

**BREAKING BAD NEWS:
A PHENOMENOLOGICAL STUDY INTO
THE GIVING AND THE RECEIVING OF A
CANCER DIAGNOSIS**

Submitted in fulfilment of PhD requirements

May 2006

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DECLARATION

This thesis is submitted in total fulfilment of the requirements of the degree of Doctor in Philosophy. I declare that this thesis is entirely my own work unless otherwise acknowledged and has not been previously submitted as an exercise for a degree at Trinity College Dublin or any other university.

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SUMMARY

Breaking Bad News: A Phenomenological Study into the Giving and the Receiving of a Cancer Diagnosis.

Background: Breaking bad news to patients or being present when bad news is given is part of the daily activity of many healthcare professionals. With over 20,000 new cancer diagnoses each year and an annual increase of 2.3% in the incidence of cancer within the Irish population, the way in which a cancer diagnosis is disclosed and the impact of that disclosure on the recipient of the bad news is of great importance to all involved. The majority of the literature on breaking bad news stems from a physician orientated and physician focused perspective, with little research giving voice to the recipient of the diagnosis or acknowledging the contribution of the nurse within the disclosure of a cancer diagnosis. Whilst attention is currently being given to the funding of healthcare, accessing healthcare and adequate provision of services, there is little consideration given to the actual experience of the recipient in relation to receiving a cancer diagnosis, or indeed the experiences of healthcare professionals working within such scenarios. This research study will provide an opportunity to explore the phenomena of giving and receiving bad news from the perspective of the recipient, the doctor and the nurse involved in caring for such patients.

Aims: To explore I) the lived experience of receiving a cancer diagnosis, II) the lived experience of having to disclose a cancer diagnosis, III) the lived experience of being present when bad news is broken, and IV) the lived experience of the nurse in caring for a person who has received bad news.

Methodology:

This study was guided by the philosophy of hermeneutic phenomenology. Three groups of participants were involved from four geographical areas in the Republic of Ireland. Data were collected through in-depth interviews with 10 recipients of a cancer diagnosis, 20 nurses, and 8 doctors all of whom were working in general medical or surgical areas. Ethical approval was gained from the Joint Ethical Committee, Federated Dublin Voluntary Hospitals and St James's Hospital. Ethical issues relating to autonomy, informed consent,

anonymity and confidentiality were addressed. Trustworthiness, situatedness and authenticity were assured throughout the study by demonstrating goodness as an embedded component of the research process.

Results:

Breaking bad news was conceptualised through the framework of 'Tripartite Transition: a Process of Inclusive Knowing'. Findings from the study indicate that the recipient experiences bad news as a trajectory. Three themes emerged for the recipients entitled: 'Disturbance of the Everyday World', 'Surfacing within the Lived World' and 'Embodiment within the Lived World'. Two themes emanated from the nurses' interviews, these were entitled 'Connectedness: Journeying as Professional within the Everyday World' and 'Connectedness: Exclusion as Professional within the Everyday World. Nurses journeyed with the recipient of bad news through professional companionship. However, their sense of exclusion from the multidisciplinary team and the disclosure of bad news resulted in the nurse being disempowered, uninformed and hampered in their ability to be authentically present to the patient. One theme emerged from the doctors, entitled 'Objectified Connectedness within the Everyday World'. There would appear to be a dissonance between the experience of the recipient of bad news and the doctor delivering the diagnosis. For the recipient, bad news is seen as a trajectory whereas for the doctor it is seen as an event which is planned for and delivered.

Conclusion:

Breaking bad news is perceived as a process for the recipient. It requires a multi-professional approach that recognises the changing information needs of the recipient as they experience the trajectory of bad news. Difficulties encountered within the multidisciplinary team appear to be due to exclusion of nurses and role ambiguity. Whilst doctor and nurse endeavour to provide high quality sensitive care, they appear to be working in professional isolation, which results in fragmented care. There is a need for a collaborative and inclusive approach to care that has clear shared objectives and open communication systems.

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“It took me a long time to get myself up off the floor after it. That was the final insult. You have violated my body. You have done all this awful stuff to me and NOW YOU ARE TELLING ME I HAVE THIS! [said with great emphasis, standing out of her chair, voice very angry., thumping the table with her hand on the last word]

Fucking HER2! I though - oestrogen dependent take Tamoxifen, yea yea yea, but HER2! Percentages and all the rest of it ... I was devastated

... I think cancer is an obscenity.

The treatment is barbaric and medieval and I cannot see myself ever reaching a day where I can say I am glad that happened to me, that it taught me important lessons about life. I cannot ever see that happening to me, ... I just can't.

In the whole thing I think that I was fortunate to have met professional people, really professional people; caring people. And I think that's what I expected. ... I had high expectations of them, and they did not let me down”.

Maise June 2003

**‘People know that you cannot always “make it better.”
All they want is for you to be “with them” when life is
unspeakably awful.
Not to abandon, but to accompany. Not to cure,
but, ALWAYS, to care’**

(Wendler, 2005: 190)

CHAPTER 1

INTRODUCTION

Breaking bad news to patients or being present when bad news is given is part of the daily activity of many healthcare professionals. Throughout this study, receiving and giving bad news relates to the giving and the receiving of a diagnosis of cancer. The most recent figures issued by the National Cancer Registry, Ireland (National Cancer Registry Ireland, 2004) suggests that Cancer diagnosis (using the EuCan classification and cancers classified by ICD-10) has seen a steady increase for both genders. In 1994 the incidence of cancer diagnosis was 19307 and in 2000 (the most recent figures available) this number had increased to 21909. On these figures, it can be seen that potentially there are on average 60 new diagnoses of cancer in Ireland every day. With over 20,000 new cancer diagnoses each year and an increase of 2.3% per year, it presents the healthcare professional with ongoing challenges, not only in relation to prevention and treatment but also in relation to how the diagnosis is given and how the recipient of the diagnosis is supported throughout their journey. The care and intervention required for these people demands that we provide the highest standards of knowledge and skill. However, there is little empirical evidence as to the needs of the patient when the diagnosis is given, and even less empirical evidence as to the needs of the healthcare professional involved in giving the diagnosis. This thesis sets out to address this deficit so that a conceptual framework can be generated from the narratives of those involved; the recipient of the news, the nurses involved with clients and the doctors who have to break the news to their patients.

1.1 Research Propose

The overall purpose of this study was to explore the experiences of healthcare professionals relating to breaking bad news (in this case the giving of a cancer diagnosis), and also to explore the experiences of the recipient of the news. The literature reveals that much empirical work has focused on breaking bad news, but mainly from the perspective of the healthcare professional, and more specifically from the physician/patient perspective. This study will address this apparent

imbalance by initially focusing on the experiences of the recipient of bad news in an attempt to offer some insight into the phenomenological meanings attributed to this experience. The second part of the study will elicit the views and experiences of nurses and doctors in giving, or being part of the process of giving, bad news to patients.

1.2 Background to Study

This research study is both timely and relevant in the current climate of healthcare provision. Whilst attention is currently being given to the funding of healthcare, accessing healthcare and adequate provision of services, there appears to be little attention is paid to the actual experience of the recipient in relation to receiving a cancer diagnosis or indeed the experiences of healthcare professionals working within such scenarios. Within the ongoing healthcare crisis, there is a need to ensure that the voices of the consumers of our services and the experiences of professionals involved in the delivery of bad news are heard.

1.3 Research Aim

The overall aim of this study is to explore the phenomena of;

1. what it is like to receive bad news,
2. what it is like to have to give bad news,
3. what is it like to be present when a patient is being given bad news,
4. what is it like to care for a patient who has been given bad news.

From this a tripartite conceptual framework will be developed, which offers perspectives from the recipient of the news and depicts the practices of healthcare professionals in breaking the news and supporting the patient during this period.

1.4 Research Question

The study is guided by two fundamental questions:

“What are the experiences of the recipient when they are given bad news?”

“What are the experiences of healthcare professionals involved in the disclosure of bad news to clients?”

1.5 Research Design

This study was guided by the philosophy of hermeneutics. The writings of Dilthey (1923), Husserl (1977), Schleiermacher (1977), Heidegger (1962) and Gadamer (1975) were influential in forming the emerging philosophical basis for this study. Data were collected through in-depth interviewing. Three groups of participants were involved. Data were collected from 10 recipients of bad news, 20 nurses and 8 doctors.

1.6 The format of this Thesis

This thesis is presented in three sections. Section one (chapters 2 and 3) provides the background for the study, offering reflective insights into the forestructures of the researcher. It contains an introduction to the thesis and a review of the literature which is sub-divided into two parts. Chapter 3, part (A) presents an overview of substantive literature relating to a nursing perspective of breaking bad news; part (B) discusses the literature surrounding disclosure of diagnosis with a specific focus on the physicians’ perspective. Part (C) explores the literature that pertains to the experiences of recipients of a cancer diagnosis.

Section two contains chapters four through seven. Chapter four details the search for a philosophical framework and presents the chosen research methodology. This chapter presents the literature pertaining to phenomenology and more notably

hermeneutics, and offers an insight into the emerging and developing philosophical views that underpin the study. Chapter five provides a detailed account of the strategies used to investigate the topic. It offers a discussion on the ethical issues pertaining to the study and addresses issues of access to the sample groups. Chapter six offers a discourse on the use of the data collection tool and supplies the reader with an account of the interview process employed. Chapter seven presents a description of the hermeneutic analysis employed in the study. The emerging adapted analytical framework is provided and data are presented throughout in an attempt to offer transparency. The chapter offers a discussion on the establishment of rigour and the emergence of 'goodness' throughout the study.

Section three contains chapters eight through twelve. Chapters eight, nine and ten provide a presentation of the findings from each of the three groups. Chapter eleven provides an overall discussion of the findings within the context of current literature and provides a tripartite conceptual framework from which to view the phenomena of receiving bad news and the practice of disclosure by the healthcare providers. The final chapter offers a discussion on the implications of the research and makes recommendations for education, nursing practice, medical practice and future research.

CHAPTER 2

BACKGROUND AND FORESTRUCTURES

2.1 Establishing the ‘I’ within the study

In an effort to contextualise the study and the ‘lived experience’ of the researcher, it was decided to abandon the formal and traditional format of presenting academic writings, especially at doctoral level. The study did not happen ‘out there’ in some lofty academic tower that was divorced from reality and practice. Whilst the focus is the healthcare professional and the recipient of bad news, the research process involved another. In much research writing this ‘other’ is often invisible, as if they had little impact on that which was studied. To be true to my understanding of the phenomenology of the research process I want to present myself within the thesis. This study occurred in what Schön refers to as the ‘swampy lowlands’ (Schön 1983): the ‘low-lands’ of the participant’s reality and the ‘low-lands’ of the enquirer. To remain true to my own phenomenological journey I intend to present this doctoral study in a way that makes it accessible and understandable to the reader. The use of the first person will be used and a reflexive style will be intertwined throughout the thesis.

An analogy that I have used throughout the process is that of some fine cross-stitched tapestry which is on display. The product on show can be beautiful and admired, but on the reverse side one sees the marks of the true workmanship and the integrate nature of the craft. My goal therefore was to present a thesis that was more open to re-presenting the realities of messy, creative, at times fragmented and complex reality of qualitative enquiry (Bailey, White and Pain, 1999), and in so doing provide the reader with insights into the reality of the research process.

I feel it is important that this work presents the ‘true’ journey of the research. The overarching concept of goodness, discussed in chapter five calls for a shift away from linear neatness within ethical issues, and I would argue also calls for a shift away from the dichotomy of researcher and researched. To this end, this thesis will begin with my own story. I had contemplated putting this in as an appendix or at the end of the study. However, who I am and what I have experienced has

influenced not only the choice of focus for this doctoral study and the methodology chosen, it has also influenced my interaction with the participants, the data and the findings. It is only right that I provide a context from which you, the reader, can meet the writer. I am offering you an opportunity to see the 'reverse of the canvas' so that you can fully appreciate the completed picture on display.

2.2 Prologue: Personal experiences of receiving bad news

As a first year student nurse I received a call from my family saying that my father was in hospital and I would need to come home as quickly as possible. As I was training in England and my family lived in Ireland this meant arranging a flight at short notice. I asked repeatedly if he was alright to which I was repeatedly given the answer, "...yes, but you need to come home." I discovered once I arrived in Ireland later that day that my father had died that morning. The family had wanted to protect me and ensure that I was around them when they eventually told the truth.

This was my first experience of a death in the family and also my first experience of what I could only call bad news. It was to impact me for the rest of my professional life. My attitude towards the patient and their significant others was altered. I often reflected upon my feelings at the time of the initial telephone call and also my feelings at the moment of truth disclosure. I would draw upon these reflections numerous times throughout my clinical practice and as a nurse lecturer. As a clinician I was often unhappy at the way patients were told their diagnosis, or not told as was often the case. The experience of being present with someone when they were given bad news has often left me questioning my role in the process of breaking bad news.

It was to this area that I turned when contemplating my doctoral study. The following study is an attempt to make sense of the lived experience of healthcare professionals when faced with having to give bad news to a person. It also allows for the voice of the recipient of bad news to be given an opportunity to express the lived experience of receiving that news.

The following five situations occurred during my doctoral study. I provide the vignettes as a means of offering context to my own lived experience whilst undertaking the research. I will return to these later in the study and explore them in light of the findings gained.

During the years of this study there were five separate yet distinctly interwoven situations in which I received bad news. The threads that connect them all are the impact they had on my being. They demonstrate a taxonomy of bad news; each impacting in similar ways and yet each differing in their implications on me and my family. I will present them chronologically, as this is how they occurred in reality.

2.2.1 The hard drive

Near the end of my second year working on this doctoral study I had what can only be described as every researcher's nightmare. I had spent most of the Saturday working at the computer, carefully saving my work regularly throughout the day. I returned to the computer on the Monday morning, powered up but to my surprise the computer was unable to find the right path to execute the request. I spent most of that day and subsequent two days on the phone to the computer helpline but was still unable to gain access to my work. I kept reassuring myself that one can 'never really lose work on a computer' as there will be backup copies of the files stored somewhere on the hard drive. Eventually, I took the computer into the college computer service department, where a group of people worked on the problem for a number of days. By this time my anxiety was increasing, but I quickly refused to entertain it. The following week the department rang to say that they were unable to repair the fault and suggested that I send it to the UK as there was a specialist data recovery company who could retrieve the work. I was now very worried but was still holding out hope that the research would be salvaged. I received a call within 5 working days with the news that there was a major fault with the hard drive and that all stored information was lost. My initial reaction to the news was disbelief and shock. I explained to the technician that

my doctoral research – 2 ½ years work was on the hard drive, so it must be there somewhere. When asked if I had made backup copies of my work I replied I had but they too were on the hard drive. When the faulty drive was returned to me I sat for hours just looking at it. I could not believe that all my work was really gone. I was unable to sit in front of the computer again for about two months. People, in an effort to reassure me said things like “... it will all come back to you once you get going again.” It did not come back and I found myself in a state of bereavement.

The news had a huge impact upon me and even now over two years later, I still fear a recurrence. Needless to say I have purchased a hard drive, an external zip drive and a USB memory stick, to which I save everything! The actual hard drive still sits on my office shelf – a testimony to my loss.

2.2.2 The loss of a friend.

Carmel was a close friend of the family. A single girl in her late 30's who shared a house with Kate, another friend of ours. She was a regular visitor to our home, joining us each Wednesday evening. She had complained of a chest infection for a number of weeks which had not responded to antibiotics. We laughed and joked about her 'smokers cough' (she had never smoked), and her 'sexy' horse voice. After her third course of antibiotics her family doctor sent her for a chest X-Ray. The result was not good and her doctor rang and asked to see her. At this point she was referred to a chest specialist but not given any diagnosis.

Carmel had a rear fast growing tumour in her lung which had spread. She was dead within six months. She was the first of our contemporaries to die and we walked the long, at times confusing and often painful journey with her. Kate was a nurse and took the last two months off work to look after Carmel at home as she did not like hospitals. She had a 'good death' – the words of her mother on the evening she died. She was in her own room surrounded by her friends and was pain free.

The impact of the news of her diagnosis and subsequent deterioration was shared by us all, but the burden of facing one's mortality was something that she had to do for herself. Even after she accepted that death was imminent, many around her could not and really believed that she would be healed. A prayer chain was set up and people were praying for her healing continually. Those of her friends who were healthcare workers recognised the signs of rapid deterioration. Carmel had come to terms with the fact that she was dying and was at peace. Indeed, so strong was her faith that she would often pray with her visitors, not for herself but for them. She had accepted her mortality, but many around could not. Even after we buried her and met together for a meal people still felt numb and shocked at her passing. One year on, we are only beginning to adjust to our Wednesday evenings without her. In this case, the news was not directed towards us personally but we journeyed with a friend as she came to terms with her own bad news. We had to deal with the impact of bad news on one another and deal with our own reactions and experiences from outside.

2.2.3 The Car crash.

It was the fourth day of constant rain on a cold, winter November morning. I had dropped my two youngest children to school and was returning home, ready to face another day with the computer. I was stationary at a set of traffic lights. In my rear view mirror I could see a speeding car approaching, it was not slowing down. It all happened in what must have been three seconds, although in flashbacks it always appears in slow motion. The impact was intense and although I was wearing a seatbelt I was thrown around the car like a toy. I jumped out of the car; my concern was for the driver who had crashed into me. He seemed fine but was also in shock. His brakes had totally failed and unfortunately my car had taken the full impact.

I felt fine initially, it was only hours later that I noticed that my back was stiffing up. The following morning I could not move and my wife took me to the accident and emergency department at our local hospital. I eventually was seen, x-rayed

and discharged home with a diagnosis of whiplash. Strong analgesics and a soft neck collar was given along with an appointment for the fracture clinic the following morning. The following day I could hardly stand or walk, but after a wait of 5 ½ hours I eventually got to see the orthopaedic specialist. A short history was taken and repeats of the x-rays ordered. Following the x-rays I hobbled back to the clinic and was brought straight into the consultation room. There were now three doctors present, and all were looking at the x-rays. “I am afraid I have some bad news,” the consultant said.

I had fractured my cervical spine in two places and was immediately placed in a ridged neck brace. All I could think about was my research and how was I going to keep working on it. I spent ten weeks in the brace, unable to sit or walk for any distance. The medication affected my concentration and as I was unable to sit comfortably I was incapable of working at the computer. For sixteen weeks I endured physiotherapy twice weekly with only temporary relief from the constant pain. I felt I was never going to be pain-free again and the thought of never completing the dissertation was becoming a frightening reality. The sense of powerlessness and helplessness was enormous. In this case, the breaking of bad news was not so significant; it was dealing with the implication of the news and processing the impact the injury was having on my life that had a profound effect

2.2.4 The gatekeepers

Joshua, our youngest son, was a typical 7 year-old, full of life and vitality. I had noticed that a small spot on his left cheek had turned darker over a period of months. In January 2003 I took him to our family doctor and expressed my concerns. I was ‘reassured’ that it was nothing to worry about and told to come back if I felt concerned. The spot grew to twice the size but did not get any darker. In March I returned and insisted on a referral to a skin specialist. The specialist examined the spot, again ‘reassured’ us that it was probably nothing to worry about, but said that he would like to remove it in three weeks. I challenged

the specialist and asked what it was, as there was a family history on both sides of skin cancer. Again we were ‘reassured’ and told to come back for the procedure.

I was present when the growth was removed and again expressed my concerns about it being a melanoma. It was only after some considerable pushing that I was told that it would be sent for histology. My wife and I were convinced that it was a melanoma but no one was willing to even entertain the idea. We had spent four months with our suspicions, asking and wanting someone to agree at least that it might be but we were constantly ‘reassured’ that it was nothing to worry about.

The growth was encapsulated and the specialist had managed to remove it all. I felt angry at being kept out of the picture. The ‘gatekeepers’ had done a good job at ensuring that. I am sure they were well meaning and did not want to worry us unduly. However, when faced with people who had already expressed an opinion it would have been more helpful to have acknowledged their concerns and supported them. Instead we were made to feel that we were overly anxious and at times made to believe that by questioning and probing we were undermining their knowledge. All we wanted was to be given the truth, simply and clearly, even if that truth was a suspicion. In this case the bad news was not forthcoming; non-disclosure had resulted in ongoing anxiety and again a sense of powerlessness. Disclosure only happened after the event, when the growth was removed and all was safe – or when the disclosure was good news (Maguire, 1998).

In summary, the scenarios are shared to demonstrate the impact of bad news on the researcher. Although I have not personally received a cancer diagnosis, the impact of bad news and the way in which the news was broken had a significant effect on how I coped with my life. As the study progressed, I came to realise that my actions and reactions are reflected in experiences of the recipients within the study.

CHAPTER 3

CRITICAL REVIEW OF THE SUBSTANTIVE LITERATURE

3.1 Introduction

This chapter is divided into four parts. In part A, I examine what is known empirically about breaking bad news from the nurse's perspective. Part B critiques the research exploring doctor-patient interaction, truth disclosure and the training needs of medical staff in relation to communicating bad news. Part C examines the views of recipients of bad news and their significant others. Part D links the review with the focus, aims and rationale for the study and sets out the research questions.

CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane, MEDLINE, Nursing/ProQuest, PsycLIT, Pubmed, and Synergy databases were the main search engines used in locating articles for this section of the review. Literature from 1980 to 2002 was retrieved and critiqued. Descriptors of breaking bad news, truth disclosure, information needs of significant other and patient, physician-patient relations, nurse-patient interaction, and communication were exploited. Additional searches of major texts, government publications, find.article.com and Google Scholar.com search engine, manual searches of medical indexes, and current publications in Trinity libraries were also employed. Non English articles were excluded as were conference abstracts. Much of the literature draws from anecdotal evidence, personal experience or expert advice from a body of knowledge gained through clinical experience.

The substantive review was carried out retrospectively and concurrently for two reasons. Firstly, the ongoing publication of current research in this area is minimal, but the review of literature published from 2003 to 2005 was carried out while the research analysis and writing up was in progress. This allowed for contemporary thinking to be used to echo whether the findings of other research were mirrored within my own data. The retrospective critique of the research occurred during the first two years of the study. This allowed for the emergence of evidence and provided a structure to the development of my thinking and the

ongoing research. It enabled me to develop inclusion criteria for the literature as follows:

1. experiences of nurses in breaking bad news,
2. views of doctors in giving a diagnosis that met the criterion of bad news,
3. experience of the recipient of bad news,
4. experience and the felt needs of significant others in relation to information relating to the patient.

Each study was examined in relation to its aims and focus, the research question, the context of the study, the methodological perspective and its strengths and limitations, the similarities or differences between study findings, the theoretical ideas presented and the robustness of the inquiry.

PART A

3.2 Nursing perspective of breaking bad news

The vast majority of articles within this section fell into the anecdotal or informative group. Much of the literature retrieved were commentaries based upon knowledge gained through experience or best practice. Unfortunately a lot of it was poorly referenced, and some articles were published without any references to the author's sources. The literature that informs this section is drawn mainly from articles published in scholarly journals, although some reference will be made to specific points raised in some of the 'less academic' publications if they support or refute some of the findings presented.

The review of the literature has identified that many patients experience distress after being given a cancer diagnosis (Maguire and Faulkner, 1988; Chaitchik et al, 1992; Charlton, 1992; Harrison et al, 1994; Chan and Woodruff, 1997) and that having to give a diagnosis is also often emotionally charged for the healthcare professional (Northouse and Swain, 1987; Chaitchik et al, 1992; Maguire, 1998), which may result in negative or blocking features during the interactions (Kruijver et al, 2000; Kruijver et al, 2001). Although communication is one of the most important aspects of cancer care (Wilkinson, 1991) and is seen as a pre-requisite

for effective nursing care (Bond and Anderson, 1987; Northouse, 1989; Dennison, 1995), it will be seen that there is often an imbalance in the communication skills demonstrated by nurses when caring for the patient with cancer. Blocking behaviours such as overwhelming the patient with medical information, failing to establish what the patient understands regarding their diagnosis and treatments (Dennison, 1995), concern with the physical care (Bond, 1983), an inability to get the patient to discuss their feelings (Webster, 1981), a failure to assess the patient's concerns accurately (Degner, Gow and Thompson, 1991) and the over usage of closed questions (Maguire et al, 1996) are just some of the issues identified as impacting on the nurse-patient communication process. Whilst Massie and Holland (1989), Bond and Anderson(1987), and Barraclough (1994) highlight the importance of promoting effective communication skills in caring for the patient with cancer, there is evidence that there is an ongoing need for nurses and doctors to improve their communication skills (Parle, Maguire and Heaven, 1997; Booth, Maguire and Hiller, 1999).

Wilkinson (1991) highlights the importance of effective communication between nurse and patient. However, from the review of literature relating to communication within a cancer context it appears that the dominant research focus has been communication between physician-patient (Kruijver et al, 2001), with little focus on the nurse-patient interaction. Much of the research into the role of the nurse in breaking bad news has focused upon identification of nurses' concerns (May, 1993b; Jarret and Payne, 1995; Morton, 1996; Morrissey, 1997) and perspectives of the role on the nurse in the bad news consultation (Davis, 1987; Thayre and Hadfield-Law, 1994; Bottorff, Gogag and Engelberg-Lotzar, 1995; Girgis and Sanson-Fisher, 1995; Hinda, Streater and Darlene, 1995; Campbell and Sanson-Fisher, 1998; Fakhoury, 1998; Farrell, 1999).

The following section will address the specific area of nurse-patient communication within cancer care and will critically review published work in this area.

3.3 Communication Issues

Connecting with people through verbal and non-verbal interactions is a central component in contemporary nursing (Long, 1999). Nurse theorists have recognised the importance of belief and meaning as important elements of the experience of an illness for the patient and the nurse interacting with them (Patterson and Zderad, 1993; Leninger, 1995; Peplau, 1997). How a person thinks, perceives situations, feels and communicates are determined by the belief system held by the individual (Erikson, Tomlin and Swain, 1983). Giving words to one's experience and feelings is a means of giving voice to beliefs and provides a conduit to finding meaning for both patient and nurse.

Creating meaning is seen as a form of human becoming (Long, 1997), and one to which the nurse can act as facilitator. Cassell (1982) suggests that it is impossible to understand illness without taking meaning into consideration. Communication is the means by which the nurse understands the patient's experience of their illness, a channel by which nurses transfer care (Kirby and Slevin, 1992) and is the essence of caring (Leninger, 1984; Ghuahan and Ann, 2000). Numerous research studies into the search for meaning have noted the effects on adaptation in recurrent cancer (Taylor, 1983), in breast cancer (Taylor, Lichtman and Wood, 1984), and bone marrow transplantation (Steeves, 1992). Studies have also suggested that nurses may use blocking behaviours to avoid having to deal with the patient unleashing strong emotions (Maguire, 1985), due to fear of being exposed as vulnerable in front of patients (Maguire, 1998), or for fear of having to face their own mortality (Sprangers, 2002)

Dunniece (2000), in exploring the lived experience of the nurse when present with a patient receiving a cancer diagnosis, highlights seven themes that emerged from the data, which amalgamated into a structure of 'being present' (p.614). A central tenet of all themes was communication between patient and nurse. 'Being present' was experienced through providing comfort and fulfilling information needs, offering a listening role or being present in silence. Communicating openly with the patient was identified as a pre-requisite to the evolving nurse patient relationship. Indeed Dunniece suggests that there was a move from nurse-patient

to person-person communication as the nurse empathised and worked through her own feelings in a theme identified as ‘What if it were me?’ These strong personal feelings have also been identified elsewhere (Field, 1987).

Dunniece (2000) also identify four divergent feelings of inadequacy, fear, distress and anger. These were often linked to misgivings about the nurse’s ability to communicate effectively with the patient and concerned an apprehension of saying the wrong thing and thus confounding the patient’s devastation. The distress was not a fleeting experience and it is suggested that the transient feelings remained after the bad news consultation. Developing coping strategies such as ‘shut-down’ were identified and would suggest that the emotional cost of caring is a significant reality for the nurse (James, 1993; McNamara, Waddell and Colvin, 1995; Altschuler, 1997; Kelly et al, 2000).

Feelings of anger and frustration at medical staff’s poor communication skills were also identified. Issues of disempowerment of the patient through non-disclosure or closed awareness were evident and are supported by research into truth disclosure, discussed in part 2 of the review. The detrimental effect on the nurse patient relationship from medical staff’s poor communication skills was identified. Consistent with the findings of Speck (1991) and May (1993a), the nurses felt that they had to ‘pick up the pieces’ once the consultation was finished. Whilst the sample group was relatively small (n=6), the researcher does identify that the inclusion of male respondents might have added other perspectives to the findings. Another limitation of the study was the lack of operational definitions. Complex concepts such as comforting, therapeutic interactions, coping strategies and empowerment are presented but not adequately discussed.

Dewar (2000) used a grounded theory approach to explore the lived experience of twenty-two nurses in giving bad news to spinal cord patients. Whilst the study does not address breaking bad news within a cancer context, the experiences identified reflect those of research into cancer care and it was felt appropriate to include this research as part of the review. Analysis of the focus groups revealed five major themes; being the bearer of bad news, strategies employed to give bad

news, role of patients, role of families and meeting the nurses' needs. Although identified themes differ from Dunniece's work (Dunniece, 2000), there are similarities within the findings. Central issues within the findings were the areas of communication, truth disclosure and nurse-patient relationship. The nurses saw their role as providing support and education for the patient and families. Whilst recognising the prerogative of the physician for the initial disclosure of bad news, the nurses identified that there were incidences where the nurse had to respond truthfully when confronted with a specific inquiry. This resulted in the nurse having to give the bad news. Although they felt uncomfortable, they identified the need for personal integrity and trust within the nurse-patient relationship. Strategies used when dealing with the 'awkward situation' of truth disclosure revealed that nurses deflected the patients' questions to others, used standard lines of response and regulated the amount of information to the patients' needs in relation to the illness trajectory.

Maintenance of hope was perceived as a crucial aspect of the nurses' interactions with the patients. As with the findings of Dunniece (2000), this often involved 'picking up the pieces' following medical staff's poor or inadequate communication skills. All nurses discussed the stressfulness of being involved with breaking bad news, again supporting the concept of emotional labour of nursing (James, 1989; Smith and McCarty, 1992; James, 1993). The use of empathy was identified and recognition given to the support of working as part of a team in diffusing their own emotional reactions.

The study highlights the realities of nursing, where there is sustained and ongoing contact with the patient. In contrast to the guidelines for breaking bad news (Girgis and Sanson-Fisher, 1995), the nurse does not always have the advantage of planning the disclosure or the request for clarification following disclosure.

A limitation of Dunniece's (2000) study is the apparent vagueness of how the data were collected. Whilst we are told that focus groups were used, we are not told how many were performed. We are informed that one group of nurses requested not to have their interview recorded but are given no indication as to how the

researcher managed to record the actual dialogue for analysis. Another concern is the length of the interviews, approximately 30 minutes. This is a relatively short period of time for a focus group and one would question the level, content and interaction within the group in such a short time. Despite these concerns, the research findings are challenging and there is a sense of recognition or fittingness (Guba and Lincoln, 1981; Lincoln, 1995) demonstrated throughout the findings.

In one of the few quantitative studies retrieved, in which a nurse researcher investigated nurses' communication skills with cancer patients, Wilkinson (Wilkinson, 1991) argues that there is evidence to suggest that nurses' communication styles may not only be an intrinsic skill but dependant upon external issues such as ward environment, religious beliefs held by the nurse and attitudes to death and dying. Fifty-four nursing staff participated in the study, which included a self-administered questionnaire and tape-recorded interviews with the nurse and patients with newly diagnosed cancer or recurrence of cancer, and a patient admitted for terminal care.

Kruijver, et al (2001) in a study involving 53 nurses communicating with simulated cancer patients on admission to a ward, explored the interactions by using direct observation, which was videotaped. The findings highlighted that the vast majority (62%) of communication behaviours related to instrumental (providing information regarding illness and treatment and providing medical and practical care) communication. Nurses were shown to provide medical information (24%), inform about psychosocial issues (11%), provide information regarding orientation to the ward (6%), seek clarity of the patient's understanding (1%), ask the patient's opinion (1%), and make requests for clarification (0%). Thirty eight per cent of behaviours fell into the affective mode (showing respect, giving comfort, developing trust and demonstrating that the patient was understood). Of these, 19% concerned more global issues such as giving agreement, use of paraphrasing (10%), showing concern (2%), demonstrating empathy (2%), and providing reassurance (2%). The study indicates an imbalance in the nurse's use of instrumental and affective communication behaviours. It demonstrated that the nurses used a majority of closed questions, which supports

the views of Maguire and Faulkner (Maguire and Faulkner, 1988), and appeared to spend a lot of time giving information with little evidence of evaluating the patients' understanding of the information given. This supports the view of Kruijver (2001), who argues that the evidence suggests it is the nurse's agenda that predominates and determines the course of interaction with the cancer patient. The use of simulated patients in nursing research is relatively new and its validity remains to be demonstrated. Despite this, the study raises challenging issues and supports some of the findings of Webster (1981) and Maguire (1995).

The literature on the psychological precursors and outcomes of cancer and the role of the surgeon and nurse in the psychological management of early breast cancer, is briefly reviewed. A questionnaire study taped nurses' expressed perceptions of the disease and its treatment, patients' problems and the provision of psychological support (Ray, Grover and Wisniewski, 1984). Responses indicated mixed attitudes toward treatment outcomes, but a general enthusiasm for health education. Mastectomy itself was seen as posing serious social problems by half the sample, and serious sexual problems by more than three-quarters, and many felt that the support currently provided for patients is inadequate. While nurses saw themselves as having a key role in giving comfort, they were less likely to see themselves in the role of counsellor. Many of the sample felt that they had not been trained to provide psychological care at this level. Here, the skills of a specialist nurse were looked for, in the case of counselling the patient or when counselling the partners.

PART B

3.4 Doctors' perspectives of giving bad news

The literature review for this section was drawn from published material in medical and psychological literature from 1980 to 2000. MEDLINE, Pubmed, ProQuest, PsychARTICLES, the Psychology and Behavioural Sciences Collection, PsyINFO, PsycLIT and Synergy were the main search engines used in locating articles for this part of the review. As with the search in the previous section, additional searches of major texts, government publications,

find.article.com, Google Scholar.com, and manual searches of medical indexes, and current publications in Trinity libraries were also employed. Non English articles were excluded as were conference abstracts.

Much of literature draws from anecdotal evidence, personal experience or expert advice from a body of knowledge gained through clinical experience. The need for 'evidence' drawn from randomised controlled trials is highlighted by Girgis, Sanson-Fisher and Schofield (1999), who argue for the need for rigorous controlled trials as a means of providing evidence based research that can provide effective strategies for facilitating guidelines for the delivery of bad news. This is not surprising, as researchers have advocated that the guidelines be 'evidence' based (Anonymous, 1994). It is also interesting to note that almost all of the controlled trials published in the medical journals focused upon the physician-patient relationship, and the delivery of the bad news, few have the perceived needs or 'voice' of the recipient, significant other or the contribution of the nurse to the situation.

Breaking bad news to patients and their relatives is widely regarded as one of the most difficult tasks that the doctor may have to perform (Veatch and Tai, 1980; Girgis and Sanson-Fisher, 1995). The question of disclosing a diagnosis when the prognosis is not good has long been debated in the literature. In 400 BC, Hippocrates advised concealing things from the patient;

...revealing nothing of the patient's future or present condition. For many patients ...have taken a turn for the worse ...by forecast of what is to come (Hippocrates, 1923:19).

He goes on to advise that the patient's true condition should be revealed to a third person and not held in secret. Katz (1984) cites the first Code of Ethics from the America Medical Association, which was published in 1847 as stating:

The life of a sick person can be shortened not only by acts, but also by the words or the manner of a physician. It is therefore, a sacred duty to guard himself carefully in this respect, and to avoid all things which can have a tendency to discourage the patient and to depress his spirits. (p 20)

The code has changed over the years, but the spirit of the early sentiments lives on in modern medicine (Katz, 1984). Changes have occurred over the past 30 years, with doctors acknowledging the need for openness and truth disclosure (Charlton, 1992). Despite the shift from a paternalistic model of care to one of empowerment where the autonomy of the patient is recognised, problems still exist in the delivery of bad news. Whilst it is widely acknowledged as one of the most difficult responsibilities of medical staff (Ptacek and Ederhardt, 1996; Girgis and Sanson-Fisher, 1998; Walsh, Girgis and Sanson-Fisher, 1998; Ptacek et al, 1999), it appears that medical staff still receive little formal education on how to discuss bad news with patients and their relatives (Vandwkieft, 2001).

3.5 Brief history of truth disclosure.

The review of literature for this section looks at the historical perspective on ‘truth telling’ and draws from limited archival material. I have separated out the work in this fashion so that the substantive review of the literature could be controlled and managed, thus the remainder of the publications for this section will draw from outside the period 1980-2002.

Blum, Sandusk and Waterson (1960) allude to cultural influences towards illness and suggest that the historical embracement of animistic, religious and scientific belief systems all impacted upon the way illness was interpreted. The changes in the way that people died during the 19th and 20th century saw a significant shift from death in the home to death in hospital settings (Glaser and Strauss, 1965; , 1968). Advances in medical interventions, growth of institutions in which to deliver health care and the increase in life span, achieved mainly through scientific breakthrough, resulted in a decrease in sudden death and an increase in decelerate dying. The prolonging of life resulted in situations in which people faced mortality and were presented with the means of ‘curing’ or delaying the inevitable loss of life. Faced with impending death, many chose to deny it, or experience a general discomfort with the topic of dying, resulting in some denying to the individual their impending death. One of the earliest published works identified

was in 1903. Cabot (1903) conducted an experimental study investigating the concept of disclosure. He cautioned the physician to present truth to the patient in such a way as to not remove all hope. Truth telling remained something that was left very much up to the individual physician. In an interesting article Collins (1927) suggested that there be a mixing of truth and falsehood. He admitted that the longer he practised medicine the more convinced he was that every physician should develop the art of lying. Historically, the rationale for withholding of information from the patient was immersed in the view that patients could not cope with the information. It was tacitly assumed that the patient was better off kept in ignorance of his diagnosis. However, two early studies carried out in the U.S. suggest that the majority of cancer patients would prefer to be told their diagnosis (Kelly and Friesen, 1950; Samp and Curreri, 1957). In a survey of 219 doctors Oken (1961) identified that 90% never disclosed a diagnosis of cancer to their patients.

The topic of disclosing a diagnosis or truth telling to patients with cancer remained almost nonexistent in the published literature of the last century until the mid 1960s onwards. Feifel (1963) conducted a study that highlighted the desire for the dying patient to know their diagnosis. In interviews with 60 patients he found that 84% wanted to know about their condition, findings that supporting the earlier work of Kelly and Friesen (1950) and Samp and Curreri (1957).

It was the publication of research in the late 1960s by Glaser and Strauss (1965; 1968), Kubler-Ross (1969) and Brim et al (1970) that saw the topic of death and dying emerge in the public arena. The increase in published works debating issues pertaining to truth disclosure and information needs of patients with a cancer diagnosis began to appear. The work of Kubler-Ross crossed boundaries and became widely read by the general public. The publications of Glaser and Strauss (1965; 1968) did not have the same impact on the general public, but I would suggest they fuelled the ongoing debate within the medical fraternity. Theories of death and dying were presented, the issue of truth disclosure to patients with terminal cancer highlighted and the beginnings of the erosion of a belief in the concept of non-disclosure emerging. The work of Glaser and Strauss

and Kubler-Ross shattered the long held belief in the importance of the doctor doing the patient 'no harm' and highlighted that the patient could indeed cope with the information regarding their diagnosis and prognosis. The impact of truth disclosure was shown initially to have a negative impact upon the patient but this changed over time (Kubler-Ross, 1969; McIntosh and Parkes, 1974). Both these studies suggest that the impact of bad news could be influenced by the method of delivery and ongoing interactions with care staff.

In a review of 51 articles published between 1949 and 1969, addressing the management of terminally ill patients, Koenig (1969) concluded that the issue of truth disclosure remained indecisive. The developments in cancer care and the possibility of treating cancers more effectively may have led to a shift in the perceptions of health professionals and the general public (Charlton, 1997). A study carried out by Novavket et al (1979) indicated that there was a change in the attitudes of physicians towards truth disclosure since the earlier study by Oken (1961). The results, which highlighted that 97% of physicians preferred truth disclosure, seemed to confirm this shift. However, one must be cautious as there was only a response rate of 25% compared to a response rate of 95% in Oken's study, in which only 3% indicated disclosure to the patient. The findings of Oken (1961) seem more in keeping with those of Korsch, Cozzi and Francis (1968) Koenig (1969) and Friedman (1970) who identified that only 25% of physicians engaged in disclosure.

3.6 Current trends in breaking bad news:

Shifts in changing attitudes towards truth disclosure continued through the 1980s. These trends may relate to changes in ethical norms, perceptions of the impact of truth disclosure, changes in society and a shift in the expectations of health care delivery (Veatch and Tai, 1980).

In a descriptive study, Dunkel-Schetter (1984) revealed that one of the most important means of offering emotional support was to provide information to the patient. This view was supported by Bartlett et al. (1984) who argue that the

physician's style of communication has a direct effect upon the satisfaction of the patient and their ability to recall and comply with treatments. In a telephone and postal survey of people following pancreatic surgery, D'Angelica et al (1998) suggest that the communication between surgeon and patient was adequate prior to and during the hospital stay but deteriorated following discharge from hospital. These findings are supported by Blanchard et al (1988) who identified the need for information for oncology patients and the importance of the physical patient communication.

3.7 Truth disclosure and nondisclosure:

As has already been highlighted, over the past 5 decades there has been a significant shift in how the doctor approaches the concept of disclosure. This move from a paternalistic model to a client centred model becomes evident within the literature. The following section will explore articles published between 1980 and 2000 that specifically address this issue.

The reluctance of doctors and nurses to be more open in their communication or to withhold the truth through non disclosure, partial disclosure or closed awareness can be seen as hampering the patient to deal with their own mortality (Costello, 2001). This distancing of the professional from the patient may result in a sense of isolation where the person has little human status (Sweeting and Gilhooley, 1992) and where conversations are scattered with euphemisms in order to avoid talking about death (Wahl, 1995). The medicalisation of death and dying has been highlighted by Illich (1990) who describes a process in which the patient's body is 'taken over' by the professionals, resulting in a dehumanising process. Sweeting and Gilhooley (1992) imply that there is often a social death prior to the biological death of the person who is dying in hospital.

The labelling of the dying process may result in the person being perceived as an illness rather than a human being (O'Gorman, 1998). This reduction of the person into manageable items may only increase the tendency of professionals to avoid the issue of the mortality of the individual. By suppressing their emotions

(Aldridge, 1994), or masquerading the consequences of caring for the patient with cancer, the health professional may be attempting to manage the interpersonal demands they face (McNamara, Waddell and Colvin, 1995) and in so doing refuse to acknowledge the emotional cost of caring (Smith, 1992).

Dealing with truth disclosure may result in feeling uncomfortable, as James noted:

“The person with cancer and the professionals have to regulate their feelings. Even the diagnosis ...of cancer is surrounded by its own language – ‘knowing’, ‘communication’ ...in health staffs’ terms; ‘telling’ and ‘knowing’ in lay terms. At a personal level cancer generates disbelief, fear, lies and chaos which are controlled through information, optimism, routine living and social expectations (James, 1993:43)

Caring for a person with cancer can pose serious problems for the health professional and may interfere with their ability to communicate effectively with the person. The health professional is often faced with unpredictability and ambiguity as they struggle with what to say (Altschuler, 1997). It may be for this reason that the issues surrounding disclosure remain as pertinent to day as they did in the days of Hippocrates.

In a descriptive study of 167 oncologists who dealt with poor prognosis in cancer patients on average 35 times a month, discussing bad news was rated as the most difficult aspect of their role (Baile et al, 2000). In a comparative study of palliative care physicians in Europe, South America and Canada, Bruera et al. (2000) found that although physicians in all three areas identified that patients should know their diagnosis, only 52% of patients in South America knew their diagnosis compared with 69% in Europe and 96% in Canada. Twenty four per cent of patients in South America were aware of the terminal nature of their disease compared with 38% of European patients. When asked if they wanted to know their diagnosis and prognosis, 60% of Canadian patients wished to know, compared with 18% of South Americans and 26% of Europeans. Physicians who practised in South America were more likely to support beneficence and justice when making decisions, whilst physicians from Canada suggested that autonomy underpinned their decision-making. The study does highlight regional variations, but one needs to be cautious when interpreting the findings as the physicians

completed a postal questionnaire. Although the response rate was high at 84% (n=228), there is no discussion on the accuracy of the responses. The findings however, are supported by Fallowfield; Lipkin and Hall (1998) who suggests that healthcare professionals often edit the information given to patients in an attempt to protect them from potentially hurtful, sad or bad news. They further suggest that less than honest disclosure is seen from the moment that a patient reports symptoms, to the confirmation of diagnosis, during discussions about the therapeutic benefits of treatment, at relapse and during the terminal stages of the illness. As will be discussed below, this desire to shield patients from the reality of their situation usually creates even greater difficulties for patients, significant others and other members of the healthcare team. Although the motivation behind 'economy with the truth' is often well meant, a conspiracy of silence usually results in a heightened state of fear, anxiety and confusion, not one of calm and equanimity.

In a U.K. study, Burton and Parker (1997) interviewed 51 consultants, registrars and senior registrars working in NHS hospitals regarding the psychological aspects of cancer surgery. Thirty seven per cent said they always disclosed information regarding diagnosis and prognosis. Eight per cent identified that they tell virtually all their patients, while 49% said they would do so depending on the patient's and relatives' wishes. An interesting point raised was the use of the word 'growth' instead of the diagnosis of cancer. Forty nine percent indicated that they used euphemisms and would only use the word cancer if the patient pursued it. It could be argued that the ambiguous or deliberate misleading of information may afford short-term benefits while things continue to go well, but actually denies the individuals and their families opportunities to reorganise and adapt their lives accordingly.

In videotaped interviews between residents and simulated patients Eggly, et al. (1997) noted that there was a general lack of skill in the competence of delivering bad news. The instrument used contained 16 items, 9 in the affective category and 7 in the skills area. Each category was marked by 6 individual researchers using a Likert scale. Lowest ratings were allocated to the affective category which

evaluated the ability to elicit the patient's feelings. The sample group was small, (n= 25) and it could be argued that they represented a weakness on the part of the residency programme and does not reflect the competency of residents outside the study site. In a U.K. study, Cantwell and Ramirez (1997) identified that only 3% of their sample of junior house officers felt they had adequate skills in relation to psychological issues pertaining to breaking bad news, which seems to reflect those found in Eggly et al (1997).

In a review of 10 randomised controlled trials (RCT) that evaluated communication strategies with cancer patients in the diagnostic phase of their illness, Walsh, Girgis and Sanson-Fisher (1998) present evidence which could guide clinicians. A criticism of the work is that, whilst rigorous in its critique of the RCT studies, the authors failed to identify studies that focused upon the actual delivery of bad news. Instead all 10 studies reviewed looked at recollections of patients regarding their consultation and therefore the 'evidence' may be questioned. A more varied view of evidence, which critiqued research of non-RCT and that from the qualitative paradigm, might have afforded the opportunity to look more broadly at the subject.

In a more recent study, Girgis, Sanson-Fisher and Schofield (1999) rated 84 breast cancer patients, 64 oncologists and 140 nurses in what they perceived as 15 general principles and 12 recommended steps for breaking bad news. In the first study of its kind, the work drew from the three distinct groups involved with bad news. The comparative ranking of each group provided interesting similarities and differences. Ranked first was the importance of the way the bad news was given, ranked by 64.7% of patients and 76.2% of nurses and 76.2% of doctors. It is worth noting, that although 76.2% of doctors identify this as important it was ranked 7th in their list of important principles. The principle of giving accurate and reliable information, which ensured that the patient understood the treatment options, was rated 2nd by the patients, 4th by the nurses and 6th by the doctors. Patients and doctors ranked highly the principle that only one person should be responsible for breaking bad news, whereas nurses ranked this as their 6th principle. Although rankings amongst the groups differed, providing

uninterrupted time during the initial imparting of bad news, assessing the patient's understanding, and avoiding a prognosis with a definite time-scale were all rated in the top 5 steps that were desirable. Limitations of the research are adequately explored and future research areas highlighted. The study would suggest that there is some consensus amongst the groups. A replication study is needed in Ireland and the U.K. where health care systems are somewhat different.

3.8 Education needs of the doctor in relation to skill development

This section explores the literature addressing the educational training needs of doctors, communication skills in general and more specifically in the area of breaking bad news. Buckman (1984) in an interesting and challenging article, questioned why breaking bad news remained a difficulty. He highlights that there is a need for education and training, specifically in the area of communicating bad news. Ptacek et al (1999) in a review of 181 articles published between 1986 and 1996, suggest that there is consistency across physicians' recommendations and convergence between physicians and patients preferences. It is argued that there is a lack of empirical evidence presented in the literature. The review is somewhat limited as it only used MEDLINE as its search tool and restricted its parameters to breaking bad news. With a limited descriptor, published work on wider issues pertaining to bad news may have been missed. However, the paper provides a clear discussion on key issues that appear consistently throughout the literature.

It is widely held that training in the area of communication for medical students is woefully inadequate (Girgis and Sanson-Fisher, 1995). The area of breaking bad news to patients seems to be left up to experiential learning in the real situation, often without good role models and seldom accompanied by feedback. This has resulted in junior doctors feeling ill prepared and inadequate in the area of giving bad news (Firth-Cozens, 1987; McLaughlan, 1990; Eggly et al, 1997).

Finally and Dallimore (1991) highlighted the lack of training given to healthcare professionals compared with other professional groups. In a questionnaire of 150 bereaved parents, one third thought the way they were given bad news was

insensitive and offensive. An area of interest was that participants, who were broken the news by police officers, rated them as being more sympathetic than healthcare professionals who, it was felt, adopted a cold professional detachment. One needs to be cautious when accepting the findings, as the researchers do not address the issue of roles and relationship. It could be assumed that the police officer may not have met the recipients prior to the exchange and that their training enabled them to appear sympathetic and give the relatives time to assimilate the information. This is in stark contrast to the context of the healthcare professional, who may have already built a trusting relationship with the family and who once having given the news, may feel pressured to address the needs of other patients. Unrealistic expectations about interventions may also cause the healthcare professional to feel that they have in some way failed the patient and family. Olin (1982) argues that many medical students hold a belief in curing and that death signifies a failure on their part. This belief was further supported by Clark and LaBeff (1982) and Wist (1993) who suggested that this orientation may result in doctors feeling powerless and ineffective.

Communication between doctor and patient can be problematic and the difficulties can be more profound when a diagnosis of cancer is involved (Beckman and Frankel, 1984; Kaplan, Greenfield and Ware, 1989). Fallowfield (1993) suggests that it is poor training in the area of communication skills that results in doctors being unable to give bad news appropriately. They are more proficient in providing quality cancer care, but ill-equipped to meet the psychosocial needs of their patients (Cowan, Laidlaw and Russell, 1997). This lack of adequate training in medical schools remains a concern (Girgis and Sanson-Fisher, 1995), and the ongoing emphasis on the biomedical model and the acquisition of technical skills would appear to remain paramount (Cantwell and Ramirez, 1997). Whilst research has indicated that the effectiveness of the doctor-patient interaction can have beneficial outcomes for the patient in numerous areas such as improvement in how the patient adjusts psychologically to their situation (Fallowfield et al, 1990), recall of information provided (Roter, Hall and Katz, 1987) and perceived satisfaction of the patient (Bertakis, Roter and Putnam, 1991), it has also

highlighted the effects of poor communication on the patient as having a negative impact (Hoy, 1985; Quill and Townsend, 1991).

Despite the ongoing discussion in the literature regarding breaking bad news, much of the debate draws from anecdotal evidence (Brewin, 1991; Davis, 1991; Sell et al, 1993; Doyle, 1996; Mohr et al, 1999; Bruera et al, 2000) A consensus on providing guidelines on the practice of giving bad news has emerged (Girgis and Sanson-Fisher, 1995), which suggests that the primary goal in breaking bad news is to ensure that all necessary information is given and to do so in a way that does not add additional stress to the patient; secondary goals are that the news is communicated in a way that indicates that the patient is cared for as a human being rather than a diseased entity (Klein and Klein, 1987) and provides adequate time for providing emotional support (Seale, 1991). The consensus guidelines were assessed for relevance and importance (Girgis, Sanson-Fisher and Schofield, 1999) and drew on the 84 breast cancer patients, 64 oncologists and 140 nurses. There was consensus between all groups of the moral and legal right of the patient to reliable and accurate information, which should be delivered in language which can be understood and given sensitively. The study, carried out in New South Wales recognised the need for replication studies in different healthcare provider contexts, and called for strategies that would enable facilitation and adoption of the guidelines by clinicians. Maguire (1999) identifies the work of Watson (1961), Parle, Jones and Maguire (1996), Fallowfield; Lipkin and Hall (1998) and Lobb et al. (1999) as evidence of how well these guidelines are followed in practice. Most of these studies were presented prior to Girgis and Sanson-Fisher (1999) publication but could be used as a benchmark against the earlier publication of Girgis and Sanson-Fisher (1995). To date no recent studies or strategies that draw upon the work of Girgis and Sanson-Fisher (1999) have been identified in the literature.

The importance of structured experiential training through the use of role-play using simulated patients, audio and video taping and feedback from more experienced staff as a means of developing the necessary skills to facilitate effective breaking of bad news is clearly recognised (Maguire, Fairbairn and

Fletcher, 1986; Girgis and Sanson-Fisher, 1995; Mann et al, 1996). Without adequate systematic training, Maguire (1999) suggests that doctors will fall far short of meeting the guidelines and as a result fail to meet the expectations and needs of the patient. The use of training to develop communication skills has been highlighted repeatedly in the literature (Baile et al, 1991; Mann et al, 1996; Cowan, Laidlaw and Russell, 1997; Barclay et al, 2003).

Whilst it would appear that a number of training courses on breaking bad news are now available to healthcare staff, few have been evaluated for their effectiveness in changing behaviours. In a descriptive study carried out in Canada, Cowan; Laidlaw and Russell (1997) used questionnaires to elicit the changes to curriculum in all 16 medical schools regarding the teaching and assessment of communication skills between 1994 to 1996. From the 15 responses, all had indicated changes to the teaching of such skills. However, the research failed to extract if the actual content was evaluated as to its impact on practice. Dignan et al (1989) in a study of medical students, identified that they benefited from a programme of teaching in breaking bad news. Again however, one must be cautious as there is no indication of what the benefits are, or if the evaluation explored the transferability of 'new skills' to the clinical area. In a similar study to Cowan, Laidlaw and Russell (1997), Rosenbaum (2002) identified that students benefit from using an experiential learning approach to teaching skills in breaking bad news. The intervention (teaching method and style) was highly rated and students indicated that they felt more comfortable and skilled in having to break bad news when surveyed four weeks after the course. However, less than 40% responded to the survey one year later. The study is also limited in that 'confidence' and 'skilled' are not adequately explored. The focus of the research is on the effectiveness of teaching and this is measured by rating scores. Application to practice and impact of new knowledge on practice is not addressed.

In a more comprehensive longitudinal study, Fallowfield; Lipkin and Hall (1998), concluded that there were subjective improvements immediately following a three-day residential course designed to enhance skill development, knowledge acquisition and personal awareness in breaking bad news. They indicated that the

improvements were maintained three months after the course. However, as the data were collected via self administered questionnaires it may not have reflected true improvements in practice but merely perceived improvements. Therefore the findings are questionable.

In the first randomised controlled trial that measured efficacy of a training initiative of 160 oncologists in the U.K., Fallowfield, et al (2002) argued that time and clinical experience does not necessarily resolve problems with communicating bad news. Using Poisson regression analysis of counts of communication behaviours, the study highlights that attendees repeatedly rated higher than non attendees in a number of key issues; use of focused questions (35%), use of open questions (27%), expression of emotion (69%), and appropriate responses to patient's cues (38%). The attendees also demonstrated a lower rate in the use of leading questions (24%).

The review of literature on truth disclosure when breaking bad news and the educational needs of the doctor in this area has highlighted the power dynamic between doctor and patient. As will be seen in the third section, the perceived needs from the patient challenges the notion that 'doctor knows best' and would indicate that there is a need for a more patient-centred approach to giving bad news.

PART C

3.9 Perceptions of the recipient of bad news:

This section will address the literature that explores the experience of persons who have received bad news. The recipient group may be the person to whom the news pertains or the significant others involved with the person concerned. For the purpose of this review both groups will be addressed separately. I acknowledge that such a separation is unnatural, as one affects the other. However, this decision was made to assist with managing the literature and as a means of offering structure to the discussion.

The psychological impact of a diagnosis of cancer cannot be underestimated. Anxiety and depressive reactions are prevalent (Maguire, 1985; Dean, 1987;

Amber et al, 1999). The psychological distress may be disabling and has been associated with poorer overall recovery (Williard, 1995; Amber et al, 1999). Psychological care of the patient should occur from the most critical stage which is the initial consultation. However, there is a lack of relevant studies that address this important issue (Poole, 1997).

As already highlighted, whilst there are benefits to the patient from effective communication (Roter, Hall and Katz, 1987; Fallowfield et al, 1990; Bertakis, Roter and Putnam, 1991), it would appear that many doctors lack the skills inherent in effective communication (Sutherland et al, 1989; Fallowfield, Ford and Lewis, 1994) The following section will focus on studies that address the psychological needs of the person receiving bad news.

Ford, Fallowfield and Lewis (1996), in a descriptive study exploring doctor-patient interactions within oncology used content analysis to examine the structure and content of the bad news consultation. One hundred and seventeen prospective patients who were to be informed of a cancer diagnosis within an oncology department in an inner London teaching hospital gave their consent to have their consultation audio taped. Each patient had two consultations with one of five clinicians, the second consultation occurring approximately four weeks after the initial one. The main objective of the research was to compare biomedical vs. psychosocial content of the discussions, physician dominance vs. patient dominance and changing styles of the physician according to the prognosis, gender, and age of the patient. The study highlighted that patients were rarely given 'space' in either of the consultations to express their fears or ask questions indicating that patient-centred consultations were low, with a dominance of the clinician in the interaction. Larger volumes of biomedical information regarding the condition and treatments were offered and highlighted that the psychosocial areas were poorly addressed. It was further suggested that this may be indicative of a lack of emotional issues being investigated. It could also be argued that it may be an indication of a lack of interpersonal skills in eliciting and responding appropriately to the psychological needs of the patient

3.9.1 The need for information:

I have shown that some of the earlier models of the patient as the passive recipient of information from the doctor, have in recent years, been replaced by a model of partnership between doctor and patient, which recognises the need for empowerment and autonomy. The following discussion will focus on the felt needs of the patient regarding information giving and decision making.

Having pertinent information has been shown to increase confidence and enable patients to discuss treatments and options (Valanis and Rumpler, 1985), increase compliance with treatments (Crosson, 1984), experience less anxiety (Dodd, 1988) and assist the patient in accepting their diagnosis (Sawyer, 2000). The 'felt needs' of patients in relation to information has received considerable attention in the literature. Findings would indicate that patients want to know about their condition, and learn as much as possible about cancer, the treatments, possible side-effects and what problems they might encounter (Laurer, Murphy and Powers, 1982; Brandt, 1986; Karani and Wiltshaw, 1986; Witt, 1987). The amount of information and the level of complexity or detail can have a negative effect, resulting in the patient being unable to understand and retain the information (Luker et al, 1995).

Information may be through dialogue with another, the doctor, nurse, other healthcare professional, family members or friends. For the sake of this review I have chosen to focus on information given verbally by the doctor or nurse. The information may also be conveyed through a variety of media such as written or audiovisual. There is evidence that both verbal and audiovisual methods can be effective at communicating information. Information booklets have been shown to be effective when used with interaction between patient and healthcare professional (Huchcroft et al, 1984) and can help to generate further discussion and questions relevant to the cancer (Dennison, 1997). Written information cannot replace the patient-healthcare interaction, it must build upon what is already known (Luker et al, 1995). The issue of readability and production is also of concern as the material may be illegible or pitched at the wrong level (Foltz and Sullivan, 1996; Scriven and Tucker, 1997). The area of accessing information on

cancer from the internet has to be investigated. This will be an area that will require exploration as to the impact of the information and the type of information gained through freely available sites.

