

**Investigating Interactions: How do doctors and patients experience the disclosure of significant information in the advanced cancer setting and how do these experiences enhance practice?**

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# **ABSTRACT**

This thesis focuses specifically on the transmission of bad news from doctors to patients and their families in the context of a hospital oncology department. It uses awareness context theory as a basis for exploring communication between patients and health care professionals, particularly when the information to be disclosed is sensitive and will have a significant bearing on how people perceive their future. In order to enhance clinical practice, senior health care professionals in particular, have in the past been encouraged through government policy and professional legislation to attend communication skills courses to develop the way they communicate and interact with patients. Yet, in spite of these interventions evidence suggests that doctors and other health care professionals still find it difficult to negotiate sensitive and emotionally challenging discussions, and frequently question whether or not patients are aware and understand the information disclosed to them and whether or not information provided meets the needs and expectations of patients.

The premise of this research is that more attention needs to be given to how other more reflective and experiential professional development approaches and techniques might help doctors communicate better with their patients when disclosing sensitive information and bad news. In order to do this however, a better understanding is needed about what is going on in consultations and how each of the individuals involved experience and make sense of these interactions. It is proposed that in order to understand 'resulting interactions' more fully it is necessary to explore and compare the multiple perspectives of doctors, patients and others; including relatives and nurses. This thesis seeks to do this in an innovative way by reporting research, which involved observing and recording consultations between doctors and patients and their relatives and then conducting in-depth interviews with such people in order to explore their own insights into this process. In total, 115 episodes of data were collected and analysed from 16 patients and 16 doctors.

The insights gained from this study are presented in relation to two main analytic themes; Doctors and Patients Acting their Parts, and Sharing Uncomfortable News. The data analysis highlighted a number of approaches used by patients and doctors to manage and control their interactions within the medical consultation. The implications of the study findings are discussed in relation to both wider theoretical perspectives and ideas for how doctors working in such settings could be assisted to consider alternative strategies for these aspects of their work.

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# TRANSCRIPT CODES

All tape recordings are verbatim transcripts.

Verbatim quotes are generally indented within the main body of the text; the only exception is when extracts from the recordings of consultations have been used.

The name of each participant was replaced with a pseudonym, taken from a list of popular names and applied randomly to participants. The gender of patient participants is indicated by their title. My name has not been changed.

The following code:.....indicates that words or phrases have been omitted.

The source of quotes is listed by the participants name at the end of a quote to identify the phase of the study or whether the quote was made during a 1<sup>st</sup>, 2<sup>nd</sup> or 3<sup>rd</sup> consultation.

## **LIST OF ABBREVIATIONS**

GP = General Practitioner

SPR = Specialist Registrar

GMC = General Medical Council

WHO = World Health Organisation

# Chapter One

## Introduction

### 1.1 Introduction

This study considers the way doctors and patients who have been diagnosed with an advanced incurable cancer, interact with each other during medical consultations when talking about sensitive issues and dealing with bad news. Receiving a cancer diagnosis may be one of the most devastating pieces of news a patient and their family may hear. With this in mind, doctors and other health care professionals have been made increasingly aware of the need to improve the way they interact and communicate effectively with patients. However Mechanic (1998) asserts that:

*'Despite universal recognition of the importance of communication, the demands of medical education and practice typically results in physicians' paying less attention to their communication skills than to what are commonly viewed as more pressing medical and economic concerns.'*

(Mechanic 1998:281)

This statement suggests that the application of communication skills within clinical practice can be problematic and as such effective communication between doctors and patients can be compromised. Disclosing bad news and talking about sensitive issues has been identified as a difficult issue for health care professionals and doctors in particular (Fallowfield 1997; Maguire 1999; Innes and Payne 2009). Responses to date have primarily focused on communication skills training, but these approaches have limitations as some doctors have found it difficult to transfer and / or sustain what they have learnt on courses, to real life situations with patients in clinical practice (Fallowfield and Jenkins et al. 2002a).

It has been suggested that this may in part be because many patients do not necessarily interact in a predictable manner and emotional responses and reactions from patients and their relatives may be difficult to manage (Buckman 1984). When faced with emotional responses, there is evidence to suggest that some health care professionals may try and take care of their own emotional needs as a form of self protection, rather than meet the emotional needs of others (Anderson 2000). As such health care professionals may risk compromising the quality of their interactions with others as they fail to engage with patient's needs and current state of awareness as to what is happening to them. In order to try and understand some of the tensions experienced by many doctors in relation to how they communicate and interact with their patients, consideration needs to be given to the awareness context of those involved along with the social interactions that are occurring as well as what is actually being communicated.

The premise of the research presented in this thesis is that more attention needs to be given to how other more reflective and experiential professional development approaches and techniques might help doctors communicate better with their patients when disclosing sensitive information and bad news. In order to do this, however, we need to have a better understanding from doctors, patients and relatives about what is going on in consultations and how each of the different individuals involved experience and make sense of these interactions. I seek to do this in an innovative way by observing and recording consultations between doctors and patients and their relatives and subsequently obtaining the perspectives of those involved using in-depth interviews. Through this study I reveal the struggles, concerns and issues faced by some doctors as well as the techniques they already use to manage this aspect of their work. The knowledge I generate through this study also builds on the literature to demonstrate how the disclosure of information does not necessarily lead to a realistic and open awareness, and reveals some of the reasons why this may be the case.



## **1.2 Setting the Scene – Personal Reflections**

A combination of circumstance and experience contributed to my decision to undertake this particular study. As a senior nurse, working within an Oncology clinical trials team, situated within a large NHS Trust Hospital, I had a close working relationship with a number of doctors; as we were each involved in the care and management of patients entering into phase I clinical trials. A team approach was adopted within this clinical setting, whereby people worked alongside their colleagues to manage, organise and deliver care to patients, yet the majority of information given to patients about their diagnosis, prognosis and treatments, was by their doctors in the medical consultation. During these encounters, complex decisions were frequently made about how, what and when sensitive information and bad news should be disclosed to people diagnosed with an advanced incurable cancer. Decisions were also informed by the doctor's perception of the person's prior knowledge and understanding of their illness and their need or desire to receive further information. In addition to this, I was often able to share my knowledge and any concerns I may have of the patient with the doctor, as my clinical role afforded me the opportunity to spend a longer period of time talking with the patient prior to and proceeding the medical consultation.

During conversations with patients it was not uncommon for them to share information that made me question their understanding of their situation and to question what they had or had not been told by their doctors. If I was not present in the medical consultation, I was not always informed of the discussion that had taken place. As such I needed to be guided by what the patient told me until such a time when I could talk to the doctor to seek clarification. The following provides an account of a situation which made me feel uncomfortable and uncertain about how I should respond to a comment made by a patient. The name of the patient has been changed to ensure anonymity.

*Mrs Smith was being reviewed regularly to monitor the effects chemotherapy was having on her cancer and her latest scan results indicated that her cancer had grown slightly. The doctor relayed this information to Mrs Smith and explained that at the moment they did not need to make any decisions but forecasted that they may need to have a conversation about stopping active cancer treatment in the near future. During my conversation with Mrs Smith following this consultation I was not certain that she had fully understood the implications of what she had been told. Although I tried to clarify and summarise things for her, I was not convinced that she had understood me. On Mrs Smith's next visit to the chemotherapy suite I raised my concerns with her doctor prior to the medical consultation. The doctor assured me that she would speak to Mrs Smith again to try and prepare her for what was likely to occur in the forthcoming months. On this visit, circumstances prevented me from joining them in the medical consultation, so I did not know what had been discussed. As I sat talking to Mrs Smith following her consultation with the doctor, I expected her to ask me some difficult questions for which I was prepared to answer. Instead she appeared calm and relaxed and told me that since she had last seen me she had booked a dream holiday for the following year. My reaction was a mixture of bewilderment and concern. I knew that there was a very significant chance that she would not live long enough to go on this holiday. I did not know how to respond to her as she appeared to be so excited. I thought an appropriate place to begin was by asking her if she had mentioned this trip to her doctor. She said that the doctor hoped that she would feel well enough to enjoy her holiday. This response came as a surprise and made me even more uncertain about how I should respond to her. In addition I felt that I had been placed in a very difficult position, which may have been alleviated if I had received some feedback from the consultation. Mrs Smith did not live long enough to go on this holiday.*

This and other related experiences arising in clinical practice were quite frequent and made me wonder what actually happened in the medical consultation. Despite assurance that Mrs Smith's doctor would try and prepare her for what was likely to

happen in the forthcoming months, I found myself in a situation whereby I was uncertain about what had and had not been communicated in the consultation and did not know how to respond to Mrs Smith in those few moments. Had Mrs Smith and her doctors actually had this conversation, or was it a case that Mrs Smith was unable to listen to or comprehend what she was being told? or was Mrs Smith trying to ascertain my reaction to test whether or not she was being given consistent information? As I sat with Mrs Smith I did not know the answer, yet felt that I needed a deeper understanding in order to support her further.

In sharing my concerns with a number of doctors they described how it was often difficult to negotiate sensitive and emotionally challenging discussions and frequently questioned whether or not (a) patients were aware and understood the information that they had been given (b) whether or not they had communicated this information to them in an appropriate manner; and on occasion would turn to nursing staff to ask for feedback. In addition to this, some doctors (both senior and junior) expressed concern that they did not know how patients' perceived their interactions and were not always clear about what their patients wanted from them and whether or not they met their patients' expectations. These dilemmas constitute the prime focus for my research and explain why I as a nurse practitioner was especially interested in doctors' roles in such situations. My major interest was to understand doctors' behaviours better and to reflect upon possible professional development activities which could inform the complex dynamics and working relationships between nurses, doctors and patients. Although we worked alongside each other, fulfilling our various nursing and medical roles to manage, prescribe, organise and deliver patient care, there was still a need to enhance team working, to try and prevent difficult situations arising before, during and after consultations with patients.

### **1.3 Background to the Study**

The fear induced by the mention of the word cancer is considerable. Despite vast improvements in the past 15-20 years in the way people are treated and cared for;

cancer remains one of the most feared diseases of our time (Murray and McMillan 1993; Beach et al 2005; Cancer Research UK 2007a; Richards 2007). Cancer is perceived by many as a life threatening illness. This perception of the disease is not surprising when one considers that in 2005 cancer accounted for approximately 7.6 million deaths worldwide (World Health Organisation 2006). However, due to the national cancer programme, mortality figures in the UK are continuing to fall, (Department of Health 2009), but because people are living longer, it means that in reality; nearly every one of us will be touched by cancer in some way.

When people become ill or routine investigations identify something suspicious, they will undergo a series of diagnostic investigations to try and ascertain what is wrong with them. From a clinical perspective it is necessary once a diagnosis of cancer has been confirmed to consider the 'stage' of the cancer. Staging provides vital information about the growth of the cancer and identifies whether or not it has spread to other areas in the body. The chance of cure is increased if the disease remains within a local or regional area. In contrast, the chance of cure is significantly reduced if the cancer has advanced in growth and disseminated (metastasised) to other organs within the body (Bosman 2006). In the latter case, patients are diagnosed with an incurable cancer and their prognosis is generally considered in months rather than years. These people will face many challenges in a relatively short period of time and their perception of their future life is likely to change dramatically.

How one communicates this news to patients has come under considerable scrutiny over the years. Fundamentally, there is no easy way to deliver bad news to people because of the nature of the information the patient is about to receive. Yet, the way in which it is delivered can have significant consequences on the way patients receive and understand the information and how they perceive their relationship with their doctors. From the doctors' perspective disclosing bad news to patients has been identified as one of the most difficult dilemmas they face (Buckman 1984). In

the past, there was a tendency for many doctors to avoid telling patients they had cancer as a way of trying to protect them from distressing information (Taylor 1988; Fallowfield 1993). Moreover, reports indicate that some doctors have also been known to protect themselves from potentially difficult and emotionally challenging conversations with patients during medical consultations, by choosing not to disclose diagnostic and prognostic information (Richards 2007).

In addition, the dominance of impersonal hospital regimes has also been influential in determining whether or not bad news was disclosed to people. Glaser and Strauss's (1965) classic and influential study of *Awareness of Dying* showed how health care professionals frequently controlled or manoeuvred situations whereby they did not have to disclose information to the patient that they were dying; some patients would instead look for cues in an attempt to confirm their suspicions. In her study to address the issue of what physicians tell patients, Taylor (1988) also found that a number of doctors tended to act as 'gatekeepers' of information.

In Glaser and Strauss (1965) study, many doctors were reported as thinking it was not always necessary or in the patients' best interests to disclose the full details of a person's illness. As a way of controlling what they did say they often applied routine procedures through their interactions, regardless of the needs of the individual sitting before them. The work of Glaser and Strauss (1965) and subsequent researchers would also suggest that some doctors were unwilling to disclose diagnostic information for fear of patients asking them questions, especially if the patient had a poor prognostic outlook for fear that disclosing the truth may be too distressing and destroy any hope for a positive outlook (Glaser and Strauss 1965; McIntosh 1974; Roter and Hall 1993; Fallowfield and Jenkins et al. 2002a, Maguire and Pitceathly 2002).

However, in the recent past much attention has been focussed on moving away from such 'paternalistic practices' in favour of facilitating a culture of 'open awareness.'

In the clinical setting and in the way health care professionals, and especially doctors interact with their patients.

Senior doctors and nurses are now encouraged to be open and honest with patients when presenting information pertaining to diagnosis, prognosis and treatment options (Department of Health 2009). Various reasons have been proposed to explain why an open awareness culture came to be. The growing awareness of patients' rights for information about their health care over the past 40-50 years or so means that a move towards open disclosure is necessary to ensure that people understand what is happening to them so that they can make plans and informed decisions about their future. As such this change in awareness has been influential in a number of policies and procedures which govern health care and professional development within the United Kingdom (Department of Health 2000; National Institute of Clinical Excellence 2004; Department of Health 2007; Department of Health 2009). From a broader sociological perspective, this change has implications for the way the traditional relationship between doctors and patients is perceived and acted upon (Light 1995; Timmermans 2005), in essence attempting to reduce the inequalities of knowledge and power which have existed between doctors and patients.

Although much is known about the benefits of effective communication and how it plays a central feature in the formation of the therapeutic relationship between doctors and patients (Balint 1965; The 2002), questions of effective communication are still critical and worthy of attention. There are clear indications that problems exist in terms of how well many doctors and patients interact with each other. This is demonstrated in the number of complaints made against the NHS about communication related issues (Pincock 2004; Citizens Advice Bureau 2006). Problems can arise if the patient and doctor have differing agenda's or the patient feels that bad news has been communicated to them insensitively (Brown and Crawford et al. 2006). Despite the developments which have taken place in relation

to communication in health care settings, there is evidence to suggest that although there is a greater tendency to disclose diagnostic information (Innes and Payne 2009) the disclosure of prognostic information has not necessarily improved, particularly if the prognostic outlook is poor (Hagerty and Butow et al. 2004).

A major emphasis has been placed on trying to improve the way doctors communicate information, and much of the literature has focused on the way doctors' control and manage the disclosure of information. However, it has been suggested that it is too 'simplistic' to assume that just because information has been disclosed to a patient that this leads to a state of open or realistic awareness (Innes and Payne 2009).

#### **1.4 Research Aim, Objectives and Design**

The purpose of this study was to investigate the experiences of patients diagnosed with advanced incurable cancer and the doctors who conducted their medical consultations, particularly in relation to talking about sensitive issues and dealing with bad news. The objectives and design features of this study were influenced by the 'awareness context' theory, initially developed by Glaser and Strauss in the 1960's and taking into account the subsequent modifications proposed by Timmermans and Mamo in the 1990's. This theory offered a theoretical framework for undertaking this research and offered an opportunity to build upon existing theory by exploring the multiple and combined perspectives of doctors and patients and their relatives, at a much deeper level, as they interacted with each other and communicated information within an Oncology setting. An interdisciplinary approach, drawing on sociology, health and education disciplines and knowledge bases has been applied to this study. The data generated is used to inform how clinical practice may be improved through the incorporation of the learning from such experiences into an individual's continued professional development. To this end the research objectives were purposefully broad in order to facilitate an open-ended inquiry:

1. To observe and examine how doctors and patients manage and control the disclosure and receipt of sensitive information and bad news in an Oncology outpatient setting.
2. To explore the feelings associated with dealing with sensitive information and bad news, when patients are first referred to the Oncology department and as they progress through their illness.
3. To examine how the concept of 'awareness contexts' can help understand the perspectives of both doctors and patients in the consultation and explore the impact and influence an individual's own awareness context has on the consultation experience..
4. To critically reflect upon doctor-patient communication in such situations with a view to considering future strategies for doctors' continuing professional development.

I wished to explore key aspects of doctor and patient interactions, from various perspectives, to explore the meaning individuals attribute to their experiences; to explore the changing nature of social interactions as doctors and patients meet on various occasions; to explore the nature of relationships particularly within the context of disclosing and sharing sensitive information within an Oncology setting which may have some influence on changing awareness and be consequential to future interactions. I also wished to reflect upon the data generated through this study to explore if this data can inform the way we proceed to improve doctor's communications and interactions with their patients (and relatives); to explore where there is a need to focus efforts in order to make a positive contribution to future professional development in this area. In addition to this, there is a need to consider what lessons can be learnt for the broader health care team in relation to their interactions with patients, relatives, and colleagues.



In thinking more critically about the context of communication and the way interactions are played out, a qualitative approach incorporating observation and semi-structured in-depth interviews was chosen in order to capture and explore the expectations, knowledge and agendas participants bring to the consultation which may shape the way doctors and patients interact with each other, as well as exploring their combined perspectives of experiences within medical consultations. The study was undertaken with 16 patients who were attending an Oncology outpatient department and 16 doctors working within the same Oncology department of a large NHS Trust. Where possible, patient consultations were observed and audio recorded on more than one occasion and as such some patients were interviewed on more than one occasion

## **1.5 Thesis Outline**

Within this thesis a review of the literature is presented, focusing on key issues central to the present study and proceeds to describe the methodological issues and the process of conducting this study, including sampling, recruitment, methods of data collection and analysis. The themes that have emerged out of this work; Doctors and Patients Acting their Parts and Sharing Uncomfortable News – offer an account of the ways doctors and patients approach and experience consultations; highlight the multifaceted nature of the doctor and patient relationships within the cancer setting and draw attention to the way they negotiate and share knowledge with each other and how this informs their interactions with each other; and shows that not only professionals the awareness context but patients do too. In addition, the findings bring light to some of the concerns and struggles faced by doctors and their need for additional support to help enhance their professional development. Finally, the main issues raised throughout this study are considered in relation to their contribution to existing knowledge and the implications of these findings for professional development are presented.

# Chapter Two

## Literature Review

### 2.1 Introduction

Doctors and patients generally come face to face within the medical consultation. Yet it is only in the past 50 years or so that these encounters have come under the close scrutiny of, for example, sociologists, health care personnel and educationalists (Brown, Crawford et al. 2006). The way doctors and patients interact and form relationships with each other within this context are inherently complex and it is recognised that there is a need for doctors to develop supporting and trusting relationships with patients and their families (Hagerty, Butow et al. 2005). The development of such relationships is seen as particularly important when disclosing bad news about a life threatening illness (Silverman, Kurtz et al. 2005).

Disclosing bad news about a life threatening illness has, however been identified as a difficult issue and many doctors do not find this information easy to communicate (Buckman 1984; Maguire and Faulkner 1988b; Maguire 1999; Faulkner and Maguire 2001; Silverman, Kurtz et al. 2005) and patients do not find it easy to receive (Faull, Carter et al. 2005). As such the two way exchange and receipt of information can be difficult for all concerned. These difficulties are frequently characterised by apprehension and avoidance of difficult conversations and misunderstandings between patients, their families and health care professionals (Glaser and Strauss 1965; The 2002; Sinclair 2006).

As the nature of the doctor and patient relationship evolves, there is a growing need to understand how they interact when sharing sensitive information and bad news, taking into account various perspectives and motivations for behaving in a particular manner. This can be explored further by considering for example, what shapes

doctor and patient encounters; how doctor-patient relationships have evolved; how information exchange can be controlled, shared and explored; how various forms of protection and self preservation are used to help doctors, patients and their relatives manoeuvre difficult and often challenging junctures, which arise when faced with a life threatening illness.

In an attempt to help develop this aspect of clinical practice, recommendations have been made from a body of evidence to support the need for doctors and other health care professionals to improve the way they interact and communicate with patients by attending communication skills courses (Department of Health 2000; National Institute of Clinical Excellence 2004). This literature is considered further in the later stages of this chapter. In addition to this, the review builds on this literature to consider the more complex nature of learning from several theoretical perspectives, including communication skills education, experiential learning, communities of practice and reflection and reflective practice. The purpose of presenting these perspectives is to explore the potential barriers to effective communication. I intend to do this - both from my own and others personal experiences and reflect on those in relation to some critical factors which will need to be contextualised within complex social situations. Above all I want to consider the value of learning from real life clinical situations. I recognise that although these perspectives will be presented as discrete views, they do not exist independently of each other as there are clear overlaps between each of them.

Various steps were taken to ensure a comprehensive systematic retrieval and review of the literature was undertaken, to meet the aims and objectives of this study. This was an interdisciplinary study which exposed me to nursing, sociological, health and education literatures. I needed to take advice and guidance from others who had relevant experience and expertise of working in these disciplines to help guide my search of the literature. Experienced others included my supervisors, a senior research fellow and medical sociologist, who directed me towards original theories

and empirical sources of data that included key literatures pertaining to awareness contexts, communication in health care, social interaction and communication skills development. A sub set of literature and empirical evidence to ensure a broad spectrum of issues relating to the format of the medical consultation and the formation and qualities of the therapeutic relationship between doctors and patients were also searched to help contextualise the problem this study seeks to address.

My approach to systematically searching the literature was based principally on the use of computer based search engines including: ASSIA (Applied Social Sciences Index and Abstracts), BMJ (British Medical Journal), Cochrane Library, Google Scholar, Department of Health Publications Library, General Medical Council, JAMA, Ovid Online, PubMed, Sage Journals Online, Science Direct, SwetsWise and Wiley Inter Science. In addition, journals which I considered to be relevant to this research study were scanned and browsed to pick out any key articles that may not appear in the published literature (Saunders and Lewis et al. 2009).

The searches were predominantly performed from the 1960's onwards to include significantly similar, relevant and up to date materials. A mass of resources was retrieved, some of which were considered relevant or irrelevant in terms of whether or not they met the objectives of this research (Hart 2005). The search strategy was at times broad and then narrowed down as parameters became more defined. Searches were conducted using a number of terms including; advanced cancer, awareness, awareness contexts, communication, interactions, cancer, decision making, diagnosis, prognosis, emotions, emotional labour, patient preferences for information, doctor preferences for communication and information disclosure, patient centred care, paternalism, doctor-patient relationships, self awareness, self efficacy, continued professional development, reflective practice, experiential learning, communities of practitioners, communication skills training, and professional development. When new concepts failed to emerge, and when I became familiar with the names of authors cited in publications I believed that this

was a good indicator that I was reaching a point of saturation (Beyea and Nicoll 1998).

## **2.2 Framing the Research Theoretically**

Through this study I set out to investigate the experiences of patients diagnosed with advanced incurable cancer and the doctors who conducted their medical consultations, particularly in relation to talking about sensitive issues and dealing with bad news. The purpose of this chapter is to frame this research within a relevant theoretical context. This is predominantly achieved in relation to 'awareness context theory' which was originally developed by Glaser and Strauss in the 1960's.

Glaser and Strauss (1965) studied the process of dying in six hospitals within the San Francisco Bay area of the United States. During this work they became intrigued by the fact that more often than not, people were often unaware of the fact they were dying. In contrast, hospital personnel and family members were more likely to have this awareness. To try and understand this phenomenon further, Glaser and Strauss (1965) analysed how 'structural conditions' including organisational secrecy, resulting interactions and changes in awareness impacted on the way people interacted with each other within the hospital setting. Glaser and Strauss (1965) focused on the knowledge of dying and the management of, and willingness to share this knowledge through social interactions between, patients, relatives and health care professionals (Mamo 1999; Hellstrom and Nolan et al. 2005). Awareness, was defined as,

'What each interacting person knows of the patient's defined status, along with his recognition of the others' awareness of his own definition'

(Glaser and Strauss 1965:10)

From their findings, Glaser and Strauss (1965) were able to identify four main types of awareness contexts; three of which reflected a tacit unspoken consensus of silence:

- |                                   |   |
|-----------------------------------|---|
| <i>Closed Awareness:</i>          | The dying person is unaware that they are dying but others including their family and friends and those caring for them are aware, but may not necessarily choose to talk about it.   |
| <i>Suspected Awareness:</i>       | The patient has an idea that all is not well but does not necessarily have their suspicions confirmed through open dialogue, instead they are on their guard to look for cues in another's behaviour to confirm their suspicions. |
| <i>Mutual Pretence Awareness:</i> | The patient, relatives and health care professionals know that the patient is gravely ill, but do not talk about this openly with each other.   |
| <i>Open Awareness:</i>            | The patient and health care professionals are aware of impending death and openly acknowledge this with each other through their interactions.  |

In *Awareness of Dying* Glaser and Strauss (1965) describe how doctors and nurses frequently controlled the way information was disclosed and shared with people who are dying. At this time it was not uncommon for patients to die within a closed awareness context. Glaser and Strauss (1965) illustrate how the issue of what and how much information to disclose to patients was not of concern to some doctors as they took the approach that it was in the patient's best interest to conceal the full extent of the truth from them and withhold information (Maguire 1985).

For example, silence was used to keep the knowledge of certain death from patients and knowledgeable relatives were, at times, made collaborators of this silence

(Mamo 1999). While some may suggest that this approach was used with the best of intentions to try and protect the patient from the emotional burden of this knowledge and to protect the doctor's therapeutic relationship with the patient (Glaser and Strauss 1965; Silverman and Kurtz et al. 2005), others have been more critical. In his review of Glaser and Strauss (1965) work of 'Awareness of Dying,' Seale describes the behaviours of doctors presented throughout this study as engaging in,

*'Machiavellian complexities of deception and manipulation, coupled with a sometimes shocking propensity to inhumane acts.'*

(Seale 1999:198)

A number of doctors were described as orchestrating a state of closed awareness by creating 'a fictional future biography' in response to patient's questions about their future. Additionally, an impression of 'doing something care' was created whereby some patients underwent surgery, or received palliative treatment, all of which were presented as curative to give the impression that all was being done to try and save the patient's life when they were in fact dying (Seale 1999). While Seale (1999) describes this as an unforgiving act of trickery and deception, he recognises that it is difficult to judge such behaviour, as the motivations of and accounts of doctors in particular, were, in his view, not explored fully.

Although, this study has come under some criticism, it is considered to be influential in terms of raising awareness about the process of dying within hospital, particularly at a time when people did not like to talk about death and dying (Timmermans 2007). As well as raising the profile of death and dying, this work has also '*given rise to a sub discipline of communicating bad news in clinical encounters*' from which training programmes have been developed to help doctors and others develop their communication skills in breaking bad news (Timmermans 2007).

Although health care practice is considered to favour an 'open awareness context' which has been a significant change from health care practice in the 1960's when Glaser and Strauss (1965) first developed their theory of awareness contexts, there is an extensive literature to suggest that the use of openness in health care practice can be contested (Field and Copp 1999; Salander and Spetz 2002; Hellstrom and Nolan et al. 2005). In the context of dying, it is difficult to know if such disclosure is accomplished and if it is necessarily accepted or wanted by patients (Field and Copp 1999). Rather than impose information on people due to an '*idealistically based insistence upon the moral and practical virtues of full disclosure*' Field and Copp (1999:466) believe that a conditional open awareness be assumed, whereby health care professionals are encouraged to take a more 'pragmatic stance' towards meeting the information needs of their patients. This point is elaborated on by Salander and Spetz (2002) who demonstrated the complex and often competing need for information of those diagnosed with brain tumours and their partners, whose states of awareness did not necessarily coincide. Unfortunately, the experiences of doctors and other health care professionals in managing and / or acknowledging these encounters were not explored.

In their critiques of the original awareness context theory, others including Timmermans (1994) and Mamo (1999) have noted that the primary focus of knowledge and a willingness to share knowledge does not take into account other factors which play a significant part in shaping awareness and impact on open awareness context. As such modifications to the original context have been recommended. For example, Timmermans (1994) felt that knowledge does not necessarily lead to awareness. Using an introspective ethnographic approach, to interpret his reactions following his mother's terminal diagnosis, Timmermans (1994) provides a modification of the original awareness theory to incorporate the existence of emotions and cognitive ways of knowing. He argues that being given information through an open awareness context, does not necessarily mean that people are able to grasp or retain what they are being told in an emotional crisis because emotional



reactions may interfere with the way they are able to process information. This may ultimately have some bearing on their state of awareness as they may try and block out information, or question the accuracy of information given to them in an attempt to maintain hope (Timmermans 1994). As a consequence of this, Timmermans (1994) believed that the context of open awareness proposed by Glaser and Strauss needed to be extended further to include

*Suspended Open Awareness:* Patients and relatives in this context receive on several occasions an explicit diagnosis and sometimes even a prognosis but disregard this information because they may feel that it is false or overly pessimistic.

*Uncertain Open Awareness:* The patient and their relatives may choose to disregard the negative aspects of information and hold on to the hope that things might work out better than expected.

*Active Open Awareness:* When confronted with information, the patient and family accept the implications of the message and act on this accordingly.

In Timmermans (1994) modification to the original theory, the act of 'knowing' was significant from both cognitive and emotional perspectives and helped determine what people chose to do with the information given to them by their doctors. He concluded that in a time when open awareness was accepted within health care practice,

*'family members and patients are powerful actors in the construction of an awareness context and that information does not necessarily lead to open-awareness, but that the way patients and relatives emotionally cope with the terminal information determines the kind of open awareness context.'*

(Timmermans 1994:335)

Although Mamo (1999) believed that Timmermans (1994) provided an important extension to the original awareness theory proposed by Glaser and Strauss (1965) in terms of identifying an 'omission of emotional crisis' during terminal illness, she believed this extension of the theory did not go far enough. She proposed that further modification needed to be made to the original awareness context theory to ensure that 'emotions and cognitions are entwined' (Mamo 1999:32). Although Mamo (1999) believed that it was important to consider the way emotions influence the process of knowing, she believed that it was also necessary to explore the emotional 'work' people engaged in, which determined how they reacted and acted upon the information they had been given to sustain a desired awareness context.

To explain this further, Mamo (1999:33) explores through her introspective ethnography how *'awareness emerges and subsides in a complex web of emotions and cognition'* and suggests that people create their own interpretations and ways of managing their emotions as they face a critical juncture in their lives. For example, she describes how, in the earlier phase of learning that a loved one was diagnosed with a terminal illness, the patient and family members did not ignore this information but chose to focus on the 'uncertainty' of not understanding and knowing exactly what this diagnosis meant and what might happen in the future, in order that they might be able to carry on living day to day. This reaction has been observed in other empirical studies which have applied the theory of awareness (McIntosh 1977; Salander and Spetz 2002; Hellstrom and Nolan et al 2005). In response to this evidence, Mamo (1999) considers whether or not an open awareness context is necessarily the best approach to use within the context of dying.

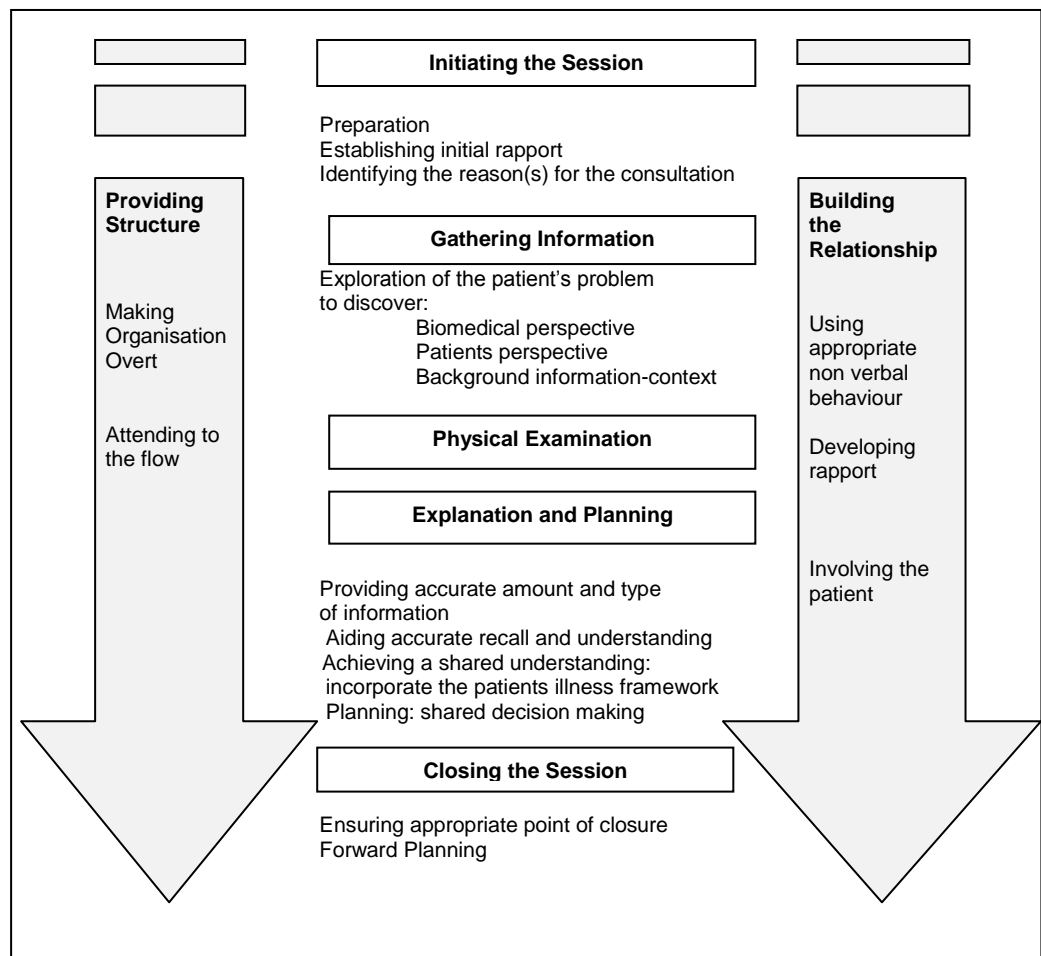
In summary, the original awareness context literature has provided an important foundation from which others have been able to modify the theory of awareness context to expand understanding of how emotions and emotional work are used by people to help them live through a crisis in their lives, particularly within an open awareness context. As such, this theory has been extremely influential in health care to date, not only in its application to the study of death and dying but in other fields of health care, including the speciality of dementia care (Hellstrom and Nolan et al. 2005). In addition, this work was influential in raising awareness about the importance of communication between health care professionals and patients, particularly when the information to be disclosed is sensitive and will have a significant bearing on how people perceive their future.

Much of the 'awareness context theory' has been developed from a sociological and introspective ethnographic approach. Modifications to the original theory have been made in relation to the original 'open awareness context', which are informed by emotional and cognitive factors, which can be consequential on resulting interactions. I would suggest that in order to understand 'resulting interactions' further it is necessary to explore and compare the multiple perspectives of doctors and patients and others; and observe such encounters. This theory is particularly suited to this study as it provides a basis for exploring communication between patients and health care professionals, particularly when the information to be disclosed is sensitive and will have a significant bearing on how people perceive their future. In the Oncology department the communication of information predominantly takes place within a medical consultation.

### **2.3 The Doctor and Patient Encounter**

The medical consultation is a purposeful meeting between a doctor and patient in which both parties may tend to behave stereotypically according to tacit traditions and unspoken rules (Silverman, Kurtz et al 2005). In the majority of situations it is the doctor, who sets the structure of the consultation and determines how the discussion will proceed and often the patient tends to follow the doctors lead (Byrne

and Long 1976). Too often doctors fail to integrate a communication model (to help them conduct the medical interview) and traditional medical history (which describes the content of the interview) which would help them manage a consultation most effectively (Kurtz and Silverman et al. 2003). Consequently, closed questions are used to elicit biomedical information from the patient; rather than taking steps to try to develop rapport and seek information from the patient about their feelings, concerns and expectations (Kurtz and Silverman et al. 2003). This is despite a move towards a collaborative approach to health care and patient interaction, whereby the emotional needs and concerns of patients are considered and addressed (Corner and Bailey 2004). To try and ensure that both the content and process of consultations are addressed by doctors, Kurtz and Silverman et al (2003) propose that doctors use the following guideline to help them conduct and manager consultations. In this guideline, they propose that the medical consultation should use 'five sequential tasks' which include a list of objectives to be achieved within the medical interview – as shown in Figure 1.



**Figure 1: Five sequential tasks – Objectives to be achieved within medical consultation (Kurtz and Silverman et al. 2003:806)**

Using this model, the doctor directs the management of the consultation and has the power to determine how long they will take on any given task, dependent upon what they hope to achieve in that consultation. In addition to this, the structure is thought to help doctors conduct consultations which are flexible but ordered to help inform patients of what is likely to happen; the structure is also designed to encourage patients to be participants in the consultation and enables efficient information gathering and giving and ensures that time is used effectively (Silverman, Kurtz et al.2005).

Encouraging patients to be participants in their consultations has not always been encouraged or witnessed within consultations. Byrne and Long (1976) recorded

over 2500 interviews with doctors and patients and observations of consultations in primary care and found that doctors were very much in control of their consultations and used a closed approach to information gathering. In this study doctors were observed to have a set of agendas which they followed, regardless of the problems presented to them and the behaviours presented by their patients (Byrne and Long 1976). Rather than '*viewing the patient as a person, the person is viewed as a patient*' (Mischler 1984:10) and as such their voice and perspective are ignored and an emphasis on disease, diagnosis and treatments prevails throughout the course of the doctor and patient encounter. Consultations managed in this way tend to be doctor-centred and patients are prevented from being able to tell the doctor their concerns (Byrne and Long 1976). Through their observations of medical consultations, Levenstein et al found that if doctors failed to elicit and address a patient's agenda in preference for their own, there would be an unsatisfactory outcome as the doctor would fail to gain full insight into the patient's illness (Levenstein, McCracken et al. 1986).

This is echoed in a more recent study conducted by Barry and Bradley et al (2000) who interviewed 35 patients attending at GP surgeries. In this study they found that only 4 out of 35 patients felt that they had been able to voice all of their concerns (Barry, Bradley et al. 2000). In some cases, patients went home with prescriptions for treatment that they did not necessarily want (Barry, Bradley et al 2000). This showed that these patients were not always able to express their agenda's effectively which lead to therapeutic outcomes which were not desired by the patient. While this study was constructive because it provided a more recent account of patient experiences when attending general medical consultations it did not explore the doctors accounts of their experience and motivations for providing therapeutic interventions, based on their understanding of the patient's needs.

Silverman et al (2005) explain that whether they like it or not, a doctor's behaviour does determine how much freedom is given to patients to interact with them during

medical consultations. A useful insight into this debate was provided by several patients participating in the study of Byrne and Long (1976). When comparisons were made with the data, it was identified that four patients who attended the GP practice more than once, behaved differently with different doctors. The behaviour of the patient was determined by the way the doctor behaved during the consultation. If the doctor exercised more control over the consultation the patient became less communicative, whereas patients were more vocal if the doctor was less controlling. In their conclusion, it was suggested that patients accommodated their behaviour to that of their doctor (Byrne and Long 1976).

Rather than consider the way patients behave in response to the behaviours of their doctors, Street et al (2005) set out to understand why many patients vary in their willingness to participate in medical consultations. In their study, Street et al examined the extent to which a patient's participation in a medical consultation was influenced by the patient's character, the doctor's communication style and the clinical setting. They found that a patient's participation in a medical consultation was dependent on a complex interplay of personal, doctor and contextual factors. Nevertheless, the strongest indicator of patient participation was related to the clinical setting and the doctor's communicative style (Street, Howard et al. 2005) which is in line with the findings of previous studies. In addition to this, the degree to which patients actively participate in their medical consultations is influenced by a number of other factors, including educational background, age (Greene and Burleson 2008) and the extent and seriousness of their illness (Butow and Dowsett et al. 2002a). Patients diagnosed with an advanced incurable cancer generally felt that their preference for involvement in their care diminished as their disease progressed and their relationship with their doctor changed (Butow and Dowsett et al. 2002a).

Moreover, Tuckett et al (1985) believed that patients could exert more control during consultations which would have an influence on the way their doctors interacted with

them, as those who were more likely to ask questions were responded to in an appropriate manner by their doctor. Yet, their research demonstrated that patients didn't always share their concerns or ask questions in consultations because they either didn't think they could (36%); they were afraid of how they would be perceived (22%); they were frightened of receiving a negative reaction from their doctor (14%); they felt too flustered or distressed to ask anything (27%); they did not think their doctor could give them any more information at that time (22%); they delayed asking questions for another occasion (36%) and finally 9% feared hearing the truth (Tuckett, Boulton et al 1985). These findings may well support the idea that a general social attitude accepts or acknowledges that the doctor and patient relationship is inherently unequal.

Although some patients may not necessarily like to behave assertively during their consultations with their doctors and share their concerns, it is clear from the work of Silverman and Kurtz et al (2005) that attempts have been made to try and encourage this behaviour. The start of this move came about in the 1960's through the work of Michael and Enid Balint. Through their work with General Practitioners the Balints tried to encourage doctors to find alternative approaches to the way they interacted and communicated information to their patients (Balint 1969). Michael Balint suggested that doctors suspended prejudged decisions and their agenda within the medical consultation to focus their attention on the needs of their patients and listen to what patients had to say to them, in the hope that they could work to a mutually agreeable arrangement (Balint 1965).

The use of specific communication skills can help towards overcoming some of the problems doctors may face when testing out alternative techniques, whereby reciprocity rather than dominance is practiced. By encouraging doctors to experiment with the way they conducted medical consultations Maguire and Booth et al (1996b) asked participants of a workshop on communication skills to interview actors who had taken on the role of a patient diagnosed with cancer, for twenty



minutes to elicit the patient's main concern pre-workshop and post-workshop. Maguire et al found that the use of open questions and empathy encouraged patients to talk more openly about their fears and concerns (Maguire and Faulkner et al.1996a).

In addition to this, attempts have been made in more recent years to try and find ways of helping some patients participate in their consultations. For example, Brown et al (2001) conducted a randomised controlled trial with a sample of patients diagnosed with cancer to determine if the use of a 'prompt sheet' encouraged patients to ask questions during their consultation. The researchers hypothesised that patients who are encouraged to ask questions are better informed and will have an improved psychological well being. Although there was not a significant increase in the number of questions asked between the two control groups; those who received a prompt sheet appeared to be better prepared to engage in discussions with their doctor, particularly in regards to their prognosis. Those who felt the doctor addressed their question reported less anxiety; however, apart from specifically answering the question it is not clear if the manner in which the answer was given had any impact on the patient's psychological well being. When asked how they felt about the use of the prompt sheet, some doctors were apprehensive that having raised the issue of prognosis, they would then need to engage in a more lengthy discussion with the patient which would excessively lengthen the consultation and have a detrimental effect on the clinic overall (Brown et al. 2001).

Interestingly, in the study conducted by Langewitz and Denz et al. (2002) when they asked doctors not to talk in the opening minutes of a medical consultation to allow patients to voice their concerns, patients were willing to do this and the average time taken to express their concerns was 92 seconds, indicating that patients will generally be succinct and not take up too much of the doctors time, which is often feared during a busy clinic (Langewitz, and Denz et al. 2002). The data from Brown et al (2001) study did in fact show that giving patients a prompt sheet prior to their

consultation helped them prepare in advance by helping them identify what it was they wanted to know. As long as the doctor addressed their questions appropriately the consultation was organised and more efficient and when compared to other consultations the length of time taken to conduct the consultation was reduced (Brown et al 2001).

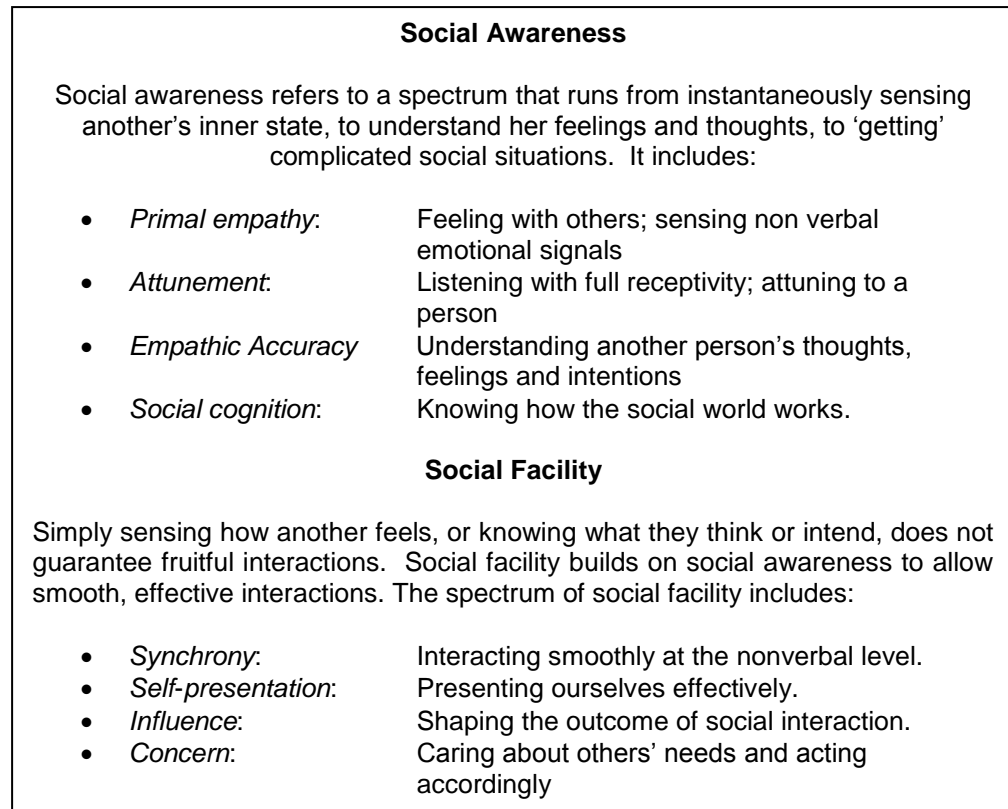
It has been argued thus far that the behaviour of doctors during medical consultations has a defining, influential role in the way patients interact with their doctors. Although patients can be more forward and confident about expressing their concerns or by asking questions, they do not always assert themselves within the medical consultation. While these empirical studies have yielded important information about how doctors and patients behave, some of these studies are over twenty years old and it would seem valid to conduct further research in this area, within the context of cancer care. In particular, there is a need to explore these issues from various perspectives, to understand their encounters more fully to understand how each interactant is perceived by the other. In their conclusion, Tuckett and Boulton et al (1985) stated that despite a move towards a more collaborative approach within the medical consultation, in practice doctors and patients still tended to assume a more traditional view of the doctor and patient relationship.

## **2.4 Doctor and Patient Relationship**

The quality of a relationship can make a significant difference to the way doctors and patients interact with each other and share information. Unfortunately the structure of consultations can take a more prominent position in the mind of some doctors as there is still a tendency for some doctors to focus on their agenda and meeting their objectives within an allotted time (Silverman, Kurtz et al. 2005). Preoccupations can however, reduce a doctor's focus, which means they are not always receptive to others and their need for emotional support, and this can consequentially have a

negative effect on the doctor and patient relationship (Goleman 1996; Goleman 2007).

From this perspective, Balint (1965) advocated that an important element of doctor-patient relationships was the doctor's ability to listen and observe interactions, to enable them to capture a more detailed impression of their patient and their needs; to try and understand what was being said and what was not being said through non verbal communication (Balint 1965). This is referred to by Goleman (2007) as social intelligence. Social intelligence can be split into two broad categories; social awareness and social facility (See Figure 2). The impact of social awareness and social facility in terms of how they are utilised within the doctor and patient relationship has however, come under some criticism. Although there are always exceptions to the rule, some doctors often fail to notice or react to patient's verbal and / or non verbal expressions of emotion, despite evidence to suggest that being empathetic and supportive towards a patient can be beneficial to the patient (Goleman 1996). These observations raise important questions about how the emotional needs of patients are managed by those providing their care.



**Figure 2: Social Intelligence (Goleman 2007:84)**

Empathy is regarded as playing an important role within interpersonal relationships and helps facilitate effective and desirable communication (Hemmerdinger, Stoddart et al. 2007). Sharing ones understanding of another's situation is a prelude to and being able to respond compassionately to another person in need by showing them that '*I notice you, I feel with you and so I act to help you*' (Goffman 2007:58).

Given that working with patients requires a degree of empathetic understanding there is a tendency for medical schools to assess whether or not potential medical students are empathetic as this quality is regarded as an important attribute in doctors (Hemmerdinger, Stoddart et al. 2007). This evidence would suggest that empathy is inherently a personal quality, but whether or not it can be learnt and developed is open to question. From one perspective, Roter and Hall (1993) suggested that empathy is a matter of personality and may not be taught as a communication skill. Whereas, Silverman and Kurtz et al (2005) believe that whilst some people express empathy better than others, the skills of empathy can be learnt

and with time and exposure to different situations, the expression of empathy can be improved and expressed appropriately through verbal and non verbal communication (Goleman 2007).

In most instances verbal and non verbal communication mirror the other and help people understand the messages being conveyed (Goffman, 1959; Silverman, Kurtz et al. 2005). When there is a contradiction in verbal and non verbal communication however, it is often difficult to understand or appreciate the sincerity of the message. Evidence presented in this thesis demonstrates that doctors, patients and other health care professionals do not always communicate clearly and openly with each other and nor do they always pick up on non verbal cues (Glaser and Strauss 1965; Copp 1999; The 2002). This may be a conscious or unconscious act, dependent upon their reasons and motivations for not expressing how they feel; acknowledging the other persons feelings and / or wanting to know the truth and reality of another's or their own situation. Consequently, this may have a negative impact on the formation, sustainment and development of relationships, if the patient and doctor remain at odds with each other (Roter 2000).

Not wishing to pick up on cues was witnessed in the study conducted by Copp (1999), whereby some patients actively avoided cues given to them by nurses if the patient believed the nurse was going to threaten their approach of coping. Drawing on evidence presented by Copp (1999), Copp and Field (2002) felt that it was appropriate to review some of the original data of Copp's study in the 1990's, to explore how patients used denial and acceptance as a form of coping, when faced with impending death. Patients who were observed to talk openly throughout their illness were considered to be accepting of their situation. In contrast, patients who could not openly talk to others about their situation were perceived to be in denial (Copp and Field 2002).

While Copp and Field (2002) consider the way that these mechanisms define the coping style used by patients to protect themselves throughout their illness, it is evident through Copp's work that these approaches may also be used by patients to help protect those around them. In her study to learn about the experiences of patients who were aware of their impending death and the experiences of nurses caring for them, Copp (1999) found, that patients in particular used an 'interplay of strategies' to protect themselves, their relatives and their nurses in various degrees and on various occasions throughout their illness. Those patients functioning within an open awareness context spoke openly about their desires, fears and concerns and / or intentions in the hope that they may relieve some of the burden from others who may be required to make decisions on their behalf (Copp 1999).

Whereas, those who were not functioning within an open awareness context did not offer such personal information in the hope that by keeping things to themselves they were protecting others from the burden of such knowledge (Copp 1999) and / or in some cases were understandably protecting themselves from the reality of their impending death (Elias 1985). In Copp (1999) study patients were aware of their impending death, but there are those who contest whether or not people always get the opportunity to try and protect themselves from this knowledge as some doctor and nurses contrive to protect them from the knowledge that they are dying (Glaser and Strauss 1965 Timmermans 2005) as they operate from within a paternalistic framework. From the data provided by Copp (1999) it was evident that those patients who were aware of what was happening to them sometimes chose not to share this knowledge and communicated and acted within a pretence context to portray a message that all was fine. This behaviour was also reflected upon by Mamo (1999) as she described the way family members interacted with their mother following her diagnosis of incurable cancer.

Another aspect of protection was discussed by The (2002) who found that at times both patients and doctors didn't always portray how they really felt to the other as a

form of self protection because they did not want to let their 'barriers down'. In addition to this, personal barriers may also be protected by '*counteracting the danger of affective ties between performers and audience*' by limiting the amount of contact people have with each other (Goffman 1959:209). Whether or not this is orchestrated by individuals to protect themselves or whether a lack of continuity occurs to meet the interests of the establishment is open to interpretation. Retaining ones personal barrier is however an important phenomenon which may explain why some doctors and nurses have an inability to give those who are dying the help and support they require, particularly if the impending death of another human being serves to remind them of their own mortality (Elias 1985). Yet, the consequence is such that social problems may arise and impede the health care professional's relationship with their patient (Elias 1985).

Through Copp's work it is evident that patients were able to control how they presented themselves to others when remissions, setbacks and progressive loses and dying occurred. This was also prevalent in a study conducted by Payne and Hillier et al (1996) who found that patients appeared to control their levels of awareness to help them cope. Through their interviews, it was evident that the patient's level of awareness differed throughout their stay in the hospice (Payne and Hillier et al 1996). This evidence is substantiated by others, who have found through empirical research that some patients diagnosed in the early or late palliative stages of illness have also been shown to use courage, perseverance and a sense of humour to help reduce feelings of vulnerability (Stand and Olsson et al. 2009). The way in which they achieve this does however vary throughout their illness and to varying degrees of behaviour. A justification for behaving in this way is provided by Bandura (1995) who states;

*'People strive to exercise control over events that affect their lives. By exerting influence in spheres over which they can command some control, they are better able to realise desired futures and to forestall undesired ones'*

(Bandura 1995:1)

Through self efficacy, patients are able to behave in a particular manner to attain a goal that is desirable to them. This is referred to by Mead (1982) as an act of 'reflective intelligence' whereby people consider what they are going to say and how they are going to behave within any given social situation; which suggests that they prepare in advance. Yet, knowing how to behave in a given situation is not always easy to determine and a patient's intention to behave in a particular way is not always transparent to others.

By gaining the perceptions of nurses to explore their experiences of caring for those who were dying in a hospice it was evident that nurses often found it difficult to know how to interact with a patient if they perceived a mismatch between what they thought were the patients portrayal of both public and private feelings (Copp 1999). In some cases, nurses were described as allowing patients to take control until the patients '*public and private feelings synchronised*' (Copp 1999:132) and tension and anxiety dissipated naturally. There were some occasions however when nurses did try and confront the patient but this did not necessarily mean the patient changed the way they behaved. On one of these occasions, the nurse reported feeling hopeful that they had created an opening whereby the patient felt they could talk openly, as and when they needed to (Copp 1999). Yet, this would imply that there was a problem to be resolved which might not necessarily be the case.

This motivational interaction is not always appreciated by patients however as others (Hinton 1998; Timmermans 1994) demonstrate that some patients find it difficult to sustain an active open awareness of their situation as they may be unwilling or



unable to let others continuously remind them that they are dying and may well decide not to talk about their illness even though they are aware that their future is limited. The examples above demonstrate how patients employ acts of protection and control through their interactions with those who care for them and about them, throughout their illness, but particularly as they are faced with their impending death. Through Copp's work, a number of nurses are shown to have some insight into the way patients behave and their motivations for behaving and interacting with others in a particular way, although they may not always understand it and know how best to intervene.

Whether or not this control and protection orchestrated by some patients is recognised and accepted by doctors is less clear and warrants further investigation. Although the evidence is sparse, there is some indication, through the works of Glaser and Strauss (1965), Sudnow (1967) and The (2002) that a number of doctors have in the past tried to control the patients state of awareness to meet their own needs and objectives, which often left the patient in a suspicious state of anxiety which could have a negative effect on their relationship with their doctor. In some cases, several doctors avoided making any contact with the patient until a time arose when they were ready to see them (Sudnow 1967).

While doctors were presented by Glaser and Strauss (1965) as being impersonal and uncaring and focused on the needs of the organisation (rather than the patient); nurses were presented as patient advocates and 'custodians of care (Glaser and Strauss 1965:204), who strived to meet the needs of the patient rather than the hospital system. Yet, at times, some nurses were criticised for complying with the doctor's wishes to maintain a state of closed awareness and as such entered into a 'game' with the doctors, whereby they intentionally 'mislead' the patient to prevent open disclosure (Glaser and Strauss 1965:35). As such, patient's appeared to be out numbered. Given that doctors and patients generally meet on a regular basis in

oncology and often need to share and disclose sensitive information and bad news, it is important to consider what patients need from this relationship.

