanism. The way to identify inappropriate humour is by being on the alert for discordance that is to say disparity between the content of the speech and the facial expressions of the patient. Although it may seem surprising some patients greet medical bad news such as the diagnosis of cancer with relief. This happens most commonly when the patient has had an illness which has been prolonged and or difficult to diagnose or which has caused symptoms which are particularly distressing or which have not been believed. One of the patients interviewed commented that he/she was actually relieved at the diagnosis of cancer because at least once they knew what was the cause of the symptoms the doctors would then be able to go ahead and treat it and that the fear of the unknown was actually worse than dealing with the reality. Obviously for these patients relief is not an inappropriate reaction, the health care professional then needs to assist them in coming to terms with their diagnosis.

Honesty was a trait valued by five of the patients interviewed, with one patient describing how it is necessary for the doctor to be honest whilst at the same time not raising false expectations.

A number of patients commented on the attributes of kindness, caring, niceness and so on in conjunction with professionalism, however

interestingly three patients use the term professional in a derogatory manner, indicating that their doctors were "cold", "unsympathetic", and "clinical". One patient commented, "the way in which the information was given was very clinical". He went on to say that the doctor who gave them the diagnosis was not particularly caring and "fortunately my wife and I are very strong people and other than the shock of having it confirmed ... we were concerned about more vulnerable patients ...".

It seems then that there is a fine line that health care professionals and doctors in particular have to tread between appearing to be caring and sympathetic towards patient's plight whilst still being able to exhibit the clinical knowledge and skills required in order to appear credible. Being too professional, that is to say focusing very much on the clinical aspects of the disease and not on the person him or herself can hinder the development of rapport and a productive relationship. It appears that doctors and perhaps some of the professions allied to medicine might be assisted by their nursing colleagues with regards how to address this problem as nursing attempts to look at the patient holistically as opposed to a collection of signs and symptoms. It is clear that the concept of caring is elusive in medical practice. The way in which doctors learn to care, or at least begin to learn is heavily influenced by the process of socialisation through which all medical students have to go. By definition this is a transforming process but there is little evidence to suggest that there is much emphasis given to aspects of caring as students travel through that process. By acknowledging work undertaken primarily in the fields of nursing and bioethics those responsible for educating doctors can go some way towards understanding what is meant by caring in a medical context. It is essential to encourage an empathetic approach to all aspects of medical practice and medical students need help to learn who and

what they are and how they might be better equipped to support and care for people with a life threatening diagnosis. Listening to the stories of patients, reading the work of other clinicians and writers who are able to portray what it may be like in the real world of someone who is potentially dying and allowing oneself to identify with people in that predicament are all ways in which an understanding of the notions of care in the cancer and palliative care must embrace a broad concept of health and illness in order that the doctors of the future know what it means to truly care. However despite such sentiments the concept of caring is an illusive one, it does not mean the same thing to individual patients. Some patients associate caring with someone who is nice (whatever that may mean). Others think health care professionals are caring because of what they say, such as expressing their own sorrow that a person has got cancer. The tone in which a diagnosis is given can indicate a caring professional to some. For others gestures such as a pat on the arm or holding a hand can indicate a caring professional.

In the last few years the concept of caring has been discussed at length by both nurse academics and nurse practitioners however, when asked to define what caring is very few health care professionals could articulate its definition in real terms. Indeed most of the relevant writing on caring for ill and dying people has been provided by the nursing profession and remarkably little has come from the medical profession. Cancer and palliative care must include respect for autonomy, justice, nonmaleficence and beneficence. The concept that death may be the inevitable outcome of the diagnosis of cancer exerts a powerful influence over what is said, received and interpreted and health care professionals must relinquish control, share the decision making and treat patients and their families as partners in care. Latimer (1991) suggests that health care professionals should act with

humanity and they have an obligation to provide caring concern. MacLeod (2000) suggests that caring can be thought of as a behaviour or as a motivation. As a behaviour it is often thought to be looking after people and seeing to their needs, as a motivation it can refer to being fond of someone, feeling sympathy or empathy or being concerned with their well-being or having a professional commitment to them. It could be argued that the most effective caring professionals show both of these aspects of care. If they care about anything or someone it is because deep caring is part of the very nature of their being, Van Hooft (1996).

Humanistic models of caring are characterised by caring as a moral obligation or duty. An individual has an obligation to promote the good of someone with whom he or she has a special relationship, such as the doctor/patient relationship. This is the type of caring that doctors and nurses are called upon to exhibit and are expected to provide. It is a caring created by the obligation to act in a beneficent manner. May (1969), Leininger (1988) and Roach (1984) support this view, and contend that care is one of the most powerful and elusive aspects of our health and must be the central focus of the helping and healing professions. MacLeod (2000) suggests that examination of the literature on caring establishes it in varying perspectives. "Caring interactions are interpreted as helping the recipient to overcome separation from others. Caring helps people to grow. One must know the person to understand the others needs and transform that knowledge into action" (MacLeod, 2000). Marcel (1981) suggests that caring is more than a physical presence. Existential presence involves availability, openness and giving to others so that a sense of value and respect are communicated. Caring is expressed in compassionate and competent acts in relationships qualified by

confidence through an informed sensitive conscience and through commitment and fidelity.

The most abstract characteristics of a caring person are that he or she is somehow responsive to a person as a unique individual, perceives the others feelings and sets apart one person from the other and from the ordinary, (Watson, 1988). Watson also suggests that care begins when an individual enters into the life world or phenomenal field of another person and is able to detect the other persons "condition of being", that is to say people who care should respond to that condition of being in such a way that the patient is able to let go of subjective feelings and thoughts he or she have been longing to release. Such a response depends upon a number of elements, firstly there is the moral commitment to protect and encourage human dignity so that individuals can understand their own sense of meaning. Secondly, there is the need to affirm the value and significance of the other and thirdly, awareness and attempt to understand the feelings of another (by an attentive presence in the relationship). Finally both parties i.e. both health care professional and patient need to be aware of the relationship and acknowledge that previous life experience exerts a power influence of that relationship (Watson, 1988).

MacLeod (2000) suggests that one of the challenges for medical educators in particular is to try to identify which of the aforementioned models of care is most appropriate for doctors in training. Grant (1998) has suggested that "medical education is about learning to be a doctor by being a doctor". Bligh (1999) suggests that learning through caring means using clinical contact as the prime element of the educational processes; however MacLeod (2000) suggests it is much more than that as modern medicine is founded on extensive and arduous scientific education aided by increasingly sophisticated

diagnostic tools. It seems clear that what health care professionals and doctors in particular need to be able to do is ultimately be able to understand how a disease affects each individual and to be able to move on from the difficulty of making a diagnosis to the more challenging aspects of medical care such as supporting patients effectively when they are giving a life threatening diagnosis and supporting them at times when active treatment and cure are no longer an option.

Despite all of the philosophical arguments associated with definitions of caring it is clear that whatever it is, patients feel it is important. During the interviews a large proportion of patients discussed the professional attributes of the doctors and other health care professionals with whom they had come into contact. The patients used descriptors such as "nice", "kind", "patient" and "caring" though they did not go on to define what these terms meant to them. In some instances professionals were deemed as being caring when they did something practical like offered a tissue to a crying patient or when they reached out and responded to a distressed patient by using touch that is to say patting their hand or putting their arm around them. In other instances caring seeming to be a much more intangible thing, indeed one patient commented, "she (the junior doctor) looked as though she cared".

At the interviews carried out as part of the study a number of issues have been identified which are of particular importance to the patients themselves and should enhance the experience of being given bad news. No patients like to be told that they have a diagnosis of cancer but some of the pain can be taken out of that news by a skilled health care professional who is honest without raising false expectations, who offers a realistic plan for management (even where that

management is palliative and a cure can not be attained) and who shows the patient that he or she is genuinely interested in them and cares about their situation and what they are going through. Clearly communication skills can be taught and with practice people can improve these skills, the Consultant Managers and Clinical Nurse Specialist who were interviewed in the third stage of this study also supported this view. However the art of caring (whatever that may be) might not be quite so easy to teach, but it is worth all health care professionals knowing that if they can manage to exhibit this trait it will be valued highly by many of the patients and relatives with whom they come into contact and it may make the difference to them coming to terms with their circumstances, rather than them potentially wasting time on blaming a doctor for their illness primarily because of the way they were told, or because the doctor failed to exhibit that he or she cared. Other issues were identified by patients as being helpful, one of these issues was the availability of ongoing support, provided by a multi-professional team and the need for continuity of care, these issues are to be focused upon in the following chapter.

CHAPTER 8

The Evolving Role Of The Clinical Nurse Specialist In The Multi-Disciplinary Cancer Team

Many of the patients interviewed, as part of the study were cared for by a number of health care professionals, including physicians and or surgeons, clinical oncologists and Clinical Nurse Specialists, which were either breast care nurses, stoma nurses or Macmillan nurses and in some instances patients were also cared for by palliative care consultants.

Advocates of a multi-professional approach in oncology can be found in the literature (Calman and Hine, 1995; NHS Executive, 1997; Department of Health, 2000). Where such an approach is effective it can benefit the patients in a variety of ways including:

- Providing a consensus regarding individual patient management in the absence of clear guidelines.
- Improving communication between professionals.
- Ensuring continuity of the information given to patients and other health care professionals.

One patient described how she had been seen by a surgeon who gave her diagnosis and explained that she may also need to be seen by a cancer specialist, she also went on to explain the support that she was offered by the Macmillan nurse and how she felt about it:

“Yes well, I was told I had cancer of my bowel by Mr S (surgeon), this was after he had looked at my bowel with a special camera and took biopsies of something which looked abnormal down

there. Then he got back to the clinic and told me that the biopsies were cancer he did say I might need some additional treatment, probably radiotherapy, no I mean chemotherapy just in case any cells had already spread elsewhere but, if I did I would see a cancer specialist to discuss it the Macmillan nurse who was with him did provide written information, she spoke to us for ages and gave us a Bacup book on colorectal cancer, later she also gave us a similar book on chemotherapy and the other thing she did was give me a phone number for other support in case I needed it.”

(Patient No. 5)

The patient was asked about the quality of the leaflet and she responded:

“They were really helpful and we read them a lot and the nurse who gave me her number was so approachable and supportive, I rang her a couple of times and she was always a great help”.

(Patient No. 5)

When asked what happened next the patient responded:

“Well I saw Dr B (the oncologist) in the clinic and the same Macmillan nurse was with him, we found that reassuring”

(Patient No. 5)

The patient managed to highlight how she felt reassured by the fact that there was a familiar face in the clinic, when she went to see a

doctor who was new to her. She felt that the professionals responsible for her care were communicating with each other, that they all had an agreed view about how she should be clinically managed. Once the tape recorder was turned off the patient also commented on how it was “nice” that the Macmillan nurse kept her GP informed of what was happening after her hospital visits. If she developed any problems whilst she was at home that the Macmillan nurse and GP could potentially visit together if that was necessary. Whilst she had not experienced this sort of joint visit, she felt reassured knowing that it could happen, if necessary because, she felt that the Macmillan nurse would ensure that her General Practitioner was fully aware of her hospital treatment and what the surgeons and oncologists plans were for her. This lady was not convinced that a hospital letter would convey the same level of information.

This patient highlighted three health care professionals in the hospital setting and her General Practitioner in the community, who were responsible for her medical care. The multi-professional cancer team should include medical and nursing staff with specialist knowledge in the diagnosis and treatment whether it is curative or palliative management of cancer. Such teams should have a lead clinician who should take managerial responsibility for the service as a whole, the core members of such a team should include: -

- Lead clinician with a specialist interest in the management of that particular cancer e.g. lung, colorectal, breast, gynaecological, etc.
- Radiologist (to assist with interpretation of scans, x-rays etc.).
- Pathologist/cytologist (with expertise in diagnosing cancers).
- Clinical Nurse Specialist with specialist knowledge of that particular cancer (he/she should be available to provide patient support and

advocacy, to facilitate communication and the flow of information and to liaise with other services both statutory and voluntary).

- Oncologist (preferably with an interest in the specific cancer managed by that team).
- Palliative care specialist (this link is essential particularly where the patient has a poor prognosis from the point of diagnosis such as in the case of the majority of lung cancer patients).

(NHS Executive, 1997).

Other team members may differ depending upon the individual cancer to be managed, for example a colorectal cancer team will also include a surgeon with expertise in colorectal cancers. Upper gastrointestinal team may have a dietician as part of the core team due to the difficulties in swallowing/dramatic weight loss experienced by such patients. Some teams are fortunate to have a social worker and or a psychologist as part of their membership whilst others do not; this is often dependent upon the resources of the individual trust.

The team's role includes both direct care for patients and families with complex problems and the provision of advice, support and education for other health care professionals who are involved in patient care such as the Primary Care Team. At any one time there should be a named clinician to whom the patient principally relates e.g. in the case of lung cancer it may be the respiratory physician in the early stages of the disease and the palliative care physician at the later stages. Such arrangements should be explicit and clearly understood by patients who should be given information about the members of the teams involved in their management.

(NHS Executive, 1998)

None of the patients interviewed, mentioned any other health care professionals, apart from physicians, surgeons, oncologists or Clinical Nurse Specialists. However perhaps this is due to the fact that patients tend not to place such importance on some of the other professionals such as radiologists who interpret scans and x-rays or the pathologists/cytologist who actually look at the specimens under a microscope. Without these health care professionals working together and communicating well the patient's diagnosis cannot be made nor can an appropriate treatment plan be presented to the patient for discussion. Despite recommendations from the NHS Executive (1998) none of the patients interviewed referred to knowing about the members of the teams involved in their management, however this could have been due to the fact that they were not specifically asked about this issue or simply that they did not know.

At the time that the interviews were conducted, specialist cancer teams should have existed for the "common cancers" such as lung, breast and colorectal cancers. However, those patients suffering from these cancers who were interviewed as part of the study did not appear to be aware of this multi-professional team approach and most patients certainly did not appear to benefit from professionals who communicated well and co-operated effectively prior to the patient ever being seen. One patient commented:

"He (the surgeon) said he entertained hopes of me not having chemotherapy but Mr B (The oncologist) though it would be advantageous"

(Patient No. 1)

In this instance, the patient felt that the surgeon and the oncologist were giving him conflicting advice, because initially the surgeon had said he hoped he didn't need chemotherapy. The patient had not been made ware (or if he had, failed to remember) that the surgeon could not be sure of this until he had got histology results back, which would confirm how advanced his disease was and whether or not he would need follow up treatment. By the time the patient saw the oncologist, those test results were available and therefore the oncologist provided advice on the information that was available at that particular time. Clearly had the patient had this explained to him and had he understood what was being said, he would not have seen this as a situation where he was being given conflicting advice. In such instances if the patients were aware of the patient pathway i.e. who they should see at different times of their disease journey and what to expect from those health care professionals, this sort of misunderstanding may be prevented.

Another patient reported being unsure as to whom he was actually seeing at a particular clinic appointment and indeed what he was actually doing there:

“At that stage we were uncertain um....., we simply knew that this was well, possibly the head of the oncology department within the hospital um....., the man who would make recommendations and suggestions for treatment. We were aware he was not a surgeon and not a radiologist and we were uncertain as to his status vis-a-vie myself as the patient.”

(Patient No. 11)

If this patient had been aware of a patient pathway which detailed which health care professionals he would see at a particular stage in his disease journey and which also highlighted what he could expect from each other individual health care professional such misunderstandings may have been reduced.

Where a team approach was not employed and the initial consultant making the diagnosis was not a 'cancer specialist' this meant that patients were basically given their diagnosis without any information regarding treatment or prognosis. They then had to wait some time before they were referred elsewhere for 'specialist intervention':

"I was given the diagnosis at Hospital B., Dr S. gave me it and he never really went into too much detail, because he said he wanted me to see Mr M (at a different hospital) and he said he would explain everything in detail".

(Patient No. 14)

It is clear that where a multi-professional team functions effectively the benefits can be great. The most important benefit of team working is that it facilitates co-ordinated care and improves communication between the health care professionals involved, ensuring that the doctors are all aware of the agreed management plan (based where possible on evidence) to be discussed with the patient. This in turn also reduces the amount of conflicting information given to patients by the health care professionals involved. Patients that are managed by a multi-professional team are more likely to be offered a range of effective interventions at appropriate times and to receive seamless care through all stages of the disease. Having a well co-ordinated

cancer management pathway is a pre-condition for optimal diagnosis, treatment and palliation.

(NHS Executive,
1997)

One patient who had experienced a multi-disciplinary team approach, having had a Clinical Nurse Specialist meet him at the time of diagnosis in the surgeon's clinic and then also being available at the time that he saw the clinical oncologist, found the continuity and the support which was offered at all stages of his disease journey to be most reassuring:

“Having her, the nurse there in both Mr S’s clinic and Dr B’s clinic was really helpful there was a friendly face and that made me relax a bit more and it was also reassuring to know that all the health care professionals involved were communicating and working together”.

Another patient reflected:

“I had meetings with both the surgeon and the radiologist (he meant the oncologist), all extremely professional and comforting. A Macmillan nurse was present on all occasions, this offered calm and quiet support there was always a contact on the end of the telephone if at any stage we felt the need for assistance or a quiet word. I do think vulnerable people would find this lifeline exceptionally helpful.”

(Patient No. 11)

Where there are dedicated nurses with the specialist knowledge of cancer available to patients they are likely to improve information flow to patients, increase satisfaction, improve pain control and symptom management and reduce patient's distress during later stages of the illness. Numerous reports exist endorsing the importance of the availability of Clinical Nurse Specialists in the practice of cancer and palliative care service delivery (UKCC, 1996: UKCC, 1998: RCN, 1996: Calman-Hine, 1995: NHS Executive, 1997: Department of Health, 2000).

When discussing Clinical Nurse Specialists it is important to differentiate between a nurse working within a speciality such as on an oncology ward and a Clinical Nurse Specialist. Nurses working in specialities provide everyday care to patients in wards and departments in cancer units and centres. Such nurses are in practice based positions with limited in-depth knowledge and experience. Although they are experienced in the care of cancer patients they need to draw on the expertise and support of Clinical Nurse Specialists. Clinical Nurse Specialists are generally registered nurses who have successfully completed higher and advanced level educational programmes. They possess in-depth and specific knowledge and skills. The RCN (1988) has described specialist nursing practice as:

'Involving a clinical and consultative role, teaching, management, research and the application of relevant nursing research. Only when a nurse is involved in all of these is he or she a specialist'.

(RCN, 1988)

More recently the UKCC, (1994) has described a specialist practitioner as someone who is:

'Able to demonstrate a high level of clinical decision-making. Able to monitor and improve standards of care through clinical supervision or practice, clinical audit, the provision of skilled professional leadership and the development of practice through research, teaching and the support of professional colleagues'.

(UKCC, 1994)

Twenty of the patients interviewed had been offered support from a Clinical Nurse Specialist, a Macmillan nurse, stoma nurse or breast care nurse. Not all of these patients utilised that support, though some felt reassured that they could access the Clinical Nurse Specialist as a resource should they require to do so. Specialist cancer nurses provide an expert resource for their colleagues working in any care setting as well as practical intervention for specific cancer related problems within their speciality. For example a Macmillan Clinical Nurse Specialist will carry a small caseload of patients with complex problems. They are well placed to provide ongoing education, clinical supervision and support for the staff working with them, as well as having a commitment to using research based interventions and carrying out their own nursing research studies. Miller (1995), suggests there are five main Clinical Nurse Specialists sub-roles:

- Clinical expert
- Researcher
- Consultant
- Teacher

- Change agent

In practice, patients view the Clinical Nurse Specialist as an 'expert' and resource in his/her particular field of nursing. They do not focus on other equally important aspects of their role except when a Clinical Nurse Specialist teaches a task, for example a stoma nurse teaching a patient how to care for his or her stoma.

Kai-Cheung (1997), suggests that Clinical Nurse Specialists deliver expert patient care that is based on advanced nursing models with two important characteristics, clinical judgement and leadership as summarised by Spross & Baggerly (1989).

By being competent in managing patient's complex health problems, Clinical Nurse Specialists are in a prime position to improve the quality of patient care. Whilst Clinical Nurse Specialists and nurses working in specialist areas provide patient care directly in the same clinical area. The patient care provided by the Clinical Nurse Specialist should differ from that provided by a registered nurse working within a speciality, especially when complex physiological or psychological patient problems are involved such as assisting a patient with coming to terms with a diagnosis of cancer or a poor prognosis. The Clinical Nurse Specialist can use his or her advanced clinical skills to accelerate the nursing process; they are able to focus on the root of the problem without wasting time on fruitless assessment (Benner, 1984). As a result of their clinical experiences and their post basic education within cancer, Clinical Nurse Specialists are able to intervene and effectively meet patient needs more than do basic practitioners (Storr, 1988). It is clear that Clinical Nurse Specialists have a number of skills, which can improve the 'cancer journey' for patients. However it must be stressed that cancer patients come into

contact with a multitude of health care professionals including general practitioners, medical oncologists, clinical oncologists, surgeons, physicians and palliative care consultants. In addition they come into contact with numerous different nurses and professions allied to medicine such as radiographers, physiotherapists, occupational therapists and so on. Not all health care professionals have specialist knowledge in cancer and some come from very generic backgrounds. Throughout the interviews when generic nurses were referred to by patients' descriptors such as "nice" and "kind" were used, no comments were made in relation to the value of their clinical skills, this contrasts with some of the description given of the Clinical Nurse Specialists.

The average GP may see just one cancer patient per year and require additional support and information to help them care effectively for their patients. A Clinical Nurse Specialist who can meet the patient in hospital at the time of diagnosis and follow the patient up in the community is ideally placed to not only support the patient and his or her family but also support the GP with specific cancer related expertise.

Once the tape recorder had been turned off, Patient No. 14 described how inadequately she felt her General Practitioner had supported her until she was put in contact with the Macmillan nurse. She speculated that following her discharge the GP did not want to visit because "he felt out of his depth" and did not have enough knowledge regarding her treatment for cancer. She also thought that he stayed away because he did not know how to talk to her about her cancer. Things changed once she had been referred to a Macmillan nurse, by a family member, the nurse got the GP to visit and actively "facilitated a discussion" between the patient and her doctor, after that the patient

reported an improvement in the doctor/patient relationship. Clearly in this situation the Clinical Nurse Specialist played an important part in improving care for her patient.

Where cancer and palliative care professionals work together as part of a designated team they tend to have a closer team atmosphere and it is much easier to co-ordinate and structure the care given to cancer patients. Where patients move from primary care to a cancer unit or cancer centre and vice versa the potential for communication breakdown and fragmentation of care is tremendous. Conflicting information or advice can leave the patient confused and despondent and he or she may give up trying to follow a regime or treatment.

As already stated in this chapter one patient described how she felt the Clinical Nurse Specialist supported the GP during her initial phase of cancer care. This aspect of the specialist nurses role could be developed for all patients because Wakefield et al (1993) describes how many General Practitioners feel excluded from decision making once a patient is admitted to hospital, as the intensity of the oncology team's involvement often excludes the participation of the General Practitioner. Dworkind et al (1994) supports this view stating that General Practitioners experience difficulties in becoming re-involved in care once the patients have actually been discharged from the acute hospital setting. The concept that there is a clear cut off between primary and secondary care settings can be serious obstacle to the delivery of effective patient care. A Clinical Nurse Specialist crossing these care settings throughout the patient's disease journey could potentially eliminate such obstacles.

It is clear that patients and families with problems and fears associated with cancer need organised and consistent care, improving

communication between professionals is the key to this. Van Der Scheuren et al (1993), Bresica (1993) and MacIImurray & Holdcroft (1993), all emphasise the need for a multi-disciplinary team approach which includes the primary care team and which will promote communication and thus aid facilitating effective and efficient care for cancer and palliative care patients. It is not only medical and nursing staff who can identify the problems when patients are transferring between different care settings but patients also recognise the difficulties in obtaining continuity of care. A patient once suggested that "you need to be well to be ill". This patient was attending a cancer support group and she was trying to verbalise how stressful and exhausting it is to find out about and actually access services both within the NHS and the voluntary sector. It is evident that if patients are to receive the best possible care with the minimal disruption and stress caused to them then they need an advocate. Clinical Nurse Specialists would seem to be the most appropriate member of the multi-disciplinary cancer team to fulfil this role.

Clinical Nurse Specialists work in a variety of ways supporting cancer patients, some work in the community, others work solely in the hospital setting. However more recently a number of posts have been established which have enabled Clinical Nurse Specialists to work both in the hospital and community settings and follow the patients wherever they have need. These nurses can meet a patient at the time that they are diagnosed, see them if they are admitted as inpatients for treatment and then follow them through into the community so long as their specialist need exists. A number of patients interviewed valued the idea of being offered such support even when they did not use it, of the twenty patients who stated they were offered support from a Clinical Nurse Specialist, ten reported accessing it. However, the patients appeared to have been offered

such support at different stages of their disease journey and because of this one patient felt that the support was offered “too late”, the remaining nine patients thought such support was helpful.