The importance of giving information to the patient has already been highlighted. Despite this, the evidence would suggest that the patient's experience of gaining the information remains problematic. Dissatisfaction with the level of truth disclosure and available information has been noted by Wiggers et al Wilkinson and Evans (Wiggers et al, 1990; Wilkinson, 1992; Evans, 1995). Evidence that patients want information, and studies that indicate ways of conveying that information abound in the literature. However, little is known about why patients want information, their perceptions of the information and the relative advantages and disadvantages of the medium in which it is conveyed. In a descriptive survey, which was part of a larger randomised controlled trial of patients about to receive radiotherapy (Hinds, Streater and Mood, 1995) conducted the first study attempting to explore the function of information and the appraisal of patients as to their perceptions of the information and the preferred medium for conveying it. Eighty nine patients completed a questionnaire pre-treatment and post-treatment. The study highlights the multiple functions for information, which were categorised into three areas; participation, anxiety reduction and enabling them to prepare for the future. Participation was the most frequently cited information function (34.6%), with anxiety reduction as the second highest rated function (30.8%). The post-treatment group revealed an inverse of this, with anxiety reduction function (28.6%) ranked highest and participation (23.8%) scoring second highest function. Disadvantages were rarely cited but when identified they had to do with receiving bad news or with the vagueness of the information given. The preferred method of receiving information was verbal, followed by written communication. The preferred source of the information was the doctor (51%) with the nurse getting (3%) in the pre-treatment and (23%) in the post-treatment group. The sample group was small and the context in which the study was conducted was a radiotherapy department. While the identified functions of information are interesting, the preferred method of receiving information may be indicative of the sample group. Reliability and generalisations are limited;

however, the study provides foundational information and highlights the changing requirements of the patient regarding information on the illness trajectory. In a similar study, Bilodeau and Degner (1996) found that newly diagnosed patients preferred verbal communication to written sources. Along with the doctor, the study identified that nurses were valued as important in information giving. Rees and Bath (2000) studied the information needs of spouses and patients with cancer and identified health care professionals as key informants. The findings indicate that for younger patients and the spouse group, the doctor should be the primary source of information. However, the study failed to identify the professional groups, repeatedly referring to them as healthcare professionals and therefore it is impossible to clarify if there were different expectations relating to doctors and nurses as information givers. This issue is apparent with a number of studies (Johnson and Meischke, 1991; Cameron, Corbett and Duncan, 1994; Luker et al, 1995). In light of the amount of time spent with the patient and the developing relationship with the family there is a need to address the role of the nurse as a provider of information in cancer care.

Ream and Richardson (1996) in a critical review of six empirical studies, evaluated the effects of information on patients undergoing radiotherapy and chemotherapy. Whilst recognising that there were some inherent limitations within the studies, it was highlighted that appropriate information was linked to a reduction of anxiety, improvement of symptoms and an increase in self-care behaviours. Despite the recognised limitation of sample size, variety of interventions available, demographic variables and instruments used, the review concludes that together, the studies highlighted the positive impact of appropriate information on the cancer patient.

In a retrospective descriptive study conducted to ascertain the information needs of a group of cancer patients from biopsy of a breast lump to results of the test, Deane and Degner (1989) highlighted the need to know a diagnosis before any other type of information, as a key issue perceived by the respondents. This was also identified by Shaw; Wilson and O'Brien (1994) and MacFarlane and Sony (1992). Degner et al.(1997), in a cross-sectional survey of 1,012 patients with

malignant breast cancer noted that the highest ranked need was for adequate information regarding the condition and the prognosis. However, only 42% felt they had achieved their preferred level of control in decision making. It could be argued that the discrepancy between the felt need for information and the lack of involvement in decision making is indicative of a deficit in truth disclosure and a lack of a patient-centred approach to information.

Dunkel-Schetter (1984) highlighted the emotional support that patients felt when given accurate and appropriate information. The benefit of having adequate information regarding a diagnosis has been linked with establishing satisfactory relationships and communication with relatives and staff (Centeno-Cortes and Nunez-Olarte, 1994).

3.9.2 Participation in decision-making:

In a study of the behaviours of doctors and responses of patients, Blanchard and Labrecque (1988) observed 439 interactions to examine patient preference for a participatory role in consultations. The vast majority of patients (92%) expressed a preference for all information 'good' or 'bad' to be given. The findings were further supported by Dean and Degner (1989), MacFarlane and Sony (1992), and Shaw, Wilson and O'Brien (1994). A smaller number (24.9%) of patients in Labrecque's study (1988) indicated that they preferred to leave decisions regarding their medical care and treatment up to the doctor. This might indicate that although information needs are seen as important, the desire for patient participation in decision making is less so. The research highlighted that this group of patients tended to be older and married compared with the patients who wanted to be involved in all aspects of decision making. Again, this would support the findings of Cassileth et al. (1980) and Strull (1984) in suggesting that older patients preferred a more traditional model of doctor-patient relationship with an adjustment towards the need for information regarding their condition. The majority of patients preferred to be involved in decision-making. However, the study also highlighted that this group were also slightly less satisfied with the

interactions. Unfortunately, the doctor's prediction as to the preference of the patients was not addressed. Strull (1984) identified that doctors consistently underestimated the patient's desire for information and over estimated the patient's desire to be actively involved in decision-making. While Greenfield, Kaplan and Ware (1985) and Blanchard and Labrecque (1988) indicate a desire for participation and a recognition of the benefits gained, Blanchard et al. (1990) suggest that there is a need to respect patient preferences, especially with elderly patients. Challenges to the more traditional authoritarian medical model was identified in younger patients and those with more formal education (White et al, 1984; Derdiarian, 1987; Newall, Gadd and Priestman, 1987). In a survey exploring the medical decision making preferences of clinicians with those of cancer patients, Bruera, et al (2000) identified that there is still a discrepancy between what the clinicians perceived and what the patients wanted.

Although the literature pertaining to information needs is plentiful, there is little research addressing the actual content of the patient's interactions with the professionals. As highlighted within this section, much of the research focuses on the need for information, the preferred methods of disclosing the information and the consultation styles of doctors; little account has been taken of the actual contribution to the interactions between patient -doctor or patient-nurse.

3.10 Experience of significant others when a person has a cancer diagnosis

As illustrated in the first part of this review, historically the significant other was often the one to whom the diagnosis of cancer was given. More recently, it appears that the patient is the one given the diagnosis. However, it does seem that this information is often without the presence of a significant other. The inclusion or exclusion of the significant others places them in a difficult position. They were often given the diagnosis and asked not to pass it on to the patient (closed-awareness), or if involved may have felt peripheral to the decision making and its implications. Wilson (1991) suggests that the role of significant others and family members is important in providing support for the patient. This support may have

an association with the patient's ability to come to terms with their situation and develop coping skills in dealing with the diagnosis and treatment (Doherty et al, 1983; Cassileth et al, 1985). It is suggested that the demands of the disease impact upon the significant other and family members in a manner similar to that of the patient (Baider and Kaplan De-Nour, 1984). Family system theory suggests that a cancer diagnosis not only affects the psychological status of the patient but impacts upon family members also (Steinglass, 1987). The impact of a cancer diagnosis has been shown to affect those attempting to offer support to the patient (Klagsbrum, 1983; Fernsler, 1986; Zahis and Shands, 1991; Yates, 1999). It is argued that stress and anxiety is not only due to the diagnosis but is also caused by the adverse effects of the treatments (Holing, 1986; Hull, 1990; Kristjanson, Sloan and Dungeon, 1996).

Derdiarian (1989) highlights the importance of the significant other in providing a support system for the patient and argues that the ability to offer support is determined by the amount of information provided. Provision of information to the significant other can assist the patient in assimilating their situation by offering clarity and interpretation to the information they may have been given. It may also assist the patient by improving their ability to cope (Gotay, 1984; Derdiarian, 1987; Northouse, 1988). Information about their relative has been identified as an important need for the families of cancer patients (Cassileth et al, 1985; Gates, 1988; Department of Health, 1991; Northouse and Peters-Golden, 1993; Department of Health, 1996a; Meredith et al, 1996).

The National Health Information Strategy (NHIS) for Ireland (Department of Health & Children, 2000) has as its first objective the need to ensure that individuals have the information they require to enable them to make informed choices. It makes a commitment to provide a health system that will empower the patient and their families; that will encourage the patient to express their needs, and that will listen to them and ensure that their views are taken into account. This concept of partnership, person-centred health care provision and a recognition of patients' autonomy is also reflected in publications in the U.K. (Department of Health, 1991; 1996b; 2000) the US (Kristjanson and Ashcroft,

1994; Baile et al, 1997) Australia and New Zealand (Girgis and Sanson-Fisher, 1995; Girgis, Sanson-Fisher and Schofield, 1999). Empowering the patient and significant others through provision of adequate information is therefore a central tenet in contemporary health care.

It is suggested that provision of information not only enables the significant other to offer support to the patient (Henneman, McKenzie and Dewa, 1992), but also provides support for the significant other (Gotay, 1984; Meissner, Anderson and Odenkirchen, 1990). Thus it enables them to deal with the anxiety caused by the cancer diagnosis (Cooper, 1984; Henneman and Cardin, 1992). The needs and expectations of the significant other may be similar or different than those of the patient. In a study by Athlin, Furaker and Jansson (1993), relatives referred to the non-existence of information and the speed at which the diagnosis was made as two areas which caused distress. Not only had they expectations with regard to the actions of the health care professional, but they also were concerned as to how they perform those actions. Kalayjian (1989) argues that the significant other and families of cancer patients not only want relevant information but perceive it as an effective nursing intervention.

In a critical review of the literature Northouse and Peters-Golden (1993) propose that the information needs of the spouse fall into three areas; type of cancer, treatment options and side-effects of treatment. This is similar to the earlier categorisations of information requirements suggested by Derdarian (1989) of disease, personal, family and social categories and which were reinforced in a later review by Kristjanson and Ashcroft (1994).

3.11 Conclusion

It can be seen that a majority of the literature dealing with how to give cancer patients bad news focused mainly on the opinion of the physician. Much of the literature draws from the perspective of the 'giver' and it would appear that it is the voice of the physician that is paramount. Although some studies have attempted to address the needs of the patient, the studies are often conducted

through the perspective of the physician. Qualitative descriptions of the realities of receiving a cancer diagnosis are minimal as most of the research findings are grounded within the quantitative paradigm. This has resulted in the patient being reduced to a 'statistical significant' or a measurable reductive entity. One of the purposes of this thesis is to contribute knowledge that emerges from the patient's perspective by analysing how patients with recently diagnosed cancer narrate the manner in which they received their diagnosis. The use of a phenomenological enquiry will allow for the interpretation of the recipients' experience of receiving bad news to be articulated. It will give voice to the recipient, and provide an opportunity to gain insight into the realities of receiving a cancer diagnosis.

It is also evident from the literature that the nurse appears invisible in the disclosure of bad news. Whilst nursing research identifies the nurse within the bad news scenario, the presence or contribution made by the nurse within the multidisciplinary team remains silent within the wider literature. This study will allow for nurses to articulate their experience regarding the cancer disclosure and their role with the patient and doctor within this scenario.

Finally, the research will explore the doctor's perspective of having to tell a patient they have cancer. It will provide a platform for the doctor to discuss their experiences from a qualitative perspective and allow an insight into the subjective thinking and experience when dealing with the bad news scenario.

Chapter 4 will explore the search for a philosophical framework to underpin the study. It will provide a reflective account of the search for structure with which to guide and design the study and offer a conceptual basis for the research.

CHAPTER 4

DEVELOPING IDEOLOGY: THE SEARCH FOR A PHILOSOPHICAL FRAMEWORK

4.1 Introduction

The aim of this chapter is to present the arguments and choices made in deciding upon an appropriate design for the study. The epistemological basis for the enquiry will be presented and a demonstration of how such a choice influenced the data collection, analysis and presentations of findings. The chapter will reveal how the process of choosing a research methodology is both complex and dynamic. It will draw from the personal and professional epistemology of the researcher as well as that of the chosen philosophical framework. It often appears from the literature that the choice of research method emerged from the research question, and whilst this is part of the process, it does not occur in isolation. In an effort to contextualise the process of choice of phenomenology as method I will first provide some of the considerations that I had to process in order to arrive at my decision.

4.2 Reflective Introduction – The Process.

I am conscious of an internal quandary as I begin to articulate a process that has been a major preoccupation of mine for the past number of years. The forms of knowledge developed through this learning process have moved from a position in which I considered that I knew the research process, to a realisation that the knowledge base although broad, was superficial. The learning process was at times painful, confusing and undermining. The acknowledgement that I did not fully grasp the philosophical underpinnings of the different paradigms led to a sense of disempowerment and a process of reflecting on my ability, or lack of it, to teach the research subject and also my ability to conduct research at doctoral level. This learning curve was challenging, and although once more I was made to feel a novice, the journey travelled resulted in a growth spurt that has seen

significant development in my understanding of the methodology chosen, and perhaps more importantly, in my ability to produce a quality piece of research.

An exploration of a range of propositional knowledge, written to inform readers of the multiple possibilities for creating a feasible research design resulted in uncertainty and a period of reflecting on my initial ideas. The research proposal, which I had considered was rigorous, became weakened as my understanding of the methodology strengthened. At the time this was very disconcerting, but I can now see that this is part of the journey as one moves to refine and hone the proposed study within the realities of the real world. The development of practical research skills, such as literature searching, retrieval and reviewing; redevelopment of the research proposal; planning and implementing the enquiry; data management, analysis and finally writing up the thesis was challenging and exciting. The process was dynamic and fraught with dilemmas, reflected in writing and rewriting, reading and synthesis of information, debating with fellow researchers and coming to a greater understanding of the both process and context of the research activity.

Underpinning the whole process was the realisation that my own espoused beliefs and values pervaded every aspect: the focus of the research topic, the identification of the research questions, the research methods, the methodology, the interpretation and the presentation of the findings. Habermas (1972) claims that much research interest is motivated from personal interest, a claim further supported by Reason and Marshall (1987), who suggests that personal interest and developments are inherent to the research process. It is inevitable that personal and professional interests are part of the fabric of my research focus. I acknowledge, therefore, that the research questions posed in this study emerge partly out of my personal and professional beliefs and values and are investigated through use of an appropriate and compatible paradigm. It was also comforting to realise that as I came to 'know', came to a sense of 'being-in-the-world' I could see reflected in the philosophical issues a representation of my own sense of ontology.

4.3 Conceptual basis for the research

Recognising that the choice of research topic is influenced by a personal belief in the nature of reality and truth as a personal construct, I acknowledge that these are influenced by context and history and fluctuate rather than remain static; they are in reality evolutionary (Dilthey, 1923:92). Whilst I would argue that some truths remain constant and are culturally bound, others develop broader dimensions and are complex and diverse. My personal beliefs have developed as a result of life experiences, cultural, educational and religious exposure. My nursing training and experience was gained outside of Ireland, and working within a variety of settings confirmed to me that culture is not specific to a country or locality but to the microcosm of family or group of individuals. Within healthcare I realise that this is also relevant for each clinical setting and, indeed, for each practitioner. This implies that healthcare professionals will encounter a range of values, beliefs and practices that impact upon them and that the recipient of bad news, likewise, will bring their own values and beliefs into their encounter with the healthcare system. There will, of course, be common threads that link each experience to the next and it is this recognition of the subjective as a reality for the individual that influences the choice of paradigm for the enquiry. Thus by asking the research question ‘What is the experience of the healthcare provider in giving bad news and the experience of the recipient of bad news?’ I envisage that their experiences will be idiosyncratic and culturally as well as contextually determined. I therefore am obliged to seek and use a research paradigm that is sympathetic to such beliefs.

4.4 The Discourse of Phenomenologies

This section will provide a brief observation of the historical turns of phenomenology as a means of offering insight into its development and the emergence of differences within its philosophy. As a movement, phenomenology made a significant shift from the traditional scientific method of the natural sciences, which as discussed previously, was heavily influenced by the mechanistic world view offered by Galileo and Descartes. Some of its early

founders, Schleiermacher ^[1768-1835] (1977) and Dilthey ^[1833-1911] (1923) proposed a shift in how science was perceived. Phenomenology offered a momentous move from Cartesian dualism, which dominated science at that time (Benner, 1994a). Phenomenology as a movement began to recognise the limitations of objectivism and shifted towards a paradigm that embraced the subjective and the interpretation of experience. The attempt to move from objectivism towards relativism - from epistemology to ontology is recognised as stemming from the work of Martin Heidegger ^[1889-1976] (1996). However, it is the work of Edmund Husserl ^[1859-1938] (1977) that is often cited as the foundation of what we call phenomenology (Polkinghorne, 1983; Cohen, 1987; Koch, 1996). And as will be seen Husserl, whilst perceived as the father of phenomenology, had a perspective of phenomenology that was strongly influenced by the Cartesian tradition and, it could be argued, was positivist in its orientation.

4.4.1 Husserlian Transcendental phenomenology

Under the tutelage of philosopher Franz Brentano, Edmund Husserl's beliefs developed from mathematics toward seeing phenomenology as equally objective and subjective (Reeder, 1987). It is interesting to note that Husserl's conception of phenomenology was as a means of offering a rigorous science of absolute knowledge (Jennings, 1986), an infallible method of scientific approach. He rejected the belief that objects in the world exist independently; that the information about objects is reliable, and argued that the external world is reduced to the contents of personal consciousness (Fouch, 1993). Husserl was strongly influenced by Descartes in the elimination of suppositions and the search for knowledge above doubt (absolute knowledge). Descartes' doubt, suggests Moustakas (1994), becomes Husserl's Epoch.

Husserl rejected the notion that the world could be objectified and interpreted through scientific fact and was concerned with the uninterpreted world of the everyday experience. 'Lebenswelt' as a concept of life-world or lived experience was introduced by Husserl and was seen as the world as lived by the person, and

not the external entity separate from or independent of him – the natural world in which we live. Central to Husserl's belief was the need to recognise the experience as the meaning of knowledge. His view of the phenomenon as independent of and prior to any interpretations, scientific or otherwise, can be summed up in his expression, "back to the things themselves" (Omery, 1983). Husserl believed that positivist science is built upon a logic that is unsophisticated and naïve and argued that phenomenology is about the return to the familiar and a re-examination of what is already known, a bringing into awareness that which has been taken for granted, the essences that constitute the consciousness and perception of the human world (Koch, 1995b). For Husserl, reality presented itself in human consciousness and his refusal to divorce reality from consciousness remained central to his phenomenology (Crotty, 1996). Spiegelberg (1975) suggests that in his quest to keep objectivity over subjectivity, Husserl actually located objectivity at the heart of subjectivity.

The centrality of Husserlian transcendental phenomenology is to uncover the essential structures of reality; in the case of the current study this would mean the reality of receiving bad news. The subjective quality of knowledge exemplifies the returning to things themselves and the uncovering of meaning of the *Lebenswelt*. It is this concept of consciousness which Husserl refers to as intentionality. It is seen as the groundwork for his transcendental phenomenology of consciousness (Husserl, 1977:41). Intentionality refers to consciousness, the process of being conscious of something (the foundation of the cause of the bad news), the intentionally related act of consciousness and the object of consciousness. Husserl argues that every act of consciousness is necessarily intentional and is always directed towards, or pointing towards, some object. The recognition of the 'intentional' aspect of consciousness is therefore a foundational position to knowledge of the world (Jennings, 1986). For Husserl, the world only existed because of human consciousness. It was this sense of seeing reality as presenting itself with absolute certainty, arising from experience and not something based upon the Cartesian concept of dualism, 'reality out there' separate from the person, that made Husserl's phenomenology a study of the lived

experience as lived by the person (Lavery, 2003), the study of phenomena as they appear through consciousness.

Husserl would posit that transcendental phenomenology can discover the truth and essence of phenomena through a process of phenomenological reduction or bracketing, a term most likely derived from Husserl's mathematical background. Husserl's belief was that authentic freedom of presuppositions could only be achieved through epoché – transcendental reduction. Epoché is a Greek word meaning suspension of judgement, abstention of judging existence. The ability to bracket out the outer world as well as individual bias is necessary if one is to suspend one's judgement and achieve contact with essences (Lavery, 2003). It is important to note epoché is the suspension of natural beliefs not the rejection of them. It is a methodological move to strip away implicit presumptions to allow for aspects of the essences to occur in consciousness. The aim of epoché is therefore to transform essential acts of consciousness into the subject of rigorous analysis (Jennings, 1986). For Husserl, the goal of transcendental phenomenology was to see things 'as they are' through intuitive seeing. He sought to show essences of consciousness of lebenswelt through careful and detailed descriptions (Osborne, 1994).

It is Husserl's refusal to divorce consciousness from reality and the location of objectivity within the subjective experience that led to a questioning of the appropriateness of this approach for this study. Bracketing or suspensions of beliefs, whilst admirable and challenging, are, I would argue, almost impossible to achieve. In the case of this study this would involve the suspension of judgements relating to the perception of what constitutes bad news and one's reaction to it. It is in these very things that the recipients and participants locate their narrative. To suspend or strip away the centrality of their experience would be to reduce the phenomenon to nothingness.

4.4.2 Heideggerian Hermeneutic phenomenology

Martin Heidegger, although never a formal student of Husserl, was a junior colleague of his when he worked as an unsalaried faculty member at Freiburg University in 1916. He was strongly influenced by Husserl's work, but unlike Husserl, whose background was mathematics, Heidegger's background was theology and it is often thought that it was this background that drew him towards a synthesis of phenomenology referred to as hermeneutical phenomenology. Heidegger's work was dense and very difficult to understand; in common with many others, my understanding of Heidegger's ideas were greatly influenced by scholars who have studied his work, such as Palmer (1969), Dreyfus (1991b), Koch (Koch, 1996), Crotty (1996), Morgan (2000), and Morgan and Mooney (2002).

Although initially sympathetic to the Husserlian concept of phenomenological reduction and intentionality, Heidegger later refuted such notions (Draucker, 1999). Whilst both phenomenologies are concerned with the life world or human experience as it is lived, Heidegger disagreed with the process of exploration as espoused by Husserl. While Husserl's focus was on epistemology – a way of knowing, a way of understanding, Heidegger's focus was on ontology – Dasein, the mode of being human (Lavery, 2003). Moules (2002) suggests that Heidegger brought the ontology of the subject and the 'something' into the 'experience of the something'. His focus was on the structure of being, and the task of hermeneutic phenomenology was to understand the mystery of being. For Heidegger, the experience of 'being-there' – Dasein was the starting position of hermeneutic phenomenology. Thus, the shift from Husserl's epistemological emphasis to Heideggerian ontological basis of 'being-in-the-world' was postulated (Annells, 1996).

Dasein was the 'being' of the enquirer, an understanding of which was achieved through what was termed 'forestructure' of understanding and then extended through a preliminary grasp of the existentials (structures of being) and finally to an understanding of Being itself (Heidegger, 1962:27). Heidegger's 'hermeneutical circle' was located within the lived experience of the interpreter

rather than in the mind of the world. Consciousness is not seen as separate from the world, but is a formation of lived experience, where understandings are deeply rooted in the ontological makeup of Dasein: care, existence, temporality, and being (Heidegger, 1996).

For Heidegger, understanding is a kind of being, a being-in-the-world. He sees people as part of the world, amongst it, being in it. The person is seen as self-interpreting, embodied; a being for whom things have significance and value, having historical context and as a person in time (Leonard, 1989). The relational view of people and world is made possible by the ‘world of shared things and practices’ (Dreyfus, 1987:263). This shared agreement is what Heidegger refers to as a pre-reflective understanding of Being (Dreyfus, 1991a). It is this understanding that forms the background that enables us to understand objects and activities. Without this pre-reflective background, things would be unintelligible. Pre-understanding is a structure for being in the world, it is not something individuals can step outside of or put aside, as it is understood as already being in the world (Lavery, 2003).

Ontological inquiry requires an understanding of Heidegger’s three-fold structure of Dasein. Firstly, Dasein requires a being-in-the-world so that “things show up as mattering – as threatening, or attractive, or stubborn, or useful ...” (Dreyfus, 1987:264). It is this ‘mattering’ which becomes the background for further reflective desiring or evaluating. Secondly, there is what Heidegger calls discourse or articulation of the situation that the individual finds themselves in – a laying out of things. Thirdly, Dasein is always a pressing forward into new possibilities; individuals do something now for-the-sake-of something in the future, something we need not have, or cannot have, in mind. This three-fold structure of Dasein represents the past, present and future dimension of time.

The transaction between the individual and the world as they co-constitute requires interpretation: claiming to be human is to interpret (Polkinghorne, 1983), and that interpretation is influenced by an individual’s background or historicity (Heidegger, 1996). For Heidegger, all understanding is connected to a given set

of fore-structures that cannot be eliminated and one therefore needs to be aware of the interpretative influences (Lavery, 2003). The interpretative process is achieved through a hermeneutic circle, which moves from the parts of the experience, to the whole of experience and back and forth again and again to increase the depth of engagement with the text (Annells, 1996). For Heidegger, the hermeneutic circle was seen as expressing the way in which understanding was 'always already' given over to that which is to be understood (to 'the things themselves' – 'die Sachen selbst').

Heidegger's contribution to hermeneutics is clearly documented and acknowledged in the literature. His ideas on the pre-reflective lifeworld has influenced and shaped many studies within nursing (Benner, 1984; Tanner et al, 1993), caring (Benner and Wrubel, 1989), the experience of everyday nursing practice (MacLeod, 1990; Taylor, 1992), the experience of psychosis (Gibson, 2000).

The challenge that Heidegger brings to the bad news enquiry is manifold. Ontologically, the concept of Dasein and the need to articulate the situation, pressing forward into new possibilities offers a plethora of new possibilities to emerge. The concept of transaction of the individual and their co-constitute world enables the interpreting of such transactions and a recognition of influence and reaction and response to the recipient and the deliverer of bad news. The concept of the hermeneutic circle is frequently lacking in the concept of bad news and this would offer both strength to the enquiry and to the process of bad news delivery.

4.4.3 Gadamerian Hermeneutic phenomenology

Hans-Georg Gadamer ^[1900-2002] a student at Marburg and Freiburg during the 1920s was influenced by both Husserl and Heidegger (Polkinghorne, 1983). He extended the work of Heidegger and considered hermeneutics as a means to clarify further the conditions in which understanding takes place (Lavery, 2003) rather than developing a procedure of understanding.

Under the influence of Heidegger, Gadamer embraced the concept of *phronesis* (practical wisdom). He conceives of understanding, and interpretation, as a practically orientated mode of insight, a mode of insight that has its own rationality irreducible to any simple rules, that cannot be taught, and is always orientated to the particular case at hand (Gadamer, 1989). For Gadamer, as with Heidegger, there was a belief that language was essential to our understanding, stating that, "... language is the universal medium in which understanding occurs; understanding occurs in interpreting" (Gadamer, 1989:389). Gadamer perceived understanding and interpretation as indissolubly bound up in each other (Annells, 1996), and interpretation as an evolving process; therefore a definitive interpretation is never possible (Gadamer, 1989). Pascoe (1996) suggests that Gadamerian phenomenology rejects the notion of the relationship of the subject-object. Gadamer's purpose of investigation was to "...discover what is common...to show that understanding is never a subjective relation to a given 'object' but to the history of its effects; in other words, understanding belongs to the being of that which is understood" (Gadamer, 1989: xxxi).

Gadamer rejects the negative connotation of prejudice, recognising that pre-understanding is a condition and necessary part of (*verstehen*) understanding. He argues that, rather than closing us off, our prejudices (pre-judgements) are, themselves, what open us up to what is to be understood (Gadamer, 1989). Therefore bracketing and phenomenological reduction was unacceptable and rejected by Gadamer. He believed that we must be situated within the world for understanding to take place and suggests that, to try to eliminate one's own concepts in interpretation is not only impossible but manifestly absurd (Gadamer, 1989). This notion of prejudice and the need to embrace pre-understandings is paramount within the enquiry into bad news

A movement towards understanding consisted of not only *Bildung* (openness to meaning), but also of fore-projection, the development of an early understanding of what has been said (Gadamer, 1989). The hermeneutic circle represents the art of understanding, an element of the ontological structure of understanding or being. Through the explication of the notions of dialogue and conversation,

Gadamer legitimises the hermeneutic circle as a primary hermeneutic process. The movement of understanding is reflected by the constant interplay between the whole to the part and back to the whole again – a process that I call the dynamism of the hermeneutic circle.

Gadamer considered language as the fundamental mode of operation for our being-in-the-world. It is the ‘...cue to ontological explanation...’ (Gadamer, 1975:161). He further suggested that:

When one enters into a dialogue with another person and then is carried further by the dialogue, it is no longer the will of the individual person, holding itself back or exposing itself, that is determinative. Rather, the law of the subject matter [die sache] is at issue in the dialogue and elicits statements and counter statements, and in the end plays them into each other (Gadamer, 1975:374).

It is in the process of negotiation between oneself and one’s partner (conversation) in the hermeneutic dialogue that the process of understanding can be seen as a coming together, as an agreement, “...the thing that has to be grasped is the objective rightness or otherwise of his opinion, so that they can agree with each other on the subject...” (Gadamer, 1975:347). Coming to such an agreement means establishing a common framework or horizon, thus understanding is a process of the ‘fusion of horizons’ (Horizontverschmelzung). The metaphor of horizon is seen as the wide superior vision that a person seeking to understand must have, to look beyond that which is close in order to view the larger whole (Gadamer, 1975). As our understandings move so too do our horizons. For Gadamer, horizons are something that move with us, rather than something which we move, as when we find ourselves in situations we wish to understand, our task is to throw light into it. He advocated that the fusion of horizons occurs when our own horizon is understood in order to understand the others (Gadamer, 1989), it is a continuous fusion of the historical horizon with the horizon of the present. It is the movement of horizon and understanding, which occur in unison.

It is recognised within Gadamerian hermeneutics that the play between prejudices and prejudgements enable us to understand the ‘things themselves’ (Gadamer,

1979:151) and that they contribute to the personal horizon and the horizon of the present, which is being continually formed (Annells, 1996). Interpretation and understanding are not different for Gadamer, but represent the same thing. Thus the process of understanding can never be achieved (ontologically) because we are always interpreting in light of anticipatory prejudgements and prejudices, which are themselves always changing. Meaning therefore is always 'coming into being' through the happening of understanding (Gadamer, 1975:257). The hermeneutic task becomes one of questioning, whereby our early understandings (fore-projections) become constantly replaced by more suitable projections, as they become clear from the text, resulting in the movement of interpretation and understanding (Gadamer, 1989).

4.5 Selecting the Phenomenological approach

There are many approaches to phenomenology available to the researcher; the challenge I faced was to embrace an approach within phenomenology that would best suit the research question asked. Hermeneutics was seen as offering the opportunity to explore the research questions raised. Understanding the distinctions between the phenomenologies and hermeneutics is important for seeking clarity on appropriateness within the study. Whereas Husserl would argue for the attention to the phenomenon, describing it as richly as possible, hermeneutic phenomenology would argue that the experiences of something are not isolated but eventual, ongoing, emergent, forming and generative (Jardine, 1992)

This study draws upon the philosophy of interpretative phenomenology; it is in the application of a Heideggerian and Gadamerian hermeneutic framework that the enquiry is located. From its early origins of Schleiermacher (1990) and Dilthey (1923), through to Heidegger (1962) and Gadamer (1979), hermeneutics can be seen as offering a significant contribution to the interpretation of our life world.

Hermeneutics has been defined as the practical art of interpretation and understanding. It aims to expose the hidden meanings (Kisiel, 1985; Allen, 1995),

offer interpretation and understanding in a human context (Chesla, 1995) and is a reflective inquiry that is concerned with “our entire understanding of the world and thus ... all the various forms in which this understanding manifests itself” (Gadamer, 1976:18). Moules (2003) suggests that it is a means of peering behind language into the contextual world of words and silence. In the case of bad news, it is the silence of the spoken and unspoken aspects of the news that will become central. Hermeneutics can be seen as organised around the clear narrative, always questioning those things we take for granted (Jardine, 1992). In so doing, the inquirer attempts to celebrate the ‘stubborn particular’ (Wallace, 1987:22), ‘calls out the ordinary’ (White, 1993:35) and gives it meaning in terms of its history, legacy, relationships, recognising how something exists and bringing things back to the place where the ‘exotic and hidden becomes apparent and true’ (Moules, 2002:3).

In offering a hermeneutic interpretive of the experiences of bad news, rather than a phenomenological reduction based upon Husserl’s ideas and philosophy, I will be expanding the horizon, offering greater opportunity to make sense of the human experience (meanings) and recognising that the worlds of the recipient and deliverer of bad news are interpretable.

4.6 Philosophical influences within the study:

One of the key concepts offered by Gadamer was that of *Bildung* (Gadamer, 1989). Openness to meaning (*Bildung*) was manifest in this study in several ways. In this section I wish to present an overview of how the Gadamerian idea of *Bildung*, was achieved through a discussion on pre-understandings, fore-projections and the interplay of the hermeneutic circle. Discussion will also be given to prejudice as perceived within a Gadamerian framework.

I will begin by presenting some diary extracts from the early days of the study – pre data collection, to demonstrate the process of coming to know and coming to see my own horizon and the bias filters that I had accrued both personally and professionally. The second section provides insights into how I worked with fore-

projections and the informants' texts to allow for a movement towards understanding and interpretation of the 'other'. Thus demonstrating what Gadamer (1989) referred to as a process of "Working our appropriate projections, anticipatory in nature, to be confirmed 'by the things' themselves", something he argued that has to be 'the constant task of understanding' (p.267). Finally I will offer some discussion on how I dealt with prejudice within the context of the study.

4.6.1 Pre-understandings

As part of the pre-interview stage of the research process I spent considerable time exploring my own pre-understandings, my prejudgements – ideas, beliefs and attitudes around the area of giving bad news to people. This was not an opportunity to 'bracket' or complete a 'phenomenological reduction' of my presuppositions (epoché). It offered space for a clearer understanding of what I knew about the experiences of bad news. This understanding remains evolutionary in that, as I explore my own pre-understandings, so the horizon moves with me. This was a vital process as it enabled me to see my own horizon before engaging with the 'conversation of the other' and thus, it allowed me to see their horizon and move towards some understandings.

The introductory text in this thesis, although somewhat personal and 'different' as an introduction to a doctoral thesis grew out of this phase of facing my pre-understandings, and as such, is I believe an important aspect in the application of a hermeneutic dialogue on bad news. To illustrate this point further, consider the following excerpts from my journal, which demonstrate recognition of and move of my horizon:

This is more difficult than I thought it would be. Why am I struggling with this area of bad news? Why am I feeling a sense of guilt? Why am I running towards that which I really want to run away from? Why am I even calling it bad news? What exactly am I really interested in, I don't know. All I really know is I want to see how we do it and can it be done better.

When I first toyed with the area of exploring bad news I felt passionate about it – I felt it needed to be looked at. Now I am not sure why such thoughts and feelings are there.

I remember the thoughts I had when writing up the research proposal for the Health Research Board funding. At that point it was research – something out there, something interesting but distant. I could objectify the process and hide behind the methodological rigour which I was attempting to articulate on paper. Even the brief literature review allowed me to ‘stay distant’. Is this what I have been doing all my professional life – staying distant? I can still remember the old saying ‘if you can’t stand the heat get out of the kitchen’ is that where I am – is this where I have been – sweating profusely in the hot house of the daily kitchen of nursing? Is my interest in bad news coming from my own stuff? Is this a means of connecting again with the patient and myself? I’m not sure at this point, but I am hooked.

I find it interesting to read back on these early entries. Without really understanding the impact of, or power contained in journaling – the re-emergence of my prejudice demonstrates the power of the text and the emergence of an understanding, dare I say pre-understanding. There is clearly a re-emergence of a new horizon for me as an individual. It can be seen in later journal entries that there appears to be a shift in perspective, a shift towards my horizon, towards understandings.

I am finding the literature fascinating. How could we not have seen the patient in all of this? I am finding some of the reading difficult as it resonates with my own experience and confirms that not only should I feel guilty but I also need to recognise a sense of failure as a professional. I can see my story in theirs. The need to distance myself from their pain as a means of protecting myself is in juxtaposition to my belief in ‘coming alongside’ and ‘being with’ the patient.

In some twisted way this research is making me face the shadow of the past. And I am finding this hard. I know I was there for people, but I also know that I was also ‘just there’ in role as opposed to in person. I still struggle with this sense of guilt, of failure. Carolyn tells me it’s my ‘Irish baggage of guilt’, I’m not so sure. It was easier when I worked in (ICU - name removed), at least there it was team work. The consultant would never go to talk to the relatives unless she had a nurse with her, and she would always insist that we write up clearly and concisely in the patients’ notes a summary of what was said. Looking back it was this collegiate activity that I liked, the sense of being part of something, of having something to offer, even if in nine cases out of ten my offering was a silent presence. It was still a presence and it was important. I

missed this involvement when I moved onto another position; I never really had it again.

It can be seen from the journal entries that there was journeying taking place. It can also be seen, that there appears to be emerging within the narrative, some clear per-understandings, some beliefs, which if not acknowledged may filter the research and offer a glimpse of understanding that are mine and not the informers of the research. Gadamer's description of how we describe and come to know that with which we believe, as our horizon (Gadamer, 1989) and the need to understand ourselves before we can understand the other, is important for the demonstration of how I came to know. It is in the recognition and acknowledgment of my own Bildung that I can provide evidence of the process. A further journal entry reveals the following:

I feel totally swamped with literature – its all so much. I have separated them into three artificial groupings; medical focus, nursing focus and patient focus. Although I have done this as a conscious act of managing the volume of material, I now realise that this is exactly how I had designed the study – recipient group, nursing group and medical group – this also was a conscious act - or so I thought.

Dose this separating, the fragmenting into parts reflect some unconscious symbol of - or pattern of seeing the world (of nursing) – the medical, the nurse and the patient. I thought that this separating of the groups within the study was done to manage the process, now I am beginning to wonder was it done to reflect how I see the process of caring – fragmented with each playing a role, independent of and yet interdependent to each other. What is my role? Am I complicit in the process of bad delivery do I make a difference in the 'good delivery' (whatever that may be) and what of the patient – what role do they play in all of this? Is 'good delivery' / 'bad delivery' the prerogative of the medic or are we all complicit?

A later entry, following the computer crash and loss of two years' work revealed something interesting....

How could I have been so stupid? Why didn't I store the material on an external source? I am finding it so hard to face people with this? I mean they all say the same thing,
'...and you didn't have backups?'

I feel like screaming – if I had - would I be in this position! It's not their fault, but it is not mine either. I am finding it so hard to even begin again. I don't think I can ever recover what I lost. Some people give encouragement such as

'... it will come back, you'll see' - (*how do they know!*)

or

'... you'll find what you write second time around will be even better...' - (*I don't think so*).

I can't even sit in front of the new computer – I hate the thing, I never want to switch it on again. What's the point, it's gone and that is that.

This sense of feeling sorry for myself and the predicament I was in went on for months. I would pretend, put on a false face to others – pretend I was actually writing (typing), but I couldn't pretend to myself. I was on the run, and it was only after my wife said very kindly one day that perhaps I should give up as it looks as if I had lost hope that I began to fight back.

She said I had lost hope. That's stupid, its not hope I have lost - it is my PhD. And yet I can't help thinking about those words; 'you've lost hope'.

I remember (can even feel the knot in my stomach as I write this) the day I had the phone call from the Data retrieval company in the UK. They were so cold and distant from my predicament: 'I'm afraid we couldn't get anything,' he calmly said.

I remember saying something like – 'but you must have got something, everyone says that the information is never lost – this is my PhD for Gods sake!' - to which he replied 'I am very sorry, but there is nothing we can do. Would you like your hard disk back?'

Carolyn was so right, this was not only about lost data – it was really about lost hope. My dream of completing the PhD had suddenly disappeared and my reaction was coming from a sense of lost hope.

Months later, I can now see this is something of an experiential exercise in the process of receiving and processing bad news. OK don't be so dramatic it was not cancer... no but it was bad...very bad for me anyway.

What role did I play, what role did the computer technician play, what role did my helpful friends, with their words of encouragement play and of course what role did Carolyn play when she challenged me?

From these excerpts it can be seen that I had to face some of my own beliefs, some of which were personally based and some of which emerged within the context of my professional life, but all of which I can now see offer lenses through

which I see the world around me, and of course the informants' stories and that of the interpretation offered during the writing of the research study. It is this kaleidoscope that enables things to change shape, colour, and texture. These are not biases but horizons towards which I faced and moved. I carried this knowledge and understanding with me as I reviewed further literature, collected the data from the informant groups, and interacted with their texts. Gadamer's (1997) sense of being aware of my own bias, so that the text was allowed to present itself in all its otherness, asserting its own truth against my own fore-projections.

My own experiences and understandings were not a benchmark against which I measured the participant's stories; I was prepared to learn from the informants, both their dialogue with me (conversational interview) and the text of their story. I was prepared to allow their experiences to inform me and tell me something new about the nature of bad news through their lens, their horizons. Koch (1993:108) suggests that this is "... a way of conducting yourself, a willingness to open yourself to a standpoint of another so that you can let their standpoint speak to you, and let it influence you".

4.6.2 Fore-projection

Bildung and the development of understanding incorporates not only recognising pre-understandings, but also a process of fore-projection or developing an early understanding of what is being shared by the informants. I found this process fascinating, time consuming and at times tedious, as I tend to want to finish something as soon as possible, so as to move onto the next challenge. I began to explore if perhaps it might be the same for the participants, the pressure to move on, get it over with or do they stay with the moment?

Gadamer's development of play (*Speil*) is important. Understanding, he argued, is central and determined by the matter to be understood; not in spite of, but precisely because of its prior involvement (Gadamer, 1989). It could be argued that the 'matter' – the bad news is the public and private negotiations of the now, of the past and of the future.

It can be seen as a reflective process of the pre-understandings influencing and emerging within the fore-projections. The play of the present (the-now) in terms of the past (historical) influencing the future (the-to-be). Dialogic play (Spiel) forms part of the hermeneutic process and was reflected in the practice of engaging with the hermeneutic circle. Bernstein (1983:161) suggests that Gadamer's explication of the play of dialogue, conversation and freedom is the 'clue to ontological explanation illustrating the nature of dialogue'.

As part of the hermeneutic circle within the interview this was reflected in the nature and process of the conversations. The interplay of dialogue, which clearly was reflected in my encounters with the informants, reflects Gadamer's notion of hermeneutic play:

When one enters into a dialogue with another person and then is carried further by the dialogue, it is no longer the will of the individual person, holding itself back or exposing itself, that is determinative. Rather, the law of the subject matter [die sache] is at issue in the dialogue and elicits statements and counter statements, and in the end plays them into each other. (Gadamer, 1975: 347)

The hermeneutic play was also evident in the interplay with the text. This interplay offered structure and schedule to the process of recognising fore-projections. It is worth noting that this hermeneutic circle is not a methodological formula – '7 steps to enlightenment of the other'. Were it a framework or model of engagement I might have found it easier, as I would have known exactly where I was and what I needed to do next. However, this might have led to a lack of richness of the content and context of the narratives and a depersonalising of the lived experience of the other and myself as one engaging with them. The process of engaging in the hermeneutic circle was performed in order to gain an understanding of the 'other' and resulted in a moving back and forth between the whole and the parts and back to the whole again.

I was reminded of Heidegger's (1962) notion of the hermeneutic circle as being located in the lived experience of the interpreter rather than in the mind and world

of the author of sacred text as proposed by Schleiermacher (1990). There was a need to 'endeavour to leap into the circle, primordially and wholly so that even at the start of the analysis of Dasein we make sure that we have a full view of Dasein's circle of Being' (Heidegger, 1962:363). I was not standing outside the circle (the text, the meanings); the horizons were metaphorically entered into. I was attempting to shift from a position of external analysis, the objectified perspective of the outsider, to that of being part of the structures of understanding and interpreting. The hermeneutical task became one of questioning. Questioning my perceptions of what it was like to be given a cancer diagnosis, and my sense of how one would deal with it – on reflection I was actually living my understandings of the other through the filter of my own copings. Likewise I began to question my perceptions of the nurses as they presented themselves within the scenario and the doctors as they broke the news. For these two groups, my perceptions and questioning grew out of my own clinical experience and therefore my filtering was through what I call the personal/professional dualism. In questioning, I shed light and as this occurred I gained further insights into my fore-projections. In facing this horizon there was movement, and meanings became replaced with more suitable projections. The hermeneutic circle became a journey of re-emergence and refocusing, a process of openness to meaning – Bildung, where revised meanings constituted the movement of understanding and interpretation.

Sifting through the texts and allowing for fore-projections to emerge took time. I entered the texts with memories of the interview, the person involved, the dynamics of the people engaged in the conversation and their journey. I constantly confronted my findings, my early understandings and challenged myself to stay with the text. This meant reading text, reflecting and returning to the fore-structures, acknowledging those and listening to interviews several times a day over a number of consecutive days.

I found this a lonely stage in the research as I became emerged in the life of the other and attempted to make sense of their story. I began to recognise this sense of isolation and private loneliness within the narratives of my recipients of bad

news. I also began to question if this isolation was perhaps an influencing aspect of professional distancing amongst the deliverers of the news. This process is discussed in more detail in Chapter 7. I include it here to give an indication of entering the hermeneutic circle and offering an insight into the process of endeavouring to leap into the circle, primordially and wholly (Gadamer, 1989).

4.6.3 Prejudice

In keeping with the theme of *Bildung*, the following section addresses the process of exploring prejudice and its place in gaining understanding within this study. Within Gadamerian hermeneutics, one's horizons are determined by the limits of one's prejudices (Gadamer, 1979). However, as noted earlier, a Gadamerian concept of prejudice is one that acknowledges that our prejudices do not carry a negative connotation, they are 'prejudgements' and rather than narrowing or closing us off from reality they are the cathartic point of opening us to what is to be understood. They represent more than judgements and reflect the historical reality of the person (Crotty, 1998). Prejudices therefore represent the biases of our opening to the world, they are "... simply conditions whereby we experience something - whereby what we encounter says something to us" (Gadamer, 1975:9). It can be assumed therefore, that to truly come 'to know' we need to face our prejudices, for if we cannot relate that which is foreign to that which is familiar we cannot make sense of the 'other'.

It is in the foregrounding of our prejudices (the laying bare—the acknowledging) that we can challenge and then value them. This includes our "...situating the other meaning in relation to the whole of our own meanings or ourselves in relation to it..." (Gadamer, 1997:267), and involves neither "...a neutrality with respect to content nor the extinction of one's self, but the foregrounding and appropriation of one's own fore meanings and prejudices..." (p.268).

In making our prejudices evident they themselves become a focus of questioning within our understanding. The aim, therefore of facing one's prejudices is that one is "... aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-

meanings..."(Gadamer 1997: 269). It is in this moment of comprehension that a fusion of horizons occurs, a moment when prejudice is challenged.

In this research study, I recognised that I am part of the whole, as the story of bad news experience was revealed; it was filtered through my understanding. Understanding occurred through interpreting (Gadamer, 1997), through the act of discriminating, not eliminating prejudices, questioning my beliefs about understanding and allowing it to say something new (Weinsheimer, 1985). The task of questioning and answering required not only a conversation with the 'other' (the informants) but demanded an ongoing conversation with the self. This internal dialogue is a requirement of Gadamerian hermeneutics, for a "...person who thinks must ask himself questions..." (Gadamer, 2000:375), and in terms of this study, the process of questioning and seeking of answers permeated not only each activity, but each encounter with the material and each page of script produced.

On reflection, there was a form of questioning of process and meanings even before I had the language of hermeneutics with which to frame it. The early diary entries reflect this process of coming to know. Throughout the study, especially during the data analysis, I engaged in relentless and continual exchange with the texts, in my attempt to understand what was there and to use this understanding to gain further meanings. I am reminded of the Biblical text from (1 Corinthians 13v12), which suggests that '...we know only in part [imperfectly]...and are looking ...in a mirror that gives only a dim (blurred) reflection [of reality as in a riddle or enigma}...' (Amplified Bible, 1987:1339).

In many ways this picture of partly seeing sums up the process of my coming to know. That which I thought I saw, which was my reflection in the text of the 'other' became clearer as I stared into the mirror of the hermeneutical circle. The cyclic nature of allowing the image of the 'other' and that of the enquirer to emerge and take its rightful place, resulted in the emerging understanding being placed under the spotlight of questioning once more and becoming once again a new meaning.

4.7 Concluding remarks

This chapter has presented an overview of the journey through the phenomenological issues as I approached the philosophical framework for the research. The choice of hermeneutics is clearly made and the leanings towards a Heideggerian and Gadamerian hermeneutics articulated. The discussion highlighted the emerging ideas of Husserl, Heidegger and Gadamer and demonstrated how the hermeneutic works developed from and emerged out of earlier works such as those of Schleiermacher and Dilthey. The influences of Gadamer's *Bildung*, pre-understanding, fore-projection and the notion of prejudice within the study are presented as a central component throughout the analytical journey.

The landscape of phenomenology, and more notably hermeneutics, which I confronted, was confusing and challenging. It would seem that at times I felt like a leaf blown in the wind – the strongest gust – be that pro Husserlian or pro Heideggerian or Gadamerian, seemed to unsettle and shift me. In the end it became apparent that the overriding methodological framework did not fit neatly into one specific 'camp' of hermeneutics. Hence my decision to go for an eclectic approach based upon Heidegger and Gadamer (see table 4.1).

Table 4-1 Comparison of Husserlian and Heidegger/Gadamer Traditions

Husserlian Tradition	Heideggerian/Gadamerian Tradition
Transcendental	Existential/Hermeneutic
	Interpretive/Philosophical Phenomenology
Nature of meaning – epistemology	Nature of being – ontological
Phenomenological reduction (bracketing)	Hermeneutic circle, Fusion of horizons, Prejudice, Legitimation (rigour) & Representation (voice)
Analysis frameworks:	Analysis frameworks:
Based upon decontextualising and recontextualising. Transcripts are disaggregated into fragments, regrouped into overarching analytic themes.	More attention to structure rather than text (Koch, 1995b). Concerned with narrative as story. Participant is self-interpreting; story is couched in narrative format & is biographical in point of view. Understandings are made rather than found (Koch, 1996)
Colaizzi (1978)	Van Mannen (1990)
Giorgi (1985)	Koch (1995a; 1996)
Parse (1987)	Leonard (1994)

Recognising that phenomenology is a movement rather than a ‘fixed paradigm’, I am somewhat comforted and assured that what influences this research is a hermeneutic orientation, rather than a hermeneutic discipleship following a fixed orientation. Thus there was a shift from fixed ideological fundamental hermeneutics towards an embracing hermeneutical framework that works for the research in question. This perhaps is a reflection of what Crotty (1998) refers to as the distinction between the original language and intention of phenomenology as advocated by European founders such as Husserl, Heidegger, Gadamer and that of the North American dissidents – the old and the new phenomenologies.

What I found difficult as a nurse and a researcher was the sense of never actually arriving at a ‘neat end’ or a ‘neat understanding’. Gadamer (1989) clearly

advances the notion that understanding is not achieved through some mystical access to an inner realm of subjective meaning. As understanding is an ongoing process, rather than something which is arrived at, Gadamerian hermeneutics would reject the notion of a final determinacy to understanding. How then as a doctoral thesis can I bring this study to a close? The thesis as a document can be finalised; however, I feel that the study and its findings may not be so easy to conclude, this may never happen –it will always be different. So the exploration of the phenomenon of giving and the phenomenon of receiving bad news within an interpretative hermeneutic philosophy is better viewed like a kaleidoscope, a new and varied lens to view the experience of bad news.

The next chapter will address the application of the hermeneutical orientation as it relates to the research strategy used, the data collection procedures employed and the measures engaged to ensure rigour throughout the process.

CHAPTER 5

STRATEGIES TO INVESTIGATE THE TOPIC: STUDY DESIGN

5.1 Introduction

This chapter is devoted to an explication of the study design, selection and access to study informants, the data gathering strategy, method, procedures and timing employed. As there is a belief in the essence of ‘goodness’ and integration of ethical principles throughout the process, the chapter will discuss these as a foundation on which the remainder of the presentation builds.

In addressing the research, I considered initially utilising a mixed method approach (Creswell, 2002). I realise that this was stemming from a need to legitimise the findings and a desire to have my medical colleagues recognise the research as valid and therefore, worthy of their involvement, and more importantly that the findings would carry weight outside the qualitative domain. Initial plans included a quantitative phase, which would collate information regarding incidences, patterns of attitudes and practices, from a large population group across the island of Ireland. However, it became evident as I grappled with some of the philosophical issues around phenomenology, and the area of epistemology and ontology that I was not being true to myself, or the philosophical underpinnings of phenomenology and was in danger of weakening rather than strengthening the study. Permission was sought from the funding body to revise the proposal before commencing the study and before approaching ethical committee stage. This permission was granted and a decision was taken to embrace a qualitative paradigm throughout the study. Triangulation within method (Begley, 1996b; Tobin and Begley, 2002) was incorporated as it was believed that, whilst it might contribute towards offering confirmations of findings which was not my primary intention, it would offer a more robust approach to ensure completeness rather than merely confirmation.

The use of a phenomenological case study attempted to capture the experience of the recipient and the deliverer of bad news. I explored the everyday experience of healthcare practitioners in relation to giving bad news, individual perceptions and

experiences of these events, interactions between nurses and doctors and between healthcare professionals and their patients, and contextual issues, meanings and values. The rich detailed phenomenological data, when viewed in its completeness, was used as the text from which to develop an interpretation of the phenomena of receiving and giving bad news, which is discussed in chapter 10.

5.2 The research intention

The study explores the experiences of healthcare professionals relating to breaking bad news and also the experiences of the recipients of bad news. From the literature review it is apparent that a vast majority of empirical work examines the process of breaking bad news from the healthcare professional's perspective (Clark and LaBeff, 1982; Bond and Anderson, 1987; Baile et al, 1999; Davis, 2000). In order to address this imbalance it was decided to conduct the study in two phases. Phase one would elicit the views and experiences of the recipients of the bad news, whilst phase two would explore the views and experiences of nurses and doctors in giving, or being part of the process of giving, a patient bad news. The study design integrates four components – a phenomenological exploration of being given a cancer diagnosis, a phenomenological exploration of having to give bad news, a phenomenological exploration of the nurse within the giving of bad news to a patient, and finally the generation of a conceptual framework that depicts the nature of giving and receiving bad news.

5.3 The research Focus

The initial research questions of “What are the experiences of the recipient when they are given bad news?” and “What are the experiences of healthcare professionals involved in the disclosure of bad news to clients?” was honed and focused into four specific research foci. These were formulated to provide specific direction to the research and took cognisance of the main players in the scenarios that occur frequently within the domain of health care. The first of these foci related specifically to the recipient of the news. The focus of the second and

third questions relate to the nurse and their involvement in the bad news trajectory and question four related to the doctors involved in delivering bad news to patients. Within each focus I have articulated the underlying aim, and identified the knowledge base that I explored and the process that the informants experienced. As a result a number of further themes were raised concerned with the following:

Table 5-1 Experiences of recipients of bad news

Aim	Knowledge	Process
To elicit insights and process of recipients when they are given bad news	What is it that they remember? How do they describe the nature of accepting? What sense do they make of their experience? What is it like to be given a cancer diagnosis? What is the meaning of being diagnosed with cancer?	What were the recipients' thought processes at the time of bad news? How do they come to view their situation? What are their perceptions of enablers and inhibitors of processing their situation?

Table 5-2 Experiences of nurses in being present at delivery of bad news

Aim	Knowledge	Process
To elicit insights and process of nurses when they are present at the time of the delivery of bad news	<p>What is it that they remember?</p> <p>How do they describe what they do?</p> <p>What sense do they make of what they do?</p> <p>What is the meaning of ‘being with’ the patient?</p>	<p>What are the nurses’ thought processes?</p> <p>How do they come to view the situation as they do?</p> <p>What are the cues that alert them to the salient aspects?</p> <p>How do they seek to support the patient during the process?</p> <p>What are the criteria they use to measure the effectiveness of their role in supporting the patient?</p>

Table 5-3 Experiences of nurses journeying with the recipient of bad news

Aim	Knowledge	Process
To elicit the insights and process of nurses as they journey with patients while they process the bad news.	<p>What is it that they remember?</p> <p>How do they describe what they do?</p> <p>What sense do they make of what they do?</p> <p>What is it like to journey with someone who has been given a cancer diagnosis?</p> <p>What is the meaning of ‘being with’ the patient?</p>	<p>What are the nurses’ thought processes?</p> <p>How do they come to view the situation as they do?</p> <p>What are the cues that alert them to the salient aspects?</p> <p>How do they seek to support the patient during the process?</p> <p>What are the criteria they use to measure the effectiveness of their role in supporting the patient?</p>

Table 5.4 Experiences of doctors in delivering bad news to patients

Aim	Knowledge	Process
To elicit the insights and process of doctors regarding the giving of bad news to their patient	What is it that they remember? How do they describe what they do? What sense do they make of what they do? What are their intentions in what they do? What are their rationales for what they do? What is it like to be with someone who has been given a cancer diagnosis? What is the meaning of 'being with' the patient?	What are the doctors' thought processes? How do they come to view the situation as they do? What are the cues that alert them to the salient aspects? How do they seek to support the patient during the process? What are the criteria they use to measure the effectiveness of their role in supporting the patient?

5.4 Gaining Access to Informants

The goal of the sampling was to gain an insider's perspective; to sample for meaning and to ensure that informants were interviewed, from whom the nature of the experience could be elicited through narrative (Luborsky and Rubinstein, 1995). Informants were selected on the basis of their experience of the phenomenon, the aim being to gain information-rich cases for study (Patton, 1990). Purposeful sampling was employed as it allowed for individuals to be chosen who had particular knowledge and experience of the phenomenon under exploration.

Access to the recipients of bad news was a major concern in the initial stages of the study. I was very conscious of the sensitivity of the topic and the intrusion the interviews might make to this group. Kvale (1996:3) presents the metaphor of interviewer as 'traveller'. I was aware that the informants had a story to tell that

might bring painful memories and I was conscious that I was on a journey with them. Wandering the landscape of their conversations, and exploring the domains of their experiences, I began to walk with my ‘local inhabitants’, asking questions that would lead them to give voice to their experiences. I was conversing with them in what Kvale (1996:4) identifies as the original Latin meaning of conversations as “*wandering together with.*”

5.4.1 Identification of Sample

The average number of newly diagnosed cancer cases increased by 2.3% annually between 1994 and 2001 (National Cancer Registry Ireland, 2004). With cancer accounting for approximately one-quarter of all deaths in Ireland (Campo, Comber and Gavin, 2004) there was a need to draw from a sample that reflected the whole of the Irish Republic (Appendix I). The population for this study encompassed the adult population from the Republic of Ireland, drawing from four geographical areas. It was decided not to conduct the study across the island of Ireland as people who live within the North of Ireland have a different health care system, which is based upon the Nation Health Service of the U.K. It was felt that access to services and treatment modalities may differ somewhat and therefore the experiences of the participants may have been significantly different.

Four different sites were chosen, Dublin, Cork, Galway and Donegal. These were chosen as geographic areas rather than cities and would take people who live within that county area. Within the Republic of Ireland radiography treatment is centralised to the Dublin area. It was therefore felt important that participants from outside Dublin be part of the study, as this would allow for expression of the impact of the news upon those who lived some distance from the treatment centre. Another reason for choosing the four sites was to allow for a reflection of rural and urban areas, and give voice to people who had news broken within large teaching hospitals and smaller district general hospitals. A final reason was that the Irish Cancer Society had established support groups within each of the four geographical areas and it made sense to use these as starting bases for potential participants.

For the healthcare provider sample, it was decided to use nurses and doctors from the four geographical sites, although it may be said that at no time was there an effort to link recipient and healthcare provider. As a nurse researcher I was very interested in the experience of the nurse within the bad news process. I was also conscious that nurses do not work in isolation and are often present when the news is broken but are not actually the ones giving it verbally. Because of this I felt it appropriate to elicit the experiences of doctors, who are the main givers (verbally) of the bad news.