In addition to wanting a relationship with a doctor who is empathetic and helps sustain a patient's hope; patients generally want their doctors to be knowledgeable and competent and they want a relationship with someone they can develop a rapport with and feel confident in the knowledge that their doctor will understand them and support them throughout their illness (Hagerty, Butow et al. 2005). All of these relationship building skills are increasingly important as patient's progress through the various stages of their illness. Several studies have reported that patients diagnosed with early stage cancer were more interested in their doctor's clinical competency and having the most up to date knowledge of treatments and clinical research (Parker, Baile et al. 2001; Brown, Parker et al. 2007). In contrast, although few researchers have attempted to elicit what is important to patients diagnosed with an advanced incurable cancer, those that have, have found that these patients require a trusting relationship with their doctor who is able to demonstrate an understanding of their psychological issues and concerns and is able to maintain hope and sensitivity (Hagerty, Butow et al. 2005).

In addition to this, 'trust' according to Mechanic and Meyer (2000) is fundamental to any form of relationship and without it, one may be in a constant state of anxiety as they watch and interpret the actions of others. In his writings, Goffman (1959) explains how people try to make a judgement of another to assess for example, their trustworthiness. In judging the behaviour of another Goffman (1959) describes how people will look for cues to assess the validity of another's claims and / or behaviours, but whether or not they choose to act on any suspicions is another matter. If one decides not to challenge their suspicions that all may not be well a 'surface agreement' is created to conceal ones concerns (Goffman 1959). This subtle interplay of interaction within a pretence context of awareness can create a 'fragile illusion' (Glaser and Strauss 1965) as those involved in the interaction

engage in an act of deception and as such fail to portray an honest and open approach to communication (Goffman 1959). While this literature is important because it provides information which demonstrates how people can and do interact with each other generally, there is little evidence to explore this issue in depth within the medical literature. Although there was evidence that this pretence context occurred and existed through various doctor and patient interactions in The (2002) ethnographic study to consider how those diagnosed with small cell bronchial cancer proceeded from the time of receiving their diagnosis until death, her attention was predominantly focused on the issue of optimism.

The value of a trusting relationship is imperative within health care, as it is within the broader context of social situations. Trust, encourages open communication and shared awareness and as such has the potential to enhance the quality of interactions, but if it is violated in any way can cause anger, hurt and humiliation (Mechanic and Meyer 2000). In their exploratory study, Mechanic and Meyer examined the concepts of trust among three groups of patients diagnosed with breast cancer, lyme disease and mental illness. Generally patients believed that trust was based on honesty, compassion, openness, responsiveness and having ones best interests at heart. Also, knowing that their doctor had interpersonal skills and were technically competent were highly important to these patients regardless of their diagnosis (Mechanic and Meyer 2000).

In addition to this, being able to comprehend the genuineness of some of these qualities was examined by Haskard et al (2008). In their study they found that patients assessed the quality of the relationship with their doctor against the tone of voice used through interactions (Haskard, Williams et al. 2008). Patients, who believed that the doctor spoke in a warm and supportive tone, were generally interested in them and gave them more information and choices. Whereas, patients who believed doctors spoke in a hostile and disrespectful tone were less interested

in them, gave less information, failed to address their concerns and were generally less empathetic (Haskard, Williams et al. 2008).

Until more investigations are undertaken, the experiences of doctors and patients who are trying to communicate sensitive and bad news with each other through mutually acceptable activities such as; listening, talking, sharing, observing, understanding, controlling, exploring and challenging each other will remain relatively unclear. It has been argued thus far, that doctors and patients are not necessarily in tune with each other, as patients try to protect and control the way they express themselves and seek further information. Yet, their motivations for controlling and protecting themselves and others are not always transparent and health care professionals may be uncertain about how they interact and what they need to say in order to establish or sustain a therapeutic relationship. Consequently, there might be some confusion and misunderstanding of what the health care professional's agenda entails and what the patient's agenda entails, which may be harmful to their relationship and to the patient's emotional wellbeing.

The emotional distress caused by a diagnosis of cancer can not only be immense in terms of how they perceive their future but how they are able to process information and make judgements about what is happening to them at any given time throughout their illness, which needs to be borne in mind by health care professionals. In addition, there is a need for health care professionals to provide emotional care as well as medical care (Lanceley 2004). While emotional care has been considered within the context of nursing, attempts to explore the emotional nature of communication from the doctors perspective needs to be considered further.

#### **2.4.1 Managing Emotion in Medical Consultations**

*'At a personal level cancer generates disbelief, fear, lies and chaos which are controlled through information, optimism, routine living and social expectations.'* (James 2004:262)

Fundamentally, the person diagnosed with cancer and those close to them generally have to manage an intense and fluctuating range of emotions throughout the course of illness. To help them manage these emotions, health care professionals are generally regarded as having a duty to share the 'division of emotional labour' by setting the context from which these emotions are managed and expressed (James 2004) through various states of awareness. This has wider implications for the way in which health care professionals interact with those in their care. It is not simply a matter of imparting information to another without due care and attention; one needs to be aware of the impact what is often perceived to be sensitive and bad news has on those whose lives are directly affected by such information and to consider and manage a number of emotions which are likely to be induced (James 2004) throughout the course of the persons illness.

Thus, the health care professionals approach and manner in supporting patients' and their families' is fundamental to their wellbeing. Mann (2005) explains that health care professionals often respond to such situations by suppressing their feelings in order to sustain an outward appearance that helps the patient and / or their relative feel cared for and in so doing, the health care professional engages in emotional labour. Emotional labour has been described as the effort of people to manage and regulate their feelings, in an attempt to induce social and culturally acceptable feelings in others (Hochschild 1983). Such action is according to Fineman (1993) crucial to social regulation.

The use of emotional labour is demonstrated through the work of Hochschild (1983) in her work with flight attendants and debt collectors. The way in which one responds to another may not portray their inner feelings but occurs out of necessity, for commercial purposes and a professional responsibility rather than genuine concern for another. Furthermore, the importance and relevance of emotional labour to that of caring has been acknowledged within nursing, by James in the 1980's. In a qualitative study by Smith and Gray to assess the concept of emotional labour,

they found that nurses believed emotional labour was 'part and parcel' of a nurses normal role and they had a duty to try and make a patient 'feel at home' and 'cared for' (Smith and Gray 2001). The regulation of feelings in relation to the medical profession has been considered in connection with empathy, although the importance and / or value of empathy within this profession is open to interpretation (Larson and Yao 2005). This is in contrast however, to the suggestions made by Hemmerdinger, Stoddart et al (2007) who describe how medical educators value the empathetic qualities of those applying for positions within medical education. Mann (2005) suggests doctors have traditionally focused on the more medical-technical matters and rationality rather than emotional intelligence and have therefore tended to leave the offer and demonstration of emotional support to nurses. In order to change this status quo, Fineman (1993) suggests that a redefinition of the job would help permit doctors to demonstrate an authentic expression of emotional support through their practice, but does not suggest how this is achieved.

Despite the emotional burden which exists within the context of cancer care it is rare for doctors and other health care professionals to receive training and support to help them manage the emotional stress which may be induced by difficult consultations with patients and their relatives. This was evident in a study by Smith and Kleinman, (1989) who found that there was little support to help medical students learn how to manage emotions within the context of their work. The medical culture supported unspoken rules about how doctors present themselves and how they try and distance themselves from emotional distress by considering the patient and procedure as an 'analytical task' and as such suppress emotional intelligence (Smith and Kleinman 1989). Consequentially, the management of patients needs may not be addressed which may have serious consequences for the patient and their relationship with their doctor (Eraut 1994).

Similarities between doctors and businessmen may shed some light on how doctors have traditionally approached the emotional aspect of care and communication.

Whyte, when describing the effective businessman, used words such as logical, reasoned and rational decision makers (Whyte 1956). Emotions were regarded as unwanted influences which prevented people from retaining objectivity and were viewed as undesirable characteristics (Whyte 1956). In contrast, Muchinsky believes that emotions within the workplace are real and significant and are not simply annoyances which deflect us from objectivity but are the essence of human life and human connection (Muchinsky 2000). In addition to this, there has been a considerable move to promote and understand the value of emotional labour and emotional intelligence within the workplace as a means of improving individual and group performance (Chernis and Goleman 2001).

The workplace however, particularly within the cancer setting can be a very emotional place, particularly when sensitive information is communicated to others that will have a significant bearing on how they perceive their future. The way in which patients control emotional labour by trying to protect themselves and others through their communications, is also prevalent in doctors, who have been shown to regulate and manage their feelings as a means of protecting themselves; to help them cope with the after effects of stress and to allow them to move on to the next patient, where a similar process may ensue (Mark 2005). However, the self management of emotional expression in this way may make the doctor appear insensitive to the patient and / or their relative and that may have a negative impact on the doctor and patient relationship, as ones actions will influence the way in which others respond and perceive the intention behind the behaviour (Cherniss 2001). Although there may be differences in the way emotions are experienced and expressed, it can be a demanding practice, trying to meet the needs and expectations of others (Cherniss 2001).

It may therefore be inevitable that a cycle of behaviour may be developed over time thereby creating habitual practices of behaviour which are often difficult to change

(Cherniss, Goleman et al 1998). In the following extract, Argyris considers how the suppression of emotion at work can affect good communication:

*'What I have observed is that the methods these executives use to tackle relatively simple problems actually prevents them from getting the kind of deep information, insightful behaviour and productive change.....and they do not surface the kinds of deep and potentially threatening or embarrassing information that can motivate learning and produce real change'.*

(Argyris 1994:77)

Although Argyris based his views on his observations of executives within an organisation, comparisons can be made with that of the medical profession. For the most part, it is not the defensive process per se that is the problem, but the fact that a defensive process generally occurs without conscious thought and / or recognition (Obholzer 2005). Through the emotional intelligence literature, frameworks have been proposed to direct individuals to reflect on and develop self awareness, self management, social awareness and relationship management to enhance working practices (Goleman 2001). Initiatives leading to improvements in managing the emotional aspects of the work of health care professionals and enabling them to recognise certain behaviours for redress have been proposed in education and policy arenas. However, this work requires further research to appreciate how doctors learn and cope with the effects of emotional labour (Mann 2005) and support people through the use of emotional intelligence when interacting with patients who control their expression of emotions to meet their own needs and whereby sensitive information and bad news is disclosed in a cancer context.

## **2.5 Tensions Associated with Disclosing Bad News**

It has been suggested that one of the most challenging tasks a doctor has to face is communicating bad news to a person diagnosed with cancer (Glaser and Strauss 1965; McIntosh 1974). It is not uncommon for doctors to report feelings of apprehension prior to disclosing bad news to patients, particularly when this



information has such a significant bearing on how the patient perceives their future (Buckman 2005). Equally it is not uncommon for some doctors to question their competence and ability to engage in these discussions (Christakis and Iwashyna 1998; Buckman 2002; Maguire and Pitceathly 2002; Rosenbaum and Ferguson et al 2004). Yet, as Fallowfield et al (2002) point out, a good deal of a doctor's time is spent communicating information and presenting treatment options to patients within a palliative context, particularly if they work in Oncology and Palliative Care. It would therefore seem appropriate that doctors and other health care professionals were better able to communicate effectively with their patients as there is a considerable risk that most patients and their families will be upset, receiving information which has a negative impact on their lives and threatens their notion of survival.

The way in which people react can be complex and may well fluctuate throughout the course of a patient's illness (Faull and Carter et al. 2005) and as a consequence of this, it may be difficult to predict how a person will respond (Kirk and Kirk et al. 2004). Silverman and Kurtz et al (2005) explain that, in a number of cases, doctors may well be unaware of the impact that the information they convey has on a patient and go on to explain that no matter how realistic a patient may be upon entering a consulting room, they may inevitably have a faint hope that they may hear some positive news. Doctors and other health care professionals need to find a way of bringing the patient's attention to the distressing news they need to communicate (Silverman and Kurtz et al. 2005), while considering the amount of information the patient may wish to receive. Yet efforts to fulfil this requirement are not always easily achieved.

While many patients describe wanting to receive information a smaller percentage of them do not. For example, Jenkins and Fallowfield (2001) found that the information needs of patients from a large study of 2331 patients diagnosed with various types and stages of cancer that 87% of patients wanted to receive as much information as possible, while 13% preferred to leave decisions about information to the discretion

of their doctor. It is not surprising therefore that some doctors are frequently uncertain or hesitant about the amount of information they should communicate to their patients.

Over the past 40 years there has been a move away from a closed awareness approach to communication, whereby information was withheld from patients, to that of an open awareness culture, whereby health care professionals are encouraged to disclose information to patients regardless of the sensitive nature of the information to be imparted (Taylor 1988; Seale and Addington-Hall et al. 1997; Field and Copp 1999). Respect for patient autonomy is now an important element of contemporary medical ethics. It is therefore recognised that sufficient information needs to be imparted if patients are to make informed decisions about their treatments and plans of care (Gattellari and Butow et al.2001; Timmermans 2005). Many patients now have greater expectations of their health care and are far more aware of health related matters.

This shift in attitude is demonstrated through the work of Seale (1991) who compared the findings of two national surveys conducted within the UK in 1969 and 1987. In these studies, Seale reported that the number of people who knew they were dying from cancer rose from 16% in 1969 to 44% in 1987. This evidence is substantiated further by Seale and colleagues in 1997, whereby a greater percentage of relatives and friends reported in 1990 that 51% of those who had died did in fact know that they were dying; as opposed to only 4.4% who remained in a closed state of awareness (Seale and Addington-Hall et al. 1997). It is difficult to know however, if these figures would have been different if the data was obtained directly from those who were dying rather than using retrospective data from another informant.

This is important as there is evidence to suggest that there can be a difference in the state of awareness between those who are dying and their family. Following a move

within the hospice movement to acknowledge the importance and value of open and honest communication, Hinton (1999) interviewed a group of patients and their relatives to ascertain whether or not a policy of open disclosure helped them become more aware of what was happening and whether or not they were accepting of their situation. The level of awareness in patients increased slightly (42%) in the final 8 weeks of the study and the awareness of relatives grew from 53% to 81%. During this time however, it was reflected through the responses of patients (18%) and their relatives (24%) that their appreciation of what was happening to them fluctuated and they failed to accept the reality of their situation. This is exemplified further through the introspective and reflective accounts of Mamo (1999) as she tried to interpret both her personal experience and the experiences of others as they shared a particularly difficult time in their lives. Through her accounts, she is able to describe how the emotional rules described by Hochschild (1983) were at times broken as people tried but sometimes failed to hide their emotions from each other. She also talks of the 'uncertainty' people faced in knowing what they could and could not say to each other, for fear of distressing another, particularly the mother who was dying, as she appeared to be unable to talk openly and appeared to ignore information she had been given by her doctors (Mamo 1999).

When patients and their relatives both received the same information, Hinton (1999) asked why their level of awareness was at times different. In answer to this question he proposed that patients may not actually seek as much information as their relatives and have the option to cope with the reality of their situation in whatever way they choose; whereas relatives needed to know what to expect and how to care for their loved one. Accordingly, Silverman and Kurtz et al (2005) describe how the emotional nature of illness can prevent individuals from being able to think clearly and rationally and this in turn hinders their understanding of what is happening to them. The study conducted by Hinton (1999) yielded important information about how patients and their relatives accept and control their state of awareness during a very difficult and emotionally challenging time, but does not explore the tensions

doctors and other health care professionals face when confronted with the possibility that patients and their relatives might have competing needs for information and by patients who may not be ready to hear what the doctor has to tell them. In addition it does not really explore how patients perceive information and what they choose to do with it.

Disclosing bad news can be complicated by any number of reasons, some of which were identified amongst a group of doctors who were asked to describe what influences made it difficult to disclose bad news (Ptacek and McIntosh 2009). These factors were categorised accordingly - doctor factors (confidence, personal impact, identifying with the patient and / or their situation); patient factors (age, emotional distress of both patient and their family, having a poor support network); institutional factors (location and mode of breaking bad news – on the phone); illness factors (poor prognosis, not being able to do anything further) and relationship factors (perceived relationship with the patient and their family, the degree to which the patient was known) (Ptacek and McIntosh 2009). In addition to this, some doctors have described how they will avoid disclosing information if the patient has not asked for it (Seale 1991; Christakis and Iwashyna 1998; Miyaji 1993), this was particularly so in regards to disclosing prognosis (Seale 1991).

In some cases, the involvement of family members has a direct influence in determining what and how much information the doctor feels they are able to disclose to a patient. In one respect, doctors have played an influential role in this matter, by choosing to disclose bad news to relatives instead of the patient. Glaser and Strauss (1965) described in some detail how relatives were often informed that a member of their family were dying and as such tried to keep this knowledge from the patient. Additionally, Seale (1991) found that doctors preferred to tell relatives about a patient's diagnosis, as they felt they were protecting the patient from such knowledge.

Through these examples, it is evident that although a state of openness may be ideal; this state of awareness appears to be ambiguous and conditional. This is supported by Field and Copp (1999) who suggest that there has been a shift away from a pure state of open awareness to that of a conditional open awareness. The view to tell people their diagnosis and / or prognosis is influenced by a number of pragmatic decisions. Field and Copp (1999) fear that health care professionals may attempt to 'exercise a degree of control within the course of their professional duties' because it allows them to retain a degree of control, however they may not be the only ones seeking control.

For example others have shown how important it was for relatives to take a prominent role in order to control, protect and act on the behalf of the patient to ensure that (from their perspective) appropriate information is disclosed or withheld to reduce the emotional distress such information may induce (Friedrichsen and Strang et al 2001; Ozdogen and Samur et al 2004). As a way of managing this problem, Ozdogen and Samur et al (2004) believe that it is important for health care professionals to communicate effectively with relatives to highlight the possible benefits and reasons for why it is appropriate to disclose information to the patient.

Yet, in some cases, doctors may actually avoid discussions with patients and / or their relatives because they prefer to distance themselves from such challenging emotional encounters (Maguire and Faulkner 1988b; Richards 2007) because for some disclosing bad news is particularly stressful (Ptacek and McIntosh 2009). Some will even use evasive tactics in the event that the patient asks direct or indirect questions that the doctor feels will induce emotional distress (Fallowfield and Jenkins et al. 2002b; Sinclair 2006). In a study by The (2002) she found that some doctors did not know how to manage emotional encounters and instead focused their attention on the medical technical aspects of care instead. In these instances however, there is a tendency to treat the patient as an illness rather than a human

being and as such, humanity may be lost and the potential to induce distress is increased (Goleman 2007).

The findings of The (2002), contrasts directly with the findings of Seale (1991) whereby a postal questionnaire was distributed to general practitioners and hospital doctors to ascertain their views about the care of the dying; in addition nurses were interviewed. In this study 70% of respondents said that they found it easy or fairly easy to deal with the emotional reactions to death and dying, whereas 26% said that they found it difficult. What is not clear from this data however is whether or not there was any distinction between the responses of nurse and doctors despite the fact that different methods of data collection were used and whether or not the data obtained from interviews provided greater depth and insight. Moreover, The (2002) based some of her evidence on her observations of doctors encounters with patients, rather than basing her findings solely on the reports from doctors, which may have provided greater insight. Seale (1991) concluded that those who found it easy to cope with their emotional reactions towards death and dying would find it easier to disclose bad news as they were more able to maintain an emotional distance. This was however a speculative comment and one that was not fully investigated in this study. While some doctors may feel comfortable and happy to engage in these encounters with patients, the evidence presented in the literature suggests that others do not and may not find it easy disclosing sensitive information and bad news.

In some cases, doctors have reported that they feel unprepared to disclose prognostic information and provide predictions of survival because they have not received appropriate guidance or training (Christakis and Iwashyna 1998; Glare 2005; Sinclair 2006). Christakis et al found that 57% of doctors reported inadequate training in prognostication, whereas only 7% believed that they had received adequate training in regards to disclosing a diagnosis of cancer (Christakis and

Iwashyna 1998). A number of problems have been identified to substantiate this evidence.

In their systematic review of the literature to explore the discrepant perceptions about end of life communication, Hancock and Clayton et al (2007) found that there were considerable discrepancies in health care professionals and patient / relatives accounts regarding the disclosure of prognostic information to those diagnosed with a life threatening illness. Not only did a number of health care professionals and patients have different interpretations about what had or had not been disclosed, doctors frequently underestimated the amount of information patients required and often failed to explore the patient's level of understanding (Hancock and Clayton et al. 2007).

Not only is it difficult to know how to communicate prognostic information a number of studies report that there is a tendency for doctors to communicate inaccurate predictions to patients, when they do engage in these discussions. Being able to predict survival in patients diagnosed with advanced incurable cancer is particularly important to ensure patients can make informed decisions about their future. This is however one of the hardest predictions to make because there are various determining factors to consider, for example the quality of a patients performance status and whether or not they go on to receive palliative / active cancer treatments (Sinclair 2006).

In their study, Lamont and Christakis (2003) present the case study of a woman diagnosed with advanced incurable cancer to demonstrate the complexities of prognosis. They captured the perspectives of both the doctor and patient in regards to their experience of the disclosure of prognostic information. The doctor informed the woman that she only had months to live; 33 months later the lady was still alive. The woman was initially upset to hear she had such a poor prognosis, because she felt that so many people depended on her for support. Although she found this information distressing she also found it helpful to know as it gave her time to

consider and prepare what she needed to do, to ensure the needs of her dependents were catered for in the eventuality of her death. The doctor was pleased but surprised that the woman had lived longer than expected and felt that in these instances, doctors should rejoice with the patient, rather than feel they have misguided the patient in some way and made a clinical error. The doctor felt that it was more concerning if patients died sooner than expected because they may be unprepared to face their death (Lamont and Christakis 2003). How the patient perceived this information in light of the fact she had prepared sooner rather than later for her impending death was not apparent in this report.

A report by Parkes in the 1970's indicated that some doctors tended to be overly optimistic when communicating prognostic information and suggested that they often wanted to offer the patient and their family some reassurance and hope that they might be able to do something for them which would extend their life (Parkes 1972). Within the literature, much has been written about the concept of hope and the hopes of patients diagnosed with a life threatening illness. For example, Kubler Ross wrote that people, who are dying, often remain hopeful to the end that a cure may be found to help them (Kubler Ross 1973). In addition to this, Glaser and Strauss (1965) found in their study that those who were aware of their poor prognosis preferred to believe that they had longer to live than was expected. In these cases, it was not uncommon for health care personnel to let them carry on believing this, despite the fact that death was imminent (Glaser and Strauss 1965).

This evidence suggests that although the information may be construed as misleading and paternalistic, decisions can be made not to disclose or change a person's perception of what is happening to them out of genuine concern, however this concern can sometimes be misplaced. In her study, The (2002) describes how some doctors were ambiguous in the way they described therapeutic responses to treatment. She describes how doctors participating in her study, frequently told patients diagnosed with lung cancer that their chest x-rays showed the patients



lungs were clear, having been treated with chemotherapy. While The (2002) felt that these doctors were not being dishonest it was evident that they were not being entirely honest either. The patient may interpret this information to mean that they are cured; however there is an imbalance in knowledge, as the doctor knows that the patient is not cured and that in most cases it will not be long before the cancer becomes more visible on a chest x-ray again. Doctors were reported as being aware of this misinterpretation of information and The (2002) referred to this as 'conscious ambiguity' but felt that some doctors made little attempt to prevent or rectify this misunderstanding.

This presentation of ambiguity is somewhat surprising if the patient is well known by the doctor because they will need to tell the patient on a subsequent occasion that their cancer is once more visible. Christakis and Lamont (2000) reported that some doctors tended to present overly optimistic information to their patients if they were well known to them and in contrast presented more accurate estimates to those they did not have the same emotional attachment with. In contrast to this, Butow and Dowsett et al (2002a) described how some doctors were more willing to engage in prognostic discussions with some patients if they felt they had developed a therapeutic relationship with them. The doctors' motivation for behaving in this way was influenced by their belief that they had a greater insight into and could understand the patients need and motivation for information (Butow and Dowsett et al. 2002a). One of the complicating features of deciding how accurate prognostic information will be conveyed is that in this health care climate patients will generally be seen by a number of doctors and there is a danger that patients may receive inconsistent messages, which may result in feelings of mistrust and betrayal. Fallowfield and Jenkins et al (2002b) believe that it may be more harmful in the long run, if patients are not told the truth about their prognosis at the beginning of their illness as they may find it difficult to adjust 'appropriately' if they learn at a later date that their prognosis is worse than expected.

There are however few examples of this in the literature. Very few studies have considered the longitudinal effects of communication. One study was however designed by The (2002) to explore the optimism of patients who had been diagnosed with advanced small cell lung cancer, over a period of five years. In this longitudinal study, having followed patients from the point of diagnosis to death, the researcher found that in a number of cases, doctors were generally uncertain about what they should tell patients about their prognostic outlook and didn't really try to engage in these discussions. There were also instances where patients expressed their uncertainty about what they wanted to hear to the researcher and so in effect both parties entered into a state of collusion with each other (The 2002). There were times however, when other members of the health care team felt that it was in the patients best interests to be informed, (particularly in the latter stages of their lives) and this caused some conflict and uncertainty amongst the health care team (The 2002). In addition to this, it was not always clear what patients had or had not been told. Situations like this can cause dissension among the health care team involved in the care of the patient and are not always easy to resolve (The 2002).

In the past, the relationship between the doctor and nurse meant that if a doctor made a decision not to disclose sensitive information and bad news to a patient, a nurse was generally obliged to remain quiet and support the doctor's decision (Glaser and Strauss 1965; McIntosh 1974). Although The's (2002) findings demonstrate that problems do still exist, there is some evidence to suggest that such straightforward compliance is on the part of nurses, less evident in today's health care practice. Kennedy and Sheldon et al (2006) pointed out that a number of nurses and doctors tend to liaise with each other more closely when it comes to deciding how or when they will communicate sensitive information and bad news to patients. In their study, they found that a team approach in which doctors and nurses interacted with each other to discuss a unified approach to managing potentially difficult situations was found to be the most beneficial arrangement when it came to communicating sensitive information to patients and their families.

While there has been a change in the way some teams approach communication, some nurses have been described as feeling ill equipped to answer patient questions because they did not have sufficient information to share with the patient and even if they did, may feel that their inter professional relationship with their colleagues, prohibits them for engaging in more sensitive and difficult conversations with their patients (Corner and Bailey 2004). As such, conversation with the patient may be guarded and maintained at a 'superficial' level to minimise the risk of causing emotional distress (Corner and Bailey 2004) and possibly further uncertainty.

The notion of uncertainty reported by The (2002), from the patients perspective has also been substantiated in other studies. Kirk and Kirk et al (2004) found that a number of patients were often ambiguous in their desire for knowledge, stating that on the one hand they wanted to know their prognosis, but at the same time they were fearful of what they might learn. A sense of ambiguity was also identified through the responses of some patients about their condition, while others felt that they were not informed and had to ask questions (Costello 2000). In Kirks' study, the researchers noted that some patients said that whilst they were aware of what was happening to them, they did not really want to acknowledge this in any way and preferred to hope that a miracle cure may be found (Kirk and Kirk et al. 2004). In cases such as this, doctors may find themselves debating the patient's status of awareness and may find it difficult to ask patients questions for fear that by doing so they may do more harm than good.

While the level of information required by some patients regarding their prognosis may not always be clear, there are examples of how some patients would like to receive prognostic information. Butow and Dowsett et al (2002a) found in their study, to consider how patients with advanced incurable cancer wished to receive prognostic information, that the female participants in particular, wanted their doctors to communicate information to them in a straightforward and honest manner (without

statistical information), but in a way that did not take all their hope away. There was a consensus of opinion amongst these patients that maintaining hope could be achieved if they were presented with options, rather than being told that there was nothing more that could be done for them, in effect 'showing them the door' (Butow and Dowsett et al. 2002a).

In summary, the awareness contexts theory has made a significant contribution to our understanding of the ways in which patients, their relatives and health care professionals interact and communicate with each other within the context of a serious life threatening illness and approaching death. Even so, a number of problems persist. For example, although the 'requirement' to communicate within an open awareness context is accepted in health care, the evidence from the literature would indicate there are a number of conditions which influence the way information is communicated, received and digested, particularly in relation to prognosis which make achieving 'open awareness' challenging.

While there is a tendency for some doctors to control and manage the way they impart information and the type of information they disclose, it is not clear if they always appreciate the sense in which patients may also play a role in the construction of awareness and acceptance. As such both parties may have different agenda's which frame their communication and interactions with each other, but the agenda's may not always be transparent to the other. In order to understand what happens during these encounters within the medical consultation, Hancock and Clayton et al (2007) recommend that research needs to be focused towards obtaining the perspectives of both doctors and patients over several consultations which can be verified against evidence obtained from their encounters.

In addition to this, evidence suggests that doctors and other health care professionals still find it difficult to negotiate sensitive and emotionally challenging discussions and subsequent responses from patients and will take measures to try

and protect themselves from difficult encounters. In some cases, a patient's need for information may be misjudged because this has not been explored with them. Moreover, some doctors question their ability to disclose sensitive information because they feel they have not received adequate training to help them communicate effectively and it would appear therefore that communication is maintained at a superficial level. Being able to communicate effectively with patients is extremely important. It is evident that many patients and their families value high standards of communication from health care professionals; unfortunately this high standard is not always met (Pincock 2004; CAB 2006). In recognition of this, the dominant response thus far within the UK, from both researchers and policy makers has focused on the need to improve the communication skills of health care professionals, through communication skills training.

## **2.6 Communication Skills Training**

While effective communication is important in any health care setting, it is significantly important in the cancer setting, due to the sensitivity of the information and the psychological impact a cancer diagnosis has on patients. In this context, communication goes beyond basic skills. In the UK, the NHS Cancer Plan reported that communication skills training would become an integral feature of the qualification process and advanced communication skills training and development would become a feature of continued professional development (Department of Health 2000). This commitment received further support through NICE guidance on supportive and palliative care (2004) which recommended that accredited courses should become available to help those working within cancer care.

Prior to this, The General Medical Council (GMC) in the 1990's came under increasing pressure to improve communication skills training courses and evaluation of communication skills for doctors regardless of their speciality and grade (GMC 1993; General Medical Council Education Committee 2002; British Medical Association 2004). In addition to this, a number of key researchers became involved

to design, facilitate and evaluate a number of post registration communication skills courses. The ways in which communication skills courses have been structured and managed for doctors and other health care professionals have been well documented (Maguire and Pitceathly 2002; Wilkinson and Perry et al 2008). Such courses have been aimed towards promoting and enhancing the disclosure of sensitive information to patients and facilitating an atmosphere of care and support (Fellowes and Wilkinson et al. 2004).

More recently, through the National Advanced Communication Skills Programme for Senior Health Care Professionals in Cancer Care (ACST) there has been an initiative to combine a number of established communication skills training courses (including the work of Maguire, Fallowfield and Wilkinson) to improve the communication skills of senior health care professionals, through experiential learning (Wilkinson and Perry et al 2008). This course is now referred to as 'Connected' ([www.connected.nhs.uk](http://www.connected.nhs.uk)) and consists of a three day programme delivered through local Cancer Networks. The course is designed to promote cognitive and behavioural learning through learner centred approaches with a view to promoting self awareness, reflective practice and participating with and receiving constructive feedback as part of the course structure ([www.connected.nhs.uk](http://www.connected.nhs.uk)).

Through a combination of learning techniques, including role-play with 'simulated patients', constructive feedback and interactive group work – directed by facilitators; participants are able to practice their communication skills, in what are often referred to as 'safe environments' (Fellows and Wilkinson et al. 2004; Skelton 2008). Role play has been a key feature of many communication skills courses (Maguire and Booth et al. 1996b; Fallowfield and Lipkin et al 1998; Fallowfield and Jenkins et al 2002a). It has been considered one of the best teaching methods, to help health care professionals practice communication skills with other health care professionals or actors (portraying the role of patients), rather than practice newly acquired skills for the first time with patients (Kurtz and Silverman et al. 2005).

Although role play is considered to be a key method of teaching to facilitate learning, some question the nature of 'reality' (Yardley-Matwiejczuk 1997) and contemplate the potential problems associated with this 'artificial' learning that occurs away from real life situations (Doyle and Hanks et al 2005; Kurtz and Silverman et al 2005). As such, these critics feel that as a method of teaching, role play is not sufficiently beneficial to learning (Doyle and Hanks et al 2005). This is a relevant point and one that requires further consideration in view of the fact that role play is frequently used to teach communication skills to help health care professionals explore communication related issues relevant to their practice and performance. To try and minimise the 'artificial status' those who value the benefits of role play believe that it is best practice to ask participants to draw on real life experiences to help them explore what happened and what could potentially happen when exposed to similar situations in clinical practice (Back and Arnold et al. 2003). In so doing, this approach is thought to help practitioners become more self aware and self directed in their learning to help them appreciate the relevance of learning within the context of a given situation (Donen 1998; Collins 2004).

It is important to consider how participants of role play assess the experience. It is clear from the literature that some participants of role play report a number of concerns, including:

- Feeling 'wary' of participating in such activities because they are unfamiliar to them.
- Feeling apprehensive about being observed and receiving criticism from others
- Finding it difficult to assume unfamiliar roles.
- Finding it difficult to act out situations they have no prior knowledge of.
- Finding it difficult to shed pre-existing knowledge which can influence how they perceive and / or act out various situations.

(Back and Arnold et al. 2003; Kurtz and Silverman et a. 2005)

In recognition of this, Kurtz and Silverman et al (2005) believe that it is important to minimise these concerns as much as possible by providing briefing sessions prior to the role play activity and de-briefing sessions following the activity. In addition to this, Back and Arnold et al (2003) believe that rules must be defined prior to the start of role play which include; non confrontational feedback, options to stop / resume role play at any time and measures to ensure that confidentiality will be maintained to ensure that people feel more at ease acting out roles in front of others.

In the past, some have been critical about the quality of communication skills courses (Hargie and Dickson et al. 1998). Some doctors have complained that their development of communication skills is poor and direct blame towards inadequacies of communication skills training (Ramirez and Graham et al 1996). Moreover, Kurtz and Silverman et al (2005) explain that the teaching and learning of communication skills is complex and bound to self-concept, self-esteem and personal styles and preferences. Furthermore, how one communicates is framed around ones personal experience and knowledge of communication styles when interacting with other people (Kurtz and Silverman et al 2005), all of which suggests that communication skills development is the responsibility of the individual and is influenced by their awareness and motivation to learn and develop new skills.

Considering these points further, it has been suggested that those who do attend communication skills courses generally do so because they are motivated to learn (Maguire and Booth et al 1996b), which raises questions about those who choose not to attend courses; or what doctors actually learn from the experience if they are encouraged to attend communication skills courses against their will. This highly important issue remains largely unexplored. Prior to attending a communication skills training course, participants are encouraged to identify a personal learning agenda (Wilkinson and Perry et al 2008). This is based on their prior understanding and experience of clinical situations and difficult interactions with others, although some may argue that not all health care professionals are able to reflect on their



performance and judge how they may be perceived by others (Borrell-Carrio and Epstein 2004).

Although there are some criticisms of communication skills courses, evidence from a number of empirical studies, support the notion that communication skills can be taught (Maguire and Booth et al 1996b; Fallowfield and Lipkin et al 1998; Fallowfield and Jenkins et al 2002a; Razavi and Merchaert et al 2003; Kurtz and Silverman et al 2005; Wilkinson and Perry et al 2008) and can be maintained over time (Wilkinson and Bailey et al 1999). While the aim of these courses is to improve the competency of those who attend them, there are those who believe that there is no guarantee that improvements will be made or sustained in the long term (Aiga and Banta 2003).

One of the limitations associated with communication skills courses is that few are designed to assess the transference of skills over a prolonged period of time (Baile and Kudelka et al.1999; Maguire and Pitceathly 2002; Fellowes and Wilkinson et al 2004; Rosenbaum and Ferguson et al.2004). Following a systematic review of the literature, including 2822 papers pertaining to communication skills training, Fellowes and Wilkinson et al (2004) recommended that more research needs to be conducted to evaluate the effectiveness and impact of such courses to determine the long term effects of such training. Additionally, Wilkinson and Perry (2008) recommend that the longer term impact of courses should be evaluated in a number of multidisciplinary groups. In studies, which have attempted to elicit information about the enduring impact of communication skills training, it has been recognised that while some skills are sustained, (for example, the use of open and focused questions), other skills decline (for example empathy, checking a patients understanding and in-depth questioning of a patients psychological wellbeing) (Maguire and Booth et al. 1996b; Fallowfield and Lipkin et al.1998; Fallowfield and Jenkins et al.2003). Why these skills are not sustained in clinical practice needs to be considered further if changes are to be addressed and made.

Optimising the long-term retention of communication skills also needs to be considered further, particularly in light of the findings by Maguire and Booth et al (1996b) who found that doctors (six months post course) felt a lack of time and a lack of emotional support had a direct influence on their ability to use good communication skills in clinical practice. This is a key issue and one which requires further consideration to ensure that the influence of external factors on the development and implementation of communication skills are minimised (Razavi, Merckaert et al. 2003; Butler, Degner et al. 2005). In addition, Maguire and Booth et al (1996b) also found that doctors described their concerns, that if they probed too deeply they may harm patients psychologically and were not convinced that such enquiry would be beneficial to either the patient or themselves (Maguire, Booth et al. 1996b).

This latter conflict along with knowing how best to communicate complex information has however been raised at the beginning of such courses when health care professionals have been asked to identify their learning needs based on their experiences within clinical situations (Maguire, Booth et al. 1996b; Fallowfield, Lipkin et al. 1998). Despite attending a communication skills course, it would appear from these findings that a doctor's initial concern about eliciting or discovering a patient's feelings or concerns, prevails post course. The reasons for this are unclear but questions have been raised regarding the extent to which the nature of the situation and / or a doctor's motivation to explore the emotions of their patients influences how they interact. Maguire and Booth et al (1996b) and Fallowfield and Lipkin et al (1998) indicate from their respective studies that a doctor's level of experience and seniority does not make a difference to the way they communicated and / or interacted with their patients and as such does seem to have much bearing on this problem.

While it is acknowledged that the development of communication skills provides a valuable contribution within the cancer setting, the evidence suggests that the

development of effective communication skills is not best achieved or sustained, having attended a communication skills course. This is a key point which raises the notion that while communication skills courses have their place they are falling short in terms of what can be achieved. It is not clear if this is related to the teaching methods used on these courses, the artificial nature of these courses or whether or not the sustainability of communication skills is influenced by personal motivations and / or external influences within social situations with patients and colleagues or a combination of all.

If effective communication skills are to be developed and sustained it has been suggested that greater emphasis needs to be placed on trying to explore the feelings and attitudes of those attending these courses to appreciate what may influence and / or hinder their development of skills (Maguire, Booth et al. 1996b). As such, rather than focusing on communication in terms of competency and efficiency of skills, further consideration needs to be given to exploring influences to learning and professional development within a broader context which takes into consideration the complex nature of how adults learn in response to trying to meet the challenging needs of patients and doctors alike. For example, these might be experiential learning, communities of practice, and reflection and reflective practice.

## **2.7 Experiential Learning**

*'Experiential learning is the sense-making process of active engagement between the inner world of the person and the outer world of the environment'*

(Beard and Wilson 2006:2)

Many doctors will only start to become actively engaged in discussions of bad news, with patients diagnosed with advanced incurable cancer during medical consultations, on a regular basis when they begin working as a Specialist Registrar (SPR) within a cancer setting. Although some doctors will have experienced these discussions in different clinical settings and within different contexts, this will

probably be the first time they manage these discussions on their own within the consultation. Having experience of these encounters can be an important source of ongoing experiential learning for doctors.

Learning from experience is considered to be a natural form of learning that is available to all and in the majority of cases all that is needed to learn from experience is the opportunity to reflect and appraise the experience, either alone or in the company of others (Beard and Wilson 2006). On the surface, this approach to learning appears to be fairly simple and relatively straightforward but this is not necessarily the case as indicated within section 2.9 of this literature review. Before taking this line of enquiry further it is however necessary to consider what constitutes an experience.

Dewey's work on exploring the notion of experience was highly influential in the development of experiential learning, however, a concise definition of what experience is, is difficult to find. Beard and Wilson (2006) believe that experience is a connection between doing something and being able to reflect on the action to help inform the development of skills. For others, experience relates to educational experiences which incorporate exercises in role-play and simulation in educational environments (Kurtz and Silverman et al.2005), however this latter example is not necessarily relevant for doctors who predominantly once qualified develop professionally through experiential learning within clinical practice, be this in isolation or through direct influences of others. One key issue relates however to what exactly do individuals learn from particular experiences and another relates to the question of what do they do with this knowledge?

While experiential learning can be very powerful, it can also be haphazard. Kurtz and Silverman et al (2005) believe that learning from experience within clinical practice is not the best approach to develop effective communication skills. Drawing on the work of Byrne and Long (1976), Kurtz and Silverman et al (2005) make the

point that doctors tend to communicate and interact with their patients following a routine, standardised approach because this is how they have always behaved during their consultations and as such fail to notice and / or learn from their experiences. This would imply that doctors are not mindful of their practice and fail to reflect on their actions and interactions with others, yet this may not necessarily be the case. In trying to ascertain if reflective practice had a positive influence on diagnostic accuracy, Mamede and Schmidt et al (2008) found that in less complex clinical cases, doctors tended to apply automatic reasoning based on prior clinical experience to inform their clinical practice, whereas, complex cases were more likely to be reflected upon which helped inform their clinical judgement. While reflective practice was not considered necessary in all clinical cases, it was deemed to be beneficial when encountering more complex, multifaceted problems (Mamede and Schmidt et al 2008). In their conclusion, Mamede and Schmidt et al (2008) question how doctors determine which cases need further analytical consideration and how further interventions may help them make these judgements. In this context, learning is more than an accumulation of facts, as learning needs to;

*'Make a difference in the individual's behaviour, in the course of action he chooses in future, in his attitudes and in his personality.'*

(Rogers 1951:280)

Despite this more insightful and purposeful notion of experiential learning, Dewey wrote of the dangers of taking a careless attitude to learning from experience and explained that some professionals may fall into the trap of believing that they do not need to change and may question the need to change because they have not fully reflected on their behaviour and / or outcomes of their behaviour (Dewey 1938). Schön and others have contributed to knowledge in terms of how communities of educators and nurses (for example) engage in reflective practice, yet there is a tendency for doctors to reflect on their own without the support of their colleagues. Although experiential learning is considered to be a personal endeavour (Dewey

1938; Rogers 1951), there is a need for others with greater expertise to provide support and guidance to help facilitate a process of experiential learning when necessary (Dewey 1938).

Through his 'reflective thoughts on a life time of trying' it is clear that Cowan believes that experiential learning helps facilitate personal growth and development through a combination of efforts, including personal initiatives / educational support / peer support, and that people need some direction to help them discover what it is they need to learn and develop, which when left to their own devices might not happen (see <http://learningtobeaprofessionalptsworks.com/f/A1+JOHN+COWAN.pdf>). Yet, evidence from empirical studies within medical practice, suggest that experienced doctors do not always engage in experiential learning and reflective practice. Whether or not they receive peer support and educational support in practice requires further investigation.

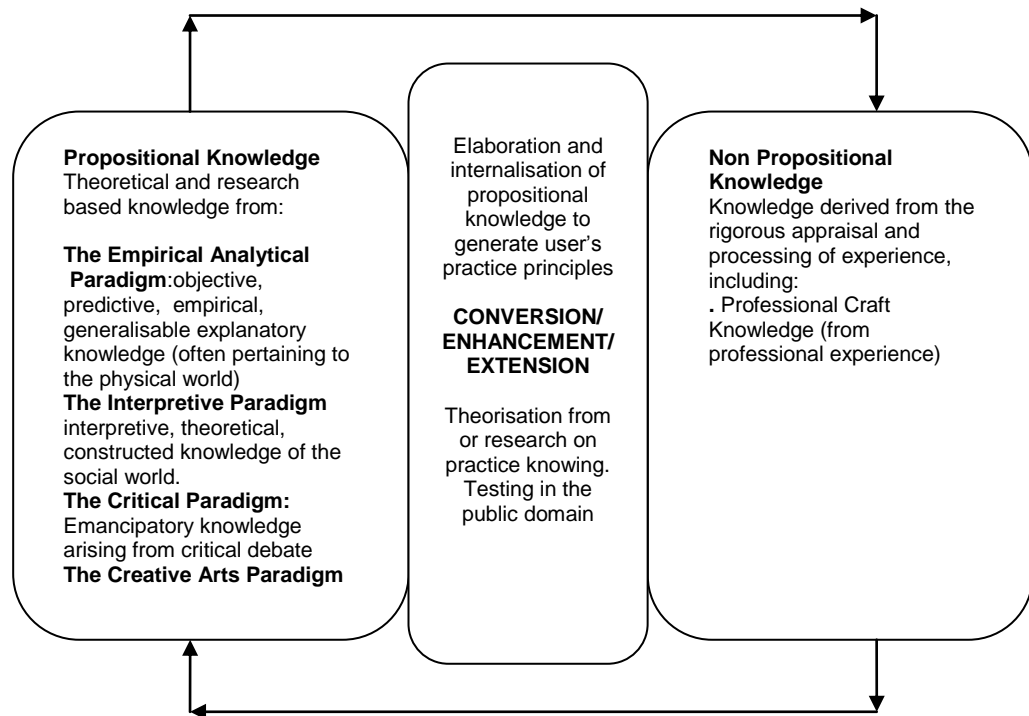
Mamede and Schmidt (2004) found in their study to assess the characteristics of professional practice and educational experiences in a group of experienced primary care physicians that there was a decline in reflective practice as many of the doctors became accustomed to the various experiences they had faced throughout their careers (Mamede and Schmidt 2004). In this sense, experienced practitioners are able in many cases to develop a skill of critical appreciation and appraisal of their practice (Higgs, Fish et al. 2004). Yet, if experienced doctors do not actively engage in experiential learning, Dewey (1938) believes that it may make it more difficult for less experienced doctors to make and establish contacts with them in clinical practice to help facilitate their experiential learning. While the reason for this is not entirely clear, it has been suggested that the clinical environment is not structured in such a way to support additional time for reflection of experience and the sharing of knowledge and expertise (Carr 2006; Knight and Bligh 2006).

This is an important point and builds on the notion of communities of practice and the expectation that practitioners will share their knowledge and experience with each other, which in reality does not necessarily happen. In addition, Beard and Wilson (2006) propose that no one actually sees an experience in exactly the same way or processes an experience in the same way and imply that learning from others is not always helpful. Yet in contrast, it is often valuable within a learning situation to try and understand the concept of experience from multiple perspectives to add to the depth and understanding of our experience. The nature of this form of learning does however vary, depending on the 'explicit or implicit' agreement which exists between people (Boud and Miller 1996).

While some experiences may be stimulating and enjoyable, others may be challenging and influence our desire to participate in similar experiences in the future. Many doctors find it difficult to communicate bad news to patients, because they question their level of competency and ability to disclose this information without causing too much distress to their patients (Buckman 2002) and yet they routinely engage in these discussions. Snell (1992) found in his study, investigating learning at work, that it is inevitable that people will face a number of 'hard knocks' within the work situation and while they may be unpleasant, provide an ideal learning opportunity. If people do not learn from these experiences Snell believes that a 'major source of personal and moral development would be blocked' (Snell 1992:5). In addition, people who experience too many 'hard knocks' may find this too overwhelming and start to withdraw from moral judgement which will stunt their personal growth (Snell 1992) or in the context of health care may lead to stress and professional 'burnout' (Ramirez, Graham et al. 1996).

There needs to be a way therefore to support practitioners and guide them through a process of experiential learning to help them appreciate the nature of their practice, and understanding of personal behaviour in order that they can make attempts to expand their knowledge or judgement of how knowledge can be applied to given

clinical situations. In order to create and modify knowledge in practice Higgs et al (2004) propose a model to identify various forms of knowledge which they believe helps support knowledge within practice (See Figure 3).



**Figure 3: Forms of knowledge used in practice and their transformation / relevance (Higgs, Fish et al. 2004)**

This model demonstrates how learning can be informed by a combination of non propositional and propositional knowledge to help create and inform an individual's knowledge base and sense of knowing. When in clinical practice the health care professional is able to consider the most appropriate form of knowledge and judge how this knowledge is best applied within a particular situation and / or how this knowledge may be modified or developed to meet the challenges of a different situation (Higgs, Fish et al. 2004). As such, the health care professional is simultaneously practising their skills and developing their practice, which is further informed by their values, judgement and beliefs about what may or may not work most efficiently and effectively in a given situation; some of this knowledge will be tacit in nature and some will be explicitly known.



In many cases the knowledge acquired by health care professionals remains a tacit knowledge of experience (Higgs, Fish et al. 2004). Tacit knowledge is generally viewed as procedural in nature and is often applied to various situations within clinical practice having been acquired through individual practitioner's personal experiences (Sternberg 2000). Tacit knowledge is often unspoken and under-emphasised and as such remains with the individual practitioner. Although tacit knowledge may never be fully uncovered (Eraut 1994), attempts can be made to ensure health care professionals share their knowledge with others to develop their understanding of knowledge and help inform and develop their clinical practice (Higgs, Fish et al. 2004) and the clinical practice of their colleagues. Under these circumstances doctors are able to ensure that their colleagues share in their knowledge and experience, defend and / or challenge assumptions and criticisms and make decisions about which elements of practice they wish to incorporate into their own clinical practice as elaborated on in the following section pertaining to communities of practice. This area is crucial to my thesis as it highlights the basis upon which experiential learning can be used as an opportunity for effective professional development, which has the potential to challenge and change dominant styles of working.

## **2.8 Communities of Practice**

Much of adult learning is informal and rooted in the life context of the learner and takes place in a variety of communities including, work, family, social situations and recreational groups (Hren Hoare 2006). One model for considering how learning takes place in social groups is that proposed by Wenger, and his notion of 'Communities of Practice'. The defining characteristics of a community of practice are conceptualised by the continual integration of learning and practice, whereby members of a community are encouraged to exchange knowledge and practical wisdom through evolving routines and ways of doing things (Wenger 1999). As such a community of practice represents a group of people who share a common bond and engage in similar / shared activities (Merriam, Courtenay et al. 2003). This

concept is further defined by Eraut (2004b) who describes a community of practice as a community of practitioners;

*'..whose identity and learning are dominated by a shared culture and participation in common activities; their domain is usually small and their approach to learning is culturally specific and often implicit'*

*(Eraut 2004b:171)*

Connecting with others seems to be an important aspect of developing ones learning. Eraut et al (2004a) found this to be the case in their study of the early career developments of accountants, nurses and engineers. Eraut et al found that explicit and implicit learning was more likely to occur through participation; working alongside others; and being able to share experiences to help overcome problems in practice and to develop their knowledge. As such Wenger, states that;

*'Learning is the engine of practice and practice is the history of that learning'*

*(Wenger 1999:96)*

From this perspective, learning is central to a community of practice and as such, examination of communities can provide valuable insights in the nature of learning. In making these links explicit it is possible to understand and appreciate how adults learn and develop their skills within a particular social context.

Within the practice of medicine, the GMC has a fundamental role to play in the organisation of medical education and has stipulated that a number of core competencies and skills be achieved and demonstrated within clinical practice or externally (on courses) to ensure doctors operate proficiently (General Medical Council 2005a). As such, doctors are familiar with the notion of learning within the clinical environment and being assessed and appraised to ensure that they are fit to practice. As members of a professional group, doctors have a shared understanding of the world that is further defined by the speciality in which they practice and

through explicit (what is said) and tacit (unspoken assumptions) knowledge within this community (Wenger 1999).

Eraut (2004b) proposes that health care professionals need to establish relationships of trust with their colleagues before they are able to engage in discussions of a sensitive nature to their practice and / or perception of practice. If this relationship of trust is not established or an individual is concerned about how they will be perceived, they are unlikely to disclose their concerns and instead will portray an image of affinity with their colleagues to limit any form of vulnerability (Eraut 2004b). Moreover, Bate et al (2002) argue that there is little scope for individuals working within the NHS to share their problems, experiences and knowledge with others or to coach each other through difficult experiences because in part, the 'rational scientific paradigm' prohibits such behaviour.

As such, Eraut (2004b) believes that this type of behaviour explains more about the culture and relationship with others within a community of practice as opposed to the actual practice. As a means of trying to address this problem, Bate and Robert et al (2002) support the idea that those engaged in communities of practice need to identify the nature of their culture to subsequently accommodate and support the idea of change to help facilitate learning and the acquisition and sharing of knowledge in practice. However, in making this suggestion Bate and Robert et al (2002) do not provide detailed recommendations for how this may be achieved but suggest that motivation and commitment to change needs leadership and support from more experienced professionals to promote the practice of shared inquiry. This ideal builds on that of Tharp and Gallimore who believe the central responsibility of the organisation within education is to assist the cognitive and behavioural development of teachers (Tharp and Gallimore 1991).

Although more experienced doctors can influence the social context and culture of learning practices, it is also worthy to note that in doing this they can help influence

and support the learning needs of less experienced doctors working within their clinical environment. In applying the principles of Benner's 'Novice to Expert' model to consider how doctors develop their competency in disclosing bad news to patients within the cancer setting it is appropriate to consider the role and appointment of Specialist Registrars (SPR) into the cancer setting (Benner 1984). When appointed as an SPR, these doctors will have decided to specialise as oncologists, having undertaken general medical training. These doctors will be competent in a number of clinical situations but not necessarily proficient in disclosing bad news to patients within an outpatient consultation because the majority of them will not have been subjected to this situation prior to this professional appointment. Although it has been reported elsewhere in this thesis that experience and seniority do not necessarily equate to doctors feeling proficient in the way they communicate and interact with their patients, individual professionals can share their experiences with others and guide each other through difficult situations and experiences (Eraut 1994). In addition open communication between professionals allows doctors to consider the problems inherent in the work they conduct on a daily basis. This is a key issue and one which is explored further within the context of reflection and reflective practice.

## **2.9. Reflection and Reflective Practice**

*'To avoid the truism that all learning is experiential.....I propose to restrict the term 'experiential learning' to situations, thus requiring a further period of reflective thinking before it is either assimilated into existing schemes of experience or induces those schemes to change in order to accommodate it'*

(Eraut 1994:107)

Reflection is seen to have a key role in enabling experiential learning to take place. Having touched briefly on the use of reflection in the previous section of experiential learning the role of reflection and reflective practice is considered further, as they are relevant to the continued professional development of doctors.

### 2.9.1 Origins of Reflection

The original work of John Dewey was essential to the study of reflection. In his philosophical writings in the 1930's Dewey distinguished between thinking and reflection. His analysis of reflection lies within his interpretive interest of trying to understand things and make sense of the world, in order to develop the process of education (Moon 2007). Dewey believed that people have a number of random thoughts, but this does not mean that they are all reflected on. Reflective thinking followed a process of interconnected ideas that followed a logical sequence in the hope of establishing a conclusion (Dewey 1933). Although Dewey was interested in the outcome of reflective thinking, the most important phase of reflection for him was the process of reflection and how people attempted to solve their problems. For reflective thinking to proceed the individual needed to deliberately seek reflective thought and engage in reflective activity (Dewey 1933). In summary, Dewey believed that reflective thinking was an;

*'Active, persistent and careful consideration of any belief or supposed form of knowledge in the light of the grounds that support it and the further conclusions to which it leads.....it includes a conscious and voluntary effort to establish belief upon a firm basis of evidence and rationality'*

(Dewey 1933:6)

Using the approach by Christopher Columbus to test his belief that the world was round, Dewey established a connection between reflection and experiential learning, as action is taken to establish and / or support our beliefs.

Since Dewey, others have built on the theory of reflection and in doing so have added their philosophical stance. Habermas also believed that reflection was best used to generate knowledge (Moon 2007). His philosophical stance differed from that of Dewey in that he believed reflection was a tool used to help individuals develop knowledge, which was of particular interest to them (Habermas 1971). Rather than focus on the process of reflection Habermas was interested in the

nature of knowledge and an individual's motivation to reflect on one thing as opposed to another. Habermas believed that reflection had an emancipator outcome; it helped people become self-aware by generating questions and understandings about themselves and society which could contribute to personal transformations and changes in society (Moon 2007).

In summary, knowledge is first developed by the individual through interpretive means before it can receive a more critical overview, through evaluation and reflective judgement. The role of reflection is explored further in relation to the reflective practitioner, through the work of Donald Schön who applied the ideas of Dewey through his work about how professionals think in action. Schön was concerned with the development of reflective practice and learning systems within organisations and communities.