Such nurses are in an ideal position to liaise directly with General Practitioners and advise them promptly of what has happened at a clinic appointment and so on. Where these nurses belong to an effective multi-disciplinary team they are able to facilitate communication from the acute setting to the primary care setting and vice versa, they have the ability to reduce red tape for patients who are in the system. For example if the patient is known to the oncologist and the Clinical Nurse Specialist is visiting and liaising with the GP in the community the patient who develops bone pain due to metastatic spread of cancer to the bone may have his symptoms effectively alleviated by some palliative radiotherapy. In such instances the Clinical Nurse Specialist could liaise back with the consultant and secure the patient a speedy appointment for assessment for treatment. Where a Clinical Nurse Specialist is not involved the patient may need to “go through the red tape” of going back to see the GP, the GP then assessing the patient, a referral from the GP then going to the consultant and so on. In the example cited once the patient was seen for treatment the nurse could then assess the effectiveness of the treatment and report back to the oncologist, he/she could also monitor the patient whilst the treatment was taking effect. This manner of working erodes artificial boundaries and improves the interface between hospital and community services. It improves satisfaction for the oncologist and the General Practitioners and for the patients themselves, as they feel that everyone involved in their care is kept up to date with what is happening and working together, it also facilitates the giving of unambiguous written materials to support what had been said verbally, as in the case of those

patients who are being asked to consider recruitment into randomised clinical trials.

In a few instances more than one Clinical Nurse Specialist with a cancer remit, potentially causing confusion to the patient and duplicating valuable resources, offered support. It is clear that if such nurses are to be used effectively then clear pathways need to exist incorporating when and where a Clinical Nurse Specialist should be involved and identifying which Clinical Nurse Specialist it should be. This pattern of working should be easy to establish where multi-disciplinary teams meet regularly and communicate effectively. However for multi-disciplinary teams to work effectively it is essential for team members to understand each others role and indeed to value each person for the different skills they bring to the team. Informal discussions with Clinical Nurse Specialists following the patient interviews have indicated that many Clinical Nurse Specialists working within the area where the interviews were carried out feel as though they are utilised effectively by some consultants. Though the majority of Clinical Nurse Specialists felt that when they were invited to join multi-professional teams they were there primarily as a token gesture or to pick up referrals when the consultant felt it appropriate, rather than being there to add to discussions or to lead initiatives. This was the majority view and there were a couple of exceptions to this. The Clinical Nurse Specialists also felt that most of the time they received referrals at an appropriate time for the patient i.e. at the time of the diagnosis being given. However, the Macmillan nurses reported being given referrals late in the patient's disease journey from some consultants; they felt this was probably due to misconceptions about their role.

It is evident that if Clinical Nurse Specialists are to be integrated into the cancer team then there needs to be consensus at least as trust level as to how they will work, what is expected of them within the multi-professional team and where they will get their professional support. As previously stated pathways need to exist detailing which professional should be involved with the patient at any one time, who should be the lead professional and who is responsible in communicating between the hospital setting, primary care team, hospice and so on.

If Clinical Nurse Specialists are to work to their full potential it is clear that they need to be seen as an equal member of the cancer team, with skills that differ from the medical practitioner. The concept of the nurse being of equal status to her medical counterparts is difficult for many nurses and doctors to come to terms with. Clinical Nurse Specialists such as Macmillan Nurses frequently suggest to doctors medications which control or alleviate symptoms for their patients; however, Porter (1995) suggests that the idea of a nurse openly recommending a course of action to a doctor is too outrageous to contemplate. This mentality could have something to do with the old style of nurse training which involved the inclusion of military style discipline and the idea that the nurse was there to assist the doctor rather than work as an autonomous practitioner. More recently the concept of nurse prescribing has come to the fore but this tends to be the realm of community nurses, though this may change as more nurse consultants are appointed (Department of Health, 1999)

Throughout the duration of the study the researcher has witnessed a subtle change in the balance of power between Clinical Nurse Specialists and other health care professionals. This phenomena has been identified by the Clinical Nurse Specialists themselves and also

by some of the consultants who were interviewed in the third stage of the study. The balance of power within multidisciplinary teams appears to have shifted and professionals appear to view each other much more equally. Better educated nurses are beginning to challenge doctors both in terms of treatment decisions, but also in the way services are developed and changed. Nurses are also beginning to usurp the role of doctors in the diagnostic and treatment process with nurses now being trained to carry out techniques such as endoscopy, colonoscopies etc. Doctors within the organization where the study was carried out have largely accepted these changes and accepted the need for nurses to challenge traditional methods of practice.

While nurses now are often perceived as an equal member of the multidisciplinary team they still do not have the same social status as doctors within either the organization or society as a whole, however, it is increasingly being acknowledged that they are sometimes more knowledgeable and certainly humanistic than their medical colleagues.

Perhaps the evolution of leadership in nursing has been one of the reasons for this subtle shift in power. Moiden (2002) states that before 1980 there was a lack of nursing leadership research in the UK and that even until the late 1980's the literature is scarce. She suggests that the debate surrounding nursing leadership is closely linked to the political and organisational changes that have influenced nurse management in the UK over the past 20 years and that while leadership and management are recognized as two separate issues, changes to one are likely to effect the other. Moiden (2002) also states that it is therefore difficult to discuss leadership in nursing without placing it in its political common managerial and historical contexts. As the body of research evidence increases, leadership is

being viewed as a complex relationship between leaders and their followers and all the variables that have an impact upon them (Yura et al, 1981).

In its early years, nursing had first a religious and then a military provenance (Abel –Smith, 1960). Florence Nightingale who organised nursing for the first time by founding a school of nursing in the late 19th century was an early embodiment of the leader figure in nursing. She certainly possessed personal power and was able to influence policy but on the other hand she did little to discourage subservience to medicine (Henry et.al, 1990). The under currents of both altruistic service and formal hierarchy established by Florence Nightingale was still present when the NHS was formed in 1948. Modern nursing, hospital administration and formalised nurse education were all to emerge from Florence Nightingale’s initial work (Simms, 1991).

For many years, nurses were actively discouraged from functioning independently and matrons were responsible for the organisation and administration of the nursing service as a whole and of the skills of nursing (Allan & Jolley, 1982). The matrons were responsible for supervising all of the nursing care provided in the hospitals, they also had responsibilities for clinical teaching and supervision of nursing students assigned to their area. During this time some responsibilities were delegated to assistants and nurses but the matrons typically had a top-down management style with centralized control. The military and religious origins of healthcare institutions had resulted in rigid hierarchy structures and a rigid leadership style (Reverby, 1987). This style of leadership did not encourage autonomous thinking or practice and resulted in the development of few changes within the system. Moiden, (2002) suggests that things did not really start to change in the United Kingdom until the 1980’s when team nursing was adopted

from the United States. In team nursing the patients on a unit were divided between among two or three groups of nursing staff. The most senior staff were then designated as team leaders who were responsible for the administration of treatments and the supervision of nursing care provided by other staff (Waters, 1985). Moiden, (2002) suggests :

“It could be argued that the team nursing model resulted in the further alienation of nursing administration from increasingly dissatisfied care giving staff as the managers provided less and less care”.

When team nursing was introduced nursing care was becoming ever more complex and it required a continual updating of skills and knowledge. Moiden (2002) suggests that this is the reason that primary nursing was introduced.

Primary nursing was established in the United Kingdom in the late 1980's (Wright, 1990). Wright (1990) suggests that primary nursing, decision making is delegated to bedside nurses. He suggests that before the system was implemented, sisters were heavily involved in decision making, care planning and teaching but with the advent of primary nursing many of the sister's functions were assumed by primary nurses which allowed managers to provide structure and support for professional nursing practice. Wright (1990) suggests that primary nursing was an attempt to align nursing practice with professional nursing values. However, at this time the centralising in hierarchy decision making structures conflicted philosophically and operationally with the primary nursing model. Rigid hierarchy structures reduced the opportunity for creative nursing practice (Moiden, 2002).

Peters & Watermann (1982) suggests that a striking characteristic of excellence in organisations is the apparent absence of chains of commands. Consequently decentralisation was introduced with the NHS in the United Kingdom in the mid 1990's. A decentralisation involves authority and responsibility being removed from a few leaders and among many employees at the front line of the organisation (Cawthorne, 1993). Decentralisation within the NHS became the means to move away from vertical organisation in which authority and decision making is vested at the top, but it was also a response to financial pressures which required fewer overheads. When this decentralisation occurred middle management layers were reduced or eliminated and the scope of nurse managers roles extended. The flattening of the hierarchical structure effectively reduced costs as fewer administrative layers were required (Moiden, 2002).

Moiden (2002) states that patient centred care was introduced into the UK from the USA around the year 2000. She describes it as a philosophy that recognizes the independence of every department in achieving a quality product and that since patient care is multidisciplinary, decision making is delegated to those involved in patient care processes. Klakovich, (1994) suggests that true patient centred care blurs the lines between management and direct care. Therefore patient centred care requires visible management. Intense communication is required to foster the involvement of grass roots level staff. It is therefore critical that staff feel appreciated and valued as integral members of health teams. After the era of patient centred care the concept of clinical governance was introduced into the UK. This is a new way of working that effects all healthcare professionals and the government have defined clinical governance as a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding standards of

care, by creating an environment in which excellence in clinical care will flourish (Department of Health, 1998; Harvey, 1998). The activities that highlighted clinical governance are clinical audit, risk management, evidence based practice, user involvement, clinical supervision, clinical leadership, continuing professional education, management of inadequate performance, reflective practice, teambuilding and peer review (Harvey, 1998; Valentine & Smith, 2000).

Moiden (2002) states that to have increased effectiveness, preparation in leadership is an essential part of the health care professionals preparation for practice. She suggests that the proper use of leadership concepts and skills allow greater understanding and control of events in work situations. However, the call for leadership in the NHS has reintroduced the matron figure who will be given authority to resolve clinical issues, such as discharge delays and environment problems such as poor cleanliness, and they will be in control of the necessary resources to sort out the fundamentals of care act up by appropriate administrative support. The Department of Health have also pledged that by 2004 there will be around 1,000 consultant nurses employed by the NHS to work with senior hospital doctors, nurses and midwives and draw up local, clinical and referral protocols alongside primary care colleagues. The NHS Cancer Plan (2000) and other documents all stress the importance of nurses as leaders if we are to redesign services with the patient at the centre. Clearly within cancer care the clinical nurses specialists and nurse consultants (where they exist) have a key role to play.

Some people are natural leaders but this is by no means true of everyone and clearly there needs to be investment made in order to

equip people with the skills and to support them to become effective leaders.

In order to strengthen leadership in the NHS the Leading and Empowered Organisation (LEO project) has been implemented throughout the UK. This framework has been developed from numerous pieces of work (Fiedler, 1967; Hersey & Blanchard, 1977; Burns, 1978; Stevenes, 1978; Sashkin, 1986; Kouzes & Posner, 1987; Drucker, 1998; Yukl, 1989; Kotter, 1990). LEO is supposed to enable professionals to develop empowerment in themselves and others by addressing responsibility, authority and accountability. It also helps individuals articulate expectations, develop autonomy, resolve conflicts, take risks and resolve problems (NHS Executive 2000). Within the organisation where this study was carried out all senior nurses F to H grades have been encouraged to undertake the programme, this encompasses the grades of the Clinical Nurse Specialists. In an additional attempt to facilitate the LEO project within the Trust other more senior people have also been required to undertake the training such as specialty managers, heads of service and the executive team within the Trust. This was not done in an attempt to equip them with leaderships skills as there was an assumption made that these people would not be in the positions that they were if they did not possess these skills, but it was more an attempt to give senior managers an understanding of the training that staff at clinical level were undertaking in order that there could be effectively supported to be leaders within their own specialities.

The local Cancer Network have also acknowledged the importance of leadership and equipping Clinical Nurse Specialists with leadership skills. They therefore have piloted a LEO programme for cancer Clinical Nurse Specialists whereby Clinical Nurse Specialists were

invited by the Trusts that make up the cancer network to undertake a LEO programme. The purpose of this would be to equip them with leadership skills but, also, because they were doing it with colleagues from other organisations, the idea was that this would provide them with the opportunity to network and problem solve from a wider perspective. The LEO programme for cancer nurses was a pilot, however, it has evaluated extremely well and staff who attended reported the networking aspects of the course as one of the most beneficial aspects of it. There has been much discussion both within the network and in professional journals regarding the need for effective leadership, but we must ask ourselves whether it is just a buzz word or whether it is really important. Effective leadership is important, it has an end project which is the high performance team. Effective leadership is the key to redesigning health services to the benefit of the patient. Nigel Crisp the Chief Executive of the NHS states:-

"Leadership is about setting direction, opening up possibilities, helping people achieve communication and delivering. It is also about behaviour. What we do as leaders is even more important than what we say".

(Crisp, 2003)

In 2001 the British Prime Minister Tony Blair stated:-

"I believe the public servants are working flat out but in a system that shrieks out for fundamental change If we do not get the systems and structures right we will never get to the roots of the problem only prune its visible branches The key to reform is redesigning the system around the user".

If healthcare professionals are to be pro-active in redesigning the systems and structures of the NHS around the needs of the patient then, clearly, the need for good leaders within all of the healthcare professionals is paramount. Kouzes & Posner, (1997) suggest that effective leadership involves the following:-

- Challenging the Process
- Inspiring Shared Vision
- Enabling Others to Act
- Modelling the Way
- Encouraging the Heart

Pond (2003) suggests that leadership is a process which:-

- Challenges the Status Quo to create new visions and scenarios
- Helps the team to articulate a realisable vision while modelling the values that underpin it
- Initiates new approaches and stimulates the creative and emotional drive in individuals to innovate and deliver excellence

Pond also suggests that leadership behaviours include:-

- Identify win/win situations
- Manage the political contexts
- Agree and communicate consistent messages
- Value staff who work in a whole system way
- Share (financial) risk
- Work with complexity
- Modelling and acting as a champion for partnership behaviour
- Developing healthy relationships with peers

- Taking joint responsibility for delivery
- Action and support system benefit
- Create whole system organizational culture

It seems that many Clinical Nurse Specialists have developed these behaviours as part of their roles, they need to work with complexity on a daily basis because of the multitude of processes which effect each individual patient. Part of their role is to be a good role model and to develop a healthy relationship with peers. They have clearly been responsible for creating changes within organisational cultures and the consultants have clearly identified that the Clinical Nurse Specialists can identify when in situations and that they are extremely valuable in agreeing and communicating consistent messages both within the organisation and to patients themselves.

One area in which many Clinical Nurse Specialists may be naïve is in how best to manage the political contexts. However there is no reason why a political awareness cannot be taught and why they cannot be equipped with tools which will enable them to manage the political context.

To support the development of leaders within the NHS, the NHS Modernisation Agency has been developing a training framework in leadership before service improvement which can be accessed by all levels of staff regardless of the discipline from which they come (Pond, 2003).

The importance of effective leadership as a way of implementing change within the NHS was also raised by of the consultants interviewed:-

“... by demonstrating, by doing things and demonstrating the benefits of that, other people come along with you. I think it is leadership that has got the crucial role here. I think if you can demonstrate, for instance, and I take a very simple example, we have patients who the median time that they are in hospital following major bowel cancer surgery is something quite like twice that of the United States. We do not have patients who are twice as unhealthy – we have attitudes that are twice as difficult to change. So you say to the ward staff this patient can have free fluids on the first post-operative day and you can guarantee that they won’t get it because it has never been done. What you have to do is demonstrate by example and take selective patients, do that, get them moving, get them sorted and you will gradually win things through”.

(Consultant No. 3)

Throughout this chapter we have discussed some of the additional skills, Clinical Nurse Specialists have been acquiring in order to function effectively within their roles some skills are clinical, like learning how to do nurse led clinics, whilst others are more to do with the development of the service, such as leadership skills. Two of the consultants interviewed articulated some concerns relating to the Clinical Nurse Specialists role and how we keep them motivated and interested:-

“... I feel very strongly that once they have become nurse specialists are they going to do the same role forever because if they are I think we are going to have the same problems as we currently have with associate specialists, the non-consultant

grades who after a while do not change, do not change with the times ...”.

(Consultant No. 3)

On numerous occasions since this interview has occurred the consultant involved has voiced his concern regarding the need to keep Clinical Nurse Specialists motivated, to prevent them from stagnating. Another consultant articulated similar concerns regarding the specialist nurse that he worked with:-

“I do worry about what will happen once she has been in post for a long time. I do not want her to get bored, but I am not sure how to support her ongoing development without her looking to other posts to fulfill her. I think this lack of career structure is a problem for all nurses, but specialist nurses in particular and I am not sure that the development of nurse consultant posts is the answer to this”.

(Consultant No. 6)

The only solution to preventing Clinical Nurse Specialists from becoming bored and stagnating which was suggested by the consultants was the development of nurse led clinics:-

“There is an issue about developing specialist nurses. I think nurse led clinics can be useful in terms of providing continuity for patients and developing the nurse but we need to ensure that we are not just turning them into mini doctors and indeed not just developing nurse led follow up clinics because we have some non scientific need to follow up patients, when in reality they could be discharged”.

(Consultant No. 4)

In the acute setting, there has been a trend for specialist nurses to develop their roles further. This has led to the establishment of nurse-led clinics both pre-diagnosis and nurse-led follow up is currently being evaluated within the Trust as part of a formal study. Many of the Clinical Nurse Specialists value this new component to their role as they feel, not only does it enhance their own skills, but it also provides a more appropriate service to patients. Once Clinical Nurse Specialist described the development of such roles within her service:-

“We currently do our own follow up clinic at the same time the consultant is doing a separate clinic in the adjacent room so we do have easy access if we are concerned and we need to have the patient seen by a doctor. I have had training from the consultant to prepare me to work in this way and it does work very well Obviously junior doctors change quite regularly and they are on a huge learning curve themselves when they first join a team and initially quite often make mistakes, that is where you’ve got a specialist nurse who has worked in that specialism for a number of years quite often they have more knowledge than the juniors.”

(Clinical Nurse Specialist No. 1)

“I think nurse led follow up is very useful because nurses can provide that continuity and have more time to address psychological and social concerns of patients.”

(Clinical Nurse Specialist No. 3)

All of the consultants interviewed were extremely supportive of Clinical Nurse Specialists developing their roles and in no way saw this as a threat or an erosion to their role. It would have been interesting if they had been asked about this issue at the outset of this study instead of in the third phase of the study, because when the study was initiated the researcher perceived the organizational culture as being very different and one where Clinical Nurse Specialists were included as a token gesture rather than that they were perceived to have any real value. One consultant however did stress the need for caution arguing that developing clinical nurses specialist roles is a good thing but this should not be confused with them simply taking on junior medical staff tasks:-

“(Developing roles) is fine, it’s complimentary and not about taking on junior medical staff tasks. You always get continuity from nurse colleagues, on the other hand the nurse brings to the clinical setting the experience and expertise of nursing training and a nursing background”.

(Consultant No. 3)

Whilst the Clinical Nurse Specialists themselves acknowledged the need to change in order to prevent them becoming bored and stagnating in their role, at the time of their focus group interview they were unable to articulate any suggestions as to how this might be done. However, at a subsequent away day for the specialist nurses this issue was made an agenda item as a direct result of them being asked about it as part of the study. The specialist nurses have agreed that the main points of that subsequent discussion can be included in this thesis. At the specialist nurse away day the specialist nurses

themselves identified that the development of nurse led clinics was not appropriate for all of them and that whilst leadership skills in training was important for them they all needed to have a wider understanding of the political contexts of both the organisation in which they worked and of cancer care within the UK. When asked how they might achieve this they came up with a number of suggestions which included shadowing opportunities with the Trust's lead cancer nurse (a non clinical role), time spent at the Cancer Network and the opportunity to attend more general cancer related conferences at a national level rather than them just attending tumour specific events relating to their area of expertise. They felt that this would give them a more rounded understanding of cancer care as a whole and help them understand the national political context. They also identified a need to understand each other's services more and some work has been undertaken proposing opportunities for them to shadow each other again to give them a wider understanding as cancer care as a whole rather than as a specific disease, i.e. breast cancer or lung cancer. Many of the Clinical Nurse Specialists acknowledge that they had expertise within their own specialty but also that they had skills in relation to teaching. Therefore opportunities have been developed to enable them to participate on teaching programmes ran by the Trust's cancer lead nurse where they will not only teach their own specialty but also some of the wider issues which relate to all cancer patients such as psycho-social care, communication skills, treatment modalities etc.

As a direct result of the research and the discussion it stimulated, the Clinical Nurse Specialists have also expressed an interest in writing for publication. In order to support this they invited someone who had had numerous articles accepted for publication to come to the meeting to speak to them. This presentation was received in an extremely

positive manner and at least three of the Clinical Nurse Specialists are currently working on articles for publication/presentation at national and international conferences.

Leadership has been discussed as a key skill, particularly in relation to implementing change in cancer care throughout this chapter, the theory to implementing change and how it translates into reality will be discussed in more detail in Chapter 9 of this thesis.

Guidelines have been issued specifically relating to the nursing contribution of cancer care, these guidelines reiterate the fact that:

“Nurses have a significant contribution to make in ensuring a coherent service working with other colleagues and across professional and organisational boundaries”.

(NHS Executive, 1999)

Kai-Cheung (1997) has argued that Clinical Nurse Specialists who have had a significant period of experience in a specialised field, in addition to extra specialist education are able not only to provide competent management of patients with complex health problems but also feel more comfortable taking on consultancy, leadership, teaching and research roles and are therefore more likely to communicate more comfortably and effectively with their medical counterparts.

Barr (1997) suggests teams need time to develop agreed aims, objectives and priorities for action; this may necessitate some time being allocated for discussion and the development of team relationships prior to projects/developments being undertaken. In

practice it is often very difficult for busy individuals to take time out from their "clinical work" to address what may be seen of secondary importance to direct patient care. This is despite the fact that there is wide spread recognition that team working has a profound effect on the benefit of patient care. A team can be defined as a group of individuals who work independently to attain individual and organisational objectives (Vaclon, 1996). A team can be differentiated from other groups by three characteristics, a reason for working together, independence, recognition that members of the group need each others experience and ability. The third characteristic is commitment and accountability; it is essential for group members to be committed to the idea of working together in a team (Ibid). Such commitment leads to more effective decision making than that of those professionals working in isolation (NHS Executive, 1997). This concept is supported by Barr (1997) who adds to the debate by defining interprofessional work "implies a willingness to share and indeed give up exclusive claim to specialised knowledge and authority".

Obstacles to effective multidisciplinary teamwork may arise at organisational level, professional level and interpersonal level (Clough, 1996). Certainly, at the time that the first 2 stages of this study were carried out all policies and procedures in existence were developed for uni-disciplinary teams and did not adequately reflect the need for flexibility, role overlap and sharing, which are all key concepts of multi-disciplinary working. Barr (1997) suggests that an illusion of teamwork can be created in which no single member wishes to be identified as obstructive and therefore insists on the development of rigid and complex decision making procedures. This is the scenario, which can be frequently observed and experienced in practice. The end result of such behaviour is ineffective decision making within the team and a

lack of vision regarding service development. Other factors, which may be perceived as barriers to effective team working, are hierarchical structures. It is not uncommon for some professional groups to defend their perceived territory in an extremely intense, "tribal" manner (Leathard, 1994). It seems from anecdotal evidence that the reason collaboration fails between health care professionals and indeed between nurses themselves is due to a lack of understanding of each others role and the fear of being "de-skilled". A further barrier to collaboration may be the confusion created when codes of language are used commonly but may be interpreted differently. Barr (1997) suggests the interpretation of words is influenced by personal and professional values, beliefs, experience, knowledge and skills which may vary among health care professionals. Such variations in the interpretation of information may result in overt or covert disagreement, conflict or defensiveness and consequently the development of factions within a team, this again can lead to reduced co-ordination of the service. It is clear that communication and inter-action is essential to effective teamwork and patient care.

Haywood (1996), suggest that cohesiveness in a group can be described as closeness and an attraction between group members and this may have influence on the quality of work produced by those members. The size and characteristics of the group also has an impact of the cohesiveness of the team, the smaller the team the more opportunity there is to interact with other members of the team and fortunately most cancer teams are fairly small. It has also been suggested that a feeling of cohesiveness can be increased where all members of the team have equal status (Ibid). Another way of increasing self-esteem amongst the members of a multi-disciplinary cancer team and also ensuring that cancer patients receive best

possible care is through education. Numerous papers exist highlighting the need for health care professionals working with cancer patients to have specialist education relating to cancer and palliative care (Wilkinson, 1991: Doyle, 1991: Kaye, 1996: Buckman, 1994: Calman and Hine, 1995: Royal College of Nursing, 1996: Langton et al, 1999: Department of Health, 2000). Recently the NHS Executive (1999) has highlighted the importance of education for cancer nurses if they are to actively contribute to the nursing contribution to cancer care. Despite this there are still many nurses and other health care professionals who “dabble” in cancer care without any specialist training. Since the Calman and Hine (1995) report this scenario applies less to medical practitioners, as they are required to see a specified number of patients with the particular cancer in which they specialise in order to maintain their expertise. The same criteria do not apply to their nursing counterparts or to those from the professions allied to medicine such as physiotherapy, occupational therapy, dietetics and so on.