5.4.2 Accessing the Sample Groups

Having spent some time trying to decide how to gain access to a group of recipients of bad news, I finally made contact with the Irish Cancer Society (ICS). This proved to be a very worthwhile contact as they facilitate ‘Support Groups’ across Ireland for people who have been diagnosed with cancer. The ICS train and support the facilitators for the groups and have a database of all involved. Following several meetings with the Director of services, in which I explained in detail the aims and purpose of the study, I submitted a request to the Board to gain access to member of support groups from the four geographical areas (appendix II). Permission was eventually granted by the committee to use the facilitators as an initial point of contact. It was a stipulation by the Board that only people who were at least five years post diagnosis should be included in the study. The ICS provided a list of names of people who facilitated support groups in four locations; Dublin, Donegal, Galway and Cork. Each facilitator was sent an information letter outlining the process of gaining access to the sample (appendix III). Five letters of invite, information sheets and consent forms (appendix IV, V and VI) were enclosed, with instructions for the group facilitator to distribute these within their locality. Each facilitator had already been contacted by the ICS and was aware of the proposed study.

Other recipient informants came forward having heard about the study, and who were not involved with any ICS support groups. They asked if they could be involved in the study and wanted their story heard. I was initially unsure as this group did not fit into my neat criteria for selection. However, the realities of

research of this nature is that the people who participate often form 'sub-groups' or 'sub-cultures', and on hearing about this research they wanted an opportunity to be heard. To exclude them on the grounds that they did not attend an ICS support group would be to ignore their experiences. In retrospect, I can now see that they offered an alternative perspective - that of the individual who went it alone, or who through personal and friendship groups dealt with their own cancer journey. I agreed to allow them to participate in the study if they met the criteria for inclusion and were willing to give their informed consent having read the information sheet and signed the consent form. All 10 recipient informants in this study had been given a diagnosis of cancer between five and eight years previously and all were 'symptom free'. Some referred to themselves as survivors and felt that they lived their lives in the realisation that they had 'conquered' their cancer. As the focus of this research study is on the experience of having bad news given and not on the long term effects of the condition, informants in this section are referred to as recipients, denoting one who received bad news.

Access to the nursing informants was made initially through a database held within the School of Nursing and Midwifery, Faculty of Health Sciences at Trinity College, Dublin. These contacts were all registered nurses who had undertaken a course of study within Trinity College in the previous 4 year period. A random selection of 20 informants were selected based on postal addresses that corresponded to the four chosen geographical sites (five from each site) and invited to take part in the study by a personalised letter, which included an information sheet and consent form (appendix VII, VIII & VI). Eight nurses responded to the letter of invite and agreed that I could contact them to arrange a convenient time to undertake an interview. At the end of each interview, respondents were provided with five sealed envelopes containing the same information sheet, letter of invite to participate, consent form and also a stamped addressed envelope (appendix IX). Informants were asked to distribute the letters to colleagues whom they thought might be interested in participating in the study. In this way a snowballing technique was used to enlist a further 12 nurse informants for the study (Northey, Tepperman and Russell, 2002:72), giving a total of 20 nurse informants.

The participation of the doctor group proved much more difficult. Letters of invitation, information sheet and consent form were sent out to a number of junior housemen and senior registrars of medical teams within four hospitals in the four geographical sites (appendix X, VIII & VI). Despite a repeated invitation to participate (two months after the initial letter), the response rate was very low. Only 1 senior registrar responded and expressed an interest in the study. The poor uptake may have been due to the initial form of contact. Lack of personal details, such as name etc made for a very impersonal invitation into what could have been perceived as a study into their own practice. This, combined with the fact that the principal investigator was a nurse, and that the study was using a qualitative approach may also have impacted on the low response rate. Eventually it was decided to use a similar snowballing approach as used with the nurse group (appendix XI). The one respondent doctor agreed to pass on four invite packs to colleagues and gave the contact name of a doctor in two of the chosen centre areas. Nurses who had participated in interviews were contacted again regarding sending out their transcripts with my identified themes for their comment. At this point I asked if they would be willing to pass on some invitation packs to their medical colleagues. One nurse already knew of one doctor she had spoken to who she felt was interested and may be willing to participate. In light of the poor response to the initial impersonal letters I asked for names of identified potential doctors. The invitation pack containing personalised letters of invite were sent to the named nurses, who agreed to pass on the packs to the relevant doctors. Through this process a group of 8 doctors were eventually enlisted into the research study.

5.4.3 Criteria for Selection

In the initial proposal it was envisaged that the recipient group would all come through a support group run by the ICS. However, as discussed earlier this was amended as people requested to have their story told. Therefore the criterion for selection of recipients reflects this change. Recipient were invited to participate in this study based upon the following criteria: They;

- were aged 18 years or over and were able to speak English,
- had a cancer diagnosis delivered over five years prior to participating in the study,
- were willing to participate in the study by giving their written consent following explanation of the study, its aims and the requirements for their participation.

Nurses were invited to participate in this study based upon the following criteria:

They;

- were currently employed as a nurse and working within a general setting (nurses working within oncology and palliative care were excluded);
- had experience of being present when a cancer diagnosis was given to a patient or involved with patients following the delivery of a cancer diagnosis;
- were willing to participate in the study by giving their written consent following explanation of the study, its aims and the requirements for their participation.

Doctors were invited to participate in this study based upon the following criteria:

They,

- were currently employed as a doctor and working within a general setting (doctors working within oncology and palliative care were excluded);
- had experience of giving a cancer diagnosis to a patient.
- were willing to participate in the study by giving their written consent following explanation of the study, its aims and the requirements for their participation.

5.5 Ethical considerations

The decision to include ethical considerations arose from its integral nature to the current study. One's ethical stance not only reflects moral, political, social and cultural location, but within the endeavour of research it also reflects one's epistemological and ontological beliefs. It is also my intention to offer this as the 'canvas' on which the research narrative is exposed. Some would refer to this as

part of an audit trail (Rogers and Cowles, 1993; Whittmore, Chase and Mandle, 2001); however, in this instance it is more – it is the essence of what I did (intentionally and serendipitously), the bedrock of purpose and action throughout the research endeavour.

The complexities of researching the experiences of recipients of bad news and that of healthcare professionals in dealing with the issues pertaining to bad news, and offering their stories within the public domain raised ethical issues, that as a researcher I felt were not adequately solved within the abstract application of ‘ethical principles’ or guidelines. Whilst these guidelines and principles informed and offered direction and a sense of boundaries, they were seen as a parallel trajectory within the research trajectory. The reality of qualitative research may seem ‘messy’ and unpredictable to those from a positivist paradigm, and indeed the reality is that this is often the case. Therefore I argue for recognition of the embeddings of ‘ethics-as-a-way-of-being’, rather than as a fixed point within a study.

The nature of this study required the first participant group (recipients) to reflect on and engage with an area of their life that may have been both painful and uncertain. The second participant group, (healthcare providers) may have the potential of facing painful memories, areas of weak practice or other linked issues. In recognising that the method of encouraging informants to engage and reflect on such issues may have potential issues of ethical significance, I was conscious of protecting the rights of the individual and the need to ensure anonymity, in particular with dissemination of findings. There was a need to ensure that decisions made throughout the study were based on ethical principles, and that an ethical framework was adhered to. Issues pertaining to autonomy, beneficence, non-maleficence, and justice were central components of my ethical thinking process. There is a dearth of literature on ethical issues pertaining to qualitative research, and more particularly when dealing with sensitive personal issues (Usher and Holmes, 1997). Conscious of this and recognising the need for the qualitative researcher to be vigilant in identifying the needs of vulnerable groups (James and Plazer, 1999), I decided to ensure that some of these issues were explored and

discussed before embarking on the study. I engaged in many discussions with diverse groups, bereavement counsellors, fellow colleagues, palliative care specialists and fellow researchers. This afforded me the opportunity to see the needs of people who had encountered bereavement and loss from a perspective other than that of my own, as a nurse. Seymour and Ingleton (1999) recognise that ethical implications, whilst identified, cannot always be foreseen within qualitative enquiry. The aim of the dialogue with bereavement counsellors, fellow colleagues etc was to expand my insights into the group of people who would participate in and inform the study.

Whilst I am attempting to articulate the process of engaging with ethics as a way of being throughout the study, I am conscious of the need to address the realities of that process. The aim of this study was to explore the subjective feelings of the informants and give voice to their stories. It was seen as imperative that the ethical issues move out from formulae of '*meeting ethical requirements*' and '*following ethical principles*' (Roberts and Burke, 1989; Holliday, 2002; Polit and Beck, 2003). This need to move out of the traditional 'mindset' and attempt to articulate ethics as reality within emerging qualitative enquiry was both challenging and uncomfortable. Ethical issues moved beyond gaining ethical approval and following ethical guidelines towards embracing an ethical perspective that permeated the many roles, functions and beliefs that I held as a person, researcher and a nurse.

Mauthner et al. (2002) highlights that much research is mainly associated with following ethical guidelines and gaining ethical approval. It appears that central to the discussion on ethically acceptable research is the notion of informed consent. It is seen as necessary by some and sufficient by many as a means of demonstrating justification for their research (O'Neill, 2003). The danger with this attitude is that ethics may become a stand-alone stage in the development of the research and is presented as a sanitized, controlled and packaged phase within the research journey. The need to present research in linear form, demonstrating a logical and sequential development has forced many to isolate ethics into a section rather than demonstrating how an ethical paradigm actually impacted on all

aspects of the process. This static and highly formalised approach to ethics within research is evident when reading the methodological textbooks. The fixed formula does not recognise the dynamic nature or the unpredictability of qualitative inquiry. There is a danger that the novice researcher may conceptualise ethics within a compartmentalised process. I am not challenging the ethics of previous research; I am challenging the presentation of the ethics within a fixed format. The complexities involved when researching personal experiences and placing narratives in the public domain raises many ethical issues that cannot be adequately addressed within the traditional confines of ethical principles such as those espoused by International Council of Nurse (1996). This section will present the realities and tensions inherent within the fluidity and inducting uncertainty of interpretative phenomenological inquiry.

The ethical principles that guide the nurse within Ireland are presented by An Bord Altranais within the Code for Professional Conduct (An Bord Altranais, 2000), who state that for a nurse involved in research:

... the principles of confidentiality and the provision of appropriate information to enable an informed judgement to be made by the patient must be safeguarded. The nurse has an obligation to ascertain that the research is sanctioned by the appropriate body and to ensure that the rights of the patient are protected at all times. The nurse should be aware of ethical policies and procedures in his/her area of practice.

It is the responsibility of the researcher, therefore, to ensure that their research is not only approved by the relevant body, but to also ensure that the participants' rights are safeguarded and informed consent made. It is also important to recognise that meeting these principles does not exclude the researcher or informants from unforeseen ethical issues that may arise during a qualitative study. Ethical approval was granted by The Joint Research Ethics Committee, Federated Dublin Voluntary Hospitals and St. James Hospital (appendix XII & XIII), and by the School of Nursing and Midwifery Research Advisory Committee, Faculty of Health Sciences, Trinity College Dublin (appendix XIV). Permission was also given by the Irish Cancer Society to invite members of

support groups affiliated with their organisation to participate in the study. (appendix XIV).

Ethics in relation to research refers to the moral deliberation, choice and accountability of the researcher throughout the research process (Edwards, 1983). It is the negotiation of ethical models and principles that are presented here. I have attempted to demonstrate the tensions that emerged as the espoused ethical issues competed with the demands of the research and the internal struggle of the researcher.

5.5.1 Respect for Autonomy

Within healthcare, autonomy is frequently equated with the person's right to determine their own behaviour (Fowler and Fry, 1988). Within healthcare research, this principle of autonomy is also clearly underpinned by the right to self determination (Burns and Grove, 2001; LoBiondo-Wood and Haber, 2002). Miller (1995) suggests that this perspective is a simplistic one and argues that one needs to explore autonomy within four senses. *Autonomy as free action* occurs when a person's action (in this case the willingness to participate) is intentional and conscious. *Autonomy as authenticity* relies on the presumed knowledge, actions and motivation of persons – as researcher I could only hope that the provision of detailed information regarding the study and the absence of a time frame to respond facilitated the informants to base their decision to participate on their own values and disposition. *Autonomy as effective deliberation* occurs when the person's decision to participate is based upon clear thought, having weighed the alternatives and their consequences. It is apparent that for this to occur, the person needs all the information required. *Autonomy as moral reflection* is seen as a process of rigorous self-analysis, awareness of alternative sets of values and an ability to put things in place (Miller, 1995:207). Whilst I could not necessarily measure the level of 'autonomy as moral reflection' prior to the data collection, it became obvious, especially with the recipient group, that they had reflected deeply on their experience and they had made their decision to participate out of a place of reflection and a desire to tell their story.

5.5.2 Informed Consent

Davis and Aroskar (1983) argue that central to the concept of autonomy is the doctrine of informed consent. The moral duty to seek valid consent recognises the person as an autonomous being, with entitlements (Beauchamp and Childress, 1994). Valid consent is that which is given when one has received enough information to enable them to make informed decisions. The right to informed consent is not only required by the Professional bodies (Smith, 1998; An Bord Altranais, 2000), but is also recognized as a legal responsibility of the researcher (Behi, 1995; Pape, 1997; Smith, 1997). Kendrick (1994) regards autonomy and informed consent as interlinked - the freedom to make choices based upon adequate information.

Conscious of the importance of autonomy and informed consent, all potential informants were afforded as much information as possible (appendix IV, V, VI & VIII) and provided with further opportunities to seek clarification from the principal investigator or the research supervisor. Reply slips were returned to the researcher, which indicated their interest and willingness to participate in the study. On meeting the participant the information sheet was once again introduced and an opportunity was again given to explore aspects of the study further – something which many of the informants availed of.

Each participant signed the consent form at the time of interview. Some assumed that the signed reply slip was their consent. I explained that the reply slip was an expression of interest, and that I felt obliged to offer a more detailed explanation of the research, what their involvement meant in terms of time, the process of the interview and their right to terminate the discussion at any time. It was also felt important to clarify my role as researcher and interviewer and explain that I too might offer to stop the interview if I felt that it was becoming uncomfortable for them. The process of disclosure of intent was considered as an important stage in the early process of the data collection. The letter of invitation (Appendix IV – XI) clearly informed the potential participant of the purpose of the study the benefits and risks, their right to participate or withdraw at any point of the process – even after the data were collected, thus demonstrating their ownership of their

story and the right to seek further clarification to enable them to make a truly informed decision. For a number of informants this formalising of the process instilled a sense of solemnity and made some feel uncomfortable, “...*God this is a bit like applying for a mortgage*”, was the response of one the recipient group.

I explained that it was important that for their own protection that I ensure that all the necessary information was not only available but that they actually fully understood what it was that they were entering into. The letter acted as my ‘terms of reference’ to them, while the signed consent was their acknowledgement that they understood the process they were committing to and agreement to participate. I stressed that although they would remain anonymous and their details confidential, their actual stories or part thereof would be used in the research and could be used in publications.

5.5.3 Anonymity and Confidentiality

A number of informants from both groups (recipient and healthcare) sought clarification as to how I would ensure that they could not be identified. Conscious of the difficulty in ensuring anonymity and confidentiality within qualitative research (Winters, Glass and Sakurai, 1993; Holloway and Wheeler, 1996; Streubert and Carpenter, 1999), I explained to each of the informants that they would be allocated a code number which would appear on their tape. This number was only known to me and was stored on my personal computer. I explained that I would be typing up their ‘story’ and at that point would allocate a pseudonym, changing the names of any individuals mentioned or places identified within their narrative. These issues became particularly important for the healthcare group, as they were concerned that specific individuals or units may be identified.

5.5.4 Beneficence

A central tenet in the principle of beneficence is the right to protection from discomfort and harm (Burns and Grove, 2001). Beneficence must move beyond doing no harm and embrace a belief in promoting positive outcomes from participation (Beauchamp and Childress, 1994). Whilst it may be easier for the

quantitative researcher to recognise aspects of their study that might cause the subjects harm, Polit and Hungler (1999) recognise that there is always the potential for anticipated problems to occur either directly or indirectly. Within qualitative enquiry it is often more difficult to recognise the potential harm, especially when exploring sensitive areas (Hudson, 2001). I was conscious of the difficulty in asking informants to recall an event which for some might have painful memories. I was potentially taking some to a place of pain once more, whilst for others it might be cathartic or indeed therapeutic to recall their stories. Ford and Reutter (1990) recognised this dilemma of opening up wounds or reliving traumatic events. It is argued by Polit, Beck and Hungler (2001) that this should not prevent us from asking such questions, but that researchers should be conscious of avoiding inflicting psychological harm by carefully considering the phrasing of questions. My training as a counsellor and my experience as a psychiatric nurse became invaluable during the interview phase of the study. An experienced counsellor was also available to meet with individual informants if they felt the need to talk further following the interview, and this was offered to everyone who took part in the study. It may be argued that the opportunity to explore their feelings and have an opportunity to talk through their 'story' might have potential benefits for the informants, and this was certainly the experience of some of the recipient group.

5.5.5 Research relationship

A central issue with all research is the relationship between the researcher and research participants. Within the traditional logico-empirical paradigm, research subjects are often not fully aware of the researcher's intent and are a human representation of variables that are controlled to offer specific measurable attributes. Within a qualitative paradigm, participants have an explicit valued role, demonstrated within this study in the recognition that they are not merely participants but informants – they are the informants to the knowledge gained.

5.5.6 Goodness

Goodness is one application of rigour suggested by Smith (1993), Denzin and Lincoln (2000), and Arminio and Hultgren (2002). I argue that in representing

rigour it also establishes ‘ethics-as-a-way-of-being’ within a study. The concept of goodness as a means of locating situatedness, trustworthiness and authenticity is discussed in the following chapter, where it is suggested that the move towards goodness allowed for a shift away from the shadow of empirical analytical expectations (Arminio & Hultgren 2002). Goodness is not seen as a separate construct, but as an integral and embedded component of the research process (Mishler, 1990). In this respect, the goodness of a study cannot be limited merely to discourse within a methodology section, but the essence of goodness is reflected by the entire study. However, the presentation of goodness as a linear process may be misleading as it could be applied solely to the writing up of projects and thus would become a ‘post hoc’ standard, dealt with in a similar vein to ethical issues within many research reports. Qualitative research is not linear, as often presented in methodological literature, but dynamic and interactive. The researcher is constantly moving back and forth between design and implementation (Morse et al, 2002). Goodness therefore becomes an overarching principle of qualitative inquiry and an interactive process that takes place throughout the study, demonstrating not only robustness but ‘ethics in being’ – the interwovenness of ethics as process.

5.6 Conclusion

It can be seen from this chapter that careful consideration was given to the selection of participants for the study. The emergence of ethics-as-a-way-of-being became the driving force behind decisions made and strategies used. The reality of moving from a paper research proposal to a live study was challenging and stretching. Ultimately, the experience and encounters broadened my own horizons as a researcher – the contentions and deliberations reflected the hermeneutic circle and the outcomes and decisions made received a welcome ‘nod’ of approval from both research supervisor and peer group of doctoral students.

The next chapter will focus on the implementation of the study with particular reference to the use of the interview as a means of collecting the narrative data.

CHAPTER 6
IMPLEMENTING THE STUDY
DATA GATHERING

6.1 Introduction:

Interviews were the choice of data collection within the study. It felt appropriate to use in-depth, unstructured interviews to enable the informants to articulate their story and uncover meanings. The interviews lasted from 45 minutes to over one hour and were carried out in three distinct phases as discussed earlier. The timing and location of the interviews were mainly driven by the informants. All interviews were recorded digitally into a handheld device, with the permission of each informant.

6.2 Epistemology of interviews

Interviews, as a means of data collection are one of the most frequently used tools within qualitative research (Britten, 2002). It has been estimated that as a data collection tool, the interview comprises over 90% of all social science research (Holstein and Gubrium, 1995; Atkinson and Silverman, 1997). As an approach to data collection, the interview has received vast coverage in the literature (Goffman, 1959; Spradley, 1979; Oakley, 1981; Gilbert and Mulkay, 1984; Carson, 1986; Mischler, 1986; Rubin and Rubin, 1995; Kvale, 1996; Denzin, 2001). Fontana and Fry (2000:647) provide an interesting historical review of the interview, citing early Egyptian evidence of its use through to the contemporary debates on its use and its purpose across disciplines and paradigms. Denzin (1995) and Atkinson and Silverman (1997) suggest that we have become an 'interview society'. Our interpretations of the world around us are strongly influenced by shared understandings and for many this comes through the form of the interviews – through the medium of modern media technology many are exposed to the interview as a means of informing their world view. Combined with a growing realization that interviews are not only neutral tools of data gathering (Fontana and Frey, 2000), I also realized that they are a complex,

interactive connectedness between two (or more) people, which is contextually based, power relational and situational. This required that I explore the process of the interview within the context of this phenomenological study.

Seal (1998) draws our attention to interview data as resource and interview data as topic, where the former perceives data as an account of the interviewees' reality outside the interview and the latter perceives data as reflecting a reality constructed between the researcher and interviewee. Whilst acknowledging the need to gather information through the interview process (data-as-resource), this informing of my perceptions of the others' reality was inevitable and, I would argue, necessary. The challenge as researcher was to not only see this data-as-resource, a reflection of the informants' 'reality of their experience', but through the interview process ensure that I enabled the respondents to uncover meanings within their story – working jointly to construct or uncover meanings; data-as-topic was strived for. Within this hermeneutical phenomenological process I was attempting to enable a consciousness of an experience (receiving, giving or being present during bad news). To reach this I had to work with the informants in facilitating their understandings through the interpretation of their story (Cohen and Ley, 2000).

In attempting to make sense of an experience that occurred outside of the interview, I used the narrative (data) as resource with the intention of utilising the narrative (data) as topic. The purpose therefore of presenting the interview data around bad news is not merely to reflect an account or story – 'reality report' (Holstein and Gubrium, 2000), but to present the realities of the interaction within the process of becoming or the process of emerging understandings. Kvale (1996) recognizes the interview as a specific form of conversation with the purpose of obtaining knowledge about the subjects' world. The view of Rubin and Rubin (1995), that the interview is like an ordinary conversation, is not only simplistic but dismisses the intentionality, activity and underlying purpose of the interaction. Rapley (2001), in discussing the interview as interaction, cites the work of Cicourel (1964) in highlighting the dynamic nature of the interview interaction and the art of interviewing as a product of social interaction – the actors being the

interviewer and interviewee. Certainly within the realms of this study, my experience as interviewer was a journey of discovery. This experience would reflect the concept of the interview as a 'social act' and a 'performance' (Kuhn, 1962). Responding to the situational imputations, strategies, emotional content of the stories and the palpable pain (of some informants) shifted the interaction from an 'ordinary conversation' into a realm of complexities and challenges.

Kvale (1995: 13) in suggesting that the research interview is 'a craft that, if carried out well, can become an art', reflects something of the process involved over the eight months of data collection. A concern while undertaking some of the interviews was my reaction to their story (this is discussed in the reflective account at the end of this chapter). Initially I felt uncomfortable and unsure of my 'research ability', but soon realized that this was part of the process of moving from novice to expert. Eisner and Peshkin (1990) recognise that there are two attributes needed for the researcher using interviews; sensitivity and responsibility to feel committed to acting appropriately. The ability to acknowledge my reactions, deal with them and any issues that emerged were evidence of my 'ethics in being' and a developing research skill. In keeping with the essence of phenomenology, the interview was seen as a reciprocal process, where both parties were seeking truth, attempting to get beyond opinions to true knowledge and meaning. Gadamer (1976:347) describes this type of genuine interaction as:

... a process of two people understanding each other. Thus it is characteristic of every true conversation that each opens himself to the other person, truly accepts his point of view as worthy of consideration and gets inside the other to such an extent that he understands not a particular individual, but what he says.

The challenge was to hear the story, grasp the essence of its meanings, acknowledge acceptance of the informant's reality and yet move them towards some understanding of the meaning – an understanding of the incident, a consciousness of their internal experiences.

6.3 The Interview Pilot

Rehearsing the session with volunteers was an essential part of the research process (Kvale, 1995; Wengraf, 2001). The pilot involved two nurses and a family friend who agreed to take part at this stage of the study. This stage of the research was important as it allowed me to develop the interview schedule, becoming familiar with the content of the schedule and allowed for it to become less of a visible tool and more of a prompt. Feedback from both groups enabled me to make some minor changes to the question stems (prompts). Of particular interest was the feedback from the 'non-nurse', who felt that I seemed almost too keen to get the information and suggested that I 'chill out' and allow the story to come. This was invaluable feedback, as it gave me permission to let the story evolve at the storyteller's pace.

For the second and third interview I purchased a clip microphone which I used to complement the flat microphone that I used initially. This resulted in a much clearer take-up and allowed me to hear my own voice, intonation etc as well as the voice of the informant. The feedback from the two participants who used the clip microphone, was that although conscious of being 'connected up', they very quickly forgot about it and felt that it did not impose a barrier in any way.

6.4 Conducting the Interviews – Practical Issues

6.4.1 Venue of the interviews

Negotiation of venue for the interviews was made on a one to one basis across each of the three phases. At times, the constraints such as travelling, availability or location and schedules of all involved impacted on the interview. The recipient group posed some initial difficulties, as once I moved out from my locality I was dependent upon the informant to identify a suitable location. Following the first recipient interview away from my locality I realised that I had assumed that they understood what a suitable location would be. Having to conduct the interview in a quiet corner of a local village pub, was not ideal (from my perspective), soft Celtic music playing in the background, whilst initially irritating soon faded into

non-existence (and thankfully did not interfere with the sound quality) and the occasional passer by did not seem to matter to the informant. I realised, on reflection, that whilst not a choice I would have made, for the informant the local pub was the centre of his world. He met all his friends there and associated it as a safe place to meet someone who although a relative stranger, wanted to talk about something that was deeply personal with some unpleasant memories. Following this situation I gave more guidance to the informants as to the venues, asking that they try and locate somewhere that would be quiet, where we would not be disturbed by other people or telephones. A place that was comfortable for them and easy for them to get to. The locations varied from informant's homes, to a room within a local community centre, local presbytery, a beautiful garden conservatory overlooking the Shannon river, a room above a coffee shop and the most interesting being a travelling library in a rural location that was closed for lunch (the informant knew the people who worked on the bus and they were more than keen to let the 'researcher from Dublin' talk to their friend.

It tended to be easier to negotiate locations with the nurse and doctor groups. Within my own locality this was either negotiated by myself or the informants, whereas outside my locality I asked if the informant could arrange for a quiet venue that was suitable for them. All but one of these interviews took place on hospital property, except for one which was carried out in the informant's home as she worked night duty and wanted to have the interview while her children were at school.

6.4.2 Preparation and management of the interviews

As discussed above, all interview locations and time of interviews were arranged to meet the needs of the informant, where possible. Occasionally I would not be available to undertake an interview at a specific time due to a prior commitment, but this was usually altered, and in terms of interviews for which I had to travel (in some cases involving a drive of between 3–5 hours each way) informants were very accommodating.

Before each interview I would always check that the recording equipment was working. I also ensured that a pack containing extra batteries and a spare pack of tissues was available. A folder specifically for interviews was also seen as an important part of the equipment. Copies of the relevant signed reply slip, blank consent forms and information pack sent to all potential informants were available as were contact information, such as telephone numbers etc, in case I needed directions or was held up in traffic.

Having attended to the normal formalities of introduction, positioning of chairs and so on, I would always start by thanking the informants for agreeing to participate. Once again, I would go through the information sheet and seek any clarification that they might have regarding any part of the research, the process they were agreeing to and the actual format of the interview. I also sought permission regarding the use of the recorder and microphones, and with their consent I commenced the recording as soon as it was possible. The rationale for commencing recording as soon as possible was to reduce any anxiety regarding the equipment and to allow for a seamless ease into the more formal part of the data collection. As discussed earlier, each informant was asked to sign the consent form once we had clarified what they were consenting to.

6.4.3 Opening questions

To enable each informant to recall his or her experience of the phenomenon, each theme was explored through an initial open ended question. I had no formal protocol, as in a semi-structured schedule, rather I used a series of prompts as a means of getting the informant to recall their story and make sense of their experience. I started by asking the following open questions:

6.4.3.1 Recipient group:

“I am interested in exploring what it was like to be given bad news, in your case what was your experience around being given your diagnosis. Please tell me about your experiences during this time”

“What did this mean for you...?”

“It might help if you start by telling me your story. Start at whatever point you wish...” (This opening question provided the informants space to locate their story and also allowed for context and location of the narrative to emerge from their perspective rather than mine).

6.4.3.2 Nurse group:

“I am interested in what it was like to for you as a nurse to be present when a patient is given bad news. Please tell me about your experiences during this time”.

“It might help if you start by telling me what this was like for you, say with a recent patient”.

6.4.3.3 Doctor group:

“I am interested in what it was like to for you as a doctor to have to give bad news to your patients. Please tell me about your experiences during this time”.

“It might help if you start by telling me what this was like for you, say with a recent patient”.

6.4.4 Recording and Transcribing of Interview

The method of recording the interviews was chosen because it allowed me to concentrate on the conversation and the dynamics of the interaction without having to take notes (Kvale, 1996). Whilst the recording offers a decontextualised version of the interview it does not adequately record aspects of non-verbal communication, such as facial and bodily expressions. Gordon (1980), identified four basic modes of non-verbal communication, where the communicant uses personal space to communicate attitudes (proxemic), the use of pacing of speech and silence within the conversation (chronemics), body movements or postures (kinesic) and variations in volume, pitch and quality of voice (paralinguistic). The digital recorder used for the interviews allowed for markers to be placed via a digital command by simply pressing a button on the hand held device. I had practised doing this in front of a mirror, within the pilot and also with some friends to see if it was noticed. Nobody noticed the gentle tap on the handheld device and so I was confident that it would not be a distraction during the interview. The codes were devised to enable me to note certain nonverbal reactions during the process (Table 6.1) thus allowing for triangulation of

communication within data during the analysis stage of the research (Begley, 1996a; Tobin and Begley, 2002). These markers allowed for the kinesic and proxemic modes to be noted. Paralinguistic and proxemic modes were marked (9) and noted immediately after the interview.

Proxemic and chronemics modes occurred dramatically on a number of occasions; for example, one informant repeatedly mouthed the word ‘cancer’ but did not actually speak the word aloud. On another occasion an informant jumped out of her chair as she spoke of her sense of anger at the way her diagnosis was given. As the digital recorder would only accept 9 markers, I therefore had to improvise as new non pre-coded cues emerged. The use of the digital marker allow me to stay fully focused and connected with the informant without having to distract the flow by making notes during the interaction.

Table 6-1 Marker Codes for nonverbal cues:

	<i>Mode of Non-verbal</i>	<i>Observed behaviour</i>
1	Kinesic	Maintaining eye contact
2	Kinesic	Avoiding eye contact
3	Kinesic	Looking uncomfortable
4	Kinesic/ proxemic	Shifting about in seat
5	Chronemics	Silence
6	Chronemics/ Kinesic	Appears tearful – not actually crying
7	Kinesic	Shaking head
8	Kinesic	Use of hands
9		No pre-code

All interviews were labelled immediately following the interview with a code system and date of interview. Each of the four geographical areas were given a code and each of the informants allocated a code which comprised of an identifier and a number. For example the recipients were coded D-R 1; G-R-5 (D = locality; R = recipient group & the number of their allocated code for confidentiality). The same procedure was used for the other groups, substituting

N for nurse and D for doctor. In this way there was ease of coding and consistency across groupings. All recorded interviews were downloaded onto a personal computer as an MP3 file and were inaccessible to anyone else. The files were stored in a secure folder that could be accessed by a password known only to myself.

Initially it was hoped that a voice activated computer programme would speed up the process of transcribing the data. However, having purchased the software it soon became apparent that it would not work as the computer had to be trained to the voice of each speaker to ensure accuracy. After some time at attempting to use the software I reverted back to transcribing manually. The process was slow, some interviews taking over 15 hours to transcribe. I had decided not to use the service of a transcriber for three reasons. Firstly, I was very conscious of the sensitivity of the material and the privileged position afforded me to share their stories. As an experienced nurse, I was familiar with many of the scenarios and contexts embedded within the narratives. However, for someone not familiar with the context of hospital life, the data might be disturbing. This is an important consideration when deciding to use transcribers who are unprepared and unused to such material (Gregory, Russell and Phillips, 1997). Secondly, I wanted to stay close to the data, and felt that by listening to the interviews through my MP3 player and slowly transcribing word for word I could immerse myself in the data. Finally, previous experience of a transcribing agency was so unsatisfactory due to time delays and inaccuracies that I decided to handle all aspects of data transfer from speech to text. Once interviews were in text form they were also stored as a word document in a computer folder protected by a password, thus each interview was saved as a data file and a word file. All references to individuals, places or events that might link the narrative text to a person or institution were altered to protect the anonymity of the informant and those involved in their story.

6.5 The Interview Process

6.5.1 Genres of interviewing experience

During the interview conversation, I used questions and interview alternatives to direct (some might argue manipulate) the informant through the complex maze of their narrative. Whilst I was conscious of the phenomenological notion of listening without prejudice (Kvale, 1995), and of not sharing my perspectives, values or opinions on a scenario, I was also aware of the informants' needs to connect with me. Occasionally, when it felt appropriate and when I sensed that the informant needed some encouragement and gentle handling, I shared some personal information, like the scenario of not knowing my son's diagnosis (Chapter 1). Whilst some would argue that this sharing is unacceptable, Douglas (1984) sees this as essential in gaining the informants' trust and confidence. The depth of exploration of experience, and thus the data, depended upon my willingness to engage with each informant and their willingness to trust me. Rogerian's concept of self, and the need for unconditional positive regard, congruence (genuineness) and empathy was interwoven throughout my interaction with the informants (Rogers, 1981; Jacobs, 1999). Much literature acknowledges the psychodynamic nature of the therapist and client interactions (Gurman, 1977; Lietaer, 1984; Thorne, 1991; Mearns, 1996; Jacobs, 1999; , 2003). However, Hunt (1989) clearly advocates that this psychodynamic process is also present within the research interview. I was conscious of this and the need to connect with the informant, but was cognisant of not allowing my experiences to frame the stories of the informants. Rubin and Rubin (1995), acknowledges the strength of the personal involvement (in my case connectedness) and caution the researcher to be aware of the problems it might create. Massarik (1981) provides a typology of interviews ranging from the Holistic-interview where there is an element of combat, through to the Phenomenal-interview where interviewer and interviewee are becoming caring companions. The nature of the interview used within this study falls within what Massarik refers to as the 'Raport interview', where I, the interviewer, emerged as a 'Human-Being-in-a-role', not denying my humanity and acknowledging the humanity of the informants, while remaining focused essentially on the subject matter and specific replies (Massarik, 1981:205). This

approach is clearly congruent with the underlying philosophic stance of interpretative phenomenology, mirrors Gadamer's (1975:347) view of openness and honesty, and sits within my own personal philosophical stance of valuing people for who they are.

6.5.2 Beginnings

Recognising the dynamic nature of the interview interaction and complexities involved in the process, I was conscious of the need to ensure that issues that impacted on my relationship with the informants might be minimal. Scheff (1968), in highlighting influencing factors that impact upon the relationship between researcher and interviewee, suggests that the validity of the interview may be threatened if issues of power and emotion are not adequately addressed. This view is also supported by Wengraf (2001), who argues that by its nature, the interview process is an interaction between people and as such will inevitably involve issues of power and emotion. I was conscious of these issues as I entered into this phase of the study, and drew from the early work of Kuhn (1962) and more recent work of Rubin and Rubin (1995), Kvale (1996) and Wengraf (2001) in addressing them. The beginning stage of the interview involved negotiating a relationship of equality with my informants in an effort to ensure quality and genuineness of data (Scheff, 1968). This was attempted through creation of a natural environment (Rubin and Rubin, 1995), and the interaction at the initial stage and pre-formal stage of interview. Putting the informant at ease, offering further detail of the process, use of good communication skills (reflecting, mirroring, active listening and responding) were used to engage with the informant as a person in their own right and not the 'subject' or 'repository of data' that was required to reach my research aims successfully. However, I was also conscious that I represented something else to the informant. I had initiated the contact, invited and created the opportunity to meet, and by virtue of being seen as the researcher (all the information provided in the letter of invitation – Appendix II & IV) there was a danger of asymmetry of power (Kvale, 1996: 126). These issues were not as great for the healthcare provider group as they were more familiar with the process of research and knew that I was also a healthcare professional. Scheffe (1968) suggests that the more open and shared an

agreement of agenda of the interview, the more control the interviewee has and the more likely that they will provide reflections of their world. The framing of the interview was seen as important in addressing these issues of the agenda or focus of the interview (Rubin and Rubin, 1995). The information pack (Appendix II & V) provided some context for the interview, but this information was again addressed informally through questions and answers at the commencement of each interview. This enabled the informants to refocus and or clarify the reasons for the study, and it also offered space and opportunity to explore their reasons for being there and for participating in the study.

6.5.3 Middle

Conscious of my personal spontaneous style (challenged during the pilot) and a need to develop a capacity of styles for the interview task (Wengraf, 2001) I strove to ensure that I not only put the informant at ease, but I also needed to facilitate their return journey to an event, which for some was painful, while for others - part of their everyday professional activities. Throughout the interview I was listening by 'double attending', a process defined by Wengraf (2001:194) as listening to understand and ensuring you address all you need to a depth that is necessary, within the timeframe available. At times I found this process physically and psychologically exhausting. The informants and I were on a dynamic journey of attempting to understand. Both were constructing a world which was forced into the arena of dialogue through the stimulus of questioning. Conscious of Gubrium and Holstein's (1998) argument of interview as storytelling, and Sarup's (1996:17) views of narrative as story (*histoire*) and discourse, it was obvious that both interviewer and informants were on a reflective encounter, where the story became the 'what' and the discourse the 'how' or the uncovering of meanings. This reflexive process is shared by Silverman (1993), Dingwall (1997) and Cohen, Kahan and Steeves (2000a), who recognise the interview as a social encounter.

I was not only aware of the nonverbal communication of the informants I was also conscious of my own nonverbal and subliminal actions. The interviews were indeed a voyage of discovery, and I experienced the sense of attentive responding

not only to the words of the informant but also to my own utterances. Dillon (1990:176) reminds us of the use of alternatives to questions, known as interviewer intervention, the use of some signal by the interviewer that he hears what is being said or the use of silence, which is a deliberate and appreciative silence. So not only was I hearing through the words spoken, but I was also hearing through the silences.

6.5.4 Endings

Effective interviewing requires preparation, good beginnings, a developed and executed middle phase and demands the establishment of competent closure. Despite an extensive internet and manual search of the literature – little could be found on the area of interview endings. Kuhn (1962) recognises the importance of what he refers to as the third stage of the interview – ‘the conclusion’, and suggests that little research has addressed this important stage. Forty two years later, despite exponential increase in research material and research discourse, it would appear that this ‘ending process’ remains the prerogative of research experience and the process of ‘good practice’.

Drawing from the area of counselling, Mearns (1999) discusses the power dynamic within the therapeutic process and suggests that due to mutuality, it does not matter whether the client or counsellor initiates the ending. The dilemma I faced was in exploring whether the negotiating of a relationship of equality with informants (Scheff, 1968), as discussed under the ‘beginnings’ section, established mutuality between interviewer and informant. The research interview is not the same process as a therapeutic counselling interview, and yet the process of developing unconditional positive regard, congruence (genuineness) and empathy were shared. Endings are seen as an integral part of the counselling process (Lietaer, 1984; Rennie, 1998; Mearns and Thorn, 1999) and I believe were also integral to my research interviews. No interview was actually ended by the informants, although their verbal & nonverbal communication directed and influenced my approach to the process of the interview. On a number of occasions, especially with the recipient group, I offered to end the interview if the informant appeared tired, upset or uncomfortable, but all wanted to continue. In

retrospect, it could be argued that a level of equality and mutuality was attained as the informants, when offered choices had freedom to choose, and exercised this autonomy.

All informants were given a signal that the interview would be coming to an end. This was usually given as a statement such as;

... well (name) we will be coming to an end of the interview shortly. You have given me a lot of detail, and I really appreciate all you have shared. Is there anything else that you would like to share that might be important for you or for the interview, that we have not yet talked about. Or is there something that you might want to talk about again?

On some occasions, this resulted in the informant providing new information which was then explored. For some, it was as if the ending of the interview signalled a need to talk further, whilst for others it provided a boundary and a point of closure.

Informants were all reminded of the provision of a free counsellor who was prepared to meet with them, should they wish. A business card with the contact details were provided to everyone. I also reminded them of my contact information, detailed within the information pack, and gave copies of this if they had not brought one to the interview. They were invited to ring me or write should they wish to talk about issues that might have arisen as a result of our talk. I reminded them of the issues of confidentiality and anonymity and sought permission to send them a copy of my interpretation of the interview, explaining that I would be looking for themes within their story and would like their feedback as to whether I was reflecting their meanings.

Winding down was seen as important as the pre-formal stage of the beginnings. Rubin and Rubin (1995) see this as an important phase of the interview and suggest that it offers the informants opportunity to wind down from the intensity of the dialogue. This debriefing was facilitated through casual talk, often over a cup of tea and as interviewer I was often reminded of the connectedness which had occurred through the sharing of personal journeys. Whilst I felt privileged to

be given access I was always exhausted from the process, and valued the time to be alone afterwards as I travelled home.

6.5.5 Self-debriefing

This fourth phase in the interview was seen as an integral and important part of the process and not as a 'post interview' activity (Wengraf, 2001). It formed part of my reflexive phase during data collection. My aim during this phase was not only to make field notes regarding nonverbal activity demonstrated during the interview, but also to provide space for 'free association' around my interview experience. Ericsson and Simon (1980) and Kvale (1995) recognise the process of debriefing for the interviewee, it is Wengraf (2001) who places the needs of the interviewer within this process of debriefing. It was seen as important to make these notes as near to the finished interview as possible. This occurred inevitably in the car park immediately following the interview. Not only did this provide sharp memories, but the writing out of my sense of the story and my reactions during the interview was a cathartic process. Drawing from suggestions of Wengraf (2001) I attempted to rewrite the story heard, as if it were not recorded. This process of recall could later be used when hearing the actual words to examine my own reaction during the interview process and also inform my understandings of the data and my reflexive journey. The brainstorming of ideas, unstructured and unorganised allowed for free-flow of thoughts, emotions and ideas and offered material which would be used to triangulate the subjective hearings and reactions to the actual spoken recorded word.

6.6 Concluding remarks

It can be seen from the discussion in this chapter that the data collection phase was a complex interaction between informants and interviewer, self and other, researcher and professional, writer and literature, espoused theory and craft knowledge. The journey was at times unsettling, confusing, exciting, frightening, and ultimately empowering. The growth and insights could not have been accomplished were it not for the phenomenological experience of doing and

being. The next chapter will discuss how the data gathered were analysed and interpreted.

CHAPTER 7

DATA ANALYSIS AND INTERPRETATION

7.1 Introduction

The propose of this study was to explore the phenomenon of being given bad news, the phenomenon of having to give bad news and the phenomenon of being there for the patient who has received bad news. Philosophical hermeneutics drawing from the works of Heidegger (1962) and Gadamer (2000) provided the grounding for the collection and analyses of data. The process of data gathering has been discussed in the previous chapter. This chapter will focus on the processes of phenomenological analyses used within the study. Analysis occurred in two phases and to present a singular perspective of the ultimate or final analytical framework would be to misrepresent the phenomenological experience of uncovering the essence of the phenomena. The actual analytical processes encountered were diverse and fraught with conflicts and concern as I engaged with ‘analysis-as-a-way-of-being’.

Data analysis were influenced by a number of principles based mainly on the frameworks proposed by Miles and Huberman (1984), and Lincoln and Guba (1985). Although various other texts were also consulted, it was the four distinct stages offered by Miles and Huberman (1984) that initially guided my approach. The four stages to the process were: data collection, data display, data reduction and conclusion drawing and verification.

The process of data analysis implies progress that can be measured by stages or steps (Cohen, Kahn and Steeves, 2000b). The reality of my research experience was that this process was neither liner nor sequential, and was therefore difficult to assess in terms of progress. In the early stage of the research I was consistently challenged as I struggled to remain true to the philosophical underpinnings. Insecurity with my data and a concern that I might miss something or that I might introduce a perspective that was not there was challenging and motivating. This resulted in driving me deeper into the data; engaging with the text as I sought to

find meaning and interpretations. Alongside this process was the growth of my understanding on phenomenology.

This chapter will present the analytical process in two distinct phases, as in reality this is the process in which the analysis was undertaken. Both phases of analysis are important and worthy of note as both offer an insight into the complexities and realities of engaging with philosophical hermeneutics and the spiralling and reframing that occurs. The first phase of analysis is labelled **'2000 – 2003 Phase'**. This initial phase occurred during the early stages of the study and reflects to some extent my understanding at this stage of the enquiry. The second phase occurred laterally as I continued to revisit the research data and engaged with the analytical process further. This stage is referred to as **'2003-2005 Phase'**. A rationale for each phase is presented within the relevant section and a critique of the process offered at the end of the chapter.

Whilst a Heideggerian-Gadamerian tradition presents structure in terms of philosophical thinking and acting, it fails to propose a methodological approach to analysis. This lack of an analytical framework within the phenomenological tradition did little to offer direction and posed a major challenge. Similar to Lawler's (1998) work, it was the lack of exemplars from within the literature that made the transition from philosophy to methodology, from methodology to data method and from data to data analysis difficult.

7.2 The Hermeneutic Circle

The movement between the data collection process, digital voice files and the textual data was inevitable within the hermeneutic circle. Koch (1995) suggests that it is this movement or ongoing conversations which sets hermeneutics apart from other phenomenological perspectives. Throughout the study, interpreting and understanding texts involved the engagement with and in the hermeneutic circle. For Heidegger the challenge was not to get out of the circle but rather to come right into it. This is evident from Heidegger's thinking as he argues:

This circle of understanding is not an orbit in which any random kind of knowledge may move... it is not to be reduced to the level of a vicious circle or even a circle which is merely tolerated... What is decisive is not to get out of the circle but to come into it the right way.... (Heidegger, 1962:195)

The challenge was to ensure that both the researcher and participants were central to the circle. It was this moving between the parts and the whole (application of analytical framework) in a circular fashion that encapsulated the entering and moving within the hermeneutic circle. This movement involved the study of the text of transcriptions, the voice data files, and my field notes. I was in essence looking from the whole to the parts in search of meanings of the phenomena and holding these up against and alongside my own pre-understandings. This process was dynamic and challenging and I came to recognise that the interpretations I formed and the judgements reached derived from my own horizon of understanding as an experienced nurse and fellow human and from the interpretations of the experiences of the participants.

Wolcott (1994) proposes a distinction between analysis and interpretation. He further develops this, by suggesting that analysis has a more limiting and defining role and should be restricted to ‘...examination of data using systematic ...procedures’ (Wolcott, 2001:33). Interpretation, he argues should not be derived from rigorous specified procedures, but should draw from sense-making. He believes that we should allow for intuition, recognition of past experiences, and emotion – basically the personal attributes of the researcher. This is further supported by Dey (1995:78) who argues for the use of the three ‘I’s’ – ‘insight, intuition, and impression.’ This use of sense-making, intuition, insights and impressions became central throughout the analytical phases. Examples of this emerging ‘sense-making’ can be seen within the reflexive diary excerpts contained within this thesis.

7.3 2000 – 2003 PHASE

The goal of analysis was to provide descriptions that capture and communicate the meaning of a lived experience (Cohen, Kahn and Steeves, 2000a). My aim therefore was to provide descriptions which were rich or ‘thick’ enough to allow the reader to recognise or capture the experience and also to demonstrate trustworthiness (Geertz, 1973; Lincoln and Guba, 1985). As the research explored the phenomenon of the breaking and the receiving of bad news from three distinct yet interwoven aspects, the analysis takes place initially as three separate units. This is in keeping with hermeneutics, as the hermeneutic analysis attempts to give ‘... greater access and understanding of the text in its own terms, allowing the reader to notice meanings...within the text’ (Benner, 1994b:101). It was seen as important that each of the participant groups were analysed separately to allow for the specific meanings to emerge within each grouping.

7.3.1 Framework for Analysis

Whilst the underlying principles were based upon Miles and Huberman (1984) the framework used for the analysis of data was based upon an adaptation of procedural steps as advocated by Colaizzi (1978). This procedural framework offered a stepwise approach to analysis (Fleming, Gaidys and Robb, 2003). Colaizzi recognised that there was a need to be flexible and that the steps advocated may need to be modified depending on the philosophical approach used. A major change within the procedural steps occurred within the step in which originally Colaizzi advocated having the participants review the exhaustive descriptions for validation. Within the recipient group, many of the participants did not wish to undertake or become involved in the process to review the material. Talking about their experience was difficult for some and they not want to return to it as a paper exercise. Koch (1993) identified a similar problem when using Colaizzi’s framework when she was dealing with older patients within her study. Many of her participants could not engage with the review process as they died shortly after the interviews. Koch developed Colaizzi’s framework and it was decided to draw from Koch’s adaptation of Colaizzi to assist with the analysis

of the data (see Table 7.1). Hereafter referred to as Koch's Adaptation framework.

Table 7-1Comparative model of Colaizzi (1978) and Koch (1993)

Steps	Colaizzi Framework (1978)		Koch's Adaptation framework (1993)
1.	<u>Engaging with the protocols:</u> Read descriptions/protocols	1	<u>Protocols – Descriptions:</u> Read through the entire subject's descriptions for a sense of the wholemaking sense of them (Koch, 1993:224)
2.	<u>Participant validation:</u> Return to participants for validation	2	<u>Extracting Significant Statements:</u> Extract significant statements that directly pertain to investigated topic (Koch, 1993: 225)
3.	<u>Extracting statements:</u> Extract phrases-significant statements	3	<u>Analyses of individual transcript:</u> Continue extracting significant statements from each interview (Koch, 1993: 232)
4.	<u>Formulating Meanings:</u> Meanings of significant statements	4	<u>Development of Clusters:</u> Compare the whole data set, grouping together significant statements into clusters that represent commonalities of experience (Koch, 1993:234)
5.	<u>Creating clusters of themes:</u> Aggregate meanings into clusters	5	<u>Development of Themes:</u> The strong clusters were integrated ...into themes (Koch, 1993:234)
6.	<u>Exhaustive Descriptions:</u> Integrated description of investigated topic	6	<u>Production of Exemplars:</u> Transcripts were re-examined to select exemplars of significant statements to illustrate clusters and themes (Koch, 1993:237)
7.	<u>Identification of fundamental structures:</u> Exhaustive description of investigated phenomenon. Create statement of identification of phenomenon's structure.		

7.3.2 Application of Koch's Adaptation Framework

The following section will provide an overview of the framework as it applied to the (2000-2003) phase of analysis within the study. The framework was applied to each of the three data sets – recipients, nurses and doctors.

7.3.2.1 Protocols – Descriptions:

Read through the entire subject's descriptions for a sense of the whole ...making sense of them (Koch, 1993:224).

Following the recording of the interviews digitally as files on an MP₃ (digital file for audio streaming) player, each interview was downloaded and saved as a data voice file on a personal computer. Data were then reduced into manageable units (Huberman and Miles, 1998) through the transcription of narrative data into textual data. The texts were then saved as a word file on a personal computer. All interviews and filed notes were printed and stored within a clip file. Each group-set was saved within separate folders on the computer and printed off on different coloured paper. Throughout the process of listening, transcribing, checking for typing errors, filing and generally reading the text I became very familiar with the content.

7.3.2.2 Extracting Significant Statements:

Extract significant statements that directly pertain to investigated topic (Koch, 1993: 225).

Selecting significant statements commenced immediately following the first interview and continued throughout the entire process of data collection. Dreyfus (1987:264) suggests a basic characteristic of Dasein is that '...things show up as mattering – as threatening, or attractive, or stubborn, or useful ...' It is these very 'matterings' that became issues of significance within the data. With the recipient group-set, for example I asked 'What is it that makes the receiving of the news significant for them?'; 'What is it that enabled them to receive and process the news?' For example one significant statement was: "I was told not to worry". An example of this from the texts is:

Bill: I know I trusted him when he told me it was probably haemorrhoids, but I wasn't getting better and to be honest I was worn out with the whole thing; it had taken over my life. *He told me not to worry* and that he was sure everything was fine. I got an appointment for six weeks later and just waited. ... I kept thinking that the doctor was right and I was just worrying over nothing.

Rhoda: They knew I had my suspicions and yet the GP tried to fob me off with the reassuring words "*It's probably nothing to worry*

about". I put him in his place and said the reason I was there was because I was worried – I was very worried.

From the nurses' interviews-there was a sense of being there for the patient but being invisible to the medics. A significant statement relating to this centred on "Not being involved". This was often articulated as:

Nurse A: Sometimes I think the doctors don't even see us. It's as if we somehow don't exist or don't have anything to offer at times like this....

Nurse S: Sometimes you only find out that the patient has been told by the doctor and you know nothing about it..

There is also some evidence that I was intuitively picking up on some of the significant statements (foci) within my reflective journal. These entries were made in 'free-flow' following interviews. They were the pre conscious analyses and interpretation; they were a record of my initial reactions following the interview:

There is a real sense of frustration at not being involved. She was really upset at being excluded. I can remember my own surprise when I was asked to join the consultant in the ICU when she was going to see the family. There was no sense from Nurse X that she had ever experienced that sense of involvement, that part of being involved truly as the team... How do they cope with the exclusion, I would be so frustrated with not being involved with my patients....

7.3.2.3 Analyses of individual transcript:

Continue extracting significant statements from each interview (Koch, 1993: 232).

Searching for significant statements within each interview across the three group-sets continued throughout the data collection period. Each group-set of interviews occurred as stand alone phases for example, all recipient interviews were concluded prior to commencing the nurses' interviews. These were completed prior to commencing the doctors' interviews. Statements from each individual interview were then explored within the group-set for similarities. In reality the significant statements began to emerge within the transcripts and also new ones

would emerge as the interviews progressed. A total of eighty-four significant statements emerged from the recipient group, one hundred and ninety four from the nurse group and seventy seven from the doctor group.

7.3.2.4 Development of Clusters:

Compare the whole data set, grouping together significant statements into clusters that represent commonalities of experience (Koch, 1993:234).

The overall significant statements were clustered into manageable units (categories) which allowed for the commonalities of data to be grouped together. As with the significant statements in step 3, the clusters were draw up within the specific group-sets. A total of fourteen clusters emerged from the recipient group-set, seventeen clusters from the nurse group-set and eight from within the doctor group-set.

7.3.2.5 Development of Themes:

The strong clusters were integrated ... into themes (Koch, 1993:234).

For the recipient group-set, the eighty-four significant statements became fourteen clusters which then emerged as four themes. The one hundred and ninety four significant statements from the nurse group-set formed the basis for seventeen clusters which then emerged within five themes. The doctor group-set saw the seventy-seven significant statements cluster into eight categories and finally emerge within four themes.

7.3.2.6 Production of Exemplars:

Transcripts were re-examined to select exemplars of significant statements to illustrate clusters and themes (Koch, 1993:237)

Group-sets were to be initially presented separately. Within each group-set the themes were drawn from relevant exemplars from the interviews. At this stage of the study, it was suggests that the essence of receiving bad news was composed of four themes and fourteen clusters, the essence of being there for the patient was composed of five themes and seventeen clusters and the essence of delivering bad news was composed of four themes incorporating eight clusters.

7.4 2003 – 2005 PHASE

Employing Koch's (1993) Adaptation framework in the 2000-2003 Phase proved useful as it allowed for prolonged engagement with the data. Miles and Huberman (1994:10) posit that the strengths of qualitative data rests centrally on the competence with which their analysis is undertaken. My concerns and unease with the process of decontextualising the data in order to reconstruct an interpretation that was entirely mine (researchers) as opposed to a merging of self-interpretations (researcher's preunderstandings and participants) left me seeking to reengage with the analytical process. I recognise this was part of the hermeneutic cycle and was methodologically rigorous. However, my own hermeneutic nod was not evident – I knew additional insights and information would emerge as part of the analytical process and was determined to remain with the data until the essence of the phenomena became more evident.

7.5 Emerging Framework

At what point does understanding merge into the past and rest? I came to realise that understandings are like horizons; they move and change – they are not static. As I engaged with the hermeneutic circle, relevant readings and my reflective journal, I came to realise that my understandings of phenomenology were like the changing preunderstandings of the phenomenon of bad news – it was moving. Geanellos (2000) recognises that the explicating and reviewing of preunderstandings (and in my case phenomenological understandings) enables entrance to the hermeneutic circle and is required to remain orientated to the phenomenon.

Whilst Caelli (2000) challenges Crotty's (1996) attack on contemporary phenomenological nursing research and supports the notion of the deliberate choices made to embrace and develop new ways of applying phenomenological philosophy to research methodology, I was left wondering as to the analytical framework I had embraced. Koch's Adaptation framework (1993) was based on the work of Colaizzi, mainly because of difficulty with returning to participants

and this was partly the reason that I initially chose the framework. However, it is to this very exclusion of participants that I now return. In embracing a framework that was adapted from Colaizzi, I came to suspect that not only was I excluding those whom I was trying to understand (participants), I was also accepting an approach that was based on decontextualising and recontextualising the text as data. Koch (1996) began to recognise this and suggests that the frameworks of Colaizzi (1978), Giorgi (1985) and Parse et al (1985) were basically Husserlian in orientation. On further examination of both Colaizzi's (1978) framework and Koch's (1993) Adaptation framework I began to see some discrepancies between the proposed steps and the requirements of a philosophical hermeneutic approach. Colaizzi and Koch's adaptation model both recognise the significance of statements made by participants and the need to develop or cluster these to arrive at some themes which would become descriptor of the phenomena. I would argue that development of thematic analysis from significant statements and clusters which ignores or fails to acknowledge overtly the interplay of the researcher's preunderstandings is an anathema to the requirements of philosophical hermeneutics. This, coupled with a lack of integrating the essence of the hermeneutic circle within the analytical framework renders both frameworks suspect within philosophical hermeneutics.

It was this need to ensure that an analytical framework would recognise and integrate the preunderstanding of the researcher, acknowledge the movement from the whole to the parts and back to the whole (hermeneutic circle) and place the data as contextualised life events that led to the emergence of a modified analytical framework for the 2003-2005 Phase of analysis (see Table 7.2).

Table 7-2Modified Analytical Framework

Steps	
1.	<p><u>Provoking Preunderstanding</u> Articulation of preunderstandings so as to move into first contact with text</p>
2.	<p><u>Meanings Within the Parts:</u> Identifying meanings within individual texts. Creation of significant statements from examination of each line of text.</p>
3.	<p><u>Essence Within the Whole:</u> Engaging with text & data file in full. Search for expressions that reflect essence of the whole.</p>
4.	<p><u>Meaning for Understanding:</u> Merging of the parts into the essence of the whole. Analysis of statements from individuals (parts) to the whole.</p>
5.	<p><u>Shared Understandings:</u> Participants asked to comment on the emerging themes within their specific group-set. Construction of themes which reflect the emerging meanings of the parts and identified essence of the whole.</p>
6.	<p><u>Merged Understandings:</u> Meeting of horizons between other and I – researcher and participants. The blending of preunderstandings with that of the text.</p>
7.	<p><u>Exemplars:</u> Creation of exemplars of shared understandings & meanings. Presentation of passages to give insight into phenomenon as understood.</p>
8.	<p><u>Phenomenological Essence:</u> Presentation of the essence of meanings within the phenomena. The structures of the identified phenomena.</p>

7.6 Application of Framework

The following section will present an overview of how the framework was applied to the existing data during the 2003-2005 phase of analysis. The framework was applied separately to each of the group-sets. Participants from the recipient group who had initially expressed an interest in engaging further with the findings through reading their transcripts and offering comments on my interpretations were contacted again and invited to join the process once more. Four of the original ten recipients agreed to participate. Six from the nurse group-set and two

from the doctor group-set also agreed to participate in this stage of the analysis. I met with each of the participants again and together we discussed the study and I reminded them of its aims and explained in simple terms, the context of the philosophical underpinnings and why I was endeavouring to develop the findings further at this stage.