### **2.9.2 A Reflective Practitioner – Donald Schön**

Schön explored the nature of professional knowledge because he believed from his professional experience that professional knowledge was dominated by a 'technical rationality' model of knowledge acquisition which was based on a positivistic epistemology of scientific theory and techniques to solve problems with predetermined rules. Schön saw this as a crisis and believed that a positivistic epistemology was not applicable, relevant or easily applied to professional practitioners because of the complex and fluid nature of their working environment and thus failed to take account of how professionals worked in order to try and meet their objectives (Schön 1983). In response to this philosophical belief, Schön reconsidered the question of professional knowledge and proposed the following:

*'If the model of Technical Rationality is incomplete, in that it fails to account for practical competence in 'divergent' situations, so much the worse for the model. Let us search instead, for an epistemology of practice implicit in artistic, intuitive processes which some practitioners do bring to situations of uncertainty, instability, uniqueness and value conflict'*

*(Schön 1983:49)*

In his search, Schön highlighted the role of 'professional artistry' which offered a complementary role to professional knowledge, to be used in situations which were uncertain, unstable and unique (Schön 1983). He was mindful however, that professional practice was unique to the individual and as such it was difficult to apply descriptive guidelines to help inform reflection within clinical practice. Instead, he proposed two general principles; reflection-in-action and reflection-on-action. Each of these principles will be considered but prior to doing so it is reasonable to suggest that Schön has come under some criticism for not making his vision of these principles clear. Eraut (1994) for one believed that Schön failed to present a sustainable argument to defend his definition of / and principles of reflection in action and failed to take into consideration the 'time' it would take to engage in such activities. Schön was also criticised for failing to describe the process of reflection, although this did not seem to dissuade people from regarding Schön's work as an influential contribution to the advancement of knowledge in relation to the reflective practitioner (Smith 1994).

To introduce the notion of reflection-on-action it is appropriate to use the words of Schön;

*'When we go about the spontaneous, intuitive performance of the actions of everyday life, we show ourselves to be knowledgeable in a special way. Often we cannot say what it is that we know. When we try to describe it we find ourselves at a loss, or we produce descriptions that are obviously inappropriate. Our knowing is ordinarily tacit, implicit in our patterns of*

*action and in our feel for the stuff with which we are dealing. It seems right to say that our knowing is in our action'*

(Schön 1983:49)

In this statement, Schön emphasis's the notion that reflection is personal and in this sense occurs within the context bound nature of the clinical situation to help practitioners make sense of a particular situation or experience, while generally thinking on their feet. As such reflection-in-action is a problem solving activity, whereby a problem is considered and alternative forms of action may be tested out which will inform future practice. In order to engage in this activity, the practitioner is believed to look at the experience as it unfolds and make connections with their feelings in order to compose new solutions (Smith 1994). Although practitioners often think about what they are doing, their knowledge of their behaviour is not always easy to articulate and remains tacit in nature. Knowledge is therefore described as being inherent in intelligent action (Schön 1983).

Reflection-on-action is distinguishable from reflection-in-action, in that it refers to a way of thinking about a situation which has already taken place (Johns 2004) or a virtual situation which may arise in the future to consider the pros and cons of potential actions (Schön 1983). Reflection occurs in response to a feeling that a situation is / was not necessarily normal and requires critical attention as a way of trying to understand the conditions of the situation and consequent behaviours. This is important to try and understand what happened and what could be done to enhance this experience in similar situations in the future (Schön 1983). In this sense, active experimentation occurs to see what might happen or it occurs in the hope that a desirable and intended outcome is produced. Yet, this is not simply a matter of a means to an end; a practitioner needs to consider if the intended outcome was worthwhile and acceptable to all concerned (Schön 1983). For example, a doctor may wish to disclose specific information to a patient and in doing so, their intended outcome is produced. Yet if the patient was not happy about



receiving this information or they were not happy with the way the information was conveyed, then one could question whether or not this was an acceptable outcome.

Reflecting on practice is all well and good but questions need to be asked and answered about what needs to be done in regards to developing professional development opportunities that build on experiential learning and reflective practice to explore and consider new ways of getting people to unravel their understanding of their experiences. This is useful in terms of providing an alternative perspective from which to begin to examine the issues, as it provides an ongoing and accessible learning opportunity from real life situations within clinical practice to examine, how doctors felt during and after consultations and how patients and their relatives responded to various forms of interaction.

A skilled and experienced practitioner may come to realise the importance of reflecting in and on an action to ensure that an acceptable outcome is achieved, having built up their knowledge and skills within a particular area. Yet, they may find it difficult to explain what they know to a less experienced practitioner;

*‘..an experienced practitioner cannot convey the art of his practice to a novice merely by describing his procedures, rules and theories, nor can he enable a novice to think like a seasoned practitioner merely by describing or even demonstrating his ways of thinking’*

(Schön 1983:271)

A novice can however gain from discussing their experiences or concerns with an experienced practitioner who can help them consider their values and beliefs and behaviours through a form of supervision within the context of situated learning (Maudsley and Strivens 2000a). To be able to develop their clinical ‘artistry’ through reflection in and on action practitioners need exposure to clinical situations to help consolidate their learning (Schön 1983; Moon 2007).

Even though individuals are able to connect to something within them through mindfulness and reflective practice, this is not always sufficient as they need the help and support of others (Johns 2004), to offer constructive advice and feedback to add to the individuals body of knowledge in relation to a given situation (Schön 1983). Being mindful is however, something that is not easily taught and needs to be cultivated in learners to help them reflect (Epstein 1999) as some practitioners are more mindful of their practice than others (Mamede and Schmidt 2004). Having said this, people can feel vulnerable about sharing their experiences with peers if they do not feel safe to do so (Johns 2004). Schön believes that the effects of professional groups need to be considered further as examined within section 2.8, and is considered further in the following section: reflective practice.

### **2.9.3 Reflective Practice**

In the preceding sections, reflection was conceptualised in a number of ways; from Schön's examples of reflection-in-action and reflection-on-action (Schön 1983) and as a problem solving process (Dewey 1933; Schön 1983) and reflection as a means of generating knowledge through self-reflection and self-understanding and an individual's motivation to reflect on one experience over another (Habermas 1971). Habermas (1971) argued that self-reflection and self-understanding may become distorted by social conditions. Health care in particular is complicated by many social determinants and is further complicated by the medical profession's inability to talk to each other about difficult situations which are not technically orientated. Schön (1983) believed that a professional body would best be served to utilise the practice of reflection to consider the values and 'frames' from which they currently practice, rather than impose all responsibility on the individual practitioner.

Reflective learning is broadly accepted as a current paradigm of learning in professional education and this has been demonstrated clearly through the work of practicing professionals through various disciplines in health care (Mann 2008). Furthermore, empirical studies on the nature of reflective practice are rare in

medicine, particularly in respect to those in post registration positions; as opposed to the disciplines of teaching and nursing for example, where reflection has been explored further and applied to clinical practice (Redmond 2006; Mamede and Schmidt et al.2008). Although, research has been conducted to explore the use of reflection in undergraduate medical training, (Dornan and Carroll et al.2002; Ker 2003) there is little evidence to suggest that reflection is practiced once qualified. This is despite the fact the GMC recognises the value and importance of reflective practice (Mamede and Schmidt 2004) and the general public expect doctors and other practising health care professionals to practice safely and appropriately and maintain professional competency (Mann 2008).

Reflective practice, alternatively referred to in medicine as critical thinking is relevant to medical practice because problems do not always present themselves in clearly defined ways and doctors need to adapt to situations and apply reflection-on-action (Maudsley and Strivens 2000a) which will in turn enhance respect for their patients, and ethical decision making and shared collaboration (Boud et al. 1985; Schön 1987; Ker 2003). Although reflective practice may well enhance learning and promote a better understanding of clinical situations and patients needs, little is known about the benefits of reflective practice in connection with the patients experience (Mann 2008).

Although Eraut (1994) has been critical of Schön's notion of reflective practice, there are links with Eraut's 'deliberative processes' and 'process knowledge'. These processes require a combination of propositional knowledge, situational knowledge and professional judgement (Eraut 1994). Medical education has however come under some criticism for dismissing any form of practical knowledge as if it were an automatic response to a situation as opposed to a complex set of practices (Maudsley and Strivens 2000a). Mamede and Schmidt (2004) found however, through a questionnaire designed to elicit information about reflective thinking, administered to a group of primary care physicians, that reflective practice within

medicine did require effort and was employed by some but not all as a deliberative attempt to learn (Mamede and Schmidt 2004).

It is necessary to explore why some practitioners engage in reflective practice and others do not (Jarvis 1992). In order to do this, Jarvis believes that one needs to consider;

- The relationship between thought and action
- Consciousness of the individual
- Social Context

While Jarvis recognises that not everyone has the intention to develop their knowledge through reflective practice, either because they feel compelled to habitualise their practice, or they find it difficult to switch from technical-rationality because they prefer to keep an emotional distance between themselves and their patients; there is still a need to try and foster and nurture an environment that does support reflective practice (Jarvis 1992). Everyone has the ability to learn through reflective practice but not everyone is mindful that they need to reflect and not everyone has the opportunity or encouragement to do so. This view is supported by Roberts and Stark (2008) who believe that others need to support those who demonstrate unprofessional behaviours to help them become self aware and be able to self regulate their behaviour. Jarvis (1992) suggests that managers and educators should ensure that there is time and opportunity for practitioners to think and reflect on their actions; actions which are not simulated or created for learning to occur, but through situations and experiences that already exist and are created through real encounters with patients.

## **2.10 Summary**

Disclosing sensitive information and bad news has been identified as a complex challenge for health care professionals and doctors in particular. The response thus far, has been driven towards health care professionals attending communication skills courses to develop their skills in this area. While it is acknowledged that

communication skills courses have their place, there is evidence to suggest that they are falling short in terms of what they can achieve in terms of sustainability and transferability of skills into clinical practice (Maguire and Booth et al 1996b). A combination of efforts including both professional and personal development initiatives need to be taken into consideration.

In this thesis, alternative approaches to supporting learning and development in this area are considered which may be more appropriate to support learning and skills development in this area. This is particularly so, when one considers that communication goes beyond disclosing information; as people do not necessarily become more aware just because they have been given some information; people are seen to control their awareness. Before engaging with such approaches to learning and professional development, it is acknowledged that a greater understanding is needed about what goes on in consultations between doctors and their patients and how they experience imparting and dealing with difficult news, within highly complex social situations and social interactions. This is particularly important when the primary focus on knowledge and a willingness to share information is not the only issue to be taken into consideration. Other factors which play a significant part in shaping awareness and impact on open awareness contexts include emotions and cognitive ways of knowing (Timmermans 194) and the emotional work people engage in to help them sustain a desired awareness to help them carry on living day to day (Mamo 1999) need to be examined further.

The rationale for undertaking this research is therefore twofold. First this research sets out to explore key aspects of doctor and patient interactions from various perspectives, to explore the meanings individuals attribute to their experiences; to explore the changing nature of social interactions as doctors and patients meet on various occasions; to explore the nature of relationships particularly within the context of disclosing and sharing sensitive information within an Oncology setting which may have some influence on changing awareness and be consequential to

future interactions. In addition, I wish to explore the impact and influence an individual's awareness context has on the consultation experience.

Secondly, I reflect upon the data generated through this study to explore if this data can inform the way progress can be made to improving doctor's communications and interactions with their patients (and relatives). In particular I intended to explore the possibility for developing richer and more effective approaches to developing new kinds of professional development activities for staff working in this area.

The next chapter will set out the overall study aim and objectives in more detail and explains how this study was carried out.

## **Chapter 3**

### **Research Design and Methods**

#### **3.1 Introduction**

This Chapter begins by providing an account of the methodological considerations which informed the development and design of the present study. This is followed by an account and description of the methods used to collect data and an explanation of how the data was analysed. This chapter then concludes with a section on reflexivity.

#### **3.2 Research Aims and Objectives**

The purpose of this study was to investigate the experiences of patients diagnosed with advanced incurable cancer and the doctors who conducted their medical consultations, particularly in regards to talking about sensitive issues and dealing with bad news. To this end the research objectives were purposefully broad in order to facilitate an open-ended inquiry:

1. To observe and examine how doctors and patients manage and control the disclosure and receipt of sensitive information and bad news in an Oncology outpatient setting.
2. To explore the feelings associated with dealing with sensitive information and bad news, when patients are first referred to the Oncology department and as they progress through their illness.
3. To examine how the concept of 'awareness contexts' can help understand the perspectives of both doctors and patients in the consultation and explore the impact and influence an individual's own awareness context has on the consultation experience.

4. To critically reflect upon doctor-patient communication in such situations with a view to considering future strategies for doctors' continuing professional development.

I wished to explore key aspects of doctor and patient interactions, from various perspectives, to explore the meaning individuals attribute to their experiences; to explore the changing nature of social interactions as doctors and patients meet on various occasions; to explore the nature of relationships particularly within the context of disclosing and sharing sensitive information within an Oncology setting which may have some influence on changing awareness and be consequential to future interactions. I also wished to reflect upon the data generated through this study to explore if this data can inform the way we proceed to improve doctor's communications and interactions with their patients (and relatives); to explore where there is a need to focus efforts in order to make a positive contribution to future professional development in this area. In addition to this, there is a need to consider what lessons can be learnt for the broader health care team in relation to their interactions with patients, relatives, and colleagues.

### **3.3 Why choose a Qualitative Strategy?**

Empirical enquiry can be viewed in a number of ways as attempts are made to make sense of the social world. The various approaches encompass both theory and method and have been the focus of many complex discussions and arguments. Much of this debate has centred on the characteristics and distinctions of qualitative approaches and quantitative approaches to research (Murphy, Dingwall et al. 1998). It has been customary to characterise these methods as positivistic or naturalistic; objective or subjective and realist or relativist (Denzin and Lincoln 1994). However, while researchers are influenced by their epistemological and methodological beliefs Murphy et al (1998) and Hammersley (2002) believe that the nature of the research question should ultimately influence the choice of approach to be used within a study to ensure that the research question is answered in the most effective and efficient



manner, otherwise a preoccupation with philosophical issues can detract from the main purpose of the study (Hammersley 2002).

Although there are distinctive philosophical and theoretical approaches to qualitative inquiry, it is commonly accepted that they are naturalistic and interpretive in nature (Denzin and Lincoln 2003; Snape and Spencer 2003). Qualitative research approaches have been shown to provide the sort of experiential understanding that the present study aims to achieve by seeking to understand how doctors and patients describe and attribute meaning to their experiences and how they are observed to interact with each other during consultations within the cancer setting. In the present study an ethnographic approach to qualitative inquiry was chosen and the rationale for this choice is now presented.

### **3.3.1 Utilising an Ethnographic Approach**

Ethnography as a tradition has primarily been associated with anthropological research and has been used within the social sciences and the discipline of sociology in particular. In more recent times however ethnographic research has been used within a number of different settings including education (Wolcott 1999) and health and medicine (Bloor 2001). Many writers have been reluctant to define the concept of ethnography because of its complex history and broad field (Wolcott 1999; Bloor 2001; Hammersley and Atkinson 2005), however, it is generally recognised that:

*'Ethnography is not one particular method of data collection but a style of research that is distinguished by its objectives, which are to understand the social meanings and activities of people in a given field or setting, and its approach, which involves close association with and often participation in, this setting.'*

(Brewer 2000:11)

Ethnography is particularly suited to helping researchers understand interactions as they occur in their natural settings, as is evidenced in the work of Glaser and Strauss's ethnographic study of death and dying in American hospitals during the 1960's. Although there are variations to ethnography, one of the common features sees the researcher getting out in the field (in the natural setting) and observing how people interact with each other; taking into consideration how and why they behave in the way that they do during face to face encounters and how they apply and express meaning to and from their actions / interactions within the context and location in which this all takes place (Wolcott 1999; Timmermans and Tavory 2007).

These activities occur and evolve over time and provide an opportunity for the researcher to see how situations change and / or meanings change through a series of interactions, and as such capture a number of realities that have been constructed through their experiences. This was observed in an ethnographic study conducted by The (2002) over a five year period to monitor the process of illness among patients diagnosed with lung cancer. In this study, she explains how the ethnographic approach provided her the opportunity to follow a group of patients throughout their illness and observe their many and varied interactions with health care personnel and family members, an approach which in many ways aligns and typifies my reasons for selecting this methodology. In using an ethnographic approach The (2002) was afforded the opportunity to explore the often tacit aspects of knowledge in relation to 'optimism' and how patients viewed their futures and how health care personnel viewed their interactions with patients.

The meanings and interpretations of experience are fluid and as such influences and produces participants reality and their perception of truth at any given time, something which is constantly being shaped by their actions and interactions (Strübing 2007). One of the strengths of being present as interactions occur means that the researcher is able to capture material first hand, rather than retrospective

reflections which may result in more general abstractions (Timmermans and Tavory 2007). The design of the study follows on from the stated approach taken.

### **3.4 Research Design Decisions**

The nature of my research questions means that a simple hypothesis, testing positivistic research design would not be appropriate. The clearly stated intention of the study was to explore the in-depth experiences and meanings that individuals apply to their social interactions with others. Whereby, meanings are informed by multiple and shifting realities which are influenced by both personal and social factors, which may confront personal beliefs and behaviours. The objectives and design features of this study were influenced by the 'awareness context' theory, originally developed by Glaser and Strauss in the 1960's and subsequent modifications proposed by Timmermans and Mamo in the 1990's, which have been presented in Chapter Two, Section 2.2 of this thesis. The theory has primarily evolved from within the context of death and dying but has since been applied to various disciplines of health care (Hellstrom and Nolan et al. 2005). The theory is central to the study of interaction and communication, which I seek to explore further in this study.

Much of the 'awareness context theory' has been developed from a sociological and introspective ethnographic approach. Glaser and Strauss (1965) were originally surprised to learn that a number of patients in hospital were unaware that they were dying. Through their investigations to primarily observe how patients and hospital staff interacted with each other when communicating information they noted, how a state of secrecy was often created by hospital staff and a number of relatives. This led them to explore how people managed the disclosure of information; to explore whether or not people were willing to share information, and to observe the resulting interactions. Glaser and Strauss (1965) attended various wards within a number of hospitals in order that they could compare their observations from one setting to another.

In their critiques of this original awareness context theory, Timmermans (1994) and Mamo (1999) have noted that the primary focus of knowledge and a willingness to share knowledge does not take into account how other factors play a significant part in shaping awareness, particularly within an open awareness context; and modifications to the original context were recommended. Both of these researchers use introspective ethnographic approaches to explain why their proposals were valid. Timmermans (1994) believed that emotional influences interfered with one's ability to process information and Mamo (1999) extended this belief further to suggest that people engaged in 'emotional work' to help them cope with the information they were given. Mamo (1999) believes that emotional work, whereby people construct a particular image to hide or control how they are feeling in front of others is not always recognised or acknowledged within biomedicine (Mamo 1999).

I argue that in order to understand 'resulting interactions' further it is necessary to explore and compare the multiple perspectives of doctors and patients and others; including my observations of their encounters to deepen an understanding of their experiences and motivations for interacting in a particular manner, as they meet within the medical consultation. In doing this I consider how they manage and control the disclosure and receipt of sensitive information and bad news and explore how this impacts on the other and whether or not the doctor in-particular is insightful of their patient's needs, concerns and emotions. I also explore the feelings associated with these discussions from the time the patient is referred to the Oncology department and as they progress through their illness. I argue that there is a need to understand the behaviours of doctors better within the medical consultation and to do this use an interdisciplinary approach, drawing on sociology, health and education to inform how clinical practice can be improved through continued professional development to improve patient care.

In addition to framing this research theoretically, there is clearly a need for a framework to guide the research process (Mason 2002; Silverman 2005). The main framework I chose to use to guide this study is summarised below;

<b><i>Empirical –</i></b>	Data was to be gathered from observing medical consultations and from interviewing both doctors and patients during semi structured interviews proceeding each consultation.
<b><i>Prospective –</i></b>	A group of doctors and patients are identified and followed forward in time to explore their experiences from their initial meeting with each other and throughout the course of the patient's illness.
<b><i>Located within - an Oncology outpatient department</i></b>	To explore the contexts of awareness situated within clinical practice, whereby sensitive information and bad news is communicated

During the earlier phase of the study, time was spent formalising and clarifying this framework. This phase of the study was informed by drawing on my experience and the experience and knowledge of my supervisors and medical colleagues and through a review of the methods which had already been used in similar studies to this. Although this framework remained throughout the conduct of the study, adjustments were made from the original plan as the study was undertaken in practice.

It became evident early on that the study could be conducted in two parts. Prior to conducting the main part of the study (with doctors and patients) a preliminary study was undertaken with doctors alone. The rationale for this was to gain an understanding of:

- How doctors felt they prepared for their consultations
- How doctors felt about communicating bad news to patients with advanced incurable cancer
- How doctors felt they interacted with patients
- How doctors developed their communication skills

The findings of this preliminary study were used to inform and supplement information generated from the main study. The selection and recruitment of doctors is documented in Section 3.6.2.

Patients were recruited into the main part of the study. A longitudinal, prospective approach was applied to this part of the study with a view to exploring doctor and patient experiences as they occurred within medical consultations. In contrast to this approach, retrospective studies seek to explore the views of people about their past experiences (Gilbert 2005). Yet, it was clear from the outset that a prospective approach enabled me to collect rich, in depth data at the 'individual / micro level' (Cohen and Manion et al. 2000), which had featured successfully in similar studies to this (See The 2002).

A cohort approach was chosen, to capture the experiences of a group of patients over a specified period of time (Cohen and Manion et al.2000) from initial referral and as patients progressed through their illness. This decision had been made because disclosing sensitive information and bad news does not occur during a single encounter but during various consultations throughout the patient's illness. Additionally a patient's illness does not remain static and as such, they may receive sensitive information and bad news on more than one occasion. Changes may also occur in the way patients are treated with active cancer drugs throughout the course of their illness, which means that their expectations and hopes may change as one treatment is stopped and they wait to see if another treatment is started.

It was envisaged that patients diagnosed with an advanced incurable cancer were likely to receive bad news within a relatively short space of time. With this in mind, a decision was made to see patients at the following time points; during their initial consultation with the Oncologist, and then again at 2, 4 and 6 months. Through a reflexive process, adjustments were made to this part of the plan as the study was undertaken in practice as it was deemed unworkable and naively simplistic. Making changes during the conduct of qualitative enquiry is not uncommon;

*'The design of a qualitative study should be able to change in response to the circumstances under which the study is being conducted, rather than simply being a fixed determination of research practice'*

(Maxwell 2005:7)

Rather than adhere to a strict schedule, I liaised closely with clinic co-ordinators to find out when patients were due to be seen in the outpatient department and to learn of the purpose of each visit. I was mindful that patients may associate my appearance at their consultation with that of hearing bad news, and wished to try and avoid this as much as possible by attending a range of consultations, for example; a follow up appointment because the patient had completed or stopped taking a course of active treatment; or when they may were attending the clinic to learn of the results of recent investigations; or because they had been unwell and wished to be seen by their Oncologist.

Patients were informed from the outset that I may attend any of their consultations and were asked prior to each consultation if they were happy for me (or not) to attend their next consultation. While the intention from the outset had been to see patients on more than one occasion, this was not always practical in reality. Some patients were lost to follow up, either because they were referred to another hospital for treatment, or because they died during the conduct of the study. To help the reader understand what a single case was and what developed over several

meetings, reference will be provided by each case, to provide this information in the analysis chapters. The loss of subjects to cohort studies is inevitable (Cohen and Manion et al. 2000) and even more inevitable when the people to be investigated have a life threatening illness. Due to the uncertain nature of their illness and the various treatment options available to patients, it was difficult to foresee what the attrition rate would be throughout the study and how / where patients were to be treated, although it was expected that most patients would remain in follow up at this centre.

One of the primary objectives of this study had been to understand how doctors communicated the discontinuation of active cancer treatments and to explore how patients felt about this; to understand what happened to them at this time. In reality, however, it was difficult to define the end of active cancer treatment. Some patients stopped treatment due to disease progression or because they could not tolerate the side effects of treatments, but this did not mean that they did not receive further treatment at a later date or a 'wait and see policy' ensued whereby the option of treatment in the future was deemed possible; while others continued to have treatment indefinitely and some patients did not go on to receive active treatment at all. Therefore, it was difficult to focus on this aspect of care alone, as each case was different.

In addition to this, further adjustment needed to be made once the study was undertaken in regards to the sample. Doctors and patients were the primary focus of this study as through my clinical practice and close working arrangement with doctors, I had become increasingly aware of some problems doctors and patients encountered with each other when disclosing and sharing sensitive information within the medical consultation. Although doctors were the primary information giver in this Oncology department I was aware that outpatient nurses generally accompanied patients (and their relatives if present) into the consulting room and tended to offer additional support in some cases once the patient left the consulting



room. As the consultations were to be observed, the interactions and involvement of relatives and nurses was also integral to this study and could not be dismissed. However, in reality, nurses frequently removed themselves from the consulting room, which meant that their involvement in this study was limited. This issue is considered further through my reflexive accounts (See Section 3.10.2).

Furthermore, information is not always disclosed by one person, patients may see a number of doctors throughout the course of their illness which may have some bearing on their actions / interactions and how they apply meaning to their encounters. Although, some may question the comparability of the data it is normal practice for patients to see different doctors when attending their consultations, so the data is directly related to real life situations. Although it is common practice for some clinical nurse specialists to manage consultations or be directly involved in the disclosure of sensitive information and bad news, this was not common practice within this department. For this study, it was necessary to generate theoretical interpretations based on existing practice within the cancer department in order to consider how insight gained from this study could contribute to professional development in this area.

### **3.5 Research Ethics**

Ethical approval was obtained from the Local Research Ethics Committee and from the local Research and Development Department. In keeping with good research practice, the Principles of Good Clinical Practice (Appendix I) provided the ethical guidance for this study.

The Ethics Committee were predominantly concerned with if / how I would intervene if I felt that a doctor was not communicating effectively with a patient during a consultation, which was considered to be detrimental to a patients care. In response to this question, it was explained that I was not an assessor or trainer of communication skills and was therefore not in a position to judge a doctors ability.

However, as a nurse I was governed by my professional code of conduct and would discuss any concerns with a relevant other and respond accordingly. The Ethics Committee were satisfied with this response.

In addition, the Ethics Committee were advised that due to the sensitive nature of this study, the psychological wellbeing of patients was taken into consideration during the design of the study. General Practitioners were to be sent letters (Appendix II) to notify them that one of their patients had consented to participate in my study and that should the patient become distressed their services may be called upon. The Ethics Committee approved of this action, but there was no need to call upon the services of

General Practitioners service within the context of this study.

### **3.6 Sampling Decisions**

Devers and Franklin highlight the need for a researcher to make the design of their study 'more concrete by developing a sampling frame' (Devers and Frankel 2000:2). This frame incorporates the criteria for selecting a research site and research subjects with a view to answering the research aims and objectives and with a view to explaining how research subjects will be approached and recruited into the study, bearing in mind the ethical principles of the research and informed consent. Given these recommendations, the sampling and recruitment issues are discussed in detail below.

#### **3.6.1 Research Setting and Negotiating Access**

The research was conducted in a large cancer centre of an NHS Trust Hospital. The cancer department is one of 34 cancer centres in England and Wales. In 2004 / 2005 the department saw within the region of 19,700 patients within the outpatient department. Access to this department was obtained by seeking the support of the Director of Oncology and Haematology. Arrangements were also made to meet the Head Nurse of Oncology and Matron in charge of the outpatient department. The

nature and purpose of the study were explained in detail and questions were encouraged and answered.

As this research would take place within the outpatient department arrangements were made to discuss the nature of the study with the outpatient nurses. The intention was to gain their support and to minimise any concern that they may have in regards to my presence within the department. The nurses were integral to the running of the outpatient department and were likely to be present during patient consultations. Verbal consent was obtained from each of the nurses to allow me to observe their interactions within the consultation and while escorting the patient out of the consultation.

During the planning of the research, my interest in conducting this research was generally supported by nurses, doctors, and clinic co-ordinators who would become an integral part of this study. Several concerns were raised however, in relation to the timing for approaching patients to participate in the study. This was particularly important bearing in mind that I wished to observe new case consultations with patients and their doctors. For example, some patients were seen in the Oncology outpatient department within a couple of days of learning they had cancer. There was some concern that these patients may learn of their diagnosis, having received a letter in the post inviting them to participate in this study. In meeting the requirements of Good Clinical Practice it was necessary to send patients letters, inviting them to participate in the study, at least 24 hours in advance so that they had time to consider whether or not they wished to participate in the study. It was felt that they should not be approached to participate in the research if there was a danger that they had not been informed of their diagnosis through the appropriate channels.

Furthermore, some patients may receive additional information, inviting them to take part in clinical trials and it was felt by one Consultant that it may not be appropriate

to burden them with an additional request to participate in research. This view did however, have a paternalistic overtone, which meant that the patients choice to participate in this study may be removed from them. In such cases, it was considered important for patients to be informed of the advantages and disadvantages of taking part in this study, should they wish to speak with me, and to ensure they were informed of their right to withdraw from the study at any time without their care being compromised in any way, should they wish to participate.

### **3.6.2 Selection and Recruitment of Doctors**

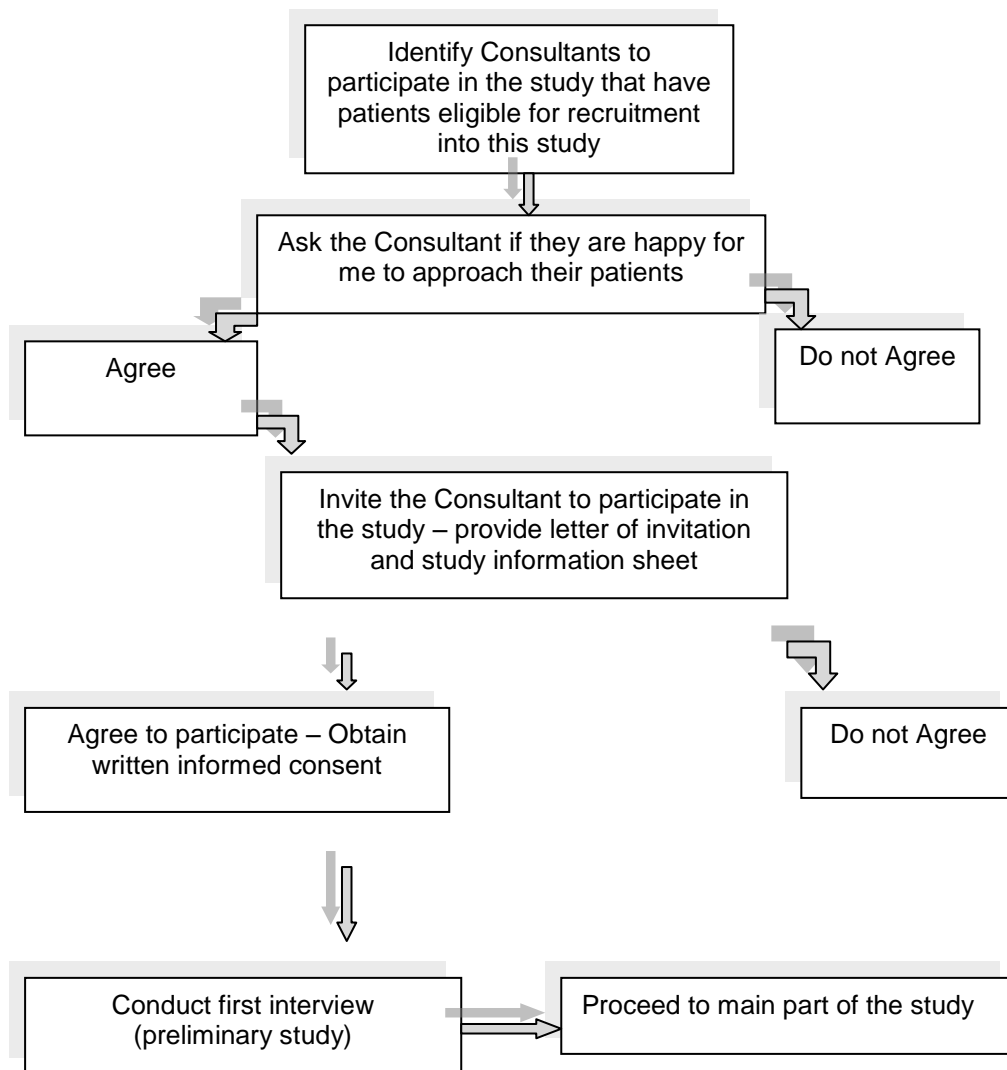
Participants are chosen with a view to providing specialised knowledge and / or experience of a phenomenon to be investigated (Burgess 1991) and as such purposive sampling was employed (Silverman 2005). Defining the sample is the first step towards determining the inclusion and exclusion criteria for selecting participants (Ritchie and Lewis 2003). In the present study, doctors were selected on the grounds that they would inform the study through their knowledge and experience of communicating and interacting with patients diagnosed with advanced incurable cancer. As a starting point, I identified Consultants who treated and cared for patients diagnosed with advanced incurable cancer who worked within the cancer centre.

#### **Consultants**

The rationale for selecting Consultant Oncologists to participate in this study was twofold. Firstly, it was necessary to recruit Consultants who were willing to participate in the study and managed the care of patients diagnosed with advanced incurable cancers. Secondly, as the Consultants acted as gatekeepers to patients, I needed to select and recruit Consultants who were willing for me to approach their patients. This was an important element of the selection and recruitment process as one of the aims of the study was to observe the interactions between doctors and patients and to obtain their combined perspectives of experiences within the consultation.

Four Consultants within the Oncology department were identified who regularly treated and cared for patients diagnosed with an advanced incurable cancer. Each of the Consultants were approached to discuss the research proposal and to ascertain their views about participating in the study. A letter of invitation (Appendix III) and information sheet (Appendix IV) were also given to each of the Consultants. Each of the Consultants expressed their interest to participate. However, one of these Consultants left the department before the study had commenced; his replacement was fortunately willing to participate. In addition to this, another Consultant expressed concern that it would be difficult to access his patients in time for me to observe the patients new case consultation because of the speed in which he received his referrals and met the patient in the outpatient consultation. The 'turn around' was somewhere in the region of 48 hours and this factor made it difficult to send the patient an information sheet in time to give them 24 hours to consider their participation in the study. There was a danger that these patients may not be fully informed of their diagnosis of cancer. A mutual decision was therefore made to exclude this Consultant from the study. One of the Consultants who did agree to participate in the study played a significant part in the initial design of the study and acted as a Clinical Supervisor. His involvement was however limited in regards to data collection and analysis decisions in the hope that this would reduce any bias that may result from his involvement.

In total, three Consultants proceeded to provide written informed consent (Appendix V) to participate in the study. The selection and recruitment process took place in preparation for the preliminary part of the study to begin. The selection and recruitment process for Consultants is presented in Figure 4.



**Figure 4 - Recruitment of Consultants**

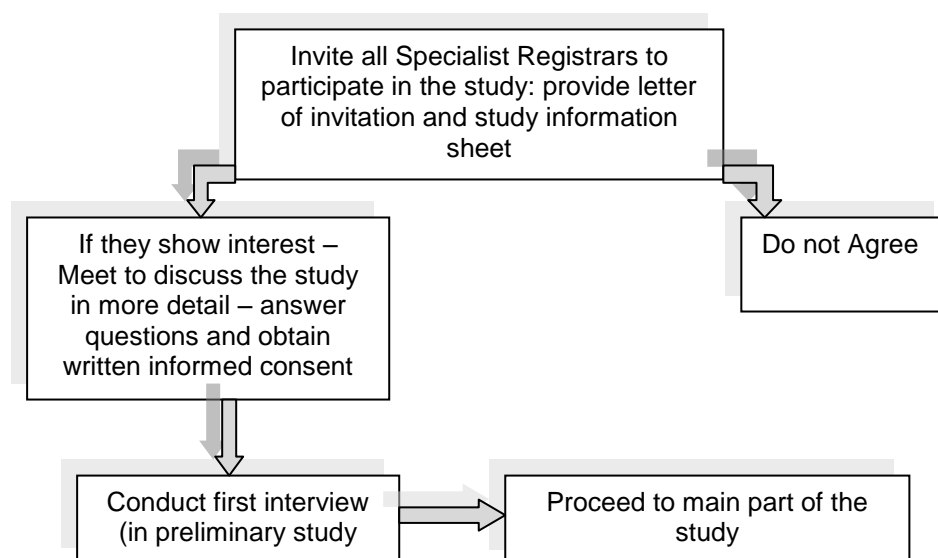
### **Specialist Registrars**

Having identified the Consultants who were willing and able to participate in the study, I also needed to bear in mind that Consultant Oncologists do not run their outpatient clinics alone. Having prior knowledge and understanding of this department, I was aware that Consultants were supported by a team of Specialist Registrars (SpR). It was necessary to approach all of the SpR's who worked within the cancer department to ask if they would be willing to participate in the study. To put this in context, a Consultant and SpR work alongside each other in the outpatient clinics. The patient may therefore, be seen by either the Consultant or by the SpR.

It was necessary to approach all of the SpR's for their participation in the study as they each rotated between Consultants on a four monthly basis and because they cross covered for each other in clinics if a doctor was absent. If any of the SpR's declined to participate in the study, this would need to be borne in mind when a patient attended their outpatient consultation to ensure they were seen by a doctor who had agreed to participate. Only one SpR declined to participate in the study because he felt he already had too many demands on his time.

Each of the SpR's were sent a letter of invitation and an information sheet in the internal post. They were asked to either notify me in person, by email or to use the reply slip attached to the back of the information sheet to notify me of their decision to participate (or not) in the study. Once notification was received, an appointment was arranged with each of the SpR's to provide verbal clarification of the study and to provide the opportunity for them to ask questions, which I tried to answer. Each of the SpR's who agreed to participate in the study provided written informed consent (Appendix V). A summary of the recruitment strategy for SpR's is illustrated in Figure 5.

To aid clarity, the term 'doctor' has been used generically throughout the written text when describing Consultants and SpR's. Many of the doctors were approached in May 2006 and three more were approached in January 2007 when they started working within this cancer centre. Demographic details of doctors can be found in Section 3.6.5.



**Figure 5 Recruitment of SPR's**

### **3.6.3 Selection and Recruitment of Patients**

Patients diagnosed with an advanced incurable cancer were approached with a view to recruit them into this study if they had been referred to one of the Consultants participating in the study. Patients were approached to participate in the study if they had been diagnosed with oesophageal cancer, small cell lung cancer, non-small cell lung cancer with metastatic disease, gastric cancer and metastatic colon cancer. The expected median survival time for these patients was within the region of 6-12 months, which meant that they were ideally suited to this study if I wanted to capture various stages of their illness, whereby sensitive information and bad news may be disclosed, to explore how contexts of awareness were managed and experienced.

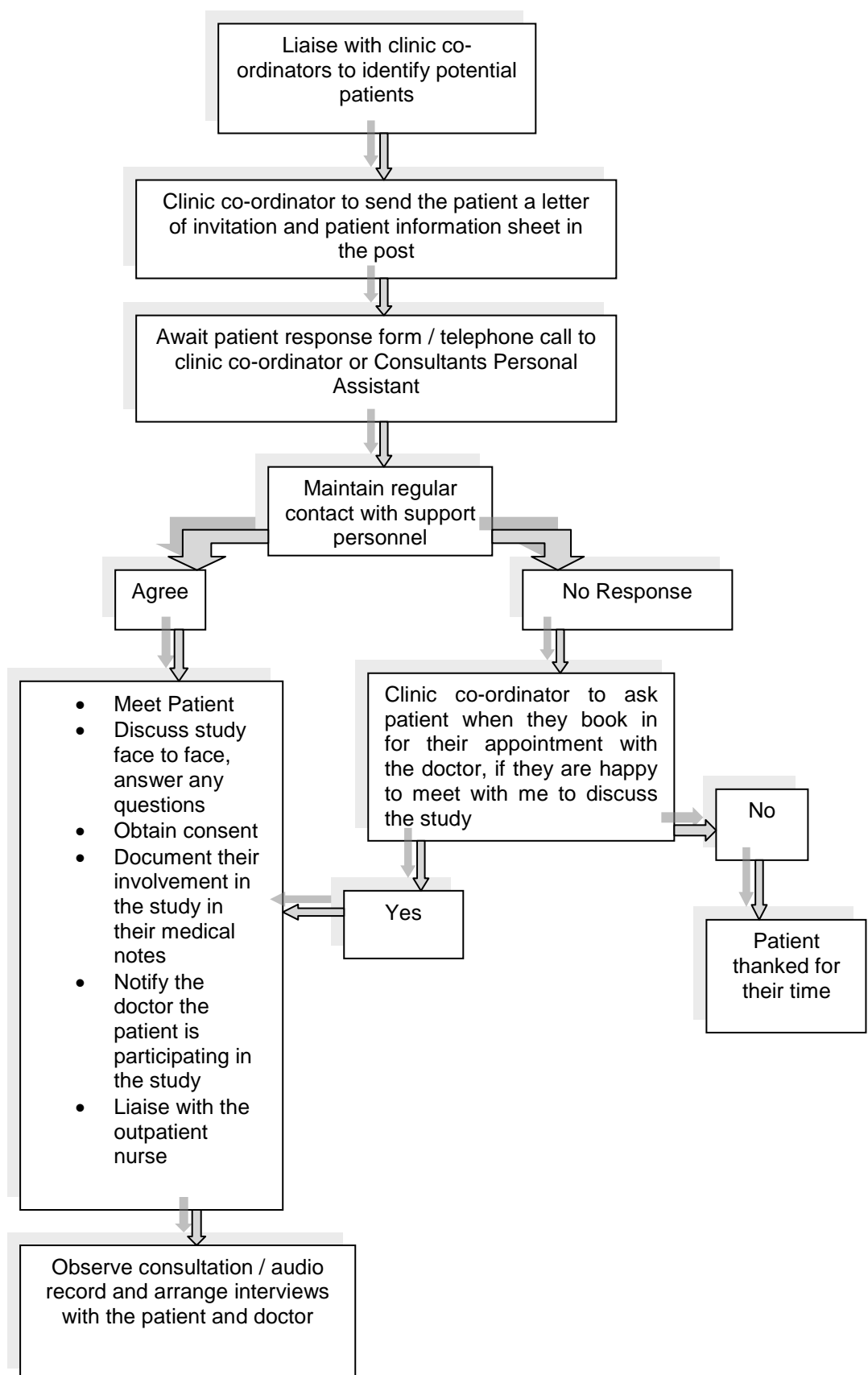
The selection and recruitment of patients was very much reliant on the support and involvement of clinic co-ordinators. Each clinic co-ordinator who worked for one of the participating Consultants were asked for their help and support and any advice they may be able to offer in regards to approaching their patients (for further information go to section 3.6.5). The criterion for patient inclusion was:



- Over 18 years of age
- Have a new diagnosis of advanced incurable cancer or a recurrence of disease which was progressing
- A median survival period between 6-12 months
- Willing to participate in the study and provide written informed consent
- Patients must be aware of their diagnosis

A decision was made to recruit patients over the age of 18 because it was believed that the needs of patients under this age may differ from those of adults. Patients were excluded from being approached if they were unable to consent for themselves or if they had a cognitive impairment, whatever the aetiology as this would make it difficult to interview them and ask questions about their experiences

A summary of the recruitment strategy for patients is illustrated in Figure 6.



**Figure 6 - Recruitment Strategy for Patients**

An initial decision had been made to try and recruit between 20 and 25 patients. Although there is little guidance to help determine the size of samples (Gerrish and Lacey 2006), it was felt that this was an appropriate number to aim for because it was apparent from the qualitative literature that this number of participants would generate a significant quantity of rich data. However, during the recruitment phase of the study a decision was made to stop recruitment with 16 patients.

The rationale for this was twofold. Firstly, the longitudinal nature of the study had an influential effect on the decision as a significant amount of data was being generated. Since qualitative research is used to collect in-depth data, it was more appropriate to retain depth rather than breadth in terms of the sample size as highlighted by Ritchie and Lewis (2003). Secondly, it was initially anticipated that the recruitment of patients and collection / analysis of data would take approximately 12 months; however, this had proved to be optimistic. It was initially envisaged that it would take within the region of 3-4 months to recruit patients to the study and the remaining 8 months would be spent collecting data through various stages of the patient's illness and analysis would occur concurrently with data collection. The actual recruitment period lasted for 9 months; from August 2006 until April 2007. During this time 16 patients were recruited into the study. Although the figure was lower than anticipated, a decision was made at that point between my supervisors and myself to halt patient recruitment. Having already started to analyse the data there was some confidence that categories were emerging and a number of comparisons could be made within the data. The demographics of patients who participated in this study can be found in Section 3.6.5.

It was unfortunately inevitable that some patients may be lost to follow up during the study. It was envisaged that these patients were experiencing a difficult time in their lives and may decide that they did not want the added burden of participating in a research study. Those who did agree to participate may also sadly die during the conduct of the study; I had no control over these factors. Once recruited into the

study, patients did not withdraw their consent, however, some did sadly die and some were lost to follow up as they were transferred to another hospital for care.

#### **3.6.4 Issues of Consent**

Written informed consent was obtained from doctors and patients in line with the Local Research Ethics Committee request to do so. As Gerrish and Lacey (2006) highlight, it was necessary to ensure that doctors and patients continued to provide their consent due to the longitudinal nature of the study. This was ensured by asking both parties if they were happy for me to attend and observe their consultations and for me to interview them following the consultation.

It was not uncommon for relatives to be present during consultations or for them to be present during interviews. In instances such as this, Mason (2002) asserts that a researcher has a responsibility and a moral obligation to consider the implications of this within their research practice. Relatives were not the key focus of the study, however it was anticipated that they would be present during consultations. As such verbal consent was obtained from them for me to observe their interactions and involvement during consultations.

The same relative often accompanied the patient on their visits to the outpatient department and as such they were present during my initial discussion with the patient about the nature of the study immediately prior to obtaining the patient's written consent. As such the relative received the same information about the nature of the study and had the same opportunity to ask questions. In addition, some of the relatives were present during the conduct of interviews with the patient, (this was often at the patients request) and inevitably participated in the discussions. In these cases, the relative was asked if they were willing for me to use the information they provided. This question was asked on each occasion, either prior to the interview or following the interview. None of the relatives refused.

### 3.6.5 Study Participants

#### Doctors

All of the doctors, except one were interviewed during the preliminary stage of the study. Basic demographic details can be seen in Table 1. Once recruited, all of the doctors remained in the study.

Grade	Gender
3 Consultants	2 Male 1 Female
13 Specialist Registrars	6 Male 7 Female

**Table 1: Demographics of doctors participating in the study**

Some doctors participating in the present study knew me as a nurse and colleague, as I had worked in the cancer department for a number of years as a senior nurse. As such I had already established a number of relationships based on trust and co-operation albeit within a different capacity. Jorgenson (1989) highlights that establishing relationships based on these qualities helps the researcher gain a rapport with others and make friends within a particular research setting. I was however apprehensive about how I would be perceived within my role as observer as I was acting and interacting with them in a different capacity. Some doctors explained however, that they became accustomed to my presence in consultations, with some offering assurances that they 'forgot I was there'. In other instances, particularly in the earlier stages of the study, some of the SpR's said that they felt conscious of my presence and they questioned whether or not they had acted differently towards the patient. In addition, several doctors indicated that they thought I was present during their consultations with patients to assess their performance and as such wanted me to offer them feedback; something I resisted doing. Through these experiences I became sensitive to their insecurities and was able to explore issues around support, assessment and feedback and why they felt

they may have acted differently towards a patient due to my presence in the consultation.

## **Patients**

I met with clinic co-ordinators on a weekly basis to identify potential patients. If a patient fulfilled the eligibility criteria a letter of invitation (Appendix VI) and a study information sheet (Appendix VII) was sent to the patient in the post. The clinic co-ordinators did this on my behalf. In most cases, the recruitment process for each patient needed to be completed within a week of the patient being referred to the cancer department via the multidisciplinary team meeting or from external referrals. In the event that we had not received confirmation beforehand that the patient wished to talk to me about the study, the clinic co-ordinator would approach the patient in the outpatient department to ascertain whether or not they wished to speak to me about participating in the study.

A decision had been made from the outset that clinic co-ordinators would speak to the patient about this study when the patient 'booked in' with the clinic co-ordinator to inform them of their presence within the department. This approach was used to try and limit any feelings of coercion; we felt that if patients were approached by me in the first instance this may influence their decision to participate in some way. If patients were willing to speak to me, they would be taken to a consulting room, where I would introduce myself and explain the study in more detail and the reasons for conducting the work. Prior to obtaining the patient's consent (Appendix VIII) they were informed that they were free to withdraw their consent at any point during the study, without having any negative bearing on their future care and treatment. The issue of anonymity was also stressed and patients were advised that the audio recordings of their consultations would be destroyed once the study was completed.

An excel spreadsheet was designed to collect demographic data on patients who were approached by the clinic co-ordinators to participate in this study. During the nine month period 68 patients (16 women and 52 men) were sent letters inviting

them to participate in the study. In total, 16 patients agreed to participate in the study. Details of these patients can be seen in Table 2. Of the 52 patients who declined, only a few of them provided reasons for their decision. Those who did offer explanations tended to say they felt too unwell whilst several said that they had not received a letter of invitation and information sheet in the post, explaining the nature of the study.

From the 16 patients who did participate in the study, 13 went on to receive chemotherapy and some went on to receive radiotherapy to help palliate their symptoms. Two patients died before they could commence treatment and one patient refused chemotherapy. The patient who refused chemotherapy had considerable knowledge of treatments and explained that he did not want his quality of life compromised further. Three of the patients had initially received surgical intervention when they were first diagnosed with cancer (approximately 18-24 months prior to their participation in my study). Each of these patients had experienced a recurrence of their disease, hence their new referral to see the oncologist. The remaining 13 patients had been newly diagnosed with cancer and most had learnt that they had cancer within the past month. Two of these patients knew there was a possibility that they had cancer but their diagnosis had not been confirmed.

Characteristics	Number of participants
<b>Gender</b>	
Male	12
Female	4
<b>Age</b>	
<59	5
>60	11
<b>Marital Status</b>	
Married	15
Single	1
<b>Type of Cancer</b>	
SCLC	1
Gastric	2
Oesophageal	4
Pancreatic	6
Other	3
<b>Ethnicity</b>	
White British	15
Asian	1
<b>Occupation</b>	
Retired (Foreign Minister/Police/Dairy worker/Company Executive/Process, Plant, Machine Operator)	6
Sales and Customer Services	2
Housewife	1
Process/Plant/Machine Operator	2
Farmer	1
Health Care	1
Professional	1

**Table 2. Demographics of patients participating in the study**



During the study, 10 patients were lost to follow up; 6 patients were seen again for a second consultation and 3 patients were seen again for a third consultation. A breakdown of this is presented in Table 3, along with the names of the doctors they saw on each occasion.

Patient ID	Doctor ID	New case Consultation	1 <sup>st</sup> follow up Consultation	2 <sup>nd</sup> follow up Consultation
Mrs Brown	Dr Taylor	I	L	L
Mr Johnson	Dr Taylor	I	L	L
Mr Hart	Dr Davis	I	D	D
Mr Robinson	Dr Roberts Dr Taylor Dr Taylor	I	I	I
Mr Thompson	Dr Davis Dr Evans	I	I	D
Mr Rogers	Dr Roberts Dr Skelton Dr Mason	I	I	I
Mr White	Dr Taylor	I	L	L
Mrs Edwards	Dr Wright	I	L	L
Mr Lewis	Dr Hall Dr Jones	I	I	D
Mrs Martin	Dr Taylor	I	C	C
Mr Jackson	Dr Williams	I	D	D
Mrs Moore	Dr Wright	I	D	D
Mr Baker	Dr Davis Dr Davis	I	I	D
Mr Young	Dr Wright	I	D	D
Mr Hollis	Dr Harris	I	D	D
Mr Anderson	Dr Davis Dr Hall Dr Davis	I	I	I

**Key:** I = Interview. D = Died. L = Lost to follow up. C= Chemotherapy

**Table 3: Consultation Profile for Main Part of the Study**

The names of participants who agreed to participate in the study were replaced with a pseudonym to provide them with anonymity when presenting research findings.

While patients did not know me prior to this study a decision had been made to introduce myself as an oncology nurse and a researcher. In the interests of the study my role as researcher was emphasised more. It was important for patients to know that I was an experienced oncology nurse as I hoped that patients and their relatives would feel comfortable and at ease in my presence. In addition, it was necessary to be honest with participants in the hope that a trusting relationship would develop between us. However, attempts were made to explain that during the conduct of the study, I would primarily assume the role of a researcher in the hope that patients would not rely on me to provide them with detailed medical information or intervene in their care. When there is a potential conflict in roles, the researcher has a responsibility to try and limit any concerns and possible complications (Jorgenson 1989). Furthermore, I did not want to appear insensitive or aloof to patients and their families in assuming an observer participant role if I sat in the background and observed interactions and behaviours with doctors and nurses during their consultations. I did however take on a more participatory role if the situation dictated it.

### **3.7 Data Collection**

Ethnography has been described as an approach to research which seeks to understanding the meaning people attribute to their interactions and actions within a particular social setting (Wolcott 1999; Brewer 2000; Timmermans and Tavory 2007). As such the researcher embarking on ethnography needs to seek access to a particular social setting with a view to observing, documenting and describing the phenomena under investigation (Hammersley and Atkinson 2005). It is possible therefore to collect different kinds of data through various forms of observation, interviews and field notes whereby comparisons with the data can enhance understanding and interpretation of the social phenomenon being studied (Hammersley and Atkinson 2005).

As the aim of this study was to explore doctor and patient descriptions of their experiences of consultations and observations of their interactions, a multiple

method approach was utilised. This incorporated participant observation and semi structured interviews and the audio recordings of consultations. The rationale for this approach centred on accessing medical consultations within the oncology outpatient department, to observe and record consultations and to elicit information from participants about their experiences, beliefs and values. A detailed account of the data collection procedures is included in this section.

### **3.7.1 Rationale for Data Collection and Choice of Methods**

A multi method approach to data collection incorporating semi-structured interviews, observations, audio recordings of consultations and diary keeping (optional) was selected to elicit information in accordance with the research aims and objectives. I believed that one method of data collection would inform the other (Hammersley and Atkinson 2005), to provide an in-depth and insightful understanding of the data from multiple perspectives. Some are however, critical of this form of data collection, believing that the use of multiple methods may be confusing and does not necessarily lead to an overarching reality or ultimate truth (Silverman 2005).

A decision had been made to explore the combined perspectives of doctors and patients to develop a broader understanding of what they each believed transpired during their interactions with each other. It was envisaged that multiple accounts would provide a richer and more inclusive insight into their experiences, something that has been lacking in empirical research to date. It was also important to be theoretically sensitive to the data to understand doctors and patients accounts of their experiences. I thought it would bring an added dimension to the study if I were to observe both doctors and patients and relatives if they were present during consultations; as a way of bringing in an outsiders insight. As well as hearing the talk that emulated form doctor and patient interactions, I could also observe their non verbal communications and get a sense of the atmosphere and mood within the consulting room.

Whilst it was important to observe interactions, it was also necessary to listen to what the doctors and patients had to say to each other. The consultations were therefore, audio recorded to provide a reference of their discussions. Audio recordings provide a valuable record of naturally occurring interactions which offers a reliable and authentic source of data which the researcher can keep referring back to, as a reminder of what happened (Silverman 2001).

During the 20 month data collection period (main study) 25 consultations were attended. This meant that in total; 25 interviews were conducted with patients; 25 interviews were conducted with doctors; 25 consultations were observed (field notes were made) and 25 consultations were audio recorded. Patients were also given the opportunity to keep diaries, to record any thoughts they may have had about the consultation once they had gone home; only two patients did this following their first consultation. To demonstrate the overall scope of this study Table 4 presents the number of interviews, observations and recordings of consultations undertaken throughout this study, all of which were transcribed and analysed.

	Interview with Doctor	Interview with Patient	Observations	Recordings of Consultations	Sub Total
<b>Preliminary Study:</b>					
	15	N/A	N/A	N/A	15
<b>Main Study:</b>					
New Case Consultation	16	16	16	16	64
2 <sup>nd</sup> Consultation	6	6	6	6	24
3 <sup>rd</sup> Consultation	3	3	3	3	12
<b>Total Episodes:</b>					<b>115</b>

**Table 4: Breakdown of Interviews, Observations and Recordings of Consultations.**

### 3.7.2 Participant Observation

Participant observation is synonymous with ethnographic research and has been described as;

*'spending long periods watching people, coupled with talking to them about what they are doing, thinking and saying, designed to see how they understand their world'*

*(Delamont 2004:218)*

In the context of the present study participant observation was an appropriate method of enquiry as the aim was to observe interactions between doctors and patients within the context of medical consultations in the oncology outpatient department. As such, observing their interactions was an integral part of the study.