Patients can identify lack of education and training, one patient who was interviewed as part of this study commented:

“It was a young doctor, I took it he was a registrar and um he seemed to be a bit reluctant to say too much about anything to me”

(Patient No. 12)

Following the formal interview this patient actually went on to describe how sorry he felt for the junior doctor not only because he appeared to feel uncomfortable when dealing with the patient himself, but also because he seemed to be ill prepared and not trained in dealing with

such situations. Clearly if the doctor had adequate training in communication skills he may have felt more confident in talking to the patient and the patient would not have identified his discomfort.

A lot the criticisms patients had about their management in the hospital and community environments could have easily been avoided had the health care professionals involved been the recipient of some very basic cancer related education. For example patients whose primary care doctors appeared to be unaware of the psychological impact of a diagnosis of cancer were told things like

“you should have come sooner”

(Patient No. 16)

This patient was advised that he should have presented his symptoms to the General Practitioner at an earlier time; this in turn led the patient to question whether he was ultimately responsible for his cancer progressing. Such comments are particularly unhelpful and often cause the patients additional anxiety; they start blaming themselves for their predicament or become angry and do not wish to see that doctor again. Other doctors seemed unaware of the frustrations experienced by patients who weren't given enough information at the time of diagnosis:

“He gave me the diagnosis and then told me I had to see someone else who would tell me about treatment, but all I thought was well how long is this going to take and what is that treatment going to entail? And when I tried to ask him about it he just wouldn't commit any further, he said that he was just referring me on to a specialist, he obviously had no concept of how much trauma that wait would cause me, and how much in

limbo you feel till you actually do know what is going to happen I was quite annoyed about that”.

Patient No. 32 also highlighted how frustrating it was not to be given all of the information she required regarding her proposed treatment; clearly this sort of problem would not have occurred had an effective multi-disciplinary team managed her:

“Well this consultant came in and brought a junior with him and they sat down and told me it was cancer and that they couldn’t treat it with surgery, so he was going to get me to see someone else to discuss some other treatment, to be honest I switched off as soon as he said the word ‘cancer’ even though I had prepared myself for it. I just felt ‘Oh God’ I am going to die. I don’t think he really had any idea of what he wanted to do with me at all, and you know something he didn’t look me in the eye once, when I left the room I just thought he was relieved so that he could pass me on to someone else and I would be their problem. I know it must be hard telling someone that they had cancer, but you shouldn’t be in that job if you can’t do it should you? The junior was a nice kid though, at least she didn’t avoid looking at me and although she didn’t say anything she looked as though she cared”.

(Patient No. 32)

Another patient commented on how a nurse specialist gave him lots of information about the side effects of the treatment he was about to undertake, whilst the doctor who had given him the diagnosis was unable to give him any real details about treatment because he was being referred on:

“B was great, I was waiting to go and see the cancer specialist and she came out to home to see me and she answered all of my questions. She told me what radiotherapy meant and she told me what chemotherapy meant, the other doctor just told be me that I might have to have these treatments but this cancer specialist would be the one to decide which was the most appropriate if any, and I didn’t know what they entailed and it was nice to have a nurse explain them to me in language that I could understand. When I look back on it now, it is strange that the first doctor did not do that and I wonder whether it was because he was worried about treading on another doctor’s toes or was it because he honestly didn’t know, and even if he had given me a bit of basic information I think that I would have liked that. Certainly the fact that B had talked things through with me sort of in my own home environment was much more comforting and much less stressful and it meant that when I did see the cancer specialist I could understand what he was talking about and that bit of advanced knowledge helped me make a decision with him about what was the best course of treatment for me.

(Patient No. 5)

Other comments like “he didn’t have a clue what he was doing” or “it is always someone else’s job to tell you about so and so and then they have to go and find that person”. All indicate that patients identify poorly educated/ill prepared health care professionals who are unable or unwilling to spend time with the patient dealing with their fears and providing them with correct and appropriate information. It is evident that where an effective multi-disciplinary team does work these problems are dramatically reduced. Patients value the team working

between professionals and know that in such an environment if one professional can not answer a particular line of questioning then they will act as an advocate for that patient ensuring that information is brought back in a timely manner.

A well educated Clinical Nurse Specialist who works across all care settings is in a pivotal position to facilitate effective communication and multi-disciplinary team working and thus has the potential for dramatically improving patient care. Ways in which a Clinical Nurse Specialist may facilitate health care professionals working together will be explored in the forthcoming chapter. Without effective team working and communication the process of informing and supporting cancer patients in the initial phase of their care will not be improved.

CHAPTER 9

Implementing Change in Cancer Care

“The NHS is 50 years old. Every government since 1948 has re-evolved its founding principles, but there is less agreement about how services based on these principles should be organised. Alongside remarkable stability in the espoused purpose of the NHS, there has been almost constant structural change. . . . There is a paper mountain highlighting advice on reforms, restructuring and managing change. Yet many behaviours do not change, the puzzle is why the NHS has been so unchanging, given the barrage of attempts to reform it.”

(Plamping, 1998)

Many people who work in and care deeply about the NHS agree with this insight regarding behaviours remaining the same, and this was reinforced in a number of the interviews carried out during the third stage of this study, most notably those interviews carried out with consultants and the Focus Groups with senior managers and specialist nurses:

“The problem is that working in the NHS we are constantly being forced to change, it feels that we are being asked to change almost on a daily basis and it makes people sceptical about yet another change. Usually change is imposed from above and at the moment much of the change certainly around cancer care is coming direct from the DOH and I know I’m a bit sceptical about the evidence base of some, not all of it”.

(Consultant No. 6)

This view was also supported by one of the managers who was interviewed:-

“..... there are some individuals and, come to think of it, departments who are permanently dealing with one change after the next and sometimes they have had to deal with change for changes sake, so they get quite cynical and faded”.

(Manager No.5)

Consultant No. 6 went onto speculate why some people were sceptical about change:

“The DOH is constantly publishing things on which we are asked to implement to make changes in cancer. In the last few years we have had Calman-Hine, the Improving Outcomes Guidance, the Cancer Plan etc. and only last week they published The National Cancer Patients Survey or whatever it’s called. The problem with that is it was published last week (2002) but the survey was done in 1999 and 2000 which was before many of the changes we have already implemented, they are not reflected in the report because it simply wasn’t carried out and published in a timely manner. What’s frustrating is that it’s now a matter of public record but it doesn’t accurately reflect cancer services anywhere in the UK in 2002”.

(Consultant No.6)

Another consultant added his view that changes which are imposed from above i.e. the Department of Health can often create many frustrations for staff at clinical level:

“..... as a result we have spawned committees, no of whom have got any mandate that I can see to impose cancer care, none of whom have got any remit other than to keep themselves going.”

(Consultant No. 3)

Consultant No. 3 provided an example of change at a clinical level but advised caution if you are expecting change in cancer care to occur quickly:

“..... for instance, nasogastric tubes that used to be endemic throughout the surgical ward are now a rarity because people realise they are an absolute waste of time except for under certain circumstances. So 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 then you will be rewarded.”

(Consultant No. 3)

The overriding view from the managers focus group was that the majority of staff are receptive to change, so long as they understood the reason for it:

“I think most people are receptive to change in this organisation at any rate, I think partly the reason is because from an organisations 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”.

(Consultant No. 3)

“I think we’re fortunate here because the Trust sees modernisation of services as a huge priority and that is demonstrated modernisation team in house training the Chief Executive has recently been seconded to the modernisation agency”.

(Manager No. 1)

Interestingly, whilst consultants acknowledged the need for change in the way we provide cancer care, they saw themselves as supporting initiatives rather than implementing or leading them. Conversely, the managers and Clinical Nurse Specialists, saw the management of change as a key component of their role, with the Clinical Nurse Specialists seeing themselves very much as a change agent and leader (this concept has been discussed at length in Chapter 8 of this thesis).

The counter argument to this is the significant changes in clinical interventions that are constantly taking place and, it can be argued, that substantial changes already feature in the NHS and that patients across the country are benefiting as a result. An example of this relating to cancer care would be the work done by the Cancer Services Collaborative who report a huge amount of change aimed at improving cancer care/services across the country.

There is however little disagreement that whatever change has been implemented so far, and there has already been a substantial amount within cancer care, the Health Service needs to transform itself further allowing more people to access effective services.

It is clear from the focus groups and interviews carried out with health care professionals as part of this study that both managers and health care professionals are showing a growing interest in understanding how they can develop the skills and attitudes necessary for the kind of continuous change and learning required in a modern health service. A study carried out by the NHS Service Delivery and Organisation (FDO) National R&D Programme in March 2000 largely supports some of the issues highlighted by managers and health care professionals in this study. In both instances managers and health care professionals identify the following as issues which affect their ability to cope with and implement change within the organisation:-

- Multiple priorities competing for time
- Changing external pressures
- Challenging demands on staff

It is evident that many managers and professionals feel a need to bring together disconnected external initiatives and internal requirements into one coherent manageable approach. Clearly, initiatives like the NHS Cancer Plan (2000), and the "Improving Outcomes Guidance" which have been developed for a number of cancers are meant to help do this, but the reality is that many health care professionals and managers feel that these papers are simply external edicts, which, in reality have little bearing on their day to day clinical practice. Indeed three of the six consultants interviewed actually voiced concern about the "Improving Outcomes Guidance"

because they were sceptical about the evidence base cited within these publications.

The managers on the other hand were keen to explore effective mechanisms of change management, but they did comment that there was little evidence about effective change management available in the journals and much of their knowledge regarding the implementation of change was experiential.

Nearly all changes which are implemented within the NHS have a wide range of effects, some of these are planned and some are unplanned which often affect other departments than the one where the change was actually implemented for example one manager commented:

“When you implement a change you think that it is quite straightforward, for example, by having a one stop clinic for haematuria patients. We thought that we could process them quickly, improve patient satisfaction, get a diagnosis in a more timely manner and speed up patient flows. It is true we could do all that, but we just thought it was a case of implementing a one stop clinic and having the relevant consultant available and the nursing staff to support him. Clearly it is not as straight forward as that and what we actually do (but we didn’t realise this at the outset) was linking with outpatients regarding the way that these patients were booked, then we needed to link in the Pathology Department with regards some of the tests that we would require and they had to change their working practice to be able to give us the results in a timely manner and it just goes on and on. Whatever you do impacts on another service because you can’t work an individual service in isolation as they are all linked to

other services, particularly when you are talking about cancer patients. This is the problem – you may be able to do something within your own service, but very often you need the co-operation and sometimes some funding really from other departments to actually support their end of it. What I am really trying to say it that it is just never as clear as you think it is and it is always more complex.”

(Manager No. 1)

The NHS Service Delivery and Organisation National R&D Programme (2000) highlights that different people involved in change will have different views of what actually triggered that change in the first place, as the underlying causes of the problem and of the desirable outcome of the change process. It is clear that whoever is implementing the change needs to think carefully about what measures of effectiveness are used in order to evaluate that change process.

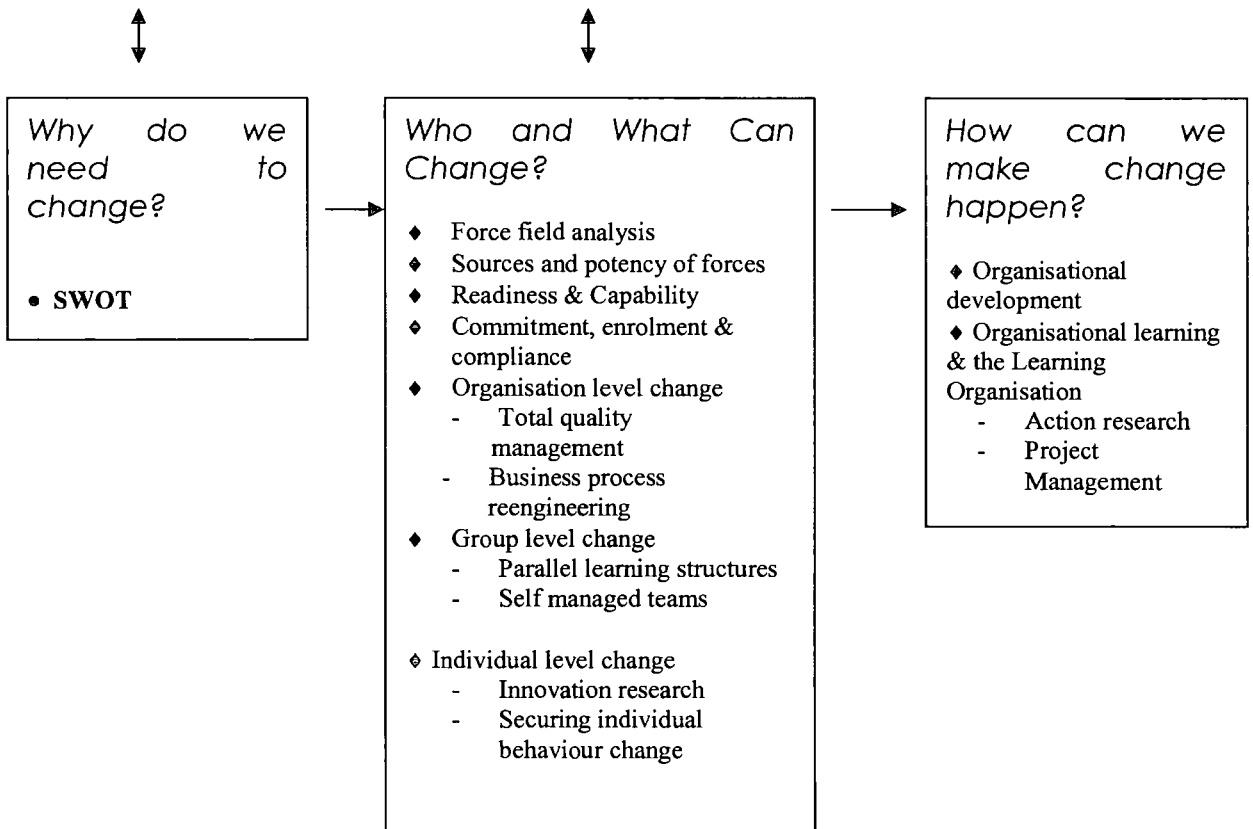
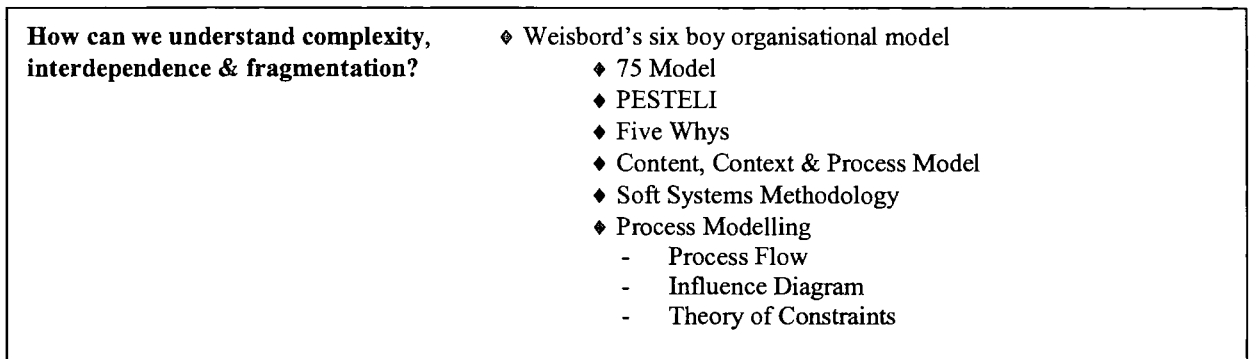
There is a substantial amount of literature relating to change which has been published over the last 50 years or so, however the size and the scope of the literature can make it hard for managers and health care practitioners to focus upon. (Iles and Sutherland, 2000)

Iles and Sutherland, (2000) attempt to create a pathway for change by grouping models in four main clusters focusing on key questions:-

1. How can we understand complexity, interdependence and fragmentation?

2. Why do we need to change?
3. Who and what can change?
4. How can we make change happen?

The National Co-Ordinating Centre for NHS Service Delivery and Organisation R&D (2000) offer a selection of models for each cluster to assist in the management of change in the NHS:-



The approaches cited by NCCSDO (2000) and Iles and Sutherland (2000) range from comprehensive methodologies to single tools, but all of the methodologies cited can provide an insight into understanding and dealing with multiple priorities and pressures which, as already stated, was an issue highlighted by service managers. A sample of some of the tools and methodologies cited in the model on the previous page will be discussed throughout the remainder of this chapter. The content, context and process model was developed by Pettigrew and Whipp (1991) as a means of generating insight into why some private sector organisations were better able than others to manage strategic change and improve their competitive performance. It suggests that successful change is a result of the interaction between:-

- Content of **what** of change (objectives, purpose and goals)
- Process or **how** of change (implementation)
- Organisational **context** of change (the internal and external environment)

The model also reminds us that change is influenced by historical, cultural, economic and political factors. It suggests that there are five interrelated factors important in shaping an organisations performance:-

1. Environmental assessment
2. Human resources as assets and liabilities
3. Linking strategic and operational change
4. Leading change
5. Overall coherence

This model has been widely used in analysing and learning retrospectively from change programmes. It was also extended and tested in a major empirical study of change in the NHS (Pettigrew, Ferlie and McKee, 1992).

Shaping Strategic Change

The model provides diagnostic checklists which can be used to assess the likely reception of a particular intervention in a specific locality. Clearly the model has some uses in particular scenarios but may have limited attraction to managers in the NHS because many changes are implemented by a top down approach i.e. from the Department of Health and the timescale for implementation is very short. Many of the changes that managers are asked to implement are also a fait accompli and therefore to some extent the likely reception is irrelevant because the change is going to be imposed anyway.

Where the focus is a single problem event, such as an inpatient complaining that she didn't get written information about her disease, then such an analysis may not be necessary. However, the interrelationships which led to that event, i.e. the consultant or specialist nurse not providing her with written information, will still need to be considered and one model for doing so, is to ask five "why?" questions.

If a problem occurs the first why? question is asked "why did this happen?" a number of answers may be found and for each of these the next "why?" is asked:-

"Why is that ?" the whole process is repeated until five consecutive "why?" questions have been asked and answered. The five "why's" is

simple tool which can be applied in many situations to get to the route of the problem

(Senge et al., 1994)

NCCSDO (2000) suggests that this tool helps managers resist the temptation to deal with symptoms rather than causes and certainly this model has been used to try and implement changes and streamline the process for colorectal cancer patients within the organisation where the study was conducted.

Process modelling and associated approaches stress the importance of an integrated approach to change and to the planning and delivery of services which is crucial to the development of cancer services within the organisation. As a result of some of the work carried out earlier on in the study with the colorectal pathway for colorectal cancer patients a large scale process modelling exercise was carried out as there was an acknowledgement that colorectal patients were receiving fragmented care. The audit department confirmed that there was little baseline data available and although outcome measures were specified in the Improving Outcome Guidance for Colorectal cancer, which is a national document, not all were actually implemented in practice. A multidisciplinary colorectal pathway was identified by all the key stakeholders and areas where there were bottlenecks or constraints were identified. Work is currently ongoing to address those bottlenecks and constraints, one example of this is work that has been carried out in collaboration with the Cancer Services Collaborative is the modernisation of Endoscopy services within the Trust. This has resulted in changing the service for endoscopy patients which in turn has speeded up the time of diagnosis for colorectal cancer patients and patient satisfaction surveys, which were

part of the project, have indicated a greater satisfaction with the service provided.

Using a process modelling tool has helped implement successful change, because all the stakeholders in the colorectal cancer journey were invited to participate and seen as equally important in the process, regardless of their status within the organisation. This in itself has proved to be successful in reorienting services towards an approach which was multidisciplinary, more susceptible to audit and which most importantly centred on the needs of cancer patients and their carers.

Strengths and weaknesses are internal to the team or organisation, while opportunities and threats are external. SWOT stands for strengths, weaknesses, opportunities and threats. A SWOT analysis focuses attention on the match or lack of match between what the team or organisation is geared up to offer and what the world outside needs and wants. Carrying out such an exercise encourages people to view their organisation, group or team from a range of perspectives. A SWOT analysis is a very widely used strategic planning tool (NCCSDO, 2000). However there is little published evidence on the relative value of SWOT analysis as a technique. Some suggest that it can result in very long lists of factors, general or meaningless descriptions, a failure to prioritise issues or no attempt to verify any conclusions. However, NCCSDO suggests that this should not invalidate the use of SWOT but does reinforce the point that SWOT analysis needs to be used carefully and with the end in mind rather than as a process in its own right.

Total quality management or TQM, refers to a management process which is directed at establishing organised continuous improvement

activities which involve everyone in an organisation in an integrated effort towards improving performance at every level. The focus of TQM is on processes of work rather than on the workers themselves and through a process of data collection, analysis, hypothesis formation and hypothesis testing, changes to processes can be devised. TQM approaches have been implemented in health care systems. These aim to involve clinical staff in quality management, suggesting that many may need to develop skills in:-

- Working effectively in teams
- Understanding work as a process
- Collecting, aggregating, analysing and displaying data on the outcomes of care and also on the processes of care
- Designing work processes
- Collaborative exchange with patients
- Working collaboratively with non-medical managers

(NCCSDO, 2000)

Clearly the number and complexity of processes involved can be off-putting and also difficult to evaluate methodically. There are few empirical studies to provide comparative information about the impact of TQM on health care organisations and those evaluations that do exist have often been piece meal and rarely focussed on care organisational processes such as clinical practice. Instead they have tended to concentrate on more peripheral or administrative activities. That is not to say that this would not be a useful tool to employ within the NHS, but probably there needs to be more studies which compare information about the impact of TQM on individual health care organisations.

Hammer and Champy (1993) define Business Process Re-engineering (BPR) as:-

“ . . . the fundamental re-thinking and radical re-design of business processes to achieve dramatic improvements in critical, contemporary measures of performance such as cost, quality, service and speed . . . ”

The main concepts that underline BPR include the following:-

- Organisations should be organised around key processes rather than specialist functions
- Narrow specialists should be replaced by multi-skilled workers, often working in self managed teams
- In contrast with incremental techniques such as TQM, BPR involves total disassociation from current practices and radical re-thinking
- The direction for the requisite radical re-thinking comes unequivocally from top management.

Kings College Hospital, London has used a range of specific techniques for its change programme. The programme includes tackling outpatients appointment systems and helping staff to deliver bad news more effectively (both areas are appropriate to the delivery of cancer care). Each project is started by mapping a common understanding of the current situation. This is often done by developing a process map of a system, this is done as a team with facilitation to reflect not what should happen but what happens in reality. It is a highly visual method and has been found to alter individual perceptions as for example, doctors suddenly realised that nurses do a range of tasks that they never knew about and vice versa,

or, as happened in the organisation where the study was carried out, people became aware of different processes that clerical staff were carrying out, some of which were unnecessary and just added to individuals workload.

One of the potential problems of BPR is that two of the central principles i.e. the radical, revolutionary approach to change and the erasing of historic context are fundamentally incompatible with the traditions, culture and politics of the NHS. This is potentially why BPR has not been adopted in a more wide spread manner across the NHS.

However, a more recent evaluation of the implementation of BPR, without the NHS, has indicated that some re-engineering techniques can be used without entailing a whole organisation approach. The NCCSDO (2000), cite the National Patients Access Team who include amongst its initiatives the National Booked Admissions Programme. This programme makes use of re-engineering or re-design techniques. Re-design can be defined as thinking through the best process to achieve speedy and effective care from a patient perspective. Within the organisation where the study was carried out, re-design processes have been used successfully within a number of areas including the colorectal patients pathway, the Endoscopy Unit, Radiology Department and the Gynae Oncology Department.

On a practical level, whilst there needs to be commitment from top management, it is clear from the work that has been done as part of this study that without ownership from all the stakeholders whether they be ancillary, admin structure or health care professionals change will not be sustained. Also to implement process re-engineering is

quite a time consuming process and it needs people with process mapping and process re-design skills to facilitate it. This sort of work has been most effective where hospitals have designated modernisation teams who have the skills to facilitate such projects and to give ownership back to the individual clinical areas once the achieved change has been implemented, it is then the clinical area's own responsibility to ensure that change is sustained. Fortunately a Modernisation Team now exists in the organisation where the study was conducted, although at the time the study was commented this was not the case.