7.6.1 Stage 1: Provoking Preunderstandings

This commenced early in the study and has been explored and discussed in some detail in chapter 2 and chapter 4. Explorations of preunderstandings were revisited constantly throughout the research process. As part of the analytical framework for this phase I decided it was essential to spend time focussing on my preunderstandings in an effort to ‘provoke’ an articulation of the essence of my fore-structures, particularly relating to bad news. What follows is a summary description of how I see myself; it is an attempt to re-explore my *Being-in-the-world*. In reconnecting with this as an overt part of the analysis I am providing insights into how, and perhaps why judgements were made during the study. I am very conscious of van Manen’s caution that we do not merely present autobiographical accounts of one’s private life (Van Manen, 1990:54), and also aware that I have already given some insights in chapter 1 and in greater detail in chapter 4 sections 4.6.1 to 4.6.3. What follows draws from the earlier explorations and offers an overview of my provoked preunderstandings through the three aspects of Heidegger’s structure of interpretation; fore-having, fore-sight and fore-conception. It is offered as a summary overview and is not intended to replace the discussion in chapter 1 and 4.

7.6.1.1 Fore-having

Heidegger suggests that *fore-having* is ‘something we have in advance,an appropriation of understanding (1962:192). I came to this study as a nurse who had worked in general and mental health nursing. Having specialised in intensive care (ICU) nursing I became somewhat disillusioned with the way we met our patients and their family’s psychological needs, and so I decided to undertake my postgraduate psychiatric nurse training. It was during this period that I became interested in the nurse-patient relationship and the power of a relational base to my

practice. My personal belief was that nursing was relational and that the nurse-patient relationship, whilst goal orientated was fundamentally about relationship and trust. In presenting as a nurse to my patient I was presenting myself. The challenge was to offer professional practice that allowed for the emergence and recognition of who I was as a person and as a nurse. Returning to ICU nursing and taking up my first charge nurse position brought with it challenges. The balancing of an extremely busy unit and the need to come alongside and be present for patients, families and staff was stretching, and at times I feared I failed all three. In dealing with the demands of the job, I can now see I had developed a mechanism for survival – distancing. This study will challenge this distancing and make me face my relational-based practice philosophy.

It is worth noting that as a result of my father's sudden death (chapter 1) and the way the news was broken (staged and protective) I can see that my attitude towards truth and disclosure has a strong influence from a personal perspective. I can also reflect back on a long career, especially in the early years when a terminal diagnosis often brought a sense of having failed the patient and at times there was a sense of guilt accompanying this. As a father who suspected a change in a mole on my son's face, I experienced something of the worry and stress around seeking a diagnosis. The need for information and the need to be kept informed at an appropriate level has impacted on how I now look at the way information is given to people. As someone who lived through watching another friend receive a cancer diagnosis and eventually die, I have walked the road as a significant other, being in the supportive role and know what it is like to be left behind.

My *fore-having(s)* as presented, and more importantly as lived, is what I bring to those I seek to understand. Apart from never having received a cancer diagnosis, I am bringing who I am as a person, as a husband, a father, a son and a significant other. I bring my age, my gender, my upbringing, and my beliefs as expressions of *Being-in-the-world*. It is shared, it is something others may relate to and it is woven throughout my research study. These things are who I am. They form the fabric of the presenting me. To suggest that I leave them behind as I don my

research character, is to suggest that I do to the role of researcher, what I did to my role as a junior nurse - hiding behind the security of the white coat, separating the presenting caring nurse from the real me. Who I am is what I bring to the study, who I am is what I brought to each of my participants, it is the filter through which I heard their stories and the sieve through which meanings begin to merge.

7.6.1.2 Fore-sight

Fore-sight is the perspective brought to the investigation which leads to effective interpretation. It is drawn from *fore-having* and seeks to provide understanding rather than merely being in the background (Gibson, 2000). Here I will attempt to articulate what it is I will see in advance as a man, a nurse and someone who has experience of having received differing types of bad news.

I was challenged at times during the data collection and realised during my reflexive journaling that the issues of gender and how men see things had not really been considered before commencing the study. From reviewing my journal writings, I came to realise that I may expect to find people struggling to come to terms with facing into altered body image and learning to readjust within their relationships. My *fore-sight* as a nurse suggests that I may find people who have stories of having received inadequate information. I may expect to find that people were often not given the opportunity to clarify issues and had a period of uncertainty. From some of the published theories on bereavement (Kubler-Ross, 1969; Taylor, 1983; Rando, 1986; Creagan, 1993) I may expect to find people expressing reactional stages to their diagnosis.

Concerning the lived experience of healthcare professionals, I expect to find nurses who were involved closely with their patients and who assisted in helping the patient come to terms with their condition. I expect to find doctors who believed they had delivered the news in as good a way as bad news can be given. From my experience in the UK of facilitating workshops with medical staff on communication issues I expect to find that the doctors will believe that the patient understood the information given. My *fore-sight* suggests that I will find that healthcare professionals share a common goal orientated care delivery belief

structure. However, I also expect to find a lack of understanding of how the ‘other’ actually works within that ‘shared’ care delivery structure.

7.6.1.3 Fore-conception

For Heidegger, *fore-conception* relates to the connections between the expectations of findings and expectations of interpretation. “...interpretation has already decided for a definite way of conceiving it, ...it is grounded in something we grasp in advance – in a *fore-conception*.” (Heidegger, 1962:191). Whilst I would dispute that I knew the answers to my questions I must acknowledge that I entered the study with a preunderstanding (*fore-structure*) of the people involved. Therefore I have some thoughts as to the outcome of the study. I suspect I will find recipients who had lived through an extremely difficult period in their lives; recipients of a cancer diagnosis, who for a time had familiar faces and unknown people playing a significant part in their life-story. I suspect I will find nurses and doctors struggling to give the best care they can, whilst recognising that in their professionalism as in their humanity they have strengths and weaknesses. I expect I will have mirrored in the stories of the recipients and the healthcare professionals elements of my life experiences as a person, as a professional and as a researcher.

7.6.2 Stage 2: Meanings of the Parts

This is similar to stage two and three of Colaizzi (participant validation and extracting statements) and stage two and three of Koch’s Adaptation model (extracting significant statements and analysis of individual transcripts). ‘Meanings of the parts’ represent the extraction of the parts of the data, the release of meanings within individual narrative accounts. It calls for a line by line exploration and analysis. For this stage of the analysis I drew from the line by line analysis completed during the 2000-2003 Phase. The original eighty-four significant statements from the recipient group, one hundred and ninety four from the nurse group and seventy seven from the doctor group were reviewed and brought into this stage of the analysis. Participants who had volunteered to participate in this second phase of analysis were contacted and each of them sent a

breakdown of the emerging thematic statements. The lists were presented without any numerical attachments (they were not ranked in order of importance or in terms of numbers of participants who supported them). Participants were asked to review and make comment on any of the statements – offering challenges to my interpretations or seeking clarifications or further information.

7.6.3 Stage 3: Essence of the Whole

This step involves the researcher attempting to identify meanings within the individual texts and searching for expressions that reflect the essence across the whole data. This involved a prolonged time of listening to the voice data files and reading the corresponding transcripts within each of the three group-sets. Knowing that I was to meet with some of the participants provided the impetus to engage again with the data and allow familiarity and connection once more with the individual as they presented within the data. This became easier than I anticipated. Listening to the stories and hearing the voices brought the voice data and textual data to life. I was surprised and relieved that memories of individuals came back so clearly. Indeed, I was reminded of how strong the memories for specific recipients were when they started sharing their stories; some of them could even remember the smell of the doctor's aftershave or the colour of their tie. I came to realise that memories can be extremely provocative and I too could remember peripheral issues from the interviews. Things like the strong smell of fresh coffee and the sight of a frost covered garden in Maise's home or the irritating Celtic piped music in the background of the lounge as I interviewed Bill. Things I can now see as important as they were a link to the past, a means of enabling the emergence of a contextual memory. These things assisted me in connecting once more with a sense of the whole data.

7.6.3.1 Meanings of the whole – Recipients:

For the recipient group-set, the meanings of the whole can be summed up in a sense of seeking truth against a background of anticipated fear and uncertainty.

There were experiences of clinging to hope in the face of an unknown future. There was a sense of handing over to another – the healthcare professional. For some, in handing over there was a sense of letting go and letting the ‘other’ make the decisions. There was an impression that one became a diseased entity with a loss of identity. Combined with this was the undertaking for the emergence of self. This was often articulated through embedding their story within who they were as parents, partners, professionals etc.

7.6.3.2 Meanings of the whole – Nurses

The nurse group-sets’ sense of the meaning of the whole can be summed up in the struggle for maintenance of therapeutic relationships and excellence of care in the light of professional exclusion and restricted dialogue. There was a sense that they were at the ‘coal face’ and knew their patients extremely well. The impression of picking up the pieces, as they journeyed with the patient was evident across the group. Disempowerment through forced disengagement resulted in professional conflicts articulated through the analogy of walking in a fog.

7.6.3.3 Meanings of the whole – Doctors

For the doctor group-set the meaning of the whole can be described as the need to inform and impart the news with caring sensitivity. There was a sense that although difficult to do, it had to be done, and they were the ones that had to do it. There was an impression that the ‘buck stops here’. There was an indication of being available and ensuring that they ‘checked out’ the patients understanding through returning conversations. Other healthcare professional were informed of the diagnosis having been given rather than involving them in the giving of the diagnosis. There was a sense of believing in a multidisciplinary approach to care but one that was hierarchical and led by the doctor.

7.6.4 Stage 4: Meanings for understandings

This stage of the analysis involved the merging of meanings of the parts, from within each group-set, with the identified meanings from the whole from within each group-set. During this stage each of the significant statements were looked at within the overall sense of the ‘whole’ from the data sets. Example statements that fit into this are shown below. These statements relate to the doctors and their sense of; ‘although difficult to do, it had to be done, and they were the ones that had to do it.’ Examples of statements that fit into this ‘whole meanings’ were:

D. J. ...it is always difficult, but the patient has to be told. Once I have enough of the results to give a firm diagnosis I have to prepare myself to give the news to the patient. They are my patient and they expect me to help them ...

D. R. ... I used to hate it as a junior doctor but it was one of the jobs we had to do, so you just had to get used to it. I still find it hard having to give the diagnosis, if the outlook isn't too good.

This merging of the parts into the whole allowed for a recognition of individual meanings to be consumed into the more generic or ‘whole’ meanings attributed to each of the group-sets. It allowed for the confirmation of my interpretations of the whole through the applications of the parts. This led almost seamlessly into the next stage.

7.6.5 Stage 5: Shared Understanding

This stage saw the identification of themes which reflected the shared understandings of emerging meanings of the parts and the whole. It saw the collapsing of the statements from the parts and the sense from the whole into a manageable cohort of themes. This stage draws from Wilcott's (2003) encouragement to engage in rigorous procedures with sense-making.

Participants were sent a copy of the emerging themes within their specific group-set. Each participant who agreed to participate in this phase of the study was contacted between seven to ten days following posting of the themes. They were invited to meet up at a time convenient to them or talk with me on the phone, at a

time convenient to them. The majority of the participants requested the phone conversation. This was somewhat understandable as they had already given a significant amount of time to the interviews and then to the reviewing of the themes. Arrangements were made to call back when they had the information sent to them available. Discussions were interesting and offered confirmation and corroboration to the emerging themes. There were some challenges posed in relation to my use of some words, which once given an opportunity to discuss with the relevant participant, were either agreed upon or altered.

7.6.6 Stage 6: Merged Understanding

This stage differs considerably from that of Colaizzi and Koch's adaptation framework in that there is an overt acknowledgement of preunderstandings and their merging into the overall understandings. The hermeneutic circle was central to the process identifying shared understandings, drawing from the data collected and from my preunderstandings and reflexive journaling. Whilst separated out as a distinct phase, in reality this stage was the natural outcome from Shared Understandings. This stage allowed for the emergence of my own pre-understandings (fore-having, fore-sight and fore-conceptions) alongside the developing understandings of the three participant groups. It actually allowed for acknowledgement of personal filters and provided a type of holographic infrastructure around which I could see the essence of the phenomena of the participants. It provided a kaleidoscope or prism effect by which I could perceive the data as living and changing.

7.6.7 Stage 7: Exemplars

Unlike the stage from Koch's adaptation framework in which she re-examines transcripts to select exemplars of significant statements, this stage examines transcripts and preunderstandings to provide exemplars from both the participants and the researcher. This stage facilitates for the merging of understandings and

acknowledges the merging of horizons, allowing for a true presentation of the emerging phenomenological essence.

7.6.8 Stage 8: Phenomenological Essence

This stage allows for the articulation of the essence of the phenomena under investigation. It drew from the understandings of the participants and the preunderstandings of the researcher. It presents the structures that assist in the exposure of the phenomenon of the breaking and the receiving of bad news. In this study, the phenomenological essence of having to receive bad news is a trajectory encompassing three phases; disturbance within the everyday world, surfacing within the lived world and embodiment within the lived world. For the nurse involved in the breaking of bad news the essence is categorised within two phases, the centrality of which reflect a sense of connections with patient and disconnection with the medical staff. The essence of breaking bad news for the doctor is represented as objectified connectedness as they prepare for and engage with the bad news encounter.

7.7 Managing the Data:

There were large amounts of data generated within each of the three groups-sets. To manage the digital voice files a folder was created on a personal computer and backed up to an external device for security and retrieval. Textual data were also stored on a personal computer but managed within a computer software package. NUD*IST (non-numerical unstructured data indexing, searching and theorist) was the chosen software for managing the data. NUD*IST served as a text-base manager, storing the huge volume of interview transcripts and offering ease of access and retrieval of data. It facilitated the interpretation and management of the complex data and enabled the seeking of patterns and meanings (Janesick, 2004), allowing for the construction of explanations as they related to the data (Silverman, 2004).

7.7.1 Use of NUD*IST in the analysis process

7.7.1.1 Storing & Organising:

Microsoft Word files were converted into ASCII files and copied into the computer software. Each file was renamed with the pseudonym and given a link code, for example Mary N, Jack D, Amy R, where the N, D, R tells me the group-set; Nurse, Doctor or Recipient.

7.7.1.2 Searching for categories:

As each interview was read and reread the particular section would be tagged by applying a free-nodes. The software codes the interview line by line, thus making retrieval of specific sections easier. Each free-node related to concept or area which was of interest and which would form part of the analysis. For example, within individual interviews from the doctor group-set a free node emerged which I labelled 'getting ready'. This was articulated in different ways across the group-set but the free-node tag enabled the pulling together of all linked texts so that further analysis could occur. These sections could then be merged together and printed off or analysed on the computer screen.

7.7.1.3 Crossing categories:

The package allowed for free-nodes to be examined across themes. For example the free-node 'getting ready' was merged with 'knowing the facts' and this allowed for the generation of another perspective and the merging of text to provide a matrix that allows for an expanded view of the category.

7.7.1.4 Diagramming

NUD*IST allows for categories to be developed pictorially within a hierarchical family tree. The tree diagram has at its base a root, which then has parent and siblings. This provides a diagrammatic representation of how the significant statements (free-nodes) become clusters (minor categories) and then form themes (major categories).

7.7.1.5 Developing memos

NUD*IST allows for the insertion of memos or notes within specific free-nodes. This enabled me to enter ideas, thoughts, feelings, and hunches etc regarding specific nodes. This was useful at times as it allowed me to merge some of my pre-analysed thoughts from my reflective journal and post interview dialogues (with myself) into the data set. It also allowed me to pose questions, which I could come back to later in the analysis as I delved deeper into the data.

7.7.1.6 Reporting

One of the main benefits from the package was its ability to pull together large sections of tagged texts within categories and merge them into a new file. This was invaluable when it came to merging text into the final dissertation and again was a means of managing and handling large data sets with ease.

7.7.1.7 Critique of NUD*IST within this phenomenological study

I commenced using this computer-assisted software with a naivety and a sense of false comfort. In reality, the software was confusing to use and an inordinate amount of time and effort was spent attempting to master the programme. At times I felt that I was forced to distance myself from the actual data and that the programme was yet another example of depersonalising and decontextualising the data from the participants' stories. I found myself not in control of the data, but being controlled and directed by the requirements of the package. Whilst at times this discipline proved to be effective, in that it made me look at the text in a different way, there was often a sense of it leading me rather than the data informing me. Often I found myself sitting with sections of printed text forming piles of categories. This manual grouping and handling of data gave a sense of remaining close – I recognise that this was more to do with the comfort of familiarity rather than a shortcoming of NUD*IST. I took reassurance from one writer who admitted that he "... still prefers physically cutting up the field text and regards forming a mess of actual piles of text excerpts on slips of paper as crucial to the analytic process" (Cohen, Kahn and Steeves, 2000a:75). I would suggest that the use of NUD*IST aided in an aspect of analysis and representation of data, but would caution its use without adequate training and support. While

NUD*IST offered an effective means of managing and organising the data it must be stressed that it assisted in the process of analysing the data – it did not undertake the analysis for me.

7.8 Quality assurance activities

Language is the basis on which philosophical beliefs are articulated and communicated. As language differs within philosophical perspectives, it is argued that the transference of terms across paradigms may be inappropriate (Hamberg et al, 1994). The philosophical essence of epistemology and ontology of differing research paradigms may not be comparable and may therefore be semantically incompatible. This has led to a number of developments in qualitative inquiry, especially in the areas of quality and robustness of research. However, establishing a consensus on criteria for assessing quality of a qualitative study remains elusive. Indeed, some authors have questioned whether consensus can or will be achieved (Wainwright, 1997; Sparks, 2001; Seale, 2002). Difficulty arises because of a tendency to discuss philosophical and technical issues in the same context: 'Philosophical issues relate to questions of epistemology...technical issues bespeak the consideration of the superiority or appropriateness of methods of research in relation to one another' (Bryman, 2002:14). The former (epistemology) is theoretical and has been discussed in Chapter 4, the latter (methodological) is intensely practical and will be presented here.

7.8.1 Legitimising the research

Debate around the relevance and use in the qualitative paradigm of the terms validity, reliability and generalisability has continued over 20 years (Guba and Lincoln, 1981; Sandelowski, 1986; Mishler, 1990; Lather, 1995; Lincoln, 1995; Morse et al, 2002). Much of current understanding of the difficulties associated with these concepts has emerged as researchers have striven for clarity of purpose in qualitative methodologies (Lather, 1993; Altheide and Johnson, 1994).

7.8.2 Rigour as legitimacy

Rigour is a means by which integrity and competence are demonstrated (Aroni et al, 1999). It is a way of demonstrating the legitimacy of the research process. Without rigour, there is a danger that this research may become fictional journalism, worthless as contributing to knowledge (Morse et al, 2002). This need to incorporate rigour, subjectivity and creativity into the scientific process of qualitative research has fuelled debate over the issues of bias and the process of demonstrating validity (Johnson, 1999). Smith (1993), Van Maanen (1995), Denzin and Lincoln (2000) and Armino and Hultgren (2002) have all challenged the concept of rigour, arguing that by its nature it is an empirical analytical term and therefore does not fit into an interpretive approach. This view is refuted by Aroni et al. (1999), who suggest that concern about the demonstration of rigour is due to a struggle for legitimacy in a discipline that is dominated historically by the positivist paradigm. The representation of reality is the means of legitimizing the research and demonstrating the researcher's integrity (Slevin and Sines, 2000). Rigour is the means by which I attempt to demonstrate integrity and competence: it concerns ethics and politics, regardless of the paradigm. Lincoln (1995:287) suggests that '... the standards for quality in interpretive social science are also standards for ethics'. The attributes of rigour span all aspects of this study (goodness). It is the construction, application and operationalisation of these attributes that require innovation, creativity and transparency (Tobin and Begley, 2003). The criterion used to ensure rigour within this study originates from Lincoln and Guba (1985), who introduced the concept of trustworthiness.

7.9 Establishing Trustworthiness

Trustworthiness criteria is a means of judging the quality, rigour or goodness within a qualitative study (Lincoln and Guba, 1985; Skrtic, 1985). For trustworthiness to be evident, there must be four areas demonstrated within the study; credibility, transferability, dependability and confirmability (Lincoln, 1995). Clayton and Thorne (2000) argue that credibility and confirmability are foundational if one is to demonstrate truthfulness.

7.9.1 Credibility

Credibility (comparable with internal validity) addresses the issue of 'fit' between respondents' views and the researcher's representation of them (Schwandt, 2001). It poses the questions of whether the explanation fits the description (Janesick, 2000) and whether the description is credible. Central to the premise of seeking affirmation is the notion of verification (Anfara, Brown and Mangione, 2002). Creswell and Miller (2000) identified prolonged engagement and peer debriefing as two of eight verification procedures referred to in the literature and support the view that at least two of the eight verification processes should be evident within a qualitative study (Guba and Lincoln, 1989; Creswell, 1998; Crawford, Leybourne and Arnott, 2000). Credibility is demonstrated within this study through a number of strategies: prolonged engagement, persistent observation, member checks, peer debriefing, and audit trails (Lincoln, 1995).

7.9.2 Prolonged engagement

Lincoln and Guba (2000) relate to the need to establish an understanding of the culture of an organisation and research site. Whilst research sites were not part of this study, there was a sense of ensuring that an understanding of the culture (context) of the participants was established. This also facilitates a level of trust between researcher and participant. This began from the initial contact and continued throughout the interview, in some cases it continued after the interview. It could be argued that prolonged engagement in this situation was situational with the participants as opposed to a geographic area or organisation.

7.9.3 Persistent Observation

This is achieved by identifying and focusing on the issues investigated (Lincoln and Guba, 1985:304). This was achieved through engaging with the voice data files and text files. The use of NUD*IST and its ability to label and group nodes together ensured that I was constantly engaging with and observing the essence of the phenomenon of bad news. Engaging with the hermeneutic circle also facilitates this persistent observation. The data analyses phases of '2001-2003' and '2004-2005' ensured that I remain in a steady and continual state of contact with the data thus constructing a persistent observant engagement.

7.9.4 Member Checking

Also referred to as member or respondent validation (Holloway, 1997; Schwandt, 2001), this process involved offering participants the opportunity to check out interpretations, seek clarity or challenge any issue. As discussed earlier, some of the recipient group did not want to receive copies of texts or my interpretations (analysis). However, all participants were allowed to check issues as part of the interview process. This occurred through a mixture of using paraphrasing and reflecting/mirroring. In doing this I was able to offer back to them, what I thought they were saying. This provided opportunity for them to seek clarity, offer correction and so contribute further to the dialogue. Participants from the nurse and doctor group-sets were sent a copy of their transcript and a concise version of my interpretations and emerging themes.

One of the inconsistencies that is not addressed and still exists within Guba and Lincoln's (1994; 1995; 2000) work is the philosophical contradiction of member checking (Gallagher, 1995; Silverman, 2000). A major critique offered by Smith (1993) challenges the appropriateness of procedures such as member checks when the philosophical idea of multiple realities has not been addressed. Another challenge to the use of member checking is offered by Ashworth (1993) who suggests that it may not be a true measure of trustworthiness as participants might not want to disagree with the researcher. With this in mind I was conscious of seeking further affirmation regarding my interpretations. This affirmation occurred in two main ways; peer debriefing and the emergence of the phenomenological nod. I include them here as they contribute to the transparency and trustworthiness of the study.

7.9.4.1 Peer Debriefing

This occurred in three main ways. Firstly, throughout the study the research supervisor was engaged in discussing and offering challenges to the process and interpretations. This consistent 'critical eye' offered space to explore, debate and review each aspect of the research as it occurred. Secondly, as part of a research seminar group which met monthly, I was challenged frequently as I discussed aspects of the data analysis. Critique of presentations and discussions were

ongoing as members shared progress of their work. Thirdly, a small group of five fellow academics who were all involved in doctoral research met bimonthly and offered support and a critical challenge to ongoing developing of each others work. Each of these three debriefings offered 'formal' and 'informal' challenges to the ongoing development of the study.

7.9.4.2 Phenomenological nod

Van Manen (1999: 27) suggests that '... the phenomenological nod indicates affirmation by readers (or audience) that they recognise and can relate to the described experience.' The 'nod' came in different forms and at different times and venues. As discussed above, peer debriefing offered the 'nod' of affirmation on numerous occasions. This affirmation from fellow colleagues, doctoral students and experienced researchers was important, as it afforded some sense of achieving a level of truthfulness at a time of vulnerability. When the nurses' experiences of being present when a patient receives bad news was presented at a conference in Ireland (Tobin, 2005a) I received nods throughout the audience and afterwards numerous conference attendees sought me out to affirm that the findings reflected their experiences as nurses. Aspects of nurses perceptions regarding their contribution to the patient during bad news was presented at an international conference in Jordan (Tobin, 2006). Following this presentation numerous nurses from the Middle Eastern region, who were working in situations vastly different from the context of nursing in Ireland also confirmed that they identified with the nurses in the study. When I presented the findings of the recipient group at an international conference (Tobin, 2005b), conference delegates confirmed afterwards that the narratives and the interpretations of meanings were true for them (two had been treated for cancer, one in Ireland and one in the UK and a third participant, a nurse from America was currently looking after her daughter who was dying from cancer). Finally, as friends and acquaintances heard of my study they would often seek me out to talk about their experiences. Whilst not familiar with the study findings, process or interpretations they often shared an 'unknowing nod' by mirroring in their story the experiences of those within the study.

7.9.5 Transferability

Transferability (comparable with external validity) refers to the generalisability of the study (Denzin and Lincoln, 2000). In a naturalistic study, this concerns only case-to-case transfer. Qualitative researchers need to recognise that the comparable 'external validity' is substantially different in qualitative inquiry, as there is no single correct or 'true' interpretation in the naturalistic paradigm. Donmoyer (1990) argues that rejection of traditional perspectives of generalisability is required, as naturalistic inquiry has individual subjective meaning as central. Leininger (1994: 106) suggest that transferability refers to when a study's findings can be transferred to another similar context, whilst preserving the particular '...meanings, interpretations and inferences.' The ability to apply transferability from this study is facilitated within the inclusion of thick descriptions from the participants. Transferability occurs with the reader as they make connections and learn from the study.

7.9.6 Dependability

Dependability (comparable with reliability) is achieved through a process of auditing. Researchers are responsible for ensuring that the process of research is logical, traceable and clearly documented (Schwandt, 2001). Dependability is demonstrated through an audit trail, where the reader can examine description of methodology and rationale for it choice, the methods chosen and their application, decisions made, the analytical process and the interpretations and findings. Throughout the presentation of the thesis I have endeavoured to present a true reflective account of the process as it happened. Excerpts from the reflective journal are offered throughout and the writing style throughout is one of a reflexive style. Reflexivity is seen as central to the audit trail and therefore I have strived to present the realities of the phenomenological study. At times this may give an impression of a study which lacked cohesion. It is the presenting of a self-critical account of the actual research process that I believe offers the reader an insight into the real world of research and should offer an honest, dependable

audit trail for others to peruse. Auditing can also be used to authenticate confirmability.

7.9.7 Confirmability

Confirmability (comparable with objectivity or neutrality) is concerned with establishing that data and interpretations of the findings are not figments of the researcher's imagination (Schwandt, 2000), but are clearly derived from the data. Lincoln and Guba (1985) suggest that neutrality is established through audibility, credibility and transferability. Throughout the thesis the use of participant's voice is offered as a means of ensuring neutrality.

7.9.8 Authenticity

Sparks (2001) challenges the concept of trustworthiness and argues that the starting point for Lincoln and Guba was that of the conventional researcher. He argues that their aim to develop parallel (comparable) criteria to replace the inappropriateness of the 'trinity of truth' (validity, reliability and generalisability) is questionable. Smith (1993), Gallagher (1995), Bloor (1997) and Silverman (2000) all highlight the inconsistency of developing criteria that are parallel to positivist criteria, while rejecting the positivist paradigm. The concept of 'checking', as advocated by Lincoln and Guba (1985) is certainly antithetical to the epistemology of qualitative inquiry and does reveal some philosophical inconsistencies. Member checks and peer debriefing were not undertaken within this study as a means of ensuring robustness and completeness and not to ensure a numerical confirmability.

Reflecting on their earlier positions and recognizing the critical comments, Guba and Lincoln (1994) addressed these imperfections by introducing authenticity as a fifth criterion (Christians, 2000). Authenticity is regarded as a feature unique to qualitative research (Schwandt, 2001). It is demonstrated by showing a range of different realities, with depictions of associated concerns, issues and underlying values. This notion of depicting realities is clearly offered within this phenomenological study as the phenomenon of receiving and giving bad news is

presented as it is self-interpreted by the participants. This demonstration of a sophisticated understanding and enlargement of personal constructions of the phenomenon being studied are referred to as ontological authenticity (Guba and Lincoln, 1994). The ability to help people appreciate the viewpoints and constructions of others is indicative of educative authenticity. Catalytic authenticity is verified by stimulating some form of action, while the fifth marker of authenticity, tactical authenticity, is established through empowering others. Educative and tactical authenticity can only be evaluated post publication of the research, and as such cannot be a measure of rigour at this stage.

Morse et al (2002: 2) argue that there is a fundamental problem with trustworthiness and authenticity criteria because they provide a post hoc strategy for evaluation of a study. In so doing they avoid focussing on the process of verification during its conduct, thus running 'the risk of missing serious threats to the reliability and validity until it is too late to correct them'. They further suggest that the subtle move from constructive (during the process) to evaluative (post hoc) procedures has led to a situation in which there is little or no distinction between procedures that check validity during the course of inquiry. I would argue that the process of demonstrating goodness as an overarching concept combined with the measures to ensure that trustworthiness and authenticity within this study, ensured that the process was not a post hoc, end stage evaluative measure. Truthfulness, credibility, transferability, confirmability and authenticity became part of the fabric of the hermeneutic circle and ongoing conversations between researcher and the research process.

7.10 Concluding Remarks

This chapter offered an overview of the analytical process, providing examples of how the analytical endeavour allowed for the emergence of both a description and interpretation of the lived experience of receiving and giving bad news, filtered through the preunderstandings and fore-structures of the researcher. It presented the two phases of analysis to offer the reader an insight into the

complexities of the process as it was experienced. The chapter has attempted to present a phenomenological hermeneutic account of ‘being-in-the-analysis’. It presented a summary of interrelated processes of analysis of the hermeneutic data, namely the exploration of thematic analysis, the analysis of exemplars and a search for phenomenological essence. It offered an eight step framework which was developed to provide an infrastructure to that process.

On reflection I believe that the presentation of the ‘actual’ process adds to the authenticity and credibility of the study. The following chapter will offer a discussion of the findings relating to the recipients’ data that makes explicit the phenomenological essence of the receiving of bad news.

CHAPTER 8

PRESENTATIONS OF FINDINGS - RECIPIENTS

8.1 Introduction

Van Manen (1990) suggests that if an appropriate means of presenting hermeneutic interpretation is not available, then the researcher should create one. In the presentation of the results of this investigation, three key issues had to be considered: how to present the phenomenological triangle of recipient, nurse and doctor whilst maintaining the uniqueness of the essence of the phenomena and recognising the interconnectedness of each; how the phenomenological tradition will be represented; and how to offer the reader an opportunity to meet the participants of the investigation in a way that did not dehumanise or decontextualised their lived experiences.

The results of the analytical process will be presented in the following three chapters. Each chapter will focus upon the chosen group-set and each will have three sections: participant's stories, thematic categories and phenomenological essence.

8.2 Introduction to Recipient Group

The aim of this phenomenological study is to seek meaning and understanding of the experience of delivering bad news and receiving bad news. This section presents the stories of the recipients - those participants who received bad news. The interviews were conducted with a diverse group of people drawn from four areas across Ireland. Six women and four men participated in the study. All had been given a diagnosis of cancer and were now 'symptom free' (appendix XV). Some referred to themselves as survivors and felt that they lived their lives in the realisation that they had 'conquered'. As the focus of this research study is on the experience of having received bad news and not on the long term effects of the condition, participants in this section are referred to as recipients and not survivors. Whilst acknowledging their centrality in the study, it was felt that for the sake of clarity, the use of the title 'recipient' was felt appropriate as it enabled this sample grouping to be identified within their selection group i.e. recipient of

the bad news, as opposed to the nurse and doctor groupings – deliverers of the bad news. It is in no way an indication of depersonalisation or lack of concern for them as persons, indeed the inclusion of their stories places great emphasis on their experiences as individuals.

For the recipients involved in this study, receiving the diagnosis was life-changing. Whilst the hearing of the diagnosis was an event in time, the recipients contextualise the event by a number of related issues. It will be argued that receiving bad news is more than an isolated event. It is a process that occurs over a period of time, often involving a number of people and for the recipient there is a mechanism of internalisation and processing. Therefore there is a need to realise that whilst breaking bad news may be seen by the deliverer as an event in time, for the recipient, bad news may be given and audibly received (hearing), but the actual processing (receiving) of the news occurs over time. As will be seen, hearing the news may not be the initial phase but, depending on the recipient's knowledge, may be the second stage in processing bad news. For some participants, there had been a period prior to hearing the diagnosis of the disease in which they struggled with their own internal fears or worries. Some were looking for confirmation that they had something wrong with them or that it was not what they feared (cancer) but all were looking for truth.

The aim of this section is to allow the reader to 'get to know' more closely the ten people who experienced receiving a cancer diagnosis. It is anticipated that in allowing the reader access to the stories, the reader may connect with the participants, as each share their experience and describe the meanings attributed to this life event. It is through the richness of narrative that insights into their experience are obtained. It is hoped that their words will illuminate the meanings associated with the phenomena.

As nurses we can learn from the experiences of others through connecting with them. Narratives can provide a path to that experience and thereby improve nursing knowledge (Frid, Ohlen and Berghom, 2000). At this initial presentation of data I wish to present the person behind the narrative – the person behind the

diagnosis. The rich data emerging from the life stories of individuals who shared what it was like to be given a cancer diagnosis can broaden our horizons and offer an understanding of their journey. Within their stories lie uncovered elements which may not have previously been identified.

8.2.1 Recipient as Narrator

In this section I want the narrators to be present through their stories. Rather than presenting themes and categories – which place the researcher as the narrator, I want to offer a brief insight into unique experience of the phenomena of receiving a cancer diagnosis and describe the meaning the people involved attributed to this experience.

As will be discussed later in this chapter, the findings from the recipient of bad news indicates that receiving bad news was perceived by some as becoming labelled with a cancer diagnosis. The subsequent impact of this was to feel dehumanised. This is referred to within the study as the ‘transformative power of diagnosis’ and represents the shift from an identity of self to an identity of pathology. This became evident in the experiences of many of the recipients. In an attempt to avoid further dehumanisation of I wish to initially offer an insight into the world of each of the recipients of bad news. In so doing themes become contextually located within the realities of life as it is lived for each of the recipients.

A number of recipients asked to have their own names used within the study. However, I explained that it was a requirement of the ethical committee that anonymity and confidentiality be maintained throughout the process. Some found this difficult, as they considered that whilst I was prepared to use their stories and give voice to their experience, I was unprepared to give authenticity to their personhood. It was an interesting situation, and one that I had not envisaged happening. Was I as researcher prepared to use their narratives and their anonymity to provide the research data required and in so doing, keep them anonymous, despite their request for exposure? There may have been deeper issues surrounding this request (Breaden, 1997; Leigh, 1999; Dirksen, 2000).

Having survived the experience of having a cancer diagnosis and living with the condition, the people involved may have felt that they wanted to acknowledge their survivorship by using their names. Considering this issue, the letter of invite could have been worded to give each research participant the right to decide if they wished their personal identity to remain fully anonymous or to have it revealed. In this age of freedom of information, perhaps it is time to allow research participants to decide which they preferred. It was argued by one of the recipients that real names of individual recipients could have been used within the study, keeping the names of institutions and others involved anonymous. It was finally agreed with three of the recipients, who felt very strongly that they wanted their names to be used, that I would use their first names. They and only they can identify who they are. All other information which may potentially link them to an institution, doctor or family has been altered so as to protect these 'others'. I have made no indication whose names are a pseudonym as it was felt that it was important to ensure respect to the whole group involved.

8.2.2 Narrative Chaos

At times I wondered if I was getting to the meaning of their experience and often found myself questioning the worth of the interview. Frank (1995) reminds us of the need to listen not only to stories as people strive for meanings but to recognise and respect the chaos of narrative. Frank (1995) refers to the chaos narratives as those which may appear confused and lacking in coherence. He cautions us not to prejudge but rather to respect the dignity of the human story. Frank's encouragement to allow the chaos of narrative resulted in recipients taking 'the pen' and 'writing' their story. It became apparent that whilst I was interested in their experience around the issues of receiving bad news, for them it was important that they were allowed to talk about the whole episode in their life. Of immense importance therefore was that receiving bad news was not an incident but rather an episode; not an encounter but rather journey. It was in allowing recipients to locate the story within their journey (setting the scene) that enabled the phenomena to emerge.

8.3 Stories

Benner (1994a:38) refers to paradigm cases as a cases which have a particular experience that stands out and provides a means of gaining a rich understanding. It could be argues that all participants offer an individual case and each is itself representative of a paradigm case. A brief overview of all participants is offered to provide some contextual background. It is felt necessary to have this background in order to help illuminate the experience and meanings attributed to receiving a cancer diagnosis, as made by the recipients. My intention as researcher is to ensure that not only their diagnostic experience is presented but to try and offer a picture of the actual individual involved. It took courage and commitment from each recipient to share their story. As their stories unfolded it became clear that the experience of being given bad news could not be separated out from who they are as people.

8.3.1 Amy

When I met with Amy she was in her mid thirties. She was married with three children, the youngest of which was six and it was while breast feeding this child at 5 months that she discovered a lump in her breast. Amy was very easy to talk to and wanted to share her story. She took the lead in the interview from the opening question. She said she wanted to tell her story and had spent considerable time thinking back over the events in the days leading up to our interview. This sense of connecting back or preparing to allow the presenting past to re-emerge was common amongst all of the recipients. Her story, like all the stories from the participants has a 'before and after' point of reference. This interruption of the every day world of life is significant and offers a place of location from which to contextualise the experience. Her story tells of the shock of finding a lump and the way she moved from being a happy mum of three, the youngest being breast fed to that of being a breast with a lump.

I was only 33 years old when I found the lump in my breast. I couldn't believe it when I first felt it. I had been breastfeeding Olivia [her 5 month old daughter] and was beginning to wean her off the breast. I

was checking to see if I had enough milk. I was concerned that my milk was drying up and Olivia might not be getting enough.

Anyway, I felt the lump – I was in a total state of panic and screamed for John [Amy's husband]. He didn't know what was wrong but knew by me that it was serious.

I had him feel for it and he felt it also, it wasn't big, ah it was about the size of a pebble. But it was definitely there.

From the initial shock of feeling the lump, Amy talks about the sense of becoming almost invisible. This sense of being invisible or dehumanised was something felt by many of the recipients.

I was a patient going for surgery. I felt I was actually a breast lump and not me. Not Amy -, a mother of three and a wife, who held down a responsible job until the birth of my last baby.

No... [*pause - 6 seconds*] I was in a gown waiting to be passed over to someone else to have my lump removed. It was strange really I felt totally out of control, everything was done for me or to me and it was as if I had little say.

Her story describes her experience of being catapulted from the joy of ordinariness to a place of utter panic and the subsequent struggle for confirmation of what she suspected. Despite presenting herself to numerous professionals she was repeatedly 'reassured' that everything was probably all right. The placation of the recipients through 'Don't worry' did little in reducing anxiety, and in some cases compounded the sense of becoming invisible. It was this sense of not being heard which Amy found particularly difficult.

We rang the GP immediately and I spoke directly to him. He reassured me that it was probably a blocked milk duct and told me not to worry.

"Not to worry!" – there hasn't been a day since that morning in June '99 that I haven't worried. Worry has become the fabric of my daily life. (Long silence -8 seconds, looking past me as if I were not in the room)

Amy's struggle for truth and confirmation of her fear was reflected in her persistence, even though at times she doubted herself. She needed to be heard and once she finally had the courage to seek a second opinion from an oncologist she then had to deal with the realities of living with a breast lump was might in fact be cancerous.

Like many of the stories told by the recipients, Amy's was at times rambling and not necessarily in logical order. She spoke of the early days of shock and the sense that this could not be happening to her. The sense of becoming processed or being moved through the system was common to others also. She perceived the doctors to be more knowledgeable and in wanting to trust them she had to let go of her fears. Something which for many telling their stories only brought temporary relief as for Amy there was always the fear of *'what if'*.

8.3.2 Bill

Bill was in early fifties, married with five children when he began to worry that something was not right. Now six years on since his surgery for bowel cancer he lives at home with his wife and two youngest children, one who is in her final year of university and the second youngest who is working but living at home. Bill was a carpenter by trade and although retired continues to do small 'odd jobs' for family and friends. I interviewed Bill at his local pub, a choice he made as he wanted to 'get out of the house and away from Rita [his wife]'. He told me later over a pint of Guinness that he still finds it difficult talking in front of Rita, as she kept pushing him to seek help and he kept putting it off. He also talked of the constant fear of reoccurrence and the silent unspoken fear of having to go through it all again.

He spoke of the sense of total shock and the sense of not wanting to go for help.

... total shock. I was in total shock. I had no idea, no idea at all, so I had. I was having problems down below for about a year. At first I just decided to ignore it, I thought it was something I had eaten. Then when the blood was there I just thought it was haemorrhoids. It was my wife that insisted I go the doctors. Eventually I did go and he agreed with me that it was probably just haemorrhoids.

He describes how it was the constant nagging by his wife that eventually led him to seek medical advice. He talked of feeling foolish and then relieved when the doctor put his mind at rest.

That's right. I felt a bit of a fool going there but at least it put my mind at rest. ...I went really because of the wife, I knew there was nothing wrong and he confirmed it for me.

Anyway, it didn't get better and the treatment he gave me did nothing, I was still passing blood each time I went the bog and I was having terrible bouts of diarrhoea and then I would be constipated.

This reassurance helped him to get on with his life. It was only as things began to deteriorate over the subsequent twelve months that Bill, again on the insistence of his wife went back to his doctor. He hung to the notion that the blood following a bowel movement was due to haemorrhoids and nothing more. Eventually he returned to the general practitioner, who decided to refer him to a specialist at the local hospital. Bill was now moving from being dismissive to a place of fluctuating between the 'what if' and denial. Unlike some of the other recipients, Bill clung to the words 'don't worry' in an attempt to support his wife and children. He wanted them to embrace this idea also. This is evident in the next extract from our conversation.

Relieved really, I know I trusted him when he told me it was probably haemorrhoids, but I wasn't getting better and to be honest I was worn out with the whole thing, it had taken over my life. He told me not to worry and that he was sure everything was fine.

I got an appointment for six weeks later and just waited. You can't help worrying really, but I kept thinking that the doctor was right and I was just worrying over nothing. I really convinced myself that everything was OK. I put on a brave face for Rita and the kids.

Bill spoke of the time of waiting for information. Having denied that anything was wrong for a year and then waiting six weeks to see a specialist, he recalled the period of waiting for information following his endoscope and then the realisation that perhaps something might be wrong.

... they said they couldn't give me a proper diagnosis until they had all the results back. But I got a phone call from my GP within a few days saying that I was anaemic and that he wanted to put me on Iron tablets. He said it was nothing to worry about and was probably due to the bleeding I was having over the past few months. I asked him if he had heard anything from the hospital, but he said he hadn't apart from the blood results.

Rita got a telephone call from the hospital saying I had to come in right away. She was in pieces, they only said that the consultant had a bed for me and that he would like me to come in on the Monday, the call came in on Friday afternoon. They couldn't give her any information over the phone as that was not hospital policy. ... we just spent the weekend waiting.

The need for truth competing with the need for protection from that truth was a common theme amongst the recipients. For Bill it was evident throughout his journey. It is interesting to note that issues relating to truth disclosure and levels of disclosure also appear within the nurse group and the medical group. For Bill, as opposed to Amy, the 'Don't worry' mantra offered permission to hide from his suspicions. Hiding from his doctor, hiding from his diagnosis, and hiding information from his family was a common thread throughout Bills story. Eventually following surgery he sought the truth regarding his condition. His story reveals not only his awareness of the situation and the suspicion of cancer, but also the difficulties of facing that situation amongst an environment that was not been entirely truthful itself.

Before I went home I had a long talk with one of his [consultant] doctors and asked him to be honest with me. I said I wanted the truth, and that I needed to know everything so that I could look after my family. ... All I really wanted to know was ... was I going to die and how long I had to live.

However, for Bill the need to protect his family and continue hiding the issue of his fears seems to be the way he manages his survivorship. On one level he looked for and indeed demanded the truth, yet dealing with that truth and how much to share with others was an ongoing dilemma for him.

Rita and me, we are there for each other and I know we are real, but then I worry about putting her under too much pressure and sometime I find myself not wanting to talk about things.
But it lives with you, it never really goes away, it's the silent thing that we don't talk about but its always just there in the shadows.

In his interview, Bill revealed that despite going through periods of embracing the 'Don't worry' mantra, he also wanted to be told the truth. The 'not telling' actually fed into his ability to deny and hide. When he eventually came to the

place where he wanted to know if he had cancer he had difficulty getting those caring for him to use the word. This use of euphemism was a common thread throughout many of the recipient group and will be discussed further when we meet Rhoda.

Bill was so caring and worried much for his family. He seemed to be carrying a lot. It was clear from his body language and his response to some probing questions that he did not want to get into how he was currently coping with his situation. His closing remark was sobering.

The only ones who were really honest were the other patients. They were great, we had a good old laugh, you had to laugh to get through it. And then you hear about someone dying from cancer and you think God I'm lucky. But its always there, you always have a fear of it coming back.

Eight months after talking with Bills during the second phase of analysis I had a telephone call from Rita. Bill had a recurrence of his cancer – he had secondary growths in his liver and pancreas and died within a number of weeks. Rita said it was as if he just gave up the will to live and died.

8.3.3 Rhoda

Rhoda is 47 years old and has lived in the rural part of Ireland for over 15 years since she and her husband returned there from London. She has two children, both of whom were born in Ireland. She trained as a nurse and health visitor in England and currently works as a public health nurse in, covering the rural area where she lives. She was very keen to tell her story and although at times found it painful to relive some of the experiences she insisted on completing her story.

She began her story by saying how the experience of being ill totally changed her perspective on health, life and illness. She found the experience of being a patient frustrating and the distance from 'specialist' care difficult.

He thought it was just a fatty lump. I wasn't happy and asked for a referral. I waited two months for an appointment; I tried to influence the consultant's secretary by telling her I was a nurse. I can still remember her response "you could be the queen herself and I still couldn't fit you in any earlier.

For Rhoda, her search for confirmation of her suspicions was one in which she had to actually introduce the word cancer into the conversation. Like Bill's experience, Rhoda found that doctors and nurses used euphemisms when describing her condition.

I eventually managed to get admitted – I think about three months after I first felt the lump. Even as an inpatient who was to have a lumpectomy with query mastectomy I found that people would constantly refer to it as a lump. It drove me crazy really. Now I know they were only trying to be kind and to offer some sort of hope. But it's not as if I didn't suspect I had cancer, and it's not as if I didn't know what was going on. Eventually I actually said to one of the doctors that I knew it was cancer and that it was alright to call it by what it was. She did do so but she seemed awkward initially. She must have mentioned it to the consultant, because next time he spoke to me he used the word for the first time. I was relieved really, at last someone was thinking as I was...or was feeling that they could be honest with me, I gave them permission I suppose.

Her experience of euphemisms was also reflected in the stories of other recipients. Words such as blockage, bowel problems, wart, swelling, shadow to name but a few. For the recipient this play on words only served to actually distract from facing the reality of their condition. Indeed one recipient five years on, despite having had surgery and chemotherapy was adamant that it was not 'C' (she would not use the word cancer), it was a 'cist' which they had to remove. This discussion on the use of euphemisms will be visited once again when we look at the findings from the healthcare groups. Rhoda spoke of a sense of isolation and of being almost invisible, something which was also present in the stories of the other participants.

She is back at work full time and feels her experience of having cancer has totally changed how she approaches her patients. She is active in her community in supporting others who 'face down the road of cancer' and feels

that she has gained much through the ordeal. She believes she is enriched as a result of her illness.

8.3.4 Maise:

Maise is a senior partner in a solicitors firm. She is married with two children and lives on the outskirts of a large town in the west of Ireland. Despite a mix up in her diagnosis, Maise is very positive about her experience and feels that everything that could have been done was done. Maise's began to locate her story through telling of her friend's experience.

For my neighbour Alice, it was having to take off of her clothes which she remembers most. I didn't care about taking off my clothes I just wanted someone to tell me everything was O.K. To look at me and tell me I was alright....

The night before going in to hospital for a hysterectomy Maise felt the lump in her breast. She said she knew straight away that it was more than a lump. She didn't tell her husband but kept it to herself until she was in hospital.

I was going into the XXXX for a hysterectomy, 'cause I had a pre cancerous polyp and they had advised me to have the womb out. I was sitting reading late at night, my hands were cold. I slipped my hands in under - I had a vest t-shirt on. I slipped it in under the bra to warm the hand ... and it landed on the lump. And I knew from the minute I felt it, I knew that this was cancer.

Throughout her story, Maise strives to keep her husband from having to find out too much information. She informs him out of desperation as the diagnosis unfolds and she has to face the fact that rather than having a benign cancer she in fact had a very aggressive cancer which required surgery, chemotherapy and radiotherapy. Her story tells how she strives to remain the person she was prior to her cancer diagnosis. She spoke of having her family photographs on her bedside locker so that people knew who she really was. She made decisions to wear makeup and to face each day as it came. She also spoke of the crushing effects of coming to terms with her condition and her many nights of crying and questioning. She spoke of her need to take control of the situation and at times how she would direct the medical team by confronting them with questions and

challenge them when she felt threatened and unsure. Her story reflects that of a frightening journey from pre-diagnosis through treatment and presents the bad news journey as a trajectory which represents a process of coming to know rather than an event of disclosure. The trajectory was not necessarily linear nor was it predictable.

8.3.5 Eddie:

Eddie is a 59 year old married man. He had smoked since he was a teenager, although he gave up prior to his cancer diagnosis, when he began to become short of breath. His wife still smokes about 30 a day, but he jokes that she does it outside and not in his presence. He is a construction worker and has, in his own words been lucky as his employer has moved him off the site and into the depot yard, where the work is not as physical. He has two children and openly chatted about them and their careers. He is extremely proud of their achievements, his oldest daughter is in teacher training and his younger son recently started at university in Dublin. The family seem very important to him and he refers to their support and encouragement throughout his journey. He was relatively fit prior to his lung cancer and was “not one to go to the doctors”. He was easy going and appeared to want to share his story. He felt he had overcome the cancer and was enjoying all that life had to offer.

8.3.6 Jack:

Jack runs a very busy farm in the south east of Ireland. His wife works on the farm with him and during his illness she had to take over the full running of it. He is now back working again, but feels that he is not quite 100%. He was 53 years old when he was given a diagnosis of lung cancer. He has never smoked and neither has his wife. There was a history of lung cancer in the family, which up until his own situation he had put down to smoking. He has one son aged 16 and he is a great help around the farm. Jack was never in hospital prior to this illness and found the whole experience quite intimidating and frightening. He appeared to have no difficulty talking about his situation at home prior to his

illness or indeed since ‘getting the all clear’. He had some difficulty discussing the actual experience of being told his diagnosis. I have included his story as I felt that even though his was the shortest interview, it was important for him to have his story told and for him to feel that he actually contributed something to the study which he so eagerly participated in.

8.3.7 Daphne:

Daphne is a chatty single lady of 60 years, who lives with her younger sister, who is also single. They have lived together for over 30 years and are very close. Daphne would see herself as the boss of the household and her sister as the worker around the home. Daphne had been hospitalised 30 years earlier for minor surgery but other than that had been fairly healthy. She talks about the good relationship she has with the GP and it would appear that they have a good network of neighbours and friends around them. Mary, Daphne’s sister has diabetes and regularly sees their local GP. Daphne often accompanies her on these visits. There is a sense that these visits provide an opportunity for the two sisters to get out together.

There is a family history of cancer; their father dying in his 50’s from lung cancer, a memory very much still alive for Daphne and her sister. She found the whole hospitalisation and diagnosis quite traumatic and got right into discussing this even before we formally began the interview. Her sister was present in the house while I was conducting the interview and frequently came into the room checking to see if Daphne was alright even before we began. Eventually I asked Daphne if she wanted her sister, Mary to join us. She asked if this would be OK and we agreed that she could if she wished. She did so immediately, but actually did not verbally contribute at all throughout the discussion. Her presence was important for Daphne and there was often non-verbal contact between the two as Daphne shared their story. I could see how the separation caused by the hospitalisation must have impacted them.

8.3.8 Catherine:

Catherine was 36 years old when she discovered something was wrong with her. She is extremely confident and appears quite outgoing. She runs a very successful firm of accountants and is very positive about her career. She lives alone and is very happy to talk about her experience. She mentioned that she is not one to fuss and likes to strike from the hip, hence her frustration at not been involved or informed fully during her illness. She felt that lack of information was more difficult to cope with than the actual diagnosis. She appears highly motivated and mentioned on a number of occasions how she accessed the web for information when she suspected breast cancer and subsequently since she had her surgery. Her elderly parents live near by and she sees them frequently.

8.3.9 Jeanette:

Jeanette was given a diagnosis of ovarian cancer five years ago when she was 43 years old. She is married with three children and works full time at home. Her understanding of her condition was rather limited as she did not feel the need to know too much about her illness or what she had done while in hospital. She knew she had her womb removed, but other than that she was unsure. She did not know the name of the surgery and as she joking said – ‘didn’t want to know either’, she has been on hormone replacement therapy since her operation. For Jeanette, the cancer was gone, ‘they caught it in time!’ and that was enough. She confided in me that she had suffered a period of depression one year after the operation and that this lasted approximately six to nine months. She was treated by her GP for the depression and felt that it had nothing to do with the previous cancer diagnosis. She talked openly about her experience around the time of the diagnosis and had vivid memories of time and events, this in stark contrast to her understanding of the actual type of cancer and treatment she received.

8.3.10 Rachel:

Rachel worked as a care assistant on the ward where she had her surgery. She had been working on this ward for three years and felt she knew the nursing staff quite well, although her contact with the medical team would have been negligible. She gave up her job as a care assistant following the surgery as she felt she could not go back to work on the wards. She currently works as a librarian assistant in her local library. She was 45 years old when she had her diagnosis of ovarian cancer, which was five years ago. She has four children and is separated from her husband. Their marriage broke up the same year that she discovered she had cancer. Her husband lives about five miles away with his new partner and her two children. He would often come to visit Rachel and their four children. She talked openly and frankly about the split in her marriage and felt it important to have this highlighted as she feels that there was such a lot going on in her life around the time of the diagnosis and surgery that it would be impossible to talk of the ovarian cancer in isolation. Rachel talked about how initially, she was quite philosophical about her illness and felt that although it was a cancerous growth, she had little use for her womb and it was just as well to have it out. However, as time has gone on she spoke of having to come to terms with her loss and the fact that due to the circumstances at the time of the illness she had not taken on board the significance of the surgery. At that time, she said her main concern was her fight for survival for her children and her marriage.

8.4 Emerging Themes

The identification of themes emerged as the analytical framework was applied. In this section, parts of all the participants' stories are included to fully demonstrate the meanings that emerged. Four themes emerged during the analysis. These are: 'Disturbance of the Everyday-World', 'Surfacing within the Lived-World and 'Embodiment of being within the Lived-World' and 'Processing as being'. Each theme is comprised of a number of categories which provide demonstration of the essence of the phenomena.

Table 8.1 outlines the themes and categories which were revealed through the analytical framework steps 1-7.

Table 8-1 Themes and Categories - Recipients.

THEME	CATEGORIES
<p style="text-align: center;">THEME ONE</p> <p style="text-align: center;">DISTURBANCE OF THE EVERYDAY WORLD</p>	<p style="text-align: center;">Suspected - Knowing:</p> <p style="text-align: center;">Dismissive Mantra</p> <p style="text-align: center;">Truth – Knowing</p>
<p style="text-align: center;">THEME TWO</p> <p style="text-align: center;">SURFACING WITHIN THE LIVED- WORLD</p>	<p style="text-align: center;">Transformative Power of Diagnosis</p> <p style="text-align: center;">Emerging Self</p>
<p style="text-align: center;">THEME THREE</p> <p style="text-align: center;">EMBODIIMENT OF BEING WITHIN THE LIVED-WORLD</p>	<p style="text-align: center;">Subliminal Uncertainty</p>

8.4.1 Theme One: Disturbance of Being in the Everyday - World: An Interpretation

This theme refers to a period during which the participants move from a place of knowing within everyday life to a place of needing to know. It is categorised by a sense of discovery or knowing, in which the participant's world has faced a challenge. It is the challenge of the diagnosis which alters the normalcy or ordinariness of every day life. Disturbance of being can be located to a specific period of time or a specific impartation of information or a specific suspicion that all is not well. For the participants this can be seen as a point of foci from which there is a clear before and a definite after point. It is the mid-point of the before and after which becomes the pivot on which the participant moves from the point of lived experience of the everyday world to a lived experience of the lived world. This pivotal point marks a severance of normalcy, a discontinuity of the known and disengagement with life expectancy. The pivotal point does not necessarily refer to the time when the bad news was given. For some the point commences when their suspicions were raised and continues until they are confirmed. It varies in duration and intensity and is influenced by the participant's ability to assimilate the information.

It is displayed in a number of ways in this study. Disturbance of being in the everyday-world became visible as '*suspected – knowing*', '*dismissive mantra*', and '*truth-knowing*'. The next section will offer my interpretation of each of these, as they sit within the Disturbance of the Everyday - World. In illuminating each I will also present supporting data from the participant interviews.

8.4.1.1 Category 1: 'Suspected Knowing –'knowing and yet not': An interpretation

'*Suspected – Knowing*' refers to a timeframe during which the participant enters a period of suspicion, they are suspended within a phase of 'knowing and yet not'. It is characterised by a sense of anxiety and trepidation. This phase is the uncovering of something unexpected. It may incorporate a lengthy period of not

knowing and yet suspecting something. It may include a period of unknowing or dismissing something; a period of choosing not to know. It may also be episodes which occur as a result of feeling a lump or witnessing some other presenting symptom, of which there is uncertainty but an intuitive 'feeling' that something is not right. For many this period sees the 'drawing in' or involvement of significant others as questions are asked and fears realised. It is characteristic of the impact point of 'disturbance of the everyday world' and the commencement of a journey from everyday world experience to the lived world experience. It represents the launch in their search for meanings and answers. It is interwoven with anxiety and a desperate need to know – a sense of wanting to be told something is not right. It is symbolic of the need for confirmation combined with a need for protection. It is seen as wanting to be told but hoping to be relieved of what they think it might be. For all participants this 'suspected-knowing' phase represented a realisation of fears though of but not entertained before. The need to be told that their suspicions are incorrect, that in fact what they have is not what they think – knowing it might be cancer and yet hoping it is not.

8.4.1.2 Suspected-Knowing – 'Knowing and yet not': Findings

This sense of knowing something was not right and yet not knowing was articulated by many of the participants. The discovery of something which altered their lives was clearly remembered and very significant. It was the point by which they each marked a turning from their 'everydayness life' to life lived (lived world) – the before and after. This can be seen from the following excerpts

Maise: I was sitting reading late at night, my hands were cold. I slipped my hands in under - I had a vest t-shirt on. I slipped it in under the bra to warm the hand ... and it landed on the lump. And I knew from the minute I felt it, I knew that this was cancer. I knew, ... I just knew [said with emphases].

Catherine: I knew that I had a lump and it's not that big a leap to suspect that it was cancer. Most women who find a lump automatically think its cancer. I was scared really. I read everything I could about breast cancer; the more I read the more convinced I was that I had it.

The above excerpts would suggest that whilst the discovery of the ‘lump’ was unexpected, the leap to a self diagnosis of cancer was immediate. There was expectancy within the unexpected. However, for some, the link from discovery of something untoward to making a self diagnosis was not so immediate. As can be seen from the next extracts:

Bill: At first I just decided to ignore it, I thought it was something I had eaten. Then when the blood was there I just thought it was haemorrhoids... I think neither of us wanted to face that it could be something serious... so I really did convince myself that it was nothing to worry about.