In assuming the role of observer, researchers need to make their role clear within the research field. There are some criticisms that researchers tend to distinguish their role between participant and non participant observers but this is not sufficient and requires further clarification from the researcher as there are further variations to be made in association with these positions (Atkinson and Hammersley 1994). For example, complete observer, observer as participant, participant as observer and complete participant (Junker 1960). In the present study I adopted the role of observer as participant.

In addition to defining a role, the researcher needs to give thought to how they will present themselves and behave in front of study participants and consider how others may perceive them prior to entering the field. In entering the field;

*'Negotiations and decisions about relationships involving trust, respect, mutual disclosure and obligation are part of the process as well as shaping the process and of course the data'*

*(Mason 2002:95)*

This was particularly significant in the present study for a number of reasons. I needed to be alert and conscious to the potential issues associated with how participants perceived and distinguished my role of nurse, colleague and researcher.

### **3.7.3 Interviews**

In addition to participant observation, semi-structured interviews were undertaken with doctors and patients participating in the study. Semi-structured interviews are generally designed around a 'loose structure' and comprise of open ended questions that relate to the area to be explored (Britten 2006), and prompts to help direct the researcher during the interview (Rapley 2004). As such, the intention of the interview is to capture the personal perspectives of participants with a view to exploring their experiences within the context of the area under investigation (Ritchie and Lewis 2003).

In the present study, three interview guides were developed; one for the preliminary study with doctors, one for the main part of the study for doctors and one for the main part of the study for patients. Each interview guide had a set of open ended questions directed towards exploring emerging themes and concepts and to seek clarification of observations from practice and each guide had a list of additional prompts to help guide the interview and explore responses in greater detail (Appendix IX). Prior to commencing the study an earlier interview guide had been piloted with a doctor and a friend and adapted according to their feedback and my experience.

In describing his personal experience of interviewing people, Rapley (2004) explains how interview schedules are useful to help focus and direct the flow of the interview, but may be used differently within different interviews, dependent upon how the interview is progressing. During the piloting of the interview guide in the present study, it became apparent that I needed to be more relaxed and flexible in the way that questions were asked, as I tended to systematically work my way through the questions and failed to explore their responses further with additional questions.

Moreover, Rapley (2004) describes how much 'methodological debate' is directed towards 'interviewer conduct' and suggests that researchers need to try and develop a rapport and trusting relationship with research participants in the hope that they will feel comfortable and will find it easier to talk. With this in mind, I commenced initial interviews with a brief summary of who I was and what the interviewee could expect during the interview; this format became more relaxed during the course of the study as participants became more familiar with me and the nature of the study. In regards to patients, I did generally start each interview by inviting them to tell me what had been happening to them in the hope that this would make them feel more at ease and to give them the opportunity to say what they wanted to say.

Although participant observation and interviews are presented independently of each other in this chapter (for ease of presentation), it is recognised that interviews within ethnographic research encompass, not only informal interviews as described above, but also include informal conversations with participants which form part of the observation process (Hammersley and Atkinson 2005). Interviewing doctors and patients gave me the opportunity to talk to them without being interrupted away from the main hustle and bustle of the clinical area. The longitudinal nature of the study provided the opportunity to explore and clarify the meaning and / or context of participant's comments and behaviours further and to explore other areas of enquiry further in light of new themes and concepts emerging from the data. In essence an iterative approach was used (Strauss and Corbin 1998; Hammersley and Atkinson

2005). As such, I was able to develop the interviews in light of previous observations and interviews. This enabled the interviews to develop into a natural conversation.

### **3.7.4 Recording Field Notes**

One of the biggest problems in observational research of this kind is knowing what to observe and what to write about (Delamont 2004) and when to write it (Hammersley and Atkinson 2005). Delamont (2004) advocates that essentially the researcher should;

*‘..observe everything she can, writes the most detailed field notes she can, takes time to expand, elaborate and reflect upon them outside the field and / or as soon as time permits..’*

*(Delamont 2004:225)*

In this study the dialogue between doctors and patients and relatives if present was audio recorded, having obtained prior permission to do so. Observations were therefore focused on the ways participants’ interacted and behaved with each other, their expressions of emotions, roles, the atmosphere in the room and any disturbances. Field notes were therefore made with the intention of noting the various features and properties of these social processes (Hammersley and Atkinson 2005).

During the early stages of the research I found that I tried to capture and record everything. As the study progressed however, I found that my observations became more focused. This behaviour is inevitable according to Hammersley and Atkinson (2005) who report that during the early days of a research project the scope of a researchers observations is wide because of their uncertainty about what they should or should not record. As the study progresses however, the researcher becomes more attuned to the study and is more likely to focus their observations



and notes. However, others report their concerns of not recognising things if they became too focused and realising the significance of what they have missed at a later date (Johnson 1975). For example, while I made notes to record the way relatives behaved in consultations, I did not fully recognise the significance of their presence in the initial stages of the study. As I became more alert to the presence and position of relatives my notes became more detailed.

Hammersley and Atkinson (2005) suggest that a researcher should try to make notes as soon as possible after the observed action has taken place, otherwise recall may be lost and episodes of observation may become 'muddled'. However, they acknowledge that it may not always be appropriate to make notes during the field (Hammersley and Atkinson 2005). During the actual consultation, I found that it was possible to jot down prompts to help me recollect observations. At other times, for example when accompanying the patient out of the consulting room or following my interviews with them; or when spontaneous conversations took place; or whilst they were observed to interact with others outside the consulting room, I felt it was inappropriate to make notes as this could be potentially disruptive and intrusive. An overall strategy was adopted, whereby more detailed notes could be made at the first available opportunity, this was usually sometime during this day or the following day at the latest. I found that I preferred to make more detailed notes on the same day wherever possible while the events were still fresh in my mind.

Field notes initially took the form of hand written documents which were later transcribed into a word document on my computer and subsequently updated into NVIVO; a data analysis software package. The field notes were made identifiable to each event by date, the location, and the codes attributed to each participant. These codes were later changed and pseudonyms were applied to each of the study participants as this felt more personal in the 'writing up' phase of the study. The notes were developed and organised into categories based on Strauss and Corbin (1998) model of memo writing.

Prior to describing the data collection process in more detail, the data collection period for this study is presented in Table 5.

Year 2006											
Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
				Preliminary study interviews with Drs							
							Main Study: Recruitment of patients				
				Data Collection							
				Analysis – ongoing							
Year 2007											
Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Recruitment of patients											
Data collection - continues											
Analysis – ongoing											
Year 2008											
Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Data collection											
Analysis - ongoing											

Table 5: The data collection period

### **3.7.5 Observing Consultations**

Observing interactions in the consultation gave me a sense of the atmosphere in the room and I was able to observe the expressions of emotions, empathy, support or any form of disharmony expressed through the participants' interactions. I generally sat on the periphery of the consulting room, in a position that enabled me to observe doctor and patient and / or relatives interactions, behaviours and emotional expressions.

Although the focus of the study was to gain an understanding of the doctors' and patients' experiences, relatives were present during a number of consultations and as such they played a part in contributing to the data and outcomes. For example, at times I was alone with the relative during the consultation, while the doctor and patient (and nurse if present) were in an adjoining room. On such occasions, I was able to engage in discussions with them and / or express empathy if they were distressed. At times the relative provided a different account to that of the patient, in terms of how the patient was feeling and coping. In addition to this, it became interesting to observe how doctors interacted with the relatives and to ascertain through interviews, how doctors perceived them within the consultation. It became apparent throughout the study that relatives played a significant role within the consultation, although this was not explicitly observed in all cases or alluded to by some of the doctors.

In addition to observing the consultation between doctor and patient (and relative), I would sit in the consulting room while the doctor prepared for the consultation before the patient was called to meet with the doctor. During these moments doctors would sometimes share their concerns about the patient, or take this opportunity to teach medical students by describing the patient as a case study. Moreover, I accompanied the patients and their relatives and the nurse (if present) out of the consulting room following the consultation and observed their interactions further

until they either left the department or until they started to talk through the practicalities of us meeting again.

Throughout the duration of the study, patients would be contacted by phone, or asked prior to their consultation (if unattainable via phone) if they were happy for me to observe their consultation and arrange an interview with them following the consultation. This was arranged once the clinic co-ordinator had confirmed that the patient would be attending the outpatient consultation for a follow up consultation. In addition, I would make attempts to learn from the clinic co-ordinator, which doctors would be present during the outpatient clinic (when the patient was due to be seen) to forewarn them that I would be present in the outpatient department and may observe one of their consultations.

For my visits to the oncology outpatient department, I elected to wear everyday smart clothes, in keeping with the dress code of the department. I did not wear my uniform as I did not want to add further complication and confuse participants as to my role and purpose for being in the department.

In practical terms, my role did encapsulate more than that of an observer and while I did observe, at other times I made myself useful by offering assistance within the consulting room. While Hammersley and Atkinson (2005) suggest that some distance needs to be maintained, there are times whereby the researcher needs to offer assistance. Costello for example, describes how he at times felt a need to intervene if he felt that the care of a patient was being compromised (Costello 2001). This view was reflected in my practice and can be explained in terms of wanting to help others in times of need (Gerrish 1997).

### **3.7.6 Conducting Interviews**

Interviews were undertaken either on the same day as the observed consultation or within a week of the consultation having taken place, as I wanted to capture the perspectives of doctor and patient experiences as near to the consultation having

taken place as possible. In retrospect, there were times where I may have found it more valuable to reflect on my experience of the consultation further prior to conducting the interview to help inform my choice of questions. However, I was able on a number of occasions, to ask further questions during future interviews.

On most occasions, the patient was accompanied by a member of their family. This did not concern me as they were generally there in support of the patient and at the patient's request. Two spouses were particularly vocal however, during the interviews and I was concerned that they may prevent the patient from speaking freely. While this may have been the case they also supplemented information given by the patient and generated further discussions. Although doctors and patients were the primary focus of the study, relatives offered relevant and valuable information.

## **Recording Interviews**

Recording ethnographic study where possible through the use of audio or visual recordings has been perceived as a desirable option (Hammersley and Atkinson 2005), in light of the fact that the researcher can be freed from making notes during the conduct of interviews, therefore freeing up their time and allowing them to focus on the interviewee (Legard, Keegan et al. 2003). Despite the added benefits, some warn of the dangers of relying solely on recordings as the quality of recordings can at times be compromised and moreover, the researcher needs to be prepared in advance for the possibility that they may lose data (Hammersley and Atkinson 2005). In the present study one interview was lost. In addition it is rare for participants to refuse to have their interviews recorded as long as the researcher provides an explanation as to the purpose of the recording and offers assurances of anonymity and safe storage of recordings (Legard, Keegan et al. 2003).

All of the doctors and patients agreed to have their interviews and consultations audio recorded. In addition, patients were asked if they would like to receive a copy of the audio recording of their consultation. Four patients felt that this would be

helpful as a memory aid but one patient declined as he felt it would be too 'macabre' for his family to hear the recording following his death. Each interview typically lasted between 15 and 90 minutes.

### **Location of Interviews**

Patients were given the option to choose where they would like their interviews to be conducted. Some patients chose to have their interviews conducted following their consultation in a private room within the outpatient department, while others chose to have their interviews conducted within their homes. An influential factor in their decision appeared to be whether or not their car parking ticket was about to expire or not. Consultants were interviewed in their office however this was not feasible in the case of SPR's as they shared offices. The SPR's were therefore interviewed within the cancer department in a vacant room which afforded some privacy. This was either in one of the Consultant's offices if they were empty and available or in one of the consulting rooms within the department. Most of the doctors did not express any concern about where they were interviewed; only one doctor expressed feelings of discomfort being interviewed in one of the Consultant's office and arrangements were made to conduct the interview elsewhere.

### **3.7.7 Transcription of Data and Data Management**

In total 115 transcripts were created through interviews, field notes, or through audio recordings of consultations. The transcriptions were transcribed using Microsoft Word. I transcribed many of these interviews but also enlisted the help of a transcribing agency and friend. Following transcription, I listened to each of the recordings, while reading through the transcripts to capture any errors. This strategy also helped me become re-familiar with the data. Transcripts and field notes were stored in a secure environment. All research data was labelled using a code number to identify each participant.

The transcriptions were then imported into NVIVO (version 7). Many have appraised the process involved in using these packages and their overall benefit but the

discussion continues within the literature as to the pros and cons of using such programmes (Spencer, Ritchie et al. 2003; Hammersley and Atkinson 2005).

### **3.8 Data Analysis**

Analysis of ethnographic research is not a distinct phase in the research process, as it begins prior to the researcher entering the field and continues throughout the duration of the study and during the writing phase of the study. As Hammersley and Atkinson (2007) explain:

*'Formally it starts to take shape in analytic notes and memoranda: Informally it is embodied in the ethnographers ideas and hunches. And in these ways, to one degree or another the analysis of data feeds into research design and data collection.'*

*(Hammersley and Atkinson 2007:158)*

This iterative process of data collection and analysis was utilised within the present study, with each stage informing the other. As themes and concepts emerged from the observations, interviews and recordings of consultations it was necessary and appropriate to pursue these further in subsequent interviews and observations.

It is common for qualitative data analysis to identify key themes, concepts and categories (Spencer, Ritchie et al. 2003). The nature of how they are generated does however vary between different approaches (Hammersley and Atkinson 2005). In the present study techniques associated with a constant comparison method were used to help identify, define and refine the theoretical categories as they emerged from the data (Strauss and Corbin 1998). While Glaser and Strauss (1967) and Strauss and Corbin (1998) describe various techniques and steps to help guide the analysis process, Hammersley and Atkinson (2007) warn that there are no clear steps which should be taken to guide the analysis of ethnographic data and instead stress the importance of thinking about the data and becoming sensitised to the data.

Constantly making comparisons within the data helped me analyse the data from interviews, observations and recordings of consultations, in order to describe and interpret the views of those being studied and bring substantive meaning to their experiences. Although carrying out data collection and analysis is demanding and time consuming, it is essentially imperative to ensure that the data collection remains focused and does not drift in different directions (Hammersley and Atkinson 2005). Utilising a constant comparison approach allows the researcher to consider variations within the data and to act on them accordingly as and when they arise and to retain a sense of focus (Strauss and Corbin 1998).

In managing the data, the following steps were adhered to, following a fluid and cyclical process (Hesse-Biber 2007), adopting some of the analysis techniques proposed by Strauss and Corbin (1998) as a guideline.

## **A. Coding**

Data was coded using either line by line analysis or larger units of text, dependent upon the context of the data. In some cases, line by line analysis was relevant but at other times paragraphs were coded if there was a risk that the context of the data may be lost. Some of the first codes were modified as the research progressed. As codes were created, comparisons were made and codes which were conceptually similar were merged.

## **B. Memo Writing**

Memos were written, to consider the deeper meanings of each code and to help sensitise me to the data. Questions (how, what, why, where, when) were asked about a whole range of issues including: the significance of observations, interpretations, and experiences, meanings behind comments and about the characteristics of concepts. Writing memos helped me consider emerging concepts and interrelationships between concepts which helped build categories and their sub categories. Memos were also valuable in order to consider different conditions and causal conditions (for example: sets of events or happenings – context of



environment), intervening conditions (for example: changing one's mind), contextual conditions (for example: reasons why people behave in different ways) and actions / interactions be these strategic or routine.

### **C. Axial Coding**

During this process, categories and subcategories were examined further to try and identify links and relationships between phenomena and look for properties within the data. A number of questions are again asked about the data, (why, how where, when, what) to try and understand causal conditions, identify different situations and contexts to understand, strategies used by people to handle different situations and to consider the consequences of actions. On some occasions, links may have been missed or aspects of the categories may not have been considered, but moving backwards and forwards with the data or collecting new data was helpful. It was also helpful to create spider diagrams to help me consider and visualise the relationships between categories and subcategories.

### **D. Theoretical Sampling**

In addition to making comparisons within the data, some comparisons were also made by considering issues outside the subject area. For example, using in-vivo words or phrases to consider how they may be interpreted in other contexts, or through making comparisons with personal experiences. Although these general approaches were applied to the analysis of the data, there was some variation between the types of data sets and as a consequence, I will break the analysis process down into further sub sections, following an overview of how the theoretical focus was used to interrogate and order the data.

#### **3.8.1 Theoretical Focus and Coding Format**

The coding format was informed by the theoretical framework and research intentions. My primary objectives were to explore how doctors and patients manage and control the disclosure and receipt of sensitive information and bad news; to explore the feelings associated with dealing with such information from when

patients were first referred to the oncology department and as they progressed through their illness; to examine how the concept of awareness contexts can help understand the perspective of both doctors and patients in the consultation to explore the impact and influence an individual's own awareness context has on the consultation experience; and to reflect upon doctor and patient communication in such situations with a view to considering future strategies for doctors' continuing professional development. With these objectives in mind, the theoretical framework helped me to interrogate and order the data to consider the following points:

- How information was managed
- Whether or not information was tailored to meet the needs of the individual (if these needs were in fact known or explored)
- Whether or not people were willing to share information – medical or emotional
- How emotions interfered with cognition
- Whether or not people were able to share their emotions and with whom?
- To consider what people did with their emotions and how they used them
- How people presented themselves in front of others and whether or not they were aware of their behaviour / interactions
- How states of awareness were managed and what happened when they changed
- What were the contributing factors to changes in awareness and the results this had on interactions both at a particular time and in future interactions
- How meaning was attributed to experience
- What helped or hindered the way people communicated and interacted with each other in the medical consultation

The following sections show how each of the data sets were managed and how the coding frame was broken down further.

### **3.8.2 Observation Field Notes**

Field notes were typed and imported into NVIVO. Observation field notes were used in several ways; (a) to help verify and inform data collected from interviews and recordings of consultations and (b) to record and make comparisons between observed behaviours, interactions, emotions and the location and atmosphere within the consulting room. Observation field notes were particularly valuable in regards to capturing and generating theoretical properties relating to relatives and their involvement in consultations and the impact that this illness was having on their lives (see section 4.2.2). I became sensitised to the way doctors interacted with relatives and how patients often looked to the relative for support. I also became sensitised to how relatives behaved when the patient and doctor left the consulting room to go into an adjacent room for a physical examination to be performed. In addition I was also able to compare my observations with the recordings of consultations to look for categories and subcategories, in doing this I was also able to build on existing categories and subcategories.

### **3.8.3 Recording of Consultations**

To help with the analysis of the recording of consultations I initially created a colour coding system to highlight and identify different phenomena (for example: repeated patterns). This helped as a way of managing the vast amount of data. I was able to make comparisons between the various stages of the consultations including:

- Introductions / endings
- Social history
- Physical examination
- Diagnostic information
- Prognostic information
- Cancer treatments and plans of care

- Patient / relative expectations – subsequent management
- Opportunities given to ask questions
- Emotional responses – expression / management

The categories and subcategories evolved from these original codes. Having recorded the consultations I was able to see a pattern emerge in the way consultations were managed and how few doctors deviated from a standard consultation model.

### **3.8.4 Interviews**

Just as in the case of the 'recordings of consultations', in order to help with the analysis of interview transcripts I initially created a colour coding system to highlight and identify different phenomena, for example:

- What did patients like about their consultations / interactions with doctors
- What didn't they like about their consultations / interactions with doctors
- How did patients express themselves (passive – active)
- How did they feel about the experience
- Did they get the opportunity to say what they wanted to say
- Patients understanding and recollection of what they had been told
- What was the doctors impression of the consultation
- Doctors understanding and recollection of what they had told the patient and what did they think the patient understood
- What was the doctors main aim in the consultation
- How did the doctor think the patient was feeling and what were the patients main needs

This was only a starting point to help me begin to immerse myself in the data. In addition to this, the theoretical focus used to interrogate and order the data helped provide the evidence that was used in the analysis and discussion to show how the aim and objectives were met. Although this evidence is interspersed throughout

Chapters 4 and 5 and discussed further in Chapter 6, some examples of evidence (and general location) influenced through 'awareness theory' are shown below;

- Willingness to share information                      Sections 4.2; 4.4, 5.2,5.3
- Management and control of information              Sections 4.2; 4.3; 4.4; 5.2;
- Managing conflicting situations  
(information provision)                      Section 5.2; 5.3
- Changes in awareness                      Sections 4.2; 5.2;
- Being aware of how others wish to  
manage their awareness                      Sections 4.2; 5.2; 5.3
- Emotional work – how people choose  
to react and act upon information              Sections 4.2; 4.3; 5.2; 5.3
- Exploring the changing nature of social  
interactions as people meet on various  
occasions                      Sections 5.3
- Having an appreciation of another's  
awareness                      Sections 4.3

When I first started to look at the data, I initially started by analysing every piece of information but as the study progressed I became more selective about which data to use for analysis.

### **3.8.5 Inclusion / Exclusion of Data**

It was not possible to use all of the data collected in this study. A decision needed to be made about what to include / exclude. The decision was governed by its relevance to the study – in other words, whether or not the data helped inform and meet the aims and objectives of this study.

While many patients spoke of their experiences about how they first learned of their diagnosis, this data was not explicitly alluded to as these discussions occurred outside of the oncology setting, although these experiences did on occasion have some bearing on social relations and interactions within the oncology outpatient consultation. In addition to this, some patients described aspects of their care and aspects of their stay in hospital which they felt could be improved upon; information which although very important was surplus to the intentions of this study. In addition to this, data was included / excluded based on whether or not there were any interrelated connections between existing concepts. For example, during the analytical process, I became aware of recurring comments or strands in the data which aligned to these occurrences such as a patient's view or action alluded to the fact that the 'doctor knows best' and as such data was grouped collectively and assessed for its strength and relevance. As Strauss and Corbin (1998) explain, as my theory came together and I had started to commit myself to a theoretical scheme I was able to 'trim' off poorly developed categories and subcategories which did not seem relevant to the study.

Data analysis did not end until I finally started to write the analysis chapters. Even up until this stage, I was still immersed in the data as I evaluated and re-evaluated the data time and time again. In the final stages of the analysis, I was able to refine the theory by drawing from memo's (which evolved throughout the data collection and analysis) and I was able to create more detailed spider diagrams to help me visualise interconnections and relationships to help create more substantive theories.

### **3.9 Issues of Reliability and Validity**

The value of scientific research, regardless of the discipline or methods used is dependent on the researcher's ability to demonstrate the 'credibility of their findings' (LeCompte and Goetz 1982). In an attempt to achieve this aim the concepts of reliability and validity have been chosen. Although these concepts have been primarily associated with quantitative or scientific traditions, the principles are

applicable and transferable to qualitative inquiry (Seale 1999; Ritchie and Lewis 2003).

## **Reliability**

Reliability has been classified in two ways; internal consistency and external consistency (Hesse-Biber and Leavy 2005). Internal consistency is associated with trying to determine if the data gathered is reasonable and appropriate in the interests of the research study and whether or not the data has been captured in a consistent manner. In addition, external consistency is associated with verifying and cross checking data (Hesse-Biber and Leavy 2005). In the present study the study design, data collection, analysis and presentation of findings are clearly described and presented and supported with evidence from within the literature.

## **Validity**

Validity seeks to ensure that the confidence in the research is well placed and is essentially concerned with the 'trustworthiness' of the study (Golafshani 2003; Hesse-Biber and Leavy 2005). Validity may be considered in relation to a number of concepts including; the moral integrity of the researcher which is perceived through their actions, whether or not the research has been checked, how well the researcher has investigated the findings under consideration (Hesse-Biber and Leavy 2005). As such, there are a number of ways to check for validation (Murphy, Dingwall et al. 1998).

The first example, is concerned with looking at and including negative or deviant cases (Hesse-Biber and Leavy 2005). This process helps to ensure that any potential bias of the researcher does not interfere with and alter the perception of the data and as such encourages them to critically analyse the strengths and weaknesses of their arguments (Hesse-Biber and Leavy 2005).

The second example, involves checking for accuracy – going back to respondents to check for clarity and interpretation (Hesse-Biber and Leavy 2005) or through a

process of constant comparison (Glaser and Strauss 1967). In the present study, I summarised any key points with participants upon meeting them again to ask for clarification or to encourage further elaboration. In addition, comparing and checking concepts as they emerged from the data from various methods of data collection ensured that I was constantly treating data in a comprehensive manner.

The third example, acknowledges the importance of checking the validity of research findings by employing various methods of data collection to improve the clarity of the research findings; this approach is also referred to as triangulation (Murphy, Dingwall et al. 1998; Ritchie and Lewis 2003; Hesse-Biber and Leavy 2005). In the present study a multi-method approach incorporating observation, interviews and audio recordings of consultations allowed for comparative checks and interpretation of data.

### 3.10 Reflexivity in Ethnographic Research

*'...ethnography is made out of ordinary ingredients, has customary features by which it is generally recognised, and yet is dependent on no single ingredient and in every instance takes its unique shape and form at the hands of the individual who crafts it'.*

*(Wolcott 1999:242)*

This statement distinguishes ethnography from other forms of social research by emphasising the role of the researcher within the context of the study. Although an ethnographer is able to produce good quality descriptions they are capable of doing much more; in essence 'making sense of what they observe' through their interpretations of behaviour and 'recognising elements that warrant further attention (Wolcott 1987:39).

Traditionally, attempts have been made within social research to reduce the effects the researcher has on the research by either encouraging them to maintain their



distance or by encouraging them to completely engage with the 'culture' they are researching (Davis 1999; Hammersley and Atkinson 2007). However, attempts to obtain purely objective accounts in these ways have since been recognised as futile (Hammersley and Atkinson 2007) due to the social interaction which takes place between researcher and researched (Davis 1999; Wolcott 1999). A researcher is part of the social world they are investigating, and as such the role they take throughout the research process and their social status within the research setting need to be borne in mind (Gerrish 2003; Allen 2004). As such, researchers are encouraged to question their influence on the research process (Davis 1999). This practice of reflexivity has been defined as;

*'..a process through which a researcher recognises, examines, understands his or her social background, assumptions and how they can intervene in the social process. Being sensitive to important situational dynamics between researcher and researched that impact on the creation of knowledge.'*

(Hesse-Biber and Leavy 2005:146)

To this end, some researchers have provided reflective accounts of the ethical dilemmas faced while collecting data (Gerrish 2003) and others have reported advantages and disadvantages of being known by research participants (Bonner and Tolhurst 2002; Borbasi and Jackson et al. 2005). To promote a more rigorous account of the way in which ethnographic research is conducted and reported upon, Allen (2004) recommends that researchers make transparent not only their personal interpretive accounts of their expectations and emotional responses within the field but also the social practices which influenced their behaviours and research practice. I have sought to address this by providing an account of my role as an insider clinician and the role I had in contriving to discover the data, through the following lens:

- Familiarity- my role as an 'insider' clinician and role impact on social practices;
- Dilemmas of having a dual identity;

### **3.10.1 Familiarity – My Role as an 'Insider' Clinician**

Ethnographic methods have been used in a number of nursing studies, by nurses, to explore various aspects of health care practice (James 1989; Savage 1995; Gerrish 2000; The 2002). The relative advantages and / or disadvantages of researching within a familiar group, society or culture has been debated (Allen 2004; Shah 2004; Bonner and Tolhurst 2002; Anderson and Francis Taylor 2006), yet there does not appear to be a right or wrong answer to this debate. Some believe that those with insider knowledge and experience are able to provide an authentic account (Allen 2004) as they are in a unique and privileged position, which helps them gain access and rapport with research participants (Gerrish 2003). Moreover, having a superior understanding of the group's culture; ability to interact naturally with the group and a previously established relationship with the group have also been highlighted as advantageous (Bonner and Tolhurst 2002).

In contrast, others believe that being an 'outsider' is preferable because these researchers do not have a prior affiliation with those being researched and are more likely to provide an unbiased account (Allen 2004; Anderson and Francis Taylor 2006). Some acknowledge that being too familiar may distort what one sees or does not see within a particular setting, but in doing so fail to describe how a marginal position may be achieved (Patton 2002; Borbasi and Jackson et al. 2005).

In addition to this, others propose that a researcher's status as an insider or outsider is not easily defined as their status will change throughout the course of the research as they face various situations and various participants (Allen 2004). Shah (2004) adds to this argument, by reporting that we are all insiders and outsiders in different ways and in different settings, because of the way we are perceived by others.

Rather than focus on familiarity, Shah (2004) believes that it is more important for the researcher to 'get on' with respondents as this will have bearing on the quality of data collected through the study and the opportunities awarded to the researcher to participate within the research setting.

In undertaking this research, I acknowledge that my position was that of an 'insider' clinician. I was privileged to have a prior knowledge and understanding of the group's culture and what was going on within the research setting; where to obtain the data I required to meet the aims and objectives of this research and to be able to identify and / or be sensitive to any changes that took place. While some researchers may need to establish relationships with research participants, others may already have involvement with those being investigated and as such need to consider existing subjectivity, interactions and emotions (Barton 2008).

In the broadest sense, I set out to research a group of people I was familiar with, within a familiar setting. As Shah (2004) points out, it was important for me to 'get on' with the research participants and build on existing relationships (some of which were stronger than others, because some of the staff participating in the research knew me better than others) in the hope that my relationship with them would not only help me in my research endeavour but establish or build upon trusting relationships. In some cases, researchers describe how their participation in clinical practice, helped them develop a degree of acceptance and rapport with those being studied (Savage 1995). Building rapport has been described as;

'...developing good personal relationships with people within the research setting that facilitate access to activities and information necessary for conducting the study'

(Schensul, Schensul et al.1999:28)

The development of relationships within the field can raise ethical issues and concerns. For example, this definition has been criticised for essentially focusing on 'rapport' as a technique and a means to an end approach to qualitative inquiry (Marcus 2001) and as such fails to consider how relationships are established and valued. These concerns have been raised as the focus of ethnographic inquiry has shifted from what was once considered to be the unfamiliar to familiar fields of inquiry (Marcus 2001). In this context, Springwood and King (2001) state their concern that the traditional essence of rapport is no longer appropriate within ethnographic inquiry. For example, they question whether or not the ethnographic researcher fully appreciates the implications of using words and information against those who have provided them (Springwood and King 2001).

This concern is exemplified through the experience of Savage (1995) a practising nurse ethnographer. Savage (1995) found herself in a position whereby participants started to share much more personal information than she had originally expected to hear. During the course of her study she found that some relationships had turned into friendships and as such she needed to make decisions about whether or not it was ethical to include their comments in the writings of her study. A compromise was made, whereby she included data obtained during the course of the working day and excluded data obtained during social occasions. In this context, Holloway et al (2002) believe that rapport does not necessarily equate to having an 'intimate' relationship with participants. However, rapport should be equated with trust and honesty (Holloway and Wheeler 2002; Hesse-Biber and Leavy 2005).

My experiences taken from field notes illustrate some of the tensions and the ambiguity of boundaries in the field work experience. My position as an 'insider' clinician proved to be both a help and a hindrance during the collection of data. My 'insider' knowledge had an effect on the research and those being researched, but we know this to be problematic in qualitative research. Other nurse researchers,

including Savage (1995) and Gerrish (2000) have described similar problems in their research accounts.

Prior to interviewing the doctors, I had reservations as to how they would perceive me. I had worked as a senior nurse within this department for a number of years and I knew many of the doctors. I cannot say whether or not doctors would have behaved differently with me if they had not known me prior to commencing the study. Surprisingly, some of the doctors did however share some very personal and sensitive information with me during their interviews. Some provided information about themselves, their insecurities and opinions about fellow colleagues in relation to their working relationships and one doctor demonstrated emotional distress. On two occasions the doctors explained that they felt the interview had been like a 'therapy session'; several others felt the interviews were deep and meaningful or philosophical. On occasion I left the interview feeling some concern that the doctor may have been left feeling distressed in some way, yet I was unsure how best to acknowledge this with them. I had not expected such a deep response from them. As evidenced through the example provided by Savage (1995) my experience was not exceptional, as she too describes the discomfort she experienced as others shared sensitive information with her.

Although being sensitive to the research environment is considered a strength it can also mean that routine behaviours are sometimes overlooked and not explored fully (Bonner and Tolhurst 2002). For a time, I was unaware that a change in practice was occurring because of my presence within the consultation. Although, I was familiar with the way the outpatient department was managed by the nursing team, I started to learn more about how this was managed during the conduct of the study. While it was common practice for the nurses and health care assistants to accompany patients into the consultation and remain there while the consultation took place, there were times whereby the nurse might be running between two consulting rooms and would need to divide their time accordingly. As such, they

were not always present throughout the consultation and I was not surprised if a nurse or health care assistant did not remain within the consultation. However, by staying in the consultation (as an observer) I started to discover that I was inadvertently replacing the nurse who might have stayed in the consultation. The change was at first subtle but as time went on, it became more obvious that some of the nurses and health care assistants were purposefully removing themselves from the consultation because they thought I would replace them.

To explain, I needed to liaise closely with the nurses and health care assistants within the department to ensure that I was present while the doctor prepared for the consultation and to ensure that I was already sitting in the consulting room so as not to cause any added disturbance when the patient came into the room. I was conscious however, of the way the nurses and health care assistants perceived me and I did not want to appear as though I was simply 'hanging around' and not contributing in any way. In order to fit in, I would make myself useful if I was waiting to see a patient by helping collect their notes from the clinic co-ordinators, offer clinical advice if requested, or answer their phones or volunteer to make cups of tea. As Allen (2002) states, these acts demonstrate how ones emotional or psychological needs at times influence the role we adopt in fieldwork.

It was while I was liaising with the nurses and health care assistants prior to a consultation that some started to comment that if I was going into the consulting room then they didn't need to. While my presence within the consulting room was that of an observer, I was not adverse to helping out if need be, but I did not want to replace the role of the outpatient nurse as I was keen to observe their interactions within the consulting room, and as they accompanied patients out of the room at the end of the consultation. It was easy to explain to them that I was not there to replace them, and to explain that my presence should not have any bearing on their normal practice. Yet I found myself repeating this message on a number of occasions. On some occasions I noted that they were genuinely concerned that there may be too

many people in the consulting room, while at other times it was convenient for them to remain outside. Additionally, I believe that some of the nurses, were used to seeing me in the department as a senior research nurse, who would on occasion accompany patients into the consulting room and found my dual role confusing. The implication of these actions meant that some of the nurses purposefully removed themselves from the consultation and as such their involvement in the study was limited and inherently had an impact on the study findings.

Furthermore, it is important to note that if nurses or health care assistants were present during consultations, they often accompanied the doctor and patient into the physical examination room, adjoining the main consulting room. While the doctor examined the patient, this afforded me the opportunity to sit with the patient's relative(s). On such occasions, it became frequently common for the relative to express their emotion or share additional information with me about the patient, which sometimes contradicted the patients account of how they were feeling and / or coping emotionally with their illness. At first I did not consciously try to encourage this outpouring of information and simply responded to the relative's cues. However, as the research progressed I did at times actively engage in experimentation to test out whether or not my role had any effect by asking relatives how they were feeling or how they were coping. In hindsight I do not think that my active pursuit of information was needed, as some relatives appeared only too willing to disclose their emotions and / or concerns. Looking back through my field notes, I came to realise that some relatives may have seen me as a confidant or a stranger to whom they could express their emotions without fear of distressing their family further. Some of the female relatives in particular chose to hide their feelings from their loved ones in order to protect them from an additional burden. This was evident through their discourse and actions, as they tried to hide their emotional distress from the relative when they re-entered the consultation room. On occasion I was asked to say something funny to them or to change the subject to help them re-compose themselves. These occasions, were somewhat secretive and at first unexpected,

but they became integral to this study as my observations of relatives and the way they interacted with others in the consultation increased and helped direct my line of questioning further.

### **3.10.2 Dilemmas of having a Dual Identity**

Having a dual identity has been shown to prove difficult for some to differentiate between the roles of nurse and researcher (Fowler 1988). I tried to alleviate this problem from the outset by sitting down with the outpatient nurses to explain the nature of the study; to describe the purpose of my role within the department and the support I required from them. For example I needed the nurses and health care assistants to inform me when they were about to call a patient to see the doctor, to ensure that I was present and prepared for the consultation. As I have previously stated, some nurses and health care assistants found it difficult to differentiate between my dual roles. Experiencing problems of identity is not uncommon in health care practice, particularly whereby health care professionals conduct research in their own or similar practices (Fowler 1988).

Some nurse ethnographers have explored the dilemma's they faced by virtue of their dual identity – that of a nurse and a researcher. For example, Gerrish (2003) writes of the ethical and moral dilemmas she faced in justifying her position and perceived intrusion into what she considered to be a highly emotional and significant encounter with a patient, whereby other health care personnel were going to discuss aspects of the patient's terminal illness. Gerrish (2003) describes the difficulties she faced in trying to maintain a marginal position and in distancing herself from highly emotional encounters with others, in order to achieve an element of objectivity. The account given by Gerrish is a prime example of a researcher who is interested in advancing knowledge but is equally concerned with the well being of others. In addition to this, the health care professional sees the participant as a patient but as a researcher they perceive the participant as an informer (Holloway and Wheeler 2002).



In this study, I was keen to ensure from the outset that patients and their relatives (if appropriate) were aware of my dual role; that I was an oncology nurse, with experience of working within this department. There were various reasons for this; I wanted to be honest and truthful; I wanted them to know of my clinical background in the hope that they would feel more at ease knowing that I had professional knowledge and experience within oncology; and I hoped that by having knowledge of my clinical background would help explain why I wanted to conduct this research. However, the advantages that this knowledge may bring may also prove to be problematic. It was important to me that patients knew of my clinical background but I was aware that some may try to use this knowledge to meet their own needs. For example, asking for my clinical opinion and / or asking me to provide further information and support.

In some instances however, interventions of a professional nature may not always be possible and as such ground rules need to be established from the outset (Holloway and Wheeler 2002). It was therefore necessary to take measures to overcome any potential problems to ensure that I was able to maintain a marginal position within the research setting. As I talked to patients about the study, prior to obtaining their consent, I would tell the patient something about myself (in a professional capacity) and explain that while I was a nurse, I was acting in the role of a researcher in this capacity and because of that I was unable to clarify things for them that had arisen in the consultation and advised them that if they were unsure of anything then the doctor would be happy to clarify this for them. This was however, easier said than done on occasion. Whilst I felt that many of the patients respected my position, there were occasions whereby questions were asked and while I tried to divert some of these questions back to them to encourage them to reflect, this was not always possible.

However, it is recognised that it is not always possible for researchers to detach themselves completely from participants, particularly during emotional and highly

sensitive situations (Holloway and Wheeler 2002; Gerrish 2003; Hesse-Biber and Leavy 2005). I found myself in some highly sensitive and emotionally charged situations whereby I felt very uncomfortable trying to maintain a personal detachment. The following, is an abstract from my field notes made following a consultation with a patient and my interview with him directly after his consultation;

*I sat willing the doctor to turn away from the computer and look at him as he looked so sad and not his usual cheery self as he was trying to tell her that he was not coping emotionally with his illness. She didn't turn round to look at him for ages, and I felt frustrated that she was missing something important. She didn't even seem to be listening to him. I felt so frustrated and a little angry at the doctor but most of all, extremely concerned for the patient, I wanted to reach out to him, but did not want to intervene during the consultation. I felt torn. I noticed that the nurse sat looking at him with a concerned look on her face but she didn't say anything – she said later that it was not her place to say anything, but she thought he should have been referred to the Psycho-Oncologist, but if the doctor didn't suggest it then how could she?*

*During the interview, while trying to find out what his main concerns were at this time, he looked sad, deflated and lonely. I felt a need to reach out to him and offer him some emotional support. He told me he was scared of dying. I was faced with a conflict – did I try and support him or did I continue with the interview? I switched off the recorder (it felt intrusive to record at that moment) and asked him what he was thinking. He basically wanted reassurance that people would continue to support him and try to ensure that he did not die alone and in pain. While we discussed this he seemed to visibly relax. This conversation took approximately two minutes and then we were able to continue with the interview – I felt so sad for him, but at least I felt some assurance that he had been able to voice his concerns and hoped*

*that in a small way I had offered him some reassurance. I knew I had done the right thing to try and help him, but didn't know if I had been wrong to switch off the recorder.*

In this case and on other occasions, I endeavoured to question my actions and motivations for taking the course of action I did and as such turned to others for their support, guidance and advice; a course of action supported by others (Holloway and Wheeler 2002; Hesse-Biber and Leavy 2005).

As an ethnographic researcher, Gerrish (2003) describes how nurse ethnographers need to take into consideration the research objectives, a particular situation and the values and interests of research participants to make ethically informed decisions throughout the conduct of the research. On other occasions, rather than intervene it seemed more appropriate to walk away from a situation. While I inevitably invaded the private lives of participants at particularly vulnerable times in their lives, there were times when I felt it was particularly important to afford the participants some privacy. On one occasion the doctor left the consultation to speak to the Consultant, having told a patient and his wife that his disease could not be cured. They broke down in tears and held each other so tightly; while they spoke of their fears and interpretations of the information given to them, it felt morally wrong to sit there and watch and listen to what was an extremely passionate display of emotion. While this action may be challenged by some, it felt wholly appropriate to walk away and return once they had had time alone.

In providing these reflective accounts, I have endeavoured to provide a reflexive account of my inclusion in the field as an insider clinician and my emotional responses to others. The purpose of this endeavour was to enhance the readers understanding of how my involvement in the research setting influenced and / or impacted on social interactions which would have had bearing on data collection and subsequent analysis.

### 3.11 Summary

This chapter has provided an account of the research strategy, the research design, as well as a description of the way the research was conducted and the issues surrounding this approach to research. The methodological approach enabled me to explore how doctors and patients describe their experience of consultations and how they managed the disclosure and receipt of sensitive information. Furthermore, it allowed me to observe and record their interactions, while they talked about sensitive issues and dealt with bad news in a cancer context, which would otherwise have been difficult to explore fully.

The challenges and issues associated with this approach and research perspective have been raised along with the tensions of conducting research within one's own professional environment. By adopting a reflexive account, I have attempted to consider my position as researcher, and have explored issues that can arise from this approach overall.

The methods used to collect data and the concurrent analysis of data was extremely time consuming and took longer to achieve than initially expected. However, the richness of the data that this research approach has helped create, means that a clear and detailed account has emerged from the study.

The findings of the study are presented in the following chapter and encompass two themes:

- Doctors and patients acting their parts
- Sharing uncomfortable news

The themes offer an account of the ways doctors and patients perceived and acted out their roles during consultations and how they experienced the sharing of uncomfortable news in relation to the patients diagnosis, prognosis and how they managed the transitions of starting / ending and waiting for more treatment to be

prescribed. Each theme is illustrated by verbatim quotes from interview transcripts and is supported with reflections from my field notes and actual recordings of consultations. These illustrations are drawn together through the inclusion of an accompanying commentary and supportive literature to aid clarification.

## Chapter Four

### Doctors and Patients Acting Their Parts

#### 4.1 Introduction

*'While the doctor may see the consultation as one of many routine encounters, for the patient it may be the most important or stressful aspect of their week.'*

(Kurtz, Silverman et al.2005:14)

This quotation succinctly captures the distinction between the way doctors and patients seemed to approach consultations within the Oncology outpatient setting. The doctors performed a number of consultations in any given week and had a number of tasks they needed to achieve within the consultation and often took on a directional role to ensure these were performed in a logical structure. Patients and their relatives, on the other hand often entered the consultation uncertain about what would happen to them, it was only as they attended follow up consultations that they became more familiar with the way consultations were conducted and how the system worked.

The emotional context of their encounters and their prior expectations as to how they should behave and interact with each other had the potential to complicate the way information was conveyed and received. While some of the doctors tried to grapple with emotional issues, others seemed less able or willing. In addition to this, doctors did not necessarily make aspects of communication easy for each other. This chapter has been entitled doctors and patients acting their parts because they each seemed to act out different roles within the consultation regardless of what they may be thinking or feeling at any given time. The way doctors and patients interacted with each other did not always appear to show the true extent of their feelings or

frustrations during the consultations. In comparison, it was interesting to observe that some relatives appeared to be more openly expressive about their feelings and concerns, which sometimes seemed to make it more difficult for doctors to know how to interact with them.

This theme was developed from participants descriptions of their experiences and through outsider observations. Excerpts from the data and case studies are provided to illustrate this theme of 'Doctors and Patients Acting their Parts.' The role of each doctor is identified by placing a C – Consultant and SpR – for Specialist Registrar at the side of their name, to identify their status. The categories and sub categories, which make up this theme are presented in Table 6.

Theme	Category	Sub Category
Doctors and Patients Acting their Parts	Potential Deviations	The Referral Position of Relatives
	Expression of Emotions	Learning to Support Offering Emotional Support
	Compliant Patient	Holding Back Doctor knows Best

**Table 6: Categories and Sub Categories relating to 'Doctors and Patients Acting their Parts'**

Each of these categories and their sub categories are presented in turn. Extracts from doctor and patient interviews are used to present the cases to be discussed and these are supplemented with my observations and excerpts from the recordings of their consultations.

## 4.2 Potential Deviations

Doctors described and appeared to conduct their consultations following a standard consultation model similar to that described by Byrne and Long, who's earlier

qualitative study, identified six phases of the medical consultation (Byrne and Long 1976). Although the following extract provides a typical example of the way doctors described the way they structured and conducted new case consultations with patients, there are many similarities here with follow up consultations:

*'I have got a fairly standard plan that I apply to everybody. So what I tend to do is okay, before they come into the room I go through how they came to us, I go through their radiology in detail, I go through their history in detail and I kind of see where I am going to take this person and what I am going to offer them. Having done that the first stage is to talk to him first about his presentation and about what investigations they had and what they found and that first of all allows him to talk freely and allows him to express what he wants and in a sense ask questions. I can either answer those questions there and then or I can defer them for later. But it allows this common ground of knowledge. And so it is quite formulaic so you then go on and examine them and say right okay well we can sit down and talk about what we are going to do about this. So it is very formulaic'* (Dr Harris, SPR – source: 1<sup>st</sup> phase of study)

Having control over the way the consultation was structured was seen as a way of *'anchoring the conversation and making sure it doesn't get out of control'* (Dr Wilson, C). While these views explain the desired process of the consultation from the doctors' perspective they also portray an unequal relationship of power between doctors and patients. Doctors were frequently observed to be in control of the consultation as they followed a routine approach to meet their agenda. This finding is not dissimilar to the findings of previous studies whereby doctors controlled and managed the structure of the consultation to meet their objectives (Glaser and Strauss 1965; Byrne and Long 1976; Taylor 1988; Barry and Bradley et al 2000).



In this study, patients seemed to understand that the doctor had a 'job to do' and didn't generally mind that the doctor structured the consultation, so long as they felt the doctor was interested in them and gave them an opportunity to and respected their wish to participate in the discussion. Dr Wilson (C) recognised that patients may have '*burning things that need to be addressed*' and so adaptations needed to be made. At the beginning of a consultation, particularly new case consultations, the doctor usually asked the patient an open ended question, inviting them to tell their story about what was happening to them and then continued to direct the flow of the consultation. On occasion however, deviations occurred which could potentially disrupt the prescribed flow of the consultation. The main examples (of deviations), which emerged through the data are considered in this section.

#### **4.2.2 The Referral and Singing from the Same Hymn Book**

Prior to meeting a patient, the doctor would generally prepare for the consultation by spending a few minutes reading through the patient's notes. Being familiar with the patient's medical history was considered important for a number of reasons. Firstly, doctors appeared to feel it was important to know that they had all the necessary information for and about a patient in order to try and '*resolve all of their issues*' (Dr Hughes, SpR) within the consultation. One doctor however, was sceptical that they could achieve this as in most cases the patient was entering into unknown territory:

*'And this is the thing I have difficulty with because you have to go through history, the notes, what has been going on and all stuff like that, examination and then you get to the point of talking about it and you have already gone through a lot of information. And the thing I find difficult is then to say right this is the information I want to relay to you and then I want time for you to ask me any specific questions and I feel that I can relay information to them but they don't have time for it to sink in and they don't have time to say well these are the questions that I want. Because they have sat there and they*

*don't know what their expectations are because they don't really know what I am going to say to them'* [sic] (Dr Wright, SpR – source: 1<sup>st</sup> phase of study)

Secondly, not having appropriate information was considered '*unprofessional*' and could make them look '*stupid*' in front of the patient. While it was not common practice for doctors to prepare the medical notes in advance prior to meeting patients in clinics (this was the role of their clinic co-ordinators) some felt that 'poor preparation' reflected badly on them. Maintaining a professional image in front of the patient was paramount and having appropriate information to hand was crucial. Problems emerged however, when appropriate information was not present about a patient and there was a lack of communication between doctors and other health care professionals which could disrupt the flow of the consultation and have a negative impact on the patient's experience.

As doctors spoke of their experiences of consultations, a problem emerged whereby poor communication between colleagues could have a knock on effect to patient care. Poor communication between colleagues could have a negative impact not only on the way doctors felt they were able to share information with patients but also in regards to how they were able to proceed with the management of a patient's care. Two examples emerged whereby blame was attributed to the patient's initial referral to the Oncology department and a lack of openness in regards to disclosing information from both referring doctors and fellow Oncologists working within the same department.

In the event that poor communication (between colleagues) had a negative impact on a consultation with a patient and their relatives, some doctors described their concern about how the patient may then perceive them personally and whether or not the patient then questioned the doctor's ability to care for them appropriately. The following section presents some of the doctor's accounts and some examples of

how the 'referral' in particular interfered with the management of several consultations, observed within this study.

The patients participating in this study all had a diagnosis of advanced cancer and it was important to establish what they knew about their illness and the impact this would have on their future. When patients were first referred to the Oncology department for new case consultations, the Oncology doctor was very much reliant upon referral correspondence from colleagues in other disciplines of medicine / surgery to help provide this information. In addition to this, Oncologists, tended to use information from the referral letter and multi disciplinary team meetings to help them decide which treatment option was the most appropriate for each patient. However, in some instances doctors spoke of needing to re-consider their plans for a patient.

The need to change a plan might arise if the information provided in the patient's referral letter did not correspond with the patient's version of events or the doctor assessed the condition of the patient differently to that of the referring doctor. In their study to investigate the role of case presentations in socialisation of the health care professional, Lingard and Garwood et al (2003) cited the '*limits of professional agreement and the limits of faith in the patient's / parent's accounts*' (Lingard and Garwood et al. 2003:605) as two of the main sources of uncertainty in medical practice. Handling uncertainty was seen as an inevitable feature of a doctor's clinical practice but there was an art to how they presented their uncertainty through their discourse and actions (Lingard and Garwood et al. 2003). In my study, the extent of uncertainty was never fully portrayed by doctors in the presence of the patient. The dilemma or frustration they felt often became apparent as they spoke to me during their interviews. The following narrative provides an example of a case presentation to demonstrate the way the doctor's uncertainty was managed with regard to discussing a new patient's plan of care, during their initial meeting.

### **Case study 1 – From Plan A to Plan B**

Prior to seeing Dr Davis (C), Mr Hart had been lying down on a couch in one of the physical examination rooms adjoined to a consulting room. He had been experiencing some pain and found it difficult to sit for prolonged periods of time. His wife sat on a chair by his side. As I sat with them, he described feeling anxious but was relieved to be seeing the Oncologist for the first time. It had taken a long time him to be diagnosed with his cancer and he had started to lose faith in the medical profession. He hoped that he would find out during this consultation what the doctors intended to do to help him.

When Mr Hart eventually meets Dr Davis (C), the doctor explains:

*'I have discussed your case at a meeting that we have when the x-ray doctors and Oncology doctors and everybody else gets together...and I understand that you saw Mr (B) in the endoscopy suite?'* (Dr Davis, C)

Mrs Hart responded by saying that they met Mr (B) (Surgeon) the previous day but the endoscopy was not performed. Dr Davis (C) tells them that she knew of this and explains that Mr (B) was:

*'concerned about how poorly you are feeling.....so I was very keen to meet up with you today to see how things have been.'* (Dr Davis, C)

After Dr Davis (C) has finished asking Mr Hart to provide a summary of his medical condition and after she has completed a physical examination of Mr Hart in the adjoining examination room, they return to the consulting room to discuss Mr Hart's diagnosis in more detail. Mr Hart looked concerned as Dr Davis (C) explained:

*'..what we have found are secondary cancers. Now at the moment it's not clear to us where the primary cancer is. That sounds unusual but actually it*

*is a situation that we find ourselves in and there are a group of patients that we see that even if we do lots and lots of tests we never actually find the primary cancer.'* (Dr Davis, C)

Dr Davis (C) then proceeds to explain that the tests conducted so far have not identified the primary cancer but she feels that:

*'..there is a blood test in particular that I think would be really helpful and that will give me a very good idea about where it is...and what I can then do is I can actually plan for you to have some treatment.'* (Dr Davis, C)

Mr Hart simply replies with a 'yeah' and then asks what his treatment may be.

During the interview with Mr Hart following this consultation, he explains that he does not feel very '*comfortable*' about how his care has been managed prior to this consultation. He describes how he felt like a '*yoyo going from here to there*' as he was seen by one doctor after another; both in private and NHS care. When asked what his thoughts were about this consultation he described Dr Davis (C) as being:

*'..polite, understanding, she explains things which I need to know, she try to make me understand what she is going to do.'* [sic] (Mr Hart)

Although Mr Hart understood what Dr Davis (C) had to tell him, his wife did not have the same level of understanding, as English was not her first language. Although she accompanied Mr Hart on his visits to the hospital, he explained things to her in more detail once they returned home. On this occasion, Mr Hart's opinion of the doctor gave him '*confidence in her, whatever she's going to do, she will try her best for me,*' this was despite not having a clear plan of action, which he had been longing for, for some time. Dr Davis (C) described feeling '*surprised*' when she met Mr Hart because she had been told by the referring clinician, the previous evening

that in their opinion Mr Hart *'was really poorly'* and didn't think she was *'going to be able to do anything.'* Dr Davis (C) explained that she was *'geared up for that'* possibility and had planned to treat Mr Hart with best supportive care rather than chemotherapy. When Dr Davis (C) saw Mr Hart, however she considered changing her mind. She explained:

*'My plan A just clapping eyes on him changed to plan B and then plan B was scuppered because he hadn't had the test that I had requested because the surgeon felt that he had been unwell.'* (Dr Davis, C)

When asked to describe her views of the consultation, Dr Davis (C) explained that she felt not having an identified plan of treatment was never particularly very good, *'a consultation should be when you can say right this is what we are going to do'* and that the *'uncertainty'* was often difficult for patients.

The need to propose a clear plan of action to patients in their new case consultations appeared to be important to the doctors. In the case presented here, Mr Hart didn't mind waiting another week to find out what would happen to him. Yet, when asked how she felt Mr Hart had responded to her and this proposed plan of action, Dr Davis (C) was not really sure, but felt that he may have been a little frustrated, although she did not necessarily get this impression from the way he interacted with her; she was simply guessing. From her perspective, Dr Davis (C), felt that the consultation was *'okay but not great'* and was concerned that Mr Hart went away without really having any answers or a plan of treatment.

This sentiment was borne out in the frustrations of another doctor who was unable to present a clear diagnosis and plan of treatment to a patient because they hadn't *'been given a proper letter of referral.'* Rather than criticise the referring clinician Dr Taylor (C) was critical of the pressures they faced from *'political directives'* which stipulated the need for health care professionals to meet *'waiting time targets'*

(Department of Health 2000). Dr Taylor (C) felt that the '*imperative was on speed but doesn't allow us to have all the information to hand when the patient comes to see us.*' The patient in this case had a complicated disease and the pathologists were still in the process of trying to make a diagnosis, as she attended her new case consultation to see Dr Taylor (C). The patient in this case was philosophical:

*'The pathologist is obviously still working on things so he has obviously got a bit of an unusual case as well so I am hoping he comes up trumps and he gets that bit right. But I appreciate that I am not really going to know one way or the other. But it is a lot more, I am going home happier than I was expecting to.'* (Mrs Martin)

When interviewed, Mrs Martin felt that Dr Taylor (C) had been as '*honest and truthful with me as he could be.*' Being familiar with the nature of their illness was important to these patients, as was knowing that the doctor was taking an interest in them. While it was frustrating for doctors that they did not have sufficient information to proceed with a desired management of care, Mr Hart and Mrs Martin were content in the knowledge that the doctor understood them and expressed hope that they could do something to help them. This was seen in a study conducted by Hagerty and Butow et al (2005) with patients who had been diagnosed with a life threatening illness; for these patients having a relationship built on trust was very important. Similarly Roter and Hall (1993) emphasised, that although patients turned to their doctors to benefit from their medical expertise they also wanted to develop a relationship with someone with whom they could depend upon to do their best for them. In contrast it was important, for Dr Davis (C) and Dr Taylor (C) to provide an appropriate plan of action that was fully informed through medical evidence in a timely and efficient manner. Yet, despite the fact that Mr Hart and Mrs Martin had not had a particularly good experience prior to their new case consultations in Oncology, the approach used by each of these doctors towards them, had a positive

impact on the way they perceived what was happened to them in these consultations.