The learning organisation is increasingly popular as organisations become more adaptable and responsive to change. They attempt to develop structures and systems that nurture innovation. Much of the literature relating to learning organisations describes how organisations should be designed and managed to promote effective learning. It is therefore less a model than a school of thought. There is relatively little systematic research to support these suggestions, however there is a growing consensus about features that characterise the learning organisation. The main characteristics of a learning organisation are:-

- Structure
- Information Systems
- Human Resource Practices
- Organisational Culture
- Leadership

In terms of structure learning organisations have managerial hierarchies. This should enhance opportunities for employee involvement in the organisation. Members are empowered to make

relevant decisions, such structures support team work, strong lateral relations and networking across the organisational or boundaries both internal and external. Learning organisations require more information beyond that used by traditional organisations. Transformational change requires more sophisticated information systems. They need to facilitate rapid acquisition, processing and sharing of rich complex information that enable effective knowledge management.

Within a learning organisation people are recognised as the creators and users of organisational learning. Human resource management therefore focuses on provision and support of individual learning. Appraisal and reward systems are concerned to measure long term performance and promote the acquisition and sharing of new skills and knowledge.

Learning organisations have strong cultures that promote openness, creativity and experimentation amongst members. They encourage members to acquire a process and share information, nurture innovation and provide the freedom to try new things, to risk failure and to learn from mistakes.

Like most interventions aimed at securing organisational change, learning organisations depend heavily on effective leadership. Leaders reflect the openness, risk taking and reflection necessary for learning and communicate a compelling vision of the learning organisation, providing empathy, support and personal advocacy needed to lead others towards it.

The NHS is in a constant state of flux, however, many hospital trusts, including the one where the study was carried out, have tried to

implement some of the features which characterise a learning organisation. Within the organisation where the study was carried out there is much work, which is ongoing, to develop sophisticated information systems that facilitate rapid acquisition processing and sharing of much complex information to the clinicians who actually input that data in real time. It is hoped that this will enable effective acknowledgement management at both the patient and managerial level. The organisation also has an appraisal and reward system which looks to measure long term performance and which tries to promote the acquisition and sharing of new skills across the whole of the organisation, this is currently being linked to the clinical governance agenda within the organisation. The organisation also has a culture of openness, creativity and experimentation amongst staff. People are encouraged to acquire, process and share information, innovation is nurtured and the organisation is actively working towards a blame free culture.

Leadership is also of high importance within the organisation and the role of a leader was identified by the specialist nurses to be in an important component of their own roles. The organisation has supported this by providing special LEO (Leader Empowered Organisation) Courses for all levels of staff and one has been especially commissioned for cancer nurse leaders within the Cancer Network area. This of course fits in with national documents which stress the importance of leadership within the NHS (Nursing Contribution to Cancer Care, 2000; NHS Cancer Plan, 2000; The Manual of Cancer Service Standards, 2000; Making a Difference 1999)

Berwick (1998) states that Action Research is a form of collaborative, critical enquiry based upon organisational learning and usually

conducted by practitioners and managers rather than expert academic researchers. In the field of health he advocates the use of small scale short cycled tests based on plan, do, study act learning cycle. He suggests that this particular form of action research enables health care teams to learn on the basis of action and its observed effects rather than the basis of theory alone. This is certainly the approach the Cancer Services Collaborative has used within the organisation and they report their successes in terms of the numbers of plan do, study, act cycles that have been implemented.

Action research has proved to be successful within the Trust with a variety of change programmes, some of which have been instigated by the Cancer Services Collaborative but some have also been on a slightly larger scale and have been as a direct result of this study.

Success in both instances have found to be largely dependent on the organisational context and where difficulties have been identified they have tended to be rooted in political and personal conflict between researchers and managers.

The work carried out by NCCSDO (2000) was reinforced via the interviews with consultants and the focus groups with the senior managers and the specialist nurses. It is clear that in every day situations most people are concerned about a number of issues relating to the implementation of change. They want to know who wants the change and why. Managers want to know how powerful it is, people very clearly need to know whether the proposed change has come from within the service itself or from the organisation or whether it has been imposed upon them from the Department of Health. People also want to know who is opposed to the change and why. Managers need to know whether the change fits in with other

performance objectives set for their directorate, or the organisation, and what priority this change should be given. They also wish to know how radical is the change needed and is the organisation already doing something to address the issues involved in the initiative. In terms of performance measurement people want to know who is measuring the success of the change and how is the success actually measured. They also want feedback regarding both successful and failed change management initiatives.

All staff wish to be consulted, people need to know what professional groups are involved or affected by the change as already stated in this chapter, people who are not directly involved in the change may still be affected by it and they need to know about the change. When planning change, managers and health care professionals want to know how easy it will be to involve stakeholders in discussion and in the development of the solution. A key issue for everyone interviewed was whether the staff groups concerned were already involved with a number of other changes. It is clear that by asking such questions at the outset of implementing change, managers and professionals will be able to orientate themselves in relation to the need for renewed change and to start planning and implementing the change.

The reality however is that as the change initiative gets underway those leading of the change, tend to find themselves experiencing, and being drawn, into a range of tensions and dilemmas. All of the experienced health care professionals and managers who were interviewed had spent a number of years within the health service and had been affected by several ways of change initiatives. In some instances they felt that each new change just washes away the deposits, good and bad left by the change before so that such

experiences had made health care professionals and managers “wary” of change and in some instances people become “disconnected”.

In reality, changes are often imposed upon managers to meet priorities which may differ from the priorities perceived as most important by the key opinion formers (these are often consultants). There can be a tension between the instruction to “gain ownership” of a particular change and the instruction to deliver that change quickly and this issue was highlighted by a number of managers who were interviewed. When people are being bombarded with new initiatives on a day to day basis, it is often easy to lose sight of the original objective of a change programme and sometimes what happens is that a series of actions are implemented, rather than the change programme overall and the actions which may be implemented may not be the most relevant.

In terms of communication many staff members are cynical about consultation processes. This is often because of previous poor experience, often where change has been associated with curbing costs. This makes people very sceptical about change, particularly if it is one which they have not generated themselves and which they do not feel that they have direct ownership of.

In addition to scepticism about change implementation itself, there is a lot of scepticism around change techniques, particularly those which have been imported from the private sector. Clinicians traditionally value evidence about virtues of a change in a form which they are familiar, the example of credible evidence cited in many interviews was the need for published randomised clinical trials, however, this may not be either available, particularly when a large scale change is being implemented, nor may it be appropriate. Another thing people

are sceptical about is the time that it takes to plan and implement change and when clinicians have been involved in the planning process, this obviously takes them away from patient time and the costs can be measured in lost patient care.

NCCSDO (2000) also highlight the fact that managers tend to stay in post for shorter periods than their clinical colleagues and thus they are not able to see a change programme through from start to finish, nor to learn from the results. This may be true of the wider NHS but this is not true of those managers who were interviewed as part of this study.

In this chapter it has only been possible to briefly discuss 8 of the models/tools highlighted by Iles and Sutherland (2000), however it is clear that whilst specialist nurses, consultants and managers may not be aware of the actual name of the model, they are aware of the principles of change and have experienced a number of these models/tools in practice. It seems clear that there is no one model which is suitable for all situations within the NHS and that it is up to those who are responsible for implementing change for deciding what model or tool will be the most effective for that particular organisation and team. It is clear that, whatever the focus of current concerns, individuals need to consult the literature with regards evidence relating to the topic that is causing concern but also review literature relating to organisational change. People need to talk to specialists in change management both inside the organisation and outside the organisation, particularly if change is to be wide spread and if it is to be sustained in the long term.

Within the organisation where the study was undertaken there is a Modernisation Team that can be consulted regarding change management and outside the organisation, but within the region there

is the Northern and Yorkshire Learning Alliance who will act as consultants in change management. The Clinical Governance Team within each NHS Trust can also be helpful in implementing and sustaining change. However more staff need education regarding change management, simply to raise awareness of the processes within the organisation. Change agents also need access to those who can help to provide objective advice and support in order for them to implement change at clinical level.

However it is clear from this action research project that where there are motivated individuals working together with the same aims, i.e. to improve the care of cancer patients, changes can occur relatively painlessly and can be sustained in the long term. This is because the professionals involved have ownership of the changes. In addition working together to implement change has promoted team working and indeed relationships within teams.

A number of changes and innovations in cancer were implemented throughout the duration of this study, those that have not already been discussed in detail will be addressed in the forthcoming chapter.

CHAPTER 10

Innovations in Cancer Care

A number of issues were raised during the patient interviews including lack of equity for patients across the cancer unit i.e. some patients received a very good service (as defined by them) whilst others were told of their diagnosis in a “brutal” manner and felt that they lacked information about diagnosis and treatment. Some patients stated that they had not been offered support whilst others felt they had been supported during the initial phase of cancer care.

It is evident from the patient interviews that were conducted at the time the study that patients experienced very different cancer journeys. Some patients were offered Clinical Nurse Specialist support, others were not, some people were offered support materials to reinforce what had been said to them verbally, others were not. Indeed, patients seen by the same consultant were not always offered the same type of support and this needs to be addressed. As a result of the study pathways of care now exist for breast, colorectal and upper gastrointestinal cancers.

These pathways are multiprofessional documents which are utilized by all of the health care professionals involved in the care of upper gastrointestinal, colorectal and breast cancer patients. Thus ensuring that all professionals write in the same notes with the aim that professionals can be informed of the contribution of colleagues to an individual cancer patient’s care. In addition the pathways include a flow chart of the patient journey, highlighting which health care professionals should be involved at different stages of that journey (see diagram 1) therefore ensuring that all patients diagnosed with a

particular cancer are offered the same support regardless of the individuals involved.

Diagram 1

Upper Gastrointestinal Cancer – Flow Chart

UPPER GI CANCER JOURNEY (Current Practice Surgical Route)

SYMPTOMATIC PATIENT

(Referred from General Practitioner)



OUTPATIENTS/DIRECT FOR GASTROSCOPY

(Surgeon or Nurse Practitioner)



Samples sent for histology

OUTPATIENTS FOR DIAGNOSIS/TREATMENT DISCUSSIONS

(Given diagnosis by surgeon seen by Clinical Nurse Specialist, counseling, support and follow up offered. Written information given also pre-admission visit to ward offered. Dietetic referral also made)



ADMISSION



SURGICAL INTERVENTION

(Ongoing dietetic and Clinical Nurse Specialist support offered. Physiotherapist intervention)



DISCHARGE

addition

Specialist support if

**FOLLOW UP
BY SURGEON**

(and Clinical Nurse Specialist)

ONCOLOGICAL INTERVENTION

(seen by oncologist and Clinical Nurse Specialist)

(Referral to community support as appropriate in

to continued dietetic and Clinical Nurse

required)

PALLIATIVE CARE

(Macmillan and or hospice support)

To date the use of the pathways have been audited and everyone involved in patient care is recording their interventions in the same documentation. Even one consultant who was initially reluctant to use the multiprofessional documentation has recently acknowledged the benefits of improved communication and a seamless approach to care, facilitated by sharing the same documentation.

Patients are also given a flow chart as detailed in Diagram 1, the purpose of this is to advise them what they might expect during their initial phase of cancer care. This is supplemented with Bacup booklets relating to the specific cancer site, for example upper gastro intestinal patients are given a booklet entitled "Understanding Oesophageal Cancer" or "Understanding Stomach Cancer" depending on the site of their cancer. Further information regarding contact numbers for support, and about specific treatments are also given as appropriate. Dietary advice is also reinforced in written form. There is a checklist in the documentation to be ticked when such literature is provided to patients. Since this process has been implemented only seven upper gastrointestinal patients have been seen, however a patient satisfaction survey has indicated 100% satisfaction with the information and support given during the initial phase of cancer care. One area yet to be addressed is the need to provide information booklets and flow charts in larger print, Braille and tape recorded format, however the intention is to provide these resources within the forthcoming year.

The current drawback relating to the introduction of pathways is that they only extend to the cancers already mentioned and patients presenting with other cancers still have no formalized approach regarding which professional should see them at what stage of their disease journey, this is despite the fact that the NHS Executive have produced guidance regarding the management of a number of cancers and are due to produce more in the near future.

Following the non-participant observation stage of the study, all of the doctors who participated were given feedback following analysis of the detailed notes that were taken during each observation. Frank and open discussion ensued with the doctors regarding the potential way forward following the non-participant observations, as a result the doctors have all modified their behaviour somewhat, all three doctors who participated in that phase of the study now have protocols in place relating to what information (written) is given to patients to support the verbal information they have received. In addition there is now a box holding the appropriate leaflets in the clinic room, at every clinic, with the clinic nurse responsible for ensuring that the box is well stocked and new leaflets are ordered and so on. It has been agreed that all of the newly diagnosed patients are offered the support of a Clinical Nurse Specialist and where there isn't one available due to sickness or study leave etc., the patient will be advised that someone will be getting in touch with them within the next 48 hours. It is the Consultants responsibility to ensure that a referral goes to the appropriate Clinical Nurse Specialist at the end of that clinic. As far as the seating arrangements of the rooms are concerned this remains a problem simply due to the size of the examination room commonly used by the doctors. However, the doctors do try to sit on chairs wherever practical and have tried to change their behaviour as a response to the results of the study.

The consultants, who participated in the non-participant observation phase of the study, reported that the study served to raise awareness of their own communication skills and encouraged them to look at ways to enhance their practice. One of the consultants has subsequently become interested in the idea of providing the patient with an audio tape of the bad news interview. McHugh et al (1995) carried out a study to assess the efficacy and acceptability of providing the patient with an audio tape of the bad news interview. 117 patients who were to be given potentially

distressing information were recruited into McHugh's study and the patients were randomized into an intervention and a non-intervention group. All of the patients in both groups were followed up a mean of five months after they had been recruited into the trial. Those patients who were recruited into the intervention group were given copies of interview tapes and encouraged to listen to them at home following the interview. The control group were not given interview tapes. Five months after the interview the patients were asked to complete a questionnaire which included a 14 item hospital anxiety depression scale, and information retention questionnaire and the intervention group received an attitude to tape questionnaire. The results indicated that the intervention group showed improvement in: recall of information on test, results, treatments, side-effects of treatment and self-care. The patients in the intervention group also had higher quality of life scores where they had a good prognosis, however, those patients in the intervention group who received the tape had poorer quality of life scores when they were told their prognosis was poor. It is clear from the results of this study that providing patients with audio tapes of the bad news interview may be particularly beneficial for those patients who are thought to have a good prognosis, but for those with a poorer prognosis this may not be the best way of providing support materials to reinforce what has been said verbally or, they may indeed require other follow up support such as psychological support provided by Clinical Nurse Specialist or psychologist. The current situation regarding the proposed audio taping of such interviews in the cancer unit is that the Consultant has got a tape recorder suitable for the purpose and plans to record the interview for his own purpose (so that he can remember what he has actually said to each individual patient) and also to provide a copy for each patient. He is concerned about McHugh's results and is looking at tools that actually identify patients coping styles so that the audit tape can be given to those patients who it is most likely to help.

Two main psychological coping styles for dealing with cancer have been identified, the first one is defined as monitoring (attending to) and the second one as blunting (avoiding) potentially threatening information. Miller (1995) carried out a study to assess whether monitoring versus blunting styles of coping with cancer influence the information patients want and need regarding their disease. The monitor-blunter style scale was used to assess and categorise patients with regard to these coping styles and to predict their differential responses to various cancer related screening and management regimens. Miller (1995) found that patients characterized by a monitoring coping style were generally more concerned and distressed about their cancer risk, experienced greater treatment side-effects and are more knowledgeable about their medical situation and less satisfied with and more demanding about the psychosocial aspect of their care. This group of patients also preferred a more passive role in clinical decision making and were more adherent to medical recommendations. They also manifest greater psychological morbidity in response to cancer related threats. She concluded that patients fare better behaviourally and psychologically when the information they were given about their medical condition is tailored to their own coping styles. Generally those with a monitoring style managed to do better when given more information and those with a blunting style do better with less information. However patients with a monitoring style who are pessimistic about the future or who face long term intensely threatening and uncontrollable medical situations may require not just more information but also more emotional support to help them deal with their disease. It would seem that those patients with a monitoring style of coping may be helped by being given a tape recording of their consultation, but they may also require more support if they face uncontrollable medical situations such as poor prognosis. However at the moment no decision has been made regarding whether to go forward with assessing styles prior to making a decision about tape recording a consultation. Recently it has come to the attention of the cancer team that

the Consultant Haematologist working in the cancer unit has been audio taping his breaking bad news interviews for a number of years and does not distinguish between which patients should get a copy of the tape and which one shouldn't, anecdotally he reports that those patients who have a poor prognosis or who cope by using denial as a coping mechanism do not choose to listen to the tape once they get home but, in some instances find it helpful to pass onto friends and relatives so they do not have to repeat the information they have been given. It is clear that if tape recording of breaking bad news interviews to be introduced to other areas within the cancer unit then this process needs to be evaluated properly.

As discussed during the results chapter of this thesis a number of patients in the study commented upon the quality of the written information that they were given, a group has since been set up at the local cancer network (i.e. the cancer units that link in with the local cancer centre) to examine the quality the literature being given to all cancer patients and to try to agree some standardization across the network in order to ensure that patients are being given consistent information. However, the drawback of this group is that it is made up of professionals and there is clearly a need for a patient group to evaluate the literature and decide upon its suitability for patients themselves.

The need for a multi-professional approach in oncology has been well documented, and it largely undisputed (Calman and Hine 1995; NHS Executive, 1997; NHS Executive, 1998; Department of Health, 2000). Since the commencement of this study a number of site specific cancer teams have been formed within the cancer unit namely colorectal, upper gastrointestinal and gynaecological (those that were in existence at the time that the study commenced particularly the lung and breast cancer teams have clearly tightened up their working practice and function as much more effective multidisciplinary teams). Multi-professional site specific teams now exist for breast, lung, colorectal, upper

gastrointestinal, head and neck, gynaecological and haematological malignancies. Plans also exist to develop site specific teams to manage urological cancers. Each site specific team works in different ways but, all are now starting to work towards the same goals such as shared documentation, carrying out mapping exercises which identify which health care professionals should be involved in a patient's care at predetermined points in their disease journey. Multi-professional rather than uni-professional audit and implementing new Department of Health led cancer related initiatives, such as the Manual for Cancer Standards are all on the current agenda. The colorectal site specific team is an interesting model which has developed, it has a Lead Clinician but site specific team meetings which are held on a monthly basis to look at service evaluation and developments, are led by a Macmillan Clinical Nurse Specialist. The site specific team is made up of specialist nurses both from a variety of backgrounds including Macmillan, stoma and colorectal nurse practitioners, radiographers, dieticians, physiotherapists, ward and outpatient based nurses, surgeons, oncologists and so on. This reflects the current trend of encouraging senior nurses to become leaders both within their own fields but also in a multi-professional environment. This multi-professional team have taken time out with the support of the trust to agree common aims, objectives and priorities for action and part of this process was quite painfully initially, as individuals needed to take time to understand and appreciate each others roles and to develop team relationships. Once work had been completed to ensure that all of the team members understood and appreciated each other roles, an exercise was carried out within the team in order for team members to identify how they interact with other team members and to reflect on the action and behaviour of individual members and the parts people played within the group. Belbin's (1999) Self Perception Inventory was an exercise completed by each team member. Belbin (1999) suggests that for an effective group there are eight useful types of team roles, he classifies these roles in terms of key team roles and the primary characters for a

successful team. The most consistently successful teams were "mixed" with a balance of team roles. The role a person may take within the group is not fixed and may change according to circumstances. There is a suggestion that individuals may also have a "back-up team role" with which they may have an affinity other than their primary team roles. Team roles are identified as:

- Company worker - who typical features are conservative, dutiful and predictable;
- Chairman – who typical features are calm, self-confident and controlled;
- Shaper – whose typical features are individualistic, serious minded, unorthodox;
- Resource investigator – whose typical features are extrovert, enthusiastic, curious, communicative;
- Monitor evaluator – whose typical features are sober, unemotional prudent;
- Team worker – whose typical features are socially orientated, rather mild, sensitive.

It is clear that different individuals are more suited to certain tasks than others and the Macmillan Clinical Nurse Specialist who leads the site specific group was primarily a shaper, she was chosen to lead that group because it was thought that a lot of networking needed to be carried out and a dynamic individual needed to lead that group. Positive qualities of shapers as defined by Belbin (1999) include drive and a readiness to

challenge inertia, ineffectiveness and complacency. Whilst it is recognized by the multidisciplinary team that initially such an individual would be particularly useful in achieving objectives quickly, in the long term it may not be appropriate or sustainable to have this person as the lead. The group have clearly recognized that, and intend to re-evaluate the leadership of the group on a regular basis. Any new leader of the group will be determined upon the needs of the group at that particular time and not on traditional medical hierarchy where the consultant automatically takes the lead.

Practice has changed quite dramatically in a number of areas since the study started. The most striking changes are related to the support patients are offered during the initial stage of cancer care. All patients currently suffering from lung, breast, colorectal, upper gastrointestinal, head and neck, gynaecological haematological and urological malignancies receive written information about diagnosis, treatment and support to supplement what has been said to them by their consultant and Clinical Nurse Specialist (who is now available from the point of diagnosis throughout the disease journey). Evaluations of these interventions have been positive, but are limited and more work needs to be done to evaluate these innovations. However, despite the changes in practice, it is necessary for health care professionals to constantly reflect on their practice and not to lapse into a state of inertia just because some significant changes have been made.

The Trust itself also has a much greater understanding of the processes that cancer patients have to endure. Many services such as the colorectal service, gynaecological and lung service have been process mapped, i.e. each stage of the patient journey identified and timed, then documented in form of a flow chart. This had led to multidisciplinary teams actively taking ownership of the services as a whole, reviewing and

where appropriate redesigning and streamlining the processes in order to provide a speedy yet more patient orientated service.

However implementing change has not been easy for some teams and a variety of methods were used to bring about change some of which were discussed in the previous chapter.

CHAPTER 11

Discussion and Conclusion

It is evident that one cannot generalise from such a small-scale study, however a number of themes emerged from the data which were consistent with issues cited in the published literature relating to communicating with cancer patients. Such issues included the need for honesty, usual reactions exhibited by patients on hearing a cancer diagnosis, the need for continuity of care and so on. One area, which was not really found during the literature review process, was the importance of health care professionals exhibiting a "caring" attitude. In some instances this was much more important to the cancer patients interviewed than the quality of factual information they were given or the support they were offered post diagnosis. However, health care professionals need to strike a balance between "showing that they care" whilst still giving appropriate clinical information to assist a patient to make appropriate choices regarding their clinical management. Interestingly, those patients who felt they had been given their diagnosis in an unsympathetic manner described their doctors as very 'clinical' and 'professional' and the use of such terms became derogatory. It is evident that those health care professionals responsible for telling cancer patients their diagnosis need to have good communication skills, the knowledge base to give appropriate information, and they need to be able to convey this information in a sympathetic and caring manner.

It has been shown that many patients experience a wide variety of feelings and emotions at the time they are given a cancer diagnosis, all of these feelings may be normal, including those reactions such as anger and frustration, which may be perceived as negative by health care professionals. Indeed, in some instances patients may be deemed to be reacting in an abnormal manner when they exhibit relief when told they

have cancer. However, this sort of a response needs to be viewed in context of the situation, relief at a cancer diagnosis is not necessarily an abnormal reaction when a patient has been experiencing uncertainty during a long period of investigation and is frightened about what is going to happen to them. Fear of the unknown is often worse than fear of the reality. Once a patient knows what the reality is, he or she can then focus his/her emotions on coping and dealing with the proposed treatment options. What has been demonstrated throughout the study is the need for health care professionals to deal with patients and their own reactions at the time of diagnosis on an individual basis. It may be helpful to try and analyse patient's coping styles in order to anticipate how best to give them further information but this is not practicable in all circumstances and no one locally has incorporated assessment of coping styles into their practice to date, although there has been a lot of debate regarding potentially piloting this by the trust's Palliative Care Team.

Informing a patient that he or she has been diagnosed with cancer is a potentially distressing process, both for the patient and his or her family and also for health care professionals. In order for health care professionals to impart such information sensitively and begin to establish a trusting relationship with the patient, the health care professionals need to do much more than simply give facts, they need to show that they care about the individual patient. Caring was an attribute which was more highly valued than many professional skills by the patients interviewed in this study. In addition to being skilled, knowledgeable practitioners who can provide accurate information relating to diagnosis, prognosis and treatment options, health care professionals need to show that they genuinely do care about their patients and are interested in their psychological and social well-being as well as their physical well-being, and perhaps this should be taught routinely as part of any communication skills training provided for health care professionals and in particular doctors. As a result of this study and recent Department of Health

recommendations an "in house" training course has been developed and specifically targeted at health care professionals who are responsible for breaking bad news and supporting patients through their cancer disease journey. The course gives people a model for breaking bad news, provides an opportunity to practice in a protected environment and stresses the importance of health care professionals being approachable and exhibiting their caring natures. The course has evaluated well and is currently running on a monthly basis, professionals have been particularly interested in the fact that patients value a "caring approach" as much as clinical expertise and a number of course participants have stated this knowledge has helped them re evaluate the way in which they communicate with cancer patients particularly at times when they are going to impart some bad news,

It has emerged that the patient's needs during the initial phase of cancer care are much wider than simply the need for relevant information to be given in a timely manner. What was more important to some patients were the attributes of the health care professionals who were imparting information and the ability of the patients' to access support at a time which is appropriate to their need and not that of the health care professional. Communicating with cancer patients is clearly a complex issue and there are many factors both verbal and non-verbal which influence the effectiveness of communication and these have been discussed throughout this thesis and have been incorporated into the aforementioned course.