Bill dismissed that he might be ill; he convinced himself that it was something he ate. As the presenting features of the bowel cancer worsened his ability to rationalise his symptoms became more specific. He was now diagnosing haemorrhoids. This distancing from the condition was his way of coping with the disease.

For Rachel it was extrinsic factors which kept her from allowing a self-diagnosis of cancer to be made. The needs of her children were her focus. This offered a temporary phase of not having to face her fears. As a care assistant on a surgical ward she had heard the women’s stories and although aware she had chosen not to allow herself to dwell on what she thought it might be. For her the very extrinsic motivation – her need to be there for her children eventually became the motivation to face her fear.

Rachel: ... the funny thing is that I remember looking after the women on my ward and thinking ‘how could they have let this get so bad before doing something about it?’ (slight laugh) irony is I did exactly the same thing. I convinced myself that it was nothing and had to keep going for the kids. The loss of weight was an added bonus and I just didn’t let myself dwell on what it might be... in the end I had to face it, something was not right and I knew what it was – I had seen it enough times at work...

Feelings of anxiety and trepidation were common amongst the participants. Many had friends who had cancer or knew someone who had died from it.

Some had parents or siblings who had died from cancer and it was this knowing that provided the backdrop to their anxieties:

Daphne: ...you see my father had died of lung cancer. I was only 12 at the time and I was not supposed to know. But I knew. I knew he wasn't right – all that coughing and wheezing, and those blood stained handkerchiefs. I watched him going away in the ambulance (short pause, as she pursed her lips). I never saw him again. Children were not allowed to visit the hospitals in those days. He died two weeks later ... I used to imagine what it was like for him. Now I was faced with my own lung cancer and I can tell you I was so bloody scared.

Jack: ... all my family smoked - everybody did back then, you know! But I never smoked, I hated the fecking things. I had asthma as a child but grew out of it as I got older. When I first started getting short of breath I convinced myself that the fecker was back. I was scared really 'cause I knew this was different. I had watched my brother die of lung cancer when he was only 38 and it was not nice. ... I knew I had cancer and I was so frightened, I knew what was fecking coming, and I knew it was not going to hard...

The extracts above provide a glimpse into the fear and anxiety experienced by the participants as they came to that place of 'suspected-knowing'. Feelings of fear, anticipated pain, discomfort and potentially death were interwoven throughout some dialogues. For Jack, what caused him anxiety as he faced his own 'suspected knowing' was that he had lived through his own brother's painful death from lung cancer. For Daphne it was the memory of not knowing what happened to her father once in hospital. Her reference frame was measured against the observational memory of a 12 year old girl as she witnessed her father's deterioration over a number of months. The unspoken journey of her father was becoming her 'suspected knowing' as she faced her own cancer. For many of the participants, the period of 'suspected-knowing' became a time of involvement of significant others. For some as with Bill, it was the need to protect his wife (Rita) which drove him to such lengths of denial.

Bill: I don't remember any of the discussion afterwards with Rita. I just sort of went into myself. I know she was worried but I just felt shut down. ... we are there for each other and I know we are real, but then I worry about putting her under too much pressure and sometime I find myself not wanting to talk about things.

Rhoda: Although I suspected that it was cancer right from the word go, I didn't say anything to John (husband), there was no point in the two of us worried out of our minds.

For others the involvement of their significant other was an extension of their knowing. The significant other was important in enabling the participant to process their 'suspected knowing'.

Eddie: Mary was there for me throughout – I wouldn't have got through it without her. She was a tower of strength. She was always pushing for more info. Whereas I would just close down; she was the fighter....

In summary, 'suspected-knowing – knowing and yet not' within the context of Disturbance of *Being* in the Everyday-World has numerous aspects and interpretations attached to it. This phase of moving from a place of everydayness to a place of suspected-knowing became the precursor to knowing the truth. It was a significant phase in the course of receiving a cancer diagnosis. For some, this phase allowed scope for hope and denial, while for others, as with Maise, it was this point at which she knew her suspected-knowing became her 'truth-knowing'. Before reaching that point of 'truth-knowing', many of the participants had to deal with having their 'suspected-knowing' dismissed, undermined or trivialised. The next category will illuminate this further.

8.4.1.3 Category 2

Dismissive Mantra – 'Don't worry': An interpretation

The 'Dismissive Mantra' refers to the response of others to a need for confirmation of the 'suspected-knowing'. It represents the inability of the other to stand with the person and acknowledge their fears and anxieties. It is categorised by a trivialising of the suspicion which may be interpreted as indifference. It is the silencing of the unspoken before it is uttered. In dismissing the suspicion there is a dismissing of personhood. The 'dismissive mantra' speaks of the need for closure and a nonchalant approach to the issue. The removal of the suspicion allows for a return to '*Being* in the Everyday-World' – to normalcy.

The dismissive mantra may provide a buffer for the listener and enable them to side step the realities of the suspected knower. It appears to have been offered not necessary as a blasé response but seems to have been interpreted by the suspected knower as such. In its indifference, the dismissive mantra silences the suspected knower and suggests that the listener may be unconcerned. It can be seen as patronising and flippant.

The opposite may also be a characteristic of the dismissive mantra. The listener may be using the dismissive mantra to offer comfort when there are no words to offer. It may be seen as reassuring the person. It may be used as a tool to allow scope for exploration. It may also signify the listener's inability to explore the concerns or to cope with the discussion. For the suspected knower it may result in undermining their suspicions and preventing them reaching some level of truth. It can result in feelings of not being heard, not being taken seriously, and create a sense of being invisible. In trivialising the suspected knower the dismissive mantra trivialises their belief in personhood. Ultimately, it may also result in a delay in seeking help and treatment.

8.4.1.4 Dismissive Mantra – ‘Don’t worry’: Findings

The ‘Dismissive Mantra’ represents the experience many of the participants endured as they sought confirmation of their ‘suspected knowing’. It speaks of the frustration the participants felt as they sought truth but found people who were unable to meet them in truthfulness. Participants described frustration at the dismissiveness of family and close friends as follows:

Maise: And everybody, everybody I told, said ‘you’re exaggerating’ ... **everybody** [with emphasis]. It’s nothing, or you’re in a panic blab blab la la la, and I hated that, I hated it!... I was being minimised, the terror I had was being minimised - it was being ignored. And every single person I said it to did this. Nobody said to me ‘Jesus that must be terrifying!’ ... Nobody, ... nobody...

Catherine: I was scared really. ... Even my parents didn’t want to believe that I had it. They thought I was over- reacting and that I was beginning to panic. I wasn’t panicking; I was trying to get people to hear what I was saying. Everyone told me not to worry. What was I meant to do – I could do nothing else, could I?

Whilst the above excerpts highlight the impact of the dismissive mantra from significant others it also demonstrates the sense of isolation created by having ones suspected-knowing trivialised. The dismissive mantra was also evident amongst the healthcare professionals. In seeking truth and assurance the suspected knower received instead a response which was not reassuring and in many cases not at all helpful. It was this dismissing of their concerns which resulted in a sense of being minimised.

Daphne: Well now you see I had already been to my GP and he had sent me to see a specialist. I went to the GP because I was feeling very tired and I had lost an awful lot of weight ... He said he wasn't too concerned and that I was not to worry. ... he played it down really, said I had nothing to worry about.

The above excerpt highlights of the level of trust that the participant had in the healthcare professional. Despite a worsening condition and a growing sense of unease, the participant was prepared to suspend their suspected knowing and attempt to return to normalcy – to '*Being in the Everyday World*.'

Not all participants were so compliant with the dismissive mantra. Some were not prepared to accept the reassuring words of do not worry and sought further clarification and investigation.

Amy: He [GP] reassured me that it was probably a blocked milk duct and told me not to worry.
Not to worry! – there hasn't been a day since that morning in June '99 that I haven't worried. Worry has become the fabric of my daily life. (Long silence, looking past me as if I were not in the room). ... He examined me and again told me not to worry. He felt it was panic over nothing that it was normal for some women to get a blocked milk duct. He knew what I was thinking, I wasn't saying it but he knew what was going through my mind.

Rhoda: ... they knew I had my suspicions and yet the GP tried to fob me off with the reassuring words – 'It's probably nothing to worry about.' I put him in his place and said the reason I was there was because I was worried – very worried.... I wasn't happy and asked for a referral.

There was a sense that the dismissive mantra of the healthcare professional may have actually erected a barrier which may have prohibited further exploration of the suspected knower.

Amy: But everyone I spoke to said 'don't worry' it was nothing. I spoke to a friend who was a midwife and she said - you guessed it - a blocked milk duct. ... the GP was lovely, he reassured me that there was nothing to worry about. Said I was too young and that breast feeding would actually reduce the risk of getting cancer. And I believed all that, ... I needed to believe it. And anyway the doctor knew what he was talking about. ... He would know just from feeling it that it was a blocked duct. I really believed him. I really believed what he had told me. The funny thing is that I wasn't any less anxious, even though I believed him there was a niggling little voice in my head saying 'what if'. . So again I had to keep telling myself to stop worrying and put it all behind me. ... I felt I was going to go mad. Everyone was telling me it was nothing and yet deep down I knew it was. No one believed me and I began to think they were right and I was wrong.

While the above excerpt illuminates Amy's suspected-knowing and the impact of the dismissive mantra, it also demonstrates the power of trivialising the concern. The result here was that the participant felt she was wrong and everyone else was right. There was a disempowerment resulting directly from a lack of corroboration or acknowledgement in the legitimacy of the suspected-knowing.

Interestingly, some of the participants did not seem to be aware of the dismissive mantra, or its impact on pursuing further investigations. Their loyalty to the healthcare professional was paramount throughout the interviews.

Eddie: I don't know really. When I said it to the doctor (GP) he seemed to think that I was imagining it all. He began to ask me if I was stressed at work. I felt so stupid having said it to him. But I was so worried, especially as I had already had three lots of antibiotics. ... I didn't go back to see him again for another few months and I only went then because the wife made me...

Jeanette: She (GP) told me that heavy periods were common at my age. So I just accepted it and got on with it. It was only months later when I felt something in my tummy that I went back to her. Even then she told me not to worry, it was probably nothing, probably a small cyst. She's a great GP and she got me into hospital really quickly....

In summary, the dismissive mantra offered by the significant others was a means of ‘opting out’ of engaging with the taboo subject of cancer. This may be understandable, and it could be argued was used as a means of giving reassurance. However, in reality it did little to offer support and reassurance to the participants. Instead it resulted in a loss of identity and a sense of being unheard. For some, the isolation and lack of corroboration in their suspected-knowing only compounded their struggle for truth and increased their anxiety. For others it afforded an opportunity to lay down their suspected-knowing, and despite their continued poor health status they accepted the views of others.

The mantra as use by healthcare professionals resulted in some participants accepting the advice in spite of their presenting symptoms. The power of the medical dismissal provided permission to return to ‘*Being in the Everyday-World*’. For others the frustration of not being taken seriously gave momentum for seeking further clarification or referral to another healthcare professional. For some participants this resulted in the further seeking of truth to their ‘suspected-knowing’. For others, ‘truth-knowing’ was not sought actively, but was rather delivered to them at some point by a healthcare professional. It is this notion of ‘truth-knowing’ which formulated the third category within this theme.

8.4.1.5 Category 3

Truth-Knowing: An interpretation

Truth knowing refers to the process of coming to know ones diagnosis. It is characterised by two distinct and overlapping components; ‘coming to know as process’ and ‘coming to know as outcome’.

‘Coming to know as process’ may well have started prior to receiving the bad news (diagnosis) from a healthcare professional, and represents the seeking of a diagnosis. It is motivated out of ‘suspected-knowing – knowing and yet not’. ‘Coming to know as outcome’ refers to the receiving of a diagnosis from a healthcare professional following some form of consultation.

Central to truth-knowing is the impartation of the diagnosis. However, it is important to recognise within this category that it is not the diagnostic interaction that denotes the ‘truth-knowing’ but rather the process from seeking (suspected-knowing) to receiving the diagnosis. As with the ‘before and after’ pivotal point of suspected-knowing there is also a ‘before and after’ pivotal point within truth-knowing. This is characterised by the ability to specify clearly a point in time when the diagnosis was heard.

It is important to recognise that within this category, truth-knowing may not imply acceptance of the cancer diagnosis. For a number of participants acceptance came some time after the giving of the diagnosis as we shall see when we discuss the third theme.

8.4.1.6 Truth-Knowing: Findings

For many of the participant’s truth-knowing reflects coming to know their diagnosis. It is often a process which commenced prior to seeking a medical consultation. The emergence of truth-knowing out of suspected-knowing occurs almost subconsciously, when the participant arrives at the point of knowing (as opposed to ‘knowing and yet not’). Having come to a place of subliminally acceptance there is a need to have ones ‘knowing’ confirmed.

Amy: One of the nurses was excellent. She just spent so much time with me, listening to me and not trying to patronise me or give me the usual – don’t worry. For the first time someone was actually listening to me, to my story,...yes she was hearing me. For the first time someone actually told me that it was natural to feel fear and that I was right to worry about the lump. She also told me of the large number of women who come in for lumpectomy and find it was not cancerous. But she was honest and did also say that some have to come back for more surgery and treatment. I was scared but also relieved that someone was actually with me.

Catherine: The consultant was very nice and I felt he heard me and acknowledged that I had a lump; he didn’t use the word cancer. He said he would have to do a biopsy to check if it were serious...I remember saying to him do you mean cancer. Then he explained that it could be cancer but it might be a type that was not malignant.

For some participant's there was a sense of almost relief when the word cancer was used. Indeed for some it was necessary to hear the word spoken aloud. Their journey from 'suspected-knowing' to 'truth-knowing' required acknowledgement that things were indeed not right and that the presenting features might indeed be symptomatic of a cancerous growth. It was the recognition of the possibility that allowed for the admission that suspected-knowing was legitimate knowing. It was the point at which the recipient felt heard, and this was an important step in the process of truth knowing. The following two excerpts demonstrate how the recipient had to introduce the word cancer into the dialogue. It was important for them as it denoted clarification and acknowledgement of their truth-knowing. It meant they were heard and they were visible.

Catherine: Well they used words like, lump or mass but never cancer. In fact it got to the point that I would say to them, you mean cancer don't you. Some of them found this quite threatening I think. They were not used to people being so up front with them – I think they thought I was an awkward patient.

Bill: He would use the term blockage and I would stop him and say cancer. I remember thinking he knows I know and he still won't use the bloody word. Eventually I remember saying to him, look I know the blockage was a cancer, can we just use that word.

Truth-knowing as outcome is confirmed when the actual diagnosis is given to the recipient. For some this comes as a form of confirmation of their 'suspected-knowing' and emerges out of truth-knowing as process.

Maise: ... it is engraved on my memory, every word is carved in my brain, ... carved in my brain. And he was very carefully, slowly spelling this out for me. He was wanting me to hear this message.

Bill: One of the nurses came and sat by my bed for a while and asked me outright what the doctor had told me. I was a bit taken aback at her bluntness but I appreciated her wanting to help me understand. I told her about the blockage, the bleeding and the fact that he said that it was the best of the cancers to get. She laughed at that one, but I knew she was just thinking exactly what I was. ... but what she really did was let me talk. She was good at that. I felt she really knew what I was going through

For some participant's truth-knowing as process was not part of a suspended-knowing. Truth-knowing occurred as a result of having the diagnosis of cancer given, even though the participant was not prepared to hear the diagnosis.

Daphne: ... I had a phone call from the hospital. It was some doctor – I never got his name. He asked if I was Daphne X. ... He then just came out and said he had some bad news and that I needed to come into the hospital immediately for some further tests. I was devastated, at first I thought I had misheard him and so I asked him what did he mean bad news. ...on the phone I just went quiet and let him talk. Mind you, I don't remember much of what he said, but I do remember the words 'shadow in you lung'. I was devastated ...

Jack: I suppose I really didn't want to know. When the doctor told me it was nothing to worry about I let it go. When the hospital doctor told me there was a problem with my lung X-Ray I was gob-smacked. When he told me it looked like a tumour on my lung - you could have blown me away. Still if I am honest I had thought of this all those months before. He was the first person to actually use the word tumour ... and that left no room for doubting....

From the excerpts it can be seen that Daphne and Jack were not prepared for the news of cancer. Daphne had been to her GP and she accepted the dismissive mantra that there was nothing to worry about. Jack had been told that it was just a recurrent chest infection which did not respond to treatment with antibiotics. The reassurance given in good faith by the GP's provided Daphne with the sanction not to pursue her fears and Jack the authorisation to ignore his initial concern based upon his family history. It was not until they were told by another doctor of the suspicion of a shadow on her lung/ tumour on his lung that they began to move to a place of truth knowing.

The pivotal point of truth-knowing is clearly etched in the memory of each participant. Each could locate with utmost clarity the exact moment when the cancer diagnosis was given by the healthcare professional.

Bill: When he eventually did come (the surgeon) he was really awkward and almost embarrassed. ... he was very nice and I remember he pulled the curtains around the bed when he came to speak to us. But even that sent my stress levels up ... he just wanted, I don't know, I guess he just wanted to give us some privacy. ...He said that

the scope had found a blockage in my large bowel and that this was causing the bleeding and the diarrhoea. He said it was quite large and that they wanted to remove it as quickly as possible. ... I asked him outright if this blockage was cancer. He looked me straight in the eye and said that it was a possibility ...

Rachel: I remember the smell of his aftershave and the colour of his tie – isn't that awful. Here he was telling me I had what was probably cancer in my cervix and that I would have to have a major operation and I can still smell his aftershave (silence 4 seconds – slight laugh). I can't stand the smell of it – even if I am out in the pub and get a whiff of it I am right back in the ward ... right back hearing cancer all over again...God love him, it wasn't his fault. He was only the messenger, I felt sorry for him really. It's an awful job, isn't it...

In summary, truth-knowing provided the space or arriving at the point of having their suspected-knowing confirmed or corroborated by another. For some it occurred as process, for others it was an unexpected outcome. All of the participant could locate the moment of confirmation of the diagnosis. It was as Maise stated “engraved on my memory, every word ... carved in my brain...” Hearing the diagnosis differs from acceptance of the diagnosis. The second theme addresses the process of moving from truth-knowing to acceptance of the truth.

8.4.2 Theme Two:

Surfacing within the Lived-World: An Interpretation

This theme refers to that period of time following ‘truth-knowing’. It is a place of otherness, a place of ‘after’ rather than ‘before’. The existential experience of *Being* within the Everyday-World belongs to the ‘before’. That changed with the disturbance of *Being* in the Everyday-World, caused as a result of ‘suspected-knowing’, the experience of the ‘dismissive mantras’ and arrival at a place of ‘truth-knowing’.

The Lived-World differs from the Everyday-World. The Lived-World is that existential experience of living post receiving bad news. In this study, it is lived experience caused by the power of the label ‘cancer’. It represents the recipients struggle as they redefine who they are in the light of a life-threatening illness.

Being in the Lived-World represents the lived experience of processing the diagnosis and walking alongside oneself.

Surfacing within the Lived-World emerged from the data analysis. The blending of the researchers preunderstanding and fore-structure with the participants stories indicates that there is a process of re-emergence that occurs following ‘truth-knowing’. Surfacing can be seen as a progress through two phases: namely, ‘personhood to pathology; and ‘visible-occupancy’. It represents the process from which a recipient is redefined as a result of leaving the Everyday-World and entering the Lived-World.

The Lived-World is characterised by the recognition that personhood is different from pathology. There is an emergence of the self from within the diseased pathology. ‘Truth-knowing’ does not necessarily define the person who has the diagnosis; rather it offers a platform from which some redefine who they are.

Surfacing denotes breakthrough from a place of disempowerment. It offers the potential for the emergence of the true (new) self. The true self whilst labelled as a cancer suffer experiences the life-world from a new perspective. My interpretation of the essence of ‘Surfacing within the Lived-World’ will draw from the two categories of ‘Transformative Power of Diagnosis’ and ‘Emerging self – visible occupancy’.

8.4.2.1 Category 1:

Transformative Power of Diagnosis: An interpretation

‘Transformative power of diagnosis’ refers to the impact on the recipient from having a diagnosis of cancer. It denotes a process of movement, in which metaphorically the recipient revolve 360⁰ from personhood to pathology to a new perspective of personhood. It is symbolic of growth and change as the recipient experiences the effects of disempowerment brought about through labelling. The ‘truth-knowledge’ and diagnosis of cancer brings a redefining of

how the recipient views themselves. It also changes how others perceive them. It becomes the defining element for many.

Diagnostic embodiment occurs when the person becomes defined by their pathology. In this study, the recipients become defined as the person with cancer. For some, diagnostic embodiment is an internal dialogue, something which they place upon themselves. For others diagnostic embodiment is placed upon them by the labelling of others and especially by healthcare professionals.

The nature of the transformative process varies; some recipients remain within that place which defines them as pathology whilst others move from a place of defining pathology to a place of personhood.

8.4.2.2 Transformative Power of Diagnosis: Findings

The sense of moving from a place of personhood to a place of pathology was articulated by a number of participants. A central tenant of this category was how the participant needed to locate their experience within who they were prior to the emergence of suspected-knowing and the resulting disturbance to their Everyday-World. This is evident in the following excerpts:

Eddie: Before all this I was so fit and healthy, not a days illness, you know. ... I have a great family and love life to the full. ... You know I used smoke like a trooper, I used to work six days a week outdoors in all sorts of weather, I loved it. Now, well now things are different....

Rachel: I was happily married, or I least I though I was...we have four beautiful children, great kids really. I used to work as a nurse you know. I was a nurses aid on a female surgical ward, hard work that but I loved it. ... it all changed when I got cancer...my world fell apart...

The sense of a before and after was evident in all the participants stories. For some, as with Eddie and Rachel they commenced their story with the backdrop of their Everyday-World as a stark contrast to their Lived-World. For other participants there was reference made to the Everyday-World, through mention of family or employment. Often the reference was made as the participant talked of their attempts to re-emerge from their diagnostic embodiment, as the next extracts show:

Rhoda: For Gods sake! It was so frustrating, everyone saw me as helpless and I could feel them thinking “poor Rhoda”. Poor Rhoda my arse! (*laughing and sitting upright*). I am who I am, Jesus Christ, I worked with these people, they know who I am ... suddenly I am different - NO. I DON'T THINK SO! (*spoken one word at a time and with great emphasis*)

Catherine: ... one of the hardest things for me was going from running my own accountancy firm to being a patient. No one seemed to see me – you know what I mean? I had become this hapless female with breast cancer.

Amy: I was a patient going for surgery. I felt I was actually a breast lump and not me. Not a mother of three and a wife, who held down a responsible job until the birth of my last baby. No I was in a gown waiting to be passed over to someone else to have my lump removed. It was strange really - I felt totally out of control ... They were more concerned with the bloody lump than they were about me. I just wanted it over and to get back to normal.

The struggle to emerge out of diagnostic embodiment –was clearly evident as recipients sought to re-establish who they were. For Rhoda, her struggle for recognition was compounded by the struggle to have her suspected-knowing investigated and confirmed. For Catherine it was the need to be recognised as who she was in her own right. She was not ‘hapless’ before her illness and was certainly not going to allow others to treat her as such. Amy’s struggle was articulate by her realisation that her body was not simply a breast ‘... out there for the world to see’. She felt she had to take back control. For her this did not happen until after her surgery.

For some recipients, the diagnostic embodiment provided space to come to terms with their situation. It offered a cocoon of safety. For these recipients the shock of diagnosis resulted in a ‘shut down’ – a protective place from which they eventually emerged. Their emergence was slow and not necessarily reactionary as with the excerpts above.

Bill: I was so shocked ... I could hardly think straight ... I couldn't think of anything ... I was still so frightened that I didn't even feel anything. I was there but not there if you know what I mean. I was too afraid to ask anything.

Daphne: I just went to pieces really. I'm usually the strong one – you know the boss but ... I just felt my world collapse around me. ... I wanted to feel reassured. I only wanted to hear the good things.

For other recipients the diagnostic embodiment resulted in passivity. It was as if the transformational power of diagnosis did not occur. For these patients, surfacing within the Life-World was determined by their recovery and survival.

Jeanette: I just wanted them to get on with it. Don't tell me - just do what needs to be done. I remember being told and after than I just wanted to forget. I'm here to tell the tale ...

Jack: I don't know and don't want to know really. Feck it, they're the professionals. I put my life in their hands and I am here, aren't I...

It could be interpreted that Jeanette and Jack did not come to terms with their diagnosis. Within their narratives there is an acknowledgement that they had cancer. But unlike some of the other recipients, Jeanette and Jack's surfacing within the Lived-World happened as a consequence of their recovery rather than as a result of taking control of their situation.

In summary, it can be seen that there was a diagnostic embodiment for all the participants. For some this was fought against aggressively as the recipient sought to re-establish their identity within the Lived-World. For others the diagnostic embodiment became their defining state from which they eventually journeyed to a place of personhood once more. The transformative power of diagnosis was evident in all participants and illuminated the path from 'truth knowing' to personhood within the Lived-World.

8.4.2.3 Category 2:

Emerging self – visible occupancy: An interpretation

'Emerging self – visible occupancy' refers to the need for the person to be seen for who they are and not what they represent. It differs from diagnostic embodiment in that emerging self represents the need to emerge in the Lived-World as the person they know themselves to be. It is characterised by the

journey the participant takes following their diagnosis and represents a point of destination where the person faces the physical and psychological demands of their treatments. Whereas diagnostic embodiment places the person within the constraints of their diagnosis, emerging self does not allow the person to continue to be defined by their illness. It encourages the person to surface within the Lived-World as they wish to be seen.

Visible-occupancy relates to a representation of the true self. It is characterised by the sense of achievement and contribution which is made by the person following their illness. It relates to a shift from disempowerment to empowerment and signifies a coming to terms with or surfacing into the Lived-World.

There is no equivalence between the recipients and no apparent consistency across the genders. Depending upon the type of diagnosis and treatment modality, the emerging self – visible-occupancy may or may not be represented by a physical awareness and it is specific to each person's situation. The degree of the presenting emerging self varies in accordance to the person presenting. For some recipients the emerging self remains within the domain of diagnostic embodiment, whilst for others it allows for the confidence of acknowledging their uniqueness. It represented an ability to pick up the pieces and move on to the next level. It may represent a reintegration of a somewhat disintegrating self.

8.4.2.4 Emerging self – visible occupancy: Findings

A number of participants spoke of their need to come through the treatment modalities as 'normal'. For some this normalcy related directly to body image and the need to be accepted. It was important for some and vital for others that they had come through their experience with cancer 'looking good'. For Maise it was vitally important that she ensured the surgeon knew what she meant when she proclaimed that pretty is important!

Maise: I remember looking directly at him (the surgeon) [at this stage Maise, unconsciously had put her hand up to her breast]. He

had done an operation on my husband, he had, and he had left him with a very ugly scar. And I really didn't want an ugly scar on my lovely breast. So I said to him Mr Z it's very important that you remember here that pretty matters.

It was really significant for Maise, that she retain her sense of beauty. Despite being faced with a diagnosis of cancer, the need for surgery and the requirement for chemotherapy afterwards, Maise maintained and stood her ground on the issue of her appearance following the surgery. Catherine, on the other hand was dealing with her mastectomy when she was faced with the prospect of undergoing chemotherapy: They elaborate as follows:

Maise: So he said, amm, I will do whatever is surgically necessary. And I said, no I'm really sorry Mr Z, we have to agree in advance that pretty matters. And he and I had a bit of a ding-dong, with me saying pretty matters and he saying clinically and surgically necessary is a priority. ...as it turned out, it was all grand and pretty and all the rest of it.

Catherine: I couldn't believe what he was saying – chemotherapy. I remember thinking Oh my sweet Jesus I am going to die. I kept thinking of loosing all my hair. Bad enough being mutilated but now to go bald – I couldn't go there. It was just too much. I remember thinking this can't be happening, they made a mistake. I will wake up and this will have been a nightmare. But it was very real Even fighters give up some times. There were times when I felt like giving up. Knowing you might have cancer and then being given the actual diagnose is really hard. On one level I wanted the truth and then when the truth was given I just wanted to runaway. I wanted to know everything and sometimes that was too much to hold.

Other participants spoke of a sense of exposure and vulnerability as they were examined within the hospital. The disempowerment of the emerging self is clearly articulate by Amy, when she said:

Amy: everything was done for me or to me - I had no say. ... I never had so many people examine me – it was embarrassing at first, then I just got used to it and then I hated it, being poked and prodded. It was my breast after all – they would just assume that I didn't mind having it out there for the world to see. ... it's just...it's just such an assault. ...Assaulted is too strong a word. But I did feel violated, not that anyone did anything. Its just ...(pause) well its just after trying to tell everyone that I was worried about this lump, suddenly everybody

and their aunt wanted to feel it. I felt I was not me anymore, I felt I was a breast lump.

For Bill and Amy there was a sense that although prepared for surgery they were not fully aware of the mutilation that was to be part of the treatment. It was this sense of not being prepared that impacted their emerging self.

Bill: I suppose at this stage I was swinging between dreading the operation and worried about the cancer. ...I had the operation and really was out of it for a few days, the pain was something else. But I wasn't prepared for the bag. They had mentioned it but I never really understood. It was the worst thing of the whole experience. The thought of my 'stuff' coming out of me into a plastic bag. Oh God I still feel disgusted. I was sure that everyone could smell me ... it was worse than having my bowels cleared out on the commode in the ward. (looking down at the floor with no eye contact) ...It was such an awful thing to have to cope with. I mean I felt that everyone knew and everyone could see it and smell it. I couldn't even look at it. Having the nurse change it was one of the most difficult things I have had to endure. When she asked me if I wanted to look at it I nearly vomited. In fact I think I was retching when she took the bag off. When I did eventually look at it a few days later I felt sick. How could Rita come near me with this thing? We didn't talk about it for days and eventually she brought it up. I couldn't talk about it and refused to have anything to do with it ...

Amy: The worst part of all this is that I when I woke up they had taken my breast off. I was so upset. I thought I was going down for a lumpectomy; but I came back with my breast gone. ... I felt lost and exhausted. I had fought for months about the lump and now it was gone and so was my breast.

Altered body image did not seem to have an issue for some participants who had undergone mutilating surgery as they surfaced within the Lived-World. For Rhoda, it was not the altered body image that she struggled with as she sought the emerging self; it was the sense of being invisible. Her return to work and her family provide the means of presenting her self once more – different, yet the same; she felt enriched and focused.

Rhoda: when I was trying to get someone to believe me, you know about my breast lump – I felt no one was hearing me. When I was eventually diagnosed and had the surgery it felt as if no one actually saw me. I felt invisible - I was so lonely, I felt so isolated – I (with

emphasis) had become the cancer. ... this has totally changed how I see my patients.

For participants who had undergone treatment that did not alter their outward appearance the issue of emerging self is represented by physical occupancy. The focused would appear to be on the need to regain a sense of pattern in their lives. Male participants seemed to be directed towards returning to work and resuming their daily lives once more. For the females it would appear that the need to be there for their families was the conduit through which they experienced their emerging self. It is this sense of fulfilment or contribution that fulfils the concept of visible occupancy. As with Rhoda, it is the need to be physically present and recognised for 'who they are' rather than for 'what they were' (someone with cancer), that is important.

Jack: getting back to the farm is the most important thing for me. I am not used to hospitals, I hate those places. No, once I was back in the fields and doing what I knew best I knew I was going to make it. All the time in hospital I was actually scared. I had no control and felt as if I had no say...

Rachel: ... at the time in hospital I was on automatic. I got through one day at a time. Funny thing really – I was on the ward I worked on, but once I was in the bed it all felt very different. ... now I am here for the kids, they need me more than ever

Eddie: my family is all that matters to me now. Funny how something like this makes you appreciate all you have. ... I am lucky really; my boss has moved me off the construction site and into the yard. The work is lighter but at least I can still work, I'd go mad if I was stuck at home all the time...

In summary, it can be seen that for the participants, the emerging self is an important journey as they surface with the Lived-World. Their altered world represents their adaptation to life following a cancer diagnosis. There was a need to emerge not as someone defined by their illness, but rather as someone defining their existence as worthwhile.

8.4.3 Theme Three:

Being within the Lived-World: An Interpretation

This theme refers to a process of consolidation of *Being* as the person moves on in their journey of knowing and accepting. It remains very much part of the phenomena of receiving bad news and is characterised by recognition of the emerging self within the Lived-World; which is itself evolving and changing. It is seen as the acknowledgment, that although not embodied diagnostically, there is an awareness that one often lives with the threat of cancer returning. Evoking *Being* within the Lived-World became visible in the data through '*subliminal uncertainty*'. The following section will present supporting data to support the category.

8.4.3.1 Category 1

Subliminal Uncertainties: An interpretation

'Subliminal uncertainties' represents the fear that living within the Lived-World carries for the person who has received a cancer diagnosis. It is characterised by an awareness that suspected-knowing may arise again. There is a recognition within the Lived-World of the ongoing present and the presenting future. Subliminal uncertainties recognise that there is always an ever present probability of recurrence. Facing ones mortality brings a tension of focus between surviving and living. It is this tension which encapsulates the subliminal uncertainties. It is the potential of suspected-knowing waiting to materialise once more.

Subliminal uncertainties remain within the process of the lived experience of receiving bad news. It lies dormant within the unspoken word or the silent touch. It becomes the silent refrain of the suspected-knower. It is the ever-present uncertainty of anticipated pathology. It is the waiting to be told once more, the antithesis of things hoped for. It remains unseen and often unspoken but ever felt within the existential Lived-World.

8.4.3.2 Subliminal Uncertainties: Findings

Participants lived with the uncertainty of the potential of recurrence of their cancer. Whilst not dominated by the fear of its return there was a sense that it lay dormant and was persistently present subliminally. Subliminal uncertainty forms part of the lived experience of receiving bad news as it is ever present within the Lived-World of the recipient. It cannot be separated out into ‘another’ phase of the percipients journey, as it is intrinsically linked to the entire experience. It is formed and informed by and out of the experience of suspected-knowing, dismissed mantra and truth-knowing. For some participants it was as if there was almost a fear of believing that it would not come back.

Amy: It’s only the beginning of a long journey. I finished my radiotherapy and got the all clear ... but they gave me the all clear at the beginning too. They told me not to worry and that’s all I have done ever since.

Bill: Even now when I have the test I wonder are they telling me the truth or just being nice to me. It’s awful really, I just want to know and no one will be real.

There is a sense that the dismissive mantra which Amy and Bill endured has left an unconscious inability to trust in the words spoken. It was Amy’s struggle to get people to see beyond the 33 year old breastfeeding mother and the apparent ‘blocked mild duct’ that left an indelible mark. For her there is a need to push beyond the platitudes of empty reassurance of the ‘don’t worry’ mantra. There was a severance of trust with the healthcare professional resulting in a persistent unknowing regarding her health status.

Bill had used the ‘don’t worry’ mantra as permission to dismiss his fears and continue in a place of denial of his suspected-knowing. Having endured a bowel resection, colostomy and chemotherapy he was left with the ever-present threat of its recurrence. The experience of healthcare professionals who used euphuisms left Bill experiencing difficulty in trusting them. He lived the remainder of his days suspecting that he was not being told the truth. His closing statements in the interview are sobering and challenging for all healthcare professionals. He adds:

Bill: I think I just wish people were open and honest from the start. The nurses were, but only after the consultant told me about the blockage,... maybe the nurses didn't know either. The only ones who were really honest were the other patients. They were great, we had a good old laugh, you had to laugh to get through it. And then you hear about someone dying from cancer and you think God I'm lucky. But its always there, you always have a fear of it coming back

For some participants it was as if there was almost a fear of believing that it would not come back.

Catherine: Keeping people in the dark isn't all the best thing ... even if your trying to soften the blow. I know I wanted to know and I did – I still do. All I wanted was for people to be real and honest with me. ... I go for check ups regularly and I always fear hearing more bad new again. I sometimes worry about if they are not telling me everything. It something you live with always – it never really lets you go once it has you. (Silence)

There is the constant interpretation of others reactions. Having experienced a level of partial disclosures or masked disclosures (euphuisms) some participants found they were examining the non-verbal behaviours as well as the verbal when communicating with some healthcare professionals.

Eddie: I don't know if it's because of what I went through but I am much more sceptical now when talking to the doctor. I hear one thing but I have this niggling doubt in what he's saying. It's crazy really but I even watch to see if he is making eye contact with me when he is talking to me.

Not all subliminal uncertainties were the result of negative experiences. Maise, who had had three separate disasters during receiving of bad news (see appendix interview) was quite positive about her encounters with the healthcare professionals, and as a result was confident about her future.

Maise: I think cancer is an obscenity. The treatment is barbaric and medieval and I cannot see myself ever reaching a day where I can say I am glad that happened to me, that it taught me important lessons about life. I cannot ever see that happening to me, I just can't. In the whole thing I think that I was fortunate to have met really professional people, caring people. And I think that's what I expected, amm I had high expectations of them, and they didn't let me down. ...

I kind of knew and I made a decision very early on that I could crawl under the duvet and howl, and I felt that if I did that I would never come out from under the duvet, or I could put on the lipstick and go. That didn't stop me crying, I cried oceans, I cried and cried and cried and can still cry. I can still cry about it.

In summary, subliminal uncertainties are an ever present process for the recipients. It can be seen that the negative encounters and lack of trust which ensued out of the earlier experiences with healthcare staff, coupled with a realisation of the tension between surviving and not surviving has left many in a place of suspended suspected-knowing. There would appear to be ongoing difficulties in establishing trust with some of the healthcare profession as a result of previous experience.

8.5 Conclusion

The findings highlight that receiving bad news occurs within a trajectory. The trajectory is represented through the phases of disturbance, resurfacing and embodiment within the lived world. These phases are not necessarily linear nor are they cyclical. They represent a process of coming to knowing; a place of meaning, a place of being.

It suggests that receiving of bad news is not a one off event but rather is comprised of a series of processes. Processing the bad news can be seen as infiltrating all three of the recipient themes. Processing recognises the trajectory of bad news. Commencing with a 'Disturbance of *Being* in the Everyday-World' through suspected knowing, processing continues throughout the 'Surfacing within the Lived-World' and remains central to the theme of '*Being* within the Lived-World'.

Re-establishing ones self within the Life-World requires an adaptation within the trajectory. Receiving bad news is contextualised within a continuum on which the future is unknown. Living within the Lived-World, therefore presents challenges which require ongoing adjustment as one learns to deal with the process of living. It is represented as an evolving-knowing and adaptation as the recipient comes to a place of *Being* within their Lived-World.

CHAPTER 9
PRESENTATIONS OF FINDINGS:
HEALTHCARE PROFESSIONALS - NURSES

9.1 Introduction

This purpose of this chapter is to present the interpretations from the 2004-2005 phase of analysis. The chapter is devoted to presenting findings that emerged from interviews with 20 nurses and eight doctors drawn from four geographical areas. All healthcare professionals were working in acute medicine and surgery. Although a number of participants may have had a short exposure to oncology or palliative care during their training, none had worked within these settings since qualifying. All were involved in some way with patients who had received a cancer diagnosis.

In chapter 8 the discussion and interpretation of findings commenced with the presentation of the participant's stories as it was necessary to contextualise the experience of the process of receiving bad news within the narrative of the recipient. A decision was made not to present individual stories for the healthcare professionals as it was felt that it was the professional experience which was of significance rather than the personal stories. Where Healthcare professionals make reference to personal stories within their narrative it will be discussed as part of the findings. The first part of the chapter is devoted to the interpretations of the nurse sub-group. The latter part of the chapter will focus upon the medical sub-group.

9.2 Emerging Themes

This section will present the themes that emerged from the nurse sub-group. Sections of participant's narrative text are included to illuminate the meanings that emerged.

Two main themes emerged from the nurses’ narratives and within each theme a number of categories were identified (Table 9.1). These are: ‘Connectedness: Journeying as Professional within the Everyday World’ and ‘Connectedness: Exclusion as Professional within the Every Day World’. Each theme is comprised of a number of categories. Theses will be presented to make explicit the multiple dimension of providing nursing care to patients receiving bad news.

Table 9-1 Themes and categories - nurses.

THEMES	CATEGORIES
<p style="text-align: center;">THEME ONE:</p> <p style="text-align: center;">CONNECTEDNESS: JOURNEYING AS PROFESSIONAL WITHIN THE EVERYDAY-WORLD</p>	<p style="text-align: center;">Ubiquitous Past</p> <p style="text-align: center;">Professional-companionship</p> <p style="text-align: center;">Filtered-Disclosure</p> <p style="text-align: center;">Fractured-Trust</p>
<p style="text-align: center;">Theme Two:</p> <p style="text-align: center;">CONNECTEDNESS: EXCLUSION OF PROFESSIONAL WITHIN THE EVERYDAY-WORLD</p>	<p style="text-align: center;">Professional-collegiality</p> <p style="text-align: center;">Collaborative Distancing</p>

9.2.1 Theme One:

Connectedness: Journeying as Professional within the Everyday World: An interpretation

This theme refers to the nurse-patient relationship and the bonding that occurs between nurse and client. It reveals the notion that the relationship is a developmental one that sees the connection between care giver and recipient evolving over time. It is characterised through a sense of knowing the patient. This 'knowing' speaks of a place of privileged convergence, where the nurse and patient form an unspoken alliance. It is an aspect of the role of nurse that is highly valued and can be seen as a central component of the therapeutic relationship. It allows the nurse to act on behalf of the client and proceed as their advocate. Thus, the connectedness-role incorporates acting with and for the patient. It is perceived as walking alongside and ensuring the patient is supported in their journey as they deal with their specific situation. Journeying encompasses both positive and negative aspects of being there for the patient. It is seen as difficult at times to be 'fully-there' for the patient. Connectedness is influenced by a multiplicity of issues, namely; nurse- patient issues, nurse-work issues, nurse and multidisciplinary issues.

The 'Everyday-World' of the nurse refers to the activities and responsibilities of the nurse in caring for patients. Whilst it incorporates delivery of the physical, psychosocial and spiritual care, it is not defined by the giving of that care. The 'Everyday-World' incorporates the sense of being present for the patient and is characterised by a sense of being there for them, even when not physically in the patient's immediate surroundings.

Connectedness is also characterised as a professional task. Whilst the connection is very present in the activities of the nurse, it is seen very much as functionary. There is a professional space which affords the nurse the place of disconnecting or distancing from the patient as appropriate. This can be seen with the changing relationship on discharge and with the need for the nurse and patient to move on.

Connectedness as journeying for nurses within their Everyday-World emerges as ‘ubiquitous-past’, ‘professional-companionship’, ‘filtered-disclosure’, and ‘fractured-trust’.

9.2.1.1 Category 1

Ubiquitous Past: An interpretation

The ubiquitous past refers to the ‘ever-present-self’ within the nurse. It is characterised by the need to locate professional attitudes and behaviours within the known Everyday-World of the person, as opposed to isolating the presenting nurse within the confines of the Everyday-World of the professional. It reveals itself as the emergence of the ‘I’ within the story. The centrality of ‘I’ is both the contextualising of the personal narrative within professional experience and the recognition of a linkage with the patients. It is seen as the need to link who they are with what they do – the merging of the personal and professional. The ubiquitous past also allows for the acknowledgement of other patient contacts. The presenting of past patient issues is a way of making sense of the present situations.

9.2.1.2 Ubiquitous Past: Findings

Throughout the interviews nurses repeatedly returned to their own personal stories. Like the recipients, there was a need to contextualise their narrative and for many the conduit for this was the personal accounts of their life outside of nursing. This is evident in the following excerpts:

Nurse B: I’ve had personal experience which is why I am so... probably why I am so clear about the good and the bad. Some good and some very bad....

Nurse M: I was so angry with the way he just sauntered off the ward having told the patient. It was just the same way when my father was diagnosed with lung cancer – the doctor told him and then just left him...

The above extracts offer some insight into why the nurses sometimes react as they do. It can be seen how past experience of the personal Everyday-World impacts upon professional practice. In the context of Nurse M, she was dealing

with her own anger at how her father was given his diagnosis of cancer and this was presenting itself in her need to protect her patients. As a result of this Nurse M acted as ‘protector’ and ‘advocate’ for her patients when she felt that they were not receiving adequate and appropriate interventions. She goes on in her narrative to recall how she would address the situation with the doctor:

Nurse M: ... I make sure that I have words with him [doctor]...they mustn't be allowed to speak to patient like this. He wouldn't do it again if I am on duty

Nurse B had learned from her own experience when her partner was given a diagnosis of cancer that there are ‘good’ ways and ‘bad’ ways of giving a diagnosis. Unlike Nurse M, she did not feel that she could confront her medical colleagues and instead it becomes apparent from her narrative that she sees her role as that of helping the patient to come to some form of understanding of their situation.

As well as drawing from personal narratives of encounters with cancer through their family, some participants presented the ubiquitous past in recalling situations with friends and neighbours.

Nurse L: Sometimes it hard, ‘cause you might know someone who is going through it [cancer] and you have to sometimes ... sort of try and separated things out, am I making sense? You know, like... when I was looking after this young woman who had breast cancer, she was the same age as my friend who had died three years ago from breast cancer. Sometimes its hard to stop thinking back... [Long silence – 8 seconds – no eye contact].

Nurse P: One of the mothers at my son's school is going through chemo at the moment and I find it hard. ‘cause she thinks I have all the answers and I only want to avoid her. I face it at work and then I have to face it at home – God this sounds pathetic – its not like I go out of my way to avoid her but sometimes I just don't have the answers...

It can be seen from the above excerpts that the merging of the personal and professional is multi-directional. It is the Everyday-World of the personal interacting and influencing the Everyday-World of the professional and visa-versa. Participants also drew past clients into their narrative. For some, the

reflection on past patients provided a means of understanding the present. The swampy-lowlands (Schön 1983) of Everyday-World practice emerging within the presenting self.

Nurse G: I always think of a patient I had who had an amazing insight into her situation. She was so together... she actually helped us (nurses) deal with her situation ... I learned so much about dealing with cancer from just being with her, she was amazing ...

Nurse Q: He went to pieces and I let it happen. I just stood there and watched what was going on. I felt so helpless really, what could I do? I was only junior and no one seemed to think that what happened was bad ... so I just kept quiet.

Many participants demonstrated the ongoing presence of the ubiquitous past through making personal linkage to the patients they cared for. It is this form of connectedness that was articulated as follows:

Nurse H: I should be there for them. I know what they are going through ... I have kids the same age and it was all just too close...

Nurse J: You know ...mmm, like she is around the same age as me and has kids the same age. I can't help thinking what would I do in similar circumstances. I know that's crazy and you cannot survive if you go around thinking like that all the time. But if I am honest that is how I was feeling. And you know... its hard, to be detached all the time.

It can be seen that for some participants the used of the ubiquitous-past enabled them to make sense or explore aspects of conflict or unease.

In summary, the emergence of the ubiquitous past was strong and gave a platform for nurse participants to contextualise and boundary their narrative. The apparent filter of narrative chaos (Frank, 1994), although difficult to work with, allowed the nurses to begin to find meaning in their own narrative.

9.2.1.3 Category 2:

Professional-companionship: An Interpretation

Professional-companionship is a metaphor for the nurse patient relationship which is imbued within patient-centred care. It is characterised by five

demonstrative actions: ‘knowing the patient’; ‘being with the patient’; ‘giving and receiving’, ‘attending’ and ‘bearing’.

Professional-companionship is considered important and central to the role of the nurse in providing competent care. It recognises the centrality of the relationship in determining the means of journeying with the patient. It distinguishes the individuality of the patient and strives to meet their specific physical, psychosocial and spiritual needs. It is seen within the awareness of the relationship as both dynamic and challenging.

9.2.1.4 Professional-companionship: Findings

‘Knowing the patient’ is seen as essential for the nurse. It is the ability to move beyond the specific generalised knowledge of the condition or treatment modality. It embraces general knowledge and moves to a place of a specific knowledge of the person within their context. This can be seen in the following extracts:

Nurse A: After all – we know the patients; we spend more time with them and have a relationship with them...we meet the family and, you know ... we get to see the bigger picture ... I think we know more how they think and feel...

Nurse U: Well, you know how it is, you really get close to some patients, well you get to know them all but some just seem to click with you ... I always try to really get to know my patients...otherwise all you are doing is conveyer belt nursing....

Nurse K: God yea! I know my patients better than the doctor or anyone else on the MDT [multidisciplinary team]. They may spend all of five minutes a day with the patient and that is usually if they are doing something to the patient. I am there all day, usually for twelve hours at a time ... you do get to know how they click and sometimes you find that you’re pre-empting their reaction...

Knowing the patient is in itself a journey. It is seen as a privileged position which is arrived at through skilful-caring and accessibility. Knowing the patient becomes an outcome of investing time and energy with the patient. This has been intimated at in the previous extracts and become more overt in the following segments of interview which highlights the importance of availability.

Nurse K: ... it's not only about years of experience. I think it more about wanting to connect in a real and specific way. You can do the nursing thing and get through the day or you can be the nurse and make a difference to your patient.

Nurse E: some people see the assessment as a paper exercise that has to be done, you know, part of the admission and all that, all the pat questions ... I see getting to know the patient as part of the assessment – it is not a paper exercise, it's about digging in, spending time and really getting to know them. If you want to make a difference you have to be there for them...

Nurse S: ... your either out there doing [raising hands making inverted commas in the air] or you're out here being. For me it about being with the patient when I am doing what I need to do....

'Knowing the patient' is achieved through skilful assessment of the specific care needs and providing patient-focused competent-specific care to meet the individuality of the patient. It is the facility to remain open to the patient's stories and attend to their specific needs that allow for the development of the relationship.

The nurses' ability to remain patient-focused allows for acknowledgement of the importance of the second demonstrative action 'being with the patient'. Whilst 'being with the patient' incorporates the provision of physical care (doing to) it also recognises being with the patient in all their fullness. It is about connecting on many different levels and again can only be achieved as a result of knowing the patient.

Nurse O: ... sometimes it's not about what you do. Rushing around and getting the job done may be great for a smooth operation and a well managed ward ... I don't think that's what makes a difference for the patient, I think they just want to know that you're with them...

Nurse F: I always remember the first staff nurse that I admired. She was loved by the patients because she made them feel special. ...she made them feel that she was there just for them. She had the knack of just recognising their needs even before they knew it ... she really knew her patients and was always there for them [laughing out loud] Sometimes the other nurse would dead her as they would say "Oh no it Staff nurse X, we'll get nothing done"...

Nurse D: I guess it's about getting them [patients] to really understand their situation. It's more about being able to fill in the gaps and recognise things ... yea its like you hook up on a deeper level – it's like, you know, it's like being real...

'Being-there' is the ability to move beyond providing physical care within the demands of a busy workload. It is the nurses' capacity to make space for the patient by providing competent-care which recognises the uniqueness of the person within the context of their 'Lived-World' experience.

'Being-there' also communicates that in professional-companionship there is a need for reciprocity. Reciprocity relates to the nurse-patient relationship and the processes involved in giving and receiving. It is required if the nurse and patient are to journey together. This reciprocal relationship can be seen in the following excerpts:

Nurse N: ... some [patients] keep you out there [extending her hands fully in front of her], others want you to be right there for them. You learn quickly who's who. Am I making sense? ...it's like you have to read each one [patient] and sometimes their family too ...

Nurse T: You can't rush the patient. Sometimes they are so shut down or locked in their own pain that all you can do is give them time to open up. Eventually you can build up a rapport that convinces them that you're interested in them and want to be there for them. It can take time, you have to be patient with them, but in the end you usually have a breakthrough ...

The sense of creating time and sticking with the patient – giving them space and working at making the connections demonstrates that there is a sense of collaborating between patient and nurse. Collaboration is necessary if the reciprocal relationship is to emerge. 'Knowing the patient' and 'being with the patient' are the prerequisites of reciprocity.

Nurses recognised that in giving to the patient they may also receive. Receiving may be intrinsically orientated, as in the form of a sense of satisfaction from a job well done. It may also be extrinsically orientated as expressions of thanks and gratefulness or an acknowledgement from the patient of the nurse's sense of being. The following two excerpts provide evidence of this:

Nurse A: At the end of the day, there is nothing like going off duty knowing that you did the best you could for the patient and that sense of pride that you managed to make a difference ... I just love that feeling.

Nurse N: ... we were so busy and I was to give him an assisted wash. I was exhausted, it was a crazy morning. When I went to him he took one look at me and told me to forget it, he said I looked as if I needed a break, and I did [laughing]. I hadn't stopped going all day. I insisted on continuing but he just said no and told me to come back later when I had a cuppa...I was really touched that despite his pain he had the capacity to see my need

Attending relates to the nurse providing skilled care to patients which is focused and competent. It relates to the physical psychosocial and spiritual care delivered in a therapeutic manner. It is characterised as much by absence as it is by action. The ability of the nurse to recognise the need to give the patient space and time are as much a part of attending as providing the actual interventions of nursing. The following extended excerpt offers an opportunity to see this:

Nurse R: You want me just to talk about how I cared for this patient? [This question was asked as a probe to an earlier answer in which Nurse R appeared to be dismissing the importance of what she did for the patient]

Well he wasn't the easiest of patients. But then again he was struggling to come to terms with his own stuff. ...he was angry and seemed to be either hitting out at staff or totally shut down. Some staff disliked him, found him aggressive, I saw something in him. ...I would often just sit with him in the evening and talk about car racing – he had books on his locker on this so I used this as a way of getting him to talk. It worked! He eventually started talking about his days as a racing driver. I had no idea he had such an interesting life. Anyway he seemed to forget his situation and just opened up; he became animated for a while.

.... he was in a real need of a wash and shave; he just wasn't caring for himself and didn't want the nurses doing it either. Because of his attitude some of the nurses just avoided him. I was looking after him one weekend and really wanted to get him into the bath, but I knew that was my stuff. He refused to even get out of the bed. Eventually, when I had cared for my other patients I returned to him again. This time I just sat with him and talked about anything and everything. Then out of the blue he started to cry. I just let him, I didn't try to stop him or even offer him a tissue. I just sat there in his room and left my hand on his. Eventually he asked to be left on his own and so I just left him. Before I went off duty I checked to see if he was OK. He nodded and gave me a dismissive wave.

My interpretation of Nurse R's intervention is that she recognised the uniqueness of the patient and respected his need for space. Her ability to collaborate (in this case with a patient who appeared resistant) demonstrates her ability of being present for the patient and offers the essence of reciprocity. She acknowledged his need for making decisions and valued his needs above her requirement to having him presentable (feeling clean and shaved). She used her professional-companionship to meet him at a place of certainty (car racing) and used this as a means of building connections. Her ability to simply allow him to cry and not feel the need to console or stop him demonstrated a skilled-career who was willing to absence herself from doing and simple allow space for the patient 'surfacing within his 'Lived-World'

'Bearing' is characterised by the recognition of the emotional cost of journeying with the patient. It relates to the impact that professional-companionship has on the nurse. It can be seen from the interviews that its origins appear to lie in two areas, emotional-linkage to the patient and frustration at the information the patient has or has not been given. This is evident in the next two excerpts:

Nurse C: ...I call it "picking up the pieces". The doctor does his bit, if he is any good he'll ask if there are any questions and then remove himself from the situation, leaving us to put things back together again. It's a bit like after a cardiac arrest, you know when they call off the code and leave you with the dead patient ... and you just pick yourself up, maintain the last bit of dignity that the patient has and clear up ...

Nurse M: ... I couldn't help think that she was so like me. Same age, same number of kids, God sometimes it's hard to separate off and not allow yourself to think.

The sense of guilt was evident, which may indicate that for some nurses professional-companionship came with a price. It is clear from the nurses' narratives that this sense of connecting with the patient is a delicate walk between professional connecting and personal exposure.

Nurse Q: I often wake in the middle of the night wondering how the patient is. I find it hard sometimes to switch off and leave it behind, especially when you know the patient is really struggling ...

Nurse L: There is a sense of guilt because I wasn't there or maybe because I knew and didn't let on to the patient. ...

Nurse C: ... and if you are keeping information back from them it makes it difficult....

The sense of vulnerability, exposure and a sense of having failed the patient in some way is characteristic of the emotional cost involved with journeying with a patient. For Nurse L it was at times almost too much to carry:

Nurse L: it's like walking on egg shells – everything is so vulnerable and sometimes I just want to run away and get away from it all.

In summary, the importance of professional-companionship and the evolving nurse-patient relationship weaves its way throughout many of the interviews. It is this the very uniqueness of the connection and the level of trust that develops between nurse and patient that forms a backdrop for nurse sub-groups' experience of caring for the patient receiving bad news.

9.2.1.5 Category 3:

Filtered-Disclosure: An Interpretation

Filtered-disclosure is characterised within the connectedness journeying as a constraint upon professional-companionship. It reveals itself as a frustration for the nurses and highlights the difficulties of multidisciplinary working within a hierarchical system. It is evident in the use of language, avoidance of discussion and distancing. This category represents a challenge for the nurse in maintaining the components of professional-companionship of 'knowing the patient'; 'being with the patient'; 'giving and receiving', 'attending' and 'bearing'. It can be seen as an antithesis to professional-companionship and yet is a parallel experience for nurses as they struggle to maintain integrity and loyalty to both the patient and the multidisciplinary team.

9.2.1.6 Filtered Disclosure: Findings

For many nurses there was difficulty surrounding discussions that may focus on diagnosis or prognosis with their patients. The nurses need to connect with, and walk alongside the patient as they come to terms with their diagnosis was strong. However, as many of the nurses were not present when the diagnosis was delivered there was a sense that they were at a disadvantage and that their job of supporting the patient was made more difficult. The resulting pattern of behaviours seems to be originating from a place of uncertainty. As evident in the following:

Nurse D: Sometimes you're washing a patient or just chatting when they begin to confide in you. You know, it's like they are checking you out to see if you will say the same thing.

Nurse B It makes my job harder when I don't know what the patient knows. It's unfair on them and us. We care for them and it's often us they confide in ...

Nurse A: How can we help the patient if we have no idea what has been said. ...you're afraid of saying the wrong thing or of saying too much or contradicting what the doctor said. God, sometimes its impossible... it's so hard to know where to go with the conversation...

The lack of information results in a form of curtailed-dialogue with the nurse unsure of how to proceed.

Nurse T: ... sometimes you know they suspect something but are not actually saying anything. You find yourself hoping that 'it' will not come up. It can be exhausting at times as you are always aware of what is not being spoken.

Curtailed-dialogue is often used in an effort to protect the patient or in some instances it is used as a protection for the nurse not stepping outside perceived professional boundary. Nurses talked of hedging and dodging as they tried to use the words of the patient in the hope that they would not be called upon to elaborate on the patient's suspicions.

Nurse A: It was so easy when you were a student [laughs] you could just say 'have you spoken to sister or I'll get sister to talk with

you'. Now I can't do that anymore and so I dance about hoping that the question will not come up.

Nurse S: ...on the outside I appear calm and together. Inside I'm dreading the patient asking me, 'cause I don't know what they know and I don't want to put my foot in. It's a bit like dodging the questions that might lead somewhere.

Curtailed-dialogue may also be indicative of the nurses attempt to tread carefully as they come to know the level of understanding that the patient had. This is evident in the following excerpts:

Nurse B: It's difficult if you don't know what the doctor has said. ... It's like walking in a fog, knowing you could trip up, but you have to keep going..

Nurse G: ...sometimes you're doing something with the patient when he drops it on you and asks outright if he is going to die? ... you just get a sense from the way the patient is acting or talking that there is something going on and you begin to think ... does he know? has someone spoken to him? This is hard ...you have to walk carefully ...

Filtered-disclosure was complicated by the use of euphemisms. This resulted in confusion over the language used by patients when talking about their condition. Frequently, the language used by patients and healthcare professionals became an issue in how the nurse might proceed with the conversation. Often the language used appeared to be a means of talking about the diagnosis without actually using the term cancer.

Nurse S: But he actually never mentioned the word cancer the whole time. I was probably with him for over an hour and he never once mentioned the word. ...He used the word blockage.