Through these examples I have shown how problems can emerge within new case consultations which disrupt the flow of the consultation; particularly from the Oncologist's perspective. However, problems also emerged in follow up consultations as some doctors and other health care professionals failed to communicate with each other (either in writing or in person) what information they had disclosed to patients and their relatives. This is reflected in the following quotes:

*When these people are seeing lots of different people that can make communication with the patient difficult because they have been told different things by different people and you don't know what they have been told and that is a problem that can break down levels of trust between patients and physicians. I think it is something that doctors and nurses need to get better at communicating with each other, so we can all be singing from the same hymn book when talking to the patient.'* (Dr Green, SpR- source: 1<sup>st</sup> phase of study)

*'And I saw them for the first time after a change of job in the chemotherapy clinic, with another scan result which I discussed with them and it came as a huge shock to them that they had any particular disease in that area at all. So they didn't know about it at all...I could see the familiar tension coming up as well in between and that is something I would definitely want to avoid with all my life. And that is not conducive atmosphere, for where I can talk about the treatment for what needs to happen and what not. And I put that down to lack of information which could just be missed by someone on the ward or it has been wilfully suppressed I don't know.'* [sic] (Dr Walker, SpR- source: 1<sup>st</sup> phase of study)



It is evident from these accounts that some doctors were very much aware of the problems that may arise, not only for themselves but also for their patients if inconsistent information is disclosed by colleagues or in the event that information may be withheld, either intentionally or by mistake. The way in which doctors chose to communicate information to patients appeared to be more complex than previous studies may have indicated. Although there has been a general move towards a culture of openness; whereby health care professionals are encouraged to disclose information to patients, regardless of the sensitive nature of the information to be imparted (Taylor 1988; Seale and Addington-Hall et al.1997; Field and Copp 1999), some SpR's spoke of needing to adapt their ideal approach to open disclosure to meet the preferred method of disclosure adopted by each Consultant. Dr Wright (SpR) described how on several occasions she had been criticised for disclosing sensitive information (upon request from the patient) because the Consultant had not wanted the patient to know the severity of their situation.

While there was evidence from Glaser and Strauss (1965) that doctors and nurses controlled how much patients and their relatives needed to know, the level of control adopted by Consultants was not always communicated to SpR's. Through Goffman's portrayal of 'team' he described how members of a team have a mutual understanding of how they should perform and interact in front of others (Goffman 1959), yet in this case some of the junior members of the team were not necessarily aware of the rules of the game and what might be expected from them. As such, there appeared to be some difficulty in responding to the patient's need for information and ensuring SpR's synchronised their approach to communication with that of each Consultant without unduly compromising their ideal practice and the needs of each patient.

#### **4.2.3 Position of Relatives**

Family members regularly accompanied patients to their consultations. Many patients appeared to value the support of their family during the consultation.

Although it has been suggested that some relatives have a tendency to take on a dominant role within consultations (Faulkner and Maguire 2001) this did not appear to be the so in many of the cases I saw. Patients and relatives often appeared to offer each other practical and emotional support albeit in various degrees.

The position of relatives within consultations was not a primary focus of this study however their interactions on occasions, played a significant role in the way the consultation was conducted. While some doctors recognised and valued the presence of relatives in the consultation, as they helped support the patient and '*identified questions*' that might not otherwise have been asked, others found their presence difficult to manage. To illustrate two of the main issues that arose, two case studies are presented: one relating to the management of a father's concern for his son, which was raised when his son was absent from the room and the second considers the way a wife's need for information was handled as her husband's health deteriorated.

## **Case Study 2 – Fathers Concern**

Mr Jackson, a man in his forties, attends his consultation, accompanied by his father and mother who have travelled a considerable way to be with their son during his first consultations with the Oncologist. During the consultation, Mr Jackson is asked by Dr Williams (SpR) to describe his symptoms. Mr Jackson tells Dr Williams (SpR) he has some pain and some indigestion but does not elaborate on these symptoms; he seems to be more concerned with learning about his prognosis. When probed by Dr Williams (SpR) to answer his questions Mr Jackson provides information, which is supplemented by his father. Mr Jackson appears quite content with his father's input and they look to each other for what appears to be confirmation of what they are each saying. When Mr Jackson moves into the adjoining room to wait for Dr Williams (SpR) to come through to perform his physical examination, the father has the following conversation with Dr Williams (SpR):

Mr Jackson father: *It certainly took him a long while to recover from his operation didn't it?*

Dr Williams: *Yes*

Mr Jackson father: *Diet wise, he still wont go out with us for a meal or anything*

Dr Williams: *umm*

Mr Jackson father: *Although he eats quite well now he gets very loud indigestion*

Dr Williams: *umm*

Mr Jackson father: *smaller portions yes but he gets violent indigestion after a meal*

Dr Williams: *ah I see*

Mr Jackson father: *and it sounds a bit like a cow in labour*

Dr Williams: *(laughs)*

Mr Jackson father: *and it doesn't worry him too much but he wouldn't want to do that in public*

Dr Williams: *umm*

Mr Jackson father: *as you might say*

Dr Williams: *right I understand that*

Mr Jackson father: *and I just think a lot of his nutrition is his beer really*

Dr Williams: *right*

Mr Jackson father: *but he likes that so*

Dr Williams: *okay*

Mr Jackson father: *and at this stage it seems wrong to criticise*

Dr Williams: *sure, sure I understand that*

Mr Jackson father: *certainly when we're with him he's very disciplined with his drinking isn't he?*

Dr Williams: *umm*

Mr Jackson father: *but one gets the impression he probably drinks for longer periods when we're not there, we can assess that from telephone calls don't we? It's difficult to say*

Dr Williams: *yes, I'm just doing a quick search on the cancer website just to get you the figures that you need.....excuse me a moment*

Mr Jackson father: *certainly, yes.*

It is not uncommon for relatives to have a number of questions and / or concerns that they wish to raise with doctors and other health care professionals that arise out of concern, ignorance and uncertainty and in terms of knowing what to do to help their loved one and / or what to expect will happen in the future (Timmermans 1994). It is evident from what Mr Jackson's father is saying to the doctor that he has some concerns about his son's physical symptoms and his consumption of alcohol. As this discussion takes place Dr Williams (SpR) remains seated at the desk with his back to Mr Jackson's parents and he focuses his attention on the computer screen in front of him. This example illustrates a prime example of the doctor evading the father's comments and need for information. From an observers perspective this behaviour appeared rude and insensitive, although this was not reflected in the demeanour of Mr Jackson's parents. Long and Byrne (1976) suggest that doctors tend to use this tactic when they either do not want to 'commit' to an answer or are reluctant to share information. In this case, Dr Williams (SpR) later described in his interview a reluctance to commit to a response:

*'I was deliberately vague and just used kind of verbal cues to accept what they were saying. And I didn't want to say anything because their son wasn't there so I didn't feel uncomfortable. I just thought well they are your issues and well I accept that so I just used 'umms' as kind of cues to just say that I accept what they're saying but I can't really do anything about it.'* (Dr Williams, SpR).

Dr Williams (SpR), statement typified the concerns of some of the other doctors who found it difficult to talk to family members without the patient being present or without

having the patient's permission to speak to family members. This is in contrast to the findings of previous studies whereby there was a tendency for health care professionals to disclose more information to relatives because it was generally recognised that family members needed to know what was happening so that they could prepare for the future, because they were the ones going to be left behind (Glaser and Strauss 1965; Seale 1991). In Copp's study, nurses appeared to recognise and accept that the relatives of those who dying require as much if not more support on occasion to help them adjust to the difficult and trying situations, they face throughout their loved ones illness (Copp 1999).

Doctors in this study who found it difficult to share information with relatives, reconciled their position by emphasising that their '*duty is to the patient*' and not the relatives. While Mr Jackson's father and mother did not appear to show any outward signs of distress or annoyance with the way Dr Williams (SpR) interacted with them, Faulkner and Maguire (2001) suggested that the best course of action is for the doctor to negotiate an agreement with the patient as to who and what information they share with relatives to try and prevent difficult situations from occurring. For many doctors in this study, this course of action only appeared to occur as a 'reactionary' response to a situation as opposed to a pre-determined plan of action between doctor and patient. A prime example of this is provided in the next case study.

### **Case Study 3 – A Wife's Need for Information**

Mr Rogers and his wife are in their early seventies and are regular visitors to the Oncology department. Mr Rogers appeared (through his non verbal communication) to understand the information conveyed to him in consultations, but in fact he hardly ever heard what his doctors told him, as he explained during his interview on the second time of us meeting. The way Mr Rogers interacted with the doctors, portrayed an image to them that he '*knew what was happening*' (Dr Roberts, SpR) and was '*quite jovial and optimistic about things*' (Dr Skelton, SpR). Mr Rogers was

in fact hard of hearing and his wife had to explain things to him when they got home. This is reflected in the following extract after being told that his chemotherapy had not worked:

Mrs Rogers: *..she said it hadn't worked, done what they expected it to do, it was the bit where she said it had grown, some of it had grown, that upset me more than anything. If she'd have said it hadn't worked but it was, in a matter of fact it was worse you see. So that upset me but I don't know whether (Mr Rogers) heard that bit*

Mr Rogers: *I didn't. I didn't hear that*

Mrs Rogers: *He didn't hear that bit you see*

Mr Rogers: *no*

Mrs Rogers started accompanying Mr Rogers's to his consultations because he would come home having forgotten or having not heard '*half of what he had been told.*' Another problem also became evident through Mr Roger's discourse during his interviews. As a consequence of how he perceived the medical profession, he was inhibited from asking questions or clarifying things he did not hear because he considered that doctors were '*above me and I can't talk the same language.*' The impact of this perception and subsequent interplay between his interactions with his doctors meant that he was not always fully informed as to what was happening to him. Mr Rogers grew to rely on his wife to seek and clarify information on his behalf. Mrs Rogers was more assertive and needed to know what was happening to her husband. This became particularly evident when his health started to deteriorate quite considerably.

On the day before Mr Rogers was due to come for his outpatient consultation (my third time of meeting him) I phoned him at home to ask if I can attend his consultation. He was at a day centre for respite care but Mrs Rogers said that they would not mind as they liked seeing me. She tells me that she has some questions

she wants to ask the doctor but didn't know if she could ask them or not. It is not uncommon for relatives to wonder if they can ask questions during medical consultations. An example of this is provided by The (2002) who found that some relatives did not know if they could ask questions, but when questions went unanswered they continued to have outstanding concerns after the death of their partner..

Mrs Rogers described on the telephone how she could see that her husband's health was deteriorating and started to cry as she spoke to me. When she could talk to me Mrs Rogers explained that she wanted to know what would happen to her husband next and how she would care for him as his health deteriorated. She also wanted to be able to forewarn her daughter who was currently living in America so that she could get home in time to say goodbye to her father before he died. There was however, a slight conflict in the family as her son had warned her not ask questions because he felt that his dad did not want to know the answers. Mrs Rogers was troubled because she did not know what to do for the best. As Glaser and Strauss (1965) point out, the need for information intensifies as relatives become more aware of and witness the deteriorating health of their loved one. In this case, however the conflicting need for information between family members was evident, as they all sought to try and protect each other (Copp 1999), in one way or another.

On the day of the appointment, Mr and Mrs Rogers entered the consulting room with their son, who had travelled down from Edinburgh to be with them. On previous occasions, Mr Rogers had entered the consulting room looking jovial and upbeat, regardless of whether or not he received good or bad news, but on this occasion he looked sad and vulnerable. As the consultation progressed, Dr Mason (SpR) asked them if they had any questions they would like to ask and to Mr Rogers, Dr Mason (SpR) asked *'Do you want me to discuss anything with your family? I am quite happy to do anything, it is up to you.'* Meanwhile, Mrs Rogers didn't hesitate to ask *'well*

*you know, how long do you think we have left?'* Dr Mason (SpR) slows the conversation down and asks Mr Rogers again how he would like to proceed. Mr Rogers whispers that he would like to know the answer, but then starts to cry and holds his head in his hands. After some negotiation between Dr Mason (SpR) and Mr Rogers, Mr Rogers asks to leave the room whilst Dr Mason (SpR) talks to his family. After hugging his wife, he leaves the room with the health care assistant who has been sitting quietly at the back of the room; I later discover that they went for a walk.

Dr Mason (SpR) moved his chair to sit close to Mrs Rogers and her son, who were sitting side by side. As an observer, I noticed how calm people appeared to be and yet apprehensive about what was about to unfold. In one sense I was compelled to listen to what needed to be said and yet in another sense I wanted to be somewhere else. Although I could see for myself that Mr Rogers was dying I did not want this confirmed through words. I initially struggled to remain emotionally detached from this discussion in order that I might be able to observe the situation with some objectivity. The discussion was managed by Dr Mason (SpR) calmly and slowly and with compassion. Dr Mason (SpR) looked as though he had all the time in the world to spend with this family. Before they proceed to talk about Mr Rogers prognosis in any detail, Mrs Rogers and her son explain that it is difficult to get Mr Rogers to talk to them because he *'doesn't really want to know.'* In this case, Mr Rogers was controlling and managing his state of awareness by not asking questions, but not wanting to talk gave rise to tension within the family as they had competing needs for information. This scenario was explored by Mamo (1999) as she described the competing needs for information of her partner's family, when faced with terminal illness and how they each tried to manage their individual conflicts and needs to cope with what was happening now and what was likely to happen in the future.

According to Glaser and Strauss (1965) distinction between states of awareness, Mr Rogers was at this time in a state of suspected awareness, whereby he suspected



that something was wrong but did not want to have his fears confirmed. During my interview with Mr Rogers the following day, he explains that he spent the night awake worrying about what his family had been told. By allowing the doctor to speak to his family in his absence Mr Rogers realised that the doctor would not have given good news. After a sleepless night he asked his wife to tell him what had been said because he didn't want to *'lie there again wondering what was going to happen,'* as he explained:

*'we talked this morning quite a lot and now know what we are doing a bit better now [sic], but you've got to get over the shock you know. All right you've got two things going through your mind, did the chemo work and is it, can I have some more and that's what's going through your mind. Well it has been in the past but not now, not after yesterday.'* (Mr Rogers)

Mr Rogers was clearly and understandably in a state of crisis. Although he knew that his health was deteriorating he was hopeful that more treatment would be forthcoming to help prolong his life further and as such his state of awareness could have been described as 'uncertain' (Timmermans 1994). Yet, following recent events, his 'uncertainty' or desire not to know what was happening to him was unintentionally confronted by the needs of this family to know what they faced in the near future.

It is often difficult to know how to manage such consultations where patients and their relatives have *'competing needs'* for information (Faulkner and Maguire 2001). As Clayton and Butow et al found from their qualitative study, relatives needed or wanted to prepare for the future but some patients were less willing to hear what had to be said about their prognosis, particularly as their condition deteriorated (Clayton and Butow et al. 2005a). In this case, Mr Rogers remained hopeful, even up until this time, despite experiencing deterioration in his health, that he may still be able to have some more chemotherapy.

This case also demonstrates how the emotional needs of relatives can influence the way the consultation is conducted and managed. In asserting their need for information, it was not clear how much thought had been given by this family as to what would happen next. Although Mrs Rogers and her son had talked about their need for information and what this would mean in a practical sense, it is not clear if the consequences of having this information had been thought through fully. When family members know the truth, maintaining a state of uncertain open awareness becomes more difficult to sustain (Timmermans 1994). Although Glaser and Strauss (1965) believe that knowing the truth may tempt family members to convey the truth to their loved one, this case highlights how Mrs Rogers and her son were privy to some bad news about Mr Rogers and he knew this.

According to Dr Evans (SpR), some patients stipulate that they particularly do not want their relatives to know what is happening to them because at the end of the day the patient will be able to tell from their loved ones expression if the news is distressing:

*'I can think of patients who for example their relatives are desperate to know their prognosis because they want to care for them, to plan and they want to look after them, yet the patient doesn't want to know and they are adamant their relatives don't know because otherwise they can guess from their face.'*  
(Dr Evans, SpR).

When Dr Mason (SpR) was interviewed following the consultation with Mr Rogers and his family, he was very conscious of the family's competing needs for information. When situations arise, whereby the relative expresses their concerns to a doctor who in turn fails to offer them support or information they are in danger of leaving the family vulnerable without an appropriate support network to help them (Faulkner and Maguire 2001). Yet the difficulty of negotiating concerns and needs of both patients and relatives can make the doctor's role more complicated (Clayton

and Butow et al. 2005a). When asked for his thoughts about the various needs of this family, Dr Mason (SpR) replied:

*'..in that instance the wife and son said yes in front of him and they didn't give him the option as to whether he wanted to know or not and they were already ready for me to go through all the detail but you can see that he is not going to cope with the answer. He probably knows, he probably knows that. An instance when you sent the patient away and the family stays it is always going to be bad news. But I don't think he was ready to hear it himself and I think that is very important to give him that choice but get his consent. If he had said no I don't want you to talk about it with any of the family then I wouldn't.'* (Dr Mason, SpR; 3<sup>rd</sup> Cons)

Although Dr Mason (SpR) did not know Mr Rogers or his family, having never met them before, he was happy to have this discussion, having confirmed he had the patient's permission to talk to his family. He was also aware that although the family needed to know what was happening, Mr Rogers reaction depicted a clear message that he was not ready to hear the same information. Although the disclosure of terminal news has been described as an emotional experience for both the doctor imparting the information and the patient and / or their family who receive such information (Taylor 1988) Dr Mason (SpR) described how for him this was a routine consultation, and one that he felt comfortable conducting.

Schön (1983) identified this level of professionalism as the 'artistry of practice' whereby experienced professionals are able to deal with situations that may have an uncertain or variable condition about them. Through their discourse, less experienced doctors demonstrated their uncertainty about how they should approach some situations, particularly emotionally charged situations where relatives were present in consultations. They spoke of '*testing out*' different styles of communication to help them negotiate their way through difficult situations. Being

confrontational or offering reassurance were two such styles which they tended to use. The use of these styles or approaches is portrayed in the following extracts:

*'..every time I was talking to the patient he (the relative) would keep butting in and getting very aggressive by the minute and then I thought the best thing to do was just ignore him because the patient kept on apologising to me you know, sorry don't pay any attention and he kept on, and then you know I just had to say I am sorry sir I am not talking to you I am just talking to my patient, my duty is to my patient and carried on talking to her and then they left.'* (Dr Smith, SpR- source 1<sup>st</sup> phase of study)

*'I try to reassure them the reason why they ask is because they do care for their loved one and that the reason that they want to know is because they are trying to be nice if you like, but it sounds abrupt no matter how you phrase it. To say that I am sorry because they don't know or they won't give me permission, I can't disclose it with you because that makes the relative feel very much rejected.'* (Dr Evans, SpR- source: 1<sup>st</sup> phase of study)

It was evident through their discourse that some doctors found it particularly difficult to deal with the emotional expressions of relatives, who appeared to them to be; *militant, protective or angry*. Negative experiences often evoked a stronger emotional response on the part of these doctors that meant they were better able to recollect what had happened to them and were able to remember situations in more detail. As such difficult experiences within medical consultations tended to offer a greater learning opportunity. It is not uncommon to be able to 'recall' experiences that have had a negative effect on us and this has been observed within a number of different situations (Maynard 2003). This may be due to the fact that people are more likely to spend time reflecting on the incident that has caused them distress until they remember it with vivid memory (Maynard 2003). The general management

or learning associated with difficult situations will be considered in the following category, 'Expression of Emotions'.

### **4.3 Expression of Emotions**

Despite the certainty that most people will get upset having been told that they or their loved one has a life threatening illness, there was a tendency for doctors, patients and their relatives to express and or show some difficulty in sharing these emotions with each other and colleagues. The way patients and relatives acted out their emotions and frustrations are part of this theme and will be considered in the following section 'Compliant Patients'. The experiences and observations of doctors are referred to in this section.

This phenomenon is complex and as I observed a number of consultations and explored the views of doctors, several factors arose which were of relevance. These included whether or not the doctor felt that they had the relevant skills to show empathy to their patients and how they sought to learn appropriate interactions, regardless of whether or not the doctor thought it was part of their role to explore emotional distress and offer emotional support. On the occasion that emotions were publicly displayed or alluded to by the patient and or / their relative, some doctors failed to notice or react to the patient's cues sensitively whereby concern and empathy may have been demonstrated through their interactions. Some doctors were observed to ignore emotional distress even though they thought experience had helped them identify when emotional support may be required. Each of these scenarios played a part in contributing to a doctor's ability or inability to express emotional support.

#### **4.3.2 Learning to Support**

For some of the doctors participating in this study the need to offer emotional support and empathy to their patients was very important to them, but they did not necessarily know how to demonstrate this appropriately. For some it was not a

matter of as Mann (2005) suggested, suppressing their emotions in order to portray a message to the patient that they feel cared for (regardless of how the doctor was feeling), it was more about them trying to find suitable ways of expressing empathy which would convey a message that they were genuinely compassionate of the patient's situation and that they wanted to help them, but doing so in a manner which was beneficial to the patient. Some doctors were however, more insightful of their need to improve their skills than others. The next case study presents the trials and tribulations one doctor faced as he searched for a way of offering emotional support to his patients and their families.

#### **Case Study 4 – Supportive Touch**

For Dr Roberts (SpR) his difficulty in relation to offering emotional support was more of a personal matter. He realised that he had difficulty offering emotional support through touch, and by this I refer to the touch of an arm or a knee to make some form of physical connection with a patient who may be distressed. He thought that touching a person in this way may help demonstrate empathetic understanding. Dr Roberts (SpR) had observed his colleagues use touch in their consultations and had felt it had been used to good effect and he wanted to learn how to use it effectively in his practice. Dr Roberts (SpR) recollected using 'touch' during an interaction with a patient but the patient moved away from him and Dr Roberts (SpR) felt *'it had actually made things worse and I thought oh damn'*. In this case, he believed that the patient was not receptive to the use of touch, and as such his intention to offer empathy failed as his interaction was rejected by the patient. Dr Roberts became wary of using touch in future interactions as he was worried about how the interaction would be perceived but equally he didn't want to appear *'uncaring'* or *'standoffish'* but did not know what other techniques he could use. This example, demonstrates how care may have been given to portray a supportive impression to a patient, and yet as Goffman (1959) describes, anxiety is experienced if the intended impression does not appear to be rightfully accepted by the other.

Dr Roberts (SpR) described how he attended a communication skills course in the hope that he could learn alternative techniques to help him build on his understanding of social awareness, through social facility to allow for more intuitive and effective interactions with his patients. This doctor actively sought to ensure that he thought about what he did or proposed to do in various situations whereby the consequences of his actions held significant importance to the patient, yet his problems persisted. Initially, Dr Roberts (SpR) felt the course had given him:

*'Techniques to cope with difficult situations and...it has also kind of opened my eyes to sort of say there isn't a right or a wrong way of doing things, there are just techniques of communicating and you have to try and use techniques, firstly that you are comfortable with I think and the second thing is what is right in that situation. I came away with a few you know four or five techniques that I have tried. Some have worked and some haven't worked...just because they didn't work first time doesn't mean I won't use them again'* (Dr Roberts, SpR- source: 2<sup>nd</sup> phase of study).

From the outset, Dr Roberts (SpR) acknowledged that he had a problem expressing emotions and empathy towards patients. For him, empathy wasn't an inherent skill, but was something he wanted to learn and to demonstrate through his interactions with his patients. He initially found it useful knowing there were various techniques he could try in clinical practice to help him. When asked at a later date how he was getting on, he said he had run into problems, *'rather than have a structure to pin it on, I was kind of going I can take this and not that'* and in his view, it went horribly wrong. For Dr Roberts (SpR) having a range of techniques to try in practice had a negative effect on what he was trying to achieve. As Eraut (1994) points out, using alternative techniques can be challenging and the road to success is not always guaranteed.

Although Dr Roberts was trying to learn techniques that were helpful and comfortable to him, he also began to think that it was important to maintain a '*professional divide*' with his patients, because at the end of the day the patient was coming to him for his help and support and he needed to be rationale and objective. As a way of attempting to establish this professional divide, Dr Roberts spoke of becoming '*impartial*' but in reality he was being perceived by patients as '*uncaring*'. Knowing how to present himself to his patients appeared to be a difficult and challenging endeavour, which became more apparent to him after receiving some negative feedback from a patient. In this case, the feedback offered an insight into what Dr Roberts did as well as the consequences of his actions. When feedback is received in this way, it is often unexpected, particularly if the feedback is provided by a patient or their relative in the form of a complaint. Dr Roberts described feeling upset by this but did not quite know how to change, he felt lost. Accepting negative feedback and admitting failure was difficult for some and this is reflected in the following extract:

*'..and to be able to admit to someone, actually I don't think I handled that very well, how could I have done that better? It is very hard for a doctor to do that because you are sort of admitting a failure in some way'* (Dr Wright, SpR- source: 1<sup>st</sup> phase of study)

This extract reflects how difficult it can be for some doctors to talk openly with someone about their concerns of how they may have interacted with a patient for fear of being judged in a negative light. I for one was taken by surprise that Dr Roberts was able to share his problems with me as he did at times appear unapproachable and brusque. Yet, the information he disclosed to me gave me a greater insight into this man which enhanced my respect for him and desire to try and help him, by letting him talk of his experience(s) through our interviews. From previous experience I was aware that some nurses tried to ensure that patients who were about to receive bad news were not seen by this doctor in clinic (if he was



present - in preference for another doctor) as they feared that the experience would cause the patient additional distress as they felt his expression of empathy left a lot to be desired.

In their communication skills courses, Maguire and Faulkner have been impressed that doctors and nurses are able to submit themselves to close scrutiny (Maguire and Faulkner 1988a). Yet, some doctors in this study felt that nurses were more '*open and honest*' about sharing negative experiences with each other, a practice which Dr Wright (SpR) was particularly envious of, as opposed to doctors who tried to '*cope*' in silence because they could not share things with each other. This is discussed further in the next chapter under the sub category of 'Concealing a Difficult Experience'. There was however, a distinction between areas that they felt they could be open and honest about. There was a consensus of opinion that the SpR's could speak to each other or their Consultants about medical-technical matters but they could not talk freely about their experiences of communicating bad news and the emotional issues that were associated with this.

There was only one instance where a doctor described actively seeking help from their Consultant. Dr Roberts (SpR) felt that he had become '*muddled*' and needed help to clear his mind and formulate an appropriate direction to follow in order to offer emotional support, whilst aiming to retain his professional identity. Rather than distance himself from emotional distress which is in contrast to the 'unspoken rule' described by Smith and Kleinmann (1989) Dr Roberts seemed to want to portray an impression that he was empathetic to the needs of his patients and still maintain an impression that he was able to make logical and rational decisions and suggestions on their behalf. Dr Roberts (SpR) thought that the support offered to him was '*superficial without any intent*' and instead turned to the literature on communication skills to help him resolve his issues. Dr Roberts (SpR) described feeling disappointed and let down and continued to try out alternative techniques until he found styles of communicating that he felt comfortable using. This example

demonstrates how a willingness to learn is crucial to one's learning but a lack of support from others may hinder one's progress and in return affect clinical practice.

For the majority of the SpR's learning how to offer emotional support and developing their own styles of communication appeared to be a lonely journey and one of trial and error. Moon (2007) describes this, not as a lonely journey but as a private process of '*working with meaning*', whereby the individual is able to identify that they need to do something to make a change to enhance their knowledge or performance and draw upon the support of others or other learning aids to help them develop. In this study, some of the doctors felt their culture was restrictive and prevented them from seeking the help of their colleagues. The necessary help required appeared to be holistic in as much as they appeared to need help and support to assist in the reflection of challenging experiences and personal support to help them identify their professional image and how they wished to practice and develop both professionally and personally.

#### **4.3.3 Offering Emotional Support**

During the interviews, some doctors mentioned ways in which they felt their interactions and communications with patients had changed over time. Some felt that as they had grown in experience, their confidence had developed and they felt better able to judge how to respond to patients and their relatives in any given situation. This is brought to life in the following example:

*'I think I have become more able to, I may be wrong, but my interpretation is maybe I can understand a bit more of what they are feeling more quickly and I have probably seen most of it on several different occasions and can now find the words more easily than I used to.'* (Dr Taylor, C- source 1<sup>st</sup> phase of study)

This gradual development in skills and confidence emerged through various processes of learning and professional development. Eraut (1994) identifies a number of professional learning processes that include propositional and process knowledge. Analysis of the data in this study highlighted the importance of doctors developing their professional skills and expertise through experiential learning and some spoke of attending formal communication skills courses. While they were not always consciously aware of reflecting 'on' or 'in' their actions, it was also an activity of learning they sometimes engaged in. Learning from experience was seen as a continuous activity but some situations appeared to be more meaningful than others and received more attention. In the context of offering emotional support some doctors were more insightful of how they interacted than others. Some doctors actively sought ways of trying to develop their skills, while others were perhaps oblivious to the way their interactions impacted on their patients. For some their interpretation or assessment of their personal attributes was different to that of their patients. There was a consensus of opinion from the doctors that situational knowledge gained from within their day-to-day interaction with patients and their relatives had helped them learn to interpret the emotional needs of patients, but this was not always reflected in their actions.

There were times when doctors were observed to distance themselves from the emotional needs of their patients and / or their relatives. Faulkner and Maguire (1988a) suggested various reasons why doctors tend to distance themselves from patients. They believed that some doctors do not know how to '*handle difficult emotions*' so try to avoid them and try to rationalise their behaviour. An example of this may be a '*fear that probing into how a person is adjusting*' may do more harm than good or they felt that doctors distance themselves in order to protect themselves from '*some of the stress of caring*' (Faulkner and Maguire 1988a). In addition to this, emotional distress may be ignored in order to sustain the awareness context as it is, thereby avoiding calling attention to the reality of the situation and maintaining a semblance of normality (Glaser and Strauss 1965). As identified in the

study by The (2002), doctors tended to concentrate on the 'medical-technical' aspects of patients care, and tended to avoid emotionally charged situations, thereby distancing themselves from the expressions of emotions within their consultations. This is exemplified in the following case where the doctor felt that the emotional support of patients was the responsibility of others.

### **Case Study 5 - Distancing**

Mr Lewis attended the clinic for a follow up consultation with his wife, having completed his chemotherapy and radiotherapy. This was the second time I had met Mr Lewis. Mr Lewis was to be seen by Dr Jones (SpR), a doctor he had not met before. As he walked into the consulting room Mr Lewis looked very down. This was in stark contrast to the way he had appeared when I met him previously. Mr Lewis had at that time portrayed a jovial image and when asked about this he explained that he did not want to 'offload' his worries to his doctors.

When Dr Jones (SpR) asked him how he was feeling, during her opening remarks, Mr Lewis replied: *'not bad at all health wise. Mind wise I am lacking'*. Dr Jones (SpR) then asks him *'what has been the problem?'* and Mr Lewis tells her that he has *'given up in my head.'* Dr Jones (SpR) replies with *'oh right'*. The nurse sitting quietly in the room looked at Mr Lewis concerned, as I feel, did I. I was surprised by his comments, bearing in mind his previous desire to keep things to himself. Mr Lewis had previously explained that he felt doctors were *'powerful people'* and recollected how he had looked up to his GP as the all-powerful figure within the community whilst he was growing up. It was hard to tell in this situation, if Dr Jones (SpR) was actually listening to what Mr Lewis was telling her because she sat looking at Mr Lewis' notes and did not really seem to acknowledge what he was saying. Although Mr Lewis did not make any reference to this, when probed, it was an issue commented on by other patients and their relatives. In a different situation, a relative explained that it made them feel happier if the doctor *'talked to us...were looking into the face, and they weren't looking at papers all the while and talking to the sheet of paper, which you do get'* (Mrs Moore's husband).

Once Dr Jones (SpR) had asked some of the standard questions about physical health, she asked Mr Lewis what he was able to do on a daily basis. Mr Lewis explained that:

*'I feel as though I am wasting what time I have left because I can't think to do anything particularly. I can't be bothered.....I am quite content just sitting there for hours on end really thinking things over and obviously get depressed from what I am thinking'. (Mr Lewis)*

Dr Jones did not explore with Mr Lewis what he was thinking and proceeded to ask him *'how old are you?'* Dr Jones (SpR) later explained to me that she thought Mr Lewis was *'having a normal reaction to his illness.'* During my interview with Dr Jones (SpR) following this consultation, she felt that the emotional issues of patients were important but it was not her *'primary focus'*, when asked to explain why she thought this she replied:

*'I think as an oncologist, what we are trying to do is control the disease and this is what our primary role is... I have to draw the line and say I can give some support but only to a point.'* (Dr Jones, SpR)

The point at which this support began and ended was unclear, as was the type of support she felt was required. Dr Jones (SpR) felt it was the responsibility of other health care professionals to offer emotional support and family and friends should provide additional support. Rather than help Mr Lewis talk about some important issues, this example, was an illustration of a doctor *'passing the buck'* in order that someone else can provide the support (Faulkner and Maguire 2001).

While Brown and Crawford et al (2006) support the notion that doctors are to care for the emotional wellbeing of their patients; they also recognise that there are certain problems worthy of consideration. Caring for the emotional needs of patients, if the

patient chooses to express them, may not be best acted out within the medical consultation as time restrictions limit what can be achieved by a doctor who already has a list of objectives they need to achieve (Brown, Crawford et al. 2006). There is no easy answer to this, yet the danger is such that if the patient's expression of their emotional distress is not explored the health care professional then fails to identify the real needs or concerns of the patient (Faulkner and Maguire (2001). In this case, Mr Lewis was actively seeking to share his concerns with his doctor, who did not appear willing to listen. Exploring how emotions are managed and expressed is key to understanding the state of a patient's and /or their relative's frame of awareness. By engaging in an introspective examination of his emotions, following his mother's diagnosis of a serious illness, Timmermans (1994) came to realise that family members and patients are powerful actors in constructing and managing their states of awareness as information does not necessarily lead to an open awareness but the way in which people cope emotionally with information does determine the state of open awareness they are in.

In addition, Mr Lewis had in the past presented himself as a jovial man who did not like to express emotion in front of others and yet here he was, willing to share information with the doctor about how he was feeling and why he was concerned. If Dr Jones (SpR) had explored Mr Lewis feelings in the case presented here, she would have discovered that Mr Lewis was preoccupied with thoughts of dying in pain and alone, without the support of health care professionals. He disclosed these concerns to me with little probing, following the consultation in our interview. He did not necessarily need any medical intervention in this case, he needed the opportunity to express his concerns and receive reassurance that he would not be left to die alone and unsupported. Mr Lewis died about a month later.

While Dr Jones (SpR) felt that it was not her responsibility to manage emotional issues within consultations, other doctors demonstrated through their discussions a belief that managing emotional issues was part of their role, thus indicating how

'emotional distress' is not always 'invisible' to doctors (Mamo 1999). These doctors demonstrated an awareness of how important it was to interact with their patients in an efficient and supportive manner. This is reflected in the following extract:

*'Breaking bad news, discussing treatment options or diagnosis with patients and families, especially for young patients can be very difficult and emotionally draining. Difficult mainly in terms of personal emotions and how I am delivering the news and how the subject is receiving the news. And what sort of an impact is it going to have on that person and that family. And also, what sort of an impact is it having on me in the long run?'* (Dr Hughes, SpR- source: 1<sup>st</sup> phase of study)

The very nature of sensitive situations whereby significant information is communicated means that emotions will often run high (Brown, Crawford et al. 2006) but in the extract presented above, Dr Hughes (SpR) also considers the impact the news will have on all concerned. In the following extract the wife of a patient explains what the new case consultation means to her and her family:

*'We have been waiting for this day for a couple of weeks and it is good. You just feel that as you go along that something is being done you know. It's just we will be getting the results today and you kind of build up your hopes and there's nothing to build up. I mean I keep thinking the worst is over, we have been told he's got cancer but it's how long he's got. You can face things when you know what you are up against. Today I am hoping we will know what we are up against.'* (Mrs Hollis)

As Mrs Hollis spoke, she broke down in tears. Losing composure in this way was sometimes seen by relatives as a positive action. Mrs Hollis felt that she '*needed to get this out of her system,*' and seemed relieved to have the opportunity to cry. Similar situations arose with other relatives who broke down in tears during the

consultations. They described to me, the emotional burden on them and their loved ones when the patient and doctor were often in another room. This strategy enabled some relatives to turn to someone else to release some of their emotional tension as they purposefully tried not to let their loved one see how upset they were. As Mrs Hart explained to me, she *'tried to keep going, I cry sometimes but not in front of him.'* She did this because she felt that she needed to be strong for her husband and didn't want to burden him further. In each of these cases, it was a matter of making the invisible visible through a momentary lapse when they let their guard down. In moments such as these, there was an opportunity for others to explore how they were feeling or what their concerns were, but this did not necessarily happen.

Despite the willingness of some doctors to offer emotional support, they did not always manage to achieve this. In the event that a relative became upset in a consultation their distress was rarely acknowledged. Mrs Hart, for example sat crying while her husband was in the adjoining room with the doctor. I sat and held her hand in a gesture of support while I listened to her talk. She told me how distressed her husband was and how pre-occupied he was with thoughts of dying and she felt she could not help him. As Dr Davis (C) walked back into the room, Mrs Hart's distress was ignored. Dr Davis (C) simply walked between us to wash their hands at the sink behind me. When asked about this in the subsequent interview with the doctor it was explained:

*'I need to focus the consultation on the patient and if you have got a distressed relative it can distract from the consultation quite significantly. But I think if the patient is holding it together and they are asking for the information then you have to respect that and give it. And it may well be that that relative may be distressed for a number of consultations and if you bring them back a day or two later, they may still be distressed. So I try not to get*



*too sort of involved in it but again try to acknowledge if someone is upset.'*

(Dr Davis, C; 2<sup>nd</sup> phase)

In this case, Dr Davis (C) felt that she did not need to acknowledge Mrs Hart's distress because I was offering her support. In reality, Dr Davis(C) would have discovered significant information about Mr Hart's concerns and fears but this information was lost.

On another occasion Dr Taylor (C) initially thought a patient's husband was quite angry during a consultation as he resisted his attempts to engage in the conversation and this made Dr Taylor (C) feel quite '*uncomfortable*.' He described trying to ask the husband a direct question to '*bring him into the conversation*' but in doing so realised that the husband was in fact very upset with tears in his eyes and appeared to be unable to speak. As this part of the consultation was observed, there appeared to be some tension in the room, and Dr Taylor looked quite uncomfortable and unsure about what to say next – there was a moment of silence. The patient broke the silence, explaining that her husband was upset and moved the conversation forward in a light hearted manner and Dr Taylor (C) followed her lead. On this occasion the husband's distress was not explored further and there was no further opportunity for him to express his concerns. During my conversation with this couple later, I learnt that the husband had an unresolved anger about the way the surgeon had informed his wife that she had cancer. The husband thought the surgeon had been insensitive and uncaring.

In addition to this however, there is a social obligation to acknowledge such distress in any situation. This is supported in the views of Spaulding et al (2003) who believe that in Western Cultures it is generally accepted that people will respond to emotional expressions of distress by trying to assist people in either rectifying their problems or by offering emotional support. Having said this, they suggest that there are situational contexts which can inhibit people from offering emotional support; a

lack of confidence in one's ability to offer emotional support or pressing demands on one's time, are offered as examples (Spaulding, Sullivan et al. 2003). Although, some doctors seemed to understand how important it was to help people because they were mindful of the impact a diagnosis of cancer had on patients, their willingness to help was not always acted upon.

#### **4.4 Compliant Patients**

Through a variety of sources, doctors are encouraged to interact with their patients, whereby they strive to seek an awareness and understanding of them (Pollock 2005). Yet, few studies have sought to explore the interactional processes that occur between doctors and patients from various perspectives within a palliative context, to explore whether or not this is achieved in any great depth. In The (2002) study, examples were provided to demonstrate how doctors and patients frequently failed to communicate in a full and open awareness context with each other in regards to the longer term issues of prognosis and dying. Doctors were frequently unsure about what information they should disclose to a patient and patients were often unsure of what they actually wanted to hear, and as such they both seemed to skirt tentatively around these issues on a superficial level (The 2002). In this study, it became evident that some patients seemed to 'control' how much information they shared with doctors as a purposeful act. This was not necessarily information about how they controlled everyday activities or how they accommodated treatments as seen in a study by Copp (1999) but in how they perceived their doctor and their doctors actions. Rather than challenge, some patients chose not to make their feelings or opinions apparent through their actions and complied with their doctors' requests regardless of what they thought. This was reflected in our conversations where they described ways of managing how they were perceived by others. This is illustrated through their reticence and their decisions to comply with their doctors' decisions or requests and through their belief and hope that the 'doctor knew best' and had their best interests at heart. In the next chapter this theme is extended to

include the notion that patients didn't always want to reveal a difficult experience for fear that their treatment and care may be compromised.

#### **4.4.1 Holding Back**

During my conversations with patients it became evident that some patients and their relatives chose not to express their frustrations to their doctors. The extent of their frustration was linked to their individual experiences, of what was happening to them at the moment, what had happened to them in the past and their concern for what might happen to them in the future. As seen in the study conducted by Byrne and Long (1976) patients were generally seen to interact in response to their doctor, rather than initiate any form of interaction themselves, regardless of how they may be feeling. This is illustrated in the following examples.

During the diagnostic phase of the consultation the doctor needed to ask questions in order to understand the patients experience thus far in order to help them make an informed opinion about how to manage the patient's future care (Byrne and Long 1976) but also to try and learn how much and / or what they needed to say to the patient based on the patients prior understanding and awareness of their illness. The doctor's reason for asking these exploratory questions about a patient's medical history or social status was not however always made clear to the patient. Some patients felt frustrated at being asked to provide this information, which is expressed through the words of one patient who recollected thinking '*oh I have got to tell my story again.*' The wife of Mr Johnson also expressed her '*surprise*' that the doctor had asked her husband to provide a summary of his medical history, during his new case consultation in the Oncology department as she felt that the doctor should already have '*the medical stuff.*' In addition to this another patient, Mr White and his wife were extremely anxious that Dr Taylor (C) had asked them for information about their children (to ascertain their social support structure at home) as they interpreted this to mean that his cancer might be genetic. While a specific line of questioning might seem simple and straightforward to the doctor the meaning behind such

questions is not always apparent to the patient. During my conversation with Mr White a highly intelligent Managing Director, he said his wife had a sleepless night worrying about why this question was asked and what it might mean for their children. Mr White described how they hadn't liked to enquire as to why Dr Taylor was asking this question during the consultation, but it was evident when I met him the following day that Mr White was desperately trying to seek clarification from me.

In regards to questioning patients about their medical history, Robinson and Heritage believe that the way patients are asked to provide this information may have some bearing on what the patient thinks or feels about answering (Robinson and Heritage 2006) these questions, but this did not appear to be a concern in this study. Participants were more frustrated about the repetitive nature of having to provide this information, yet this was not reflected through their actions. In fact in one case where the patient held back from communicating her frustration to the doctor, she said she actually liked the way the doctor posed the question, when she had thought about it. She felt the doctor did so in a relaxed, almost '*laid back manner*' which directed her to 'tell me about it,' she said she found this '*quite sort of therapeutic*' (Mrs Brown).

It was not uncommon for patients and / or their relatives to comply with a doctor's request for information without expressing their reservation to do so. The wife of Mr Johnson brought her diary along to the new case consultation to remind her husband of the dates of his various investigations, or his episodes of illness, or his admissions into hospital in preparation to answer such questions; this was despite her frustration at having to repeat this information with various doctors. The following case study presents in more detail a situation where one patient in particular was reticent about being asked to provide such information.

## Case Study 6 – Continuity

Mrs Brown came along to her new case consultation, accompanied by her husband. She was being treated for cancer at a different hospital but her Oncologist wanted her to be seen by another doctor for a second opinion, as Mrs Brown had a rare form of cancer. When asked by Dr Taylor (C) at the beginning of the consultation to tell him about her medical history, Mrs Brown complied, appearing calm and relaxed as she did so. She also gave a clear and concise reply to this questioning. Dr Taylor (C) sat and made notes periodically as she did so, but also sat back in his chair looking and nodding to her in response. Mrs Brown and Dr Taylor (C) looked very relaxed with each other. When I interviewed Mrs Brown following the consultation I was surprised to learn that she felt generally frustrated with having to provide information about her medical history. She felt that this was a constant exercise, which is reflected in the following extract:

*'...it tends to be stand ins and it will be a different person every time and then you've to go through your medical history...I have got it down to a five minute...yeah I have this, yeah I have that and I just reel it off. I know it sounds daft but you get bored with telling the same story.'* (Mrs Brown)

For this patient, the underlying problem was the fact that she did not feel that she had received any continuity of care. When she attended outpatient consultations she was nearly always seen by a different doctor. She actually felt that no one actually knew her or was interested in her. This feeling was exacerbated by the fact that she was asked each time to provide a summary of her medical history which was a reminder to her that once more she was seeing yet another doctor. She generally felt that she was *'wasting the time'* of her doctors who were in turn *'wasting her time'* because they didn't appear to be interested in her and she constantly needed to repeat herself. She spoke of managing the expression of her frustrations by being *'chatty and bubbly'* because she just wanted to:

*'get in and out, so they probably think I'm quite an easy going patient really because I practically snatch the prescription out of their hands as I am running out the door.'* (Mrs Brown)

In this case, I was unable to explore this issue further with Mrs Brown over subsequent consultations in this Oncology department because she did not attend the department again. She was left with an open appointment to return in the future should she or her Oncologist feel that this would be appropriate. Mrs Brown's description of her behaviour exemplifies her attempt at creating a careful performance to be performed in front of doctors she does not know. This is not an uncommon behaviour, as Goffman described in the 1950's how people often relax the way they interact with people they have known for some time, but may '*tighten their front*' when interacting with people they do not know (Goffman 1959:216). The expression of joviality described by Mrs Brown was also portrayed through the discussions and actions of other patients as well, who used it as a defence for disguising their true feelings to their doctors. Not wanting to appear miserable, was a phrase used by some patients to describe why they acted in this way. They did not however, disclose this information to me without being probed. Some patients were observed to appear jovial within the consultation, regardless of whether or not they had just been given some very sensitive information or not. It was only when they were asked to describe how they were feeling or to explain why they behaved in a particular way that they tended to use this phrase to describe their motivations.

In Mrs Brown's case, she tried to justify her unwillingness to tell doctors how she really felt by saying '*well what am I supposed to do? Because it isn't a sort of counselling session.*' She felt that the disclosure of her frustrations and concerns would only take up more of the doctor's time and it was not their responsibility to listen to her concerns. In this case, Mrs Brown did not clarify who she felt should listen to her concerns, but it was evident in the way she interacted with her husband that they spoke openly to each other and tried to resolve her concerns through his

interventions (i.e looking for information on the internet). Similarly, others appeared to draw upon the support of their family to help them, or chose to utilise the support offered by their General Practitioners, particularly if the GP was seen to take an active interest in their wellbeing. Others also spoke of the need to meet their Macmillan Nurse, although a number of patients and their partners didn't like to '*bother*' their Macmillan Nurse because they did not want to take up too much of their time and didn't perceive themselves 'needy' enough to use them. These patients tended to believe that Macmillan Nurses were better served to tend to those who were dying and they did not tend to include themselves in this category.

The patients' interpretation of a doctors' role was also interesting. On several occasions, I was struck by the exasperation some patients and their relatives felt because they did not think their doctor had listened to them or identified their particular concerns or needs. As McIntosh (1974) and Macleod Clark (1988) state, patients diagnosed with advanced cancer need their health care professionals to communicate effectively with them in order to understand what their needs are. Yet, there were instances where patients were loath to talk about their concerns and portrayed a particular image to disguise their feelings because they felt that it was not the job of the doctor to '*listen to silly little worries.*' The 'silly little worries' were often serious concerns about what was happening to them or what was likely to happen to them in the future. In the case presented here, Mrs Brown's concerns were having a negative impact on the way she perceived the management of her care. Where participants did not disclose how they were feeling, there was the chance that the doctor would have trouble recognising that there was a problem. This is reflected in Dr Taylor's (C) comments about Mrs Brown:

*'You never really know what people are thinking, but she did seem relatively content at the end of the interview, as far as I could tell, but she like every other patient may have been polite.'* (Dr Taylor, C; 2<sup>nd</sup> phase)

If patients want to negotiate changes to their care, they have a responsibility for expressing and articulating their issues (Roter and Hall 1993). Some patients were however concerned about what had happened to them in the past. The extract below reflects why one family decided not to articulate their concerns that it had taken too long for the patient to be diagnosed with cancer:

Mrs Moore's husband: *Myself, I was quite angry about it when we got the results because they've had all that time. If they'd have caught it earlier enough it might not be as severe as it is now.*

Lynn: : *did you tell anybody how you were feeling?*

Mrs Moore's husband: *Well you can't really because they're going to look at her and your, I wouldn't know what they're going to think, it might get their back up...the average patient or patients wife or husband, they can't stand up and tell consultants anything really can they? You know it is not etiquette to say why didn't you do this and why didn't you do that....'*

Mrs Moore: *We never even got that far did we? Let's face it.*

Mrs Moore's husband: *But you don't get their back up do you? You don't want them to think oh he's going to be a bloody nuisance. Is she going to get the same treatment or is she going to get nothing?...that's what you think.*

Mr Moore silently challenged the provision of care his wife had received leading up to her diagnosis but held back from saying anything for fear that her future care would be compromised. Mr and Mrs Moore simply proceeded to comply with the doctor's requests and justified their decision to do this based on their belief that the Oncologist had the appropriate skills to care for her. In each of these cases the patients and relatives' unwillingness to disclose how they felt added to the risk of the doctor not being able to resolve their issues.



#### 4.4.2 Doctor Knows Best

When it came to making decisions about treatments, a number of patients were prepared to leave the decisions to their doctors and comply with their instructions, as they believed that the 'doctor knew best,' this was a finding reported by other researchers (Cox, Jenkins et al. 2006; Elikin, Kim et al. 2007; Vogel, Bengal et al. 2008). When asked if they wanted to be involved in making decisions the common response (regardless of their educational background and age) was:

*'No not really. I would rather look upon them as the qualified person, you know if they don't know what they are doing then who does?'* (Mr Robinson- Source: 1<sup>st</sup> consultation)

*'..you know whatever stuff that goes into you, chemotherapy, medicines or tablets, they are the people to work that out, not me. I don't know what will kill the cancer..'* (Mr Lewis- Source: 1<sup>st</sup> consultation)

Patients generally believed that the doctors were better informed to make decisions about prescribing active cancer treatments, which is reflected in the view of Mr Baker:

Mr Baker: *I would sooner they just say let's do this and just do it*  
Lynn: *and why is that?*  
Mr Baker: *Because I don't understand anything*  
Mr Baker's Wife: *They are the experts*  
Mr Baker: *Well you hope they are (laughs) that's all, they know much more than me so leave them to do their best.*

Seale et al (1997) reported that people have generally become more sceptical about the 'expert authority' of the medical profession and are more likely to question decisions. As such they report that the medical profession has needed to take steps

to encourage patient centred medicine, which they suggest is particularly evident within terminal care through expressions of emotional warmth (Seale et al 1997). Although a number of patients participating in this study trusted that their Oncologists would do the best for them as they deemed them to be far more knowledgeable, some patients did at times express dissatisfaction with the way a doctor interacted with them but were loath to disclose their dissatisfaction for fear that future care may be compromised. This did not necessarily equate to a trusting relationship with their doctor but a relationship built on need – a need to receive treatment to prolong their lives. Only one patient participating in this study made his own decision not to have chemotherapy, despite the fact that this had been recommended by his Consultant. This was because he had considerable knowledge of chemotherapy agents and did not feel that the chemotherapy agent, which was best suited to treat his type of cancer was very effective. He thought it was a nasty drug with *'intolerable side effects.'*

In contrast to faith placed on doctors by their patients, some doctors were not always confident about what the best course of action may be. This element of uncertainty was reflected through our conversations. Trying to *'balance up whether or not it is worthwhile'* (Dr Wright, SpR) to prescribe what are often toxic treatment regimes to patients influenced preliminary decisions, while some doctors questioned the appropriateness of their decisions once a patient had been commenced on chemotherapy. This is reflected in the following quote:

*'..and you kind of go well we did everything that was right and sometimes you do query about whether you did the right thing or not but that is natural'*  
(Dr Roberts, SpR)

Concerns such as these arose if the doctor witnessed the patient's suffering and demise in condition as a consequence of the treatment, as they ultimately wanted to promote their quality of life rather than longevity of life – although the patient

frequently seemed to hope for the latter. The uncertainty expressed by doctors in determining what the right course of action may be was not only reflected in the comments made by SpR's but also in the thoughts of Consultants. The doctor's objective in some cases was to encourage patients to share the decision with them:

*'...very often the patient will say I want you to make the decision because you are the expert. It is very difficult to then try and convey to them that you may know quite a bit about the disease but decisions aren't always black and white and they can't or don't like that, quite reasonably they want a very clear steer but they need to be involved because the treatment decision has significant implications for them.'* (Dr Taylor, C- source: 2<sup>nd</sup> phase of study).

Although patients were generally encouraged to be involved in the initial decision to have treatment, when first seen by the Oncologist, this involvement appeared to be less apparent as patients discontinued one treatment and waited to see if and when another treatment may be prescribed. This is reflected upon more in the following chapter under the heading 'Managing the Next Stage.'

With the odd exception, the most important thing for these patients and their relatives was to know that something was being done to help them; a finding that supports that of The (2002). As opposed to other fields of medicine where patient compliance towards treatment has come under close scrutiny (Brown and Crawford et al.2006), concerns of compliancy in regards to active cancer treatments were less of an issue for the patients participating in this study because without treatment their future looked bleak. Patients were generally keen to receive treatment because they felt that they had little choice, because it offered them a chance of survival or prolonged life (Goldberg and Cohen et al. 1998). Apart from Mr Jackson who decided he did not want to receive chemotherapy because he had prior knowledge of the chemotherapy agent, only one other person declined chemotherapy in the first instance.

Mrs Moore, had been led to believe (by her Gastroenterologist) that chemotherapy would be of no value to her and she should consider not having it. During her initial consultation with the Oncologist Mrs Moore let it be known that she did not want to receive chemotherapy. In trying to ascertain her reasons for this decision Dr Wright (SpR) learned that the Gastroenterologist who had been caring for Mrs Moore up until this point had told her that chemotherapy would not be beneficial to her as it would not extend her life. While Dr Wright (SpR) appeared quietly persuasive with Mrs Moore during her new case consultation, it was apparent during my discussion with Dr Wright (SpR) later, that she was quite angry and disturbed by her colleague's behaviour because she believed that he had misinformed Mrs Moore. While most patients were anxious to start chemotherapy or radiotherapy as soon as possible, Mrs Moore was persuaded by Dr Wright (SpR) to give chemotherapy a go, under the promise that she would find it beneficial in alleviating her physical symptoms and thereby improve her quality of life. While I did not see Mrs Moore again within the context of this study, I did see her on several occasions on the chemotherapy unit with her daughter and she had found the chemotherapy improved her symptoms somewhat and was relieved that she had decided to give it a go.