It is evident that communication skills training is important for all health care professionals coming into contact with cancer patients particularly in the initial phase of cancer care. Whilst a number of guides to breaking bad news already exist there is a need for more imaginative and experiential methods of teaching communication skills and the course facilitators are currently experimenting and rigorously evaluating their teaching methods.

However, not all organisations are providing such training despite the fact that all cancer patients deserve to be given information in a skilled and supportive manner. In an attempt to address this the Cancer Action Team at the Department of Health have recently commissioned the delivery of some communication skills courses using different communication/breaking bad news models aimed at unprofessional groups, these are due to be evaluated later this autumn with a view to rolling out the most successful models nationally.

In the meantime the Trust will continue to provide its own in-house education programme and will continue to do so for all staff groups once the national programme is rolled out as this currently only focuses on medical and trained nursing staff. Whilst this is a start it has become clear from this action research project that it is not just the medical and nursing staff who communicate with cancer patients and sometimes the first people they see is the receptionist or ward clerk and that can ultimately affect the rest of their experience within the hospital setting.

Health care professionals have a responsibility to listen and use language so that unclear, unhelpful patterns of communication no longer persist. In this way health care professionals can truly embody what Benner (1984) termed the 'helping role'. Where education programmes relating to communication skills already exist, it is essential that the impact of such educational programmes on patient outcomes is evaluated. New methods are being introduced into medical training which have previously been utilised in nurse training such as the use of reflective diaries, the use of such tools may encourage medical students to reflect on individual interactions with patients, identify areas of success and failure and encourage them to be proactive in changing their practice accordingly. These initiatives are quite encouraging as anecdotally they seem to have been successful particularly in post-registration specialist training of

nurses and they encourage medical students to spend time reflecting on 'human issues' rather than 'scientific issues' which have been the focus of traditional medical training.

For communication to be effective it has been shown that where effective team working is evident the patients feel better supported. There is also plenty of evidence to suggest that where specialist teams exist they tend to gain more positive appreciation than their generalist colleagues (Cox, Bergen and Norman, 1993; Field, Dand, Ahmedzai and Biswas, 1992). Such studies suggest that patients perceive specialist teams as having a greater amount of time which they can devote to patients and increased continuity of care is most appreciated. In contrast, where patients have been dealt with by generalists they still provide reports of poor communication and delayed transfers between services. It is clear that availability and continuity of service and specialist expertise were seen as essential to all the patients interviewed during this study and this was echoed in the body of published research. Patients directly commented on negative aspects of communication as well as the positive aspects of communication and some negative comments were made about communication within particular teams and also between specialist and generalist teams i.e. consultants not communicating effectively with general practitioners and vice versa. There appears to be enormous potential for Specialist Nurses to cultivate relationships with their primary care colleagues in order to ensure the flow of timely and accurate information. Specialist nurses also could play a vital role in influencing the way in which their medical and allied health care professional colleagues communicate with cancer patients.

As part of this action research project a number of initiatives have already taken place to try and improve team working and these have been discussed at length in a previous chapter. There is a need for more pathways to exist for all of the cancers that are to be potentially treated

within the cancer unit and that has not happened to date. Pathways currently exist for the common cancers but not for some of the more unusual cancers. The drawback with existing pathways is that they tend to focus on the acute period of care and do not follow patients through to the community where they will be followed up, indeed pathways could actually start in the community at the point of diagnosis as very many cancer patients are diagnosed in the first instance by their general practitioner and then referred to the acute units for intervention. There is clearly a need for more multi-professional documentation and that documentation should start at the point of diagnosis and go with the patient wherever he or she goes, whether that be hospital, community, nursing home, specialist cancer centre and so on. Written communication between health care professionals is not a substitute for verbal communication but it can be useful in emergencies where health care professionals may have difficulty in liaising with colleagues in other units and would serve as an interim measure to indicate what has been happening to a patient and highlighting their particular problems. Giving patients their own hand-held documentation would also give them some control back and ensure any information regarding their care was with them regardless of whether they were in hospital or at home. Implementing such initiatives seems very simple, although there are often many prejudices to overcome, including health care professionals not wanting to share documentation and having difficulties in giving up ownership of documentation.

There is also a need not just for health care professionals to look at the standard of written materials given to patients, but for patient groups to actually review patient information leaflets and to tell health care professionals what they want to see in them and how they should be presented and so on. These sorts of initiatives are not without cost implications and need time to establish.

The information routinely communicated to cancer patients has changed during the last ten years. Health care professionals now see a cancer diagnosis as the patient's information with the patient having the right to be given that information. There has been a trend in recent years for this to be taken very literally and for health care professionals to assume that patients should be told absolutely everything, whether they want to know it or not. However, this trend seems to be reversing somewhat and it appears certainly in the cancer unit where the study was conducted that most patients who are dealt with by experienced practitioners are given the opportunity to decide how much information they want and when they want it. This sort of practice should be advocated widely and those patients who do not want to know much information should have their wishes respected, but health care professionals should ensure that they have the opportunity to return at any time should they change their mind and they should still be offered the same support networks as those patients who have been told everything about their diagnosis and prognosis. Perhaps the key to supporting cancer patients in the initial stage of cancer care is making sure that they have access to support networks at times that are appropriate to them and which they can access easily, without having to return to the GP in order to be re-referred.

There are a number of ethical issues, which were raised during the study which are particularly pertinent to those providing care to cancer patients. Whilst it seems obvious that patients have a right to be told of their diagnosis and prognosis, and indeed all of the patients interviewed valued the doctor telling them the truth regarding their diagnosis, even when they did not wish more details to be given subsequently. In reality this often presents doctors with difficult dilemmas, for example where they think that if they tell a patient his or her prognosis then that patient will give up hope and just "go away and die" (these dilemmas have already been discussed in length within the literature review chapter of this thesis). The concept of informed consent and how it is actually applied in the clinical setting is

also another important ethical consideration for health care professionals as is the concept of patient autonomy and the idea that the nurses role is as a patient's advocate.

Branson (1985) suggests that for many years the relationship between patient and doctor has been based on the belief held at least by the patient, that the doctor would do whatever was appropriate to treat that patient's ailment. The doctor usually made the decision regarding how much discussion and explanation was necessary. The mere act of seeking a doctors advice implied consent to investigation and treatment and no formal recognition of this consent was needed, the area where an exemption applied was when patients were required to give formal consent for surgery in the form of signing a consent form. However, more recently there has been an increasing requirement for doctors to obtain "informed consent" from patients before submitting them to any treatments or procedures. Much of this impetus has come from the United States of America due to the desire of the American medical profession to protect themselves from litigation. As Branson (1985) suggests, there are other reasons for the increasing requirement for informed consent. The relationship between patients and doctors has changed considerably since the public have become better informed about medical matters. Patients now often realise that the decision as to which treatment is best for them is far from simple there may be several equivalent treatments. Willard (1995) suggests that the process by which informed consent to medical intervention is sought in the clinical area rarely appears to fulfil either the ethical or legal requirements of respect for autonomy, which is central to the issue of informed consent. Willard (1995) suggests the importance of obtaining the consent of a patient prior to that patient undergoing medical or nursing procedures or treatments has a firm basis both in law and ethics.

Civil law recognises that touching a patient without their consent constitutes a trespass, which may lead to the patient bringing an action for battery, (Jones, 1989). The foundation for the prohibition of battery is closely related to the ethical perspective, which emphasises the principal of respect for autonomy. Willard (1995) also suggests that the desirability for autonomy originates from utilitarian and deontological ethical theories which basically claim that there is a moral requirement to respect a persons autonomy, such an approach argues that human happiness which is fundamental to their argument is largely dependent on the exercise of autonomy and therefore autonomy should be respected. The deontological view is that morality requires autonomy, as the individual is required to rationally reflect on his or her moral duties and act accordingly, in doing this it follows that if individuals are to be moral agents then their autonomy ought to be respected. The concept of autonomy has become increasingly important over the last two decades and is particularly applicable to the practice of medicine due to the fact that patients have become increasingly dissatisfied with their role as passive recipients of health care, (Pellegrino and Thomasma, 1998). Autonomy can be defined as self-determination or self-rule but a simplistic definition does not account for the complex concept, which lies at the heart of all discussion about informed consent. Dworkin (1988) suggests that autonomy is rarely found in a pure form and instead functions as "moral, political and social ideal" however, the literature suggests that more autonomy is considered to be better than less. Dworkin (1988) also places self-determination as the central feature for autonomy and recognises that the achievement of self-determination is dependent on the fulfilment of several other conditions including the idea of independent and influential freewill to make decisions i.e. freedom from coercion or deception, rational, reflective thought and information and knowledge. Willard (1995) reflects that by using such criteria some individuals will indeed be considered incapable of autonomy for example those patients with some forms of mental illness, demented patients, or those with cerebral metastasis and

those who are too ill to make rational decisions. Buchanan and Brock (1989) suggest a further factor to consider in relation to autonomy is that there is likely to be a relationship between the capacity to be autonomous and the type of decision to be made. It is therefore important for all health care professionals to remember that the patient's ability or not as the case maybe to act autonomously is not necessary permanently fixed and may fluctuate according to their mental and physical state and the context of the decision to be made.

Willard (1995) suggests that in the oncology environment as in most health care specialities, patients are treated on a voluntary basis and as such their consent to care and treatment is tacit rather than written and this was evidenced during the non-participant observations. The exception occurs when surgical and or invasive treatments are required, and then written consent is needed. Within the oncology setting patients are usually required to provide written consent if they are becoming involved in clinical trials, but that has traditionally occurred in order for the doctors to protect themselves from litigation in case problems occur. However, research by Byrne et al (1988) and Lavelle-Jones et al (1983) suggests that 'lip service' is sometimes paid to the fundamental principle underlining consent that is respecting autonomy, since the manner in which the consent is obtained does not fulfil the criteria established by Walkin (1988). It is clear that informed consent involves more than asking the patient to sign a piece of paper or inferring that the patient's presence in the hospital is sufficient to constitute consent. Varracchio and Jassak (1989) suggest that informed consent is an ongoing process rather than an isolated incident. Willard (1995) suggests that regarding the disclosure of information to cancer patients there appears to be two schools of thought. One school of thought suggests that patients are unnecessarily distressed if they are given too much information and this can cause uncertainty, confusion and make decision-making virtually impossible and in fact may lead to decisions that are ultimately not in the patient's best

interests. The second school of thought is based on the premise that information not only supports patient autonomy but also helps to reduce patient anxiety.

From experience, and supported by the results of the study, it appears that patients who are given too much information at a time when they are unable to absorb it, such as immediately after they have been told they have cancer. Or, information which they can not absorb because it is jargonistic, often become overwhelmed and distressed, finding it impossible to make decisions. However, those patients who are given information in a timely and understandable manner are often reassured and appear more able to make appropriate treatment decisions. Perhaps the key to supporting patient autonomy is not about deciding how much information is appropriate but is about ensuring that it is given at a time when the patient can absorb what is being said and is then given further time to come to a decision he or she is comfortable with. Clearly in those circumstances where patients are given too much information for them to absorb at that particular time, the Clinical Nurse Specialist has an important role as the patient's advocate. Indeed, he or she has the moral responsibility for intervening in order to slow down the flow of information from the doctor to the patient and has a responsibility to ensure that the patient has fully understood what has been said.

Research by Kerrigan et al (1993) suggests that patients, including the very anxious appear to be reassured by very detailed information about proposed treatment and possible side-effects. However, it must be noted that Kerrigan et al's study consisted of patients undergoing elective hernia repair and it would be unwise to generalise their findings to cancer patients since the amount of anxiety and distress attached to the diagnosis is likely to vary enormously. Willard (1995) suggests that it is arguable which health care professionals are best placed or sufficiently skilled to gain the patient's consent since in the past both medical and

nursing staff had received criticism about deficiencies in their communication skills, (Porter, 1998; Wilkinson, 1991 and Doyle 1991).

In reality it is very difficult to decide who is best placed to gain the patient's consent, many Clinical Nurse Specialists witness doctors who are poor communicators primarily due to their use of jargon or inability to assess the patient's understanding of what has been said. It is therefore not uncommon to encounter patients who have consented to treatments without having fully understood the implications of them. However, the counter argument, usually proposed by doctors is that nurses do not have sufficient knowledge regarding either the disease process or treatment options to give the full information to the patient which is necessary if informed consent is to be given. Another view is that the person who has the best rapport with the patient is in the most appropriate position to seek informed consent and whilst this may be true if the patient has been an in-patient on a ward for a period of time. The majority of cancer patients are informed of their diagnosis and treatment options in an outpatient clinic by someone who they have probably only met briefly once or twice before, such as the consultant surgeons, physicians or oncologists.

An appropriate option maybe to have a Clinical Nurse Specialist who has specialist knowledge in both the disease process and treatment options and who has also had training in communication skills, hopefully such an individual would be equipped to deal with all of a patient's questions in order to obtain informed consent. Another advantage of having a Clinical Nurse Specialist addressing this aspect of cancer care would be that he or she could reinforce the information/answer questions over a period of time appropriate to the individual patient rather than making the gaining of consent a one-off exercise in the clinic situation which is required by law. Another advantage of a Clinical Nurse Specialist giving information regarding specific treatments maybe that biases towards individual treatment modalities maybe reduced for example a consultant trying to

recruit into a clinical trial may be biased towards that treatment when other treatment modalities may also be appropriate for an individual patient.

However, the British legal position places the responsibility for obtaining written consent directly on the shoulders of the doctor. Willard (1995) argues that the issue of informed consent in the oncology setting is far from straight forward and recommendations for improvement in practice will depend on the choice between its interpretation in law or ethics. It can also be said that through the use of a professional standard of disclosure, the law is unlikely to respect the individuals autonomy. This is not to suggest that the physician be compelled to disclose everything to the patient or that there is no place for the doctor to use discretion in relation to disclosure. Rather, the suggestion is that autonomy is a sufficiently important principle in health care and a principle that will assume even greater significance when a patient is faced with a life threatening disease. Health care professionals need to view informed consent as a multi-staged process in all but emergency situations, to enable this to happen the contact between patient and physician needs to be unhurried and guided by a patient-led agenda so that information can be given to facilitate informed choice. In reality most patients report being given the opportunity to ask questions in order to clarify issues, though four patients in the study felt they had been given too much information for them to make an informed decision, a further two did not want much information, a few patients reported wanting more information relating to their proposed treatment and its probably side-effects. One patient felt the doctor was the 'expert' and therefore did not know 'what to ask'. In all of these instances, the giving of information occurred as a 'one off' event with the information being given during one consultation although some patients were offered the opportunity to come back for further discussions the following week or the opportunity to see/contact a Clinical Nurse Specialist if they had further queries. However, this approach is not multi-

staged i.e. the information being given gradually over a period of time and therefore does not conform to current recommendations found in the literature. The primary reason for this is probably due to the doctors simply having too many patients to see in their allotted clinic times and therefore finding it difficult to find time to see patients in clinic on a number of occasions in order for them to be equipped to give informed consent. Willard (1995) also suggests that mechanisms should be created to provide emotional support at the time of disclosure or at a later stage if required, the Clinical Nurse Specialist maybe ideally placed to provide this. Varracchio and Jassak (1989) state:

“Informed consent is a process not an isolated incident. It therefore requires that health professionals approach the process with expert knowledge, open communication and a willingness to participate in shared decision making.”

Over the past 25 years nurses have become more aware of their responsibilities towards legal, ethical and professional issues and that the concept of patient advocacy has become increasingly important due to having received wide coverage in the nursing literature. Cahill (1994) argues that in the context of terminal illness the nurses role as patient advocate centres around the concept of respect for autonomy and justice, beneficence and non-malficence, negligence and malpractice, she therefore stresses the need for nurses to be more aware of legal and ethical issues that affect their clinical practice in order for them to function as patient advocates and to cope with the decisions that are not solely of clinical or nursing nature but also of a legal or ethical nature. Kendrick (1994) also highlights the importance of the nurse acting in the patient's best interests and suggests that it is to that end that the nurse is expected to act as a patient advocate. The Concise Oxford Dictionary (1992) defines an advocate as:

“person who pleads for another”.

As Kendrick (1994) argues, such sentiments seem laudable in their abstract form but reconciling them with the reality of clinical practice is a complex and demanding task.

The traditional image of health care has the doctor, nurse and patient all playing key though differently weighted roles. However there is a tremendous disparity between the levels of power each group enjoys.

“Traditionally, the doctor has been portrayed as all knowing and powerful; the nurses caring, unselfish, obedient and submissive; and the patient as helpless and utterly trusting”

(Chadwick and Tadd, 1992).

In such a situation the patient is placed in a subservient and passive position against a background of doctors being seen as being influential and controlling the power base in health care. Kendrick (1994) suggests that if the power in the health care equation were balanced equally between patient, nurse and doctor the need for advocacy would be greatly diminished if not totally outdated. This notion is also supported by Penn (1994) who cites the work of Abramms (1978), which states “the need for advocacy is the result of the failure of the health care structure to function as it should”. Kendrick (1994) argues that health care delivery is laden with issues of power and this can add to a patient’s feeling of disenfranchisement and vulnerability. Penn (1994) reflects that many patients are somewhat reluctant to discuss how they feel with doctors and very rarely challenge doctors decisions. MacKay’s (1993) study also reflects such views stating “patients are well aware of their role as the audience and as a performer: they know what is expected of them. They know to be deferential when the great consultant visits them and deigns to chat. They have been prepared for this great visit by the nursing staff.”

This adaptation of roles has tremendous implications on the impact on who defines the patients best interests and how this relates to care giving. Kendrick (1994) argues that a power relationship exists between doctors and nurses and as such it is debatable whether nurses are in the position to act as patient advocates. If a nurse is to act as a patient's advocate it should be on the patient's terms and should reflect the patients interpretation of his or hers best interests. Nursing is so implicitly constrained by issues of power inherent to the health care system that true advocacy is rarely achieved (Ibid). Allmark and Klarzynski (1992) reflect that:

“ To suggest that a patient has an advocate when it is that very person who may be involved in the treatment that the patient is trying to resist is analogous to suggesting that the police can act as advocates to people in custody”.

There are of course incidents that can occur in practice which clearly allow and demand that nurses act as a patient advocate for example if a patient has not understood a doctors explanation of a given treatment it is not uncommon for a nurse to intervene and seek clarification on the patients behalf. Therefore the concept of advocacy should not be totally dismissed from the nurses remit. As Kendrick (1994) argues there is a need for nurses to critically reflect on and examine the themes surrounding advocacy in relation to their own practice. It is not enough to act as an advocate when the individual feels it is safe and comfortable to do so, to represent a patient's interests in a way which is contrary to the dominant themes of a medical model and its power base demands careful consideration, insight and understanding. The person dying with cancer may want a lethal injection in order for them to “die with dignity” but such a scenario has strong moral and legal arguments, which counter any suggestion that such actions could be accepted as part of the nurses role. Kendrick (1994) argues that what has emerged is a form of advocacy

which is relative to context and situation so that on occasion it is fine to advocate but not in others.

As more and more cancer treatments become available the doctor is increasingly under pressure to determine which one is best for his or her individual patient, this in itself presents a number of problems because in some instances there is no obvious 'gold standard' treatment available and it is ultimately subject to the individual preference of the doctor. This can often cause the doctor difficulties when trying to explain that a number of treatments may be available for a particular cancer but, he or she does not know whether one is better than another (a common scenario with clinical trials). This can cause the patients confusion and lead to lack of trust in their doctor because after all, the doctor is often seen as the 'expert'. However, there is hope of the horizon, as more and more clinical trials are carried out and organisations such as the National Institute for Clinical Excellence review the evidence base for treatment modalities. Hopefully in time this problem will become less frequent.

It is clear that all patients suffering from cancer are vulnerable. Their vulnerability may in part be caused by their state of health, they may also be confused, frightened or too weak to question the decisions of health care professionals or to ask for fuller explanations of their condition and/or treatment. A patient's vulnerability can be increased directly by the attitude of health care professionals towards them and also by environmental factors. It is therefore easy for health care professionals to assume that patients may not want to know more or do not want the responsibility of making decisions. In some instances health care professionals may even decide that the patient cannot possibly understand the implications of what is being said to them. This does not only apply to telling a patient that he or she has a poor prognosis but also applies to much less dramatic information such as why a particular x-ray or blood test has been requested or how a patient's medication will act

upon him or her. It is clear that all health care professionals want to maximise the benefits of any proposed treatment and minimise any harmful side effects but in order to facilitate this process patients need to be offered plenty of information and the chance in the decision making process. If we are to comply with the old adage that "hospital should do the patient no harm" then they need to be aware of potential benefits and the potential negatives associated with a particular course of treatment. For example a patient who has decided to undergo chemotherapy in order to try and "shrink down a cancer" may be doing so because they want to live as long as possible at any costs, the patient may be happy to tolerate side effects such as nausea, vomiting, fatigue, diarrhoea and so on, however if the proposed treatment is not going to cure them and the side-effects of the treatment become particularly distressing, they may actually survive longer but their quality of life may be poorer than if they had never had the treatment in the first place. In such an instance patients need to be aware of all of the potential side-effects and need to be assisted to identify what their priority is, is it that they want to live as long as possible regardless of any side-effects they may encounter along the way, or is it that they want to be comfortable and free from side-effects so that they can have the best quality of life possible for whatever time they have got left. It is obviously very difficult for doctors and other health care professionals to discuss such issues with patients and indeed for patients to face up to reality of the situation themselves. However, during episodes of illness it is necessary for the autonomy of patients to be maintained throughout treatment.

"The active participation of patients in their own treatment should be facilitated by means of open and sensitive communication"

(Royal College of Nursing, 1976).

McHoul & Grace (1993) present a different view. They state that there are several forms of confession which include interviews, conversations and autobiographical narratives among them. This includes doctor/patient interviews and indeed those carried out for research purposes. The point they make is that no matter what form the confession takes it is a ritual which unfolds within a power relationship. As Foucault (1978) has stated:-

“.... The confession became one of the West's most highly valued techniques for producing truth. We have since become a singularly confessing society. The confession has spread its effects far and wide, it plays a part in justice, medicine, education One confesses one's crimes, one's sins, one's thoughts and desires, one's illnesses and troubles. One goes about telling with the greatest precision, whatever it is most difficult to tell. One confesses in public and in private, to one's parents, one's educators, one's doctors, to those one loves; one admits to one's self, in pleasure and in pain, things that would be impossible to tell anyone else, the things people write books about Western man has become a confessing animal”.

Foucault suggests that confession is an instrument of domination and clearly the fact that the consultant or other healthcare professional has knowledge about a diagnosis and of treatment options that the patient does not have access to, (until the healthcare professional chooses to divulge that information) means that the power within the doctor and patient relationship sits with the healthcare professional. Cribb (1993) suggests that the basic framework of Foucault (1979) analysis of power and social control can be described in a few sentences. According to Foucault the human sciences are allied to and closely into all of them with professional groups and forms of government. In this instance government does not simply refer to the exercise of macro political power but it encompasses less overt or deliberate and more subtle forms of

control. It has been suggested that typically these forms of government are built into relations of "power/knowledge" in which those in the know monitored those who are not, he suggests that "this surveillance" acts as a technology of control, irrespective of the intentions of the professionals involved. Cribb suggests that if we take Foucault's analysis seriously we should be equally sceptical about more personal and homely interventions such as a consultant disclosing a personal experience of cancer to a cancer patient. Cribb (1993) also suggests that we should look particularly closely at those interventions that are legitimised by talk of participation or empowerment because these ideas are meant to be incompatible with professional domination and in such instances may be used to oil the new mechanisms of social control.

It is clear that Foucault (1973) feels that medicine is a parable about social control, however, it must be recognized that there have been significant changes in the way in which healthcare professionals communicate with cancer patients and current policy initiatives are challenging medical dominance especially in Britain.

Providing cancer and palliative care can be fraught with a multitude of ethical dilemmas however the majority of these dilemmas can be addressed by health care professionals communicating effectively and honestly with patients, carers and other colleagues. Communication should not be about exerting power but it should be based on an open and honest approach with all of the facts being presented so that the patient can make an informed decision.

It has been shown that many health care professionals and probably nurses in particular do not understand the ethical principles underpinning the delivery of cancer and palliative care and there is a need to ensure that more education is focused on these areas in order that health care

professionals can provide truly holistic care for their patients at a time when they are particularly vulnerable and disadvantaged.