It was recognised by some nurses that this may be indicative of where the patient was at, and they needed to respect this. At other times, it appeared that the nurse was frustrated at the use of euphemisms as it seemed to prevent the patient from facing the truth of their situation.

Nurse V: Sometimes the patient will use the word 'blockage' or 'wart', and I know they are using the word that the consultant gave them. I heard her say that to the patient when giving the diagnosis, but it is

couched in such a way that the patient is not to worry because the blockage can be removed.

Nurse E: ... yea... it is hard when they hide behind words. Understandable, but all the same we are then left trying to work around the words used. God, the patient is about to undergo major surgery and it's still only a lump or a wart. The number of patients who would say 'at least it was not serious'. We are not doing them any favours by not being up front with them – they have a right to know if it is cancer.

The use of euphemisms resulted in the nurse having to continue to hedge and dodge. They had to gently work with the patient until they sensed that it was 'safe' to move the conversation on. Nurses often retreated to using avoidance through the use of selective-silence in an effort to ascertain what the patient understood.

Nurse C: It's difficult looking after a patient when they have not been given their diagnosis. It's hard to be real with them when you know something about them that they don't know themselves.

Nurse R: ..., they want you to do what you have to and let them get home. And others will not let you go there....and it's as if they [patient] want you to play their game of 'lets not go there'...[holding up her hands and making inverted comma sign]

In summary, the use of curtailed-dialogue, euphemisms and silence compounded the sense of filtered-disclosure and was felt to contribute to difficulty in the nurse-patient relationship. Ultimately filtered-disclosure impacted on the nurse-patient relationship and undermined professional-companionship.

9.2.1.7 Category 4

Fractured-Trust: An interpretation

Trust is at the heart of professional-companionship and forms the basis on which the nurse and patient build their relationship. It is an unspoken expectation that exists. Fractured-trust is characterised by a severing of that expectation. It presents itself as a result of the nurse believing that there has been a broken bond with the patient. Fractured-trust concedes that the nurse has let the patient down or has failed them in some way. It challenges the nurses' belief in their integrity

and honesty. It can result from a challenge given by the patient or family or it can exist within the mind of the nurse without the patient awareness.

9.2.1.8 Fractured-Trust: Findings

The sense of having damaged or broken the trust-bond that exists between nurse and patient was supported by a number of participants. This sense of having let the patient down was paramount and impacted greatly on the professional-companionship, as can be seen in the following excerpt:

Nurse T: All I know is that I can remember patients that I had a good relationship with before they discovered their diagnosis and it changed once they knew they had cancer. It was as if I had somehow misled them, and in some cases my silence probably gave them a sense of security. They had put their trust in me and I had somehow broken that.

Nurse B: I suppose for me it's the thing of honesty and integrity. If we are not fully open with the patient it means that we all try avoid the subject. In some ways it is more exhausting than facing the issue.

From the above, it can be seen that the nurse perceived that there was a fracture in the relationship. It is interesting to note that for Nurse T and B it was an internal conviction which challenged their sense of professionalism. The patient had not confronted them with the issues of covertness, but it was their own internal dialogue that challenged the essence of their professional-companionship. For other nurses, this becomes an issue when the patient recognised that they had been misled or let down by the nurse.

Nurse L: There is a sense of guilt because I wasn't there or maybe because I knew and didn't let on to the patient. ...sometimes all I can do is ...just be there for them ...sometimes that means taking the brunt of their anger. That can be hard...

Nurse S: I think I lost his respect for a while. I certainly got the brunt of the family's anger – it was as if it were my fault that the truth was out. ...and now that he knew and knew that they knew there was an awkward period of pussyfooting about. It was like walking on eggshells.

In not been more ‘open’ with the patient the nurse has compromised their own level of integrity and honesty. The nurse has to deal with the sense of personal loss which merges with and radiates from a sense of professional loss. For some nurses this became a ‘heavy load’ which they had to carry.

Nurse F: I still felt very upset by it all. ... we had left the patient in limbo. When it blew up it made us look uncaring. I suppose it rocked my relationship with him and to be honest it’s still difficult. I feel that I had let him down and in avoiding his questions I was preventing him for facing what he said he already knew.

Nurse S: ...I was partly to blame because I’d not been honest either. If you look at healthcare – it is the nurse that had the most contact with the patient and their families and it is us who has to turn around and deal with having lied, at least that is what one of my patients accused me of – and that was very hard to take, but in some respects it was true...

Nurse C: ... I feel dishonest, you know...[silence]... they trust you as their nurse, and they look to you for help and support. And if you are keeping information back from them it makes it difficult.

In summary, it can be seen that ‘connectedness as journeying within the everyday world’ of the nurse is both complex in its creation and fragile in its operationalisation. The nurse has to balance the patients need for support through ‘being there’ against working as part of a wider team. The tensions created by euphemisms, lack of knowledge and partial-disclosures impacts greatly on the delicacy of professional-companionship. As highlighted in the next section, the fragility of the professional-companionship is further compounded by the nurse’s identity within the multidisciplinary team and their perceived role within the disclosure of bad news.

9.2.2 Theme Two

Connectedness: Exclusion as professional in the Everyday-World: An Interpretation

This theme relates to the working relationship and the role and function of the nurse within the multidisciplinary team. It specifically focuses on the nurse-doctor association. It reveals complex circumstances of medical and nursing

roles that form the social and cultural expectations of 'hospital life'. Exclusion relates to a sense of isolation within the breaking bad news scenario. It results in a form of prohibition, where the nurse cannot fully be there for the patient. This provokes a sense of disempowerment and raises questions as to ownership, affiliation and loyalty. It creates a medium which forces the nurse to distance themselves from 'being-there' for the patient and results in the nurse being complicit in the disclosure-non-disclosure continuum.

It recognises that the exclusion may offer benefit to the nurse in that it provides permission to withdraw. This sense of protective-avoidance is located for some within perceptions of professional guidelines. The theme demonstrates that although welcomed by some, exclusion can have a detrimental effect on professional-companionship with the patient and professional-collegiality within the multidisciplinary team.

'Connectedness: Exclusion of professional within the every-day world' becomes visible through a sense professional-collegiality and collaborative distancing.

9.2.2.1 Category 1:

Professional-collegiality: An interpretation

Professional-collegiality refers to that sense of belonging to or being part of a wider team of healthcare professionals. Whilst professional-collegiality normally encompasses working relations with fellow nursing colleagues, within this study it refers directly to the nurse doctor relationship. It is characterised by healthcare professionals working together. It recognises that each professional has a contribution to make to the patients experience of receiving bad news. Professional-collegiality provides a working framework which distinguishes role differences. It acknowledges that the nurse and doctor work as a team and that within that team there is support, recognition and open dialogue. Professional-collegiality values working partnerships and concedes that there are clear professional boundaries which govern work patterns. It allows for reciprocity between the two groups and assumes and values the contribution of the other.

9.2.2.2 Professional-collegiality: Findings

Throughout the interviews with the nurse group-set there was reference made to the multidisciplinary team. This sense of partnership, whilst referred to in the narrative was not what participants experienced. Many nurses felt very involved in the patients care and felt very strongly that they have a connection with the patient and yet often felt 'left out' when it came to disclosure of the diagnosis. This is evident in the following excerpt:

Nurse C: Sometimes the first we know is when the patient tells us, and that's not good enough.

Nurse S: You only find out that the patient has been told by the doctor and you know nothing about it...

Nurse B: ...it's difficult when you don't know what the doctor said ...

Nurse G: I wouldn't even know that they have been told by the doctor, sometimes it comes out in report or I might have read it in the notes...

It is clear, that the exclusion from information regarding when the patient will be given their diagnosis and what information will be given has an impact on the nurse. As highlighted earlier, this can have a direct influence on the nurse-patient relationship. The inference from being excluded was that there is no recognition of their role in the patients' journey and therefore a diminishing of the contribution made by the nurse:

Nurse A: I mean it could make their job easier if they spoke to the nurse before talking to the patient. Instead they barge in and start giving information overload and then leave...

Nurse P: it can be upsetting to discover that the doctor didn't even bother to come and talk to me before seeing the patient. It makes you feel as if what you do doesn't matter.

Nurse T: you get disheartened really. You know, you work your ass off building the patient relationship, getting them to trust you. You know you know your patient and want what's best for them ...I suppose you want – not so much to protect them but more like to be there so you can sort of be a buffer...

As the primary care-giver, nurses felt very strongly that they had a connection with the patient and yet, although they might be informed, they were not involved when the patient was given the cancer diagnosis. This exclusion results in the nurse feeling invisible to her medical colleagues. This sense of having an invisible-presence; there but not seen, was articulated as:

Nurse A: Sometimes I think the doctors don't even see us. It's as if we somehow don't exist or don't have anything to offer at times like this. . . .

Nurse H: Hello! What do they think I do all day? I am the one who really knows the patient, what they think how they react, where they're at. Yet I am never asked for my opinion . . . I sometimes wonder, why bother?

This sense of being dismissed contributed to feelings of powerlessness. That left the nurse feeling unable to contribute in an effective way at the point of delivery of the news. They were not allowed a presence and therefore prevented from actively participating.

Nurse N: . . .I think I have a lot to give if only someone asked me. Instead I don't think they see me as having anything to offer at all. In fact they don't even talk to me sometimes . . .

Nurse H: Sometimes I think that they think I'm only there to carry out their orders. It's as if I do nothing except give basic nursing care. It makes me really angry because I know I have a lot to offer my patients and I know they [patients] know this. It's hard to be there and not be part of the whole thing. . . . yea, sometimes I wonder why bother. Just get on with it and do what needs to be done . . .

While Nurse H describes her sense of powerlessness and the resulting apparent apathy towards professional-collegiality, she did proceed to speak with passion about her need to be there for the patient whether or not she was involved in giving the bad news. For her it was the patient's needs which took precedence over her perception of being dismissed and excluded.

Nurse H: . . .well I've come to the conclusion that at the end of the day it's all about the patient. It may be awkward and difficult but if the patient trust you and you have a good rapport with them you'll

eventually be in that place where you are needed [emphasis] and where your skills can be used [emphasis]...

Two participants saw being involved in the delivery of the bad news as something which lay outside their professional role. They recognised that they had to be there to help the patient come to terms with their diagnosis but saw no need to be present when the news was given. For them exclusion offered a form of protection and did not seem to infer any negativity regarding nurse-doctor collegiality.

Nurse T: ...it must be an awful thing to have to do, to tell someone they have cancer. I'm glad it's their job, they're welcome to it. Just let me get on with my job thank you very much. I am quiet happy just to be there for the patient...

Nurse O: not knowing what they said can be hard. But you know what? You can always ask if you want to ...I am glad that I don't have to break the news...

In summary, for many there was a sense of wanting to be involved in the process to assist the patient to come to terms with the diagnosis. The sense of powerlessness emerged from being excluded and there was a sense that although part of a multidisciplinary team, there were clear boundaries in place and the nurse was, for the most part, excluded from the delivery of the bad news. . . Expressions of anger and guilt resulted from this sense of powerlessness. Exclusion resulted in lack of knowledge and this impacted how the nurse interacted with the patient as can be seen in the next category.

9.2.2.3 Category 2:

Collaborative Distancing: An Interpretation

Collaborative-distancing concerns the effort of the nurse to ascertain the level of patients understanding. It can be considered as that space which is created between the nurse and patient in an effort not to have a discussion on the patient's diagnosis or suspected diagnosis. It represents a conscious effort on behalf of the nurse to erect barriers or to use blocking techniques within the nurse-patient interaction. Erecting barriers and the use of blocking techniques may include use of silence, the avoidance of engaging in certain topics of

discussion or the use of referral to another member of the multidisciplinary team. It differs from filtered-disclosure as its aim is based upon solidarity and corroboration with the multidisciplinary team. It is characterised by a conscious awareness. The nurse is alert to her behaviour and draws upon interactional-skills to direct and control the conversation. It is not used as a means of deliberately misleading the patient. It is not used indiscriminately or inappropriately.

Collaborative-distancing can be interpreted as a response to a lack of knowledge or can be seen as a means of offering collegiate support. It is something which the nurse struggles with and it can be seen to challenge their sense of professional and personal integrity and honesty. In essence, collaborative-distancing is the means by which nurses corroborate with the multidisciplinary team. It is demonstrated by the nurse using avoidance techniques to ascertain the patient's level of understanding. It affords the nurse opportunity to support their medical colleagues and remain within the boundaries of perceived professional responsibility. It protects their standing within the multidisciplinary team.

9.2.2.4 Collaborative Distancing: Findings

It can be seen that for some participants collaborative-distancing resulted from a lack of knowledge regarding what the patient knew about their diagnosis. This was often a consequence of not being present when the patient was given their diagnosis, not being aware that the doctor had spoken with the patient or not having access to adequate documented information about the information given to the patient.

Nurse D: ... It's difficult if you don't know what the doctor has said. You know,... you do the usual thing of asking them questions about what they know and what was said and who said it. But it's difficult as they don't always remember ...or they only remember one thing or even worse totally misunderstood what was said.

Nurse U: ...'cause sometimes I don't have a clue what was said I usually find myself trying to avoid the conversation at all costs. Sometimes I'm just glad to be too busy to talk, it's not that I don't want to, it's 'cause I just don't know what to say...

The nurses are aware of the patients need to know and are also conscious of their own need to know. As a result of not being present when the news was broken, the nurses often have to position themselves in a place where they will not have to engage the patient in a discussion around their diagnosis. This distancing can be used as a self-protective mechanism where the nurse does not want to appear uninformed, as with Nurse U above. It may also be used to gain time before the information can be ascertained, or as with the second excerpt below, it can be used as a form of assessing the patients understanding.

Nurse E: ...if you can, sometimes its good to get away from the patient for a few minutes and try and find out if anyone knows what was said. The last thing you want to do is put your feet in it.

Nurse S: ...I've got really skilled at answering a question with a question. ...I'm not giving anything away and I can find out what the patient really knows.

Whilst it appears that the medical staff does not formally request the withholding of information, there is a sense that the nurse must be seen to be saying the same thing as the doctor. The need to ensure consistency for the patient may be driven by wanting to support them where they are at. However, there is also an acknowledgement amongst some participants that they must ensure that they do not cross the line of professional responsibility, as can be seen in the next extract:

Nurse M: It's not my job to tell the patient, that's the doctor's role. My role is to support the patient and to make sure that they know where we are all coming from. It wouldn't do now if we were all saying different things, would it? That would only confuse them

Nurse F: I'm not saying that I won't tell the patient, but to be honest I think that's the doctor's job. As nurses we are not suppose to give diagnoses but I suppose we are allowed to talk once they know

This sense of 'not being allowed to' or being 'professionally bound by', may suggest the nurse was acting within clearly defined role expectations. However, the lack of role clarification and resulting role ambiguity contributed further to the nurses' subjection and incapacity to be totally honest with the patient. The

dance of collaborative-distancing was engaged in, as it afforded the nurse a sense of connection with the multidisciplinary team and offered the nurse a means of protective-avoidance. It was this protective-avoidance which bestows a means of rationalising their behaviour. In rationalising they were attempting to justify the collaborative-distancing.

Nurse P: I'm only doing what I'm suppose to. There are rules and expectations. ...on this ward you keep your head down and get the job done ...you don't ask questions and you just get on with it and do the best you can ...its about surviving...

Nurse O: Jesus! Could you imagine if I went and said something that contradicted the doctor? I'd be hung, drawn and quartered by the sister and then probably put in my place by the consultant. ...no you know your place and that's than.

In summary, the nurses were often aware of internal personal and professional conflicts as they strove to develop professional-companionship within the confines of an organisation that does not value or recognise their contribution to the patient. Their behaviour, which may be considered irrational or unacceptable, is ameliorated by offering an apparently reasonable explanation. It is the belief in that they are bound by a professional code of conduct which supports this rationale

9.3 Conclusion

The nurses spoke clearly and with passion about their role within the multidisciplinary team. They articulated vividly how they see their role in supporting and 'being-with' the patient on their journey. Throughout the interviews the emergence of the ubiquitous past and the centrality of 'I' – the merging of the professional and personal was very evident. A sense of disempowerment appears to be emerging from a lack of involvement and the need to meet the needs of their colleagues whilst remaining true to their patients. The complexities of the role were evident as nurses strove to pick up the pieces, salvaging a bad situation and supporting the patient, family and medical colleagues. There were some examples of bad news being broken very well, with compassion, honesty and truthfulness. When the nurse was involved

in the process it appears that they were better placed to support the patient whilst working collaboratively with their medical colleagues. It would appear that the exclusion (directly or indirectly) resulted in creating difficult situations for the nurse and the patient.

CHAPTER 10
PRESENTATIONS OF FINDINGS:
HEALTHCARE PROFESSIONALS - DOCTORS

10.1 Introduction

The following section presents the finding from a group of eight doctors drawn from four general hospitals in Cork, Dublin, Donegal and Galway. All were working as senior registrars in general medicine or surgery and although exposed to a short rotation in oncology and palliative care during their medical training, they had not worked in these specialities since qualifying. As with the presentation of findings from the nurse sub-group, individual biographic descriptors of the doctors are not included in this section. Excerpts from the doctors' narratives are included to offer legitimation of representations (Berg, 2004). They are offered in an attempt to ensure faithfulness of the account (Warren and Karner, 2005).

10.2 Emerging Theme

One theme emerged from the data and it centres on the area of giving the cancer diagnosis. The theme offers a perspective of the doctor as they see their role and involvement with the patient, the multi-disciplinary team and fellow medical colleagues. For the doctor, breaking bad news is seen as an event; an inevitable part of their role and function. The event is choreographed amidst a complex set of perceived expectations and is executed with thought and thoroughness. The theme, entitled 'Objectified-connectedness within the Everyday-World', has a number of categories, which offer the reader structure to the 'unpacking' of the lived experience of the doctor as they prepare for and give the bad news to their patients. Table 9.2 offers a representation of the theme and its categories as they will be addressed within the following section.

Table 10-1Themes and categories - doctors

THEME	CATEGORIES
<p style="text-align: center;">OBJECTIFIED CONNECTEDNESS WITHIN THE EVERYDAY-WORLD</p>	<p style="text-align: center;">Allied Affiliations</p> <p style="text-align: center;">Antecedent Preparation</p> <p style="text-align: center;">Disclosures</p> <p style="text-align: center;">Authenticating Awareness</p>

10.2.1 Theme:

**Objectified-Connectedness within the Everyday-World:
An Interpretation**

This theme refers to the associations the doctors have within their every-day world when having to impart bad news to their patient. It reflects relational encounters, namely those of the doctor-patient; doctor-nurse and doctor-peer relationships. The theme reveals that the relationship differs across the three areas. It impacts not only on the specified group, but also affects how the nurse and recipient related to each other. Objectified-connectedness is characterised primarily through a perception of the doctor as leader of the multidisciplinary team. This leadership role provokes an expectation that the doctor must be seen to act in specific ways. It is this expected behaviour that results in an objectification of their connection across the three groups of patients, nurses and

peers. The everyday-world of the doctor relates to roles and activities that surround the giving of a cancer diagnosis to their patient.

Within the doctor-patient connection the theme reveals a scenario in which the doctor takes control of decisions regarding disclosure, treatment modality and interventions. The initial primary aim of the doctor is to arrive at a diagnosis based upon a thorough medical history and investigative results. The patient becomes the conduit through which a medical assessment is made. It is the presenting symptoms rather than presenting self that becomes priority. The connection is made with the presenting pathology and through that filter the patient presents for connection.

The relationship between the doctor and the nurses within the multidisciplinary team is centred on the perception that the nurse is aware of the diagnosis and the information that the doctor has given to the patient. The nurse is there by default rather than there as a contributing participant. The nurse is there to be informed rather than to inform.

Connections with fellow peers serve the need to appear competent and efficient. For the doctor, breaking bad news is an event in time. It is a point during which the patient is informed of their diagnosis. The event is prepared for through ensuring all facts are collected and an assessment made upon the presenting information.

The delivery of the bad news is made by the doctor. A decision as to when, where and how much information to give the patient is formulated by the doctor as they prepare for the event. Once the diagnosis has been given, others within the multidisciplinary team are informed of the situation. The doctor will often check up on the patient subsequently to ensure that they have absorbed the information.

Objectified-connectedness within their everyday-world is seen through the language used; the distancing of 'I' within the dialogue. When the doctor is involved in breaking bad news, their role and function is performed through professional objectification. It is characterised by a distancing of the personhood from the professional and it emerges within the theme in the following four categories: Allied Affiliations (professional relationships),

Antecedent Preparation (preparing for the disclosure), Sequential Disclosure (delivery of the bad-news), and Authenticating Awareness (checking understanding post delivery).

10.2.1.1 Category 1:

Allied Affiliations: An interpretation

Objectified-connectedness results in the development of alliances that are power based and directed by the perceived leader of the multidisciplinary team. Allied affiliations relate to the working relationships that are highlighted throughout the doctor's narrative. It represents the means of connecting and dealing with the three specific groups, patients, nurses and fellow colleagues. It demonstrates the need to be seen as leader within the multidisciplinary team and is reflected in the roles adopted.

It reveals itself in how the doctor communicates with the patient when giving the bad-news. The alliance with the nurse within the multidisciplinary team is based upon a premise that the nurse is aware and involved in the bad-news event and is represented by the doctor informing the nurse of the discussion had with the patient. Alliance between medical peers demonstrates a need to receive professional support with a focus on diagnostic conclusions and medical interventions.

10.2.1.2 Allied Affiliations: Findings

Throughout the interview the doctors spoke of having to deal with the patient in an open and honest way. The need for clarity of information was seen as paramount. It was this need to ensure that the patient had the information they needed, which influenced the doctors' decision as to how they handled the patient.

Doctor A: ... they deserve the truth and we have to give it to them. After all they are our patients and they look to us for help...

Doctor D: we have a legal obligation to tell our patients their diagnosis, it rests with us as their doctor and that means sometimes having to say things that may not be what they want to hear, but we have to get them to know their diagnosis.

The relationship between doctor and patient was based upon trust and respect. This can be seen in the above excerpts when the doctor mentions the patient's need for the information and their professional responsibility to provide it. The doctors also made reference to the expectations that patients have of them on arrival. There was an acknowledgement of the patient's vulnerability and their need to trust them, as referred to by Doctor A above and as seen in the following two excerpts;

Doctor C ...they come in and are obviously very worried to be in hospital. They have their suspicions or denials and they rightly or wrongly see us as having all the answers ...

Doctor H: The patients see us to look after them and I suppose they want to think that we can make all things better. It's their utter need on us to have good news for them that makes the bad news even harder to hear.

Whilst there is an acknowledgement of the patients' need to know their condition, this is set against the doctors' need to arrive at a medical diagnosis. This is further compounded by the professional's responsibility to inform the patient of their diagnosis. The distancing that is created between the patient as person and patient as symptom occurs as the presenting person is subsumed within the presenting condition.

Doctor S Sometimes it is difficult. We are under huge pressure from all areas; ward rounds, outpatients, other departments and of course we need to make the right diagnosis. The medical history is crucial and there is a lot of information gathering ...it's hard to balance the need for information against the peripheral stuff, you know a lot of the details are not helpful. So you end up being very directive and systematic in your questioning, otherwise you would have a life story and that's not what the history is about ... you'd be there all day if you didn't take control...

It is the presenting condition that takes precedence over the person, as the doctor strives to arrive at the diagnosis. It is not that the doctor is ignoring the person, but simply priority deems that the history is taken as part of the assessment strategy. What becomes evident is that the doctor makes assumptions about the

patient based on the limited interactions they have with them and also on information gathered from others within the multidisciplinary team.

The alliance between the doctor and nurse is based upon an understanding that the nurse is aware of the decisions made within the multidisciplinary team. The doctor is seen as leading the team and the nurse is acknowledged by the doctor as being part of it. These decisions, when made, are made within the confines of the multidisciplinary team. However, it is the doctor who makes the decision of how and when to inform the patient of their diagnosis. It would appear from the interviews that although nurses are part of the team, they are not part of the decision making process. There is a working alliance between doctor and nurse which is based upon a hierarchical system. The patient is the doctor's responsibility and although the decision making is theirs there is an acknowledgement of the need to inform and include the nurse once the decision is made or once the patient has been informed of their diagnosis.

Doctor C: ...the nurses need to know the diagnosis and we need to be working together.

Doctor H: We work as a team. They come on ward rounds and if they are concerned about a patient they always let us know, ...we work together, relying on each other ...they're very good at chasing us up if we're not about...

Doctor D: I always make sure that I tell them what I have told the patient and I always make sure that I make a note of it in the notes so that way everyone knows what's going on...

The doctor's perception of the nurses' involvement in the multidisciplinary team appears to relate to the nurses' need to know the necessary information or decisions made by the medical staff. There is an awareness of the nurse as being present on the ward and indeed, for some doctors, there is an acknowledgement that the nurse is the consistency that the patient needs.

Doctor B: We're all over the place, A&E, admitting patients, theatre ... we just can't be there all the time with the patient. The nurse is the one who brings it together and keeps it together...

Doctor R: I'd be lost without the nurses. They're the ones that keep me on my toes; you know reminding me of results or getting me to follow up on things

Doctor C: when you first start you haven't really got a clue how things work and they [nurses] keep you on the straight and narrow. We really need them to help us do our job correctly...

For most of the doctors there did not appear to be recognition of the need for the nurse to be present when the bad news was given to the patient. They saw it very much as their responsibility and they did not include the nurse in the process of disclosure. It would appear that it is not a conscious decision to exclude the nurse but neither is there a conscious decision to seek the relevant nurse out and go together to the patient.

Doctor D: Well no, I usually find that when I am there with the patient I just bring up the issue. Sometimes if there are too many around it might cause distress to the patient ...

Doctor H: It's not that I don't take the nurse with me; it is just that they always seem busy and to be honest I never know who is looking after whom. It just happens this way....

One of the doctors insists that whenever possible the nurse should be present when he gives a cancer diagnosis to his patient.

Doctor A: If at all possible I also try to have a nurse with me when I am going to break bad news to the patient. I suppose it's habit really. ... I think they can be a real support for the patient and it helps if they know what I've said ... they're still there when I go off the ward.

This particular doctor went on to speak of his training under a specific consultant who would always ensure that there was a nurse available to be part of the team giving the bad news. For Doctor A, it was seen as good practice and something which he now role modelled for his junior medical staff.

Doctor A: You have to be careful not to have too many with you as it could really upset the patient. If I am going to tell the patient on ward rounds I would usually have the team carry on to the next patient and I would stay back with the nurse ... sometimes I might come back after the rounds and see the patient when the ward was quieter ...

The alliance between doctor and fellow medical colleagues at work appears to be different from the alliance with fellow medical colleagues who do not form part of their immediate team. For those involved within the medical team there appears to be an alliance which looks for professional guidance and advice as opposed to professional support.

Doctor B: You recognise very early on that you are not alone in the team ... you always have other colleagues to advise you. The ward rounds can be quite supportive and in many ways they give you a sense of what the others are thinking...

Doctor R: ... you're never really alone when it comes to having to make a judgement call. The diagnosis is not made in isolation, there are all the results and there is always opportunity to discuss cases with the consultant.

Doctor Q It depends really on the relationship you have within the team. If the consultant is supportive then you know that you will have backup ... but not all senior colleagues are supportive. Some of them see their role in educating you through humiliation and intimidation. Most of these are gone now, but there are still one or two about that you come across. I had my fair share of public humiliations in front of patients and I would never do that to one of my junior colleagues...

One doctor felt very strongly that he received his support from peers who were not part of the immediate team. Whilst he indicated that he worked within the medical team and received guidance and advice, he was clear that his support networks came from outside the team.

Doctor S ...it's very clinical really. There is a job to be done and you have the medical team to help you do it. But when it comes to looking for support I am very careful who I expose myself to. I've learned in the past that things can be used against you. I still have a great network of friends from med school. We are always in touch and it's often over a beer and a laugh that you really get what you need ... I suppose we all understand where we are at and how sometimes you just don't have all the answers ...

Whilst many of the doctors felt that they received support, it was often achieved haphazardly rather than structured. Doctor R captured this very well when he said:

Doctor R: There is no real set up ...no real support. Well I suppose amongst the rest of the medical team we would just talk about it ourselves, you know. So I might say 'by the way I've told him his diagnosis, and the rest of them might ask how did he take it, how did it go? So that in itself is usually enough.
You can usually talk to the nurses about it as well, so ... although there is no real formal debriefing as such, just in general we might often talk about our patients out of necessity. It's usually OK, I would find it OK.

It was worth noting that doctor A, who made a point of ensuring that there was a nurse present when he gave bad news also found that he received support from the nursing staff.

Doctor A they [nurses] can really support you too... that's one of the benefits of having them with you when you break the news. Because they hear what you said or didn't say ... they can see what you went through. Sometimes when they come in and start talking to the patient it helps, because they can take some of the burden off and are not only there for the patient but often I feel they are there for me too. ...yea they understand what you went through and we can both be there for each other afterwards, we can support each other, especially if it was particularly difficult or harrowing ..

It can be seen that the alliances that the doctor forms with patients, nurses and medical colleagues are responsive and reactionary to how they perceive their role as doctor and leader within the multidisciplinary team. The affiliations form the backdrop of professional activity and underpin the doctor's practice as they prepare for and deliver the bad news to their patient.

Doctor A:you go from being unknown to suddenly being right in there with them, you know their history and all that, ...it just gives you entry ...

Doctor A makes reference to his alliance with his patients when talking about going from being 'unknown' to 'known' from outsider to gaining 'entry'. However, the 'getting to know' is about gaining insight into the condition and whilst patient orientated it can be seen to be diseased focused.

The pressure to arrive at a 'diagnosis' and provide appropriate treatment drives the alliance with the patient. It is an alliance based upon objectified distancing

which enables the doctor to stand back and make decisions that are based upon thorough medical assessment and investigative results. It is an alliance that is not dismissive of the person but rather recognises the need for an accurate picture that goes beyond the person who presents as a patient.

10.2.1.3 Category 2:

Antecedent Preparation: An Interpretation

Objectified connectedness enables the doctor to detach themselves from the presenting patient and make an interpretation of the unfolding results. It is this apparent detaching that forms part of the antecedent preparation. It is characterised by the doctor processing and filtering the information and results. It is a necessary procedure that enables the doctor to make clear decisions and arrive at a diagnosis for their patient. Antecedent preparation is often made in the light of an already suspicious understanding of the presenting symptoms. It reflects the process of arriving at a diagnosis and plan of effective treatment.

It reflects a period where the doctors prepare themselves for the actual disclosure of the diagnosis. There is an assessment of the patient and how the doctor thinks they might cope with the diagnosis. There is also a sense of the doctor ensuring that they have all the necessary factual information to hand prior to commencing the disclosure.

Antecedent preparation also represents a period of uncertainty as the doctor experiences a sense of vulnerability. There is recognition of their powerlessness in the light of patient's expectations. This can be reflected in their need to be honest with the patient whilst ensuring that they instil a sense of hope. This period of preparation represents the doctor's need to be supportive and humane as they impart news that patients may not want to hear. The dilemma for the doctor in the antecedent preparation is the need for accurate interpretation balanced against realistic expectations.

10.2.1.4 Antecedent Preparation: Findings

It is the doctor's need for information that forms a vital part of the development of the clinical picture of their patient. This medical history/assessment is the conduit through which a connection with the patient is made. It represents a process of moving beyond the presenting person to the history of symptoms. It may be this need to see beyond the person that forces the doctor to objectify and distance themselves from the person presenting. The pressure to arrive at a potential diagnosis or label can be seen as uppermost in the early encounters with the patient.

Doctor Q: The most important thing is to arrive at a diagnosis. This is a multidimensional thing. You have to see the patient in light of the results – they all knit together. No one thing stands alone – you have to make sure you have the full picture before you start divulging things ...

Doctor C: ...my job is to make an assessment based upon how they present, their family history combined with lifestyle and initial results enables me to get a fair idea of what's going on... you sieve the information and try and make sense of their situation...

Doctor R: I hardly know them and they are asking all sorts of questions, ...questions which I might not have answers to, not at that point anyway, I need to find out, ...to be sure of my diagnosis I have to have all the information...

The need to have 'all the information' and the need to make a diagnosis places the doctor under pressure to make clinical decisions that may not always seem person-focused. For the doctor, these decisions are needed if they are to arrive at an accurate picture of the presenting condition.

Doctor B: you have a battery of investigations and tests that need to be done as soon as possible ...you have to get these organised and results back so that decisions can be made. It's not that the patient is not important it's just that in order to make the right diagnosis priority must be given to getting the test done...

Doctor D: I am aware that the patient can feel pulled from pillar to post and that they are constantly being prodded or pricked ... up there on show, ... but we need to get the full picture if we are to help them and sometimes that means that they may feel uncomfortable or in the dark ...we need to know so that we can do right by them...

It is this need to arrive at a diagnosis that drives the antecedent preparation. The need to have all the information and all the facts prior to delivering the diagnosis is paramount.

Doctor A: ... you admit them suspecting something is not right, based upon their history and presenting features. You carry on assessing them and all the time you suspect something. Often the reality is that you know you just need confirmation...

Doctor B: Before you even meet the patient you may have a picture of what the situation is like. You might have the referral letter or the history from previous admissions. It's not like you go in blind, you probably already have your suspicions...

Once the doctor has sufficient results to confirm his suspicions or provide a diagnosis, he begins to prepare for the actual delivery of the diagnosis to the patient. Many of the doctors talked about having to prepare themselves for the actual event, as is evident in the proceeding excerpts:

Doctor Q: ... it's not easy to have to tell someone they have cancer. Sometimes all they will hear is the word cancer and take it as a death sentence. They might not hear anything else. That's why it is so important to pick your time for telling the patient..

Doctor S: Having to tell someone that they have cancer is probably one of the most difficult jobs a doctor has to do. Even though there are so many developments and scientific breakthroughs, it is still devastating for the patient and it's always hard to have to tell someone. I usually spend a lot of time beforehand psyching myself up for it...

It is this antecedent preparation that appears bridge the objectified distancing that initially marked the doctor-patient alliance. For some doctors there was recognition of the impact having to give a cancer diagnosis has on them:

Doctor S: Doctors are human too you know. We feel things, we may seem cold but under the exterior is someone who cares ...

Doctor A: I tend to be a person that gets involved emotionally...I would be quite sad, I would already be sad because I already know the diagnosis anyway ...and have now to see how they are going to react..

Another aspect of the antecedent preparation is a sense of dread of emotional reactions. The uncertainty of how the patient might react when they are given the news is something that many of the doctors alluded to, as can be seen in the following excerpts:

Doctor D: ... you never know how they will react really. Some just seem to shut down in front of you...you know you have given them all the information but they just do not register what you are saying...I know they are in shock but they need to be told ...

Doctor S: It's awkward if they just break down ... I still feel like 'HELP' what do I do now?... It never gets easy; people react in so many different ways and there's nothing you can do...

Doctor B: Upset is one thing. Confusion or overtly worried – over worried. Some people would ... it varies a lot, but some people would not overreact ...it's rare now, but most people do not break down and cry straight away, they just accept it.

In the antecedent preparation there is an acknowledgement of the prophetic expectations that patients often have of their doctor. An overriding issue for many of the doctors is the expectations that the patient may have regarding their knowledge about their future.

Doctor C: I just hate the 'How long' question. They nearly always will ask this and it's something I am always aware of as I approach giving the diagnosis...

Doctor R: They nearly all will ask the inevitable question of how much time they have left. I dread this because the reality is we just do not know and if we say six months it's like giving a sentence.

10.2.1.5 Category 3:

Disclosures: An Interpretation

Central to the breaking of the bad news event is the disclosure of the diagnosis. Disclosure is carried out by the doctor following antecedent preparation. Disclosures are controlled by the doctor in terms of what is disclosed, how it is disclosed and when it is given to the patient. The language used varies and the

resultant disclosures can be categorised as full disclosure, partial disclosure, sequential disclosure, closed disclosure, or non disclosure. Disclosure may be given to the patient in the presence of family members or may be given to the patient when they are on their own. Disclosures are characterised by the provision of factual information in the form of diagnostic results and ultimately culminate in a form of a diagnosis or label of cancer.

10.2.1.6 Disclosures: Findings

Although ‘objectified connectedness’ represents an objectifying by the doctor of alliances made, it does not necessarily imply that the patient is dismissed or ignored. The doctors spoke of their obligation to impart the news in a supportive way which was humane and respectful.

Doctor A: What I tend to do is find out what the patient understands, what I think they will understand, how much he will want to know. You have to go from where they are at, and sometimes it can be difficult to know where they are at ...

Doctor Q: ...it has to be done, they have to know what is wrong with them, but there are ways of breaking the news. Although the news can be devastating, the person delivering the news is not ...they have to balance the patient’s need to know with their ability to cope with the news itself.

For some, learning how to break the news came from observing poor modelling of the process.

Doctor R: I remember as a junior just out of medical school how we would dread having to tell a patient that they had cancer. Mind you, it was always done by the senior reg. or the consultant. The problem was that it was often done very badly and you couldn’t say anything ... I mean it would not be acceptable to challenge them, you just watched and observed ...

Doctor C: I would always seem to be missing when they were giving the news. I would find out later or they would tell me that they had told so and so their diagnosis. I remember asking if I could come with the consultant when he was going to break the news to the patient. He was good but very rushed, I remember thinking it was like a machine gun – bang bang bang and go ...

For other doctors there was good support and modelling provided throughout their training. They felt that they were prepared for giving patients bad news and although feeling vulnerable as junior housemen, they were exposed to good practice and felt that they were prepared well for the role of breaking bad news to patients. This is evident in the following excerpts:

Doctor A: I was lucky really, my first consultant was brilliant. He always made sure that he demonstrated good practice. If a patient was to be told his diagnosis he would have a sort of 'pre round' discussion with the team. He would ensure that at least one of the junior doctors was linked with the senior reg. or himself if he was to break the news.

Doctor R: It was so daunting and so scary really. You felt out of control and sometimes I remember feeling as if I should not be there. All I was doing was watching, was not allowed to say anything ...well not that I was not allowed - rather that it was inappropriate to break into the dialogue ...I remember thinking 'God, he's so confident and so good at talking to the patient. I will never be able to be so smooth and clear.'

Doctor S: I was very fortunate in that on my first rotation I was working with a really good senior reg. She was really into teaching and although I remember feeling overawed and out of my depth, she had a way of ensuring that you were exposed to all sorts of situations. She would always have you shadow and afterwards she would get you to talk about what you observed.

What was obvious from the narratives was the apparent lack of focused training whilst they were medical students on how actually to break bad news effectively.

Doctor A: We had some general communication training in our medical school, but to be honest it was too early and too removed from the reality of practice, it certainly did not prepare you for the difficulty of telling someone they had cancer. There is no formal training *per se*. I'm sure we had some when we were in medical school but I can't remember it really. Yes, formal training is minimal, I suppose.

Doctor D: Nothing prepared you for the real world. My medical school training was intense, but I don't ever remember ever having anyone talk to us about breaking bad news to patients. In fact I do not think we even had communication skills training in our programme, or if we did it obviously made a huge impression on me ...

Doctor Q: When I was training it was strict, we did not have much opportunity to break bad news. In general it tends to be left to slightly more senior doctors, generally the registrar or consultant. In general you do not get the intern to do it, it's not fair on both the patient & the doctor. There was no formal training as such. Most of my experience of actually giving bad news comes from when I became a registrar – about 2 years ago.

Whilst there was an acknowledgement of some communication training, it was felt that this was both ineffective and inappropriately delivered at the wrong stage of the medical training. What was obvious from the dialogue was that this group of doctors now felt that they were offering their junior colleagues opportunities to observe and learn from them as role models.

Doctor C: I always ensure that I talk to the intern about the importance of communication with their patients. The best way of teaching this is to model it for them. That way hopefully they can see how it should be done.

Doctor S: In terms of education there is a responsibility to at least provide that level of training and tell them that there are certain things that you should and should not do.

The breaking of the news, and the amount of information given to patients, is determined by the doctor. It can be seen from the following excerpts that for some there is a belief that the amount of information given during the disclosure must correspond to the patient's ability to cope with the information, whilst for others there is a belief that the patient must be told the reality of the situation.

Doctor: S: ... you have to be careful really. You don't want to over load the patient with lots of information that they don't understand or can't make sense of. It's important that you give the patient what they can cope with and sometimes that might mean holding back something. You can take your cues from the patient – you'll know soon enough how far you can go..

Doctor A: And usually in a lot of cases they would want to know straight off and I'd say something like 'we have some news from the scans, and so on and I am going to explain the scan results in more detail ...

Doctor R: You need to balance what they need to know with what you need to tell them. I think it's best to be truthful and up front. Give

it to them straight and then they know where they are at – they have a right to know the truth.

This sense of juggling the amount of information to be given represents the levels of disclosure. Whilst all the doctors felt that the patient should be given their diagnosis there was a discrepancy in the view of how much information should be given. Some felt that giving too much information too quickly did not help the patient and they opted for a sequential disclosure, where the doctor decided on the amount of information to be imparted and how it was to be given.

Doctor S: ... you can prepare them for the diagnosis by giving them hints that you are concerned about this or that and that you are waiting for the results. This way they can begin to prepare themselves for the news...

Doctor B: I would never just come out and say it. ... I would always let them know that I suspect something was wrong. They suspect it anyways and I am only preparing them for the eventual diagnosis. But even then I am selective about what I tell them and more importantly how I tell them.

Partial disclosure differs from sequential disclosure in that the language used by the doctor shades or moderates the reality of the diagnosis. Whilst the doctor speaks of the need to protect the patient there is an element of avoidance or hedging that is apparent in the dialogue.

Doctor A: So what I would normally tell them is that 'look we have certain serious concerns as to what this could be' ... and if they ask for more then I would tell them. I would tell them that that would be on our list of things we would be worried about ... So for example with the scan results we can say something like 'yes there was something there'.

Doctor Q: I might say that there was a blockage and that we need to go in and see what was causing it. I wouldn't say it was probably cancer, but they probably know what I mean. Afterwards when they had the surgery I would tell them that it was a growth ...

Doctor C: If you start talking around those things the patient would usually accept the diagnosis, usually they would put two and two together and know what's going on ... cancer. So I try to tell them as much as possible, but only given the fact that I think they would tolerate it, accept it.

The use of euphemisms is evident in many of the doctors' descriptors of how they disclose a diagnosis to the patient.

Doctor A: ... like a growth or a mass or something like that. I might not come right out and just say cancer. A lot of people tend to use the word shadow, I don't use that very often myself, I tend to say something was seen, but it's the same thing really...you're trying to tell them that there is an abnormality, something there that shouldn't be there.

Doctor D: I would use language they understand, like shadow or lump. But they usually know what I mean and will ask outright does that mean cancer – people are well informed these days ... if they ask I will of course tell them.

Doctor C: I might give him a few hints like I am worried about this thing ...I wouldn't tend to use the word cancer, at least not initially.

Some talked of full and open disclosure where they would ensure that the patient was told exactly what their condition was. The use of the word 'cancer' was evident within this type of disclosure. The patient was left in no uncertainty as to the diagnosis. It was felt that the patient has a right to know the actual diagnosis and indeed for some this was seen as a requirement if they were to enter into negotiations with the patients as to their treatment options.

Doctor Q: I think it's important that the patient is not left in limbo. They need to know the diagnosis and the only way to do this is to come out and say it clearly and sensitively. Pussy footing about only creates problems later on ... so I am very upfront and I tell them exactly what I think it is, and yes I make sure I use the word cancer...

Doctor B: Not using the word cancer does not help the patient. They are not stupid, they know if you are avoiding the issues. Usually you will have already been accosted by the relatives and they, because they are one removed will often come right out and ask 'is this cancer?'

Doctor A: The majority of times these days the family would be there, most patients wouldn't mind the family knowing or the family being there...I would usually try and get the family involved and I might give them a call myself and ask them to be on the ward at such and such a time...I'd say something like 'we have some news from the scans, and so on and I am going to explain the scan results in more detail to your husband, or whatever ...and I wondered if you wanted to come in.' That way I can be very upfront with all the family and they can all be

there for each other when I use the word cancer. It's important that they all know the reality of the situation ...

Doctor S: I find honesty is the best policy. I would use the word cancer and then might go on to say that we still have some more tests but it is looking increasingly like cancer. It's important then to make sure that you give them some hope – that it's not all bad... they need to know that you are not giving up on them...

Although all of the doctors spoke of their disclosures in terms of sequential, partial, or full disclosure, some did make mention of non disclosure and closed disclosure. Non disclosure relates to the deliberate avoidance of telling the patient their diagnosis. Closed disclosure is when the relatives are informed but not the patient.

Doctor B: ... the days of not telling the patient their diagnosis is long gone, thank God. We always ensure that the patient is kept informed; they have a right to know. The days of telling the relatives but not the patient are also gone, on the most part anyway...

Doctor D: I don't think any doctor would deliberately mislead the patient or keep the diagnosis from the patient. I believe that patients are not kept in the dark anymore. We are much more open and honest with the patients ... no one would let a patient go home not knowing their diagnosis...

Whilst they all spoke of how they deliver bad news to the patient, one doctor spoke of the patient's right not to know their diagnosis.

Doctor A: The patient has a right to not know as well as to know. If they make it clear that they prefer not to know, and I have met patients like this, they are absolutely clear that they don't want to know – 'don't tell me what it is just go ahead with the treatment'. They have a right to not know and you have to respect them from that point of view ...

In general, it would appear that the doctors ameliorate their disclosure practices to meet the needs of the patient. The range of disclosure practices represents a flexible approach to delivering the bad news.

10.2.1.7 Category 4:

Authenticating Awareness: An Interpretation

Authenticating awareness relates to a period in which the doctor checks out that the patient has understood their diagnosis. It represents a checking modality in which the patient is assessed as to their ability to grasp the information provided. It also signifies a period in which the doctor can reinforce the treatment options with the patient. As with disclosure, it would appear that authenticating awareness is doctor-led and controlled. As with the category of ‘allied affiliations’ authenticating awareness is performed by the doctor, independently of other members of the multidisciplinary team.

10.2.1.8 Authenticating Awareness: Findings

Following the disclosure of the diagnosis there is often a period of time when the patient is left to reflect on the information given. This is inevitable due to the working patterns of the doctor; they, unlike the nurse, are not on the ward for long periods of time. Some of the participants mentioned that they ‘check’ up on the patient; as can be seen in the following:

Doctor A: Very often you have to go back after you’ve done all the day jobs and check on the patient again, say 7 or 8 pm, you know...it is hard, it is very, very hard. But I think if you put in that much more effort I think the results are better.

Doctor S: ... you have to keep going ... you know, you walk away from the patient and they are probably devastated but you have to keep going for the other patients. I would always go back and check in with them later, you know, just pop in and see if they are alright...

Doctor Q: They need time ... they need to get their thoughts together and talk to their family or whatever. Usually you find they have lots of questions when you go back so it is important that you do so...

Authenticating awareness differs from sequential disclosure. With sequential disclosure there was a sense of deliberately ‘drip-feeding’ information to the patient. Authenticating awareness, although initiated by the doctor is very much about being there to clarify or answer questions that the patient might have. It is

not seen as an additional disclosure, but rather as an opportunity to check understanding.

10.3 Conclusion

Objectified connectedness within the everyday world of the doctor can be seen as their struggle to make contact with the patient, and others within the multidisciplinary team. Separation practices within allied affiliations and indeed a distancing from their own personhood may be a means of dealing with issues of mortality and recognition of limited abilities to 'cure'. It may be representative of an acknowledgement of a shifting paradigm towards caring and away from the notion of curing. It offers a perspective of the doctor making connections within a challenging and demanding area of professional practice.

The objectified connectedness of the doctor may be a product of the medical training they received. However, throughout the interviews, and within the analysis of the data, there is a demonstration of a thoughtful and caring approach to their patients needs. The study also highlights the difficulties of overcoming antecedent preparation anxiety as the doctor attempts to prepare for the bad news event. It can be seen that although objectified, there is a professional belief in the need for truth and openness.

CHAPTER 11

DISCUSSION OF FINDINGS

11.1 Introduction

This aim of this chapter is to discuss the findings that emerged within the study. The discussion offers an insight into the experience of recipients who received bad news (cancer diagnosis). It also provides opportunity to uncover the practices of doctors in delivering the bad news and the experiences of nurses in caring for their patients. The findings of the recipient group, presented in chapter 8, demonstrate the trajectory of the recipient from the disturbance of their everyday world (pre cancer diagnosis) through to an embodiment within their lived world (post diagnosis). Analysis of the data clearly signals a complex journey for the recipient as they come to a place of living with the diagnosis of cancer. Chapters 9 and 10 illuminate the complexities of the role of nurse and doctor when involved in disclosing bad news. Although many people interject with the recipient along their trajectory, for the purpose of this study the analysis focused only upon the connection with the healthcare professionals.

Analysis of the data suggests that the recipient's experience of receiving a cancer diagnosis is a journey that commences prior to contact with the healthcare professional and continues beyond their involvement with them. The bad news trajectory represents a process, which for the recipient is dynamic, challenging and transforming. The data also reveal that the nurse journeys with the patient as she walks alongside in a professional companionship role. This ability to be authentically present is hampered due to the nurse's exclusion within the multidisciplinary team and most notably from the disclosure event. The doctor perceives the breaking of bad news as an event, which they manage through objectifying their everyday world and their affiliations within it.

Participants in the bad news scenario are intertwined and interlinked. They are each influenced by the actions, reactions and omissions of the other. The study demonstrates the complexities of each perspective and interpretations within each whilst acknowledging the impact each has on the other. The complexities

that emerge from this study may be illustrated through the conceptual framework 'Tripartite Transition: a Process of Inclusive Knowing'.

The framework, separated out for the purpose of the discussion, is merged within the everyday worlds of the participants as they deal with the impact of cancer. They provide new insights through which we can gain an understanding of the triangular convergence of recipient, nurse and doctor within the bad news trajectory. For all within the triad there is evidence of transitions. For the recipient it is the transition from disturbance to their everyday world through to embodiment within the lived world. Transition reflects searching for meaning and coping with the evolving situation. For the nurses, transition related to the developing professional companionship and the changing needs of the patient. Transition for the doctor represents their preparation for and delivery of the bad news to the patient.

11.2 Limitations of this study

The aim of this research was to explore people's experiences of receiving bad news and the experiences of nurses and doctors involved in the disclosure of bad news. It was never the intention of this study to predict, generalise or generate theory, thus the approach taken was congruent with the phenomenological approach used. The following limitations have been identified:

1. The interpretations offered are drawn from a phenomenological paradigm. A belief in multiple realities and interpretations are central to the approach taken by the researcher. The interpretative understandings offered may differ from those of other interpreters/readers of the thesis.
2. The study takes a retrospective view and relies upon the participants' recollection of their lived experience. The recipients' stories were told five years after receiving their diagnosis. One may challenge the accuracy of recall and the potential for distortion of detail within the stories. However, the researcher was not interested in obtaining a neat, complete and coherent account. The chaos of narrative demonstrated how the participants were able to make sense out of their memories. The

recall of events triggered strong emotional reactions in many of the recipients and out of this place emerged a sense of repositioning as recipient of the news.

3. There was no attempt made to formulate a homogeneous group of recipients in terms of cancer diagnosis, treatment modalities or treatment centres. The study recognises that there may have been differences in terms of services provided, psychosocial profile and cancer types, but did not address these issues within the sample selection.
4. Healthcare professionals who participated in the study were not necessarily linked to the recipients involved. There was no attempt to match the recipients with identified centres or practitioners. Although the healthcare participants may articulate similar experiences, the findings of the study are in many respects context specific.
5. The study, although looking at bad news, focused upon giving and receiving a cancer diagnosis. Bad news within the context of this study relates to the area of cancer. Therefore the findings are limited to the concept of bad news within a cancer context.
6. The healthcare professionals were drawn from general medical and surgical areas in both urban and rural settings and not from specialised oncology or palliative care units. Therefore the findings may not generalise to other areas where bad news may be broken.

11.3 Research design and method used in this study

The study is located within the phenomenological tradition. It draws from the hermeneutic orientation within a phenomenological paradigm and the influences of Heidegger and Gadamer. The study demonstrates the application of the philosophical discourse with designing and managing a research enquiry. Data were gathered from three distinct groups of people within the Republic of Ireland; the receiver of bad news and the nurses and doctors involved in the disclosure of bad news. Recipients of bad news demonstrate a trajectory that commences prior to contact with the healthcare professional and continues long after their interactions with them have ceased. The healthcare professional's

connection with the recipient along their trajectory is significant and the study offers insights into how the behaviours of the professional group impact upon the recipient's ability to deal with their situation.

11.4 The Breaking and the Receiving of a Cancer Diagnosis: A Hermeneutic Analysis.

11.4.1 Research Aim.

The overall aim of this study was to elucidate the experience of receiving and giving a cancer diagnosis. In so doing it was hoped to make explicit the practices of the healthcare professional in disclosing the bad news and provide a conceptual framework that illuminates the interplay of the three central players within the bad news scenario.

11.4.2 Research Question.

The study was guided by two fundamental questions: "What are the experiences of the recipient when they are given bad news?" and "What are the experiences of healthcare professionals involved in the disclosure of bad news to clients?"

11.4.3 Research Findings: Developing the Conceptual Framework

The phenomena of the breaking and the receiving of bad news are complex and multifaceted. My interpretation of the data suggests that the recipient of a cancer diagnosis experiences three stages of adaptation as they come to terms with their diagnosis; 'disturbance of the everyday world', 'surfacing within the lived world' and 'embodiment within the lived world'. The recipient's trajectory is a parallel journey that is shared, in part, through a forced connection with the healthcare professional. The data from the healthcare professionals reveals two distinct and interrelated phenomena. It is suggested from the nurses' data that their experience within the bad news scenario comprises of two themes; 'connectedness as journeying' and 'connectedness as exclusion'. The themes are dependent upon the interchange between nurse - patient, patient - doctor, and

nurse - doctor. The data from the doctors suggest that they deal with the event of breaking bad news through a process of 'objectified connectedness'.

The disclosure of bad news is complex and tri-dependent. The interaction between the three groups impacts each other's interpretations and reactions within the bad news context. The breaking and the receiving of bad news may be understood through the conceptual framework 'Tripartite Transition: a Process of Inclusive Knowing'. This conceptual framework offers a perception in which to view the giving and receiving of bad news which is interdependent and shared by all parties involved.

The conceptual framework is multidimensional. For the purpose of the discussion each of the branches of the tripartite group will be presented separately. This artificial and deliberate separating out of each component must acknowledge the interaction and dependence each has on the other. The interpretation of the interviews offers a new way of conceptualising the bad news scenario and challenges the healthcare professional to adopt an approach that is inclusive rather than exclusive. The complexity of the interactions and the tri-dependency within the context of giving and receiving bad news adds to the existing body of knowledge. 'Tripartite Transition: a Process of Inclusive Knowing' as emerging from this enquiry, is discussed within the construction of 'transitions' as described within the scientific literature.

The conceptual framework that emerges from this study makes overt the essence of the giving and receiving of bad news. Figures 11.1 to figure 11.3 offer a diagrammatic representation of each of the participants within a bad news scenario, as evident within the confines of this study. Figure 11.4 demonstrates the interaction between the recipient and the healthcare professionals as they converge with each other during the bad news trajectory. Figure 11.5 depicts the objectified connectedness of the doctor towards the recipient and the nurse in preparation for disclosure of bad news. It illuminates the distancing and communication styles used and represents the complexities of dealing with the bad news as an event to be managed and executed. The depictions provide a means with which to understand the complexities of dealing with processing the bad news and the interplay between patient, nurse and doctor.

**Figure 11-1 'Tripartite Transition a Process of Inclusive Knowing'
Triangular Convergence between recipient, nurse and doctor**

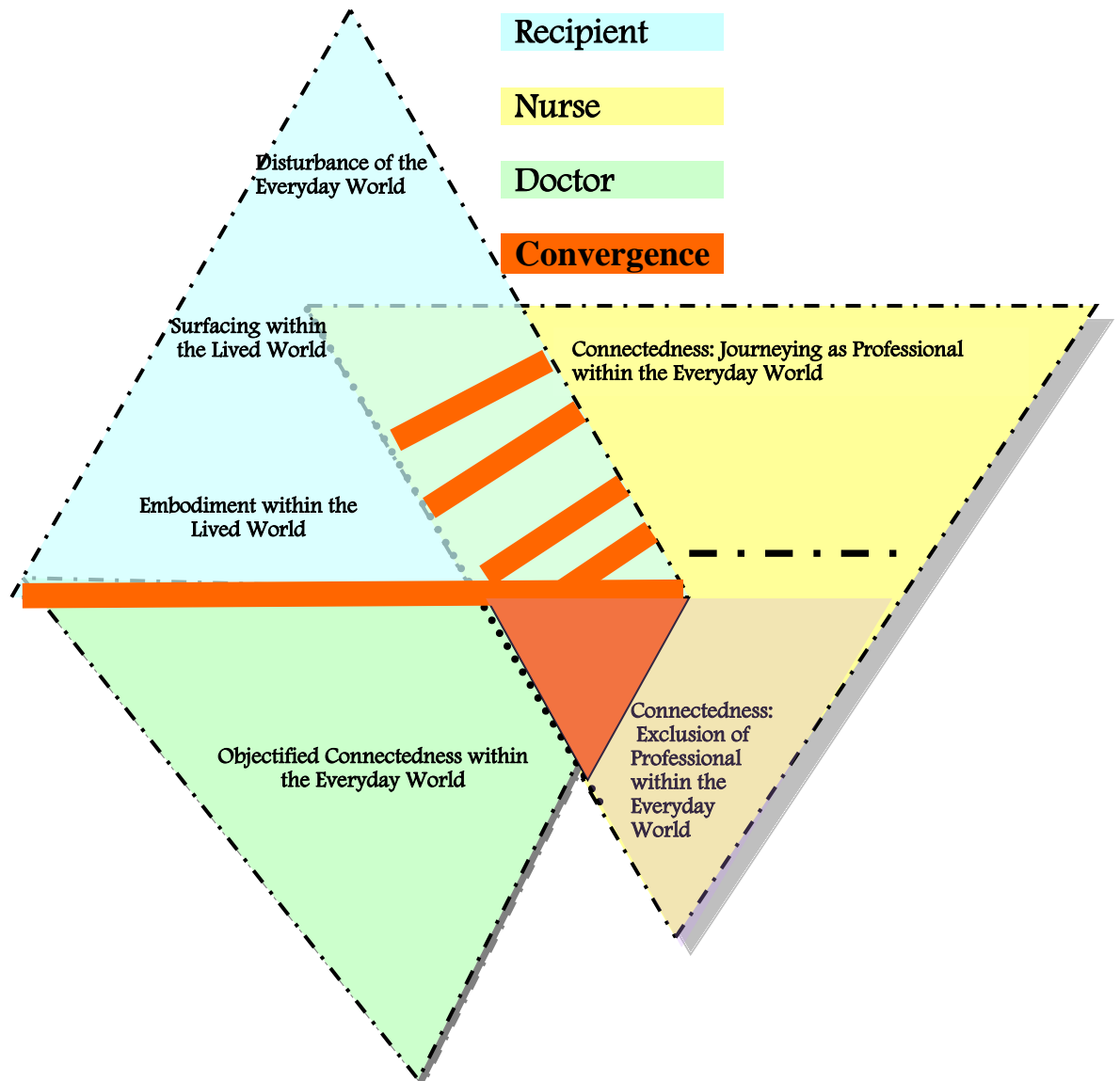


Figure 11.1 depicts the triangular convergence between recipient, nurse and doctor during the bad news trajectory. The recipient's disturbance and resulting 'suspected knowing' commences before contact is made with healthcare professional. Temporary convergence occurs with contact with General Practitioner and continues with the doctors in an objectified manner until disclosure is made. Convergence between recipient and nurse commences on admission and continues after disclosure. Triangular convergence between doctor, nurse and patient occurs only during the disclosure even. Convergence between nurse and patient over-laps all three parties, the nurse becoming a conduit between patient and doctor. Convergence between nurse and doctor is based upon a power relation and sees the nurse informed rather than involved in the disclosure of diagnosis.