Although, Mrs Moore had initially had poor expectations of chemotherapy, one doctor believed that in general patients diagnosed with cancer had greater expectations of active cancer treatments and tended to '*want to work with them rather than against them*' (Dr Skelton, SpR) in Oncology as the stakes were much higher. In fact, for most of the patients there was a sense of urgency to start treatment as soon as possible. When asked to describe what one patient thought would happen when they saw the Oncologist for a new case consultation, they replied:

Mr Robinson's daughter: *I think we were expecting treatment today*

Mr Robinson: *Well I was wondering because of the delay whether I'd missed out through not having treatment but as he explained today, now I am quite happy*

Mr Robinson's daughter *I think the thing is when he used the word cancer, you think you've got to act quickly and I think that's the general consensus that when you don't understand anything about cancer you panic don't you and think you've got to get it done now, got to sort it*

Mr Robinson was an elderly gentleman in his 80's and although very fit (he visited the gym on a regular basis and cycled) he had moved from Oxford to live nearer his daughter. As he had moved house, his care was transferred to another team of doctors and he was concerned that this move may have hindered the start of his treatment. His beliefs and fears about the speed in which the cancer was growing inside him, was a concern for many which exacerbated their desire to start treatment as soon as possible. This was particularly evident as patients raised their concerns with me during our conversations, yet few patients raised their concerns directly with their doctors. If a patient did hint their concern to the doctor, they would generally proceed to follow the doctor's advice or plan of action regardless of any reservations they may still have. The following quote reflects a sense of urgency to start treatment based on the patient's main concern:

*'I want to start treatment asap [sic] because its there and my feeling was I saw (name of surgeon) on October the 10<sup>th</sup> and its now December 8<sup>th</sup> and that cancers been growing inside me all that time and I could have been having treatment but doctor says no, its very slow growing, so it's probably no worse than it was when I saw the surgeon' (Mr Thompson)*

Mr Thompson described these thoughts to me as we talked about his new case consultation with Dr Davis (C). Although Mr Thompson was concerned that he had a prolonged period of time without treatment, he seemed to accept what the doctor had told him about his cancer growing very slowly and as such there was no great urgency to start treatment. Yet, in the following chapter his sense of urgency (and his wife's sense of urgency) to receive treatment is depicted more fully as his illness progresses.

Mr Thompson and his wife reveal their anxiety and concerns to Dr Davis (C) and Dr Evans (SpR) during a follow up consultation, more directly than other patients in this study tended to do. Dr Davis (C) appeared to be empathetic with Mr and Mrs Thompson and tried to reassure them that there was no need to start active cancer treatment immediately and that they had time to consider various options; he could either receive a standard course of chemotherapy or he could consider receiving treatment on a clinical trial if eligible. After discussing the various options, Dr Davis (C) presented Mr Thompson with some written information, to take home to read, to help him consider whether or not he wished to be considered for the clinical trial. In this situation, the doctor took an appropriate course of action, to ensure that ethical principles of trial participation were adhered to. However, Mr Thompson was keen to express his desire to be considered for the trial based on the information he had been given verbally by Dr Davis (C). As I observed this part of the consultation, it appeared that Mr Thompson and Dr Davis (C) had come to a bit of a 'stalemate' as they seemed to have competing agendas. Although Mr Thompson appeared friendly and calm it was evident that he was in a rush to make a decision, while Dr Davis (C) was trying to slow him down, to ensure that he had time to consider his options. Confronted by their eagerness to make an immediate decision, Dr Davis (C) later described during our conversation that she suddenly felt that she needed to be '*firmly direct*' with them, signalling the end of the consultation because she did not feel as though she was '*getting through to them.*' She did this by extending her arm

to shake their hands and by explaining that they could phone the following day to let her know their decision once they had taken time to consider their options.

It was interesting that although, a number of patients were keen to know that something could be done to help them, which was often their primary goal when they attended their new case consultations, very few of them actually asked any questions or raised their goal with the doctor directly. As doctors eventually spoke to them of their options, many simply responded with words such as 'yeah' or 'right' or 'fine' which was surprising in view of the fact that receiving active cancer treatment was a huge concern for them. This may however, be a reflection of their view that the doctor knows best and that they have little to add to the discussion.

#### **4.5 Summary**

Throughout this chapter a number of conditions have been identified that highlight distinctions in the way doctors and patients acted out their parts during consultations. Doctors frequently followed a standard consultation model to conduct their consultations to ensure that they obtained relevant information from the patient in order to help them make clinically informed decisions. For the most part, this meant that they had control over the way the consultation was conducted. However, despite this need for control, there were times when doctors were confronted with various circumstances which impacted on the level of control they could maintain, as deviations occurred which disrupted the prescribed flow of the consultation. Such disruptions appeared to have a greater impact on the doctor rather than the patient.

While doctors expressed some concern if they felt they were unable to achieve what they set out to achieve, patients seemed to be more accepting of what had happened if they were made aware of what was happening and why certain decisions needed to be postponed. While some actions and lines of questioning were apparent for doctors it was not necessarily apparent to patients. Dissatisfaction arose when patients were uncertain about what was happening and

why they were being asked certain questions. Yet, they did not necessarily disclose these feelings to their doctors.

Despite their need for control, it appeared that some doctors were very much reliant on their colleagues to ensure that information had been communicated to patients and appropriate investigations had been performed so that appropriate decisions and plans of care could be implemented. Several doctors described how they valued appropriate and informative referrals and detailed information in the patient's medical notes to keep them abreast of prior consultations with patients. Yet, as some patients were seen for follow up consultations there was some criticism that colleagues provided insufficient information in the medical notes to inform them of prior conversations with patients. Concern was also expressed if the information they had in front of them was not sufficient as the doctor may look unprofessional in front of the patient. A poor referral or a lack of information could also have a detrimental effect on the proposed plan of care; in some cases this delayed treatment.

Not knowing what patients had been told, or learning that patients were not fully aware about what was happening to them, meant that several doctors had to juggle with meeting aspects of both their needs (and style of communication) and the needs of their patients and their colleagues. For example, some doctors described instances whereby their superiors had not communicated openly with their patients and they had then found themselves in situations whereby they had been open with a patient and this had caused some distress to the patient because they learnt something about themselves that they didn't know. On some occasions the doctor was reprimanded by their consultant for disclosing too much, and yet the Consultation had not necessarily communicated their intentions up front with the doctor. Some doctors described the tensions this caused as they needed to compromise their ideal practice of being open with patients to comply with the actions of others who preferred to interact within a closed state of awareness. Some



doctors compromised their practice for two reasons; rather than confront and question the way their colleagues chose to interact with patients, there was a sense that they remained silent as an act of self preservation and secondly they did not want to communicate mixed messages to patients which may cause turmoil and interactional complications. Despite the change in awareness context from a closed to an open awareness approach of communication, these problems are similar to those expressed by Glaser and Strauss (1965), whereby the actions of various team members interfere or compromise the interactions of others.

The presence of relatives in consultations also provided some complications for a number of doctors. While some doctors valued the presence of relatives, others felt that relatives could be confrontational and / or they presented a dilemma for the doctor, as they were not always sure how to manage their needs for information appropriately. In one case the doctor was observed to use blocking tactics to avoid engaging in conversation with a relative because he felt this would conflict with the rights of his patient. For patients in this study, there was a strong sense that they valued the support of their relatives and in some cases they relied on their relative to ask for or provide information that they may have failed to remember.

Supporting their loved one through these often very difficult times seemed emotionally challenging and burdensome for many relatives. Yet, their needs were rarely addressed and any form of emotional expression was often ignored. Some doctors failed to notice or react to expressions of emotion from both patients and relatives, thereby missing the opportunity to learn of key concerns and vital pieces of information about how the patient was 'really' feeling. Interestingly, some relatives took the opportunity to cry in front of me when the doctor and patient were in an adjoining room. They were aware that I was a nurse but nursing staff were often not present during these times and relatives would no doubt be left in a room on their own.

While some doctors did try and grapple with emotional issues, others seemed less able or willing to do so and there was a lack of consensus as to whether or not it was their responsibility to offer emotional support. While some doctors considered it was part of their role, others did not and were observed to distance themselves from patients and / or their relatives. When asked if a doctor knew how a patient was feeling or whether or not the needs of a patient and / or their relatives had been met, an element of uncertainty was reflected in their responses. Doctors were rarely observed to explore how patients and / or their relatives were really feeling and tended to accept what they were saying on face value.

Although it has been suggested that health care professionals prefer to ignore a slip in ones expression of emotion in order to sustain a mutual pretence context, this was not necessarily the only reason in this study as the medical-technical aspect of a doctors role appeared to be influential in the way they chose to interact. In addition to this, however some patients chose not to share their emotional needs or concerns with their doctors. For some patients, their objective was to remain silent and unquestioning in order to meet their own agenda and in order not to compromise their care in any way and to preserve relationships; as such interactions were superficial and safe. This was reminiscent of a 'tactical game' being played because patients were ultimately reliant on their doctors and needed them to remain on side.

For those doctors who did believe that it was part of their role, offering emotional support did not necessarily come naturally to them. Some needed to work harder than others to achieve a form of communication and interaction they were comfortable with that was also reflected in the reciprocal actions of their patients. Some doctors were clearly more insightful about their interpersonal skills than others. It was evident however that those who did feel the need for support could not access it easily. There was a general sense, that support was available from colleagues in regards to medical-technical aspects of their work, but when it came to communication and issues of emotional support, doctors rarely seemed to offer each

other support, be considerate of each other and give thought to how their preferred styles of interaction may compete with the styles of others.

## **Chapter Five**

### **Sharing Uncomfortable News**

#### **5.1 Introduction**

One of the most difficult and challenging tasks for doctors was deciding whether or not or how they should share uncomfortable news with patients and their families, as they tried to balance hope and realism and honesty and ambiguity and manage the associated consequences of their decisions. While all of the doctors participating in this study believed that patients should be told their diagnosis, there appeared, through their talk and their actions, to be a greater sense of uncertainty and reluctance to discuss the finer details of prognosis. What should they say, how much detail should they provide, when should they say it and how would the patient respond to them?

Through participants' descriptions of their experiences and through outsider observations it was evident that a number of conditions had a contributory effect on the way that the sharing of uncomfortable news was managed and received. Sharing uncomfortable news was not a single action, but a series of actions and interactions which could occur at any time throughout the patient's illness. The consultations, in which these discussions took place, could not be considered as independent from each other as one consultation had a knock on effect to another. How patients perceived these interactions had some bearing on how they felt, how they perceived their relationship with their doctor and how they interpreted the information conveyed to them. In some cases, the awareness of patients was not fully explored and misunderstandings could arise. This then had a detrimental effect on the patient, which could potentially generate doubt and induce a loss of faith in those taking care of them. The patients rarely discussed their distress with those concerned and as such any problems were concealed and left unshared with those who could potentially benefit from knowing how their interactions were perceived. It

is not surprising therefore that some doctors were unaware of how they were perceived by their patients, and yet feedback was seen as a positive opportunity to learn and develop professionally by some of the doctors, although the opportunity to learn in this way was not necessarily forthcoming. These conditions are explored further in the categories and subcategories that make up this theme. These are presented in Table 7.

Theme	Category	Sub Category
Sharing Uncomfortable News	Fudging the Truth	Avoiding Prognostic Discussion False Optimism Euphemistic Language
	Mutual Understanding	Managing the Next Stage Concealing a Difficult Experience

**Table 7 - Categories and Sub Categories relating to 'Sharing Uncomfortable News'**

Each of these categories and sub categories will be presented in turn, following a similar format to that in Chapter 4. Extracts from doctor and patient interviews are used to present the cases to be discussed and these are supplemented with my field note observations (including background data) and excerpts from the recordings of consultations.

## 5.2 Fudging the Truth

'I am always a bit wary about what to say because I don't want patients to worry that they are completely riddled with cancer but by the same token that there might be another area which can be easily remedied with some simple chemotherapy. So I do tend to talk about hot spots but I didn't clarify with him so I don't know whether he took it on board' (Dr Davis, C- source: 2<sup>nd</sup> phase of study)

This quotation captured the views held by a number of doctors, who did not always know what to say to patients and at times tried to protect patients from the reality of their situation by using subtle, inoffensive language to limit the possibility of upsetting them and reducing their hope. Some doctors seemed hesitant and tried to avoid talk of prognosis, and others presented optimistic time spans for patients. In some cases, patients spoke of learning about their diagnosis of their cancer through a letter to attend the Oncology department as their doctor had used euphemistic language to convey their diagnosis to them. Excerpts from the data are now used to illustrate various aspects of 'fudging the truth', including reference back to the relevant literature to support this.

### **5.2.1 Avoiding Prognostic Discussion**

Although prognosis is an important factor in palliative care, the Oncologists seemed hesitant and / or avoided talk of prognosis with their patients, unless the patient indicated a need to hear this information; this was similar to the findings of a mixed method study conducted in America to ascertain doctor's attitudes and practice in regards to prognostication (Christakis and Iwashyna 1998). The following extracts illustrate this point:

*'when it comes to prognosis I probably still don't say 'do you want to know your prognosis' rightly or wrongly. I think that if people want to know then they are going to ask. Because sometimes what I think can happen is that I can say to somebody 'do you want to know your prognosis' and they will say 'yes and they haven't thought about it'.....I have been in a situation where someone asked me their prognosis and I said it is going to be less than six months and they said 'what less than six months'. Thinking I was actually being fairly optimistic and they kept saying 'what less than six months, oh I wish I hadn't asked'. (Dr Wright, SpR- source: 2<sup>nd</sup> phase of study)*

*'At the end of it I always ask the patient if they have anything else to ask and that would be the moment when the patient or any family member would ask about prognosis and if it is something known to me I will certainly go ahead and discuss it, provided the patient wants to know..... We can't be absolutely certain about prognosis all the time but if somebody asked me directly about how things are going to go I try to be honest and give them an honest answer.'* (Dr Walker, SpR- source 1<sup>st</sup> phase of study)

While some doctor's spoke of trying to be more open and honest about a patient's prognosis upon first meeting them, others were less open and suggested that they preferred to 'drip feed' information to patient's over time. Individual doctors had different styles of practice; while some appeared to be more confident in talking to patients about their prognosis (as discussed in their interviews) others seemed to have mixed feelings about how they managed prognostic discussions. This was consistent with the views of doctors dating back to the 1970's (Parkes 1972) and is still consistent with evidence from more recent studies (The 2002). This uncertainty appeared to be uniformly distributed between doctors regardless of their years of experience. For example Dr Taylor (C) said that despite his years of experience he still didn't know whether or not to give patients '*likely time spans or not*' because he didn't know whether or not this was particularly helpful to the patient.

A consistent theme emerged throughout the literature whereby miscalculating a patient's prognosis was considered to have an untoward effect on the patient, their plan of care and their relationship with their doctor (Christakis and Lamont 2000; Fallowfield, Jenkins et al 2002; Glare, Sinclair et al.2008). A prime example of this is presented in the following case study, which highlights this problem from various perspectives, but which also considers the tensions and problems associated with competing needs and motivations for managing awareness.

## Case Study 7 – Watching Grandchildren Grow Up

Mr Anderson was in his late 50's and had recently been diagnosed with cancer. During my first interview with Mr Anderson, following his new case consultation with Dr Davis (C), he explained how he had always hated going into hospitals and he had always dreaded being diagnosed with cancer. For him, the diagnosis of cancer represented a '*death sentence*.' Having been diagnosed with the disease however, Mr Anderson described adapting to his situation far better than he would ever have expected. Although when I spoke to his partner during the actual consultation, she did not appear to have the same opinion as she described him as being '*frightened and panicky*' at home. She felt that it was her responsibility to try and boost his morale and encourage a 'fighting spirit in him, to keep him going and not let him fall into a heavy depression', which she feared might happen, as he had suffered from depression in the past.

Although Mr Anderson spoke of having a terminal illness during this initial interview, he did not appear to have a realistic expectation of what this meant. This was not helped by the fact that his surgeon had led him to believe that he would live to see his grandchildren grow up, when Mr Anderson had asked him for information about his prognosis. His grandchildren were only two years of age and his prognosis was somewhere within the region of 6-12 months. He would therefore be lucky if he saw them reach the age of three. To put this into context, Mr Anderson had recently been involved in a feud with his daughter who had refused to let him see his grandchildren following a family argument. He loved his grandchildren and had missed them terribly during this short separation. During this time he had been very depressed and his partner had been very concerned about him. This scenario had an impact on how Dr Davis (C) thought she should conduct the new case consultation with Mr Anderson.

During his new case consultation with Dr Davis (C) Mr Anderson relayed his surgeon's comments to her about living to see his grandchildren grow up, but she



didn't reply to this comment and proceeded to ask him what he understood about his illness. When asked about this during my conversation with Dr Davis (C) she justified her decision for not disclosing information to Mr Anderson about his prognosis by explaining:

*'I purposefully didn't undo what had been said about his prognosis and my feeling was that Dr (surgeon) had given him very unrealistic expectations of what was going to happen. Now I only went as far as saying that chemotherapy was not going to cure him but we didn't talk about prognosis in any particular shape or form....ie I would estimate months [sic]....I made a note to myself at that consultation that we go back to prognosis and make it a bit more realistic. The reason I didn't do that was because I was worried that he had kind of been very negative and he had got into this positive state of mind and I really didn't want to completely sort of reduce that again'.*

(Dr Davis,C)

Trying to protect patients from the truth or detail of the truth occurred in different ways and for different reasons. While I cannot comment on the surgeon's decision for not disclosing the truth to Mr Anderson about his prognosis, Dr Davis (C) decided not to contradict the information provided by the surgeon, based on her evaluation of Mr Anderson's current emotional state. The relationship Mr Anderson had with Dr Davis (C) at this time was based on an uncertain and conditional awareness context, whereby some information was intentionally withheld on this occasion but the doctor was committed to being open, but preferred to drip feed information to Mr Anderson over several consultations, because Dr Davis (C) did not feel that it was appropriate to convey the full extent of the truth on this occasion for fear that it would be detrimental to his wellbeing. Glaser and Strauss (1965) took the stance however, that basing a decision on what they refer to as '*one stage in the response process*' fails to consider any benefit the patient may receive from supportive interventions. For example, Mr Anderson may have been distraught to learn that his prognosis was

within the region of months rather than years, but with the help of supportive interventions, he may have adapted to this information and had a more realistic impression of what was likely to happen to him.

During our initial conversation, Mr Anderson described feeling ‘*confused*’ prior to seeing Dr Davis, in regards to what was happening to him, as he explained:

*‘I suppose it is fear of the unknown isn’t it? But once you know then you can put it all in your own mind and think right this is the way to go about it. Whereas if you don’t know things you don’t know what to do, do you?’*  
(Mr Anderson)

When asked if he had any thoughts about what he may be told prior to his new case consultation he said:

*‘I didn’t know what to expect, I didn’t really have a clue what to expect. I mean you go to these places and they say you have got this that and the other and you have got the cancer and we expect you to live about 3 months, 6 months or a year and I thought something like that would probably, [sic] but she didn’t, she said we won’t cure it completely but we can try and shrink it and stop it and that was good enough for me. So I was pleasantly surprised in that way.’* (Mr Anderson)

Mr Anderson’s comments suggest that while he was living with the hope that he would see his grandchildren grow up, he did not necessarily expect that this would happen. Not having his fears confirmed meant that he could carry on living with the hope that this was a realistic possibility. Having received this information meant that Mr Anderson had a different level of awareness of his prognosis to that of his doctors. This state of awareness was to change however during a follow up consultation (the second time I met Mr Anderson and his partner), following a recent

progression in the status of his disease. This change in awareness was not however welcomed and proved detrimental to Mr Anderson's well being and his relationship with his doctors.

Mr Anderson attended this follow up consultation with his partner (soon to be wife), following a recent admission to hospital. He had several seizures at home and was rushed to the Emergency Department. Following investigations, Mr Anderson was diagnosed with a brain tumour which was secondary to his primary cancer. At the start of the consultation with Dr Hall (SpR) he described his latest experience as '*a bit of a set back.*' Mr Anderson had recently been discharged from hospital and his partner was not very happy with the way his care had been managed on the ward and came into the consultation room quite agitated and had a number of issues she clearly wanted to get off her chest. On this occasion her agenda was very clear and she proceeded to control the way the consultation was managed which was exceptionally rare during the course of this study. Dr Hall (SpR) appeared calm throughout this phase of the consultation and proceeded to answer her questions. In addition to this, Dr Hall (SpR) moved away from the desk and sat in close proximity to Mr Anderson and his partner. Dr Hall (SpR) directed her attention towards them both, although Mr Anderson was particularly quiet and let his partner do most of the talking.

As Mr Anderson's partner appeared to calm down and had spent some time listening to Dr Hall's (SpR) responses to her questions, she asked when Mr Anderson would be able to drive his car again, following his recent seizure (related to his brain metastasis) as she understood from friends that he was not allowed to drive for a specified period of time but did not know what this specified time was. Mr Anderson's domestic problems prompted his partner to ask this question but this meant that they were not prepared to hear the answer provided by Dr Hall (SpR). The question led to the blunt disclosure of some bad news relating to Mr Anderson's

prognosis which had never previously been disclosed fully to him. The following narrative depicts what transpired:

Mr Anderson's partner: *...I mean I assumed that if he didn't have a fit for so long after, only going on what other people [sic] that I know have had fits they have been able to drive you see*

Dr Hall: *It has to be a year.....but you know even in a years time you know I have to be honest*

Mr Anderson: *yes*

Dr Hall: *the chances of you living a year are not that high*

Mr Anderson: *Oh*

Mr Anderson's partner: *Now that has come as a shock..*

This came as a shock to Mr Anderson because he lacked insight into the stage of his disease and did not have a realistic understanding of his prognosis despite recent developments. Dr Hall's (SpR) response to the original question was not well received. Mr Anderson looked stunned and started to cry. His partner jumped out of her chair and knelt on the floor in front of him, grabbing his hands between hers. Dr Hall (SpR) looked across the room to me with a look of concern on her face which made me wonder if she had regretted having said anything about his prognosis. The atmosphere in the room was extremely tense and distressing. As an observer, I initially thought 'oh no' this is not going to go down well, and wanted to be anywhere but in that room. I felt a sense of anxiety and compassion towards Mr Anderson and his partner as their distress unfolded, and I had a mixed sense of emotion towards the doctor. I looked towards the health care assistant, who was sitting behind me who also appeared distressed. When asked what she thought later, the health care assistant described having to fight back her tears as she felt particularly distressed for them but didn't know how to help them. In effect, Dr Hall forced a direct announcement on Mr Anderson and his partner about prognostic information they were not prepared or willing to receive.

Having interviewed Dr Hall (SpR) following this consultation, she revealed that she was trying to rectify social order, based on her belief that Mr Anderson had a right to know what was happening to him, particularly in light of the fact that his disease was now progressing. She was however unaware of preceding events with this family and the reasons why Dr Davis (C) had decided not to disclose the full extent of the truth to this family. As Dr Hall (SpR) purposefully terminated the pretence which had been orchestrated and maintained prior to this occasion, she effectively brought the game to an end (Glaser and Strauss 1965). This decision may have been based on ethical and moral grounds (Glaser and Strauss 1965) but it was somewhat naive and the consequences of her actions were not well thought through. Mr Anderson's partner had not asked for information about his prognosis and as such they were not prepared to hear this response. Thus far, Mr Anderson had trusted that his doctors were telling him the truth. I felt that during my brief conversations with his partner, that she was engaged in an act of pretence with the doctors, without necessarily realising this, to protect Mr Anderson from information they felt would have a negative impact on his wellbeing. Disclosing such information to Mr Anderson was a decision however that Dr Hall (SpR) regretted having made, as she explained:

*'Well it was one of those things, at the time it seemed the right thing to do, but looking back... I now know how they have reacted to that, I would have just said well let's see how you are in a year and I would have left it at that. But you know hindsight is a wonderful thing...Knowing now what I know about his history of denial and then force the information on them which is effectively what I did you know, it wasn't helpful to anyone.'* (Dr Hall, SpR; 2<sup>nd</sup> phase of study)

This was an unfortunate incident for all involved. The disclosure of this prognostic information was at variance with Mr Anderson's and his partner's prior understanding of the truth. It conflicted with everything they had been led to believe and possibly chose to believe thus far in order to make the reality of their situation less

threatening. Mr Anderson and his partner and to some extent Dr Davis (C) had created a situation whereby they would not dwell upon Mr Anderson's poor prognosis and instead focus on positive aspects of his health and care. Mr Anderson and his partner reacted to Dr Hall (SpR) by choosing not to believe her, despite the fact that she had been the most truthful with them thus far. Mr Anderson and his partner made it clear through their talk and through their actions within the Oncology department that they did not want to be seen by Dr Hall (SpR) again. This had a profound effect on their relations with the doctors from that time onwards. Although Mr Anderson and his partner were willing to hear some information, the need to 'know' was not as significant in this case, as emotional and relational factors which had a significant impact on Mr Anderson's well being.

When asked about this incident Dr Davis (C) expressed her distress about the situation and said that she had spoken to Dr Hall (SpR) to find out what had actually happened in the consultation, with the intention of trying to help Dr Hall (SpR) learn from this experience. Dr Hall (SpR) was made aware during this discussion that Mr Anderson did not want to see her again and rather than confront the situation, they all chose not to talk to each other about what had happened and avoided confrontation with each other. Mr Anderson would only be seen by Dr Davis in clinic from then on. It could be argued that this situation may have been prevented if Mr Anderson had not been given an inaccurate and unrealistic expectation of his future in his initial consultation with his surgeon. It is evident that the management of his care in the earlier stages of his illness had an impact and influence on future consultations, because of the harm caused to doctor-patient relationships and trust.

As for Dr Hall's (SpR), she described how her moral judgement was effectively compromised following this incident as she felt she was dissuaded from experimenting with the way she disclosed information to patients in the future. She decided to be cautious in the way she communicated prognostic information to patients and not be guided by her instinct to disclose the truth in such an open and

blunt style. Dr Hall (SpR) described how she would in effect, create an ambiguous state of awareness, whereby the patient may know that they are not going to be cured but remain unaware of the actual details of their prognostic outlook.

Despite the problems which may arise when the patient becomes aware of or is confronted at a later date with the reality of their situation, it is not uncommon practice for doctors to generally overestimate a patient's prognosis (Parkes 1972; Christakis and Lamont 2000). In contrast to this some doctors in my study were critical that two patients had been given overly pessimistic outcomes and they expressed their hope to the patient that they could extend this time scale with the use of therapeutic cancer treatments. Having decided that they did not want to receive chemotherapy if their survival was limited to a couple of months, this new information had some bearing on their decision to start chemotherapy. This phenomenon was described by The (2002) as patients falling into the 'medical snare' as doctors convinced them of the benefits of treatment. Although this phrase may appear harsh, the patients participating in this study did not believe that they had been trapped into making a decision; through our conversations they described how they believed the doctor was interested in them and wanted to help them, which influenced their decision to receive chemotherapy. This finding was consistent with that of another qualitative study, whereby patients diagnosed with a terminal illness, thought it was important for health care professionals to nurture hope and coping and one way they could do this was to emphasise that things could be done to help them (Clayton and Butow et al. 2005b).

For one of the patients in my study, receiving a time scale appeared however, to be unhelpful to them despite their belief that this was something they needed to know. When I met Mr Lewis for the first time, he explained that he had asked his General Practitioner how long he was likely to live for when first diagnosed with cancer. Although he felt the doctor had been '*reluctant*' to tell him they had proceeded to give them a predicted time span of approximately twelve months. Mr Lewis

explained that he needed to know this information so that he could prepare for his future. Yet, here is an example however of a patient who was not expecting to hear such a short time span; Mr Lewis said he was '*expecting to hear five years or something like that.*' During this first discussion with Mr Lewis he talked about fighting his disease and trying to '*push*' the time scale he was given much further. He proposed to do this using his '*will power*', although he didn't '*know if they could push it much further*' beyond the twelve month time scale. Having approached this predicted time span however, Mr Lewis described in our second meeting how he found it increasingly difficult to come to terms with the fact that he was still alive. Instead of living his life, Mr Lewis described sitting at home, preoccupied with thoughts of dying. Although patients might actively seek information from their doctors about their prognosis, the information provided is not always expected and their reaction to such information needs careful consideration as some patients may find it emotionally difficult to come to terms with such knowledge. During the new case consultations however, doctors were rarely seen to give predictive time scales to patients. As one doctor explained:

*'Telling someone something and then it turning out to be just quite wrong is something quite important that you learn over the years and you say on average this is what we would expect... but it could be a bit different from that and when people say how long have I got to live, I say well I can't tell you exactly but people do vary but for your level of disease this is the average'* (Dr Hall, SpR-source: 2<sup>nd</sup> phase of study)

Considering Dr Hall's (SpR) previous comments following her discussion with Mr Anderson, there is a sense of being damned if you say something and damned if you don't. To predict an individual's prognosis is problematic and there was a tendency for some doctors to err on the side of caution. Although some doctors tended to be guarded and give general statements about prognosis, they did however provide a consistent message to patients that they would be unable to cure them as they



explained the therapeutic goals of treatment. In the majority of cases, chemotherapy was prescribed to patients in the hope that it would palliate the patient's symptoms, reduce or stabilise the growth of the cancer, thereby extending the patient's life for as long as they could. The following extract provides a typical example of this:

Dr Davis (C): *Now the disease is active again and we can see it in the lymph glands primarily but also in this adrenal gland which is over the kidney. And I am going to recommend that you have some chemotherapy*

Mr Thompson: *Umm*

Dr Davis (C): *And the reason for that is that I think that the chemotherapy will actually help in hopefully shrinking down the cancer. I'm afraid it is not going to get rid of it*

Mr Thompson: *Right*

Dr Davis (C): *And I don't have any treatment that's actually going to cure this. But what I hope is that the treatment I have will shrink things down, will make you feel better*

Mr Thompson: *Right*

Dr Davis (C): *And will keep you as well as we can for as long as we can. Okay*

Mr Thompson: *Right*

Mr Thompson's passive response towards his prognosis was typical of others in this study. Very few patients actually asked the doctor to provide them with detailed information about their prognosis, which is consistent with the findings from other studies (Fujimori, Akechi et al. 2005; Clayton, Butow et al. 2005b). This finding is in contrast however, to a number of other studies where obtaining prognostic information was seen as a priority for patients diagnosed with cancer (Christakis and Lamont 2000; Jenkins and Fallowfield 2001; Fallowfield, Jenkins et al. 2002).

The need for prognostic information did not appear to change throughout the course of my study, as the health of patients deteriorated. Rather than focus their attention on prognosis the attention of both the doctor and patient generally shifted towards what could be done to help prolong and improve the patient's quality of life. Only one patient asked the doctor for detailed information about their prognosis during their new case consultation. This will be presented in the following case study.

### **Case Study 8 – Prognosis**

Mr Jackson was a man in his mid forties and he had been diagnosed with cancer for two years. Mr Jackson had originally treated himself with one of his experimental drugs, as he was Head of a Cancer and Molecular Biology Department, despite the advice of his doctors who advised him to have surgery. When this treatment did not work he proceeded to have surgery. Unfortunately his cancer continued to grow and he was referred to see the Oncologist, to discuss his options. Prior to being seen by the Oncologist, for his new case consultation, Mr Jackson explained to me, that while he knew a lot about cancer, he did not want his professional experience to influence the way the doctor spoke to him as he was a biologist and not a medic and didn't necessarily know everything that was happening to him. Interestingly, he did not mention this to the doctor when he entered the consulting room. This was the only time I met Mr Jackson as he moved to the Isle of White to live near his parents, having decided that he did not want any further treatment.

Hinton (1999) proposed that patients do not necessarily seek as much information about their illness as their relatives, as a means of trying to protect themselves. This statement implies however, that patients' play a key part in managing their own states of awareness to suit their own needs. In this case, Mr Jackson clearly expressed his need to receive information about his prognosis. Mr Jackson raised the topic of prognosis several times before Dr Williams (SpR) answered him. The following extracts provide examples of this:

Mr Jackson: *If its chemo I may accept, I may decline. At the moment I don't know what the prognosis is, whether it is two days, two years, two months or beyond that*

Dr Williams: *umh*

Mr Jackson: *so*

Dr Williams: *okay*

Mr Jackson: *I need to know what my prognosis is without therapy or with therapy*

Dr Williams: *okay*

Mr Jackson: *what you plan to offer*

Dr Williams: *okay right okay. And just tell me a bit about how you're feeling at the moment.....*

After a few minutes talking about his physical symptoms, the doctor proceeds to ask him:

Dr Williams: *Okay, right and before I explain what we will do today is there any questions you wanted to pose right at the start?*

Mr Jackson: *well realistically it's the prognosis, the length of time I've got*

Dr Williams: *okay*

Mr Jackson: *Mr (surgeon) said that probably the report from the CT scan, the change in the size of the nodules meant it was quite an aggressive tumour*

Dr Williams: *umm*

Mr Jackson: *what that means in time I don't know*

Dr Williams: *okay, right, okay*

Mr Jackson: *so that's my only real question*

Dr Williams: *right, okay, right. So um the plan will be today, I just need to refresh on the history of how this all happened*

Mr Jackson: *umm*

Dr Williams: *and then I need to examine you*

Mr Jackson: *okay*

Dr Williams: *and then once those, I've asked as many questions as I need to and I've examined you then we can have a conversation about what, I can give you some data and facts and figures about what things, what kind of predictions for the future.*

Even though Mr Jackson had indicated that he wanted to know about his prognosis, Dr Williams (SpR) seemed reluctant to answer the question there and then and redirected the discussion towards Mr Jackson's medical history. Having indicated that questions are welcome, Boyle et al (2004) believe that it is then appropriate to respond to the patient and provide them with the answer to their question. On this occasion, Dr Williams (SpR) seemed to avoid following Mr Jackson's lead and appeared to ignore what he was saying by changing the direction of the conversation. Mr Jackson appeared to let Dr Williams (SpR) direct the flow of the discussion as he followed the doctors lead. It was only after Dr Williams (SpR) had completed his agenda in relation to finding out Mr Jackson's medical history and having performed Mr Jackson's physical examination he started to talk about Mr Jackson's diagnosis in more detail and then proceeded to give Mr Jackson some statistical figures about his prognosis. Dr Williams (SpR) directed Mr Jackson towards a National Cancer Institute Website, which he had loaded on to his PC to use as an aid in this discussion (while he did this, Mr Jackson's father, had tried to talk to him of his concerns):

Mr Jackson: *yeah but I mean you're looking at 2 years 5% survival aren't you and 3 years 2%*

Dr Williams: *Yes*

Mr Jackson: *are there points actually on the graph or*

Dr Williams: *yes I think they just nearly at about 1%, 1% at 10 years*

Mr Jackson: *so virtually a single person*

Dr Williams: *yeah*

Mr Jackson: *lucky bugger*

Dr Williams: *(laughs) so*

Mr Jackson: *okay*

Dr Williams: *so that gives you a sense of both, a rough idea of median times*

Mr Jackson: *so we're basically talking about one year?*

Dr Williams: *on average yes I guess it's on average*

Mr Jackson: *a year right*

Dr Williams: *okay, now we're moving onto what treatment options are available*

When this conversation took place Dr Williams (SpR) and Mr Jackson sat leaning over the table looking at the computer screen. Mr Jackson was clearly an articulate, well educated gentleman who was used to dealing with facts and figures in his professional life and he seemed to have a very clear idea as to what information he needed to know. When he learnt however that his chance of survival was within the region of one year, he sat back in his chair and looked visibly upset, but little time was given for this information to sink in. This discussion appeared to be an exercise in providing specific information which had significant bearing on Mr Jackson's future and yet the emotional impact this had on him was left unexplored. When asked if he had any thoughts about what Mr Jackson felt at this time, and how he had reacted, Dr Williams (SpR) said that he thought there may have been some '*clarity*' in Mr Jackson's eyes as something had '*sunk in.*' In changing the subject, Dr Williams (SpR) may be criticised for not having acknowledged the significance of the information he had just imparted. Mr Jackson, in fact described that whilst he had been expecting to hear this news, it was a:

*'..bit of a shock to the system to actually hear it and it was a relief to hear it as well to some extent, because I was expecting it and I presume I was in shock. I certainly didn't feel too upset or emotional if you like. That may come later.'* (Mr Jackson)

The comments made here, demonstrate how difficult it can be for patients to interpret and cope with this information even when they think they are prepared to hear it. Seldom can anyone be sure how they will respond to hearing bad news about their future. The benefits of knowing and not knowing this information are very much down to the individual

In this case, it was also interesting to see that this doctor actually gave the patient statistical information. Being asked to provide '*facts and figures*' made Dr Williams (SpR) feel '*insecure*' because he didn't really have a '*clear*' idea of what the figures were as he hadn't been working in oncology for long. Providing prognostic information was particularly stressful for doctors when their understanding of the disease was unclear. Some of the more junior registrars found themselves in clinical situations which they found difficult to manage because of this clinical uncertainty and they described how they would have to rely on the support of colleagues or by looking on the internet to help them find the answers to questions. In this case, Dr Williams (SpR) was the only doctor working in this clinic on this particular day and he said that there was no one around he could call upon for help. To help present statistical figures to Mr Jackson, Dr Williams (SpR) chose to use the website as a '*source of data*' to present the figures. Dr Williams (SpR) said that on this occasion he felt it was appropriate to provide such detailed information because Mr Jackson was very '*knowledgeable*'. Yet, not wanting to give figures to patients, to describe their prognosis was also expressed through the views of other doctors, as illustrated in the following extract:

*'I suppose it is only fair to say none of us can really give numbers because it is all based on averages. In fact, that is another concept whether people understand statistics; that they even know what an average means. I suppose then my style changes as to what I think they are like.....unless someone specifically says, look how long is that, I tend to talk in months or*

*years or weeks, rather than a specific number.'* (Dr Evans, SpR- source: 1<sup>st</sup> phase of study)

In addition to this, some doctors also described not wanting to '*take away all hope*' and withdrawing, hope was seen by one doctor as a '*bad thing*' to do. Similarly, not wanting to deprive patients of hope was consistent with the findings in the study by The (2002). This concern has however, come under some criticism by others who believe that there is little evidence to suggest that being honest about prognosis is damaging to a patients psychological health (Fallowfield and Jenkins et al.2002). The following section considers how doctors attempted to manage a patient's optimism, having in some cases been given an optimistic time span by their surgeons.

### **5.2.2 False Optimism**

In the previous chapter, an important point was raised to highlight how some doctors found consultations difficult if their colleagues had portrayed falsely optimistic information to patients. If they were unaware of this prior to talking to the patient and proceeded to disclose information the patient was unaware of, they could inadvertently cause the patient additional distress and make their interactions with the patient more difficult than they otherwise might have been. This issue is considered in greater detail in this section. The sense of frustration expressed by some doctors is illustrated in the following extracts:

*'Surgeons are very on the ball and they don't give exact prognosis and if they do they tend to be more positivistic [sic] rather than pessimistic... The problem comes too when you get people who aren't used to dealing with cancers that often, such as the gastroenterologists.....they don't tend to deal with cancers that often.....They probably hardly see pancreatic cancers so you could sort of just sense that, oh pancreatic cancer six months,*

*everybody thinks pancreatic cancer six months and actually with treatment that is not always the case.'* (Dr Wright, SpR- source: 2<sup>nd</sup> phase of study)

*'Not naming names here, but there are colleagues who haven't really been frank with a patient and when I have met them for the first time and they are seeing me for the first time...and I have given them some information that they were not expecting at all, perhaps it is my fault as well because I haven't actually ascertained how much they knew beforehand but sometimes things come up during conversation which you have no way of knowing beforehand and that can come as a very bad shock to the patient and that doesn't do the consultation any good.'* (Dr Walker, SpR- source: 1<sup>st</sup> phase of study)

As Fallowfield et al (2002) points out, doctors treating patients with cancer, will spend a good proportion of their time, communicating information and offering treatment to patients within a palliative context, it would therefore seem appropriate that they were able to communicate information effectively and appropriately. When information is not communicated in an appropriate and honest fashion, an unfavourable outcome is created for both the doctors and patients, which was demonstrated in the case of Mr Anderson. The following case study provides an example of a situation to demonstrate the way Dr Taylor (C) perceived the action of one of his colleagues from another discipline and how the patient and his wife tried to rationalise conflicting information to minimise a potential threat.

### **Case Study 9 – Walnut or Hazelnut?**

Mr Johnson, a retired Director of Fisheries in the Foreign Office, entered the consulting room accompanied by his wife for his new case consultant with Dr Taylor (C). Prior to this appointment Mr Johnson had been under the private care of a surgeon, who had performed major surgery on him within the past few weeks to try and remove a cancerous growth from his pancreas. Mr Johnson had waited a long



time for his cancer to be diagnosed because all of his initial investigations had proven inconclusive. During this consultation, Mr Johnson and his wife have the following discussion with Dr Taylor (C), whereby the finer details of the size of his tumour are raised:

Dr Taylor: *And that did indeed show there was a tumour on the duct*

Mr Johnson: *Ah did it? Because I was told there was nothing*

Dr Taylor: *There were no tumour cells did he say?*

Mrs Johnson: *No he did. The hazelnut, the scan didn't show anything*

Mr Johnson: *When he opened me up? Yes*

Dr Taylor: *That's what I mean*

Mr Johnson: *oh I see*

Dr Taylor: *Sorry, at operation*

Mr Johnson: *Yes at operation, yes that's right then he found the tumour. Yes at the head of the pancreas. About the size of a hazelnut, didn't he say?*

Mrs Johnson: *Yes*

**(Discussion continues)**

Dr Taylor: *Basically the tumour was relatively small*

Mrs Johnson: *yes*

Dr Taylor: *4cm by 3.5cm it says here*

Mr Johnson: *He said it was the size of a hazelnut*

Dr Taylor: *yeah*

Mr Johnson: *4 by 3.5cm was what he cut?*

Mrs Johnson: *walnut*

**(they laugh)**

Dr Taylor: *And rightly Mr (surgeon) has told you there is a risk of it coming back*

Mr Johnson: *Always, yes*

Dr Taylor: *And so I mean the fact is if it comes back it can come back in the first couple of years*

Mr Johnson: *Yeah*

When asked what he thought about this part of the conversation Dr Taylor (C) replied:

*'..in fact it was quite a bit bigger than I think his concept of it was and more extensive than he had been led to think.....Clearly it seemed to me that he had been given a very rosy picture of the future, which didn't quite go together with a 2 year survival. I couldn't quite work that one out as for me a 2 year survival would have been quite a shock if I'd been told it was very small and a good outcome'* (Dr Taylor, C; 2<sup>nd</sup> phase of study)

During my discussion with Mr Johnson, he described having a particularly good relationship with his surgeon. He felt the surgeon had always communicated information to him very clearly and honestly. Although there was some discrepancy in the information provided by Dr Taylor (C), about the size of Mr Johnson's cancer Mr Johnson also thought that Dr Taylor (C) had been very clear and direct. As Dr Taylor (C) read the results of Mr Johnson's CT scan to them; he appeared slightly uncomfortable when he thought that he was disclosing information to Mr Johnson, which could potentially portray a different message about the size of his tumour which would have bearing on his prognostic outlook. As Mr Johnson listened to the information about the size of his tumour he looked concerned and sat back in his chair but his wife made light of this information and the conversation moved on without further exploration. This look of concern was not missed by Dr Taylor (C) but he did not choose to explore this with him. When I interviewed Mr Johnson and his

wife following the consultation and asked him what his thoughts were about this part of the discussion, both Mr Johnson and his wife tried to rationalise the discussion by saying:

Mr Johnson: *Yes sort of 3-4 cm, whereas Mr (surgeon) had said 2cm, so I assume that is was, the tumour and everything around it would have been 3-4cm I suppose. Well if it is the smallest of what we took out, something like 2cm then that is a very good prognosis, if it is much bigger then I am not sure it is going to go. But he did all sorts of tests and the rest of the pancreas was clear and the lymph nodes (interrupted)*

Mrs Johnson: *well the size we were just a bit surprised. It's all gone (Laughs) it's not there anymore is it?*

Mr Johnson: *Exactly. Mr (surgeon) said it was small so (interrupted)*

Mrs Johnson: *It was directly above the lymph node, was directly there, would that be included in the size? Well it doesn't matter it has gone.*

During this discussion and during the consultation, it appeared that Mrs Johnson played a significant part in raising her husband's optimism and repeatedly insisted that the cancer had been removed so the size of the tumour was insignificant. On several occasions, relatives were proactive in ensuring the hope of their loved one was not taken away by trying to jolly them along or spoke in terms of '*picking him back up again.*' In this consultation, Mr Johnson maintained a calm and passive appearance as he sat back in his chair looking very relaxed – that was until the size of his tumour was mentioned. As the consultation progressed, he appeared to listen attentively to Dr Taylor (C) but when asked declined the opportunity to explore his prognosis further. As I spoke to Mr Johnson, I got the impression that while he

valued his interaction with Dr Taylor (C), he was resigned to believe his surgeon's description of his tumour and possible prognosis.

Dr Taylor (C) when asked described how he felt his colleague had predicted an overly optimistic survival outcome to Mr Johnson. He felt that he needed to introduce the concept to Mr Johnson that his cancer was likely to return within the next year, rather than in the next 2-3 years or longer as predicted by his surgeon.

This is illustrated in the following extract of our conversation:

Lynn: *In this instance the surgeon had told him that he had a possible life span of 2-3 years, but when we were talking you said he had probably a year. Does that affect the way that you then manage the consultation when you know they have a different expectation?*

Dr Taylor: *I think it is a really hard situation because you don't want to make him lose confidence in the person who originally treated him nor in the medical profession because that makes his future interactions with us all quite difficult. Nevertheless I thought that there ought to be some suggestion to him that it might not be as good as it was and indeed a figure of 2 years isn't really quite right....So it was a matter of trying to introduce to him the concept that it wasn't quite as accurate as it could have been without making him lose confidence in the surgeon that had told him that data.*

Lynn: *And do you think you managed to do that?*

Dr Taylor: *I hope so. I think what I failed in that interview was to be as pessimistic as probably I should have been or as realistic as I should have been but rather gave him a vague concept that it wasn't as good as it could have been. It could be quite a bit worse. But he didn't pick up on what I thought were a couple of cues I gave him to*

*ask for more specifics and he didn't ask and so I didn't (as I usually don't) push it on him.*

Lynn: *And can you explain what those cues were?*

Dr Taylor: *I said on one occasion that it isn't actually a matter of a specific length of time, it's either that you could live a normal life expectancy and I think at that point he said "yeah, you mean, anything could kill me or something but on the other hand it could come back earlier than that." And then I think I said ....that there was a significant risk that this could come back and if that occurred it wasn't something we could cure.*

There may be a number of reasons why Mr Johnson chose not to probe further. It may well have been because he had a close relationship with his surgeon, which had developed over time and he described having a considerable amount of confidence in him. It may also have been because Mr Johnson did not want to know that his prognosis was not as positive as it had been portrayed previously. Regardless of the reason why he chose not to ask questions or challenge the doctors in any way, it is clear that Mr Johnson and his wife were trying to exert some control over the way in which they perceived the information being presented to them. This is not an uncommon response, as Copp (1999) observed the same behaviour in patients as they interacted with nurses within a hospice.

Rather than take into consideration the fact that patients played a part in controlling and managing their own states of awareness, doctors generally described their concern about whether or not they thought patients had understood what they had told them despite ever asking them. Not knowing what patients really understood was a common problem and yet the evidence presented in this thesis shows that the problem is much more complex than just this. In this case, Dr Taylor (C) '*hoped*' that they had been able to convey a message to Mr Johnson that things might not have

*'been as good as it could have been'* but he was not convinced that this message had been received by Mr Johnson because he did not ask for further information when given an opportunity to do so. Whether or not it is in the patients best interests to try and make someone hear something they are not ready or willing to face has been questioned in the past (Glaser and Strauss 1965). Yet, this dilemma is still faced by doctors on a daily basis and seems to be further compounded if they do not know the patient particularly well.

In this case, Dr Taylor did not think it was appropriate to probe any further or make his point more clear. In contrast, 63.5% of doctors in another study indicated that if patients were optimistic about their prognosis then they would not even try to alter this perception (Christakis and Iwashyna 1998). Whereas, the study conducted by The (2002) demonstrated how difficult it was for the multidisciplinary team to make decisions about how best to proceed with the management of an optimistic patient. While there were instances or references made which indicated that doctors in this study did not always agree with the way disclosure was managed, it was also not uncommon to witness individuals use inconsistent approaches in the way they managed the optimism or pessimism of patients.

Dr Taylor (C), for example, was critical of his performance in relation to Mr Johnson's consultation and questioned whether or not he had been as pessimistic or as realistic as he could have been. Yet in another consultation with Mr White, Dr Taylor admitted that he had not been *'totally honest'* with the patient as he had *'given better odds'* than he should have done because he felt Mr White came into his new case consultation fairly optimistic and Dr Taylor (C) did not want him *'losing all sense of hope.'* From the data analysis, it emerged that some doctors appeared to use different approaches with different patients, depending on their immediate impression of the patient sitting in front of them. In this case, Mr White, was actually more realistic about his outlook than Dr Taylor (C) had given him credit for.

During my conversation with Mr White, he explained that the health service had invested a lot of money in his care and they would not have done this if he hadn't been worth the effort, but by the same token he felt that he had to accept what was happening to him. He used the following quote from the film 'Zulu' to express how he intended to cope with the situation he found himself in '*why us sarg? Because we are here lad you are where you are.*' In this instance it was a prime example of the doctor making an assumption about a patient's need for information rather than finding out the patient's preference (Fallowfield and Jenkins et al. 2002) and preparing him appropriately for what may happen to him in the future.

### **5.2.3 Euphemistic Language**

Boyle and Robinson et al (2004) use an analogy of rugby to explain how the '*game works*' when a patient has been diagnosed with cancer and enters into new and often unfamiliar territory. A territory that takes the patient into a new 'social structure' where the '*reality*' of their situation is played out, having significant consequences for the patient's future (Brown and Crawford et al. 2006). In this analogy, the referring clinician has a role to play in ensuring the patient is orientated to this new world so that their expectations are set before they enter the game (Boyle and Robinson et al. 2004). Brown and Crawford et al (2006) have referred to this game as '*preparing the ground*'. While some patients in this study, were pre warned about what to expect others were not even sure that they had cancer, although they suspected they might. The conditions which ordinarily helped maintain or reduce a patient's level of awareness, changed as inadequate communication raised suspicion and eventually confirmed their worst fears. Several patients had their suspicions confirmed when they received a letter to attend the Oncology department. An example of this is illustrated in the following case study.

### **Case Study 10 – Tumour**

When I arrived in the oncology outpatient clinic to see if Mrs Martin was willing to participate in my study, I was informed by the clinic co-ordinator that Mrs Martin was distressed. It appeared that the letter we sent her in the post inviting her to take part

in this study (prior to her attending her new case consultation), had confirmed her suspicion that she had cancer, because prior to this she said that she didn't know. The clinic co-ordinator felt that Mrs Martin appeared angry and upset when she arrived in clinic, accompanied by her husband. I was very concerned about this and wondered how we could have got this wrong as prior to sending the letter of invitation out in the post; I had been informed by her doctor that she did in fact know that she had cancer, hence the clinic co-ordinator arranging an appointment to see Dr Taylor (C) too. I had also read Mrs Martin's medical notes to confirm this information for myself. Before I saw Mrs Martin, I thought I had better check her medical notes again to see if there was any indication that she had been informed of her diagnosis. The referral letter from her surgeon indicated that she had been told her diagnosis and that she had been informed how serious her diagnosis was. Having read her notes, I sought Mrs Martin out in the waiting room to offer my apologies. I did however feel very apprehensive about doing this as I did not know how she would respond to me.

Mrs Martin was sitting in the waiting room with her husband. She appeared calm and didn't express any anger towards me, but I found it difficult to interpret her husband's feelings. He was unable to talk to me or even look at me, which made me feel somewhat uncomfortable. I tried to direct my attention towards both of them but he did not respond to me. When I spoke to Mrs Martin, it became evident that she knew there was a possibility that she had cancer but her diagnosis had not been confirmed. She knew she was coming to see Dr Taylor (C) but hadn't realised that he was an Oncologist. I had resigned myself to the fact that Mrs Martin was going to decline to participate in the study but she agreed to talk to me about it in more detail. She said that I was very welcome to observe her consultation and to record it, but if she felt the news she received was particularly bad, then she may withdraw her consent to participate any further. Following the consultation, she did decide to proceed with the study.



As I left Mrs Martin, I approached the nurse in charge of Dr Taylor's(C) clinic to let me know when she took Mrs Martin's notes into Dr Taylor (C) or his SpR, so that I could speak to them first. I felt obliged to inform the doctor what had just transpired. The clinic nurse took Mrs Martin's notes into Dr Taylor (C). I explained what had happened and Dr Taylor (C) appeared to be disturbed by this chain of events. As far as he was aware, Mrs Martin had been given her diagnosis. When Mrs Martin was called into the consulting room the following conversation took place:

Dr Taylor: *Thank you very much for agreeing to help her, but I mean this is appalling. I mean I'm so sorry. The letter I have had deals with it as though you've been told everything and normally we get, and normally the person who dealt with you tells you everything and in fact Mr (Surgeon) spoke to me and (interrupted)*

Mrs Martin: *Mr (Surgeon) came to see me on the Thursday I believe it was or it might have been the Friday*

Dr Taylor: *Right*

Mrs Martin: *And erm he said that they'd taken a piece of the bowel away and there was a tumour in that, also the adenum if that's the right word*

Dr Taylor: *So he did say there was a tumour*

Mrs Martin: *Yes he did*

Dr Taylor: *Oh right*

Mrs Martin: *But not whether it was malignant or what it was*

Dr Taylor: *Oh I see right, right, right*

Mrs Martin: *Okay so yes, we'd all presumed but nothings ever been said*

Dr Taylor: *Sure*

Mrs Martin: *You know for definite.*

Not knowing whether or not Mrs Martin knew that she had cancer created a problem for both Dr Taylor (C) and myself, in regards to how we interacted with Mrs Martin. Dr Taylor (C) was initially keen to offer his apologies to Mrs Martin for having

inadvertently communicated her diagnosis to her via a letter rather than through face to face contact. His initial appearance of distress soon turned to one of surprise when Mrs Martin said she had been told that she had a tumour and at this point he appeared to physically relax in his chair. During my conversation with Dr Taylor (C) he explained that he was initially concerned that *'we had let her down with poor communication but then it was clear that she did in fact know that she had cancer.'* This was a case of the doctor and patient having a different interpretation of what the word 'tumour' meant. When asked what she thought 'tumour' meant, following the consultation, Mrs Martin said *'well cancer yes, but a lot of them are benign so therefore until I am told otherwise I am not going to lose any hope.'* In this case, Mrs Martin doesn't fully know that she has cancer, but suspects that she might. In this open suspicious awareness context, the health care professional may well think that they have communicated a diagnosis of cancer to the patient (without actually using the word cancer) but the patient does not think so. To try and prevent misunderstandings such as this, another doctor felt that it was important to discover how patients interpreted medical terminology because:

*'...sometimes patients say am I terminally ill? What I would then say to them is tell me what you mean by terminally ill....And sometimes you will say your outlook is serious and the patient will say so you; you mean 10-20 years then and not any longer. But people catch you by surprise because I think when you are in the medical world and you are submerged in it for so long you kind of think that everyone thinks the way that you think. But actually these are English words and everyone has a right to interpret them how they want to interpret them.'* (Dr Evans, SpR- source: 1<sup>st</sup> phase of study)

While two other patients interpreted a 'tumour' in the same way that Mrs Martin did, another patient described in our conversation, how he thought a tumour *'grew like tennis balls inside you'* and proceeded to ask *'Do they talk of cancer as tumours do they?'* This example highlights how different people interpret and apply meaning to

the information they are given. In their study to assess lay understanding of terms used by doctors during cancer consultations, Chapman and Abraham et al (2003) found that using alternative words to mean 'cancer' were likely to affect a patient's understanding of what was wrong with them (Chapman and Abraham et al. 2003). It might be suggested however, that some patients interpret information in such a way because it helps them remain uncertain, and therefore hopeful of a better outcome. (Timmermans 1994; Mamo 1999).

Mr Johnson's and Mrs Edward's situation was very similar to that of Mrs Martin's. Both of these patients discovered that they had cancer, having received letters to attend the Oncology department. The devastating effect this had on them is portrayed through their comments. Living in doubt, without a clear diagnosis was very difficult for these patients and could easily have been prevented with the use of appropriate language. The referring clinicians had used the word 'tumour' to describe their disease. While they each thought that they might have cancer this had not been confirmed, as Mr Johnson and his wife explain:

Mr Johnson: *We got a letter of invitation to see (name of Oncologist)*

Mrs Johnson: *Nobody had said definitely to us, Mr (name of surgeon) had said in May the likelihood is cancer near the pancreas, so he had a whipples but nobody had said to either of us that it was, because well we heard the word tumour but tumour is a growth that shouldn't be where it is, like a weed. So a tumour doesn't have to be malignant it could be benign. So we both assumed it had been a cancer but nobody was telling us. So we floated for about a fortnight. That was a little bit tough. We did get to a stage when we wanted somebody to say this is what it was.*

Lynn: *So how did it feel opening that letter?*

Mrs Johnson: *That was bad*

Mr Johnson: *It was, it was not nice*

The description they offered did little to portray the fleeting emotion which was expressed on their faces as they looked at each other; an intimate knowledge of how emotional and distressing this experience had been for them. A similar sentiment was expressed by Mrs Edwards, but there was a sense of relief when she finally learnt that she had her suspicions confirmed. She said, *'I didn't want it to be but I know now and I feel better, you know what you are dealing with.'* Feeling relieved to actually hear that you have cancer, exemplifies the magnitude of this problem. Regardless of the health care professionals motivations for not using the word 'cancer' to describe what is wrong with someone, they are ultimately preventing people from adapting and being able to manage their situation in their preferred way. As seen in the case of Mrs Edwards, not knowing was worse than knowing and this problem has been highlighted by Boyle and Robinson et al (2004). As they explain, a patient is likely to have a heightened sense of anxiety when they discover they have cancer but this tends to settle down once they have had time to 'recognise what they are dealing with' (Boyle and Robinson et al. 2004). This closely reflects the views of Maynard (2003) who argues that receiving good or bad news, 'interrupts our involvement in our social world' but then helps people re-evaluate their lives.