There is clearly a lot of good practice occurring within the Cancer Unit where the study was undertaken, some of which is as a direct result of this action research project. Whilst the results may not be generalisable to the wider cancer population in this country, the innovations to practice resulting from the study are meaningful to the patients in the initial phase of cancer care who are seen within the cancer unit. The challenge now is to ensure that all services are equitable and that patients get offered the same access to information, support and knowledgeable health care practitioners working as part of a specialist cancer team regardless of where their primary site of cancer occurs. The key to further practice development as highlighted throughout this study is good communication and effective team working.

In some ways Phase 3 of the study was probably the catalyst for the biggest changes to cancer care within the unit. This phase of the study involved interviews and focus group interviews with Consultants, Senior Managers and Clinical Nurse Specialists involved in the provision of care to patients in the initial phase of cancer. It enabled the researcher to highlight to those professionals the issues which were important to cancer patients within the unit. This was supported by the existing body of knowledge reviewed as part of the study and it was gratifying to note that there was a genuine interest from the professionals to not only hear what the patients had to say about the services provided for them but to actively work together to ensure that services were improved for cancer patients. The evolving role of the Clinical Nurse Specialist within the multidisciplinary cancer team was clearly identified throughout Phase 3 of the study as was the need to continue to develop this staff group. Whilst the ways of developing this staff group were not actually covered within the formal focus group it is evident that the study acted as a catalyst to

encourage the Clinical Nurse Specialists to consider how they wanted to develop and what might be the most appropriate way of doing this and the subsequent work and development of a paper proposing their developmental needs would not have occurred at this moment in time had the study not encouraged them to be pro-active in the development of their roles.

With hindsight, the study has a number of limitations, firstly due to the small sample size one is unable to generalise regarding the findings. There were weaknesses attached to both the non-participant observations and the patient interviews, primarily due to the inexperience of the researcher. The notes of the non-participant observations were adequate but not conclusive and they would have been more complete had the consultations been videotaped and then notes made subsequently. With respect to the interviews, the data obtained was rich but perhaps a more skilled interviewer would have investigated some interesting areas more, such as what 'caring' really meant to the patients themselves. It might have also been interesting to have looked at a cohort of patients, following them through from the non-participant observations to the interviews, had that approach been utilised it may have been possible to make connections between what the patient was actually told and what he/she thought they had been told, it may also have been easier to explore their perceptions of what happened during the breaking bad news consultation.

However, despite these limitations, the data obtained has encouraged health care professionals to review their practice and make changes, which will at least benefit some of those patients seen within the cancer unit. In addition, the issues of communication and multidisciplinary team working have become priorities for all of the site specific cancer teams and that can only lead to improvements to patient care.

Since the commencement of this study the NHS in general has been in a constant state of flux, and in particular, improving cancer care and outcomes for cancer patients has become a high profile priority. There is no doubt that the current focus on cancer care nationally has facilitated the introduction of some of the changes advocated as a result of the study, indeed a number of the issues identified locally are also now on the national agenda, for example improving team working and providing communication skills training. However, there has been little work done to assess how health care professionals and more specifically those involved in cancer care (which can be a stressful speciality in its own right) cope with being asked to constantly change the way in which they practice. What seems clear from the final part of data collection is that most health care professionals really do want the best for their patients and will happily change their practice if they understand the rationale for doing so. In terms of implementing new initiatives it seems the higher up the organisational ladder a person is the easier they feel it is to implement change and innovate. There is concern that staff at grassroots level are experiencing "change fatigue" and Consultants, Specialist Nurses and Senior Managers are concerned that there is frustration at that level of the organisation because people do not understand the reason they are being asked to change. If this is the case then it is clear that more work needs to be done at all levels of the organisation to make sure that everyone understands the purpose of the change and has ownership of its implementation. It was relatively easy to secure this when implementing changes as a result of the study because cancer and palliative care are relatively small specialities where staff are easy to access. However this would not be so easy if the changes needed to be implemented on every ward/clinical area of a District General Hospital or in a trust which operates on numerous different geographical sites.

Implementing change as a result of a study is not always easy and can be complex and the key is to ensure that stakeholders are informed and

updated at regular intervals so they feel they have ownership of the study. Securing such support is essential if changes are to be implemented and evaluated and where appropriate integrated into long term practice. In order for a researcher to achieve this successfully it is not only important to develop a knowledge of the needs of cancer patients but having gained that knowledge and understanding other skills need to be developed skills such as change management techniques are essential if health care professionals are to effectively learn from research and implement new, more appropriate ways of working.

To end on a positive note cancer is now extremely high on the current Government's agenda. We have moved from having one of the worst mortality rates in Europe a few years ago to providing better diagnosis and treatment resulting in a decrease in deaths from cancer, despite an increase in a number of cases being diagnosed (Cancer Research UK, 2003). At the Britain against Cancer Conference in November 2002, Professor Peter Boyle presented evidence showing that the UK had experienced:-

- The largest fall in lung cancer mortality in men in the European Union
- Had the only stabilization of lung cancer mortality in women in the European Union
- Had the greatest decline in breast cancer mortality in the European Union

Whilst such clinical details are excellent news for both healthcare professionals and patients alike, it is the more qualitative side to cancer care which needs to be reviewed alongside such quantitative data. We need nationally to ensure people are equipped with evidence based knowledge relating to communication skills, we also need to be able to equip people with change management and modernisation skills and most

importantly of all it is essential that the patient remains the focus of any initiatives and changes that we make.

On reflection, this research project had identified more questions than it managed to answer. As a result a number of areas which would benefit from further exploration have been identified, such research would not only contribute to the body of knowledge relating to cancer care but it could also potentially make a meaningful difference to those who are diagnosed with cancer.

Areas identified for further research include:

- What does the concept of "caring" really mean to patients with a cancer diagnosis?*
- Comparisons of different methods of teaching communication skills e.g. Is multiprofessional training more effective than uniprofessional?*
- Do community health practitioners such as General Practitioners and District Nurses manage cancer patients and/or changes in cancer care policy differently to their hospital counterparts?*

This final area of research would be of particular interest given that throughout this study a number of patients cited different and sometimes conflicting information coming from General Practitioners compared to information which they have received from their hospital Consultants. It would be interesting to explore whether this was simply due to knowledge base or lack of it or if there was something about attitudes and cultures. It is also worth noting that the District Nurses approached to participate in this action research project felt that they could not contribute even when invited to do so, therefore it would not be inappropriate to explore their feelings and attitudes in relation to managing patients in the initial phase of cancer care.

On a final more simplistic note, perhaps the key to good cancer care is health care professionals asking themselves what they would like if they,

or a relative were diagnosed with cancer, remembering that that is the standard of care which should be provided as a minimum for every one.

Appendix 1

Example of Non-Participant Observation Fieldnotes

Doctor: TB

Patient: TH

This gentleman had been given his diagnosis of testicular seminoma prior to actually seeing Dr.B. who reviewed the histology results in the notes and also checked the blood result he then went into the room. The room was small with magnolia coloured walls, no windows. There was an examination couch on one wall adjacent to it a sink and a door (by which the doctor entered) on the wall opposite the examination couch was two hard backed chairs and a door (by which the patient and his wife entered). The remaining wall had a stainless steel trolley pushed against it. The room temperature was comfortable. The patient and his wife were already seated when the doctor entered. On this occasion he launched straight into conversation and did not introduce himself. It became obvious early on in the conversation that he had already met this patient and his wife. On this occasion he seated himself again on the examination couch, again his posture appeared very open, his legs apart, his hands apart, this time he laid the notes down on the couch next to him and he positioned himself directly opposite Mr. H. Mrs. H. was sat next to her husbands left.

Dr. B. Started by saying "Hello, how are you?"

Patient "Not too bad thanks, just waiting to see you" – no other small talk ensued.

Dr. B. "Well I have got your scan results, the one that you had done of chest and that's all perfectly normal so that's good news.

He makes eye contact with the patient and appears to be looking for a response, the patient nods in agreement, his wife sits with a fairly open posture but does not provide any non-verbal clues to her feeling.

Dr. B. "As you were aware, what you had was a seminoma which is a tumour of the test".

Patient sits forward and folds his arms across his chest

Dr. B. "You had a stage 1 tumour so that what we normally recommend is radiotherapy for three weeks, that's the standard treatment and that's what we would normally give".

Patient Nods

Dr. B. "The alternative is to enter you into a clinical trial, before I really tell you anymore about this trial its important to say that if you do agree to go into the trial and then you change your mind at any time, you can withdraw whenever you want and your treatment would just be the same as the standard treatment so you wouldn't be disadvantaged in any way if you did change your mind".

Patient Rubs his eyes

Patient Rubs his eyes?? Overloaded with information

Dr. B. "What we have with seminomas is that we have got a treatment that we know that works but what we want to find out in the trial setting is it is better to give less treatment and whether that would be just effective but give you less side-effects from it so that you would have a better quality of life for the time that you are having the treatment".

Dr. B. looks at the patient making and holding eye contact.

Patient "How do you mean – with side affects?".

Dr. B. "well you can get bowel upsets that's just the main side of it you do get some tiredness but bowel upsets can be the main side effects and what we need to do is randomise the patients to see whether the standard treatment or reduce treatment is the best option.

Patient Starts fidgeting and looking confused, his wife does not respond in any way.

Dr. B. Recognises the confusion actually saying to the patient "I think probably you are getting a little bit confused".

Patient Nods in agreement and then looks down at his hands

Dr. B. Continued to explain the need for clinical trials then recaps on the standard treatment and side effects, he goes on to say "some long term side effects can actually be increased chance of developing peptic ulceration and long term bowel problems".

Patient Looks up, makes eye contact with Dr. B. and say “but does that clear after treatment?”.

Dr. B. “No those problems would need treatment in themselves, these is only a small chance of developing them but you need to know that these are a possibility”.

Dr. B. “As I was saying, the alternative is to give you the same radiotherapy you would have the standard treatment but you would get 10 treatments instead of 15. We think this would actually be less likely to cause side effects.

Patient “Have people already started this?”.

Dr. B. “I haven’t personally entered anybody into this trial but other of my colleagues have”.

Patient sits very straight and looks at Dr. B., he says “I am not just going to be a guinea pig am I?”.

Dr. B. “To some extent you are, but.....”.

The patient interrupts

“Won’t I be missing out?”

Dr. B. “You mean if you get entered into the trial and you get 10 treatments instead of 15.

The patient starts to look slightly agitated and perplexed.

Dr. B. “What you would really like me to say is that one treatment is better than the other, I can’t do that, I wouldn’t enter you onto a trial if I knew what was best it would be clear cut and I would just

give you that treatment and I can't guarantee that giving you 15 treatments won't cause you any problems but I can't guarantee you that giving you 10 treatments won't cause any problems either or that one is better than the other we know the treatments work but one may have less side effects. Even with treatment I can't guarantee that you won't relapse but some seminomas that relapse respond very well to further treatment.

Patient Leans forward and rests his elbow on his kneed "Is there anything to say that I need treatment at all at the moment or is it just in case?"

The patient watches Dr. B. intently for his response.

Dr. B. "No patients with seminomas have been monitored closely without any follow-up treatment but it is hard to monitor them as there isn't a suitable tumour marker. Also the disease is slow to develop its rather indolent".

Patient Does not comment and continues to look at Dr. B. The patient and his wife have not exchanged eye contact.

Dr. B. "There is another alternative and that is chemotherapy".

Patient "So that's a trail as well".

Dr. B. Responds – "Yes, that would be just one course of chemotherapy in think probably it would be most helpful if I gave you some written information to take away".

Patient Continues to look at Dr. B. but does not respond verbally.

Short silence – appears uncomfortable.

Dr. B. "How long ago did you have your surgery?"

Patient "8 weeks tomorrow".

Dr. B. "That's the trial cut-off but I won't hold you to that exactly. Why don't you let me know later, maybe you could give me a ring tomorrow?"

Patient "We can let you know today" – he looks at his wife for confirmation and she nods her head in agreement.

Dr. B. "If you agree to have radiotherapy in the trial you will be randomised into one of two arms so what that means is that you will have a 50% chance of getting 2 weeks radiotherapy and a 50% chance of getting 3 weeks radiotherapy. If you agree to have chemotherapy in the trial setting that means that you could end up in one of three groups so you would have a thirty three and a third percent chance of getting two out of three weeks chemotherapy or alternatively a thirty three and a third percent of getting three weeks chemotherapy". Dr. B. looks at the patient.

Patient Sighs, he is obviously very confused.

Dr. B. "The reason we put patients into clinical trials is that we need an impartial decision, what happens is that if you agree to go into the trial I get in touch with Cambridge who are co-ordinating it and they will put you into one of the appropriate groups. What trials do is basically they generalise about which is the best treatment for your particular group of patients. We often know that patients who are entered into trials tend to do better than those who aren't".

Patient At this point the patients wife starts to fidget and she looks around the room, the patient himself asks "this chemotherapy, what's that again?"

Dr. B. "Well it would be an intravenous injection so it would be an injection into your vein and it would be given an hour, we would give you anti-sickness tablets to go away with and that would be the end of that, I mean apart from the fact that we would monitor you carefully in clinic anyway but we would do that regardless of what treatment you were going to get".

The patients wife leans forward and looks intently at Dr. B.

Patients Wife "If you were in his position, what would you go for? I mean you know the job, you know what is best, we don't?".

Dr. B. "I would be randomised into a trial but then again I couldn't suggest it to you if I didn't believe in it, as I said before, patients who go on trials overall do better than those outside of trials. We don't actually know why but we do know that you wouldn't be disadvantaged".

Patient "But what's the difference between the short one, the chemo I mean and ten days?".

Dr. B. again reiterated that the chemo would be a one-off injection at Newcastle where the radiotherapy is x-ray treatment and that until the trail is complete we can't say whether one would be a better treatment than another.

The patient shifted his position in the chair again and asks

"Is the chemotherapy more sever then?"

Dr. B. "Well fore a few days after you've had it, it probably is more of a short sharp shock but the radiotherapy would produce tiredness and that may last for longer".

The patient continues to fidget in the chair and says

Patient "So I'll be tired with radiotherapy?"

Dr. B. "Yes"

Patient "But I could go back to work after a couple of weeks"

Dr. B. "Yes". Dr. B. suggests that they go away and read the literature he has given them explaining the clinical trials and that they contact him when they have made a decision. He picks up the notes as if to wind up the interview, the patient then asks:

Patient "Can we have some time now to discuss this and decide what we can do?".

Dr. B. "Yeah, of course you can, you can take as long as you want, I'll leave you in peace and I'll get a Macmillan Nurse to come and speak to you to see if she can be of some help to you".

He goes to leave the room – the patient then asks:

Patient "What time will the appointments be if I go for radiotherapy?"

Dr. B. "Well, we'll try to give them at a tome that is convenient to you, it would be an afternoon the first time but after that we could try and fit around whatever your schedule was".

Patient Focuses on practicalities
Will I be able to drive?".

Dr. B. "Yeah, there's no reason why you shouldn't be able to drive during treatment". Dr. B. responds

Dr. B. Have you got any more questions?

Patient Looks at his wife and she shakes her head and he responds "no, I think we need to sort of talk about this".

Dr. B. "Oh that's fine". Dr. B. then goes to move and the patient says *(see footnote)
"How long could I have had this for?"

Dr. B. "If you assume that a tumour doubles in size at the same rate, which is not actually correct, then probably you've had it for longer than you think, that's really all I can say".

Patient Again looks very confused and uncomfortable and fidgets a little bit. "Is there anything I should be looking for now?"

Dr. B. "Not really, but obviously report anything in the other testes or anything that worries you".

Patient "Dr. R. (surgeon) asked me to come back in three months is it just for a blood test?"

* Asking important questions after the consultant has started to close the consultation is not uncommon and it is a way of the patient taking back control

Dr. B. "It is probably for bloods and x-rays, it is just keeping a close eye on you".

The patient looks at his wife, again she does not say anything.
Dr. B. looks at her and says:

"Is there anything that you are worried about or that you would like to ask?"

Patients "No thanks" she responds
Wife

Dr. B. "I'll give you time to make your decision and I'll give you an opportunity to talk to a Macmillan Nurse".

He then exits the room to find a Macmillan Nurse leaving the patient and his wife there

End of interview which took 25 minutes

Appendix 1: Example of Non Participant Observation Fieldnotes

Doctor: FH

Patient: IH

This lady had a diagnosis of colorectal cancer and the doctor reviewed the notes thoroughly before going to see the patient.

Interview was held in a fairly large room with no windows. One door by which both patients and the doctor enter into the room. Opposite the door is a desk, one chair is behind the desk and two chairs are in front of it. To the right of the desk as you went into the room is a long wall with an examination couch and an examination trolley against it. Again the walls are magnolia and there are no pictures or posters on them.

This lady was an in-patient on one of the wards and was brought down to outpatients to the clinic. She was in a wheelchair clothed in a nightie, dressing gown and slippers, she was wheeled in by the Clinic Nurse. The patient was positioned by the Clinic Nurse in the middle of the room facing the door.

Dr. H. Knocked on entering the room.

“Hello, I’m Dr. H., I work in this clinic with Dr. B. (pulls the chair away from the desk and places it next to the patients wheel chair) you were referred to this clinic by Mr. S. (surgeon) can you tell me what he has already told you about this illness?”.

Patient (Reaches out and clutches Dr. H.’s hand – in response Dr. H. moves the patients hand to the arm of the wheelchair and keeps her hand holding the patients). “Nothing, nothing at all”.

Dr. H. “Okay then can you tell me what you came into hospital in the first place for?”.

Patient (Nods) "Well I had loss of blood, I went into hospital to the maternity hospital and they gave me a scrape".

Dr. H. "I bet you hadn't been to the maternity hospital in a long time" (Humour) heightened the mood for a clearly distressed patient.

Patient (Laughs and nods) "Yeah 37 years, its what you would call a long time".

Dr. H. (Nods)

Patient "At the maternity hospital they said it was from the back and not from the front like they thought originally so they got me back to see Mr. S."

Dr. H. "Well basically you've had a growth in you back passage and that's what Mr. S> found when he did the surgery. We would like to treat you with some x-ray treatment up at Newcastle".

Patient (becomes very agitated, fidgeting in the chair and starts to cry)

Dr. H. (Responds by standing up and putting her arm around the patient). "Don't panic, we'll sort out the ambulance and things like that for you".

Patient (Nods in response)

Dr. H. "There will be some soreness around your bottom caused by the treatment but that will wear off in the long term and we can do something about it. Is that okay".

Patient "Yeah, yeah you'll give me some cream or something lie that won't that? (Patient appears to be much more calm and Dr. H.

moves her arm from around the patient and sits back down in her chair although she does reach out to hold the patient hand).

Dr. H. "When you actually come you to Newcastle for your treatment we may need to examine you a bit further and then decide whether in addition to the x-ray treatment you need some chemotherapy as well but we haven't made that decision yet. Do you understand what I am suggesting?",

Patients (Nods) "I'm not sure what that is, doesn't it make you lose your hair?".

Dr. H. (shakes her head) "Chemotherapy just means drug treatment and the sort of treatment that we would want to give you won't make you lose your hair".

Patient (Again starts to get weepy) "I had a daughter with breast cancer so I know what it's like, I know how horrible it can be" (Cries), (Dr. H. pats her hand in a reassuring manner). "Will I have to stay in for the chemotherapy I mean?".

Dr. H. "You might, but we need to decide whether you need it first and if so what is the most appropriate course of treatment for you".

Dr. H. "IS somebody at home to look after you?".

Patient "I have a daughter who just lives across the road, she's very good, very caring".

Dr. H. (Nods reassuring) "Could I possible examine you?"

Patient "Yes" (Nods her agreement, she stands up shakily but is assisted by Dr. H. to get onto the examination couch) (Patient is quite obese and not very mobile, it takes quite some time to get

her in a comfortable position on the examination couch however, Dr. H. does not rush her and assists her to do it in her own time).

Dr. H. (Whilst examining patient) "There's certainly plenty of you".

Patient (Laughs)

Dr. H. "Ah, everything seems okay there, we'll give you a couple of weeks to let this wound heal before we have you up for treatment, is that okay?".

Patient "Yeah, that's fine". (Appears to be relaxed now)

Dr. H. "Let me help you off and get you back into your chair" (Dr. H. takes time getting patient comfortable back in chair. Once she is back in her wheelchair, Dr. H. seats herself in the chair next to the wheelchair) "Have you got any questions?"

Patient "No not really".

Dr. H. "Do you understand what will happen to you?" (2nd time she's asked that question).

Patient "I'm going to go up to Newcastle for x-ray treatment, that's's right isn't it?"

Dr. H. (Nods and pats the patient reassuringly on the hand) "Yes that's what is going to happen in the first instance, but there may be a possibility of some chemotherapy as well, did you understand about that?" (Further repetition of question)

Patient "Yes, yes I understand".

Dr H. "Okay I'll get the Macmillan Nurse to give you a phone number and then if you've got any queries before you come up to Newcastle she can hopefully deal with them for you. Likewise if your family have any questions about what I have said to you today they can get in touch with the Macmillan Nurse and she'll be able to answer any questions for them. Is that okay with you?"

Patient "Yeah, yeah that's fine. Thank you Doctor, thanks you very much".

Dr. H. (Stands prior to leaving) "That's okay that's fine, you're sure you don't have any questions?"

Patient "No, not at all".

De. H> "Okay then I'll see you when you come up to Newcastle and in the mean time I'll get a Nurse to make sure you get back to the ward safely. Goodbye".

Patient "Goodbye".

This interview took approximately 40 minutes but this is primarily due to the fact that there were long pauses whilst the patient was crying and in addition it took quite some time to get the patient positioned on the examination couch prior to examination and back off the couch into her wheelchair before the consultation could continue.

Appendix II

Interview Schedule

Patients Story

Explore manner in which the 'bad news' was given

Perceived understanding of language/terminology

Amount of information given

Amount of time

Discussion re-treatment

Opportunity to ask questions

Inclusion of family members (where appropriate)

Written information – given?

Quality?

Support – from who?

Value of?

Environment

Suggestions for improving the process

Appendix III – Sample of Interview Transcript

Patient Interview No.: 7.

Interviewer Thank you for agreeing to be interview this afternoon, can you tell me a little about the time you were actually given your diagnosis, where you were given the diagnosis and who told you.

Patient I was given my diagnosis in Hospital B. by Mr. S. and B. (Stoma Nurse) she was in with Mr. S. and that's how I was given it. Emm, very straight forward, he just said I've got some, Mr. S. said, not very good news for you.

Interviewer Right

Patient and emm, he said the results have shown up a cancer and err in the colon and I was numb. He wasn't awful about it, you could tell by the expressions on his face he was very, you know, concerned, and he said yes its not very nice and he just went on. I said, I said I can't believe you're talking about me. B. was stood there as well and she was looking so, and I said I wish my husband had come in and Mr. S. said is your husband in the hospital and I said yes, so B. went out and got him and they came back in and by this time he'd told me but he started telling A. (her husband) it all again. He said, unfortunately there's a lot of plusses and minuses and because I'd had this bleeding, I was passing blood in my own motions, and um, I insisted I had piles, and I only have one daughter J. and ever since I'd had J. I'd had piles but it's not bothered me until I got older. J. was at home this weekend and em went to the toilet and I said oh hurry on I'm dying to go to the toilet and J. was at the toilet so I thought I'd hold on, I can go on the potty cause I always kept it from when she was a baby. So any road I went and go0t the potty

and um did a poo on the potty and when I looked there was some blood in it. Now we're talking a year, maybe a year and a half ago now and um any road, I went t the doctors and told him all about it and he said it could be from the piles but since then I had an x-ray about three years ago and it showed up diverticulitis as well so I was complaining about my bottom feeling funny as well. So I had diverticulitis and I had piles and every time I went to the doctors he said oh it's a combination of side effects of this. Any road, well um, I said I won't check on it every time but I will check from time to time any road I did insist after a while that I wanted to see, well not Mr. S. I said well what can I do to see where its coming from this blood so he made me an appointment, to see Dr. S. and that's how it all came about.

Interview Right

Patient So I had a sigmoidoscopy, it revealed that there was an ulcer there and I had to go and have the scan and then I had to go back and see Mr. S. and that's when he told us when B. and him were there. He said luckily, if there is a place to have cancer, he said the bowel is one of, not the best place, but the best organ to get it in and with you being so vigilant we think we've caught it in quite a short time. So I said how long do you think I've had it and he said about 7/9 months. Now this was in the beginning, somewhere around the 23 July because I broke up on the Friday and went to see Mr. S. On the following Monday or Tuesday I think it was I went and then I had to go and have a sigmoidoscopy, so we're talking the beginning of July and emm any road that was more or less, he said there's plusses that we've caught it early, that it's in a place where I can remove it and I can't say a 100% but he said at least can you give a good chance of getting over it and its up to you whether you have the operation but if you don't it will cause you problems later on when it gets back up to your liver so I said well, there's only one

way I can go and that's forward and have this operation. He said, right you look in good health that's another plus, you've made the decision and now I can tell you when you can have the operation. He said, I'm going on my holidays – this was the Thursday – on Friday for a fortnight I'd like you back in hospital on the 18 August for an operation on the 19. So that was like a month later, rough, just a month later, not a month later but like from first seeing him, first diagnosis and then I went in, had the operation. Oh, and B. she took me to one side when he first took me into another little office, and explained everything and said I'd more or less done the right thing and then told me of the back-up from B. and you know what the operation would entail as well and he was very nice, both of them were, excellent.