Figure 11-2 'Tripartite Transition a Process of Inclusive Knowing': Suspected Knowing to Truth Knowing

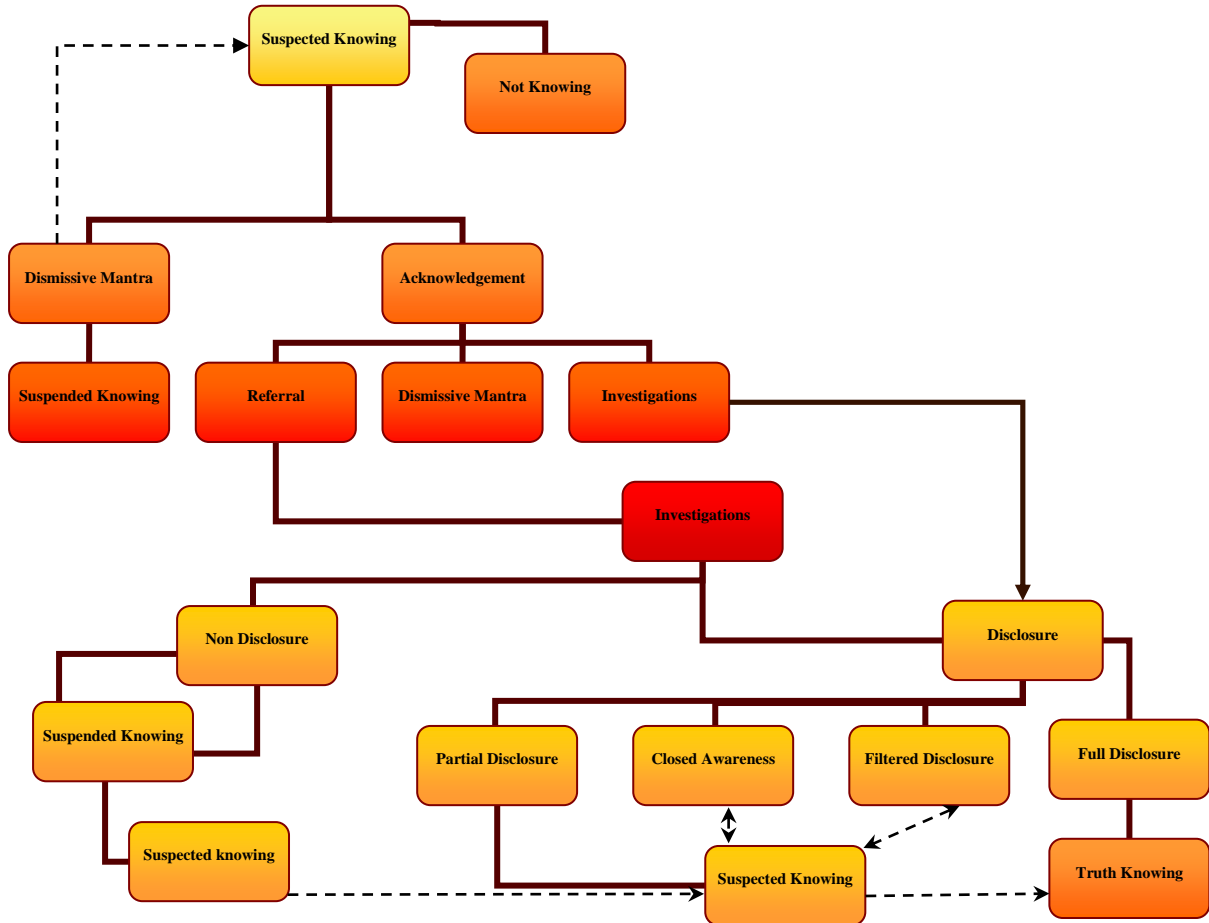


Figure 11.2 depicts the journey from suspected knowing to truth knowing. Suspected knowing represents the person’s intuitive concern that ‘something is not right’. This disturbance to their everyday world catapults them on a fact finding journey. Although the diagrammatic representation presents the journey in a logical and linear format, in reality this process was convoluted, confusing and often cyclical. The disclosure continuum ranges from non disclosure through partial disclosure, closed awareness, filtered disclosure and finally to full disclosure, leading to truth knowing.

**Figure 11-3 'Tripartite Transition a Process of Inclusive Knowing':
Bad News Trajectory**

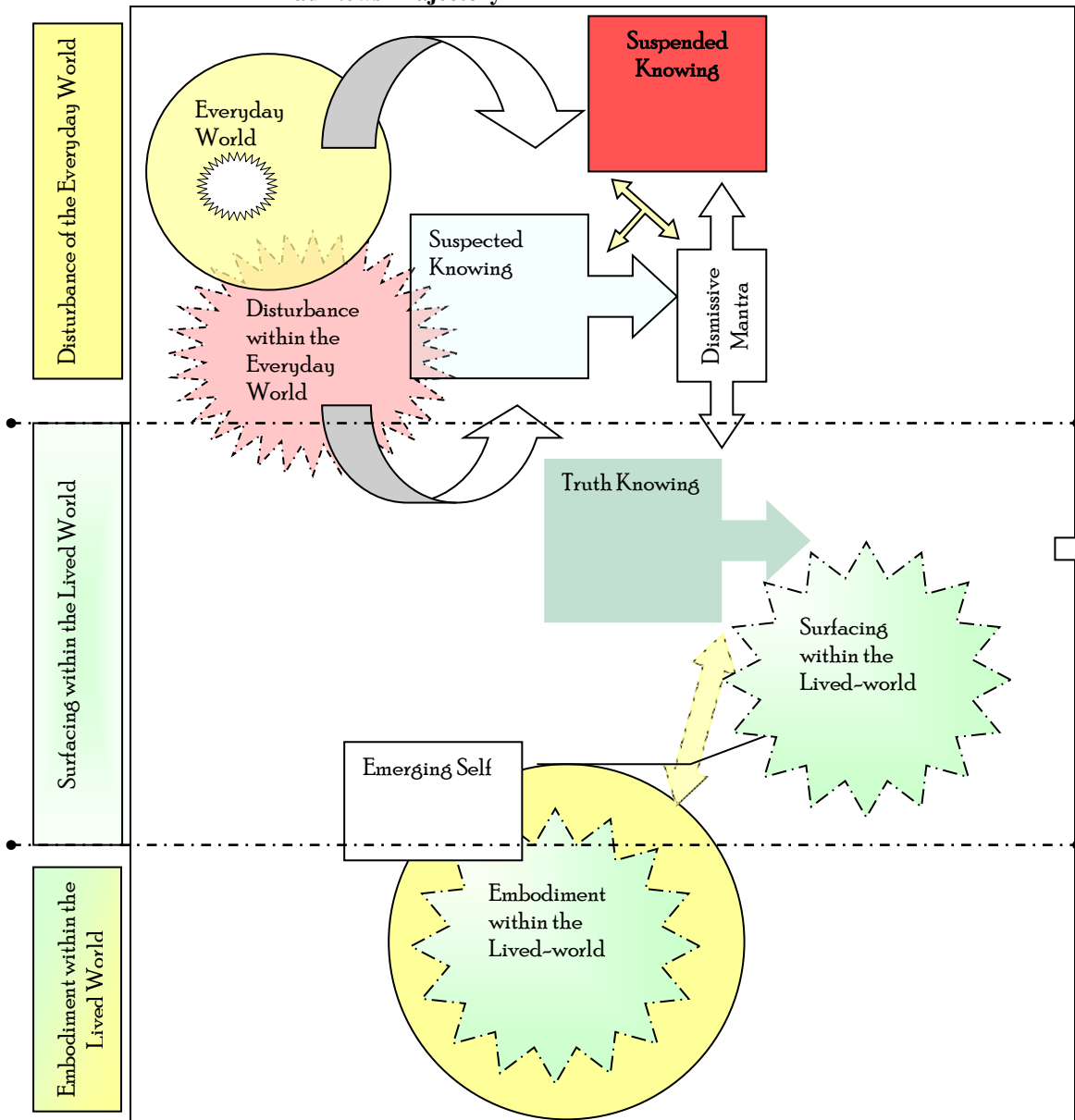


Figure 11.3 depicts the trajectory of bad news within three periods. It commences with the everyday world in which the person becomes aware of a disturbance. This leads to advice-seeking behaviours (depicted by the string curved arrows), leading to suspected knowing. On contact with the healthcare professional their concerns are often dismissed, leading to suspended knowing during which the individual oscillates between suspected knowing and the dismissive mantra. This may lead to a delay in seeking further advice. Truth knowing is eventually reached and the recipient now moves to a period of surfacing within the lived world, as they strive for recognition as an individual rather than a diseased identity. The emergence of the self leads to the final phase of embodiment, which reflects a subliminal uncertainty.

**Figure 11-4 'Tripartite Transition a Process of Inclusive Knowing':
Connectedness as journeying and professional exclusion.**

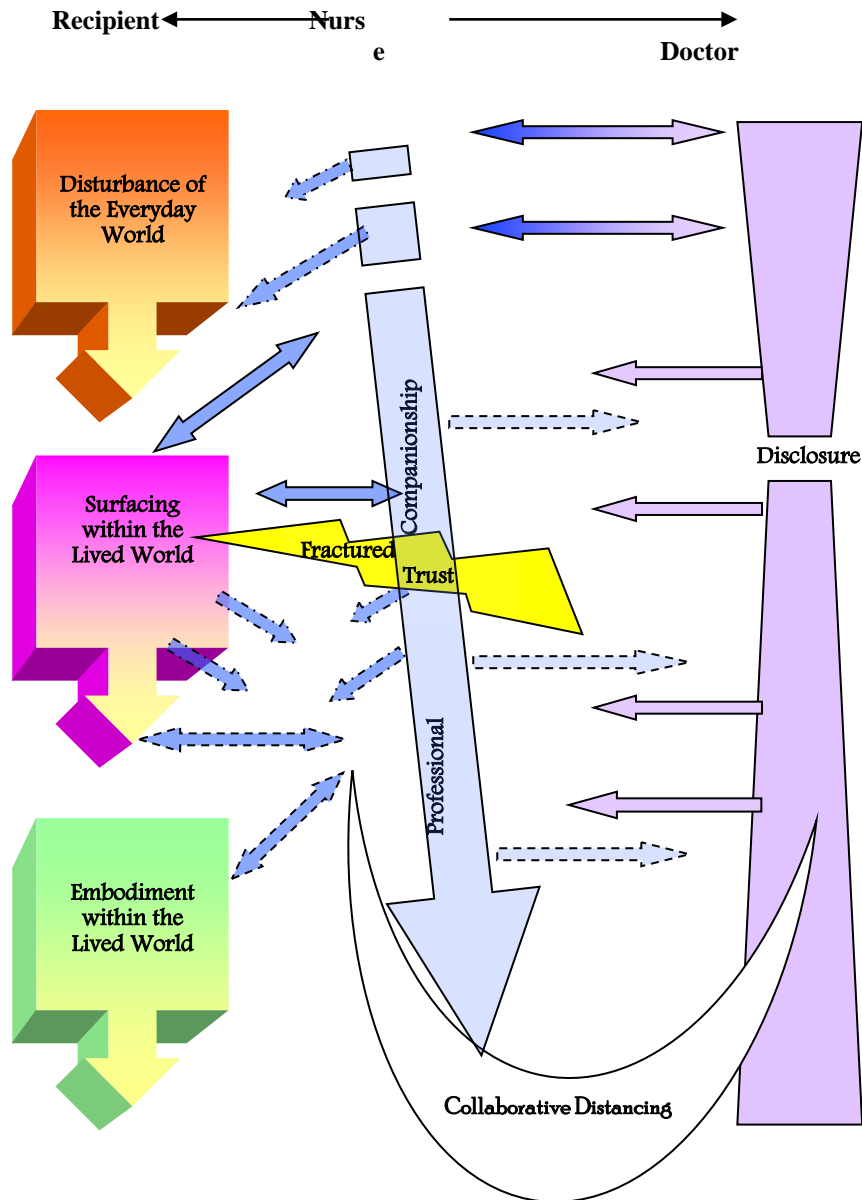


Figure 11.4 depicts the nurse journeying on the trajectory of bad news with the recipient. The figure attempts to demonstrate the development of professional companionship through the linking of nurse to recipient (broken lines). As the nurse-patient relationship develops so the strength of the connection strengthens and begins to represent reciprocity (two way arrows – continuous lines). The professional companionship begins to shift away from the recipient as the nurse struggles to deal with filtered disclosure and collaborative distancing. The connecting arrows become disconnected following disclosure as nurse becomes aware of fractured trust. Professional exclusion is depicted by the one way arrows between nurse and doctor.

Figure 11-5 'Tripartite Transition a Process of Inclusive Knowing': Objectified knowing.

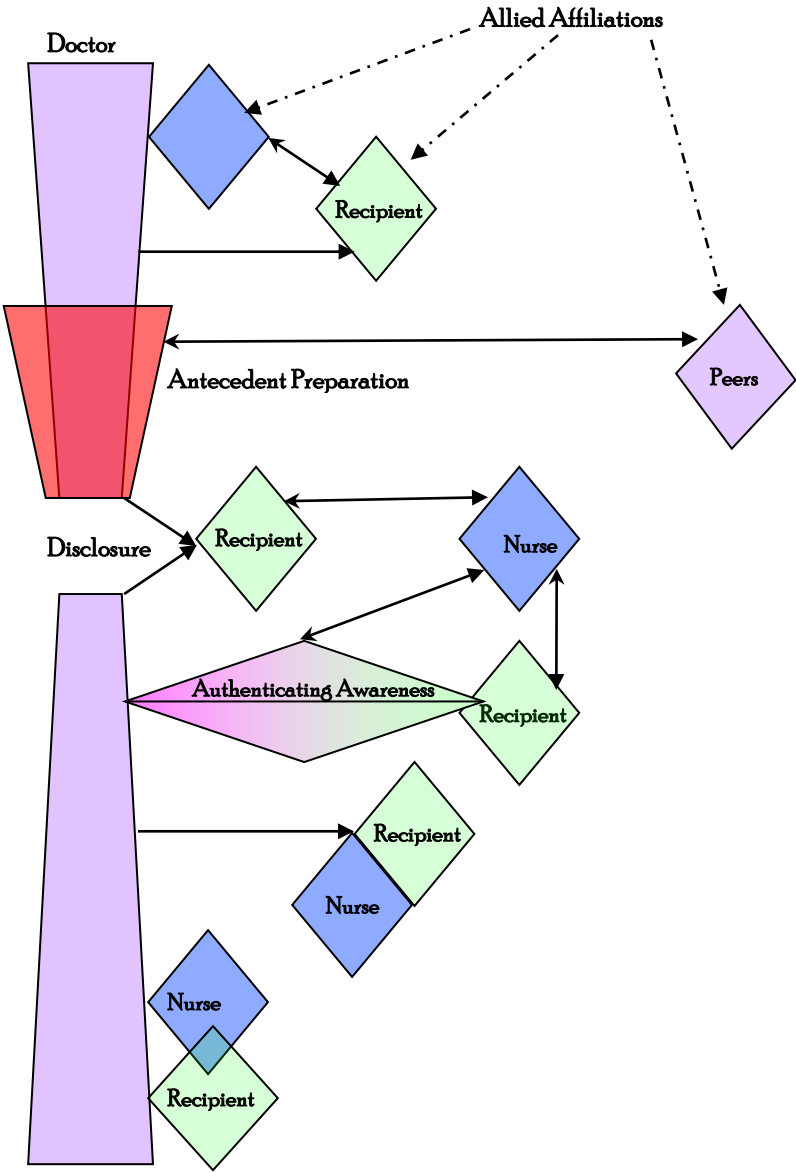


Figure 11.5 depicts the doctor's objectified connectedness within the breaking of bad news. The allied affiliations with nurse, recipient and fellow medical peers are depicted by distance and connection with broken lines of communication. Antecedent preparation is depicted as a narrowing or focusing upon the self prior to disclosure. Disclosure is to recipient, with the nurse excluded. Authenticating awareness represents a 'checking of awareness' and this is directly with the recipient and also through dialogue with the nurse. The distancing of affiliations changes prior to, during and post disclosure and is represented by distance from doctor to the recipient and nurse.

11.5 Conceptual Framework of the Giving and Receiving of Bad News as portrayed within ‘Tripartite Transition: a Process of Inclusive Knowing’ Framework

11.5.1 ‘Tripartite Transition: a Process of Inclusive Knowing’: Background

‘Tripartite Transition a Process of Inclusive Knowing’ offers a conceptual framework through which one can represent the essence of receiving and giving bad news. The framework illustrates the phenomenon of receiving and giving bad news as it emerges from the data. The data reveal the interconnectedness and interdependence between the recipient, nurse and doctor. The notion of ‘tripartite’ offers a representation of involvement made between the three groups. In essence there is a formal agreement between the three, which is demonstrated within the data as journeying within the lived world for the recipient, connectedness within the everyday world of the nurse and objectifying for the doctor. Whilst each group’s depiction is separated out within the findings, in reality they converge and diverge on a continuum within the bad news trajectory. The central component across all three groups is the experience of transition and the mechanisms through which each deal with the phenomenon. Inclusive knowing is the ultimate aim of the breaking and receiving of bad news. It represents the point at which all three participant groups converge and acknowledge the situation. It may be affected by the type of disclosure and the dynamics between the tripartite.

Each of the recipients engaged with the process of receiving bad news in their own individual and unique way. Although there were variations in terms of their experiences and modes of disclosure there were patterns that were common to all. The degree to which they arrived at a place of knowing and their ability to surface and move to a place of embodiment depended very much on their individuality and also on their encounters with the healthcare professionals involved. Inclusive knowing represents a place where all three parties overtly or covertly know of the diagnosis. ‘Tripartite Transition a Process of Inclusive Knowing’ represents the trajectory of bad news and depicts the adjustment to

loss for the recipient. For the healthcare professional the 'transition' reflects their adaptation towards the patient and each other within the trajectory.

11.5.2 'Tripartite Transition: a Process of Inclusive Knowing': Within the Context of 'Transition as Coping'

The meanings that people ascribe to illness and disease may be influenced by their coping mechanisms (Luker et al, 1996). Changes brought about by a diagnosis of cancer present major coping demands on the individual (Rustoen, 1995; Kissane, 2000). The ability to cope requires the individual to engage in a process of transition (Coward, 2003). It is well recognised within the literature that individuals coping with cancer and other life threatening diseases engage in a process of transition or personal revaluation (Lazarus, 1966; Lipowski, 1970; Pettingale et al, 1985; McHaffie, 1992; Radley, 1994; Carpenter, 1997; Taylor, 2000; Lee et al, 2004). The ability to transition within cancer has been referred to as self-transformation (Carpenter, Brockopp and Andrykowski, 1999) and as transcendence (Chiu, 2000). Meleis and Trangenstein (1994) suggest that transition differs from change as the former is generally an internal process whereas the latter is often characterised as a response to an external process.

Coping as adaptation is a multifaceted and dynamic process in which the individual appraises life threatening situations and makes cognitive and/or behavioural efforts to manage the demands (Folkman and Lazarus, 1988; Meeker and Jezewski, 2004). It has been recognised as motivational (Zimbardo, McDermott and Jansz, 1995), and sociological (Mechanic, 1968; Lazarus and Folkman, 1984). More recently a holistic perspective has emerged (Bartlett, 1998; Jones and Bright, 2001) in which the emotional/ psychological/ physiological and social aspects are recognised. Within the nursing literature, Roy's (1976) adaptation theory and Neuman's (1982) stress reduction model have offered a perspective on coping from a nursing paradigm. The recognition and importance of coping as an adaptation and adjustment within nursing is also identified (McHaffie, 1992; Bliss and Johnson, 1995; Rittman et al, 1997; Payne, Dean and Kalus, 1998).

It can be seen from the literature that transition through adaptation and coping is a recognised response to a life threatening or alternating situation. Adjustment to such life events requires the individual to respond in some way (Kang, Miller and Lee, 2006). Elders (1995) suggests that such life-events are accompanied by a loss which can be observed as a grief reaction. Loss therefore is an 'unavoidable fixture of human existence' (Thompson, 1998:p 21) and this process of adjustment may be observed as grief (Murray, 2001).

11.5.3 'Tripartite Transition: a Process of Inclusive Knowing': Within the Context of Transition and Grief in Theories of Death and Dying.

Grief has been conceptualised as a normalising process within psychological theories. Freud's (1917) concept of mourning and melancholia and associated 'grief work' was one of the earliest contributions to understanding the complex process of grieving. Lindemann's 'Symptomatology and management of acute grief' (1944) offered grief as an observed syndrome with psychological and somatic symptoms. It was the work of John Bowlby (1961) and the presenting attachment theory that saw a shift from the pathological and morbid aspects of grief towards components of healthy grief. Bowlby was the first theorist to introduce the concept of adjusting to loss in terms of phases. This phasic perspective of grief became influential in later models of grief offered by Glaser and Strauss (1965), Kubler-Ross (1969), Kavanaugh (1972), Glick, Weiss and Parkes (1974), and Pollock (1987). However, these phasic or staged models of grief became severely criticised due to their representation of grief as rigid and linear (Raphael, 1984; Corr, 1992; Neimeyer, 1998). Task theory as opposed to phasic theory began emerging in the early 90s. Resolution of the grieving process was seen as the accomplishment of specific tasks (Walsh and McGoldrick, 1991; Worden, 1991; Rando, 1993) and recognised the individuality, complexity and fluidity of the grieving process.

It is proposed that the findings of this study demonstrate that the recipient experiences a disturbance to their everyday world that results in a grief reaction that is similar to that of anticipatory grief (Lindemann, 1944; Fulton, Madden

and Minichiello, 1996). Their sense of loss as they strive to come to a place of ‘truth knowing’ was compounded by the dismissive mantra of ‘not to worry’, which was repeatedly expressed by healthcare professionals (figure 11.3). The recipient’s ability to deal with their diagnosis and the potential impact of cancer resulted in them having to cope with their loss. The impact of diagnosis on the recipients as they struggled to emerge from within the ‘transformative power of diagnosis’ was significant and supports the work of Taylor (1988), Seal (1991), Timmermans (1994) and Fallowfield (2004). The struggle for identity and recognition of personhood as the recipient moved to a place of acceptance, is reflective of an oscillation between loss and restoration-coping, and is similar to the findings of anticipatory grief articulated by Wilson (1997) and Rando (1986).

11.5.4 'Tripartite Transition: a Process of Inclusive Knowing': Within the Context of Finding Meaning.

The study reveals that the recipients journeyed from a place of ‘suspected knowing’ through to a place of ‘truth knowing’. It emerged from the data that the disturbance to the everyday world often originates from an intuitive feeling that something was not right. The recipients sought answers to their concerns and in the process turned to the healthcare professionals for confirmation or dismissal of their fears. Their search for answers became the genesis of a search for meaning. The recipients began to face feelings of disruption with their engagement and purpose in life (Kissane, 2000). Their narratives give insight into the psychological distress encountered as they began their search for answers. This type of distress and anxiety, caused by facing into unknown potential illness is well documented in the literature (Vinokue et al, 1989; Mullen, Smith and Hill, 1993; Taylor, 1993; Schnoll, Knowles and Harrow, 2002). The knowledge that something was not right resulted in a ‘dis-ease’ with everydayness. The fear of cancer was strong within the narrative of many recipients. The data show that some articulated remembrance of this fear openly, whilst other implied it by their use of euphemisms or by their referral to cancer as the letter ‘C’ – often spoken quietly or mimed. Gorman (1998),

Yedidia and MacGregor (2001) and Meeker and Jezewski (2004) have identified fear of disability, discomfort, pain, suffering and death as aspects of anxiety accompanying aspects of a cancer diagnosis and its treatment. It appears from this study that the fear accompanying cancer and its treatment is not exclusive to the post diagnosis phase of the cancer continuum but is manifest in the pre-diagnosis phase. Fear and uncertainty is evident within the ‘suspected knowing’ and continued after the diagnosis was given. This distress and anxiety was apparent in the tone, intonation and body language used by the recipients. The distress accompanying the trajectory from ‘suspected knowing’ to ‘truth knowing’ was intrusive (Vickberg et al, 2000) and a remembered reality for many of the recipients.

11.5.5 'Tripartite Transition: a Process of Inclusive Knowing': Within the Context of Reassurance and the Dismissive Mantra

It is clear from the findings that the recipients looked to many around them for some confirmation or dismissal of their fears. The repeated referral to ‘don’t worry’ responses from many and particularly from the healthcare professionals did little to instil comfort or relief for the person seeking answers. The data from the healthcare professionals demonstrate that, although striving to ensure the patient had their diagnosis, the nurses and doctors were not necessarily working collaboratively. The data from the recipients would suggest that many healthcare professionals used the dismissive mantra as a means of offering reassurance. It was not necessarily used to deny the situation but its use can be seen as paternalistic and patronising. The dismissive mantra, as used by the nurses may have been a tactic used to divert the conversation away from discussing the diagnosis, as it would appear from the nurses’ data that they felt excluded and kept in the dark regarding the recipients’ knowledge of their condition. The lack of information placed the nurses in an awkward situation in which they were unsure of what to say and so it appears that the dismissive mantra may have been used as a means of closure and diversion.

It can be seen in the study that for a number of recipients the dismissive mantra, rather than offering reassurance, contributed to a sense of frustration and anxiety. For many of the participants, it was the recognition of changes within their body that prompted them to seek medical attention. This would support the work of Gascoigne and Whitear (1999), Sanden, Larson and Eriksson (2000), Burgess, Hunter and Ramirez (2001) Leyton, Boynoe-Sutherland and Coleman (2003) and Chapple, Ziebland and MacPherson (2004). For other participants it was trivial or non-specific changes that led them to dismiss seeking advice; again reflected in the findings of Bain and Campbell (2000) deNooijer, Lechner and De Vries (2001), and Broughton, Baily and Linner (2004). It was the dismissive mantra of the healthcare professionals that led to a delay in seeking further advice for at least two participants in this study. It could be suggested that it was anxiety and fear associated with their 'suspected knowing' that underpinned this delay tactic (Littlewood and Elias, 2000; Papadopoulos and Lees, 2004). However, one cannot ignore the fact that the dismissive mantra may potentially contribute to a delay in accessing services and may have a direct impact on the outcome for the patient.

This study highlights that dismissing the person's initial concerns was almost paramount to dismissing the person themselves. The cumulative affect of this was to depersonalise and devalue the presenting self. The resulting sense of isolation and status as a person reflects the findings of Sweeting and Gilhooley's (1992) study into death and dying in modern societies. Ultimately, the dismissive mantra may prevent further help-seeking behaviours and delay treatment. There is a need for healthcare professionals to develop suitable responsive techniques that acknowledge the person's concerns, confirm they have been heard and ensure that appropriate actions will be taken. This obviously needs to be balanced with the need not to alarm the client. However, reliance on the use of the dismissive mantra as reassurance, demonstrates this is not only an inappropriate response but may also be a contributing factor to delaying and denial techniques.

11.5.6 'Tripartite Transition: a Process of Inclusive Knowing': Within the Context of Information Needs

A diagnosis of cancer can bring psychological distress, a challenge to one's self image, anticipatory grief, loss of personal control, and a threat to one's future (Leydon, Boynoe-Sutherland and Coleman, 2003; Costelloe and Nelson, 2004; Taylor, 2004). This study has identified how the search for 'truth knowing' is central to the trajectory of bad news. As discussed above, the journey from 'suspected knowing' to 'truth knowing' signifies the person's need to gain understanding. It represents the recipient's prerequisite to make sense of their situation and indicates a need to address a deficit in their knowing. In this study, the recipients' need for information was necessary to enable them make sense of the disturbance to their everyday world (Figure 11.#). It is this need for information that was intrinsically linked to the personal search for meaning during this life event (Kyngas et al, 2001; Lee et al, 2004; Kang, Miller and Lee, 2006). Information needs within cancer care has been acknowledged in the literature by many authors, (Collins, 1927; Armstrong, 1987; Bennett and Alison, 1996; Hunting, 1998; Anderlik, Pentz and Hess, 2000; Baile et al, 2002; Harris, Shao and Sugarman, 2003; Tuckett, 2004); however, they focus exclusively on the information needs of the patient on diagnosis and fail to address the antecedent phase or searching phase of the recipients' trajectory. It is perhaps notable that the use of the dismissive mantra (as discussed above) is frequently seen during this phase. It is understandable that healthcare professionals may not want to worry the patient unduly before they have confirmation of a diagnosis. However, this study indicates that due to presenting symptoms and history, the suspicions are often present on admission. It not suggested that these suspicions be disclosed, but that healthcare professionals look carefully at how they deal with the patient in the time leading up to the disclosure of the diagnosis.

Within the context of information giving, there is a need to recognise that knowledge of one's diagnosis is not only important, it is a right (Costello and Nelson, 2004). However, it would appear from the literature and from this study, that there is an assumption that disclosing the diagnosis provides the

information that satisfies the receiver. Breaking bad news, within the context of this study, highlights that it is the healthcare professional that gives, discloses or breaks the news and it is the client who has to receive, make sense of and interpret the news. As has been highlighted earlier (chapter 3), much of the literature on giving bad news has focused on the activities of the deliverer. A large amount of the literature is based on the assumptions of the healthcare professional on the perceived needs of the receiver. This study has demonstrated a dissonance between the felt-needs of the recipient and the assumed 'felt-needs' of the receiver as identified by the healthcare professional. The component of 'information needs' as identified in this study, suggests that the type of information needed changes along the bad news trajectory. During the initial phase 'Disturbance of the Everyday World,' the impetus for information arises from the recipients' 'suspected knowing' and there is a need to confirm or dismiss the concerns. The information needs are combined with a requirement to have their 'suspected knowing' recognised, acknowledged and acted upon. The information needs become more focused on the disclosure of the diagnosis as the recipients look for truth about their cancer, reflecting those identified in the literature spanning the past 50 years (Kelly and Friesen, 1950; Reynolds et al, 1981; Meredith et al, 1996; Tattersall, Butow and Clayton, 2002; Tuckett, 2004). The information needs continue to change after the 'event' of disclosure. This study highlights that the recipient continues in a state of attempting to make sense of their situation following disclosure. The recipients in this study looked for confirmation and information regarding the ensuing treatments, outcomes and consequences of their cancer, supporting the work of Dirksen (1995) and Meraviglia (2006). During this time of 'sense making', the study highlights the nurse's role as one of professional companionship and the doctors' as one of authenticating awareness.

This study suggests that as the patient surfaces within their 'Lived world' and begins to make sense of their situation, there continues to be a need for information. At this stage, for many within the study this trajectory was marked by a need to ensure that they were seen for whom they were rather than what they had become – the diagnostic label. Illich's (1992) discourse on the

medicalisation of death and dying and the resulting dehumanising process mirrors the experience of some of the recipients within this study. The labelling of the person as 'having cancer' resulted in the participants feeling that they were perceived as an illness rather than a human being (in the case of Amy she felt she went from being a breast feeding mother to becoming a breast lump – section 8.3.1).

The study demonstrates that the recipient continues to a place of 'Embodiment within the Lived World'. Throughout this stage there remains a sense of subliminal uncertainty, in which they have an ever present questioning and concern about their future. They continue to wonder as to the information given and the 'truthfulness' of the healthcare professional. This stage was marked by a sense of tension as the recipient attempted to filter the information given through the memory of the dismissive mantra, which was so evident for many during their early 'suspected knowing'. It is evident from this study that the effect of the dismissive mantra was not only present in the early phase of the journey but remained subconsciously present throughout the trajectory. It would appear that the rhetoric of reassurance through the dismissive mantra only served to create a conflict of trust and acceptance of further disclosures. It can be seen from the study that the recipients looked to the future and needed information regarding this from the healthcare professional. There was however, a subliminal uncertainty regarding their future and lack of trust in the information given by healthcare professionals. This may partly have been due to anxiety regarding a recurrence of the cancer. This study suggests that there was also a sense of broken trust with the healthcare professional, and it could be argued that this also contributed to the uncertainties as they struggle to accept or believe the information given at this latter stage.

11.5.7 'Tripartite Transition: a Process of Inclusive Knowing': Within the context of the Healthcare Professional.

This study reveals that within the breaking bad news scenario, the nurse perceives herself as connecting with the patient, whilst at the same time there

appears to be a sense of disconnection or exclusion from the medical staff within the multidisciplinary team.

Journeying with the patient is reflected through the relationship between the nurse and patient and is described within this study as emerging from a sense of connectedness. A number of studies reveal the centrality of the nurse patient relationship and the ensuing sense of knowing that occurs. Jenny and Logan (1992) suggest that knowing the patient is a complex interactional process characterised by perceiving, envisioning, communicating and showing concern, all of which are represented within the narrative of the nurse participants within this study. The concept of connectedness within this study speaks of an involvement growing out of an understanding between the participant and the nurse. This would support Tanner (1993p. 275) who suggests that knowing the patient requires an 'immediate grasp, an involved, rather than detached understanding ... an understanding that is directly apprehended...' Knowing the patient is seen as a core component of contemporary nursing (Radwin, 1995), and central to enabling the delivery of person-centred care (Lutz and Bowers, 2000; Gerteis et al, 2002; Lauver et al, 2002; Talerico, O'Brien and Swafford, 2003). Within this study, the nurses perceived the need to know their patients as fundamental to what they did as nurses. For them, it was this knowing that was essential in enabling them to develop a caring relationship with their patient. Fredriksson (1999) suggests that it is this caring relationship that is an essential concept in caring. She posits the term 'caring conversation' as a means of relating to the patient, identifying two modes of action; one that is aimed at 'connection' and the other at 'contact'. It is suggested that these modes form a continuum where connection signifies a 'caring relationship' and 'contact' is understood as a relationship with limited intensity and inter-subjectivity (Fredriksson and Eriksson, 2003).

It is suggested by Olthuis et al (2006) that three elements are essential for 'caring conversation'; presence, touch and listening. The triadic elements of presence, touch and listening are reconsidered by Fredriksson and Eriksson (2003: 145) as representing the 'norms of respect, responsibility and reciprocity...' The findings from this study suggest that nurses relate to the

patient, encompassing a wide range of strategies that reflect respect for the patient, responsibility and reciprocity. The study augments the view of ‘caring relationship’ to encompass the notion of professional companionship. As discussed, (section 9.2.1.3) professional companionship is characterised by five actions: knowing the patient, being with the patient, giving and receiving, attending and bearing. Professional companionship reflects the work of Alastair Campbell’s theology of professional care (Campbell, 1984). Campbell, a Christian ethicist and theologian presents the concept of moderated love as representing skilled companionship. He suggests that skilled companionship describes a professional relationship that is professional without being distanced or manipulative:

... it describes a closeness which is not sexually stereotyped... nor deep personal friendship. ...[It] arises often from a chance meeting and it is terminated when the joint purpose which keeps companions together no longer obtains. (Campbell, 1984:49)

Campbell (1984) ascribes mutuality, reciprocity, particularity and gracefulness as elements within skilled companionship. Each of the elements is evident within the nurses’ narratives. Mutuality speaks of ‘being with’ the patient rather than just ‘doing to, and affords the nurse opportunity to presence herself with the patient, coming alongside and drawing near. Reciprocity represents the giving and receiving that was evident from the nurse and recipients’ narratives. In an earlier work, Buber (1957) suggests that reciprocity characterises the relationship between caregiver and patient and represents their wish to stay in the relationship. The findings of this study would suggest that reciprocity and mutuality are dependent upon truthfulness and integrity. The study highlights the dilemma many nurses found themselves in due to exclusion from the disclosure process. The fractured trust that ensued once the recipient knew their diagnosis, created a dissonance between nurse and patient and resulted in a process of renegotiation and reestablishment of mutuality and reciprocity. Particularity relates to an attempt to develop relevant knowledge for helping others. It speaks of knowing the patient and is evident in this study as the nurses articulate that they are best placed to understand the patient as they ‘know them’.

In this study, this form of 'knowing' relates to a shift from broad view of the patient towards an individual view of the patient as person. It demonstrates the nurse's ability to move beyond the generalised knowledge to a place of specific knowing of the person within the context of their lived situation.

The study further expands the notion of 'skilled companionship' to encompass aspects of 'attending' and 'bearing'. 'Professional companionship' denotes this expanded view of 'skilled companionship' within the nursing context of breaking bad news. 'Attending' relates to the nurse providing skilled care which is focused, culturally competent and context specific. In this study the nurses attempted to provide physical, psychosocial and spiritual care that was characterised by action and also by the ability to absent themselves when deemed necessary and give space and time to the patient. It is reflective of Benner and Wrubel's (Benner, 1989) notion of presencing as a means of building bridges of understanding with the patient and their illness. 'Bearing', within the concept of professional companionship, acknowledges the 'emotional linkage' between the nurse and patient and the frustration the nurse experiences at having to provide care within an environment of exclusion and filtered disclosure. The concept of emotional labour, first described by Hochschild (1983) was later recognised within nursing (Smith, 1992; Martschinke, 1996; Staden, 1998; Bolton, 2000; Henderson, 2001). The findings of this study support the concept of the emotional cost involved in looking after people with a cancer. The study also highlights the cost of being excluded and having to care for patients when not fully informed of the state of disclosure, supporting Smith and Lorentzon (2005) who acknowledge the tension that may exist for healthcare workers in trying to balance the needs of clients with organisational demands.

In this study, it is evident that the relationship between nurse and patient becomes strained due to filtered disclosure, collaborative distancing and the emotional cost of caring within such situations. The issue of reciprocity and mutuality are challenged as the nurse is torn between patient and system. The integrity and truthfulness required by professional companionship was challenged and the nurses often found themselves in a place of feeling they had

somehow let the patient down. Their authenticity, required through mutuality and reciprocity was compromised and this study demonstrates that this had a potential detrimental effect on the nurse-patient relationship.

Providing care to patients is challenging within any healthcare context. Within the bad news scenario the challenge is to provide care that is efficient, effective, appropriate and seamless. The complexity of providing physical, psychological, social, spiritual and culturally competent care requires a collaborative approach from the healthcare team. The recognition of the need to move towards collaboration and professional integration has been identified (Ovretveit, Mathias and Thompson, 1997; Cummings, 1998; Zwarenstein and Bryant, 2000); however, the findings from this study would suggest that there remains a lack of collegiality and inclusiveness. The nurses' sense of exclusion within the healthcare team and the resulting professional isolation suggests that the traditional hierarchy and bureaucratic system remains within the Irish Health Care system. The doctors' 'objectified connectedness' and allied affiliations support the notion of doctor as self reliant and not interdependent. Rafferty, Ball and Aiken (2001) postulate that the complexity of health care delivery has resulted in a proportional increase of responsibilities for healthcare professionals with a corresponding blurring of professional boundaries. Whilst there has been a recognition for interdependence amongst healthcare professionals (Machanic and Aiken, 1982), this study would suggest that there remains a need to develop collaborative frameworks that will see the emergence of a collegiate working ethos amongst doctors and nurses. Castledine (2005) suggests that a collaborative rather than competitive working relationship is desirable. However, Chaboyer and Patterson (2001) and Ardern (2005) assert that collaborative practices remain variable and the exception, rather than the prevailing working pattern. Inequalities in power perpetuate the dominance of medicine within the multidisciplinary team (Davies, 2000) and contribute to the wider debate on collegiate working relationships amongst doctors and nurses (Stein, 1967; Stein, Watts and Howell, 1990; Casey and Smith, 1997; Wicks, 1998; Rafferty, Ball and Aiken, 2001). The findings of this study would

indicate that nurses perceive that there is an erosion of autonomy and exclusion from the multidisciplinary team, resulting in filtered disclosure, fractured trust and damage to the professional companionship between nurse and patient. The doctors within the study would appear to have a practice ethic that, rather than effecting collaboration and collegiality, appears to endorse hierarchical and competitive relationships.

The perception of the bad news scenario as an ‘event in time’ rather than a trajectory that the recipient experiences, is evident by the doctors’ preparation for the disclosure event. The breaking bad news phase has as its central focus the deliverer – and would suggest it is doctor-centred. Randall (2005) states that doctors break bad news and recipients receive it. The finding of this study would suggest that in order for the doctor to break the news there is a period of preparation, alienation and confirmation. It would appear that the doctor is not aware of the objectified distancing that occurs between them, the nurse and the patient. It is clear that the doctors wanted to break the news to the patient in a caring and effective way. Preparation and delivery were thoughtfully constructed and executed. What is interesting is the comparison between the doctor’s need to objectify and distance themselves and the nurses need to connect through the ubiquitous past and professional companionship.

11.6 Conclusion

The most significant findings from this study relate to the concept of bad news as a trajectory. For the recipient the study highlights the effect of an intuitive sense of a disturbance in their everyday world and the consequential thrust through surfacing and embodiment within their lived world. Their interactions and convergences with nurses and doctors offer an interesting filter through which the study can illuminate the dynamic nature of the triangular relationships. The study highlights professional companionship, which is forged between nurse and patient as the nurse journeys on the bad news trajectory. It also provides insights into the difficulties encountered as a result of professional exclusion and lack of information. The impact of the exclusion is seen as

affecting the nurse's ability to be authentically present for the recipient and the resulting fracture to the nurse patient relationship. The findings suggest that doctors perceive themselves as leaders of the multidisciplinary team, resulting in affiliations with nurse, recipient and other medical colleagues that are distant and objectified. Their disclosure is organised, prepared for and executed in isolation from the remainder of the team. The picture emerging from the study is one of a lack of understanding amongst the nurse and doctor, and whilst both are endeavouring to provide high quality sensitive care they are acting in isolation and practising in an ethos of exclusivity.

CHAPTER 12

IMPLICATIONS AND RECOMMENDATIONS

12.1 Introduction

This study offers new insights into the experience of receiving and giving a cancer diagnosis. It highlights the trajectory of bad news and demonstrates clearly how the recipient moves from a place of everydayness to a place of embodiment within the lived world. For the healthcare participants there is a sense of connectedness with the recipient, although the study suggests that this differs for the nurse and doctor. The nurse connects with the patient through caring which draws on mutuality, reciprocity, particularity, attending and bearing. The goal of professional companionship is to journey with recipient on the bad news trajectory. The study suggests that professional companionship is often compromised due to the nurse's sense of exclusion from the multidisciplinary team and the disclosure of the diagnosis. The study illuminates the doctor's perspective of disclosure of bad news as an event, which is managed through objectified connectedness. Distancing may represent the doctors' need to ensure that all the required information is obtained in order to make a reasonable judgement and arrive at a diagnosis.

12.2 Implications

The goal of phenomenology is not generalisability; the goal is to provide knowledge of an experience (Ryan, 2005). In the case of this study, the goal is to provide knowledge of the experience of the giving and the receiving of bad news.

In keeping with the concept of the process of disclosure of bad news as representative of a tripartite transition, I will endeavour to present the implications for each part of the triad and represent the impact of each within the triadic group.

12.3 Implications: Recipients

The trajectory of bad news suggests that for the recipient of bad news the journey commences prior to contact with healthcare professionals. The study highlights three phases that the recipient journeys through; disturbance to the everyday world, surfacing within the lived world and embodiment within the lived world (Table 8.1). Each phase represents a process for the recipient and each has its own implications attached.

12.3.1 Disturbance within the Everyday World: Implications

12.3.1.1 Seeking confirmation:

The journey from suspected knowing to truth knowing (Figure 11.2) demonstrates the pathway which many recipients travelled as they moved from a place of intuitively knowing that ‘something was not right’ to a place of either having their suspicions heard and responded to, or having their concerns dismissed. For many recipients there was a felt-need to have their suspicions acknowledged as legitimate. The journey from suspected knowing to truth knowing was often disjointed, elongated and unwieldy.

The accessibility of information on cancer and cancer symptoms is more widely available to people today than ever before. Access to printed material and to the internet provides many with immediate information. What this study highlights is the difficulty some experienced in having their concerns heard. The initial point of contact with healthcare services was through the primary health care team. Whilst many General Practitioner surgeries contain information leaflets and health promotion material, it would appear that for the recipients within this study, these did not play a part in assisting them in their search for meaning, once they arrived at a place of suspected knowing. What was sought was contact with another person, what was needed was the acknowledgement that their suspicions were valid and were heard. This results in the person seeking information needing to be able to access professional advice, which is accessible and responsive. For the healthcare professional the implication from this finding is that they need to recognise the importance of facilitating access to services. The findings would also suggest that whilst printed material serves a purpose in

providing information, this study suggests that there is a need to access healthcare professionals who can offer advice and direction.

12.3.1.2 Dismissive Mantra:

The study highlights the negative effects on the recipient of the reassuring, but dismissive mantra of ‘...don’t worry’. Repeatedly, recipients recalled the way healthcare professionals dismissed their concerns. Rather than offering reassurance, the reverse happened, with recipients feeling dismissed, more anxious or entering a period of ‘suspended knowing’. For some recipients the dismissive mantra resulted in a sense of being minimised, whilst for others it appeared to erect a barrier, which may have temporarily prohibited further exploration. The implications of the dismissive mantra on the recipient is that unless they receive acknowledgement of their concerns and appropriate responses they may continue to feel disempowered, minimised and dismissed as their search for corroboration and confirmation are trivialised. The implications for the healthcare professionals are that they need to examine carefully the responses made when clients share a concern that they may have. It can be seen within this study that telling someone not to worry did little to reduce anxiety. What are needed are suitable responsive techniques that balance managing anxiety, ensuring hope and acknowledging the seriousness of the recipients’ concerns. For the healthcare professional, reassurance needs to be combined with responsive actions.

12.3.1.3 Truth Knowing

Truth knowing within this study related to the process of coming to know the diagnosis. It is represented as ‘coming to know as process’ and ‘coming to know as outcome’. Coming to know as process encapsulates the journey from suspected knowing and represents the recipient’s journey to the point of receiving the diagnosis (truth knowing as outcome). It represents not only the impartation of the bad news but recognises the process of arriving at a place of knowing. There is a before and after pivotal point, which is clearly articulated by many participants as they recount the time they first heard the diagnosis from the healthcare professional. For many of the recipients there was a need to hear the word ‘cancer’ spoken. It was the use of the word that allowed for

recognition that their suspected knowing was legitimate knowing. It does not suggest an acceptance of the diagnosis, rather an acknowledgement that something was not right. The study also highlighted how the use of euphemisms impacted the process of moving from suspected knowing to truth knowing. As with the use of the dismissive mantra, the use of euphemisms did little to alleviate fears and only served to increase anxiety and perpetuated the sense of unknowingness. The implications for the recipients is that the process of moving from a place of suspected knowing to truth knowing is acknowledged as a legitimate process and recognised as part of the trajectory of bad news. For the healthcare professional this highlights the need to review our current policies regarding breaking bad news and to recognise that it is a process, not an event in time. Currently the focus is on the actual delivery of the diagnosis, something that this study would suggest is but one part in the trajectory of bad news. There are also implications for healthcare professionals to look closely at the language used, and in particular the use of euphemisms, when disclosing a cancer diagnosis.

12.3.2 Surfacing within the Lived World: Implications

12.3.2.1 Transformative power of diagnosis.

Many recipients within the study felt that they were often defined by their condition; they were perceived as an illness rather than human beings (section 8.3.1). Having struggled to have their suspected knowing legitimised, the recipients then had to resist the dehumanising process of medicalisation (Illich, 1992). The results of such medicalisation is that recipients feel vulnerable dehumanised, dismissed, and had difficulty establishing trust with the healthcare staff. The need for the recipient is that they be allowed and encouraged to establish, or in the case of some, re-establish, who they are. The implications for the healthcare professional are that they recognise the importance for the recipient of maintaining their individuality and personhood. The need to facilitate the recipient to preserve their identity is crucial for the person

diagnosed with cancer. For the healthcare professional, this will be seen as important in facilitating the emerging self of the recipient.

12.3.2.2 Emerging Self

Within this study, the emerging self refers to the emergence of the person within the Lived World. It relates to a shift from disempowerment to empowerment and signifies a coming to terms with their new situation. For some recipients this signified a re-emergence of themselves psychologically. For others it was the need to deal with altered body image. For some, it was important that they were seen as acceptable, to draw from the powerful words of Maise “...pretty is important...” The emerging self represents the adaptation to a life following a cancer diagnosis; it is the emergence of someone as defined by a life worthwhile rather than a life defined by illness. The implications for the recipient are that they are allowed to acknowledge their feelings and to have their concerns identified as legitimate. The healthcare professional needs to recognise the importance of the emerging self within the bad news trajectory. Healthcare professionals need to be aware that it is not something which is entered into post surgery but is something that the recipient of bad news begins to address from their suspected knowing and it continues throughout the cancer trajectory.

12.3.3 Embodiment within the Lived World: Implications

12.3.3.1 Subliminal Uncertainty

‘Subliminal uncertainty’ is a constant reality for people living with cancer. It is the potential of suspected-knowing waiting to materialise once more. It is characterised by an awareness that suspected-knowing may arise again. Facing one’s mortality brings a tension of focus between surviving and living. It is this tension that encapsulates the subliminal uncertainties. Whilst it could be argued that subliminal uncertainties fall outside the confines of the bad news disclosure, this study suggests that the uncertainties are present throughout the bad news trajectory. More importantly, there are implications from the way the bad news trajectory is managed by the healthcare professional. The study suggests that the recipient often had difficulty accepting information due to their experience of

being dismissed (dismissive mantra), and or their experience of filtered/sequential disclosure. Subliminal uncertainty is intrinsically linked to their experience with the healthcare staff and is related to a lack of trust and fear of not being told the truth. The implication for the recipients of a cancer diagnosis is that there is recognition that this fear is not something unique to them or something that they may feel they need to hide. For the healthcare professional, it is sobering to note that the dismissive mantra, filtered disclosure, euphemisms and other measures taken to ‘protect the patient’ have an ongoing effect on the level of trust between patient and healthcare provider. The implication from the findings of ‘subliminal uncertainty’ goes to the core of professional practice. The need to ensure integrity, honesty and openness with our patients is paramount. If in our endeavours to protect the patient, we damage the fundamental trust we seek to establish, then we fail our patient and create more long-term ‘problems’ for them as they journey on the cancer trajectory. There are also implications regarding the types of information that the recipient needs. The healthcare professional needs to be aware of the information needs pre-disclosure, during disclosure and post-disclosure.

12.4 Implications: Nurses

The study suggests that nurses perceive their role within breaking bad news as one of connectedness. The study illuminated this as two themes, connectedness as journeying with the patient and connectedness as exclusion within the multidisciplinary team (Table 9.1). Although separated out for discussion of findings it was demonstrated that the two are strongly linked with each other.

12.4.1 Connectedness: Journeying as professional within the Everyday-World: Implications

12.4.1.1 Ubiquitous Past:

The study revealed how nurses perceived their professional role and contribution to patient care through the filter of personal histories. The emergence of the ubiquitous past seems to be a conduit for the nurse to engage on a subjective level with their patients. Implication of this for the nurse is that nurses need to recognise personal and professional boundaries. Whilst locating their

professional experience within their personal stories enabled the nurse to articulate their understandings, it is important that the nurse is not working entirely from personal base. An implication for the nurse educator is the need to recognise that nurses may draw from personal experience, but should be encouraged to adopt a critical perspective. Nurses should be encouraged to create a level of synthesis and thus move to a place of learning from, rather than locating in, the personal experience.

12.4.1.2 Professional Companionship

The study suggests that the nurse journeys with the patient through thoughtful, focused and deliberate professional companionship. Through it, the nurse demonstrates reciprocity, mutuality, particularity, attending and bearing. It presented the nurses' ability to recognise the individuality of the patient and the process of ensuring that the physical, psychosocial and spiritual needs of patients were met. The study highlights that often the nurse feels that professional companionship is compromised as they balance the needs of the patient against the knowledge that they as healthcare professionals have or are excluded from having. The nurses, because they are positioned between the needs of the patient and the provision of services from the multidisciplinary team, are often hindered from being authentically real to the patient. This may result in nurses feeling that they are not fulfilling their professional responsibility to the patient and are compromising their personal and professional integrity. This may therefore impact the establishment and maintenance of the nurse-patient relationship based on respect and partnership. The implications are that nurses are placed in positions in which it is difficult to be open and honest with patients, resulting in perpetuating filtered disclosures and the creation of fractured trust within the nurse-patient relationship.

12.4.1.3 Filtered Disclosure

The study highlights the use of language, euphemisms, avoidance of discussion and distancing as mechanisms that nurses used as means of filtering disclosure. Lacking information regarding the patient's situation resulted in nurses often resorting to curtailed-dialogue as a means of protecting the patient and/or protecting their professional standards. The implications of filtered disclosure

on the nurse are linked with the discussion above regarding integrity and honesty. There are also implications as to the ongoing communication and behaviour of the nurse, as they have to use techniques such as avoidance, distancing and selective silence to ascertain what the patient already knows. These behaviours are inconsistent with the integrity required within professional companionship. The study illuminates how nurses ‘hedged and dodged’ within conversations in order to avoid having to discuss the patient’s situation. This results in nurses continuing to experience difficulty in being authentic with the patient. There are implications as to the ability of the nurse to facilitate the recipient to deal with the bad news trajectory. The use of filtered disclosure and its impact on professional companionship makes it all the more difficult for the nurse when the patient realises that they may have known the situation and had not been genuine.

12.4.1.4 Fractured Trust

Trust is central to professional companionship and the nurse-patient relationship. The implications on the nurse-patient relationship when the recipient senses the nurse was untruthful are that there may be a break in the bond of trust established as part of professional companionship. Should such a fracture occur it may have major implications on the ongoing relationship between nurse and patient and between patient and healthcare professionals in general. The study suggests that the recipient’s ability to deal with subliminal uncertainties and ongoing information from healthcare professionals may be directly related to a severance of trust between patient and professional. Therefore, the implications as to how the nurse deals with the recipient and how the nurse relates to the multidisciplinary team are co dependant. A central and key implication of this study that connects all three within the triad is the fundamental need for truth and openness.

12.4.2 Connectedness: Exclusion of professional within the Everyday World

This theme recognises the nurse’s sense of exclusion from the multidisciplinary team. The study suggests that the nurse feels invisible, informed but not included.

12.4.2.1 Professional Collegiality

Whilst professional collegiality is referred to in the interview, the experience of the nurse would suggest that exclusion from information regarding the patient's diagnosis and more specifically exclusion from the disclosure of the diagnosis, resulted in nurses sensing a lack of professional collegiality. The implication of this exclusion is lack of role clarification, and uncertainty as to the contribution and value of the nurse within the bad news scenario. Exclusion from information and the decision making process has been highlighted as affecting the nurse-patient relationship, nurse patient dialogue and nurse-doctor relationship. The implications regarding the nurses' need for information and their need for inclusion within the decision making process of the multidisciplinary team are such that, if exclusion continues, the nurse will find it difficult to establish their professional contribution and ultimately their professional worth to the patient experiencing the bad news trajectory. If not addressed, the implications are that the nurse may continue to feel disempowered and restrained in what they can bring to the bad news scenario, and their professional responsibility towards the patient will remain compromised.

12.4.2.2 Collaborative Distancing

The erection of barriers through blocking techniques, such as use of silence, euphemisms, filtered disclosure and hedging and dodging are used as effective mechanisms to manage interactions and avoid engagement in certain topic areas. The study suggests that this may be based upon solidarity and corroboration with the multidisciplinary team. Collaborative distancing has been interpreted as a response to a lack of knowledge and/or a means of offering collegiate support. The implications of collaborative distancing on the recipient are that they are not receiving sensitive care, which should be based upon integrity and honesty. Instead their care is packaged to meet the needs of the provider and the nurse is complicit in colluding with this. The implications for the nurse are that they remain uninformed and excluded within the multidisciplinary team. They remain in the precarious position of attending to the patient through professional companionship, which is fundamentally flawed due to a lack of authenticity.

There can be no real authenticity between nurse and patient whilst there is exclusion from the information required to enable the delivery of a care package that is truly patient centred and patient focused.

12.5 Implications: Doctors

The study suggests that doctors perceive their role with the patient and the multidisciplinary team as one that is objectified (Table 9.2) and distanced (Figure 11.5). Within this study, the multidisciplinary team is seen to be hierarchical and led by the doctor.

12.5.1 Objective Connectedness within the Everyday-World: Implications

12.5.1.1 Allied Affiliations

Allied affiliations relate to the relationships doctors have with patients, nurses and peers. The affiliations depict the doctor as leader within the triad and highlight alliances that are created through objectified connections. The implications for the doctor are that, in distancing themselves from the patient, they often see the presenting person as subsumed within the present symptoms. The intended purpose of such an alliance may be to enable the doctor to reach an objective judgement regarding the patients. However, the effect of such alliance on the recipient has been intimated earlier. The implications of the doctor failing to recognise the presenting person are that they contribute to the dehumanising effects associated with the medicalisation. They create a situation in which the patient begins to feel vulnerable, dismissed and ultimately they become suspicious of the information given to them by the doctor. The study suggests that this area of distrust in the medical staff can have implications on the doctor-patient and patient-nurse relationship, especially in relation to accepting information. The doctor needs to recognise and acknowledge the presenting person and locate the presenting symptoms within the context of the person and not vice versa.

Findings suggest that the affiliation with the nurse is based upon an assumption that the nurse is aware of the decisions made within the multidisciplinary team. Whilst the study indicates that the doctor sees the nurse as part of the multidisciplinary team, triangulation of findings would suggest that this is not

corroborated by the nurses' experiences of the multidisciplinary team; as they felt excluded and invisible. The study also indicates that in general, the doctor did not see the need to have a nurse present when the bad news was broken. Breaking the bad news was seen as the doctor's responsibility and it appeared that whilst exclusion of the nurse was not a conscious decision; neither was there a conscious decision to include them. The implications of such exclusion on the nurse and their subsequent relationship with the patient, has been highlighted earlier. An implication of such exclusion on the doctor is that because the nurse is not being involved and is not aware of what transpired between doctor and patient, their ability to offer support to the doctor during and following disclosure is impeded.

The affiliation with medical colleagues at work and with fellow medical peers indicates that the doctor sees the medical team as offering advice and guidance whilst medical peers offer support. An implication of this differentiation of advice and support is the perpetuating image of the doctor as in control and not needing support from those with whom he works closely.

Overall there is a need to clarify the role and function of each member of the multidisciplinary team.

12.5.1.2 Antecedent Preparation

Antecedent preparation reflects a period when the doctor prepares for the disclosure of the diagnosis to the patient. The study suggests that during this period the doctor often feels vulnerable due to uncertainty regarding patient's reactions. The potential for emotional outbursts and awkward questions regarding length of time left to live creates difficulties for the doctor. The implications arising out of this would indicate a need for the doctor to recognise that although retaining the professional responsibility regarding giving the diagnosis there is a need to see this as something with which the multidisciplinary team could be involved. The inclusion of the nurse during antecedent preparation might go some way towards alleviating the pressure regarding assessing the patient as to how they might react to the news. The nurse, drawing from her insights of the patient emerging from professional

companionship, could offer insights into the patient's character, understanding and any other issues that might impact upon their reaction to the news.

12.5.1.3 Disclosures

The study suggests that disclosure is controlled by the doctor in terms of whether it is full, partial, sequential or closed disclosure. Doctors also decide on when, where and how they will disclose the diagnosis. A decision on inclusion or exclusion of family members is also done by the doctor. The study highlights that doctors mainly learned how to break bad news as they observed others doing so. The educational preparation for breaking bad news was felt to be ineffective, inappropriate and delivered at the wrong time during medical training. The implications of this are that there is a need to review curricular content and address the timing, delivery and assessment of skills in breaking bad news.

The use of euphemisms has been highlighted across the triad of recipient, nurse and doctor. The findings would suggest that it is not helpful for the recipient, creates difficulty for the nurse and may be used by the doctor to moderate the reality of the diagnosis. The implications of the use of euphemisms has been highlighted for the recipient and the nurse; for the doctor the implications of such use are that they prevent full disclosure from occurring and only serve to keep the recipient in a place of suspected or suspended knowing.

12.5.1.4 Authenticating Awareness

This is initiated by the doctor as a means of checking that the recipient understands the implications of the information given at the disclosure of bad news. As with the disclosure, authenticating awareness remains exclusively the role and function of the doctor. The implications are that the doctor works independently of the multidisciplinary team and fails to use their understandings of the recipient to make an assessment of the situation.