What one person considers to be bad news is not necessarily perceived in the same way by another (Maynard 2003). Mrs Edwards thought her surgeon was trying to 'protect' her but she found this unhelpful, as she needed to know what was wrong with her and what would be done to help her. During our conversation she also explained that when she learnt she had cancer, she could at least understand why she was feeling the way she did, which seemed to justify her symptoms. This sentiment is reflected through the comments of Timmermans (1994). Writing from personal experience Timmermans reflects on the way both his father and himself hated waiting and not knowing what to expect in relation to his mothers illness. While there is evidence to suggest that the disclosure of diagnostic information is common (Innes and Payne 2009), the evidence presented here demonstrates some

of the problems that arise when there is a discrepancy in what the doctor thinks they have communicated and what the patient actually perceives they have been told.

While patients wanted their doctors to use the correct terminology to inform them of their diagnose, prior to receiving correspondence in the post informing them of the need to be seen by an Oncologist, the use of euphemistic language appeared best received by those in the latter stages of their illness. Mr Baker for example, seemed to value the fact that his Oncologist was trying to protect him from the reality of his situation by using euphemisms which were seen as less harmful. Mr Baker had previously received chemotherapy to treat his primary cancer and this was followed with radiotherapy to treat a metastasis in his hip. When I observed his consultation with Dr Davis (C) for a second time, she spoke to him about doing a bit of '*spot welding*' to some '*hot spots*' on his shoulder. Mr Baker appeared to find these use of words amusing as he laughed at her description of this plan during the consultation. Dr Davis, explained to me that she was concerned that Mr Baker had a bone metastasis in his shoulder and purposefully chose this terminology because she didn't want Mr Baker to go home thinking that he was '*riddled with cancer*.' When I asked Mr Baker what he understood by this terminology during our conversation, he laughed again and said '*well they found something there whatever it was*' and then he proceeded to explain that he didn't want to know what they had found. Mr Baker had recently had radiotherapy to his hip, and when I asked him about this also, the following conversation took place:

Lynn:                *You said you had treatment on your hip but you are not really sure, what they did or why, do you ever feel that you can ask those questions?*

Mrs Baker:        *He doesn't want to know*

Mr Baker:         *No No*

When I probed him further to see what kind of information he felt he wanted to know he said:

Mr Baker:       *Only the basics, just the basic stuff that is all. I don't want to know all the details.*

Lynn:            *What do you mean by basic?*

Mrs Baker:       *About as much as you know now.*

Mr Baker:        *Yes, really, yes. Just the normal stuff about it. What I have got. I mean I don't even know how long I have got. It could be ages, I don't know. I am quite happy as it is really.*

Mr Baker explained that he liked the way Dr Davis (C) spoke to him and felt that the Oncologists he had met thus far were '*direct and don't say silly things*' and his wife felt it was great that they didn't '*hide anything and they tell you as it is.*' I was compelled by this part of our conversation, as I felt that Dr Davis (C) had been ambiguous in the way she presented this information to Mr Baker and yet he described this information as direct and open, which seemed to me to be a contradiction in terms. As I reflected further upon this interview with Mr Baker, it was evident that Mr Baker was aware that he was going to die from his cancer as he mentioned dying several times during our conversation. When I asked if he thought about dying very much, he said '*no I keep putting it out of my mind, I try to be cheerful.*' The use of humour in his everyday exchanges with friends and family appeared to be important to him. As such, I felt that he received information based on his terms and as such felt adequately informed to maintain his preferred state of awareness.

Overall, patients participating in this study wanted to know their initial diagnosis and but when it came to knowing what was going to happen to them further down the line, the need for honest disclosure became less clear for some, as there was a tendency to try to shield themselves from the negative impact of their disease

progression. Similarly, Fujimori et al (2005) found that patients in the initial stages of their illness wanted to be told that they had cancer '*clearly and honestly*' but as time went on, they did not want to hear the word 'cancer' used all the time. They wanted the doctors to use euphemistic language instead, but their reasons for this were unclear. A similar finding was also presented by Sand and Olsson et al (2009) the words, bubble, him and nut were used to describe 'cancer' and vitamin C was used to describe 'chemotherapy.' These words seemed to be helpful in limiting the amount of exposure that was given to their illness (Sand and Olsson et al. 2009) but examples to illustrate these points were lacking in the report.

In this study, doctors were seen to use euphemistic language when patients attended follow up consultations. The word 'cancer' was interchangeable with the words 'tumour' and 'disease.' Rarely did anyone use language that conveyed a negative message, associated with either progressive disease or death and dying. Rodriguez and Gambino et al (2007) had previously found similar results in their qualitative study to consider the explicit and implicit language used by doctors and patients to communicate death and dying. In their study Rodriguez and Gambino et al (2007) found that implicit talk of death and dying was used in every consultation. Rather than talk bluntly about dying doctors and patients tended to use language which suggested death was a possibility sometime in the future, and they tended to focus on what could be done or achieved in life (Rodriguez and Gambino et al. 2007).

Similarly, both doctors and patients in this study tended to talk in such a way that was consistent with the continuation of life rather than the demise of life. The following extracts from two different consultations provide examples of this:

Dr Davis:	<i>And it should help shrink the cancer down everywhere.</i> <i>Now unfortunately chemotherapy is not going to cure this</i>
Mr Anderson:	<i>No</i>

Dr Davis: *The whole aim of treatment is to keep you as well as we can for as long as we can. Okay.*

**Next extract:**

Dr Roberts: *..we have known about these since the summer, you're very well and any chemotherapy that we give you is aimed to keep you as well as possible for as long as possible*

Mr Robinson: *That's right*

Dr Roberts: *There are in this kind of situation, there are two different options. One option is to give you chemotherapy now to try to shrink your cancer down and to try to get control of it as best we can*

Mr Robinson: *ummmhmm*

Dr Roberts: *And to then try and give you as long as possible with your cancer being as small as is possible. The other side, the other argument is say well why give you any chemotherapy unless you become symptomatic, ie, unless you have any problems associated with your cancer.*

These are just two examples of many, where the doctor uses language to convey a hopeful message about treatment-related outcomes. As a patient ended one treatment and waited to see if or when another treatment regime may be prescribed, doctors spoke of '*trying to get hold of it again*' or '*we will get you much better than you would otherwise have been.*' This subtle use of language tended to soften the blow and detract from the inevitable outcome of death. In nearly all of the cases, I followed through to a second or third consultation; the patient's went along with this and rarely questioned the use and / or meaning of this language. For some, as in the case of Mr Baker, information conveyed in this subtle way was explicit enough for him. While I believe that he knew what was happening to him, he took things at



face value and didn't probe further, believing that the doctor was doing her best for him. This choice of language may not however have been appropriate for others, who needed descriptive and detailed information to present the reality of their situation, however distressing this may have been for them.

### 5.3 Mutual Understanding

*'I think there are different ways of going about it and the old school is not telling anyone about it. You know because what you don't know can't hurt you allegedly and I subscribe to the other school and that is the school that I think the more informed you are the better you will cope with something provided that you are not given too much information that is too much for you. But that is the trick isn't it? What is too much information? And I don't think there is an answer to that question in general.'* (Dr Wilson, C – source:1<sup>st</sup> phase of study)

This quotation reflects the change in philosophy from that of a closed awareness to an open awareness context. Although there has been a trend towards openness, the problem lies in determining how much and what information is communicated in order to meet the individual needs of patients throughout their illness. Taking a pragmatic stance to meet the needs of each individual patient, at various points throughout their illness, seemed to be the intention of many doctors participating in this study. Yet, when questioned, many doctors could not describe what their patient's needs were and how they might feel about the information they had provided and the way they had presented such information. Yet, negotiating the specific needs of individuals is crucial in maintaining high standards of patient care and satisfaction (Innes and Payne 2009), yet this as we have seen is not always achieved.

In addition to this problem, some patients and their families may want to know what is happening to them and what to expect in terms of the care and treatment options that are or will be available to them, and yet they do not fully understand or appreciate what they are being told. As a consequence, their perspective of what is happening to them and why may be very different to that of their doctor. In this next section, consideration is given to the experiences of doctors and patients as the patients attend follow up consultations, having completed their first line of chemotherapy to help palliate their symptoms, improve their quality of life and prolong life. The difficulties associated with this phase of a patient's illness are considered from a combination of perspectives.

### **5.3.1 Managing the Next Stage**

As patients completed or discontinued a course of active cancer treatment, they continued to be seen by their doctors in follow up consultations in the Oncology outpatient department. The very nature of the disease means that changes occur throughout the 'illness trajectory' and prognosis will at some point change (Glare and Sinclair et al. 2008); changes which will vary from person to person. Only one patient out of six went on to receive a second course of chemotherapy, after his disease progressed following his first course of treatment. Another patient received urgent radiotherapy to treat a newly diagnosed brain metastasis. The other patients continued to receive best supportive care, although some were hopeful that further chemotherapy would be prescribed to them in the future. An example of this is illustrated in the following case study.

### **Case Study 11 – Wait and See**

When I first met Mr Thompson and his wife, their main concern was that he had treatment as soon as possible. The doctor on that occasion had tried to reassure them that they didn't need to rush into making a decision about treatment but this had not seemed to ease their minds. For this couple in particular it was important for them to know that '*something was being done.*' This is something I have raised

before and is something that continued to be significant for this couple after he had stopped receiving chemotherapy.

As I observed Mr Thompson's consultation for a second time, a number of issues were discussed, including the results of his latest CT scan, which showed that he had stable disease (the cancer had not changed in size) and his physical symptoms and subsequent management. The consultation appeared to be drawing to a close when Mr Thompson started to tell Dr Evans (SpR) that they had been on holiday the previous week and that they had managed to have a lovely time. During this part of the conversation Mrs Thompson suddenly raised an important question, as illustrated in the following extract:

Dr Evans:	<i>was it hot?</i>
Mrs Thompson:	<i>It was really nice, yes it was lovely</i>
Mr Thompson:	<i>yes really nice</i>
Mrs Thompson:	<i>It was really nice. Is there anything happening about, you know he stopped his chemo half way through. Is anything happening with that now? Does he start again? Or is that completely finished or..</i>
Dr Evans:	<i>That is completely finished with. Having said that you might need the same chemotherapy again because it worked well first time, whenever the occasion arises</i>
Mrs Thompson:	<i>ummmmmm</i>
Mr Thompson:	<i>Yeah</i>
Mrs Thompson:	<i>When we need more chemo, but whilst he's well we leave him alone?</i>
Mr Thompson:	<i>Oh I see</i>

The question posed by Mrs Thompson, came as the consultation was drawing to a close and clearly demonstrates how the conversation between doctor and patient

and their relative can change quite abruptly and dramatically. During my conversation with Mr and Mrs Thompson directly after the consultation it was clear that Mrs Thompson really didn't 'see' at all. When asked how they were feeling after the consultation had taken place, Mrs Thompson replied:

*'Well it is all new to us isn't it you know what I mean? We have not been through it with any family members or anything like that and you don't know what is quite going to happen so you have to accept what they say and be confident you know what they are doing haven't you really?....It seems no you are fine so we just leave it but I am not sure about that. But that is what they do, what can you do but I suppose they have got the experience of hundreds of people they have treated'* (Mrs Thompson)

In discussing a patient's loyalty towards their doctor, The (2002) describes how some patients (and in this case relatives), try to trust their doctors are making the right decisions on their behalf, even if they don't really understand their motivations. Patients in my study seemed to co-operate with the doctors because they felt that they didn't really have an alternative choice.

On this occasion Dr Evans (SpR) tried to explain to Mr and Mrs Thompson that there was no indication to treat him while he was well and that further chemotherapy would be prescribed if his condition started to deteriorate. Managing chemotherapy in this way made little sense to some patients and their families. Some believed, either because they chose to believe or they were led to believe that there was always another option; that if one treatment didn't work, or the course had been completed, they could try another one and so on. While some patients didn't anticipate a cure, chemotherapy provided a significant hope that life would be prolonged and the inevitability of death would be postponed, which for most of the patients was considered in terms of years rather than months.

Dr Evans (SpR) described how she was motivated to ensure that Mr Thompson had a good quality of life and wanted him to be as well as he could for as long as he could without experiencing the side effects of chemotherapy. Dr Evans (SpR) also explained that they were constricted by the amount of chemotherapy they could prescribe for him because the options were very limited and they did not want to act prematurely. This was an issue raised with Mr and Mrs Thompson by Dr Davis (C) when I observed their consultation for the first time. At that time, they expressed their desire to commence chemotherapy as soon as possible, but as I have explained previously, Dr Davis (C) tried to encourage them to take a day or so to think through their options. At that time, they were presented with the option of receiving a standard chemotherapy regime or a treatment within a clinical trial. Dr Davis (C) hoped that Mr Thompson would be eligible for the clinical trial, because this meant she could proceed to treat him with the standard regime of chemotherapy after, if necessary. Mr Thompson and his wife were aware of this, and opted to be 'screened' to see if he was eligible to participate in the clinical trial, but unfortunately he was not, and proceeded to have standard chemotherapy. On this occasion, Dr Evans (SpR) explained to me during our conversation that she realised managing a patient's care in this way took away some of the patients '*control*' for managing their future and instead of being able to go ahead and make any plans they tended to sit around waiting because she felt patients '*don't know what is what in regards to their future.*'

While Dr Evans (SpR) thought that Mr Thompson seemed to have a more '*philosophical approach*' and tended to be a '*calming influence for his wife,*' she also felt that she would never be able to give Mrs Thompson the information that she really wanted to hear. Clayton and Butow et al (2005b) explain that it is important for health care professionals to let patient know what can be done for them in the future, to try and offer them some form of reassurance. In this case however, Dr Evans (SpR) explained to me that she found it difficult to reassure Mrs Thompson because

she could not ultimately give her the information she needed to hear. As she explained:

*'....there is a general concept that more is better. It is trying to get that concept through that more isn't better, that with palliative chemotherapy you don't always buy the patient a prognostic life expectancy.'* (Dr Evans, SpR; 2<sup>nd</sup> phase of study)

Ultimately, Dr Evans believed that Mr Thompson's wife needed:

*'....reassurance that things so far are okay and I think ultimately she wants reassurance that things in the future are going to be okay and I think she can't accept that nobody can tell her that really.'* (Dr Evans, SpR; 2<sup>nd</sup> phase of study)

This was not too far from the truth. The following narrative between Mr and Mrs Thompson expresses what they were thinking about the possibility of further chemotherapy and his future:

Mr Thompson: *It is there if you get ill again so they can start again and perhaps reduce it again and give you a few more months or whatever. Years.*

Mrs Thompson: *We hope it does but they keep talking in months and you think oh my god.....they said months, how did she put it?*

Mr Thompson: *I don't remember*

Mrs Thompson: *They say so much do you know what I mean?*

Mr Thompson: *I don't think they think there is long to go*

Mrs Thompson: *Yes, we don't know if they are breaking us in gently, but we don't really know at this stage, well I don't want to know how*

*long I want to pretend that it is years but perhaps...(she starts to cry)*

Mr Thompson: *We would just like them to tell us that it is dormant and it is not going to be a problem anymore and obviously that is not going to happen*

Mrs Thompson saw chemotherapy as their '*lifeline*' and this had she thought been taken away from them and she found this hard to come to terms with. She also thought that if he didn't receive chemotherapy earlier then they would be '*playing catch up.*' Although she appeared calm, it was evident that she was struggling to get her head around the '*wait and see policy.*' In contrast to this perspective, Mr Thompson, appeared to be more accepting of the doctor's decision as he said he felt that they:

*'know from experience the right way to go about it....it is going to, it will advance again and start affecting me and then they will give me the chemo again [sic].'* (Mr Thompson)

At this stage however, Mr Thompson was feeling well, apart from some shoulder pain, which the doctors were investigating and trying to relieve with medications. I noticed that when the patients seemed to be relatively well with minimal symptoms their relatives in particular seemed keen for them to have more chemotherapy because they then felt that something active was being done, while they were fit enough to receive something. One of the things, which seemed to disturb people the most, was '*passivity.*' When nothing was being done, it was hard to accept. For example, Mr Lewis, compared what it felt like for him when he was receiving treatment and how he felt when it stopped:

*'and then every day I was having radiotherapy for 3 weeks and it was so intense and the concern was so intense on my well being from all quarters,*

*that it all seemed to just fall off and nobody seemed to give a damn anymore.'*

(Mr Lewis)

A desire to maintain the same level of intense attention received whilst on treatment was also identified in another study (Cox 2000), whereby patients were asked to describe their experience of participating in early cancer drug trials. This feeling of abandonment may have explained why Mr Lewis was concerned about dying alone without any support. Mr Robinson's daughter was particularly concerned that her father would not be monitored on a regular basis but did not raise this concern with the doctor, when I met them for the second time. She was worried that her father's cancer would start to '*grow with a vengeance*' while her father was not receiving chemotherapy and questioned how they would know if this was happening or not. Patients and their relatives were very much reliant on their doctors doing their best for them and being monitored closely through hospital visits was important to them. Whereas, Copp (1999) found that patients being treated in hospice, tried to control what was happening to them in regards to the way they chose to manage treatments, patients and relatives in this study, found it difficult to exert this control and while they hoped that they were being cared for appropriately, were not entirely sure that this was the case, because they could not entirely understand the rationale for treatment related decisions.

The need to receive active cancer treatment did however seem to change if the patient started to experience debilitating symptoms. It then seemed more important for them to receive supportive treatments to ease their symptoms and improve their quality of life. This was particularly so for Mr Baker, who had completed his chemotherapy regime. His main concern, was his shoulder pain and he was relieved that the doctor focused her attention on this, despite the fact that she needed to tease information out of him about his pain, as he sat being quite stoical about it. This is what he said:



*'she spent a lot on the pain which was good you know. Because when I first came in I thought it was all going to be about stomachy [sic] stuff but that was put to one side.'* (Mr Baker)

Mr Baker was not sure at this stage whether or not he would have any more chemotherapy and said that he thought this would come up for '*discussion*' after they had got his pain under control. Both Mr Baker and his wife described (during our second meeting) his pain as '*a nasty little friend who you don't like and have to take everywhere with you,*' and they wanted him gone. While some patients seemed to accept that symptoms were possibly related to their cancer, others sought alternative explanations. Mr Thompson thought his pain was related to arthritis and the doctor went along with this pretence although they suspected that the pain was more likely related to metastatic spread from his primary cancer. Mr Baker on the other hand, simply didn't want to know what was causing his pain. This behaviour was in contrast to the behaviour of some patients for whom their primary objective was to confirm through a number of tactics, their suspicions that there was something seriously wrong with them (Glaser and Strauss 1965).

In Mr Baker's case, Dr Davis (C) didn't think it was likely that he would go on to have more chemotherapy and explained during our discussion (following my second meeting with him) that she had tried to introduce the concept of the palliative care team to prepare him for what was to come. Having observed Dr Davis (C) conduct several consultations I noticed that she had changed the way she referred to the palliative care doctors. Dr Davis (C) explained to Mr Baker that '*we have got a consultant who specialises in sorting out symptoms*' rather than using the usual phrase of '*I want to refer you to a Palliative Care Consultant.*' When asked why she had changed her approach, Dr Davis (C) explained that she '*had heard someone else do it and thought it worked well.*' According to Turner (2006) this kind of assessment and re-evaluation of one's practice, occurs continuously in practice if

professionals are engaging in reactive and intuitive learning, and supports the SpR's need to observe and learn from their colleagues through experiential learning.

Learning in this way implies that one does not necessarily give prior consideration to what they say or do; until they observe someone else do something they automatically perceive to be better. Yet, in contrast, some believe that intuitive learning is a form of reflection (Moon 2007). After giving this some consideration, Dr Davis (C) described being conscious that some patients are often alarmed to hear the palliative care team mentioned and she believed that this was a much more sensitive way of introducing the referral with the patient. Dewey described this as process of reflective thought whereby the doctor in this case '*considers the grounds or reasons for their belief and its logical consequences*' (Dewey 1933). As I have shown earlier, communicating information in this way to Mr Baker was appropriate. A more direct approach would have confronted the way he chose to manage and control the situation he found himself in. This was not something however that Dr Davis (C) was aware of as she described not having met Mr Baker enough to form a knowledgeable understanding of him and the way he liked to receive information. Yet, having listened to Mr Baker describe his experience, she managed to communicate with him on a level that was appropriate to him.

In addition to this, and in contrast to the study conducted by Friedrichsen and Strang et al (2002), doctors in this study tended not to use 'abandoning' words to patients and were generally more subtle in their choice of terminology. Rarely did they tell patients that nothing more could be done for them, as they were keen to ensure that some degree of hope was maintained, whether this was related to the possibility of having more chemotherapy in the future or whether it was related to offering symptomatic relief. This meant that on occasion doctors were not completely honest with patients. Balancing hope and honesty was portrayed as a challenging task for some doctors, as they found it difficult to know what to do for the best. This is reflected through the views of Dr Hughes and Dr Wilson:

*'Some people will say yeah, I feel great and my cancer has shrunk and I am going to beat this and you kind of think well okay, so there is something for that, but I have not seen someone do that yet and I would love to see someone have a spontaneous remission but I have not seen it yet and I find that sometimes more difficult to deal with, do you pop their balloon? Or you just have to be cautious I guess.'* (Dr Hughes, SpR – source: 1<sup>st</sup> phase of study)

*'A lot of what we do is palliative care but we do it in a setting where people hope or expect that they will improve and I think managing people's expectations is very difficult and very time consuming and very draining on you psychological reserves.'* (Dr Wilson, C – source: 1<sup>st</sup> phase of study)

Managing hope and unrealistic expectations appears to be a difficult challenge for doctors regardless of whether or not they are an SpR or Consultant. This challenge has been described by Innes and Payne (2009) who question whether or not an achievable outcome is possible if patients desire hope and realism. In addition to this, doctors are also put in a difficult position if the patient wants their doctor to be honest with them, but this honesty is only really desired if the information to be imparted is good news (Innes and Payne 2009). As such doctors need to try and understand what each patient means by 'honesty' throughout their illness as their desire for information may change as their condition deteriorates. Communicating bad news is clearly difficult and Fallowfield and Jenkins et al (2002a) believe that there is a need to try and ease these difficulties by improving the training opportunities for doctors and provide 'adequate support systems' to help doctors cope with stressful situations. Consideration will be given to the support needs of doctors in the following section, where patients and doctors in their own unique ways concealed difficult experiences form each other and from their colleagues.

### 5.3.2 Concealing a Difficult Experience

Patients generally spoke positively about the way their doctor had interacted with them during consultations. They mostly seemed to appreciate the doctor welcoming them into the consulting room, listening to them and demonstrating an interest in them. As Mr Rogers and his wife explained when asked what was important to them when they met their doctors:

Mrs Rogers: *To feel that your important, that you mean something, you know, and they're going to do the best for you*

Mr Rogers: *yes...while you're sitting there you're the only one that is (interrupted)*

Mrs Rogers: *and they are concentrating on you and not thinking about what they're going to have for their tea*

Descriptions such as these reflected the views of Wenrick et al (2001) and Hagerty and Butow et al (2005) who believe that patients want to be listened to and be given the opportunity to ask questions. Being treated with dignity and compassion from those caring for them was also highlighted in another study (Clayton and Butow et al. 2005a) to ascertain the views of patients with a terminal illness about what was important to them when they were given prognostic information. While it was important for some patients in my study to receive continuity of care from their doctors because they '*know your case from the very beginning*,' it was less important for others, if they felt the doctors were sensitive to their needs. Alternative actions to these caused concern for some patients but they were loath to make their feelings known to the doctors. To highlight this issue I refer to two further case studies.

### Case Study 12 – Don't Mess on your Doorstep

As I walked through the Oncology outpatient department one day, I bumped into Mr Robinson and his daughter as they walked out of a consulting room, having seen one of the doctors. They looked very unhappy and promptly told me that they had not had a very good consultation. I was unable to explore this further with them at

this time as I was about to go into another consultation with a different patient. I explained this to them, and they appeared to understand, and we arranged to meet up again on their next visit in a few weeks time (which would be the third time I met them).

On their next visit, they were already sitting in the waiting room as I walked through the Oncology department to prepare for our meeting. I stopped to say hello and to check that they were still happy for me to see them, which they were. Within seconds of me sitting down next to them, they asked me which doctors were in clinic that day because there was one doctor they particularly didn't want to see. They explained that they hadn't had a '*good time of it*' when I last bumped into them, so I said I would find out for them, despite Mr Robinson telling me not to bother. When I told them that Dr Taylor (C) was running the clinic on his own on this day, Mr Robinson expressed his relief and said '*oh good, I like him, you know where you stand with him.*' The opportunity to ask them what had happened in their previous consultation was cut short at this point, because Mr Robinson was called to see Dr Taylor (C).

Prior to this consultation Mr Robinson, an elderly gentleman in his eighties, had commenced a regime of chemotherapy. He had a number of side effects after his first dose of treatment and was admitted onto the Oncology ward. Following this, his dose of chemotherapy was reduced and he managed to complete the full course of his treatment. When I had the opportunity to ask them about their previous consultation with Dr Harris (SpR) Mr Robinson said:

Mr Robinson: *Yeah we have had him twice haven't we?*

Mr Robinson daughter: *Yeah, he just doesn't listen. You say something and he just carries on and it was the words 'we are not going to give you anymore chemotherapy because you were really poorly'.....*

Neither Mr Robinson nor his daughter could understand why Dr Harris (SPR) had thought that he hadn't tolerated his chemotherapy and this annoyed them, particularly as they felt the doctor had not listened to them. Mr Robinson and his daughter were generally very quiet and were not the easiest people to interview but on this occasion they obviously had things they needed to discuss. However, they were very clear that it was important for them to '*see the same doctor because they know your case right from the beginning.*' A similar situation to this was reported by Friedrichsen and Strang et al (2000) who described this relationship as 'impersonal' because of the contact between 'unacquainted individuals.' The advantage of continuity is such that information and planning is consistent and reduces the risk of variation, which can be distressing for the patient and their relatives. Yet we have seen in the case of Mr Rogers and his wife that not having met a doctor before did not necessarily prevent them from liking a doctor or for asking them to disclose very sensitive information. In other cases, patients spoke of not minding which doctors they saw during their consultation as long as they were sensitive and caring and that a consistent message was portrayed. While there are variations in opinion in regards to whether or not continuity is important to patients, it was evident through these cases, that receiving consistent information from doctors was very meaningful to patients, as this also meant that doctors were taking an interest in them and taking the time to learn about them prior to their consultation.

When asked what had happened to them and why they felt the doctor had not listened to them, Mr Robinson and his daughter proceeded to explain:

Mr Robinson: *not a lot*

Mr Robinson daughter: *...dad was just doing his general talking and he didn't answer and just carried on and the bit that got me was that (name of consultant) had said when we saw him at the end of the chemo you know we will leave it for now and we will see you every so often and in about 12-18 months it will*

*probably come back and then we will probably go on from there and see what we can do. But then when we came to the last consultation he said we are not going to give you any more chemo again because you did not tolerate it, it didn't agree with you. We tried to say it was only during the first one with the hands and feet but he didn't really reply did he at all. I got the impression he had written him off and that was it.*

Lynn: *You said that you had met him twice?*

Mr Robinson daughter: *When we first met him he just kept going on about bowel cancer and I had to mention that he actually had it in his liver and lung and again he didn't react and then he sent him for a blood test and on the form it had bowel cancer and nothing else. And so I sort of thought is it all recorded properly in his notes?*

Mr Robinson: *you got the impression he hadn't read the notes*

Mr Robinson daughter: *Yeah well he was kind of surprised when I said it is the other two as well. He just sort of looked bewildered and carried on.*

As Mr Robinson's daughter spoke to me, she looked as though she was very close to crying, as did Mr Robinson, when I glanced at him. I was aware from my previous encounters with these two, that they were generally very stoical about things, and tried to laugh things off between them. This behaviour was therefore in stark contrast to how I had seen them interact on previous occasions. I felt that this incident was highly significant for them but because of my prior interactions with them, felt uncomfortable probing them about how they were feeling because this seemed a little inappropriate. Instead, I asked them to compare their previous consultation with others and they said they felt that the other doctors they had met were 'easy to talk to' and they 'listened' and 'stuck to the facts;' qualities which they

considered to be very important to them. When asked what they might have done if Dr Harris (SpR) had been in clinic on this occasion they said:

Mr Robinson: *Well we would have just had to have gone*

Mr Robinson daughter: *Well we would have gone with the flow but we would rather have someone else.*

Lynn: *apart from vocalising this to me have you told anyone else in the team how you feel?*

Mr Robinson: *No...there is an old saying 'don't mess on your own doorstep'*

Mr Robinson daughter: *Well it is not an horrific thing to complain [sic] it is just a different way of dealing with things with different people. It was just the fact that he didn't express it very well and he had just written him off and that was it, the end.*

Mr Robinson: *It was an impression*

Mr Robinson daughter: *Yes it was an impression and you know, if he had said we are not offering it to you today but that was not the way he put it over to us. But that could be that is what he was saying because (name of consultant) has said today we are leaving it for now but maybe that is what he was saying but in a different way.*

For some patients, receiving conflicting information was detrimental to the way they perceived and trusted their doctors. Trust did not arise automatically – it was earned, particularly if the patient felt the doctor was interested in them and understood them. When messages were conveyed which raised suspicions the patients tended to be drawn towards the doctor they felt more comfortable and at ease with, regardless of whether or not they had any doubt about the truthfulness of the information they had been given previously. In this case, Mr Robinson's daughter, in particular lost confidence in Dr Harris (SpR) and started to question



whether or not Dr Taylor (C) had been portraying a similar message to that of Dr Harris (SpR), but in a more sensitive manner. The following case portrays the distress one patient and his wife experienced following an insensitive encounter with Dr Harris (SpR).

### **Case Study 13 – Take what Life Throws at You**

The start of this case study is not too dissimilar to that of Mr Robinson and his daughter. As I arrived in the outpatient department to meet Mr and Mrs Rogers for our third and final meeting, the clinic co-ordinator approached me and said that there had been a few problems in clinic prior to my arrival. She informed me that upon arrival into the department, Mr Rogers and his wife had informed her that they had been upset following their previous consultation with Dr Harris (SpR) because they felt he had been insensitive, harsh and blunt in the way he conveyed information to them. They wanted to know which doctors were working in the clinic on this occasion as they did not want to be seen by Dr Harris (SpR) again. Unfortunately, he was the only doctor working in the clinic as his colleague had been called away. Mr and Mrs Rogers were upset by this news and as such refused to be seen by him. The clinic co-ordinator was sensitive to their need and said she would try and arrange for another doctor to come and see them, as Mr Rogers was not feeling particularly well and needed to be seen by a doctor. Dr Mason (SpR) agreed to come down to the department to see them. Following the consultation, during our discussion, Mrs Rogers explained what had happened previously:

*'...it was just his attitude, he just said that the tablets hadn't worked and they could put him on [sic], the chemo hadn't worked and it was still spreading. It hadn't worked. They could put him on tablets but of course if it doesn't work the first time it's obviously not going to work a second time. So I said we are going back to see Mr (surgeon) to see about operating on his liver, he said there's no good going back to him, he can't do anything for you. So he said you have to take what life throws at you I'm afraid. And he spoke like that*

*and it hurt, and he'd got no right to tell us that Mr (name of surgeon) couldn't do anything for him. He was telling the truth, I don't doubt that, but it was the way he did it. It really upset us.'* (Mrs Rogers)

Although I digress from the main point here, it is useful to put Mrs Rogers, feelings about further surgery in context, to chronicle the events which led to this consultation. When I interviewed Mr Rogers, following the second consultation I observed with them, Mr and Mrs Rogers both spoke of their optimism that the surgeon would still be able to remove his cancer. From the outset, the intention had been to give Mr Rogers some chemotherapy to shrink the size of his cancer and then he could proceed to have surgery to try and remove it. Unfortunately the chemotherapy had not worked and his cancer had continued to grow. This now meant that surgery was no longer an option, but Mr and Mrs Rogers had not realised this because this had not been explicitly explained to them. Although they had been told that his cancer had continued to grow, Mr Rogers left the consultation laughing and joking with the nursing staff and I for one was concerned about whether or not they had actually understood and / or appreciated what they had just been told. I later learnt that he only really digested this information a day or two later when he had space to think.

As I listened to Mr and Mrs Rogers talk about their experience of this consultation (2<sup>nd</sup> consultation), it was clear that although they understood that he was going to receive some more chemotherapy they were still pinning their hope on the surgeon being able to remove the cancer with surgery. They did not appear to realise that his cancer was no longer curative and that his prognostic outlook had changed for the worse. I felt uncomfortable and somewhat distressed listening to them talk of this, when I knew that surgery was no longer an option – I felt as though my silence was somehow disrespectful to them but I did not feel that it was my place to disclose such sensitive information to them. During the consultation, Dr Skelton (SpR) had told them that the chemotherapy had not worked and was therefore honest with

them but without being frank fully honest about his disease progression and what this meant in terms of his future care. Knowing this, prompted me to ask Dr Skelton (SpR) what she felt they had understood following the disclosure of the information she gave them. She felt that Mr and Mrs Rogers knew that surgery was no longer an option and didn't need to talk to them about this further and felt that they understood that things had changed in his condition for the worse. She felt that on this occasion it had been important to leave them with the message that *'it doesn't look good now, but we have still got options to try.'* It became clear to me that an opportunity to help Mr and Mrs Rogers understand his prognosis was missed because at this time, Mr and Mrs Rogers and Dr Skelton (SpR) had not fully understood each other on this occasion and a number of conflicting assumptions had been made.

This misunderstanding was unfortunately exposed a month or so later as Mr and Mrs Rogers were confronted with the truthful if not blunt disclosure from Dr Harris (SpR) that surgery was no longer an option. As they explained:

Mr Rogers: *In a way we weren't expecting it, that was the problem, it seemed to hit you*

Mrs Rogers: *We never expected anything. It's just that everything's come as a complete shock*

Mr Rogers: *When you look back Lynn to December, what's happened since December, you know it's (interrupted)*

Mrs Rogers: *There was nothing there*

Although Mrs Rogers appreciated that Dr Harris (SpR) was telling them the truth, she was clearly upset with the way he interacted with them. As I spoke to Mr and Mrs Rogers during our third and final discussion, it was evident to me that Mr Rogers was trying to move on from this situation as he advised his wife to *'forget it'* and said that he felt the doctor was *'clearly just having an off day.'* Mrs Rogers did not

however, believe this as she had discussed the incident with one of her friends, who recollected a similar experience whereby Dr Harris (SpR) had used the same phrase *'take what life throws at you'* and this had upset them too. As Mrs Rogers described what had happened to me, she was still clearly very upset by this incident as tears welled up in her eyes. Mr Rogers sat and held her hand, with a look of sadness on his face.

Although Mr and Mrs Rogers were upset by the news that he could no longer receive surgery, Mr Rogers explained that it was more about *'the way he put it over'* that upset us the most. Mrs Rogers tried to rationalise her reaction to this consultation by saying that she knew she was more *'sensitive'* than normal but she felt his *'attitude was wrong.'* When asked if they had told anyone how they felt they said no. Mr Rogers described how he wanted to try and *'let life run along nice and smoothly'* which may have been because he had just learnt that he was dying, but Mrs Rogers explained:

*'We don't want to complain about him but he's got to learn to be a bit more sensitive than he was. I mean he was doing his job and he was telling the truth, I mean there's truth and truth isn't there? He didn't even ask if you wanted to know. I mean as I say it wasn't his place to say what was happening with another doctor. We was all living for that day when Mr (name of surgeon) would operate you see, not thinking they couldn't and that was it.'*

(Mrs Rogers)

In this case and the case of Mr Robinson, both patients and their relatives described their concerns about the way this doctor had disclosed sensitive information to them, but both of them were loath to voice their concerns to the doctor directly. While evidence suggests that a high proportion of complaints are made by patients towards their doctors for matters relating to poor communication (Citizens Advice

Bureau 2006), these patients were loath to make a direct complaint and instead, raised their concerns with the clinic co-ordinator or myself. In effect, the doctor was unaware of their concerns, and evasive tactics were used; with the help of the clinic co-ordinator to ensure the patient did not see the same doctor again. In each of these cases, I was unable to ascertain the doctor's view of the consultations because the consultations had taken place at a time when I was not present. The incidents mentioned here, however were highly significant for these patients and had a direct influence on how they felt and how they managed visits to the Oncology department.

Other types of unacceptable behaviour, described by patients throughout the course of this study, were related to the way patients and their relatives perceived a lack of sensitivity and compassion in the way their doctors interacted with them. If incidents occurred within the Oncology department, it was common practice for patients and their relatives to make it known (to clinic co-ordinators) that they did not wish to be seen by a particular doctor, but the action taken to ensure that their wishes were fulfilled varied from a passive to more decisive course of action – for example, Mr and Mrs Anderson walking out of the department when they thought they would be seen by Dr Hall (SpR). On other occasions, patients did not say anything at all. Mr Lewis described how, when I met him for a second time, how he thought some health care professionals were probably very good at their job in a technical sense but would *'never develop the human skills to deal with people.'* He said this after he described his encounter with a doctor whereby he felt they were the kind of doctor who came across as

*'chop chop, lets get you out as soon as we can, no concern, no sort of feeling, your just another piece of machinery in their line of work.'* (Mr Lewis – source: 2<sup>nd</sup> consultation)

In addition to this, upon first meeting patients, a number of examples were provided whereby patients described their distress about the way they had been informed that they had cancer. In one example, Mrs Martin recollected the following incident:

*'You know when I was on the recovery trolley he just came out saying 'oh looks as if you have got bowel cancer' and stormed off you know. And the nurse sat there and opened her mouth. She said were you expecting that and I said no.'* (Mrs Martin: Source- following 1<sup>st</sup> consultation)

In this example, Mrs Martin described not wanting to listen to what he had to say, because he was so insensitive with her. She felt that she was strong willed and would not let this worry her, until someone else confirmed whether or not this information was correct. Similarly, Mr Baker and his wife likened one doctor to that of 'Doc Martin' a character on the television. Although they laughed about him and said that they had considered sending him a video of the programme to show him how not to communicate and interact with people, Mr Baker was clearly very annoyed with the way this doctor had communicated his diagnosis. During his first consultation, Mr Baker described how insensitive this doctor had been with him to Dr Davis (C). When asked what she thought about this, she explained that she thought it was appropriate to 'acknowledge' what her patients were saying when they complained about another doctor but felt that she did not want to get drawn into these discussions because she needed to use her time effectively to ensure she achieved what she needed to achieve within the consultation. On this occasion she explained:

*'I would really like to quiz the doctor who did it for their take on it because it may well be that that doctor is completely oblivious to the effect that him giving that news has really on the patient and how he is coping and somehow it would be really nice to have some feedback mechanism but it's*

*very difficult to do that without causing umbrage.*' (Dr Davis, C – Source: 2<sup>nd</sup> phase of study)

In this statement, Dr Davis (C) raises the issue of 'feedback.' It was evident that some of the doctors (particularly the SpR's) valued feedback to help them learn. This is expressed in the following quote:

*'You don't get any feedback about what you did well or what you could improve on or what someone else who is medically trained thought or just for someone to say oh well that was difficult. There is none of that and you know I think we would all like to know if we have done things well or badly or if we could improve on things, it would be helpful from time to time.'*

(Dr Hughes, SpR – Source: 1<sup>st</sup> phase of study)

A similar sentiment was expressed through the views of another doctor who felt that there was a danger that you could become complacent about the way you interacted with people. Doctors who tended to be complacent failed to question the way they interacted with others, their perception of self-awareness was often significantly different to the image they conveyed to their patients. Yet, these doctors were not confronted by the views of others and were unaware of the effects they were having on their patients. The comments made by Mrs Rogers about Dr Harris (SpR), about his lack of sensitivity was interesting because in a previous interview he had said that he felt he was '*less sensitive*' with patients in consultations because for him the consultation had become '*routine*' and it was no longer the '*unique*' experience it had once been. While Dr Harris (SpR) recognised that he was less sensitive towards his patients, he was unaware of the consequences of his actions on patients. He hoped that he '*still managed to do a good job*'.

In order to prevent complacency, some doctors felt it was necessary to have *'someone sitting in and watching and offering feedback'*, a sentiment expressed by these doctors:

*'You might be very intelligent and you might be very good at your job in the sense of diagnosing people but you might be awful at communicating. And what you need is people to pick up where you are going wrong and communicating with Oncology patients is really really hard.'* (Dr Wright, SpR – Source: 1<sup>st</sup> phase of study)

*'..having a third party sitting in and giving you assessments about what went right to what went wrong and I think that would be helpful to have an independent person sitting in and giving you feedback.'* (Dr Roberts, SpR – Source: 2<sup>nd</sup> phase of study)

In addition to receiving feedback, others valued the opportunity to observe their colleagues interact with patients. Much as they may like to do this the opportunity was less forthcoming. This was generally related to the busy demands and constraints imposed by their job. Yet learning in this way has proved to be an important feature of learning at work, as has been found in a previous study (Eraut, Stedman et al. 2004a). One doctor who was afforded this opportunity, felt that they benefited from the experience because they were able to compare their choice of words and phrases with those of their colleagues, and in doing so realised they had a tendency to be *'blunt and insensitive'* when conveying bad news to patients.

For those who did identify problems with their personal performance, they rarely communicated their concerns to their colleagues because this was not embedded in their medical culture. While the importance of developing an open and supportive culture has been proposed by the Department of Health policy recommendations (Department of Health 1998; Department of Health 1999), there were still indications



that personal and cultural climates inhibited this culture from developing. The learning of communication skills often took place through 'trial and error' and in isolation. As patients tended to conceal their difficult experiences from their doctors, there was a tendency for doctors to conceal their difficult experiences from each other. As Dr Hughes (SpR) and Dr Wright (SpR) explained:

*'...you go around the edges of how important it is when discussing it with colleagues, not necessarily show how it affected me....yes there are certain people I will talk more with about how things are but quite often it is my wife at home.'* (Dr Hughes, SpR – Source: 1<sup>st</sup> phase of study)

*'I don't think there is openness at all. I think if you start saying I have struggled with this and I struggled with that you start looking as if you are not doing your job very well.....It is very difficult sort of this hierarchy thing [sic] where you are sort of almost wanting to impress your consultant and I think deep down that is what most doctors want to do or show that you are coping. And to admit that I actually find that quite difficult is sort of engraved into you that you don't do that.'* (Dr Wright, SpR – Source: 2<sup>nd</sup> phase of study)

Comparing the patients' choice of concealment with the doctors' choice of concealment highlighted several similarities. They communicated their concerns to people they felt comfortable with and they decided not to confront people they believed to be superior to them for fear of being judged or for fear of compromising their position.

## **5.4 Summary**

Throughout this chapter a number of complex issues have been identified that present problems for those sharing and receiving uncomfortable news. Sharing uncomfortable news about prognosis, progressive disease and discontinuing active

cancer treatments was particularly problematic. Although they all liked to believe that they communicated openly and truthfully to their patients, the degree to which they were open was generally vague and superficial. When it came to talking about the finer details of what was happening to a patient and / or talking about how the future care of a patient may be managed, truthful and honest answers were not always disclosed and information was generally ambiguous.

For example, it was common practice for doctors to tell patients in their new case consultation that they could not cure the patient and then they would swiftly move the discussion forward to talk about what they could do to help them. In contrast to this however, some patients did not appear to want to know the finer details of their prognosis, and instead focused their attention on what could be done to prolong their life. When prognostic information was disclosed, the emotional impact this had on the patient was rarely explored and as such doctors were often oblivious about the effect this information had on the patient and their state of awareness. In future consultations, there was a general belief that it was the patient's responsibility to initiate prognostic discussions and as a consequence a patient's preference for prognostic information was rarely sought. Various reasons for this were identified.

Many of the doctors participating in this study appeared to juggle with aspects of uncertainty; for example, not having sufficient knowledge to impart prognostic information and statistical facts; not knowing what to say and / or how informative they should be. In some cases they were deliberately vague. In addition, some seemed uneasy about disclosing information which may induce distress in the patient, and as such assumed a paternalistic role, again without really exploring the patient's current state of awareness and understanding. Despite this tendency to err on the side of caution, some doctors expressed concern if they thought that colleagues had misinformed patients on previous occasions. Several examples were observed or provided through doctor's accounts to describe how they had tried to right what they considered to be a wrong; based on their assessment of a

situation and their preference for a particular course of action. On the occasions whereby they intervened both positive and negative outcomes were achieved.

Misinforming a patient in an earlier consultation could potentially have a knock on effect to future conversations in subsequent consultations. There was a tendency for patients to believe what they had been told when informed of their diagnosis, and if this information was contradicted in any way in the future, problems arose, particularly if they were given an optimistic outlook from the outset. Trying to go back and rectify any misconceptions was difficult for all regardless of whether or not they were a Consultant or Specialist Registrar. Deciding whether or not steps should be taken to rectify misconceptions was extremely difficult at times and doctors needed to make judgements swiftly; with the patient often sitting in front of them. If patients were given unrealistic expectations during previous consultations, it came as a shock if their perspective of the truth was confronted and could induce conflict within the doctor and patient relationship. In the case where the doctor had bluntly disclosed information to a patient which challenged and confronted their state of awareness, a perpetual cycle of 'erring on the side of caution' then ensued for this doctor.

Euphemistic language was seen to have one purpose, that of protection (for either the doctor or the patient) but produced two outcomes. Using euphemistic language, when patients were first diagnosed of their cancer had the potential to cause undue concern, uncertainty and distress, as some patients were aware of the possibility they might have cancer but were not totally sure and this concerned them. To be relieved that one finally knows they have cancer so that they can then face the illness head on, demonstrates what a sensitive problem this is. Not using the correct terminology from the outset does not actually protect the patient. Yet, when used towards the latter stages of a patient's illness, euphemistic language appeared to be less obvious to patients and the subtle use of language tended to soften the blow of the reality of what was to come. Central to this was the way patient's exerted control

over the way they perceived what was happening to them as their condition deteriorated.

It was however difficult at times to assess what patients did or did not want to know. While some patients wanted to know what they could expect in their future, they were not always prepared to hear the answers, on the occasions when honest answers were given. Most of the patients had an unrealistic expectation about how long they would live with their cancer and considered this time in years, rather than months. It is no surprise that it came as a shock for some to hear their prognosis was considerably less than they expected. While some expressed their desire for doctors to be honest, truthful and straightforward with them, and praised their doctors for communicating with them in this manner, it was interesting to see that this was not always reflected in the actions of their doctors. On occasion the doctor would give me a more realistic expectation of what was likely to happen to a patient than they would with the patient, and then they would try to justify their decision for doing so, based on their perception of the patient and their needs. Patients, were therefore sometimes oblivious to what was honest and what was dishonest and were not necessarily prepared to hear truthful information if they had previously been led to believe something else.

On occasion, there was clearly a misunderstanding between what the doctor thought the patient should already know or understand from what they were telling them and what the patient actually knew. When disclosing uncomfortable news to patient and their relatives, it was not necessarily the information that upset the patient the most, regardless of the severity of the message conveyed; the thing that upset them the most was the way they perceived the doctors interactions towards to them. For most patients in this study it was important to feel that their doctor cared for them and that they were interested in them. Those who felt their doctor had been insensitive, rarely confronted their doctor directly with their feelings, for fear that they may compromise their care in the future. Instead they tried to control their visits to the

outpatient department by speaking to other members of the health care team who could help them achieve their objectives. When instances occurred whereby a doctor was perceived to be insensitive in the way they communicated information which the patient was unaware of, the truth of the information conveyed previously by others was questioned as was their motivations.

While some doctors were keen to know how their interactions were perceived by patients and welcomed feedback and the opportunity to develop their communication skills by learning from peers; others were less reflective and unaware of how their interactions were perceived. This was not helped by the fact that patients were often unwilling to provide negative feedback. Interacting and communicating uncomfortable information to patients was challenging and some desired more support and feedback from their colleagues to help them develop professionally. This support was however lacking, and some felt that changes needed to be made within the current medical climate to help them develop these skills on the job.

# Chapter Six

## Discussion

### 6.1 Introduction

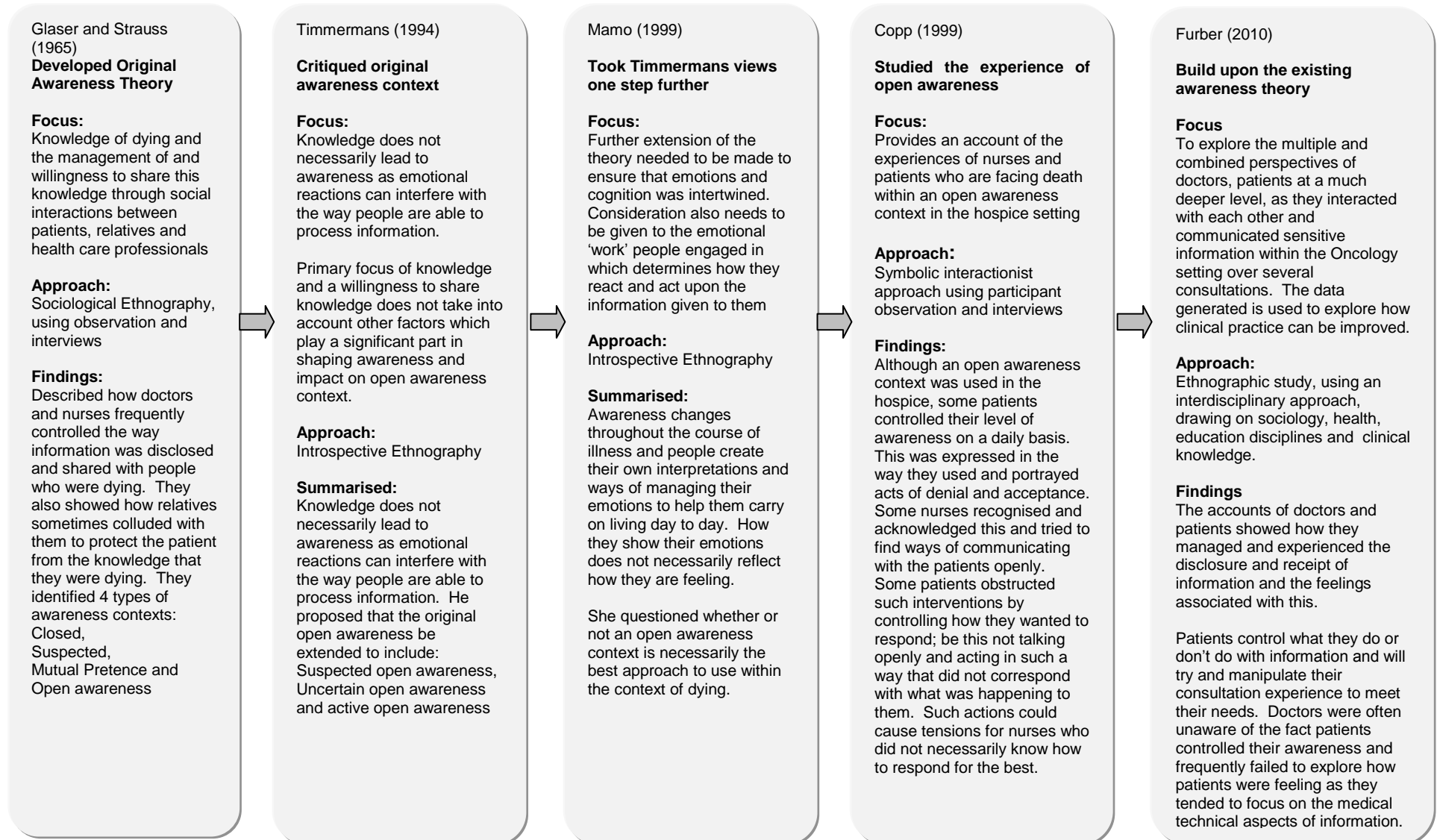
The aim of the present study was to investigate the experiences of patients diagnosed with advanced incurable cancer and the doctors who conducted their medical consultations, particularly in relation to talking about sensitive issues and dealing with bad news. One intention of the study was to observe and examine how doctors and patients manage and control the disclosure and receipt of sensitive information and bad news within the Oncology outpatient consultation. Another intention was to study the feelings associated with these discussions. A further intention of the study was to examine how the concept of awareness contexts can help understand the perspectives of both doctors and patients in the consultation and explore the impact and influence an individual's awareness context has on the consultation experience.

I sought to do this in an innovative way by observing and recording consultations between doctors and patients and their relatives, from their initial meeting with each other in new case consultations and as patients progressed throughout their illness. I wished to build upon existing theory by exploring multiple and combined perspectives of doctors and patients at a much deeper level as they interacted with each other and communicated information. Following my observation of a consultation, the perspectives of those involved were sought using in-depth interviews. My original intention had been to try and meet patients on more than one occasion to obtain a deeper understanding of their experience through various stages of their illness. For assorted reasons, it was not possible to see some patients on more than one occasion, while other patients were seen twice or on three occasions.

The awareness context perspective aligns with the work of other researchers who have sought to explore the experiences of those facing terminal illness and their awareness of dying and those involved in their care (Glaser and Strauss 1965; Sudnow 1967; Hinton 1999; Copp 1999). My data supports the conclusions of Timmermans (1994) and Mamo (1999) and Hellstom and Nolan et al (2005) that the primary focus of knowledge and a willingness to share knowledge within the original awareness context theory is inadequate. Emotions play a considerable part in helping people to process cognitive information and a considerable amount of emotional work is invested in to help construct awareness and how people present themselves in front of others (Mamo 1999). In addition, this study also makes a contribution to the theory of awareness contexts. This contribution is highlighted in Figure 7 on page 266 and in detail throughout the remainder of this chapter.

From the outset, I wished to explore if the data could inform the way doctor's communications and interactions with their patients is understood, and see if there was a need to improve professional development in this area. A goal of the research was to critically reflect upon doctor-patient communication in such situations, with a view to considering future strategies for doctors' continuing professional development. The data did in fact highlight some of the problems that ensue when communications go inadvertently wrong. Some quite serious problems of communication were observed in several of the consultations. For example, while some doctors tried to grapple with emotional issues, others seemed less able or willing to do so. Several doctors' responses appeared to be influenced by their perception of their role and what they believed their main objective to be. Some doctors failed to notice, react or explore expressions of emotions from patients and their relatives and as such missed vital pieces of information about how the patient was 'really' feeling. The most important implications of the research findings are presented in the following sections.

**Figure 7: Contributions to the Awareness Context Theory**





## **6.2 Patients Contribution to Awareness Contexts**

The work of Glaser and Strauss (1965) has played a significant role in our understanding of how health care professionals communicate and interact with those who are dying and has provided a base from which others could consider the disclosure of bad news to patients and their relatives. This work continues to be influential in health care practice today. It became evident through the work of Glaser and Strauss (1965) and Sudnow (1967) that doctors and other health care personnel controlled and organised the way information was conveyed to patients and their families. In contrast, patients were seen to assume a more subservient role and to be less influential in terms of the way information was controlled and managed. As such, the perspectives of those who were dying were often not explored in detail and as such key information and understanding about the roles patients play in such situations was lost (Copp 1999). The focus thus far, in relation to examining interactions and communication has focused on the part doctors have to play, rather than the part patient's play, in two way face to face interactions.

Although this earlier work has played a significant role in developing our understanding of how health care professionals and patients communicate and interact with each other, some believe the credibility of Glaser and Strauss' work could have been enhanced further if they had provided a much deeper account of their analysis to support their themes (Copp 1999; Seale 1999). Obtaining and reporting the perspectives of doctors, as well as the perspectives of nurses and patients was something that Seale (1999) felt would have added to their study.