Interviewer Did you think the amount of information that they gave you was the right amount of information for you at that time.

Patient Yes, Yes in fact I think I got all the information I needed, I wanted to know what the operation entailed and they said it was major surgery they would cut so much out and join it back together again, hopefully he said, he can't say until I get inside whether it would be right out for a colostomy well after he'd done the operation and he was talking to me, he said unfortunately I had to do the colostomy but he said it was in a place where it needed to rest, you know it was like in a bypass where he joined it back together again and he said we are going to reverse it you know, so he told me about the backup, there might not be some backup, there might be depending upon, but after I had the operation he told me when they took the bad out they put it under microscopes to see if everything was you know, he said there were four lymph nodes near to where the cancer was. He couldn't say that, you know it was giving not a clear reading and em he said that there could be em, something could have escaped but they'd be taken out and he didn't advise, he said

you can have you know this chemo as a backup. He told me that before the operation, if anything, I might need to have that but I did have to have it.

Interviewer So, but that didn't come as a shock to you later.

Patient No, not really because he said it was a backup really and I've had the x-rays since then and they have revealed that everything's ok, there's no cancer there but where he's joined it back together again how can I explain it, it's like narrowed it, shrunk, where he has joined it but he said don't worry about that showed me it on the x-rays because I was just there a fortnight ago, and showed my husband as well, and he said that's where it shrivelled up a bit where they've joined it back together again but don't worry about it, when I do the reversal I can widen that up, I don't know how he'll do it like but.

Interviewer Yeah, they have a thing, like a balloon that they inflate, yeah and stretch it.

Patient I thought that because my brother had a bypass and he had the thing to try and open the, you know. But yeah Mr. S. was lovely in hospital and so was his doctors who came round, everything went fine. I had one little blip where I was coming out of hospital on the Friday, Mr. S. saw me on the morning and he was off duty, but Mr. K. was on duty over the weekend and after the visitors came away on the Friday I had this funny feeling and I thought something's gone, not wrong, a funny feeling and I passed a lot of blood into my bag and err I got myself a bit upset about it, not crying but worried about it so I called the nurse and she said it was blood and she would take it up and have it analysed. So she took it away and came back and she brought Mr. K., she came back and told me she was going to see Mr. K. he's the doctor on call and he came back and told me that it was

like, and the staff nurse on the ward said the same, said it was the trauma off the operation, he said it could have collected in a pocket somewhere and its come out. I said I'd rather not go home, I said I'd rather not go home I said I'd rather stay in hospital and see Mr. S. on Monday if possible, I said if I go home I'll be worried about it and I said if I stay at least I'm on, you know, in here, and Mr. K. said, he was very nice, he said I'm sure, I'll go back and read your notes because he didn't do the operation and err he said I'll come back and talk to you. Well he got hold of my hand , he said don't worry about it he said I'm sure that's what it is and also the staff nurse said the same and err, but he said, if you want to stop in and see Mr. S. So he saw me on the Friday, he came back on the Saturday and the Sunday and he said how are you today and I said I'd passed no more blood and I did feel like I'd done the right thing stopping in and when I saw Mr. S. on the Monday he said, yes, I'm please that you've done that he said far better on call her you know if you needed any help over the weekend as go home and worry about it.

Interviewer Mmm, yeah.

Patient So yeah, everything's been fine, no complications, no criticisms at all really they were all excellent.

Interviewer Going back to like the interview when you saw Mr. S. in the clinic obviously when you were told your diagnosis you were quite shocked and did you remember much about that after he said that, what it was, you remembered it, you didn't just sort of switch off after the....

Patient Yes, yes, no I didn't switch off, I knew exactly what he said to me yeah.

Interviewer Right.

Patient How I felt was, you would think I was a lump of a body and everything had been taken away but I was listening to what he had to say yeah.

Interviewer And what about when you husband cam, I know he missed the beginning bit but when he came in and Mr. S. started telling him what was going on , do you think your husband got the opportunity to ask Mr. S. question as well.

Patient Oh yes, yes, yes

Patient No we had quite a, not a long conversation, but you know he told my husband exactly what he told me and that it was cancer and you must go ahead and pull all the plugs out and see what you can do to carry on living, because you've go so much to, well at least I have.

Interviewer Of course, and B. saw you afterwards, did she offer you support after that as well.

Patient Oh yes, yes it was a fortnight right after I'd got to know that I had to go in for this operation and B. said, she gave us her card and said if you have anything that you think is stupid or you want, maybe you've forgot something and want to ask it over again, she said don't hesitate, I'm a phone call away and she said if I'm not in there'll be somebody there to take your number and I'll phone you back. B. was excellent, she was, she was spot on, I thought ee will I get over it, will I be able to stand up to it you know this sort of thing because not only that but I was told I had, my Mam died, I left school on the Friday and saw Mr. S. on the Monday or Tuesday and then a week later on the 8 August my Mam dies suddenly, she was 87 but that was a shock. So I

had to arrange you know were just a small family and to see my Mam. J. my daughter was staying with me because they were in the process of moving house and the sale hadn't gone through so they stored the furniture and they were living in here at the time and everything was up in the air and I feel as if my Mam dying took my mind off the other.

Interviewer Mmm, yeah.

Patient As I sat, we had her cremated, J. and I went to see her, we'd all been out on Thursday night taking the dog for a walk down at Seaton, and we came back home, dropped my Mam off at 10.30 at night and 2.45 she was on the phone saying she couldn't breathe properly so J. and I went up home because A. (husband) stayed down there to look L. (Granddaughter) because she was L. 5 and we went up and had to give her mouth to mouth resuscitation you know, all in 20 minutes.

Interviewer Oh, oh.

Patient The doctor came, dialled 99 the paramedics came out, while we were on the phone to the ambulance they asked how my Mam was and they said to do the resuscitation which we could both do but it was too late. Any road my Mam was cremated on the Tuesday, she died on the Friday morning, at 3.05 the doctor from GP surgery, he was the doctor on call that night and err he came out and said she was dead at 3.05 and everything just went forward from there. We had her cremated on the Tuesday, ashes scattered on the Wednesday and on the following Monday that was 18 August I went in for my admission to hospital on the 19 August and had my operation. It was horrendous really but I have no regrets about my Mam, I did everything, we included her in our lives and you know I miss her terribly and talk to her everyday but there you go, you can't bring

them back. So yes, getting back to B. she was excellent and so was Mr. S.

Interviewer Did either Mr. S. or B. give you any written information about the surgery or

Patient Aha

Interviewer They did

Patient Yes, Mr. S. When I had the sigmoidoscopy, that when he gave me a sheet of paper saying there was an ulcer in the colon and he'd taken biopsies and I had to go and have, I wasn't aware it was a live scan, this liver scan, and I had to go back and see him the following, I think it was a fortnight.

Interviewer The sort of information that he gave you was it useful, did it reinforce what he said to you verbally.

Patient He didn't say anything to me verbally because when I had the sigmoidoscopy you know you're knocked out and it was a nurse that gave me it, I didn't see him then. I didn't see Mr. S. to talk about what happened until I saw him when he gave me the results,

Interviewer Did you get any other information at any stage, did you get any leaflets about either surgery or the chemotherapy?

Patient No, I got a book on the chemotherapy, did I, I got a book on the chemotherapy, C. (Chemotherapy Sister) gave me it but I haven't has, didn't get anything on the surgery. B. in fact asked Mr. S. what it included and he told me you know that I'd be cut and they'd take it out and join me up again and you know you know but not in any great you know medical thing. He said you

know you'll be fine, you'll be well looked after and I just knew in myself I had to go through with it, I just knew whatever I did I've just got to go on and carry on. I think I had a lot of faith in what he said and I did say you're not telling me a pack of lies but I said you are telling me the truth, you're not just covering it over and saying, you know this sort of thing and he said I'm telling you the truth. He said what's the point in that, you've got to go through with it and make the decision. As I say, I'd hate to think, I'd rather be told as assume have I got this or is it this, you know.

Interviewer Then you know what your dealing with don't you. What about the time that Mr. S. and B. gave you in that clinic when you were given all this bad news, did you think that you were rushed or were you given...

Patient No, no, no in fact, I was in quite a while in the office when he told me, and even Mr. S. when he told me wasn't rushed and there were loads of people in the surgery outside you know waiting, no I never got a feeling of being rushed or anything. I even made a remark, I said all that time taken with me you know and all them people outside. No, I wasn't rushed.

Interviewer And did you think that the interview, why both the interviews with Mr. S. and B. were very much geared towards you individually?

Patient Yes, very much. B. didn't say much in the actual room, it was Mr. S. who did all the talking there but when B. took me into another room she was excellent.

Interviewer Good

Patient And she still is, you know even if now I've got a bit of a problem, not as such, but if I've got something I know and it might be

stupid but I'll phone her up and I've kept in touch with her all the time and I even now go to the stoma group and I enjoy that as well.

Interviewer You know when you were a bit further down the line after you'd gone home and everything and then you came back to see Dr. B. about the chemotherapy can you tell me a little about that interview and the sort of information Dr. B. gave you.

Patient Well, with Mr. S. he sort of pre-warned me, told me about Dr. B. and he said all it will be is an interview and he'll be able to tell you all about it and yeah what Dr. B. told me has actually happened but I wish they would tell you more about the side effects of the chemo, it's like, I don't know whether it's just me with an inquisitive mind or what but you think is it the chemo or is there something else wrong with me. You know, like the first month I was alright but sort of tired and then I said it will be the chemo but I'm, I've got sensitive eyes, the light if I go into shops where there are bright and this sort of thing, so these symptoms that I'm having now are very similar to the symptoms of chemo, you know the symptoms I'm having now sensitive eyes and I start to get myself, you know unduly worried but is it a stroke, is it this, is it the other, you know so I just wish they would tell you more about what the side-effects are, I was talking to C. the nurse at the M. Unit (Chemotherapy Unit) and she said we don't like to discuss everything because you may not have it.

Interviewer Yeah.

Patient And worry you unnecessarily, but there are times when I'm not feeling, like today, I mean I'm feeling thick as a brick and I got these clear eye aches, headache and ear ache but I've had the flu as well but I got over that and I'm thinking is this something in my ear, so as I say, what Dr. B. said he's.... but I've never seem

him since that interview you know, umm, yeah what he said it was okay you know, I can't remember everything that he said now.

Interviewer Because it was a repetition of what Mr. S. had said.

Patient Yes.

Interviewer Did you feel as though when you were with Dr. B. that your husband got the opportunity to ask questions as well.

Patient Yes, he did, he did, he was asking questions mind I couldn't tell you what they were now.

Interviewer What about the time factor in Dr. B's clinic, did you feel as though he and time for you.

Patient Oh yes, there was not a problem, at all, he didn't rush me through or want me in and out he gave us the opportunity to ask questions you know, but you cannot think of them at the time, do you know what I mean.

Interviewer It's later isn't it.

Patient It's later than you think about it.

Interviewer Right that's covered all the questions, just one more thing really about the environment of the clinics, do you think the environment was the right sort of place to be given bad news and things or don't you think at the time.

Patient No, you don't I mean it's the only place you can expect it really, you go there to have your test taken and see the specialist and no, I, that's what you're there for to go and find out exactly

what's gone on and what's found, and find out what they're going to do.

Interviewer If, not that you would want to go through the whole process again, but if you were to is there anything any of us could have done to have made it any better.

Patient No, I don't think so. If, at the time when I was being told all this, things that were going through my mind if they hadn't said, I asked, I'm a one for not just sitting back and taking it, you've got to take it, but you've got to, if you don't tell them how you feel they don't know how you stand really do they. So I do ask questions.

Interviewer But you felt they were, everybody was happy to answer them.

Patient Yes, if fact, I've said a few times, but I've never really had anything serious wrong with me apart from I had a nervous breakdown when my first marriage broke up but that was just dealt with through doctors, but it is the first time since having J. in hospital that I've witnessed anything like that and em I was very humble to think that there was so many people out there ready to help. In fact, it's all there just waiting to be exploited really, you know, I couldn't get over how people are so helpful.

Interviewer Aha, mm that's good. I don't know if there's anything else you want to comment on in relation to the questions I've asked you whether its raised any issues at all or...

Patient No, I mean on ward 8 where I was, the girls on there were fantastic. I mean you get people who go exceptions to the cases, they've got a lot to deal with and emm, you know, the toilet facilities could have been better but there are people on that ward that are not capable of going to the toilet and that sort

of thing, but you've got to think of the amount of people that are going though. No – excellent I couldn't complain about anything.

Interviewer I'll stop the tape then thank you.

NB: After the tape was switched off the patient then started to voice her only complain/concerns in relation to the x-ray department within the hospital in that she felt that the person she saw in x-ray was not informative about the procedure that's he was having when she had a barium and was not at all sympathetic to her needs and that she was handled roughly at a time at both emotionally and physically she was quite fragile.

Appendix III

Sample Interview Transcript

Patient Interview No. 14

Interviewer Thanks for agreeing to be interviewed, can you go back and sort of think about when you were given your original diagnosis, and tell me a bit about what happened.

Patient I was given the diagnosis at hospital A, by Dr. S., he never really went into to much detail because he wanted me to see Dr. M. and he said he would explain everything in detail at N. hospital, at G. hospital sorry and I did Dr. M. and Dr. T. was present and there was someone else in the room – I can't remember his name. They did a little drawing and everything to say what the operation was going to consist of and originally it was err keyhole 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 the surgery for keyhole I was in for nearly four hours because the cancer had spread into the lymph nodes so he had to take away a lot more than he originally thought and the next thing I spoke to Dr. M. 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 think I can remember amount 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 um and I just, I couldn't really take it in I was feeling that bad at the time anyway so it didn't register really err until a few days later, one of his registrars came round again to discuss what was going to happen vaguely with the

chemotherapy and I also needed a blood transfusion because my blood count was so low but that was almost a week later when they gave me that which was upsetting because I'd felt so bad all week and I'd have thought they would have recognised that sooner but they didn't, but once I had the blood transfusion I was okay and the chemotherapy started. I had the operation on the Monday and the chemotherapy started on the Friday, that was for three days. After the chemotherapy I was allowed to go home and err the information I got about that, they explained it pretty good, they told me what it was and what the side-effects and all that were, so they gave me a lot of information about that, em and it wasn't as bad as I thought it was going to be. It was actually okay, the worst part was getting the line put in for the actual drip, that was the worst part of it all but the actually chemotherapy was fine. You get a little sickly but not too much.

Interviewer Did they, they told you verbally what the chemotherapy was about, did they give you any written information?

Patient No at the time, not before I had it, but after I had the first session I spoke to the Sister there at the time and she took me into the office and explained and gave me some leaflets, about the chemotherapy and the drug side effects you know about your hair falling out and all this sort of think and she went over them with me, that was after the first session of chemotherapy I had and that was it really, I went back another twice after that, but after the operation the most upsetting thing for K (Husband), because he had t chase them about for three days before he could get information out of them.

Interviewer He knew your original diagnosis though did he? Was he with you when Mr. S. gave you that diagnosis?

Patient He knew that but the way he was talking it was a pretty straight forward operation, in and out within a couple of days, and the same when he spoke to Dr. M. yeah, he said the same thing. After the actual operation nobody really said a lot to K., he was really upset about it, he had to keep chasing the registrars and the nurses to say like, am I going to see Dr. M. am I going to see his assistant or something like that err it was about three days as I say after before they took him in a room, sat him down and told him exactly what had gone on and what to expect so that was upsetting, for him more than me really, because as I say, although they had said things to me I just didn't take it in because I was too ill to take it in. While u was in there I had a Macmillan nurse come to see me, she was really nice, she just asked me how I was feeling and what to expect while I'm going through the chemotherapy and she arranged for someone to come in and get me a wig fitted, she was really nice, really helpful, yeah and that was it really.

Interviewer Right did anybody, I can't remember now but when you were actually discharged home, did anybody set up some support services so that somebody came to see you at home or not.

Patient I can't remember whether they did that while I was there or whether it was when I came home, it might have been a health visitor actually.

Interviewer Right

Patient They came to see me, she was lovely and I've forgotten her name now because I can remember, I don't know if it was a Macmillan nurse that came with another Macmillan nurse, she was just starting at the time.

Interviewer Yeah

Patient That was one of the first times I saw a Macmillan nurse wasn't it, I think it was her that arranged that, but it could have been the hospital.

Interviewer So from an information point of view, personally, the sort of information they gave you, I mean they drew diagrams and things like that, did he explain it well to you.

Patient Yes he did, yeah, when I first went to see him the operation he did, he explained it pretty well, drew the diagrams and told me where the tumour was and how they would take it away and how I was going to be feeling after the operation, it shouldn't make much difference really. Obviously I'd feeling, he just said you'll feel a bit lethargic, tired and that for six months to a year after, as far as he was concerned it was straight forward really.

Interviewer So really from your point of view all that initial stuff was okay, it fell down when things weren't straight forward really didn't it.

Patient Right yeah, I felt some of the time I felt as though, when I was feeling really bad after the operation I was just, I felt as if I was just left to get on with it, just get in with it you know, get in the bath yourself and by the end of the week when I got the blood transfusion I felt 100% better, I was angry because I could have had it before and I wasn't given it and I mean I just wonder why it took 4/5 days to find out the blood count was that low in the first place because he said I'd lost a lot of blood in surgery and I had seen other people coming back from theatre getting blood transfusions at the same time and I just wondered why I hadn't got it.

Interviewer And nobody explained that to you then obviously.

Patient No, they said I'd lost a lot of blood in surgery and I'd have to have a blood transfusion before I had the chemotherapy otherwise my body wouldn't be able to take it, that was the main reason they gave me it I think.

Interviewer The information, the written that they gave you, the written information.

Patient Well to be quite honest, it was just a few leaflets and when I got back home I actually phones up and they sent me information I got for chemotherapy and radiotherapy they sent me booklets through and they were really helpful.

Interviewer They were the backup ones weren't they?

Patient Yeah, they were really good, I thought they were very helpful.

Interviewer and they were better than the

Patient They were better than they were giving me from the hospital, the hospital were just little black and white like a couple of pages with things like your diet, what to eat.

Interviewer But not explanations about the treatment?

Patient No really, it was more vaguely how chemotherapy works and what it does to your body and you know, but they didn't go into graphic detail.

Interviewer Would it have been more helpful do you think if they'd given you those leaflets.

Patient If they'd been those at the hospital yes, because they were very easy to understand as well.

Interviewer Right

Patient Yeah, but you had to send away those

Interviewer What about the amount of time you know initially when you were seeing Mr. S. and Mr. M. and they were explaining about surgery and your diagnosis, do you think they gave you enough time to ask any questions and

Patient Dr. S., when I first went into the hospital and he said it was a polyp and he was going to do a biopsy after that, but when I went diagnosis and he did say it was cancer he never, he was enough don't get me wrong, he was nice the way he was saying things but em when K. was asking him questions well, what does it mean, hoe bad is it, you know, about the size of the tumour and things like that, he said well to honest I don't know what to say, it was as if he didn't want to commit himself to anything, that's the impression we got, which that made us think is it really bad you know, because he's not saying to much. All he kept saying was I would rather you see Dr. M. because he's really good in his field and he'll be able to go into a lot more detail and, but no, we didn't get a lot information of Dr. S., no.

Interviewer Did Dr. M. give you plenty of information?

Patient He did, he went though, yes he did , he did the diagrams.

Interviewer And he let you ask questions.

Patient Yes, he asked me was I worried about anything and was there any questions I wanted answering. Yes he was pretty thorough I thought he was really good.

Interviewer And he let you ask questions

Patient Yes, he asked me was I worried about anything was there any questions I wanted answering. Yes he was pretty thorough I thought he was really good.

Interviewer Dr. T. was at that consultation?

Patient Dr. T. was there.

Interviewer Did she actually say anything to you at that appointment or was she just sort of in the background?

Patient Em, come to think of it, I think Dr. B. was in there as well, I think quite possibly he was, yes Dr. B. was there but I asked him a few questions actually because I, and he was pretty helpful I asked him if the cancer was hereditary you know, different questions that I wasn't too sure about and he answered the, he was pretty good and the same with Dr. T. she answered a few questions as well but all in all they were very helpful.

Interviewer Right, was K. with you?

Patient K. was there at the time?

Interviewer And did they give K the opportunity to ask questions as well?

Patient Yes, yeah they said if there was anything he wanted to ask, he wasn't sure about or he wanted any information about, which was quite good, yeah they were very good actually before the operation, very good.

Interviewer It's a shame you had problems subsequently.

Patient Yeah, we were very disappointed after the operation.

Interviewer Well really I think they are the main things I wanted to ask apart from if you had your time over again, not that you would want to go through all that, but if you went through it again, is there anything that any of us could have done to have made it better?

Patient Em, hospital G., yes definitely, I know that they were understaffed and they were extremely busy, but I think they could have done a bit more.

Interviewer On a ward level at explaining and?

Patient Yeah, because the day I was getting chemotherapy he was come and said to me you'll be on a few hours at a time, which I just thought it was going to be, I just thought 2/3 hours and that would be it. I didn't know it was going to be on it 3 days at a time, they didn't go into to much explaining that very well and the day I went on it I got myself that worked up because they tried to put a line in three times and it wouldn't go in, that upset me and err then they wandered off and left me there for hours and I had to, I was crying in the end of it and I said look because I was that worried about not knowing what to expect, oh we were waiting for the drugs to come up from the pharmacist and we'll get you on as soon as possible, that was the morning and I think it was about 3.30pm in the afternoon before they actually and by that time I was just, I felt physically sick because I was just relieved that it wasn't as bad as I thought. I felt as though they could have spoken to me more that day, it was just an awful day as far as I was concerned, they could have done a bit more explaining but they didn't.

Interviewer And the other thing that you said was about the Backup leaflets, they might have been more use if they'd given them at the hospital.

Patient Yeah, definitely, cause as I say the only one was a little think leaflet and all it said was about the side effects of the drug and vaguely what the chemotherapy does to your body and your diet.

Interviewer Would it have been useful if when you were discharged home, I mean from what you remember, we think that you kind of got the Macmillan nurse at home because of somebody else who cam in at home to help you, would it have been useful, more useful, if you'd known that once you'd got home a Macmillan Nurse or somebody would have been out the next day.

Patient Yeah, that would have been, yeah definitely, rather than err it was a few days after wasn't it, I can't remember exactly when but it wasn't straight away I know that, no it wasn't.

Interviewer Or even if you had a phone number at this stage.

Patient Well this is it and I could have got in touch because the way I was feeling quite honestly it would have been nice to be able to speak to somebody, I was just really left.

Interviewer Right, I'll turn this off now.

Appendix IV

Focus Groups – Specialist Nurses

Participants were advised re: anonymity and confidentiality etc. before the tape was turned on. The researcher also fed back on the key findings of the observations and patient interviews.

Interviewer One of the first issues patients identified was the value of multidisciplinary working they didn't actually say "I value multidisciplinary working but they say where they had a specialist nurse involved with them there was often evidence of good communication between specialist nurses and other health care professionals. However, this certainly seemed to be reduced when a specialist nurse was involved in the care.

What I wanted to explore with you was in terms of MDT working whether you actually feel you are an integral part of MDT and whether you actually feel you can contribute to the decision making process when the MDT's are actually deciding on patients care?

Do you feel you are an integral part of an MDT/

Respondent 1 Yes, I think it depends on the individual team, but certainly the team which I work in I feel that I can discuss patients freely and that my opinion is listened to and valued. In fact, I think the nurse is in the unique position of being able to present a holistic perspective, you know give background about the family dynamics the patient 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. I do feel we have an important role to play in supporting patients and so some occasions begin their advocate.

General agreement from the room.

Respondent 2 Yes, I agree, I think we often have a greater understanding of the patient's perspective. Obviously this may or may not influence the clinical decision.

Respondent 3 It is not likely to affect the clinical decision which is primarily made by doctors but the involvement of a nurse who knows the patient may add a different dimension to the discussion as she may be able to encourage the discussions which will facilitate problem solving.

Respondent 1 What do you mean?

Respondent 3 Well like already stated a nurse can provide a more holistic perspective and so using the example already stated would know if someone was needle phobic and could work with clinicians to develop a strategy which would be acceptable to both them and their patient to deal with it. See what I mean?

Respondent 1 Yeah, I think that's true.

General agreement from around the room

Interviewer There are lots of nods around the room so do I take it that everyone feels they can bring something extra to the MDT and feel included in it?

General head nods and yes

Interviewer Is there anyone who does not feel included in their MDT?

Everyone shakes heads and responds no

Interviewer Do you think you bring added value to the MDT?

Everyone responds in a positive manner

Interviewer You all feel you have something extra to offer your medical colleagues, I wonder are you all offering the same thing and working in the same way?

Respondent 2 I think most of us offer the same things as clinicians terms of our holistic approach, our role as an advocate and so on.

Respondent 3 I think we offer more or less the same to offer to patients too, 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 is different and probably specialist as the specific knowledge relating to the disease, so I know all about breast cancer where C knows all about colorectal cancer, G. knows about chemotherapy and so on.

Respondent 4 We (looking at Respondent 5) are the odds ones out, or not the odd ones out but we differ from that, in that everyone else works solely in the hospital and we don't, we follow the patient in hospital or community, wherever they have read. This gives a different perspective again and I think by seeing a patient in different environments we are more likely to be able to identified fears and concerns.

Respondent 5 I would agree with that, patients who appear brave or stoical in the hospital setting in front of a consultant can be completely different in their own homes.

Respondent 6 Yes or vice versa.

Respondent 5 True

Interviewer Can I just clarify that what you are saying id that you all have an important role within you respective MTD's and that no change is needed to enable you to have to have a meaningful role within your MDT because that is already happening?

Heads nod and mmms of agreement from all MDT members

Interviewer When I interviewed patients I asked them whether they were aware of the MDT responsible for their care was when there was a lot of stuff coming from the DOH advocating MDT working such as the improving outcome guidance, Calman Hine etc. The patients seemed totally unaware of the MDT who would make decisions about their care, indeed the only people they tended to mention were the surgeon, oncologist and specialist nurse and

they did not appear to know that there were histopathologists, radiologists there or whatever. I do not know do patients need to know this information?

Respondent 1 Well I had a couple of patients recently who have expected things that haven't been there, I think it can be useful to explain that no definite decisions can be made until that patient has been discussed at an MDT made up of specialists in the field, so yes it's an be useful for some patients to know.

Respondent 5 Yes I agree I think they are reassured by the prospects of a team of experts agreeing the best treatment for them.

Respondent 6 Yes so long as they do not have to wait too long for that decision.

Respondent 1 Well all MDT's meet weekly so that shouldn't happen and I suppose if there was something really urgent the consultant in charge would make the decision but that would be extremely rare.

Nods of agreement from around the room

Respondent 7 In haematology patients are discussed at the local meeting and also at a Regional meeting and I think that can be quite helpful because patients know that the largest possible sphere of experts have discussed their care and I think this gives them additional confidence in those who are directly providing care to them.

Respondent 5 If we go into a patient in the community very often the information we have given is minimal and we rely on a patient to give us treatment information and so on.

Clearly is not appropriate for us to attend all of the MDT's in the hospital but if an MDT has made a decision it is really helpful when the site specific specialist nurse conveys that information from MDT to us.

Respondent 6 That happens a lot of the time particularly when the referral has come from that nurse but if the referral to us (Macmillan Palliative Care Nurses) we often are not privy to that information.

Interviewer Is that because the referrers do not have it or because they do not think you need it?

Respondent 6 I do not think anyone has really thought about it before, not that anyone is deliberately keeping information from us.

Respondent 5 Yes I think that's right.

Interviewer Okay if you are saying this would be helpful information which would improve care for your patients, how can we ensure that you got this information in a timely manner?

Respondent 6 Perhaps the site specialist nurse could do it after the MDT.

Respondent 5 She already does that when she makes a referral.

Respondent 6 No I mean at the time of the MDT on all patients.

Respondent 1 Wouldn't that give you information on patients you would never see as it may not be appropriate?

Respondent 6 I hadn't thought about that.

Respondent 2 That would mean a huge amount of additional work for us.

Respondent 6 I take your point but how do we improve things?

Respondent 8 Given that you (Macmillan Nurses) know that one of us (site specialist nurses) are present at the MDT's couldn't we just write a protocol stating that on receipt of a referral the Palliative Care Team will contact the appropriate site specialist nurse in order to be given the treatment decision information as per discussion at the MDT. It is the site specialist nurse responsibility to fax that information on a secure fax line on the same day. What do you think?

Agreement from everyone evidenced by verbal and non verbal ones

Interviewer Okay so who is responsible for making sure this happens?

Respondent 6 I'll do it with CE, if everyone's happy with that (looks around the room for agreement).

Everyone in agreement as evidence by verbal and non verbal ones.

Interviewer If patients were aware of what should happen to them at what time during their disease journey, do you think that would be helpful?

Respondent 5 Yes I think it would, I can think of one lady who was well informed about the MDT etc, but nothing was happening quickly enough for her if she'd had a diagram of what

would happen when, I think that would have really helped her.

Respondent 3 You mean a patient pathway?

Respondent 5 Yes I suppose I do

Interviewer What does everyone else think?

Respondent 7 I think it's a good idea in principle but doesn't that reflect the work of collaborative (Cancer Services Collaborative) you know they process map each journey.

Respondent 3 That's true but they don't share that with patients?

Respondent Yes

1,3,5,6,7,8

Interviewer (to respondents 2&4) What are your views?

Respondent 2 It's just a huge task and if its down to us to do it won't ever happen.

Respondent 4 That's my view too.

Interviewer Is there a way to take this forward without giving you loads of extra work to do?

Respondent 6 How about getting the collaborative to transfer their mapping information onto a patient information leaflet at least it would be a start.

Respondent 4 We don't know if it's even a valid piece of work yet.

Interviewer How about getting the Collaboration to pilot it with one group of patients for example breast patients and then if its successful roll it out. Something similar has already been done for colorectal cancer patient's has evaluated well.

Respondent 5 Okay that's worth trying.

Agreement from the others

Respondent 5 I must say that the specialist nurse (site specific) do communicate with is and the GP's well regarding individual patients.

Interviewer Do the hospital nurses fell that's true and that they are sufficiently informed or patients coming in from the hospital?

Nods throughout the room

Interviewer Can I explore another issue with you? A small number of the patients interviews were being supported by site specific and Macmillan nurses and whilst they felt they could access support it did seem like overkill and they were concerned about the duplication of effort particularly as you are seen as a ***** resource. Unfortunately this scenario was not uncommon as you would expect it to be. Do you have any mechanisms in place to reduce that sort of duplication?

Respondent 5 I think this happens a lot it's not uncommon to see patients who say I have had x nurse, if nurse new what it is you're here for now? In relation a specialism I think we need to find a way of defining where it's appropriate for one to finish and another to begin.

Nods from around the room

Interviewer There are a few nods around, does it feel that that a bit of work that would actually be worth doing something around?

Respondent 5 I think sometimes we are primarily primary care focused and I think very often the confusion is when the patient moves from the primary care setting back into the acute setting, may be that might be an area where there is an opportunity to update what is happening to the patient and perhaps getting the specialist nurse be it lung, colorectal or whatever the opportunity to update what has been happening to the patient. That might be an area where it might be useful to see who it' is appropriate to back off I suppose.

Respondent 3 I think we do that in practice anyway its just not formulised.

Respondent 1 Mmm, I think that's true.

Interviewer Is there something about defining your role boundaries as specialist nurses? Do you come across scenarios where perhaps consultants struggle with particular patients and refer to all and sundry in a hope that someone will be able to help?

Respondent 4 Yes, I think there is a whole new cancer culture whereby someone has cancer so we will refer them to a Macmillan nurse, even though that might not always be appropriate for the patient at that time. Particularly with referrals to the Macmillan Nurse, I think what a lot ward nurses tend to do

is refer to Macmillan for support on discharge and cut out the District nurse step.

Respondent 3 Yeah that's true I think we tend to cut out that District Nurse step almost completely now. From my point of view I refer direct to Macmillan to and don't always include the District Nurse.

Respondent 2 The GP's do it a lot.

Respondent 5 Yes they do and that can be a problem for us (Macmillan) because we then either have to visit inappropriate referrals or know them back and potentially alienate GP.

Interviewer Would it be better to define patient's pathways that spanned the whole patient journey? Would the assist in educating professionals now how to refer?

Respondent 1 Yes.

Respondent 6 Sometimes where the difficulties arise is where at diagnosis the patient is already terminal and they are bouncing back and forward and I think that's difficult to decide who actually is the most appropriate specialist at this stage so rather than not do it everyone does it.

Respondent 4 With my patient particularly that's true but I think we have managed to sort out who does what and when.

Nods from Macmillan nurses

Respondent 4 I raised on the ward the other way on a ward who never referred to a Macmillan nurse who always referred to he District Nurse and let them refer on when they felt it was

appropriate. But that was quite a hard and fast mile and I think you really need to look at patient need on an individual basis.

Respondent 5 I think we need to be careful not to deskill ward and district nurses by diving in there routinely.

Nods around the room

Respondent 5 I think we need to educate and empower them because before the advent of specialist nurses these nurses had a bit of a finger in all the pies, and some of them are quite happy to continue supporting these patient.

Interviewer What's the answer to that then?

Respondent 1 I think it's difficult to have clear boundaries because you will always have the patient who always want everyone and in instances I think you have to refer even though I try to give a brief overview of everyone's roles and how appropriate they are to that patient but in the end if they want referring on you do it even if you know its not appropriate.

Respondent 5 It is interesting because we've been around along time and when we have heard about the advent of site specific nurses we were nervous about where we would fit, we would have to have a meeting to agree clear guidelines and that actually I think because we do communicate well that has just been a natural progression of that pathway.

Respondent 4 Yes that's the way it works and the way it needs to work. I know when I first came into post I was going to be all thing to all people.

Laughs and agreement from around the room

Respondent 4 You know I am not that, I know that my role is and ii am quite clear about that and it might not fit with other lung cancer nurses in other organisations in fact it doesn't fit with those we were palliative care nurses first and I think they have a slightly different slant on it too. See in G (local hospital) the Palliative Care Nurses work across hospital and community it just makes so much easier.

Respondent 1 Because they are there.

Interviewer Just changing tack a little bit and this is my last main question really. Going back and focusing on the patients one thing that come out of my study was about communication in terms of the way they were given a diagnosis of cancer. I asked them about factual information which was very important and clearly they wanted someone who could give them the right facts and not conflicting information but a large number of patients wanted more than that they referred to nurses and consultants who had been very kind of factual in a way they had delivered information reading a diagnosis as "clinical" or "he was so professional". Another group of patients who felt they have been managed in an empathetic or sympathetic manner used words like "he looked so kind", "he/she was so kind", "she was really caring", "she was really nice", and they used sort of soft words to try and describe people who had given them he bad news in a sympathetic manner, they really valued their attributes of kindness and caringness. Its almost as though there is a continuum where at one end have got very clinical factual information like "you've got cancer" to

someone who still gives all the right factual conversation but did the tactful feely stuff as well as and when you go back to the literature these loads of literature that's tells you how to break bad news including where and when to do it, break it down into small bits etc. but there is nothing to tell you how to do the touchy feely stuff. A lot of nurses were said to have provided this kind of support. I suppose what I want to know is whether you think nurses came into the job because they are kind caring people or whether its something you actually learn and develop if it is something that you can learn and develop can we actually teach people to become more kind and caring?

Respondent 8 I think it's down to individual personalities of people.

Respondent 2 I think you can give people pointers of how to do things.

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

Interviewer I'm just curious to explore whether we should try to address this through education programmes?

Respondent 1 Well if you believe education encourages people to reflect on their practice, then yes it's worth trying.

Respondent 5 You know the Sheila Cassidy video?

Nods from around the room

Respondent 5 Well there are some good pointers in there.

Respondent 6 I think a lot of it hinges on the relationship between the consultant and/or the specialist nurse.

Interviewer Its interesting that you should say that the patients that I interviewed were relatively new diagnosed and they were reflecting back on the time when they were given diagnosis through initial phase of treatment and a lot of the patients were actually saying things like "I saw the consultant he was very nice but the next time I went I saw the registrar and the time after that I saw..", and they weren't necessarily getting continuity and where there is a specialist nurse involved who has communication skills training, is there a role for that person to do some of that follow up stuff so there is a rapport there? Id the consultant cannot do it and there's going to be a stream of more junior doctors doing the follow up stuff is there a role for the specialist nurse to provide that sort of support?

Respondent 1 That's something we are actually looking at the moment. We currently do our own follow up clinic at the same time the consultant is doing a separate clinic in the adjacent room so we have easy access if we are concerned and need to have a patient seen by a doctor. I have had training from the consultant to prepare me to work in this way and it does work very well.

Interviewer So in terms of rapport and communication then clearly that has got real benefits of working in such a way.

Respondent 1 Yes I think so, obviously junior doctors change quite regularly and are on a huge learning curve when they first join a team quite often make mistakes, and where you have got a specialist nurse who has worked in the

specialism for number of years, quite often they have more knowledge than the junior?

Respondent 6 Just trying to turn the tables a little bit I think I would be happy to see not necessarily the same person all the time so long as I heard the same things to my questions.

Respondent 2 I think that its right but in practice when patients get different views from doctors it's the specialists nurses they ring to try to make sense of what they have bee told.

Respondent 3 I think nurse led follow up is very often because nurses can provide that continuity and have more time to address psychological and social concerns of patient.

Respondent 5 I am sure you are right but clearly there needs to be a lot of training involved to be able to do this effectively and safely. What I mean is that patients should feel disadvantaged by getting a nurse instead of a doctor.

I agree (nods from everyone else)

Respondent 1 I take your point but I do believe patients get a better deal when they are followed up by appropriately skilled nurses in addition I certainly get a lot of job satisfaction by being able to do it to.

Interviewer I think I have covered all the things I wanted to, thanks very much for your frank and open participation. I just wonder this idea of developing specialist nurse roles to do new patient and follow up clinics would you like me to raise this with the consultants to explore their views when I do their interviews?

Appendix V

The usual conversation regarding anonymity and confidentiality occurred at the outset of the interview. The researcher also feedback on the key findings of the study to date.

Consultant C

Researcher Obviously continuity was a really important issues and patients value continuity although they did not use that term – they talked about somebody who followed them through them through the patient journey and supported them at different stages in that journey and also the fact that they got the same information via that one person and that the specialist nurse was primarily their key to continuity of care really – so I just wondering whether you thought continuity was important to patients and who thought was the key person to actually achieving that?

Consultant I think continuity is fundamental, I think we are risk of loosing that unless we accept that it doesn't matter who gives the message as long as the message is always said that therefore the key to this is having a multidisciplinary team that works thin through, that speaks to each other and has the same message to give from whatever origin, be it nurses, radiography, technical, medical. As long as the same message thereby what we have to have is full and frank discussion between all participants.

Researcher Patients identified – they didn't talk about MDT's but they talked about a number of professionals involved in their care and where specialist nurses went back and talked to the consultant, liaises with the GP, spoke to palliative care nurses or the oncologist and so on and so forth. Do you

think it is important that patients are aware that a MDT is actually responsible for planning their care?

Consultant

Indeed, and one of the things I stress after the diagnosis with patients is that they will have all aspects of their care discussed at the multidisciplinary team prior to any advice on adjuvant therapy being given and I stress that they will probably only meet 2 or 3 members of that team but that the whole 15 or 16 of us have been involved in their care on an individualised base and I think it is important to stress also that I see the role of the specialist nurse as being lubricant between the various bits of machinery and without it the machinery may well look nice but won't work, so I am very keen that patients are aware that there are things going on in the background that are fundamental to their care.

Researcher

When you talked about the specialist nurse being a lubricant in the machinery, what did you mean by that, what attributes do you think they have got that actually make everything come together or work?

Consultant

It is the ability to discuss with all different disciplines in a manner that 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 describes the ability for nurses to communicate with clinicians with whom they have built a rapport – they may not necessarily particularly like them personally but they certainly need to be able to respect them clinically, and for the nurse to have the confidence of carrying an opinion and not being brow beaten into keeping that opinion quiet – as with any team you can't have any participant of that team thinking it is a good idea as long as the team

agrees with that person. We have all got to give and take in all aspects of this team working, certainly the nurse practitioner/clinical nurse specialist sufficiently experienced will provide a key to that working.

Researcher Do you think that level of nurse is more able to do that than say a generic ward nurse?

Consultant Absolutely! Without the shadow of a doubt. I think if you speak to a generic ward nurse as to what the role specialist is you will get a very different idea from what happens in reality. Few of them realise that the nurses often work independently from the consultant, few of them realise the depth to the discussion that take place and very few of them realise the extra work involved in training and education that these nurses have gone through.

Researcher In terms of the development of the specialist nurse role, clearly within this organisation we have got a number of models where we have nurse led clinics and ranging from the new patient assessment to follow up clinics. I think there is a suggestion that we should expand these sort of roles. How do you feel about that sort of working?

Consultant I think it is fine, I don't see it as an exchange for doctors – I see it as a complimentary action. The breast nurses and colorectal nurses that I work with do not do what junior doctors did. We haven't exchanged one role for another, what they do is complement the service that we provide. They are additive rather than exchange and certainly if you look at it at the most basic level possible, at the very least if you ask a nurse to go through and do a series of tasks, they will always do the. A junior doctor will

eventually as they become more senior miss out the ones and take short cuts and it has certain attributes and advantages but if you are looking for consistency you are not going to get that whereas you will get that with a nurse colleague. On the other hand, the nurse brings to the clinical setting the experience and the expertise of the nursing training and nursing background. I think it is inappropriate to talk about the holistic because I think it has become a buzz word, but basically the complete care of the patient depends very much so on the complete professional portfolio that you have to offer the patient.

Researcher

Changing tack slightly, obviously part of the study involved actually implementing some changes and some of that work was around mapping patient pathways and then making those patient pathways available to patients so they could actually see what their disease journey would like. In sort of very kind broad terms really but so they knew what to expect, have you got any views about processes like that?

Consultant

No I think it is excellent I mean it as all part of patient education – I think this idea if them coming and being exposed to a system over which they have got absolutely no idea 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 will have your car serviced and I'm not suggesting that you deal with patients in that manner 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 of the measurement I think it is

entirely appropriate – it is part of patient education.
Demystify medicine by all means.

Researcher

There is obviously a change agenda at the moment within cancer care and we are getting loads of Improving Outcome Guidance on a regular basis to do with different cancer plan, nursing documents about change within cancer and it just seems as though we lurch from one change to another. I have concerns that sometimes what happens is we implement projects and that is what happens they stay projects and they don't ever really get integrated into practice. I am interested to know how you think we can actually assimilate changes into practice so they become longstanding?

Consultant

Think we need to simplify things – I am a scientist basically and I like the idea of devising a hypothesis and then testing the hypothesis and then putting the hypothesis into practice should it be successful and you want it to be provocative you could say that the health service has failed. The original hypothesis for the health service was that if you make the health of the population better there will be less demand on health services. That has clearly not been the case it is the reason why we still have the problems with the health service that we currently do as compared with say France or Germany who at the end of the second world war had the same problems in fact we did and nobody would accept that the UK system is better than France or Germany – it is actually considerably worse, so I think we still have that culture where nobody is prepared to say take a hypothesis, introduce it, put a project, see whether it works and then impose it and I think this failure to impose things is a major defect and as a result we have spawned

immense numbers of cancer committees, non of whom have got any mandate that I can see to impose cancer care, none of whom have got any remit other than to keep themselves going.

Researcher

On a very practical level I am interested to know how you influence individual consultants because very often it is the consultants or the ward sisters who can be the blockers to implementing change to even introducing your hypothesis in the first place and I am interested to know whether you have got any views about how to get over those barriers?

Consultant

By demonstrating, by doing things and demonstrating the benefits of that, other people come along with you. I think it is leadership that has got the crucial role here. I think if you can demonstrate for instance and I take a very simple example we have patients who the median time they are in hospital following major bowel cancer surgery is something like twice that of in the United States. We don't have patients who are twice unhealthy we have attitudes that are twice as difficult to change so you say to the ward staff this patient can have free fluids on the first post-operatives day and you can guarantee that they won't get that because it has never been done and what you have do is demonstrate by example and take selective patients, do that, get them moving, get them sorted and you will gradually win things though. So for instance, naso gastric tubes that used to be endemic throughout the surgical ward are now a rarity because people realise that are an absolute waste of time except for under certain circumstances. So 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, then you will be rewarded.

Researcher

Changing tack again the last sort of area that I want to discuss is this continuum that I have come up with. Patients seem to sort of be at one or another of a continuum in relation the way consultants communicate with them. A large proportion of the patients that I interviewed identified attributes like caring and kindness, supportiveness and things like that as being really important, really valued those things in their consultants and felt that they were the best things in addition to the clinical expertise off course that they could get from a consultant. On the other hand there were a number of patients who actually used terms like "clinical professional" in a very derogatory manner and followed it up with statements like "well Mr so and so was very clinical, he was very cold and he told me I had cancer and that he was going to refer me on almost as though he told me I had cancer and that he was going to refer me on almost as though he washed his hands of me" and they were the sort expressions that those patients used. I am interested to know whether you think the two things actually can come together and you can get somebody who is clinical and professional and also kind and caring and whether that is sort of an innate attribute things in individual or whether we can actually teach it?

Consultant

I think this has come about because there is a myth that professionalism is the white coat that you put on or a three piece suit that you wear. Professionalism in my book is where you put in whatever is necessary to complete the job irrespective of the time involved or irrespective of the effort involved. The people who are

seen as clinical and cold by large can't cope with the and news and have to put up some form of front. On the other hand if you wish to be able to deliver services that involve great emotional distress to all concerned 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 can't disassociate yourself. I think if as a professional you can't remember the names of some of the people who have 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 episode is not healthy either – there has got to be a compromise and a balance. The patient has always got to feel that 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 so I hope I get that balance right – I am sure I don't on occasions I am sure there are when I have made errors either by way of being cold or getting too involved but there is no doubt about what that without that involvement you are not going to be able to help steer the patient through a particularly difficult period and I think if they can see that you have human attributes and I have to say I teach the medical students that medicine is in 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 identifies them as individual and I make a reference to that, so for instance on Friday I saw a lady who is 10 years down the line from her breast cancer and I was about to discharge her. She was MS and I remember at the time that was a great debate as to whether or not that was a great debate as to whether or not that the medication we need would interfere it and I alluded to that

detail. It's an act, it's a performance but it is one that is necessary to get that patient's confidence.

Researcher Do you think that there is anything we can actually do or should be doing to highlight the issue amongst, not just medical staff but also amongst nursing that this important that you have this act really with patients?

Consultant Absolutely and I am sure there must be ways of identifying those people who have that ability – there must be some of testing that shows it. Let me give you an example there is one of my wife's uncle's, he is the nicest kindest gentlest man you are ever likely to meet in your life but he is as distressed as hell because he was having some cancer chemotherapy and he felt that the infusion that was being given a insufficient and he pointed this out. The nurse took an immediate objection to him, labelled him as a trouble maker, it was passed onto the medical side so he has had a really difficult time at a time when he needed our support. He lives by himself. He has had a brood through this and we have completely and utterly got it wrong. Now I think you must be able to identify those people who on the hand are not sufficiently at risk taking every patient's woe on board but on the other hand are not completely and utterly got it wrong. Now I think you must be able to identify those people who on the one hand are not sufficiently at risk of taking every patient woe on board but on the other hand are not completely devoid of any emotion and there must be some way of testing it, certainly there is no reason why as a surgeon for instance who has an inability to communicate with patients at that level if they can carry on with the non-cancer work, the technical aspect that for them is the reward and certainly I have always felt that the current system of ever increasing

grades of a level to define whether somebody should be a doctor or not is completely and utterly wrong. Most of the people that I know barely scraped in with ordinary grades are the best doctors around because they have the ability to communicate and they have a ability to give and nobody has ever demonstrated the evidence the 3 grade 'A's' correlates with a good doctor.

Researcher

They were the areas that I wanted to focus on primarily I don't know whether you have got any other comments that you would like to make relating to the questions that I mentioned or bits of the study I have highlighted?

Consultant

The only thing I would say it that we are about to find that we are going to need to ask more questions than we thought we have answered with the specialist nurse role. What happens after the specialist nurse has done the role for a period of time – where is the next step. Is this a period of transition or is it an end point. Do we have the career structure in place for nurses, the answer is no. It has always been see hither to whether we say it openly or otherwise the nurse is a role that is subsidiary to medicine. May be would stop I think it's not particularly fruitful argument or whether one is better than the other is subservient. I think one ought to be saying how we can get them better to compliment each other rather than saying anything else so I feel very strongly that once they have become nurse specialists are they going to do that same role forever because if they are thinking we are going to have the same problems as we have the associate specialists, the non-consultant grades who after a while don't change, don't move with the times and when the consultants change and the new blood comes in they

will expect their nurse specialist practitioners to change appropriately.

Researcher

Okay – thank you very much.

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