A novel feature of my study, was to address this 'gap' and collect data from clinical practice to obtain a prospective account of how both doctors' and patients' managed and experienced the disclosure and receipt of sensitive information and bad news in the Oncology outpatient setting and to explore the feelings associated with such discussions, as patients progressed through their illness. Additionally, the views and observed behaviours of some relatives and nurses were obtained if they were present

during a consultation. In all these respects my study added new perspectives to a key area of health related research.

An important finding from my study showed that not only did professionals manage the awareness context as illustrated in previous studies (Glaser and Strauss 1965; Sudnow 1967; The 2002) but that patients did so too. Some patients through their own volition or through the support of their relatives, created a context for themselves which was purposeful and purposefully managed to help them create, as Mamo (1999) would describe, a 'space to exist.' This evidence supports and adds to the findings of Copp (1999) who found when exploring the accounts of both patients and nurses working in a hospice to investigate their experiences of 'confronting impending death,' that patients use control in a number of ways. Control was used as a strategy to protect themselves and those around them to help patients cope with continued losses. In her study, Copp (1999) also found that nurses employed various strategies whereby they might encourage patients to share some of their inner most feelings; or at least demonstrate a willingness to listen as and when the patient felt able to talk.

In this study, doctors frequently seemed unaware of the fact that patients played a part in controlling their own 'awareness'. Many doctors did not explore how the patients (and their relatives) were feeling, having been told that their cancer was incurable; or their prognosis was much shorter than the patient expected to hear; or when signs of distress were expressed during the consultation. When asked to describe what they felt the patient's needs were, or how they might have been feeling during the consultation, doctors often appeared to have quite uncertain impressions. This meant that at times people were misjudged and opportunities to explore what their thoughts or feelings were; or how they had experienced what had been happening to them thus far; or what they understood or expected might happen in the future, were lost.

While, there is significant evidence to suggest that people diagnosed with cancer regardless of the type and stage of their disease want to receive as much information as possible, a number of recent empirical studies have demonstrated the simplicity of this account noting that information needs of patients are far more complex and individualistic (The 2002; Kirk, Kirk et al. 2004; Hagerty and Butow et al. 2005). Contemporary literature has focused on the need to disclose information to people about their diagnosis and prognosis in detail so that they are aware of what is happening to them and so that they can make informed decisions about treatments and their future. However, Field and Copp (1999) build upon evidence provided by Hinton (1998) and Timmermans (1994) to suggest that it is difficult to sustain an 'active awareness' at all times because it is hard to sustain emotionally. Furthermore, being actively aware is not something that everybody pursues and as such a more pragmatic response needs to be taken by health care professionals to be responsive to the communication needs of their patients (Field and Copp 1999).

Although doctors may control the way they convey a message and the way they choose what to say or not to say, in my study it was evident that patients demonstrated their use of control in relation to what they did or didn't do with the information given to them. For example, some sought further clarification or appeared to accept without question what the doctor had told them, while others dismissed parts of a message in favour of believing what they wanted to believe. While others gradually sought out information as and when they needed to, to help them understand what was happening to them. This evidence suggests that while the need for some information is immediate, the need for other forms of information is gradual and reactionary and very much dependent upon the individual.

This study provides further support (with some variation) for the view that a differentiation can be made between the need for short term and long term information, as described by The (2002). She noted that more attention was attributed to the more manageable and solvable short term problems in relation to for

example side effects and treatment options. Less attention was given by patients and doctors to the longer term issues of prognostic detail and what was likely to happen in the future with regard to further treatment and plans of care.

From the data analysis in this study it emerged that when meeting an Oncologist for the first time in a new case consultation, patients generally wanted to know what was going to happen to them so that they had an idea about what they were up against. They were, more often than not, told that they could not be cured of their cancer, which was swiftly followed by an explanation of what could be done to help them. Needing to know what could be done to help them was highly significant at this time and in the future. For many the need to know that there were various treatment options available was very important because this meant that they were doing something active to stay alive for as long as possible. For others there was a shift in need as they progressed through their illness and started to experience a progression in their symptoms, and as such tended to focus on their symptoms and wanting to feel better than they currently did. The more detailed specific information required during the first meeting with the Oncologist seemed to diminish for some as time went on. At times patients appeared to distance themselves and 'dip in and out' of seeking specific information or listening to what they were being told. Defensive action was taken to shut the true meaning of a message out and protect them from the 'actual reality' of their disease progression.

It was difficult to assess at times however, how much information people thought they needed or what they had actually understood from the information they had been given during a consultation. For example, while some said that they wanted their doctor to be honest and open with them; there were times when the doctor was not completely honest and yet patients viewed them as being honest and respected them for this. This supports Innes and Payne (2009) view that honesty does not necessarily mean providing a detailed and frank disclosure of information, for it to be perceived as such. While honesty was considered to be important to patients, they

were not however always honest and open with their doctors and chose to control how much information they would share with their doctor; either about emotional issues or physical symptoms. This meant that doctors were not always made fully aware of how the patient was feeling, or what they thought about a particular experience.

Some patients, who for example felt that their doctor had been insensitive to them or appeared disinterested, tended to engage in a collaborative, strategic endeavour with the clinic co-ordinator to ensure that they did not have to be seen by the same doctor again. As such, the patient shared their concern with the clinic co-ordinator but concealed their displeasure from the doctor. When questioned about this behaviour during their interviews, several patients described how 'you don't mess on your own doorstep' or used similar words to that effect. Concerns were expressed about how they may be perceived in the future and feared that such action may compromise their future care in some way. Responding in this way meant that patients were able to conceal their concern from those who had affronted them to retain a sense of self preservation and tried to protect themselves from confrontation and further hardship. Such action meant however, that doctors were rarely made aware of the way their interactions had been perceived and were not given the opportunity to learn from these situations and make attempts to correct the balance of their relationship with the patient.

Throughout the present study it was apparent that during their encounters with doctors, patients wanted to feel reassured and supported, they wanted to be listened to and they wanted to feel important – that someone valued their worth as a human being and had their best interests at heart. These notions of social awareness have been identified elsewhere within the literature (Balint 1965; Mechanic and Meyer 2000; Hagerty, Butow et al. 2005; Goleman 2007). Although not a new finding, this knowledge adds further weight to existing evidence that a patient's emotional state plays a significant part in the way they perceive the quality of their care and cope with

difficult and challenging situations and how they 'manage' and 'control' their own awareness of what is happening to them.

Even when doctors did express empathy and warmth towards the patient, this did not necessarily mean however, that the patient would share their concerns and feelings. According to Goleman (2007) some patients are thought to enter a 'quiet conspiracy' with their doctors. Some patients purposefully controlled the way they presented themselves to others. For example, several patients presented a jovial image to their doctor, to hide their concerns or true feelings because they felt it was not appropriate to 'offload their worries' to them. On occasion some appeared seemingly indifferent or upbeat in the consultation, even after having been given some bad news. When situations such as this occurred, Copp (1999) described how some nurses felt their relationship with a patient was tested if there appeared to be some concern that a patient was not really expressing their true feelings and they felt the need to confront them about this.

Additionally, others presented themselves as being friendly and compliant in order to use their time more effectively to get in and out of the consultation as quickly as possible because they were frustrated with the way their consultations and meetings with their doctors were managed. In each of these events, patients created a careful impression to act out a desired performance in front of another. For the majority of the time, relatives contributed to this state of pretence in front of the doctor and only broke this state, to reveal their concern to me that all was not well at an opportune moment when the patient and doctor were out of the room and at a time when it was difficult to address and raise their concerns with the doctor.

When interviewed, nearly all of the patients when probed started to express a number of significant concerns to me which they did not disclose to their doctors during these consultations. These concerns were frequently related to:

- Whether or not they were receiving the best care
- Whether or not they had the best opportunities for treatment available to them
- Whether or not their doctors would give up on them
- Fears about dying and about leaving loved ones behind
- Concerns about whether or not they were to blame for their illness
- Whether or not they could / should have lived life differently
- Some expressed concerns about the process of dying and were fearful of dying in pain, while others were concerned about dying alone
- In addition one patient expressed concern about what would happen to him when he died, would he go to heaven or would he go to hell.

Many were not ready to die and were prepared to do anything to prolong their lives further. When asked why they didn't express these concerns to their doctors many felt that in addition to not wanting to 'offload their worries' they also felt that their concerns were irrelevant and did not feel it was part of the doctors duty to listen to them – clearly articulating the notions of a traditional doctor and patient relationship as articulated by Tuckett and Boulton et al (1985).

It is clear that the interactions between doctors and patients are complex. The doctor is seeking to control the consultation to meet their own agenda in a specified time, but additionally patients are utilising a number of tactics to control various aspects of the consultation. Control is reflected by 'what they did or didn't do' with information communicated to them and reflected through their interactions and how they tried to manipulate their consultation experience to meet their own needs. Keeping confrontation to a minimum to limit the risk of treatment and care being withheld from them, should they upset a doctor was one prime example of this behaviour. As such, sharing sensitive information and disclosing bad news is only one part of the communication and interaction process in Oncology, where patients have an advanced diagnosis of cancer; there are many other features that need to be borne in

mind to try and make the consultation experience more supportive and beneficial for each patient.

### **6.3 Helpful Interventions – A Doctors Perspective**

Doctors participating in this study felt that it was necessary to learn from other members of the medical team to help develop and inform their clinical practice. Connecting with other members of one's team has been regarded as a desirable approach to learning (Eraut, Stedman et al. 2004a). Yet doctors were rarely, if ever afforded the opportunity to 'connect with others', in relation to developing their communication skills. The role of other people in supporting the learning needs of doctors is one that requires further attention. A review of the literature, pertaining to experiential learning has shown how the role of others can help encourage and support practitioners to develop their skills, confidence and competencies within clinical practice (Dewey 1933; Eraut 1994; Eraut and Stedman et al. 2004a). In a large longitudinal study of the development of 90 newly qualified accountants, engineers and nurses (LiNEA Project), Eraut (2004a) offered the term 'helpful others' to describe people within the work place who provided support and feedback to these newly appointed professionals. Eraut (2004a) chose this term in preference for mentor or supervisor as these terms could potentially mean different things to different people, working within different professional groups.

The role and availability of helpful others was however, dependent on the nature of the working relationship and the relative merits of designated helpers (Eraut and Stedman et al. 2004a). The accountants and engineers were most likely to receive support and feedback from more experienced colleagues as they often worked in close proximity to each other. The support and feedback afforded to nurses however, was often unpredictable. Nurses often had their own patients to look after and often worked in parallel to their colleagues which meant that more experienced nurses were unavailable to offer this support. This latter example has resonance with the way doctors practiced alongside their colleagues within medical consultations.



While the work of Eraut and Stedman et al (2004a) focused attention towards the early career development of professionals, the evidence gathered through my study and the studies of Gifford (2008) and Bailey (2009) suggest that the role of helpful others continues to play an important role in the development of professionals throughout their careers. In Gifford's (2008) study, pharmacists were reported to value the support of others from within their profession to help them in a practical sense, for example managing workload. In addition, they were able to describe a network of helpful others within their own professional group or other professional groups allied to medicine to help them develop professional confidence and competence. In my study, outpatient nurses were rarely observed to offer any feedback to doctors about how they felt a consultation had been managed or offer any suggestions about what interventions they thought may have benefited a patient, although one doctor did mention the value of nursing feedback if a nurse or health care assistant was willing to do this. They felt it was helpful to acknowledge a difficult consultation, but felt that time pressures in clinic often prevented this from happening.

In the present study, doctors felt that they could turn to their colleagues for help and support in relation to medical-technical matters but some of the SpR's expressed their concern about seeking the support of colleagues in relation to their experience of conducting emotionally challenging consultations with patients. Only one SpR described turning to one of their colleagues for help having learnt that they needed to improve the way they communicated and interacted with patients when disclosing bad news, but was critical that help was far from forthcoming and resolved not to seek help with this matter again. In addition to this, only one experienced doctor spoke of seeking the help of a colleague working within a different discipline of medicine, who was able to help support them through an informal arrangement when they felt the need to talk through a difficult consultation or needed clarification on how best to convey a specific message to a patient.

Furthermore, the SpR's felt that they were unable to share their concerns with colleagues in the event that they felt they had conducted a consultation inappropriately. When asked to explain why they could not raise their concerns, it was explained that the medical culture tacitly prohibits such disclosure, for fear of being judged incompetent. This has implications for practice and openness between professionals. The fact that people who regularly interact with others in the workplace face difficult challenges and 'hard knocks' has been captured by Snell (1992) who stated that this can be an ideal learning opportunity. If left unchallenged or supported people may feel too overwhelmed and their motivation to explore various strategies within their practice may be 'stunted' (Snell 1992) as seen with Dr Hall (SpR page 205) or they rely upon themselves to learn without the support of others (as seen with Dr Roberts, SpR page 169).

This problem is further represented through the work of Bailey (2009) whereby nurses and doctors working within an emergency department of a large NHS trust had limited opportunity to talk to their colleagues in relation to the more sensitive and emotionally charged elements of their clinical practice. These problems have been echoed elsewhere within the literature (Eraut 2004b) where it has been suggested that the stimulus and extent to which professionals are prepared to disclose their practice requires further investigation. In order to explore this further, it has been suggested that an examination of 'micropolitical discourse' which resonates throughout the medical profession is required to understand how learning may be affected (Eraut 2004b).

In attempts to seek help from others, many of the doctors in the my study and in Bailey's (2009) study, described how they turned to family and friends for support. The nature of these interactions were generally informal discussions at home, to help practitioners discuss the sensitive and difficult interactions they experienced during their encounters with patients. From this example, it would suggest that it is not always necessary for the person acting as a helpful other to act as a learning

resource; instead they appear to provide an opportunity for the doctor and / or nurse to talk to someone who is willing to listen – an important intervention reported elsewhere through this thesis from the perspectives of patients and their relatives.

This is an important issue, which probably warrants more professional intervention. It was evident through the doctor's discourse and through observations, that some doctors lacked confidence about how they managed prognostic discussions with their patients and had concerns about what they should say for fear of distressing their patients and providing them with information that they were not ready or willing to hear. Although most of the doctors spoke of these concerns, regardless of their years of experience and expertise, some seemed better able to determine what they should say or do in any given situation. It was evident through their interviews that some of the more experienced doctors felt able to draw upon past experiences and prior learning to help inform their current and future practices as they had an intuitive grasp of situations and were better able to visualise possible outcomes, as described by Benner (1984). Yet, at times they expressed their concern about whether or not they had interacted with a patient and / or their relative in the best way. At times, they were observed to avoid a specific line of questioning as it appeared uncomfortable to do so, and did not confront expressions of emotion, indicating distress or anger, and as such supportive intervention was not forthcoming.

In contrast, some of the less experienced doctors appeared to be at the other end of the spectrum and were in the process of learning through trial and error. In this study, it was evident that some of the SpR's 'looked up' to some Consultants and chose aspects of their practice that they liked, to adopt in their practice and in contrast they decided which interactions they did not like and vowed never to use them in their practice. This evaluation of practice did appear to be ad hoc however and evaluations were made on spur of the moment opportunities whereby they might get to see one of their colleagues to talk to a patient in their presence.

Despite the fact that most of the doctors valued the importance and benefit of experiential learning within their work environment, the learning culture within medicine does not currently fulfil this learning need sufficiently. Some of the doctors spoke of wanting a more experienced colleague to sit in on their consultations with patients and observe how they interacted, with a view to offering them constructive feedback on their performance. Furthermore, some doctors spoke of their need to sit in on consultations with more experienced colleagues to observe how they interacted with patients with a view to measuring the extent of their current knowledge and to help them model their developing practice from these experiences. Some doctors also believed it would be valuable to have someone they could turn to at work to share and reflect on their experiences, with a view to acknowledging how difficult it can be to communicate and interact with patients and their relatives.

There is evidence to suggest that doctors working within the speciality of palliative care meet with each other to discuss the physical, psychological, spiritual, social and communication related dimensions of care with their colleagues (Ramirez, Addington-Hall et al. 1998). However, doctors in the my study indicated a desire to have a less formal approach to learning and to be able to seek help and advice in response to unpredictable and uncertain clinical situations, rather than adhere to a formal learning format, a view supported by others (Grant 2002). From this perspective, the interplay between clinical practice and supportive learning needs to be acknowledged further.

#### **6.4 Learning through Reflection on Interactions with Patients**

Although this approach to learning is not currently ideal; as doctors are learning through trial and error with real patients who may be affected by some practising interactions, many of the doctors valued the importance and benefit of learning through an exposure to real life situations. While some of the doctors appeared to reflect on their actions / interactions with patients and were fearful of becoming complacent in their practice, it was evident that some doctors conducted their consultations in a similar formalised approach regardless of the patient's needs and

agenda. Complacency was referred to by Dewey (1938) as a careless attitude as doctors fall into the trap of believing that they do not need to change or learn new approaches because they do not fully reflect on their behaviour and / or the outcome of their behaviours.

Why some doctors were more conscientious about learning from their practice than others was not clear from the findings of this study. It may be that some were more able to make a connection between doing something and being able or willing to make a connection between how they felt and how they felt the patient and / or their relative may have perceived their interaction. As I interviewed doctors some described how they felt it was valuable to sit and talk about a consultation with me as it made them reflect on what they did or didn't do, why they did that and how they felt about what they were doing. Some were clearly more questioning than others. Interestingly, those who did question their practice in some detail were observed to interact and communicate information more compassionately and thoughtfully and used the opportunity to talk to me as a reflective exercise. One doctor in particular was extremely conscientious and described how they sometimes went away from our discussions, really wanting to know what the patient thought about them and the consultation so that they could learn from this experience further. In contrast those who did not appear to question their practice may have benefited from doing so.

Expert peers can also help less experienced doctors consider their values and beliefs about how they currently practice (Maudsley and Strivens 2000a) and help them consider the ramifications of their actions / interactions during their encounters with patients. In addition, peers may be able to help them consider alternative approaches and techniques in practice until they are able to internalise the knowledge or skill into their existing practice (Shon 1983). Gifford (2008) found that pharmacists valued the support of helpful others in respect to; aiding the reflective process, providing specialist knowledge and expertise, challenging existing behaviour and patterns of practice and providing vital emotional support in challenging situations. Interestingly,

however, my experience here, suggests that the person doctors turn to for support, does not need to be an experienced professional or from within their own profession, but someone they feel more comfortable talking to. As a senior nurse, I may have unknowingly fulfilled a role here, albeit in a research capacity. It is hard to say whether or not the role of senior nurses would have helped fulfil such a role if they had been present within the consultation because they were not present during the conduct of this study. Clinic nurses and health care assistants did not sit in on every consultation and their main agenda seemed to be managing and organising the clinic in an efficient manner.

According to Mamede and Schmidt et al (2008) doctors are more likely to reflect on complex cases and there was evidence to support this phenomenon in my study. When asked to describe what they felt constituted a good consultation or a bad consultation with a patient, doctors were more likely to describe in detail a 'bad' consultation as opposed to what they perceived to be a 'good' consultation. It is difficult to describe what they perceived to be a good consultation because they were rarely able to remember any, although the consultations they appeared to enjoy in this study were those where they thought they had a good rapport with a patient and were able to give the patient encouraging information, or where nothing untoward had happened. In contrast, a bad consultation was perceived to be challenging to them in some way, be this in the way their patient and / or relative interacted with them or in one case where the doctor thought they had spent too much time on a consultation and this had a knock on effect to the rest of the clinic.

It is difficult to know, however if doctors would have reflected on difficult consultations in this study if they had not in effect been encouraged to do so by talking to me about their experience. When doctors spoke of previous consultations, it was evident that their process of reflection was informal and unstructured and did not follow any prescribed reflective process. They described talking to family or friends or reflecting over an alcoholic drink or playing a sport to help relieve their anxiety. Some described

giving thought to a situation but did not necessarily know how to process their thoughts and apply this to their practice.

It was clear that, for some, there was a need to engage in reflective activity. Yet, there does not appear to be a structure in place to support such activity, to help inform the practice of individuals. The fact that there is no structured process in place within the working environment has implications for practice, as support is not available to help doctors reflect upon what they perceive to be difficult and challenging consultations. As some valued talking about a consultation as it encouraged them to reflect upon their actions, there is likely to be value in pursuing a similar intervention in medical practice. In addition, further work in this area might help explore further the reasons why some are more willing to reflect and experiment with their practice than others.

## **6.5 Concluding Points**

Steps have been taken over the past fifty years or so for health care professionals to improve the way they communicate and interact with their patients and improve the way in particular doctors develop relationships with patients. Yet, in many respects the medical profession remains drawn to a more traditional ideology of practice which focuses on the medical-technical aspects of care, as evidenced through the findings of this study and that of The (2002). This model / approach is reinforced by patients themselves in terms of the way they manage interactions. Yet, patients want their doctors to communicate and interact with them in a manner that shows respect, interest, support, compassion, truth and empathy, although this does not always seem to be fulfilled in practice.

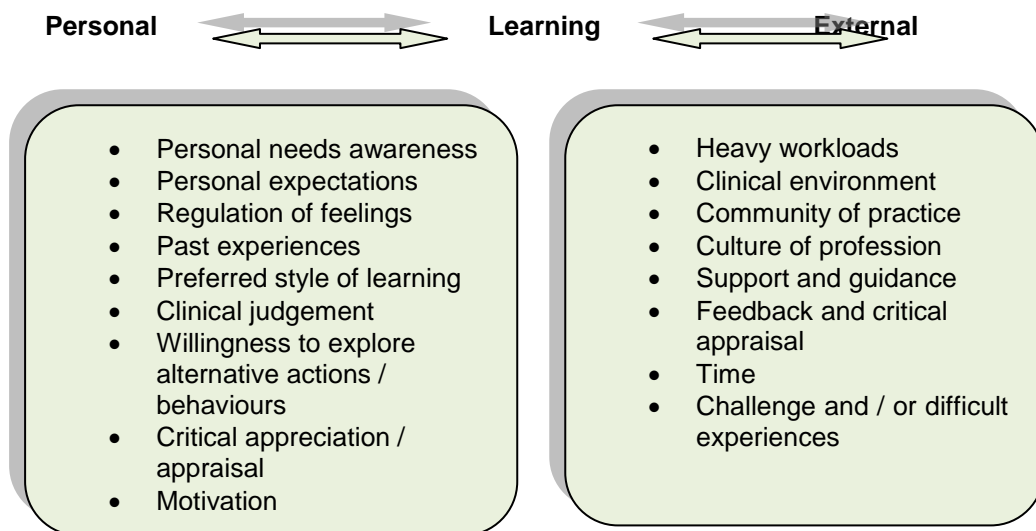
However, some doctors become preoccupied with meeting their objectives in an allotted time and fail to notice or be receptive to the needs of others and their requirement for emotional support (Silverman and Kurtz et al. 2005), which might have a detrimental effect on their relationship. As such, the opportunity to offer

emotional care is too often lost within health care practice (Goleman 1996; Silverman and Kurtz et al. 2005). Goleman (1996) is critical of doctors for being dismissive and / or sceptical about meeting the emotional needs of patients despite a growth of evidence to suggest that such care is integral to patient care. Yet, the evidence presented in this discussion has shown that patients are not always willing to share their true feelings with their doctors and from some of the evidence presented in this thesis I question whether or not doctors actually want them to be open.

Furthermore, it is evident from the work presented in this thesis that patients use various strategies to control their own 'awareness' to meet particular needs. This finding is interesting especially in light of the fact that doctors are not necessarily aware of the part patient's play in controlling their state of awareness. It may be useful for future work to consider the part patients play in controlling their awareness and therefore controlling interactions when considering how communication skills are developed further. Copp (1999) demonstrated how some nurses were able to recognise when patients may be using control to protect themselves and others and were able to explore on occasion or indicate a willingness to open a dialogue with a patient when they were ready to talk – a skill which some doctors may benefit from learning. This evidence suggests that nurses working within a clinic may be able to help doctors understand the needs of a patient better if a patient is more willing to disclose things to them; as the nurse can then share this information with the doctor.

The evidence presented in this thesis and the literature emphasised a number of subtle issues which influence how doctors learn and develop their skills within the clinical environment. A presentation of these influences is presented in Figure 8:





**Figure 8: – Subtle Influences to Learning within Clinical Practice**

Some doctors participating in the current study were more aware and willing than others to seek ways of trying to develop their ability to communicate more effectively with patients and to receive support and guidance from their colleagues – indicating a desire for a more open and facilitative culture to learning.

At present, senior doctors are required to develop their communication skills by attending the ‘Connected’ programme. Yet, evidence presented in this thesis suggests that while senior doctors may benefit from this learning opportunity, they feel that experience has been the primary source of help in development of their skills and it was the SpR’s who felt they needed extra guidance and support. Consideration needs to be given therefore to how senior clinicians can disseminate their knowledge and expertise to support and offer guidance to those who need it within the clinical environment. It is crucial that doctors receive support and guidance to help them address the complex nature of emotional care both within their profession – learning to support each other – to transcend this philosophy into patient care. From this perspective, it may be suggested that by meeting the learning needs of doctors within clinical practice through experiential learning in this setting and context of care, will influence the delivery of care for patients in the future. This is particularly relevant as patients have been shown to be influential in terms of how the consultation may

proceed. Moreover, exploring this notion of experiential learning further may develop the awareness context theory further.

## **6.6 Strengths and Limitations of the Study**

The aim of the present study was to explore how doctors and patients communicate and interact with each other when talking about sensitive issues and dealing with bad news within the cancer context. The purpose of the study was not to make empirical generalisations but rather to provide an in-depth account of the nature of doctor and patient experiences and to explore the nature of their relationships within this area of clinical practice. A key strength of the present study centred on being able to capture experiences from patients diagnosed with an advanced incurable cancer and their doctors, thus enabling a comparison of a combination of perspectives throughout the patient's illness; from initial referral into the oncology department onwards, to capture various stages of the patient's illness.

The perspectives of doctors and patients were generally obtained during their interviews, following their consultations with each other. Yet, the findings from this study however, also illustrated the significant position and needs of relatives within this area of research and as such the study may have been enhanced further if relatives had been interviewed as well to obtain a more in-depth understanding of their experiences and need for information and involvement during consultations.

Moreover, the issue of disclosing bad news has been addressed in a number of studies and in response, a number of guidelines and training programmes have been developed to help doctors and other health care professionals learn to communicate more effectively. The premise for this study was such that communication skills courses have their limitations and some doctors have reported difficulties in transferring and / or sustaining skills to real life situations with patients in clinical practice (Maguire, Booth et al. 1996b; Fallowfield, Jenkins et al. 2002a) and therefore need to examine this further as to why this may be the case.

The present study was designed with the intention of discovering what happens in consultations within a broader context to try and understand some of the tensions experienced by doctors, patients and their relatives in relation to how they communicate and interact with each other when sensitive issues are raised and bad news is disclosed. This work was conducted with a view to exploring how other alternative approaches to learning may influence professional development within this area. It was envisaged that changing emphasis in this way would add to our understanding of what needs to be achieved to develop effective communication and interactions between doctors and patients to enhance professional development and clinical practice. The findings of the present study have achieved this and have as such met the aims and objectives of this study. In addition the findings of this study have relevant implications for all health care professionals who endeavour to improve the way they communicate and interact with their patients.

## **6.7 Personal Reflections**

During my time spent observing consultations, it was not uncommon for doctors to ask me directly or indirectly to provide them with some feedback about how I felt the consultation had been managed and / or how I felt they had interacted with their patient. In addition, it was not uncommon for them to ask how the patient had perceived the consultation. Such questions made me sensitive to the importance of feedback and appraisal of their performance. However, while the study was happening I did not provide feedback except for the odd occasion where it was felt appropriate to do so. For example, one doctor became upset that I was reluctant to offer them feedback as they saw this as an important opportunity to learn about how they interacted with patients and managed consultations. In addition, if it was felt that not saying something might be detrimental to the well being of the patient then doctors involved in the care of a patient were informed of any problems or issues the patient raised during the conduct of our interviews. In most cases I advised the doctors that I would feedback the results of the study to them once I had completed the study. As such the need for such intervention has been noted and requires further investigation.

Furthermore, it was difficult during this study to remain completely detached from participants, particularly patients and their relatives. This was due to the emotional and highly sensitive nature of their situations. Listening and observing people adapt, cope and come to terms with the severity of their situations and acknowledge and voice their uppermost fears and thoughts were challenging. I could not help but be touched by the experiences of these families. On one occasion, I was sitting in the home of a patient and his wife when there was a knock at the door. Mrs Rogers went to answer the door and came back into the room with a bouquet of flowers. She thought they were from her daughter but as she read the card, she started to cry. The flowers were from her husband. Mr Rogers had learnt that morning that he was dying and wanted to tell his wife how much he appreciated and loved her. I sat and shared in this moment with them and watched on as they gave each other a hug and cried on each other's shoulder. I wanted to slip away and leave them alone but they would not let me, I got the impression they needed to and wanted to talk and in true British fashion, we did so over a cup of tea. At the end of the interview we hugged each other as we said goodbye and I walked away from the house, knowing that I would not see them again. As I reflected on this experience I realised that no matter how distressed someone might appear, this does not mean that they need to be left alone. Being empathetic and respectful of what they are 'going through' can be therapeutic and facilitate an environment where they feel able to talk.

## **6.8 Further Research**

This study has illuminated a number of key issues that provide scope for further research and development, much of which arises through a complex appreciation of interactions between doctors, patients and their relatives which has been informed in this study by the theory of awareness contexts and a doctor's desire to learn how to develop their communication skills and interactions with their patients as a direct result of their clinical experience

The aim of this study was to open a dialogue about how other alternative approaches to learning may benefit doctors in relation to how they communicate and interact and

how they develop therapeutic relationships with their patients. Future longitudinal investigation is also recommended to investigate how an alternative approach to learning within clinical practice, including support and guidance on clinical practice including feedback on ones performance; and opening a dialogue so that doctors become more at ease reflecting on their practice and sharing this personal insight with others. The aim, to help doctors develop a self-awareness and confidence to communicate and interact with their patients and their relatives more effectively bearing in mind that patients and their relatives will use tactics to control their own awareness, which needs to be explored further to understand how these tactics are engaged. In addition, by changing the current dynamics within the medical profession it would be necessary to consider the overall impact such change has on the medical culture.

Moreover, interplay between clinical practice and supportive learning interventions needs to be considered further and given the central position of the patient in this, it would be appropriate to investigate how such an intervention may influence and / or impact on the delivery of care for patients and / or their relatives.

# **Appendix 1**

## **Principles of Good Clinical Practice**

## THE PRINCIPLES OF ICH GCP

1. Clinical trials should be conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki, and that are consistent with GCP and the applicable regulatory requirement(s).
2. Before a trial is initiated, foreseeable risks and inconveniences should be weighed against the anticipated benefit for the individual trial subject and society. A trial should be initiated and continued only if the anticipated benefits justify the risks.
3. The rights, safety, and well-being of the trial subjects are the most important considerations and should prevail over interests of science and society.
4. The available non-clinical and clinical information on an investigational product should be adequate to support the proposed clinical trial.
5. Clinical trials should be scientifically sound, and described in a clear, detailed protocol.
6. A trial should be conducted in compliance with the protocol that has received prior institutional review board (IRB)/independent ethics committee (IEC) approval/favourable opinion.
7. The medical care given to, and medical decisions made on behalf of, subjects should always be the responsibility of a qualified physician or, when appropriate, of a qualified dentist.
8. Each individual involved in conducting a trial should be qualified by education, training, and experience to perform his or her respective task(s).
9. Freely given informed consent should be obtained from every subject prior to clinical trial participation.
10. All clinical trial information should be recorded, handled, and stored in a way that allows its accurate reporting, interpretation and verification.
11. The confidentiality of records that could identify subjects should be protected, respecting the privacy and confidentiality rules in accordance with the applicable regulatory requirement(s).
12. Investigational products should be manufactured, handled, and stored in accordance with applicable good manufacturing practice (GMP). They should be used in accordance with the approved protocol.
13. Systems with procedures that assure the quality of every aspect of the trial should be implemented.

## **Appendix 2**

### **Letter to General Practitioner**



[Headed Paper]

Date:

Dear Dr \_\_\_\_\_

I am writing to inform you that your patient \_\_\_\_\_ is participating in a qualitative research study. This study is being carried out by Researchers from the University of Nottingham and the Oncology Unit at (identifying hospital name omitted for thesis). The purpose of the study is to investigate the ways in which interactions in the oncology out patient clinic, particularly between doctors' and patients' help people understand and adapt to their illness and treatments.

Your patient has been chosen to participate in the study because they have recently been referred to the oncology out patient clinic at the (Identifying name omitted for thesis) to see an Oncologist. Each patient referred to the study will be followed from referral, onwards. The patients will be observed during consultations and they will be interviewed afterwards. There is a possibility that the interviews may touch on some upsetting topics. The researcher is a senior nurse with counselling and advanced communication skills but if they feel they need extra support I would like to contact you to try and arrange this.

Should you require any further information, I can be contacted by email on [ntxlf1@nottingham.ac.uk](mailto:ntxlf1@nottingham.ac.uk) or [telephone number]

Yours sincerely

Lynn Furber BSc(HONS) RN, DipHE  
Nurse Researcher

## **Appendix 3**

### **Letter of Invitation to Doctors**

[Headed Paper]

**Letter of Invitation**

Date:

Dear Dr \_\_\_\_\_

**Re: 'Investigating interactions from participant perspectives in the oncology out patient clinic: How do they help patients with cancer understand and adapt to their illness and treatment plans?'**

I am writing to ask you whether you would be willing to help Professor (identifying name omitted for thesis) myself and a team of colleagues from the University of Nottingham with a research study we are conducting at the (identifying name of hospital omitted for thesis) Hospital. This research is being conducted as a PhD project. The aim of the study is to investigate the ways in which interactions in the oncology out patient clinic, particularly between doctor and patient, impact on the patient's understanding of and adaptation to their illness and treatment plan. In order to achieve this aim the study has the following objectives:

1. To observe and examine the interactions patients have in an oncology out patient clinic from referral through into palliative care.
2. To examine how both the doctor and patient manage and negotiate the consultations in order to understand what enhances or hinders effective communication and understanding of information.
3. To examine experiences of consultations in the oncology outpatient clinic from both the doctor and patient perspectives.

The enclosed information leaflet explains our study in more detail. If you are interested in taking part in the study please notify me as soon as possible by returning the enclosed reply slip in the envelope provided. Alternatively you may email me at [ntxlf1@nottingham.ac.uk](mailto:ntxlf1@nottingham.ac.uk). If you would like me discuss the study with you further I am happy to arrange a meeting with you to answer any questions you may have.

I would like to thank you for taking the time to read this letter and hope to hear from you in the near future.

Yours sincerely

Lynn Furber  
Research Nurse

## **Appendix 4**

### **Doctors Information Sheet**

[Headed Paper]

‘ Investigating interactions from participant perspectives in the oncology out patient clinic: How do they help patients with cancer understand and adapt to their illness and treatment plans?’

## **Participant Information Sheet**

**(Doctor)**

### **Introduction**

This study is being carried out by researchers from the University of Nottingham and the oncology unit at (identifying name omitted for thesis). The study is designed to investigate the ways in which interactions in the oncology out patient clinic, particularly between doctors and patients, help people understand and adapt to their illness and treatments. You are being invited to take part in this study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

### **What is the purpose of the study?**

We are looking at the ways in which interactions between doctors and patients influence peoples experience when they have a diagnosis of cancer. In order to do this a researcher will want to talk to you about your thoughts regarding the consultation you had with your patient.

### **Why have I been chosen?**

You have been chosen because you will have contact with patients attending the oncology out patient clinic at the (identifying name omitted for thesis) Hospital.

### **Do I have to take part?**

You do not have to take part in this study. If you choose to do so it is entirely voluntary. Therefore it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. You will be free to withdraw from the study at any time without giving any reasons for your decision. If you do provide a reason this will remain strictly confidential.

### **What will happen if I take part?**

In the first instance the researcher will make arrangements with you to conduct a preliminary interview with you at a time and location convenient to yourself to ask you some general questions about your work experience of caring for and communicating with individuals who have cancer.

Each patient recruited into the study will be followed from referral to the Oncologist and onwards for up to twelve months. The researcher will sit in on approximately three of the consultations you have with your patient who has agreed to participate in the study, to observe what happens. She may take some notes during this time but

will sit in the background of the room so as not to disturb you. The consultation will be audiotape recorded. The researcher will also observe what happens to the patient outside of the consultation room in order to see how other members of the health care team, relatives and fellow patients interact with each other.

Arrangements will be made between yourself and the researcher to arrange a convenient time for the researcher to interview you, following your consultation with the patient. Ideally this interview should take place as near to the consultation as possible so that you can recollect the consultation you have had with the patient. The interview will be audiotape recorded. Each interview should take no longer than thirty minutes.

The researcher will endeavour to inform you in advance when she will be present in your clinic, in order to make prior arrangements to conduct the interview with you. The researcher will make these arrangements with you either by phone, email or face to face, depending on the method of your choice.

**What are the possible disadvantages and risks of taking part?**

There is a possibility that some of the interviews may touch on some upsetting topics, however the interviews will focus on your perspective of the interactions taking place between yourself and your patient during your consultations. However, you will not be under any pressure to talk about topics you prefer not to discuss.

**What are the possible benefits of taking part?**

We hope that the results of the study will contribute to an improvement in the service provided patients in future.

**What if something goes wrong?**

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms would be available to you.

**Will my taking part in this study be kept confidential?**

Any information or opinions you give during the discussion will be made anonymous. Audiotapes will only be listened to by the research team and will be stored in a locked filing cabinet at the University of Nottingham. The audiotapes will be destroyed once they have been transcribed. No information will be discussed with your patient or fellow doctors. You will be assigned a code so that your name is not used at any time. Any distinguishing information will be edited from any written comments so that you cannot be identified in any way.

**What will happen to the results of the research study?**

The information gained in this study will be used to enhance good quality care for patients. The results of the research will be made more widely available through journal publications and conference presentations. Patients and doctors will not be identified in any report or publication.

**Who has reviewed the study?**

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

**Contact for further information**

Lynn Furber (Researcher)

As I am based at University of Nottingham and (identifying name omitted for thesis), both addresses have been provided.

Room F, F floor  
Post Graduate School of Nursing  
University of Nottingham  
Queens Medical Centre  
Nottingham  
NG& 2HA  
Tel: [mobile phone number]  
E-Mail: [ntxlf1@nottingham.ac.uk](mailto:ntxlf1@nottingham.ac.uk)

Or

(identifying details omitted for thesis)

**Thank you for taking the time to read this information sheet.**

## **Appendix 5**

### **Doctors Consent Form**



[Headed Paper]

'Investigating interactions from participant perspectives in the oncology outpatient clinic: How do they help patients with cancer understand and adapt to illness and treatment plans?

**CONSENT FORM**

**FOR DOCTORS**

**Site: (identifying name omitted for thesis)**

**Lead Researcher: Lynn Furber**

**This form should be read in conjunction with the Participant Information Sheet Leaflet, (Doctor) version 2 dated 26<sup>th</sup> June 2006**

**Please Initial Box**

- |  |                          |
|--|--------------------------|
| 1. I agree to take part in the above study as described in the Participant Information Sheet dated..... version .....  | <input type="checkbox"/> |
| 2. I understand that I may withdraw from the study at any time without justifying my decision and without affecting my normal care and management.   | <input type="checkbox"/> |
| 3. I have read the information leaflet on the above study and have had the opportunity to discuss details with ..... and ask questions. The nature and purpose of the study has been explained to me and I understand what will be required if I take part in the study. | <input type="checkbox"/> |
| 4. I understand that all information will be treated as confidential.  | <input type="checkbox"/> |
| 5. I agree to have my interviews audiotape recorded.   | <input type="checkbox"/> |
| 6. I agree to have my consultation with my patient audiotape recorded.   | <input type="checkbox"/> |
| 7. I understand that audiotapes will be destroyed once they have been transcribed.   | <input type="checkbox"/> |

8. I consent to participate in the study.

☐

-----  
Doctor name

-----  
Signature

-----  
Date

I confirm I have explained the nature of the study, as detailed in the Participant Information Sheet, in terms, which in my judgement are suited to the understanding of the patient.

-----  
Investigators name

-----  
Signature

-----  
Date

## **Appendix 6**

### **Letter of Invitation for Patients**

**Letter of Invitation**

Date:

Dear \_\_\_\_\_

**Re: 'Investigating interactions from participant perspectives in the oncology out patient clinic: How do they help patients with cancer understand and adapt to their illness and treatment plans?'**

I am writing on behalf of a Research Nurse based at the (Identifying name omitted for thesis) and a team of colleagues from The University of Nottingham to ask you whether you would like to help us with a research study that is being carried out at the (Identifying name omitted) Hospital. We are very interested in learning more about people's experiences when they attend the Oncology Out Patient Clinic, particularly during their consultations with their doctor. We would like to know if we can improve the service we offer to our patients to make things easier for them.

The enclosed information leaflet explains our study in more detail. If you are interested in taking part, please complete the form enclosed with this letter and return it in the stamped addressed envelope provided. The reply slip asks if we may pass your contact details to the researcher, Miss Lynn Furber. Lynn is a research nurse in the oncology department but will not be involved in your care. Lynn works one day a week in the oncology clinical trials department and four days a week as a postgraduate research student at the University of Nottingham.

If you agree Lynn will contact you to discuss the study. If you are interested in participating in the study, we would be grateful if you could let us know as soon as possible so that Lynn can be present when you first meet your doctor in the oncology

out patient clinic. She will arrange a convenient time to talk to you about this study further and answer any questions you may have. If you are happy to proceed Lynn will obtain your consent.

I would like to thank you for taking the time to read this letter and hope to hear from you soon. If you have any queries, please feel free to contact any of the team.

Yours sincerely

Professor (Identifying name omitted for thesis)

## **Appendix 7**

### **Patient Information Sheet**

**‘Investigating interactions from participant perspectives in the oncology out patient clinic: How do they help patients with cancer understand and adapt to their illness and treatment plans?’**

**Participant Information Sheet**

**(Patient)**

**Introduction:**

This study is being carried out by researchers from the University of Nottingham and the oncology unit at (identifying name omitted for thesis). The study is designed to investigate the ways in which interactions in the oncology out patient clinic, particularly between doctors and patients, help people understand and adapt to their illness and treatments. You are being invited to take part in this study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the study?**

We are looking at the ways in which interactions between doctors and patients influence peoples experience when they have a diagnosis of cancer. In order to do this a researcher will want to talk to you about your thoughts regarding the consultation you had with your doctor.

**Why have I been chosen?**

You have been chosen because you have recently been referred to the oncology out patient clinic at the (identifying name omitted for thesis) Hospital to see an Oncologist.

We are looking for between 25-30 patients to take part in this study.

**Do I have to take part?**

You do not have to take part in this study. If you choose to do so it is entirely voluntary. Therefore, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. You will be asked to sign a consent form at the beginning of the study and you will be given a copy of this to keep. You will be free to withdraw from the study at any time without giving any reasons for your decision. If you do provide a reason this will remain strictly confidential. A decision to withdraw will not affect the standard of care you receive.

**What will happen if I take part?**

Each patient will be followed from referral to the Oncologist and onwards for up to twelve months. The researcher will sit in on some of your consultations with your doctor to observe what happens. She may make some notes during this time but will sit in the background of the room so as not to disturb you. The consultation will be audiotape recorded. If you would like a tape recording this can be arranged. The researcher will also observe what happens to you outside of the consultation room in order to see how other members of the health care team, relatives and fellow patients interact with each other. Following your consultation with your doctor you will be taken to a private room where the researcher will interview you. This interview will be audiotape recorded. This interview should take no longer than an hour.

If for any reason it is not convenient for you to be interviewed on this day the researcher can make arrangements to interview you at a location and time convenient for you, for instance in your home.



If you are willing, we would also like you to keep a simple diary, to write down any thoughts you may have once away from the hospital. This is because your thoughts may have changed. You don't have to keep a diary if you do not want to. If you do decide to keep a diary tell the researcher and she will give you a diary sheet with some instructions explaining what she would like you to do. If you do decide to keep a diary the researcher would like to collect them from you when she next sees you. The researcher can return your diaries to you at the end of the study if you would like to keep them or she can photocopy the diary for you throughout the study.

**What are the possible disadvantages and risks of taking part?**

There is a possibility that the interviews may touch on some upsetting topics, however the interviews will focus on your perspective of the interactions taking place between yourself and your doctor during your consultations. However, you will not be under any pressure to talk about topics you prefer not to discuss. If you feel you need some extra support, we can try and arrange this for you or contact your GP who can arrange some counselling.

**What are the possible benefits of taking part?**

We hope that the results of the study will contribute to an improvement in the service provided to patients in future.

**What if something goes wrong?**

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms would be available to you.

**Will my taking part in this study be kept confidential?**

Any information or opinions you give during the discussion will be made anonymous. Tapes will only be listened to by the research team and will be stored in a locked filing cabinet in a locked office at the University of Nottingham. The audiotapes will be destroyed once they have been transcribed. No information will be discussed with your doctor. You will be assigned a code so that your name is not used at any time. Any distinguishing information will be edited from any written comments so that you cannot be identified in any way.

**What will happen to the results of the research study?**

The information gained in this study will be used to enhance good quality care for patients. The results of the research will be made more widely available through journal publications and conference presentations. Patients and doctors will not be identified in any report or publication.

**Who has reviewed the study?**

All research that involves NHS patients or staff, information from NHS medical records or uses NHS premises or facilities must be approved by an NHS Research Ethics Committee before it goes ahead. Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits and that you have been given sufficient information on which to make an informed decision.

**Contact for further information**

Lynn Furber (Researcher)

As I am based at University of Nottingham and (identifying name omitted for thesis) both addresses have been provided.

Room F, F floor

Post Graduate School of Nursing

University of Nottingham

Queens Medical Centre

Nottingham

NG7 2HA

Tel: [mobile phone number]

E-Mail: [ntxlf1@nottingham.ac.uk](mailto:ntxlf1@nottingham.ac.uk)

Or

(identifying details omitted for thesis)

Alternatively you may contact:

Professor (identifying details omitted for thesis)

**Thank you for taking the time to read this information sheet.**

## **Appendix 8**

### **Patient Consent Form**

[Headed Paper]

'Investigating interactions from participant perspectives in the oncology out patient clinic: How do they help patients with cancer understand and adapt to illness and treatment plans?

**CONSENT FORM  
FOR PATIENTS**

**Site: (identifying details omitted for thesis)**

**Lead Researcher: Lynn Furber**

**This form should be read in conjunction with the Patient Information Sheet Leaflet, version 1 dated 01/02/06**

**Please Initial Box**

- |  |                          |
|--|--------------------------|
| 1. I agree to take part in the above study as described in the Participant Information Sheet dated ..... version .....   | <input type="checkbox"/> |
| 2. I understand that I may withdraw from the study at any time without justifying my decision and without affecting my normal care and management.   | <input type="checkbox"/> |
| 3. I understand that members of the research team may wish to view relevant sections of my medical records, but all the information will be treated as confidential.   | <input type="checkbox"/> |
| 4. I have read the information leaflet on the above study and have had the opportunity to discuss the details with ..... and ask any questions. The nature and purpose of the study has been explained to me and I understand what will be required if I take part in the study. | <input type="checkbox"/> |
| 5. I agree to have my interviews audiotape recorded  | <input type="checkbox"/> |
| 6. I agree to have my consultation with my doctor audiotape recorded   | <input type="checkbox"/> |

7. I understand that the audiotapes will be destroyed once they have been transcribed.

☐

8. I consent to participate in the study.

☐

-----  
Patient name

-----  
Signature

-----  
Date

I confirm I have explained the nature of the study, as detailed in the Participant Information Sheet, in terms, which in my judgement are suited to the understanding of the patient.

-----  
Investigators name

-----  
Signature

-----  
Date

## **Appendix 9**

### **Interview Guides**

## RESEARCH INTERVIEW GUIDE

### FIRST INTERVIEW

#### (DOCTOR)

As you know, this research project aims to explore your views about the interactions that take place in your oncology out patient clinic between yourself and your patient. Thank you for agreeing to take part in this work. I am interested to know about you, your work and experience of caring for and communicating with individuals with cancer. I hope that you will feel free to say exactly what you want to. I am interested in your thoughts and views and whatever you tell me will be treated in the strictest of confidence. (Interviewer to tell the doctor something about herself, background and interest in this area of enquiry, and ask permission to tape record the interview).

To get us started I wonder if you would mind just saying a bit about yourself, telling me how you came to be working in oncology.

Prompts:            Why cancer care?  
                          What attracted you into cancer care?  
                          What are the good bits about your work and role?  
                          What are the difficult bits about your work and role?

What I would like to do now is focus on the part of your work around interacting with patients in the oncology out patient clinics.

<u>QUESTIONS</u>	<u>PROMPTS</u>
<u>STYLES OF COMMUNICATION</u>	
<ul style="list-style-type: none"> <li><u>How would you best describe the style of communication you use with your patients?</u></li> </ul>	<u>Paternalistic</u> <u>Patient centred</u> <u>Blunt/honest/truthful</u> <u>Do you change styles?</u> <u>What influences this?</u>
<ul style="list-style-type: none"> <li><u>Do the communication strategies you use with patients vary much between different patients?</u></li> <li><u>If so how do you decide which strategy to use with each patient?</u></li> </ul>	
<ul style="list-style-type: none"> <li><u>Have your strategies changed much over time as a result of say experience and/or training?</u></li> <li><u>If so, how have they changed?</u></li> </ul>	<u>Formal training or role models</u>
<ul style="list-style-type: none"> <li><u>Would you say that your approach to patient communication has been specifically influenced by any training that you have received?</u></li> <li><u>Can you explain why this particular training has influenced you?</u></li> <li><u>Have you experienced any scenarios with a patient when you thought that went well or that went badly, if so can you share your examples with me?</u></li> </ul>	
<ul style="list-style-type: none"> <li><u>When you meet a patient for the first time in a new patient consultation do you plan</u></li> </ul>	<u>In terms of diagnosis and prognosis and treatment</u>



<p><u>beforehand what you will say to them?</u></p> <ul style="list-style-type: none"> <li>• <u>When you have got to know a patient over time do you prepare any differently?</u></li> </ul>	<p><u>options</u></p>
<ul style="list-style-type: none"> <li>• <u>Is there anything else you feel you would like to add ?</u></li> </ul>	

Thank you for taking time out to let me interview you today.

## CONSULTATION

### (PATIENT)

As you can see from the information sheet, this research project aims to explore your views about the interactions that take place in your oncology out patient clinic between yourself and your doctor. Firstly can I thank you for agreeing to take part in this work, I appreciate you agreeing to me sitting in on your consultation with your doctor and for letting me ask you questions. I am interested to know about you, your experience so far and how you feel you communicate with your doctor. I hope that you will feel free to say exactly what you want to. I am interested in your thoughts and views and whatever you tell me will be treated in the strictest confidence.

As you are probably aware I am a nurse by background but for the purpose of this work I am a researcher. Because of this I am unable to try and clarify things for you that have arisen during your visits with the doctor. If you are unsure about anything at all then the doctors will be more than happy to answer any of your concerns. You can contact their clinic co-ordinators or secretaries via the telephone number on your appointment card or hospital letter.

(Interviewer to tell the patient something about herself, background and interest in this area of enquiry, and to ask for permission to tape record the interview).

To get us started I wonder if you would mind just saying a bit about yourself, telling me about your experience so far, from when you were diagnosed with cancer.

Prompts:            what happened to you?  
                         Have you any other experiences of seeing doctors, apart from your GP?  
                         What happened on these visits?  
                         What was good about your consultations with the doctor?  
                         What were the difficult bits about your consultations with the doctor?  
                         How has your experience to date affected how you feel when you are coming to see the            doctor?

What I would like to do now is focus on your thoughts about your consultation with  
(Doctor name)

QUESTION	PROBE
<ul style="list-style-type: none"><li>How did you think the consultation with your doctor (name) went today?</li></ul>	What happened?
<ul style="list-style-type: none"><li>Would you say this is what you were expecting or were you hoping for something else?</li></ul>	Had you pre planned things in your own mind?
<ul style="list-style-type: none"><li>When you came to see the doctor did you have anything specific you wanted to ask or did you</li></ul>	What do you think helped with this or what hindered this? Did the doctor understand your

<p>have any particular needs you wanted to discuss?</p> <ul style="list-style-type: none"> <li>• If so do you think you had the opportunity to ask these questions or ask for help?</li> </ul>	<p>concerns?</p>
<ul style="list-style-type: none"> <li>• In your own words can you tell me what information you were given by the doctor or nurse in the clinic?</li> <li>• Did you understand what they were telling you?</li> </ul>	<p>Why do you think this is?</p>
<ul style="list-style-type: none"> <li>• How would you best describe the way in which the doctor told you this news or gave you this information?</li> </ul>	<p>Caring/sensitive Honest/ truthful Can you think of anything specific you liked or disliked?</p>
<ul style="list-style-type: none"> <li>• When the doctor was talking to you can you remember what you were thinking?</li> </ul>	<p>what was going through your mind? Were you able to concentrate? Did you understand?</p>
<ul style="list-style-type: none"> <li>• What do you think will happen now, in regards to your care, treatment?</li> <li>• What are you hoping for?</li> </ul>	
<ul style="list-style-type: none"> <li>• Is there anything else you would like to add about your experience?</li> <li>•</li> </ul>	

**Alternative prompts:**

Can you tell me a bit more about that?

What do you mean by that?

## RESEARCHERS INTERVIEW GUIDE

### Interview 2 onwards

### CONSULTATION

### (DOCTORS)

**Note:**

This is a preliminary guide with some general questions. The format of this interview may change to correspond with the information provided by the doctor in the first interview, to clarify any views or actions.

If the same doctor is conducting the consultation, I propose to start the interview by summarising what they have said in the first interview. I will ask if they want to make any changes or add any comments. I will then proceed to conduct the interview.

As you know, this research project aims to explore your views about the interactions that take place in your oncology out patient clinic between yourself and your patient. Thank you for agreeing to take part in this work. I am interested to know about you, your work and experience of caring for and communicating with individuals with cancer. I hope that you will feel free to say exactly what you want to. I am interested in your thoughts and views and whatever you tell me will be treated in the strictest of confidence. (if applicable the interviewer will tell the doctor something about herself, background and interest in this area of enquiry, and to ask for permission to tape record the interview).

I would like to start by focusing on your consultation with (patient name). Can you tell me what you thought about the consultation today, and what you hoped would happen before you saw (patient name).

QUESTION	PROMPTS
<ul style="list-style-type: none"><li>How would you best describe how your consultation went with (name) on (date)</li></ul>	What happened?
<ul style="list-style-type: none"><li>Would you say that you had any pre-thought out plans for how you would conduct the consultation?</li><li>If so do you think you kept to this schedule or did it change?</li><li>Do you think they had any particular concerns or needs they wished to discuss with you?</li></ul>	Why did it change? Would you have changed anything?
<ul style="list-style-type: none"><li>Did you know this patient beforehand?</li><li>If so what kind of relationship do you have with them?</li></ul>	Informal Formal
<ul style="list-style-type: none"><li>Would you say that you had any specific information you wished to discuss with the</li></ul>	Any results Treatment changes

<ul style="list-style-type: none"> <li>patient?</li> <li>If so did you achieve this?</li> </ul>	
<ul style="list-style-type: none"> <li>Can you tell me what you told the patient?</li> </ul>	
<ul style="list-style-type: none"> <li>How would you best describe how you communicated this information to the patient?</li> </ul>	Honest, truthful, blunt Patient centred paternalistic
<ul style="list-style-type: none"> <li>If conveying significant news, how would you best describe how you feel? For example do you go away and worry or are you okay?</li> </ul>	
<ul style="list-style-type: none"> <li>When you were talking to the patient do you think they understood what you were telling them?</li> <li>Can you tell me a bit more about that?</li> </ul>	
<ul style="list-style-type: none"> <li>When you were talking to the patient were you conscious at all of what the patient was thinking?</li> <li>What do you think they were thinking?</li> </ul>	
<ul style="list-style-type: none"> <li>Would you say you had any plans for the subsequent management of the patient (name)</li> <li>If so have you discussed this with the patient (name)</li> <li></li> </ul>	
<ul style="list-style-type: none"> <li>Is there anything else you would like to add?</li> </ul>	

**Alternative probes:**

Can you tell me a little more about that?

What do you mean by that?

Can you explain that a bit more for me please?

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