In summary, it can be seen that the implications from each aspect of the bad news event affect not only the relevant part of the triad, but also affects the triad as a collaborative unit. It is recognised from the study, that whilst bad news is experienced as a process or trajectory for the recipient, it is dealt with as an

event by the doctor. The implications of this are that there is a dissonance between recipient's needs and the doctor's actions. The triadic connectedness between recipient, nurse and doctor, highlights a lack of insight into the phenomenological experience of each within the relationship. The implications of this may be seen as fragmented care, which may hamper the recipient in their journey and hinder professional collaboration. Ultimately, the implications are that this leads to exclusive knowing rather than inclusive knowing, where each part of the triad has an independent and different perception of the situation.

12.6 Recommendations

The literature reviewed for this study has highlighted the singular viewpoint often taken by researchers in the past. This singular perspective on breaking bad news has given the voice of the physician dominance over the recipient of the news, and has often negated and ignored the role and contribution of the nurse within the disclosure of bad news. This study has offered a perspective that acknowledges and recognises the triadic aspect of healthcare practice. By looking beyond the singular perspective of the bad news scenario, and considering the lived experience of each part of the triad, a more vivid picture of the process has emerged. It is beyond the remit of this study to make direct recommendations to the recipients of bad news. However, it is within the remit of this study to make recommendations for healthcare professionals, future practice, and further research. With this in mind, the following recommendations are offered for consideration. These recommendations relate to the practice of the healthcare professionals within their practice discipline and also relate to inter-professional collaboration within the multidisciplinary team.

12.6.1 Recommendations for Education

This study has highlighted the inconsistencies between the recipient's perception of bad news as a process and the healthcare professional's perception of it as an event. There is a need to increase awareness of healthcare professionals' understanding of the trajectory of bad news.

Whilst many healthcare institutions and educational curricula recognise the concept of the psychosocial and spiritual aspects of the person, there is a need to ensure that this permeates not only the curricular document but also emerges within the delivery of content, assessment of theory and more importantly, that it is represented in the practice settings in which bad news is delivered. It is recommended that educationalists:

- Review current curriculum content in relation to the assessment of the individual needs of the patient with particular focus on the needs of people who are to receive bad news.
- Ensure that curricular content for all healthcare professionals reflects the concept of bad news as a trajectory
- Enable practitioners to identify the changing needs of the recipient throughout the bad news process.
- Focus upon the specific communication skills required within the disclosure event; skills such as reflective listening, empathetic responses, mirroring, paraphrasing, questioning, clarifying, use of appropriate language, avoidance of euphemisms and the skills of opening and closing the encounter.
- Create learning opportunities that provide the healthcare professional with immediate feedback on their performance. The use of video recording of simulated interviews may enable the practitioner to see, hear and reflect on their communication skills.

The study highlighted that the needs of a person who receives a cancer diagnosis may vary. It would appear that with the emergence of palliative care, palliative medicine and oncological specialities, much of the skill acquisition for professionals has tended to shift towards these areas. This study has highlighted that many people begin their bad news trajectory prior to making contact with the healthcare professionals. Indeed, for many people, this journey begins long before contact with specialist staff from oncology and palliative care fields. It is recommended that:

- Whilst there is a need to ensure that nurses and doctors working outside the cancer specialist areas receive adequate training in the process of giving bad news, there is also a need to ensure that general practitioners, nurse practitioners and community based healthcare staff working within the primary healthcare settings also need to develop the relevant skills.
- Health Service Executives provide opportunities for the ongoing staff development and training in the area of breaking bad news.

The study highlighted the discrepancies between how nurses and doctors practise within the multidisciplinary team. There appears to be exclusion and role misunderstanding that ultimately affects healthcare professional' relationships with each other and more importantly it affects the package of care provided to the patient. There is a need to address role clarification and the contribution of members within the multidisciplinary team within the bad news scenario. It is recommended that:

- The Health Service Executive facilitates the establishment of multidisciplinary training programmes which will facilitate interdisciplinary, experiential, longitudinal and mentored learning experiences for all healthcare professionals.

There is also a need to examine the segregated education and training of healthcare professionals during their initial professional training. Communication skills in general and more specifically the delivery of bad news, does not happen in a vacuum. This study has highlighted the outcomes of poor communication as fragmented care that is often exclusive rather than inclusive. Exposure to the 'Tripartite Transition: a Process of Inclusive Knowing' framework may provide valuable insights into the triadic aspect of healthcare practice. The delivery of bad news involves doctor, nurse and patient; there is a need therefore, to begin to create learning opportunities that recognise the interdependence of all three aspects of the triad and not just the dyad of nurse and doctor. It is therefore recommended that:

- Creative and innovative educational packages, which facilitate interdisciplinary learning within a safe simulated environment, be established.
- The use of real patients who have received bad news, or skilled actors who would role-play a patient from suspected knowing through to post disclosure might enable the practitioners to not only experience the process of disclosure but also within the safety of a well facilitated role play, receive feedback from the receiver and the other professional represented within the scenario.

12.6.2 Recommendations for Practice

The 'Tripartite Transition: a Process of Inclusive Knowing' framework of convergence may be used as a basis for exploring the contributions each makes towards disclosure. The use of the conceptual framework might go some way towards creating a sharing of responsibility within the disclosure process and recognition of the disclosure as a process rather than an event. It may also create opportunities for healthcare practitioners to look at their communication processes and practices. Additionally, it might also raise awareness of healthcare professionals to each others' practice issues and behaviours in relation to a more collegiate goal orientated care system. As the needs for education and development are recognised, there is also a requirement to acknowledge the need for reform and development in practice. This study has highlighted the fragmented and exclusiveness of practice within the bad news delivery scenario. The central issue appears to be role confusion and role boundaries within the multidisciplinary team. It is recommended that Health Service Executive:

- Examine the role and function of the multidisciplinary team with an aim of creating effective, non-hierarchical teams that work in a collegiate and supportive manner.
- Encourage each service provider to produce a standard statement for the types of disclosure used when the patient has to be given bad news and

recommend the avoidance of non-disclosure, partial-disclosure and closed-disclosure.

12.6.2.1 Recommendations at Local Level

At a local level, healthcare providers need to:

- Recognise the need for good role modelling by senior staff in the area of breaking bad news.
- Identify staff who would benefit from professional development in the area of breaking bad news
- Review policy and procedures, which as identified earlier, appear to be currently based upon 'evidence' from mainly physician orientated and physician focused research.
- Ensure that practitioners are aware of the potential dissonance that may exist between the perceived needs of the recipient from the healthcare practitioner's perspective and the felt needs of the recipients as articulated within their lived experience.
- Audit current practice activities in relation to breaking bad news.
- Review the organisation of care delivery to ensure that care is not fragmented and disjointed.
- Encourage a collaborative and inclusive approach to care, which has clear shared objectives and open communication systems.
- Ensure that the organisation provides an effective working role model of collegiate and interdisciplinary partnership.

12.6.2.2 Recommendations for individual doctors

In addition, it is recommended that individual doctors:

- Acknowledge and seek support from within the multidisciplinary team.
- Ensure that all members of the multidisciplinary team contribute to the preparation for the disclosure.
- Arrange to have a nurse present when the bad news is to be given.
- Refrain from using any form of dismissive mantra, ensuring that the patient is heard and receives an appropriate response to their concerns.

- Avoid the use of euphemisms and filtered disclosure.
- Ensure the information given to the patient is clearly documented.

12.6.2.3 Recommendations for individual nurses

Individual nurses are also recommended to:

- Seek clarification from the multidisciplinary team on the perspectives of each others role, function and contribution within the team.
- Ensure that all members of the multidisciplinary team have opportunity to make valid contributions towards decision making.
- Discuss with the multidisciplinary team the importance of having a nurse present when bad news is broken.
- Ensure that a nurse is present with the doctor when bad news is broken.
- Refrain from using any form of dismissive mantra, ensuring that the patient is heard and receives an appropriate response to their concerns.
- Avoid the use of euphemisms and filtered disclosure.
- Ensure that the patient fully understands their situation and has further opportunity to seek clarification from the nurse and/or doctor.
- Ensure the information given to the patient is clearly documented.
- Ensure that they act as patient advocate and strive to maintain their professional and personal integrity before the patient and the multidisciplinary team.

12.6.3 Recommendations for Further Research

The findings from this study provide valuable information and knowledge for all involved within the disclosure of bad news. Many of the findings confirm and extend those from previous studies. Findings from this study also offer a unique insight into the disclosure from within the dynamism of the triad of care. The perspective of the patient as journeying from suspected knowing to truth knowing indicates a trajectory, which commences prior to contact with healthcare staff and which is greatly impacted upon by the convergence of all three. The use of the ‘dismissive mantra’ as ineffective reassurance has implications for healthcare education and practice. Role ambiguity and

professional isolation within the multidisciplinary team has been shown directly to affect the relationship between healthcare professionals and also the client-practitioner relationship. The findings of this study serve as a basis for the following recommendations for future research studies:

- An examination and comparison of different models of disclosure of bad news across and within different care settings.
- A collaborative inquiry, which recognises the contribution of the triad as co-researchers and explores the issues of disclosure from the perspectives of each member of the triad.
- An examination of the specific factors that influence the decisions regarding types of disclosure, timing of disclosure and amounts of information disclosed.
- An examination of the language used by healthcare professionals when interacting with each other and with the client.

Whilst the focus of this research was on the recipient's experience of receiving bad news, it is acknowledged that the impact of bad news is not just on the recipient. Bad news impacts on all those connected with the recipient. It is therefore recommended that the following future research studies be considered:

- The role and contribution of significant others in supporting the recipient of bad news.
- The experience of significant others in journeying with the recipient on the bad news trajectory.
- The involvement of the significant other within the triad of care.
- The perspectives of healthcare professionals towards the involvement of the significant other within the trajectory of bad news.

12.7 Concluding remarks:

Finally, it is worth reminding ourselves that interpretations within the hermeneutic tradition are never final or complete, they are ‘always an approximation’ (Geanellos, 1998:158). Schleiermacher noted this when he suggested:

...no individual inspection of a work ever exhausts its meaning; interpretation can always be rectified. Even the best is only an approximation of the meaning (Schleiermacher, 1819:97)

With this in mind I bring the writing of this research thesis to a conclusion and in so doing acknowledge the ongoing nature of the interpretations which the reader will bring to the study.

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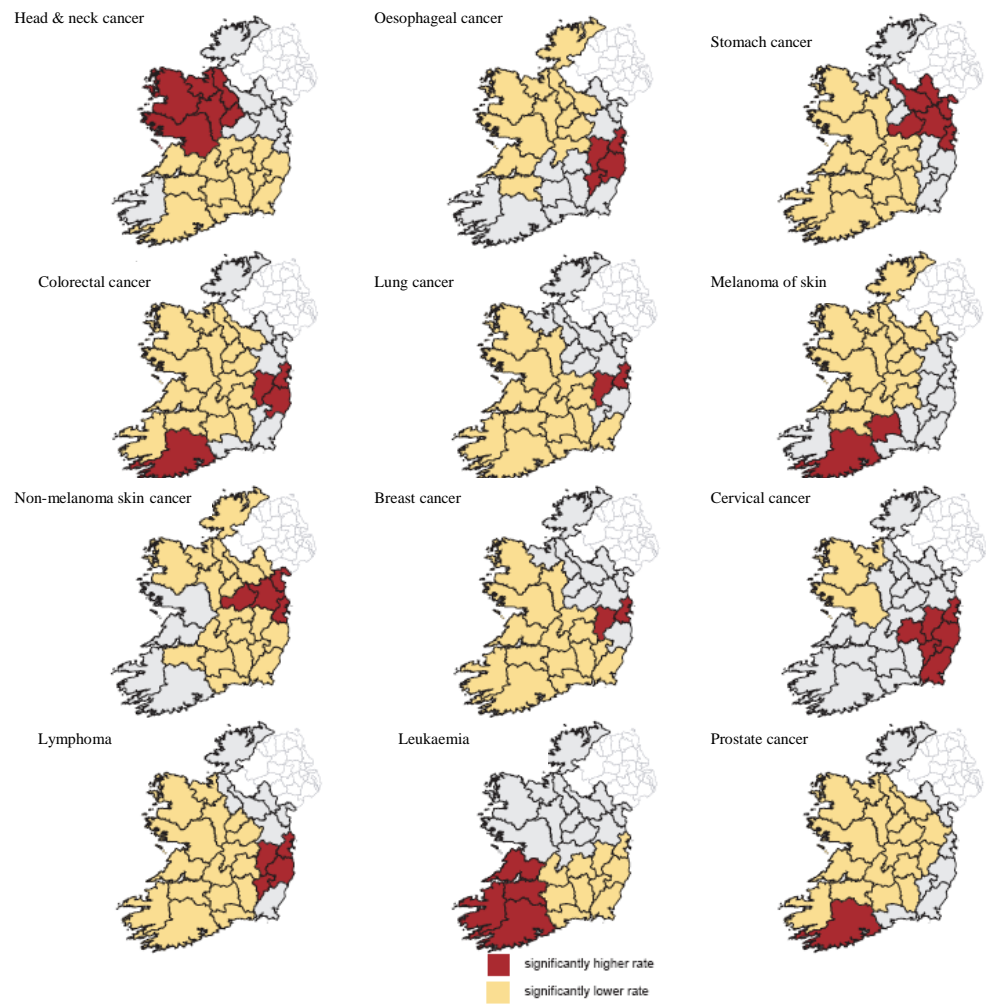
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APPENDIX I

Cancer Trends Across Ireland

Trends of Cancer across Ireland: Standardised incidence rates for
 Cancer
 (Campo, Comber and Gavin, 2004)



APPENDIX II

Letter to Irish Cancer Society

LETTER TO THE IRISH CANCER SOCIETY SEEKING ACCESS TO RECIPIENT SAMPLE GROUP

School of Nursing & Midwifery
Trinity College,
Dublin 2

Dear Ms Ryan,

Further to our meeting yesterday in which you requested that I submit a letter seeking approval from the Board of the Irish Cancer Society. Please accept this letter as a formal request to access members of the Irish Cancer Support Groups situated in Dublin, Cork, Donegal and Galway.

I am currently undertaking a Ph.D. at Trinity College Dublin. My research study entitled **“An Exploration of the Process of Breaking Bad News from the Perspective of the Healthcare Professional and the Recipient of Bad News”** – is funded by the Health Research Board.

I am writing to request permission from the Board to allow access to members of support groups from four geographical areas; Cork, Dublin, Donegal and Galway. I understand from our meeting that I will not have direct access to any database information and will only be provided with the contact information of the relevant group leader in each area. I also accept your provision that only people who are at least five years post diagnosis should be included in this study.

The proposed study has been internationally reviewed on behalf of the Health Research Board. Ethical approval was granted for the study on January 12th 2001. I have attached a copy of the documentation for ethical approval which was submitted to Mr. D. Lynch, Senior Executive Officer, Joint Ethical Research Ethics Committee, The Adelaide & Meath Hospital & St James’s Hospital, Dublin for the information of the board of the Irish Cancer Society. Also attached is an information sheet which will be sent to potential participants and letters of invite which the group leaders will be asked to distribute on my behalf.

Participants will be invited to take part in the study by undertaking an interview with the researcher at a time and place convenient to them. An experienced counselor who specialised in grief and bereavement counseling will be available (free of charge to the participants) should they wish to avail of her support following the interview. She will travel to the locality and meet with the participants on their request. The contact details of the counselor will be given to all participants on commencement of the interview and participants will be reminded of this information before ending the interview. This interview should last approximately 45 minutes to one hour and with the participant’s permission, will be recorded on audiotape. I will be the only person listening to the interview and the tape will be destroyed once the research is completed.

I would like to assure the board that the data obtained will be treated in strictest confidence and the confidentiality and anonymity of the participant and that of any healthcare professional or organisation will be guaranteed.

Thank you for taking the time to meet with me this week and for presenting this request on my behalf to the Board of the Irish Cancer Society. I do hope you have enough information to present this request, should you require any more information please do contact me.

Yours sincerely,

Gerard Tobin
Research Fellow Health Research Board
(Office: 01-6083362)

(Email: gtobin@tcd.ie)

APPENDIX III

Letter to Facilitator of Irish Cancer Society Support Group

LETTER OF INVITE TO CANCER SUPPORT GROUP LEADERS

School of Nursing & Midwifery
Trinity College
Dublin 2

Dear _____,

I am currently undertaking a Ph.D. at Trinity College Dublin. My research study entitled **“An Exploration of the Process of Breaking Bad News from the Perspective of the Healthcare Professional and the Recipient of Bad News”** – is funded by the Health Research Board.

I believe Ms. Ryan has spoken to you regarding this research study. The Board of the Irish Cancer Society has agreed to allow me access to a sample group via you as the support group leader in your locality.

It has been recommended that the leader of the support group be involved in identifying people from within their locality who might be willing to take part in the study. It is however, a stipulation of the Irish Cancer Society that people who received their cancer diagnosis less than five years ago not be part of the study. I am hoping that you are willing to act on my behalf by identifying such people and passing on to them one of the enclosed envelopes. Attached are copies of all information enclosed within the envelope for you to review. I must stress that you are not required to pass on to me any information regarding the potential participants in the study. If they wish to take part they can return an indication slip to me in the stamped addressed envelope. I will have no way of knowing who you passed the letters of invitation to and will therefore can assure you that I will not be in a position to follow up anyone who does not respond to the letter of invite.

Should the person wish to be part of the study I would like to talk to them about their experiences of having received a cancer diagnosis. The discussion should last approximately 45 minutes to one hour and with their permission, will be recorded on an audiotape. This will ensure that I have heard their story correctly and assist me with the analysis of the information. I will be the only person listening to the tapes and they will be destroyed once the research is completed.

I will be in your area during (date to be inserted) and will be meeting with a number of healthcare professionals during this time. I have attached some further information about the research study, which I hope will answer any questions you may have. Please feel free to contact me, Dr Begley or Ms Ryan at the Irish Cancer Society should you require any further information. Once people indicate an interest in taking part in the study I will contact them and arrange a convenient time to meet. An experiences bereavement counsellor will be available free of charge to all participants should they wish to avail of her services following the interview.

I would like to assure you that the data obtained will be treated in strictest confidence and the anonymity and confidentiality of everyone involved in the study will be guaranteed.

Thank you for taking the time to read this letter. I do hope you will consider contributing to this important study and passing on the enclosed envelopes to potential participants on my behalf.

Yours sincerely,



Gerard Tobin
Research Fellow Health Research Board
(Office:01 6083362)

(Email: gtobin@tcd.ie)

APPENDIX IV

Letter of Invitation to Recipient

LETTER TO RECIPIENTS OF BAD NEWS

School of Nursing & Midwifery
Trinity College
Dublin 2

Dear

I am currently undertaking a Ph.D. within the Faculty of Health Sciences at Trinity College Dublin. My research study entitled **“An Exploration of the Process of Breaking Bad News from the Perspective of the Healthcare Professional and the Recipient of Bad News”**– is funded by the Health Research Board.

I am writing to invite you to take part in this study. You have been identified by the leader of your local Irish Cancer Society Support Group as someone who might be interested in talking about what it was like to receive a cancer diagnosis. This study has been reviewed by the Board of the Irish Cancer Society and has been approved by them and also by the Ethics Committee at Trinity College Dublin.

This letter is been delivered to you on my behalf by (insert name of support group leader). I do not know who will receive this letter and will make no further contact with you, should you decide not to participate in the study.

Should you be willing to participate in the study I would like to talk to you about your experiences when you were given your diagnosis. With your permission, I would like to tape record the discussion as this will assist me with the information and ensure that I have heard your story correctly. I will be the only person listening to the tapes and they will be destroyed once the research is completed.

I will be talking to people within your region during (dates to be given) and would appreciate if we could meet up. The discussion would last about 45 minutes to one hour, will be very informal and can be stopped at any time by yourself should you wish not to continue..

I have attached some further information about the research study, which I hope will answer any questions you may have. Please feel free to contact me on the numbers listed or return the consent form in the enclosed stamped addressed envelope. If you do indicate an interest to participate, I will contact you and arrange a convenient time to meet.

I would like to assure you that the information obtained would be treated in strictest confidence. At no time will your identity, place of residence or links with any medical personnel or hospitals be exposed. All names etc will be changed to guarantee this.

Thank you for taking the time to read this letter. I do hope you will consider contributing to this important study.

Yours sincerely,



Gerard Tobin
Research Fellow Health Research Board
(Office:01 6083362)

(Email: gtobin@tcd.ie)

APPENDIX V

Information Sheet for Recipients of Bad News

INFORMATION SHEET ACCOMPANING ALL LETTERS OF INVITE TO THE RECIPIENTS OF BAD NEWS

<u>Title of the Project:</u>	An exploration of the process of breaking bad news from the perspective of the healthcare professional and the recipient of bad news.
<u>Principal Investigator:</u>	Gerard Tobin, School of Nursing & Midwifery, Trinity College, Dublin 2
<u>Research Supervisor:</u>	Professor Cecily Begley, Director, School of Nursing & Midwifery, Trinity College, Dublin 2
<u>Terms:</u>	Bad News: For the purpose of this study the term receiving bad news relates to the diagnosis of cancer. All people invited to take part must have received their diagnosis at least 5 years ago. If you have received your diagnosis within the past five years I am afraid I will not be able to interview you at this time. This is a requirement of the Irish Cancer Society.
<u>Purpose</u>	To explore the experience of people who receive bad news. To explore the experience of nurses involved in giving bad news to patients. To explore the experience of doctors involved in giving bad news to patients.
<u>Background:</u>	Although we know a lot about giving patients bad news, there is very little research which has explore this within Ireland. This study aims to explore bad news from the view of the person who has received it and will also look at what it is like for the doctor and nurses involved in having to give such information to their patients.
<u>Procedures:</u>	The researcher will meet with people who have had a cancer diagnosis and talk with them about their experience, their memories of the event and how it affected them. Nurse and doctors who are also involved in giving such news will also be invited to take part. At no time will you be linked with a particular doctor, nurse or hospital and your name or identity will not be used in the study Your story will be written up as part of a research study and be written up and presented as part of a PhD within Trinity College, Dublin.
<u>Benefits:</u>	This will be one of the first studies of its kind in Ireland. It will provide an insight into what it was like to receive a cancer diagnosis and also highlight the role of nurses and doctors in providing care during this difficult process
<u>Risks:</u>	There are no foreseeable physical risks to participants in the study. However, should anyone who takes part wish to avail of support, an experienced counsellor will be available free of charge.
<u>Confidentiality:</u>	All people involved in the study will be guaranteed complete confidentiality and anonymity. The only reference to the individual will be to place them as within the nurses group, the doctors group or the patient group. Any reference to places of work or individuals will be changed to maintain total anonymity.
<u>Freedom to withdraw:</u>	All people involved in the study will be free to withdraw at any time. Should someone wish not to have their interview used as part of the study this will be respected and the tape destroyed.
<u>Additional contacts:</u>	If you have concerns about any aspects of this study please feel free to contact either the main researcher – Gerard Tobin directly on 01 6083362 gtobin@tcd.ie or contact Dr Cecily Begley on 01 6082693 cbegley@tcd.ie You may also speak with your Support group leader or a member of the Irish Cancer Society, if you so wish.

APPENDIX VI

Informed Consent Sheet

CONSENT FORM: TO BE SIGNED BY ALL PARTICIPANT AND RESEARCHER

Part 1

Title of the Project: An exploration of the process of breaking bad news from the perspective of the healthcare professional and the recipient of bad news.

Principal Researcher: Gerard Tobin

Research Supervisor: Professor Cecily Begley

Part 2 *To be completed by participant and returned – by fax (01 60830.) or by post (using the SAE)*

- 1 Do you understand that you have been asked to be in a research study? Yes No
- 2 Have you read and received a copy of the Information Sheet? Yes No
- 3 Do you understand the benefits and risks involved in taking part in this research study? Yes No
- 4 Would you like further opportunity to ask questions and discuss this study? Yes No
- 5 Do you understand that you are free to refuse to participate or withdraw from the study at any time? Yes No
You do not have to give a reason and it will not affect you in any way
- 6 Has the issue of confidentiality & anonymity been adequately explained to you? Yes No
- 7 This study was explained to me by:
.....

8 I agree to take part in this study: Yes No

9

Signature of Participant	Please Print your Name
		Date

10 Gerard Tobin may contact me on the following number to arrange interview time and venue

Landline	Mobile Number
(.....)	(08)
(Area Code) Number
	(Best time to contact me)

Part 3 *(To be completed by researcher before the interview & a copy given to participant before commencing interview)*

11 I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

.....	Gerard A. Tobin
Signature of Researcher		Date

APPENDIX VII

Letter of Invitation to Nurses ^(First Round)

LETTER OF INVITE TO NURSES (FIRST ROUND)

School of Nursing & Midwifery
Trinity College,
Dublin 2

Dear _____,

I am currently undertaking a Ph.D. at Trinity College Dublin. My research study entitled "An Exploration of the Process of Breaking Bad News from the Perspective of the Healthcare Professional and the Recipient of Bad News" – is funded by the Health Research Board.

I am writing to invite you to participate in the study. Your name has been randomly selected from a database held within the School of Nursing & Midwifery at the University of Dublin, Trinity College. Should you wish to be part of the study I would like to talk to you about your experiences of been involved in the process of giving bad news to patients. The discussion should last approximately 45 minutes to one hour and with your permission, will be recorded on an audiotape. This will ensure that I have heard your story correctly and assist me with the analysis of the information. I will be the only person listening to the tapes and they will be destroyed once the research is completed.

I will be in your area during (insert range of dates) and will be meeting with a number of healthcare professionals during this time. I have attached some further information about the research study, which I hope will answer any questions you may have. Please feel free to contact me on the numbers listed or return the consent form in the enclosed stamped addressed envelope. If you do indicate an interest to participate, I will contact you and arrange a convenient time to meet.

I would like to assure you that the data obtained will be treated in strictest confidence and your anonymity and that of your workplace will be guaranteed.

Thank you for taking the time to read this letter. I do hope you will consider contributing to this important study.

Yours sincerely,



Gerard Tobin
Research Fellow Health Research Board
(Office:01 6083362)

(Email: gtobin@tcd.ie)

APPENDIX VIII

Information Sheet for Healthcare Professionals

INFORMATION SHEET ACCOMPANING ALL LETTERS OF INVITE TO HEALTHCARE PROFESSIONALS

<u>Title of the Project:</u>	An exploration of the process of breaking bad news from the perspective of the healthcare professional and the recipient of bad news.
<u>Principal Investigator:</u>	Gerard Tobin
<u>Research Supervisor:</u>	Professor Cecily Begley
<u>Purpose</u>	To explore the experience of people who receive bad news. To explore the experience of nurses involved in giving bad news to patients. To explore the experience of doctors involved in giving bad news to patients.
<u>Background:</u>	Much of the published work on breaking bad news draws from good practice and experience. There is very little research evidence to support the ‘way’ we do it or the ‘roles’ of people within the process. There is little research exploring the impact of the breaking of the news on the recipient group. There is no research carried out to date within the Irish healthcare system.
<u>Procedures:</u>	A qualitative approach will be used using semi-structured interviews. Nurses from four centres in Ireland will be invited to participate. Hospital based doctors and general practitioners will also be invited to participate. Finally, a small group of participants of bad news will be invited to discuss their experience of having bad news broken to them.
<u>Benefits:</u>	This will be the first comprehensive study of its kind in Ireland. It will highlight the role of nurses and doctors in providing care during this difficult process. It will also give voice to the recipients of bad news. The study will clarify the process and highlight current practice
<u>Risks:</u>	There are no foreseeable physical risks to participants in the study.
<u>Confidentiality</u> :	All participants will be guaranteed complete confidentiality and anonymity. The only reference to the individual will be to categorise them as within the nurses group, the doctors group or the recipient group. Any reference to places of work or individuals will be changed to maintain total anonymity.
<u>Freedom to withdraw:</u>	All participants will be free to withdraw from the study at any time during the interview. Should participant’s wish not to have their interview used as part of the study this will be respected and the tape destroyed.
<u>Additional contacts:</u>	If you have concerns about any aspects of this stuffy please feel free to contact either the main researcher – Gerard Tobin directly on 01 6083362 gtobin@tcd.ie or contact Dr Cecily Begley on 01 6082693 cbegley@tcd.ie

APPENDIX IX

Letter of Invitation to Nurses (Second Round)

LETTER OF INVITE TO NURSES (SECOND ROUND)

School of Nursing & Midwifery
Trinity College
Dublin 2

Dear Nurse,

I am currently undertaking a Ph.D. at Trinity College Dublin. My research study entitled "An Exploration of the Process of Breaking Bad News from the Perspective of the Healthcare Professional and the Recipient of Bad News" – is funded by the Health Research Board.

A fellow colleague of yours has participated in this study and has offered to distribute letters of invite to a number of nurses on my behalf. I am writing to invite you to participate in the study. Should you wish to be part of the study I would like to talk to you about your experiences with the process of being involved with patients when they are given a cancer diagnosis. This interview should last approximately 45 minutes to one hour and with your permission, will be recorded on audiotape. I will be the only person listening to the interview and the tape will be destroyed once the research is completed.

I will conducting data collection in your area during (date to be inserted) and will be meeting with a number of healthcare professionals during this time. I have attached some further information about the research study, which I hope will answer any questions you may have. Please feel free to contact me on the numbers listed or return the consent form in the enclosed stamped envelope. If you do indicate an interest to participate, I will contact you and arrange a convenient time to meet.

I would like to assure you that the data obtained will be treated in strictest confidence and your anonymity and that of your organisation will be guaranteed. The proposed study has been international reviewed on behalf of the Health Research Board and has been granted ethical approval by Trinity College Ethical committee.

Thank you for taking the time to read this letter. I do hope you will consider contributing to this important study.

Yours sincerely,



Gerard Tobin
Research Fellow Health Research Board
(Office:01 6083362)

(Email: gtobin@tcd.ie)

APPENDIX X

Letter of Invitation to Doctors ^(First Round)

LETTER OF INVITE TO DOCTORS (FIRST ROUND)

School of Nursing & Midwifery
Trinity College
Dublin 2

Dear Dr. XXXX,

I am currently undertaking a Ph.D. at Trinity College Dublin. My research study entitled "An Exploration of the Process of Breaking Bad News from the Perspective of the Healthcare Professional and the Recipient of Bad News" – is funded by the Health Research Board.

I am writing to invite you to participate in the study. Should you wish to be part of the study I would like to talk to you about your experiences with the process of giving a patient a cancer diagnosis. This interview should last approximately 45 minutes to one hour and with your permission, will be recorded on audiotape. I will be the only person listening to the interview and the tape will be destroyed once the research is completed.

I will conducting data collection in your area during (date to be inserted) and will be meeting with a number of healthcare professionals during this time. I have attached some further information about the research study, which I hope will answer any questions you may have. Please feel free to contact me on the numbers listed or return the consent form in the enclosed stamped envelope. If you do indicate an interest to participate, I will contact you and arrange a convenient time to meet.

I would like to assure you that the data obtained will be treated in strictest confidence and your anonymity and that of your organisation will be guaranteed. The proposed study has been international reviewed on behalf of the Health Research Board and has been granted ethical approval by Trinity College Faculty of Health Sciences Ethical committee.

Thank you for taking the time to read this letter. I do hope you will consider contributing to this important study.

Yours sincerely,



Gerard Tobin
Research Fellow Health Research Board
(Office:01 6083362)

(Email: gtobin@tcd.ie)

APPENDIX XI

Letter of Invitation to Doctors (Second Round)

LETTER OF INVITE TO DOCTORS (SECOND ROUND)

School of Nursing & Midwifery
Trinity College
Dublin 2

Dear Dr. XXXX,

I am currently undertaking a Ph.D. at Trinity College Dublin. My research study entitled "An Exploration of the Process of Breaking Bad News from the Perspective of the Healthcare Professional and the Recipient of Bad News" – is funded by the Health Research Board.

A fellow colleague of yours has participated in the study and has offered to distribute this letter of invite to a number of Doctors on my behalf. I am writing to invite you to participate in the study. Should you wish to be part of the study I would like to talk to you about your experiences with the process of giving a patient a cancer diagnosis. This interview should last approximately 45 minutes to one hour and with your permission, will be recorded on audiotape. I will be the only person listening to the interview and the tape will be destroyed once the research is completed.

I will conducting data collection in your area during (date to be inserted) and will be meeting with a number of healthcare professionals during this time. I have attached some further information about the research study, which I hope will answer any questions you may have. Please feel free to contact me on the numbers listed or return the consent form in the enclosed stamped envelope. If you do indicate an interest to participate, I will contact you and arrange a convenient time to meet.

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Thank you for taking the time to read this letter. I do hope you will consider contributing to this important study.

Yours sincerely,



Gerard Tobin
Research Fellow Health Research Board
(Office:01 6083362)

(Email: gtobin@tcd.ie)

APPENDIX XII

**Approval letter from the Joint Research Ethics Committee, Federated Dublin
Voluntary Hospitals and St. James's Hospital**

This notepaper must not be used
for prescriptions or for invoicing
purposes

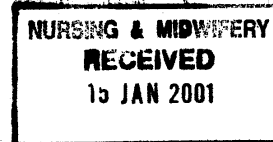


**THE ADELAIDE & MEATH
HOSPITAL, DUBLIN**

INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

TALLAGHT, DUBLIN 24, IRELAND.
TELEPHONE +353 1 414 2000

Mr. Gerard Tobin,
Lecturer in Nursing Studies,
School of Nursing & Midwifery Studies,
C/O Trinity Centre for Health Sciences,
St. James's Hospital,
James's Street,
Dublin 8.



Dr. Cecily Begley,
Director,
School of Nursing and Midwifery Studies,
C/O Trinity Centre for Health Sciences,
St. James's Hospital,
James's Street,
Dublin 8.

12th January 2001

**RE: An exploration of the process of breaking bad news from the perspective of
the healthcare professional and the recipient.**

Dear Dr. Begley,

The Joint Research Ethics Committee at its meeting on the 12th December 2000 agreed to give Ethical Approval to the above study subject to the following condition:

- 1) It is requested that the Investigator would describe the mechanism by which a subject who experiences severe pain and discomfort from explaining a "lived experience" will be referred.

Yours sincerely,

Daniel R. Lynch,
Senior Executive Officer.

APPENDIX XIII

Letter to Ethics Committee in Response to Condition Made



THE UNIVERSITY OF DUBLIN TRINITY COLLEGE
FACULTY OF HEALTH SCIENCES

School of Nursing & Midwifery Studies

c/o Trinity Centre for Health Sciences, St. James's Hospital, James's Street, Dublin 8.
Tel: + 353 1 6082692/6082777 Fax: + 353 1 4732984

January 25th 2001

Mr Daniel R. Lynch
Senior Executive Officer
The Adelaide & Meath Hospital
Incorporating the National Children's Hospital
Tallaght
Dublin 24

Dear Mr. Lynch

Re: An exploration of the process of breaking bad news from the perspective of the healthcare professional and the recipient.

Thank you for your letter of 12th January notifying me that the Joint Research Ethics Committee has given ethical approval for the above study. In response to the one condition attached to the approval, please accept the following description of how I will meet the condition of ensuring 'subject who experiences severe pain and discomfort from explaining a 'lived experience' will be referred.

An experience counsellor who specialises in grief and bereavement therapy has agreed to provide support and follow up to any participant who wishes to avail of her services. This support is being provided free of charge to the participants. Any travelling cost or overheads for providing the service will be paid out of the research fund attached to this project. Each participant will be told of this facility at their interview and will be provided with the counsellor's business card.

Should a participant become upset during the interview, the data collection will be terminated at that point. Initially, support will be provided by the researcher, who is an experienced psychiatric nurse and also a qualified counsellor. The participant will be encouraged to seek the further support of the bereavement counsellor should they so wish. A follow up call will be made to each participant following the interview.

I trust that this meets with the requirements of the Ethical Committee. If you would like further clarification on any issue pertaining to the study please feel free to contact me.

Yours sincerely,

Gerard Tobin

Email: gtobin@tcd.ie

APPENDIX XIV

**Approval letter from the School of Nursing & Midwifery Research Advisory
Committee**



THE UNIVERSITY OF DUBLIN TRINITY COLLEGE
FACULTY OF HEALTH SCIENCES

School of Nursing & Midwifery Studies

c/o Trinity Centre for Health Sciences, St. James's Hospital, James's Street, Dublin 8.
Tel: + 353 1 6082692/6082777 Fax: + 353 1 4732984

November 13th 2000

Mr Gerard A Tobin
Research Fellow Health Research Board
School of Nursing & Midwifery Studies
Trinity Centre for Health Sciences
St James's Hospital
James's Street
Dublin 8

Dear Mr. Tobin

Re: An exploration of the process of breaking bad news from the perspective of the healthcare professional and the recipient.

Thank you for submitting your research proposal to the Research Advisory Committee within the School of Nursing and Midwifery Studies. We would like to remind you that we are not an Ethics committee and do not provide ethical approval. Our role is to support and advise potential researchers on their research proposals prior to submission to an Ethical Committee.

Our committee met on Friday 10th November and following discussion would like to make the following recommendations:

1. Clarify the inclusion/exclusion criteria for health care profession staff.
2. Clarification is needed on the process of accessing participants through the Irish Cancer Society.
3. The study is put forward for formal ethical approval through the Faculty of Health Sciences, and/or other recognised Ethical Committee as relevant to the study.

Yours sincerely,

Dr Gabrielle McKee
Chairperson: Research Advisory Committee: School of Nursing & Midwifery Studies.

APPENDIX XIV

Letter of approval from Irish Cancer Society



Mr Gerard Tobin,
School of Nursing & Midwifery ,
c/o Trinity Health Centre for Health Sciences,
St James's Hospital,
James's Street,
Dublin 8 .

43/45 Northumberland Road,
Dublin 4, Ireland
Tel 01 231 0500 Fax 01 231 0555

15 Bridge Street, Cork, Ireland
Tel 021 450 9918 Fax 021 450 9759

Email info@irishcancer.ie
www.cancer.ie

National Cancer Helpline
Freefone 1800 200 700
(Weekdays, 9am-5pm)

April 2001

Re: An exploration of the process of breaking bad news from the perspective of the healthcare professional and the recipient.

Patron
Mary McAleese, President of Ireland

Dear Mr Tobin

The board of the Irish Cancer Society at its recent meeting agreed to give permission to allow access to members of the ICS support groups through the facilitators of groups in the four geographical areas identified in the above study subject to the following condition:

- 1) It is requested that the initial invitation to participate in the above study be distributed through the group facilitator. No contact details are to be provided by the facilitator directly to the researcher.
- 2) All potential participants must have received their diagnosis at least 5 years or more from the date of the data collection.

Best wishes.

Yours sincerely,

Olwyn Ryan
Patient Support Groups Manager

Registered in Dublin No. 20868
CHI 58E3  UICC
GLOBAL CANCER CONTROL

The national charity for cancer care

men's
Cancer
action

action
breast
cancer

cancer
research
institute

APPENDIX XV

Biographical Details of Recipient Group

Name	Age	Marital status	Diagnosis	Treatment
Amy	35	Married	Breast Cancer	Mastectomy Radiotherapy Chemotherapy
Catherine	36	Single	Breast cancer	Mastectomy Radiotherapy Chemotherapy
Jeanette	43	Married	Ovarian cancer	Hysterectomy Radiotherapy Chemotherapy
Rachel	45	Divorced	Ovarian cancer	Hysterectomy Chemotherapy
Rhoda	47	Married	Breast cancer	Mastectomy Radiotherapy Chemotherapy
Maise	49	Married	Breast Cancer	Mastectomy, Radiotherapy Chemotherapy
Bill	53	Married	Colorectal cancer	Bowel Resection Chemotherapy
Jack	53	Married	Lung cancer	Radiotherapy Chemotherapy
Eddie	58	Married	Lung cancer	Radiotherapy Chemotherapy
Daphne	60	Single	Colorectal cancer	Surgery – did not really know what surgical procedure she had performed.

APPENDIX XVI

Sample of Transcript of Recipient Interview: Maise's Story

Maise's Story

*G , Thank you for meeting with me and for agreeing to take part in the study. [short time spent going over the information sheet and answering any questions asked]
As you know, what I am interested in is learning about what was it like for you when you were given your diagnosis. Can you tell me about your experience at that time?*

M The first, second or third time I was given the bad news?

G Shall we start with the first?

M Actually we will need to start a bit earlier, is that OK?

G Sure, no problem. Just take it as you want to and we can go from there?

M You know the hardest thing for Anna, across the road was having to take her clothes off. She just didn't think she would have to do that. All her life the only other person that had really seen her breasts was her husband and now here she was showing them to all and sundry [short giggle, shaking her head – looking serious]. She just never thought she would have to stand there and let others see her breasts and touch them – she was mortified and horrified....

G Did you find it difficult?

M I actually didn't care about having to take my clothes off...

G Did you think about it...?

M No, for her it was very important. She was astonished. It never struck me as an issue, mmm

G Was that because you were more concerned about the lump?

M Well absolutely, Jesus, if that's the worse thing that's going to happen to you – to take your clothes of... [laughs out loud] you'd go home laughing... wouldn't ya. And am, when the one did the punch biopsy and she had to do it twice, and she was apologising for having to hurt me, and I said to her "if this is the worse thing that happens to me today, what is the problem." You know....

G *Right. Can we go back to that day? To what was going through your mind. Tell me what it was like....*

M *OK, on that day... well it was before that day really. I felt the lump by accident the night before I went into hospital for a hysterectomy.*

G *Ok... mmm...so you were going into hospital anyways..*

M *I was going into the XXXX for a hysterectomy, 'cause I had a pre cancerous polyp and they had advised me to have the womb out. I was sitting reading late at night, my hands were cold. I slipped my hands in under, I had a vest t-shirt on. I slipped it in under the bra to warm the hand ... and it landed on the lump. And I knew from the minute I felt it, I knew that this was cancer.*

G *... you just knew...*

M *I had a certainty. So anything that the hospital was going to do, anything diagnostic wise – I knew ... I just knew [said with emphases].*

I went to ... I didn't tell my husband. I woke up at daylight, at 4am. I stripped off, examined it in the mirror ... I just knew. Still said nothing to my husband, went into the hospital, showed it to the gyne when she did her rounds. And she said 'I think this is nothing, but to be sure to be sure I am going to send you to XXXX [a different hospital] to their breast clinic, when you are discharged from here.'

[Deep breath and pause, long drink from her black coffee, another deep breath]

She told me subsequently that she genuinely thought it was nothing. It wasn't ammm, she thought it was nothing.

G *... and you went ahead with your surgery that day?*

M *[short laugh] yea...I did. I was referred to XXXX. And I was surprised, 'cause I didn't know that XXXX had a breast clinic. So the memory of the hysterectomy and post hysterectomy... I remember very little of it. I was very focused on the lump and I was phoning people saying 'I have a lump.'*

G *And had you told your husband at this stage?*

M *I did. I told him when I was in the XXXX after I had the hysterectomy. And everybody, everybody I said, told it to said*

your exaggerating ... everybody [with emphasis]. It's nothing, or you're in a panic blaa blaa blaa, and I hated that, I hated it...

G *how did that make you feel?*

M *I was being minimised, the terror I had was being minimised it was being ignored. And every single person I said it to did this. Nobody said to me 'Jesus that must be terrifying...' nobody...*

G *and did you talk to the hospital staff about it, to the nurses or doctors after you had your operation?*

M *I can't remember... no ... they didn't talk to me and I didn't bring it up. I certainly remember being on the phone, I talked to my friends though...I remember phoning a colleague who's sister had had breast cancer, ...anyway... move the clock forward. I talked down the phone to the people in the breast clinic at XXXX. And I said I believe this is a very long day, ammm and asked is there anywhere I can rest between the bits of the procedures, and they said, 'No, would you like to put it off a week or so before you come in.' and I said, no I want you to do it...*

G *this was how long after your hysterectomy?*

M *well say I came out on a Friday from the XXXX, I went into XXXX the following Thursday ... in a wheelchair, into XXXX. I was a private patient for my hysterectomy, but for breast cancer it doesn't make a difference whether you are public or private. Breast cancer is a great leveller...[smiling and shaking her head]. And I do have opinions about people who go privately to see surgeons, I don't think they get good care...multidisciplinary care, and I think they are in error if they think they are getting better treatment.*

So I arrived in, and I knew it was a long day, and I knew my husband has poor tolerance of public queues, so I had a roster, and I had my nurse friend brought me, with pillows and she padded me and put me into the wheelchair, so I was wheel chaired around XXXX, then she had to go and I had another friend take over, and then I had amm, my husband.

G *so you had all the screening in one day...*

M *that's what XXXX does. Rapid access, triple assessment, same day diagnosis. Now there's some literature I've read that says that's not a good idea, that you don't have time to get your*

head around it. But I had my head around it...I knew...I already knew.

So I went and I say the nice surgeon, who's a lovely man. And then I was send off down for the mammo, and I was brought in and put back out on the corridor. [pause – 4 seconds]

And she sticks her head out and says 'Maise, can you pop back in for a minute.' And I said to Sally [her friend], 'I am fucked, this is it.' And she said, 'don't bury yourself just yet.' So I went back in did it again, back down ... and they had told me that they couldn't do any queue jumping for me because I was post hysterectomy.

G can I take you back to the point when you were called back in. To the lady who stuck her head out the door and called you in... what were you thinking when you went back in?

M I wasn't thinking I just knew ... I knew I had cancer. I didn't watch her and I didn't ask her, I just knew.

G Right...

M 'cause I knew she wasn't going to tell me, I just knew it. Subsequently at a mammo of the poor remaining breast, she called me back in, and I rooted her to the spot. I made her show it to me, I made her show me what was the problem ... ammm ... older and wiser. And she did, I can be a bully too [smiling].

So I went down to the punch biopsy queue.

G This was after the second mammogram? How were you feeling at this point?

M I was ill, I was absolutely ill. Then the breast care nurse came out, walked along with a chart thing in her hand, went into the punch biopsy people, and called me out to the top of the queue, having told me she couldn't queue-jump me. And she said to all the other women in the queue that 'I'm really sorry but Maise was post-operative and I'm sure you wont mind if I bring her in ahead of you.' And I said to Sally [friend] 'I told you,' I thought this is it, I'm finished. She had told me she couldn't queue-jump me and here I was queue jumping, so I knew.

And I went in, and they have... they have two people do a punch biopsy, and it was double read, and they said would you mind if we did it again, and that they were really sorry that it was sore, and that's when I said if this is the worse that can happen to me...she was fiddling around with the slide and not looking at me when I was leaving the room. And I said to her 'how much would it be worth for you to give me a negative diagnosis here' [smiling]

and shaking her head], and she laughed, so I went back out. At that stage my husband was there, and we were called back into Mr Z [consultant] the surgeon.

G *was this all in the same location?*

M *the same building but miles of corridors, what seemed like miles and miles of corridors and silent walking ... I think its now consolidated into the one area.*

G *with all this silent walking down countless corridors, what were you feeling?*

M *Just terror, blind white terror, sick with terror. I remember when Jinni came and I was conscious that this was her lunch break, my other friend, and we went for her to get a sandwich, and she bought me a sandwich, and at that stage I smoked like a chimney, and we went outside to have a cigarette and Jinni was encouraging me to have the sandwich, and I said I would throw it all back up all over you if I had to eat that. I couldn't possible eat, which is not like me, normally I would eat anything, my appetite never changes.*

So my husband was there at that stage, and we were brought back down to Mr Z. I was wheeled in, wheeled in and Mr Z said to me 'I'm really sorry to tell you that I have some very bad news for you.' My husband says he did not use the word 'very' [laughing slightly], I heard it that he said 'very bad news'. And it felt that Jack [husband] was sitting a mile away from me, and because I was in the wheelchair I couldn't move, it felt like a hundred miles away. So I said to him move over here beside me, and when I'm frightened I get stroppy.

So I said to Mr Z, I know the statistics, I know the mortality for cancer in this country, and given that I am an Irish woman that really is very bad news, it would be much better news if I was an American woman, I know the statistics. And he said 'you are in the best possible hospital for this. Your Oncologist is just back from America, Johns Hopkins, he will give you precisely that same treatment as your cousin in America might get, and you will get the same treatment. I promise you that.' And he was adamant about that. But all I wanted to do was fight with somebody.

So then he told me that all the signs were good. My age was ... I was young enough to be ... to get aggressive treatment. I was old enough for it not to be rampantly aggressive, the way it can be in younger women. It was in a really good spot, I didn't need a mastectomy.

G *and you could remember all that...?*

M it is engraved on my memory, every word is carved in my brain ... carved in my brain. And he was very carefully, slowly spelling this out for me. He was wanting me to hear this message. And I felt that he was hurting for me. Oh down on the punch biopsy queue I also remember looking along the queue, counting that there were ten or twelve and thinking there will probably be two of us. I am one I wonder which is the other? That's just another thought that was racing through my head that day ... what other poor woman is facing what I am facing. So the breast care nurse was with Mr Z while he was telling me that this was really very good news, that I was in the best hospital, had a great oncologist, was the right age, ... then they were saying I'd be admitted as soon as possible and ... then the breast care nurse comes in to do her little tap dance.

G Sorry Maise, did you say the breast care nurse was there during all of Mr Z's conversation with you...

M Yea, she was there all the time, all the time...

G And what role did she play in this ...

M She comes in after the diagnosis. She talks to you about being admitted.

G Was the doctor still there at this time?

M Yea, oh absolutely, absolutely, ... and she produces this little booklet to take away, and she says this will answer all your questions.

And I said 'I'm not taking that book. I have one question, and one question only about this cancer, and I doubt that the answer to it is going to be in your little book.

And Jack said it was like a frozen tableau, and that they were playing out a set piece and they had come to the point where she hands out the brochure and the grateful patient takes it. Except that this [pointing to her chest] wasn't taking it. So he was sitting there thinking, where does this go next. But she was very good and she didn't miss a beat and she 'I'll tell you what, I'll give it to your husband so that if he takes it home and maybe later if you want to have a look at it, he'll have it for you. And he took it and I felt he was a traitor [laughing]. But he said he had to take it because we were a frozen tableau and the set piece had to keep moving on, you know. This brochure had to be handed over, before we could move on to the next scene. And the next thing was I was being brought down to admissions...

G *Maise, did the nurse ask you what your question was?*

M *She bloody knew what the question was, but she didn't go there ... 'Is this going to kill me!' She knew, they both bloody knew.*

They used the word cancer, it was unequivocal. Now my neighbour across the road, she had a lump. But my other neighbour, who is very passive was shocked at the number of times he kept using the word cancer. Her doctor was different to mine but there was no way she was getting out of his office without realising that she had cancer.

Now, self delusion must be wonderful. I knew that I knew and there was no point in fooling myself – I had a lump and I had cancer. My friend across the road convinced herself that she had a lump. I say that lump, it was 5cms by 5cms, her whole breast was contorted, but she was able to tell herself that this was nothing; she still refused to think it was anything other than a lump. And even after the diagnosis the full reality of it didn't hit her. And I have thought a lot about her response and my response, and her expectation going in and my expectation going in, and I really think that in some respects she was luckier, she has a self protection going on that I didn't. For me it was full on cancer – plan the funeral. But hers is more comforting, it will dawn on her in time. She has had her mastectomy but still refuses to think cancer.

So I was given a date for admission for the following week. I was going in as a private patient and although I expect them to get cancer patients in quickly, I wondered if being private had an effect on the admission.

And I went in and I had my lumpectomy, and my nodes removed, and actually quite quickly started to get my head around it. Oh yes, another thing I said to Mr Z when he was telling me about the admission and the surgery was that, and I remember looking directly at him [at this stage Maise, unconsciously had put her hand up to her breast]. He had done an operation on my husband, he had, and he had left him with a very ugly scar. And I really didn't want an ugly scar on my lovely breast. So I said to him Mr Z it's very important that you remember here that pretty matters. So he said, amm, I will do whatever is surgically necessary. And I said, no I'm really sorry Mr Z, we have to agree in advance that pretty matters. And he and I had a bit of a ding-dong, with me saying pretty matters and he saying clinically and surgically necessary is a priority. And then the breast care nurse came in and said Mr Z will be very careful and he is a very skilled surgeon and you'll have the smallest possible scar and

blaa blaa blaaa. As it turned out, it was all grand and pretty and all the rest of it.

I did get my head around it very quickly, after the surgery. I did a lot of crying in the hospital, a lot of crying. I cried all over anybody who came near me. I have no problem crying over the fact that I had cancer, or who sees me, or I didn't then.

I don't believe in bravery. It was important for me to be physically brave, and if I was feeling this, it was legitimate, let it all hang out, be emotional you have every right.

So I was slow to heal, so I was doing topless bathing out in the back garden and I remember sitting there thinking to myself, this is going to be a brief flirtation with cancer. This is going to be fine ... and I can't remember if this was before or after they rang and said the lab results are back. Terrific lab results, 1.5cms, oestrogen dependant, clear nodes – lovely [smiling] ... grand.

G and they gave you all this over the phone?

M They actually gave it to my husband, I was really cross, I was in bed asleep when they told him my [emphasised] results. And I did feel cross, but they were so delighted that they wanted to get the news to me quickly. Then they said I had to go back and see Mr Z, and then they would have an appointment made for the two oncologists, the radiation and the medical oncologists. And I went and say Mr Z and he looked at the scar and he read out this big computer print out and repeated the lab results and said grand, your laughing kid. So it was at some stage around that that I was sitting in the back garden thinking 'a brief flirtation with cancer.' And I was escaping with my breast intact, scar.. 'cause pretty does matter.

And then I was here one Friday afternoon and they phoned and said Mr Z wanted to see me and I said Mr Z discharged me. 'No. He wants to see you on Monday. This Monday at 10.15 in the out-patients clinic.' So I said hold on there a moment, I am discharged from Mr Z and have an appointment on Tuesday morning with Mr H (oncologist), I cant understand why he'd want to see me again. And she said, he wants to see you, sometimes he just double checks on patients to make sure they are OK. And I said he was perfectly happy with me, there is something wrong, isn't there? And she said, he just told me he wants to see you on Monday. So I started to storm up the phone lines ringing the breast care nurse, the GP, the pope and of course Friday afternoon – nobody is home. And what I actually thought was, you know the way they sometimes double read X-Rays, I was now convinced that they had found a tumour in my lungs from all my smoking ... OK I now got that fixated in my head.

G *And this was Friday afternoon... can you tell me what you were feeling at this time....*

M *Terror, one more time terrified again. I was right back, right back, except I thought it was moving in to another new area. And here I was, the alarm bells going off one more time, your in serious trouble Maise.[shaking her head and staring our the patio door in to her long garden, lost in her thoughts...28 seconds silence]. There was something up and I was absolutely panic struck, really panic struck, I knew I was in trouble.*

G *Did you tell Jack at this stage?*

M *No. No I didn't. He had to go to Cork on business on the Monday, and I thought ohhh what will I do. 'cause I mean we'd both been through the mill. We'd had the hysterectomy, we had the lumpectomy, the nodes, ammm I still felt physically wobbly and my emotional state was exactly stable although I do think to some extent that I had gotten my head around it.*

G *and this is what, 5 -6 weeks after your hysterectomy?*

M *Not at all. Not at all, maybe three, if even that ... I suppose it has made me cynical of other peoples recovery, what only a hysterectomy and you didn't find a lump in your breast the night before... I have to watch myself you know. The stone in your shoe is the stone in your shoe.*

So I said nothing to Jack and I rang my friend Sally and I said Sally were in trouble again. I don't remember anything of the weekend – it is a total blank. But I do remember the phone call – etched on my brain, I was sitting out on the patio, sun shining, roasting hot day in August and the phone goes.

And so we got into XXXX and I was so jealous of Sally, she reeked of cigarettes and I didn't want to smell of them so I didn't have one that morning. So in we go, a really really mad busy surgical out-patients department and we arrive up at the desk with a hundred others. And a nurse had come out to the desk and was asking out loud is Maise XXXXX here? And I knew it, and I looked at Sally and I said wouldn't you love for once to be one of the masses where you didn't give a fuck whether they knew you or not, I just knew it. So I said I'm here and sally said I'll wait for you. So in I go and its Mr Z and another breast care nurse. And I wouldn't sit down ... and I stood with my back to the door, clutching the handle. And I was really convinced he was going to say lung cancer. And I knew I was toast if it was lung cancer [giggle]. So I said, I said, OK so you have bad news for me, what is it? I just stood there holding onto the door, I didn't actually go

into the room, I just stood at the closed door. And he said, 'Now Maise, come in and sit down and we are going to go through this very carefully. I think I argued the toss about sitting down, but he persuaded me. And they both came from around the desk and they each took a hand and they told me that the person who normally does the breast work had been on holidays when my stuff went to the lab and that all the breast work done in her absence was audited by her when she came back. And guess what [giggle] she found ... out on the edge of the margins she found another tumour, a microscopic one but a tumour none the mess. And ... he had also taken random cells from around my breast and ammmm[silence 3 seconds] there was cancer in some of those random cells also, but my nodes were still clear. And I said to him, draw me a picture of this, and he drew me a picture of it. And I said how can such a mistake happen? And he said we're appalled, we're upset, we're embarrassed. And I remember feeling so angry and saying well I hope the guy who did it in the first place is embarrassed – is he? And he said yes and we have changed our procedures as a result, this won't happen again.

So I had this notion, and I don't know why, that somebody outside this room had to hear all this, so I said to him I want you to ring my GP. I really wanted my GP to hear all of this, I suppose I thought this is medical stuff, this is a fuck-up. And I really need Dave (GP) to talk to them and to talk to me. That was just important to me. And I gave him Dave's phone number and I said do you promise me you will ring my GP and he said to me, the minute you walk out that door I will phone him. And Mr Z had been an honourable man up to this point, a very honourable man. And I felt they were very open in the way that they dealt with the cock up. Some of the nurses on the ward subsequently said I should have sued them. But oh my God it was a fools paradise for a couple of weeks, its not like they had cut off the wrong breast , but it was much worse than before ... much worse because now I needed a mastectomy. Now we are in a whole different ball game.

G Maise, did he mention mastectomy at that point...

M Yes he did. Yes he did. I would have to come back into hospital one more time and this time have a mastectomy. And I said, Mr Z just how much is a body meant to take? I've already had two wallops to me physically and I have to come in again! Immediately! for more ... and he said that although emotionally a huge thing, but physically, physically having had the nodes removed already, that having the mastectomy was nothing. Now he wasn't trying to minimise it he was just trying to reassure me.

So this was the end of the world as far as I was concerned. It really, really, really was. And I had to go back down to admissions with this new breast care nurse, saw Sally sitting outside and I just shook my head at her and said 'I'm fucked.' So she came down to admissions with me, and I noticed the breast care room is opposite, I think they have ... post-mortem liaison or [giggling] bereavement counselling or something ... and I thought Oh my God. So they booked me in, one more time [with emphasis].

And ammmm I came home here with Sally and phone calls were made and the girls [friends] start to arrive, and we have a bit of a wake. And then Jack rang to say he was on his way from the train station, so they all scampered away. I think Luke [son] was around down here so I took Jack upstairs when he came home, and I told him.

G How old were your children at this time?

M Elizabeth was living in London and Luke was in college, he was about 22 at the time. They knew about the hysterectomy and the all clear from the lumpectomy.

So here we go one more time. I was distraught and I was devastated, all around me were devastated. My GP when he came to see me was tearful, do you know [slight nervous giggle].

G And had they phoned him?

M Oh yea yea, they had immediately. And Dave said normally he would have to chase a consultant and here was a consultant chasing him and he didn't know what was up. And then when he was told he said to me that he had never heard a consultant been so frank, so inflamed, so mortified.

You know, when I went in for my mastectomy, I went down, I knew where the doctor who audited my results would be, and I shook hands with her and thanked her and said it is really reassuring to know that the health service has people like you [slightly tearful as she said this. Offered to stop but she wanted to continue]. But it actually proves the point of consolidation of serviced, the guy who got mine wrong was senior to her, he was a professor I think, but he doesn't do breast cancer all the time and he got it wrong. You have to be doing it all the time, they proved that point with me ... and I am here to tell the tail. So I did go and see her and thanked her.

G Did you have long to wait to get back into hospital this time?

M No I was in within a few days – it all went by so quickly.

G The first time you were scarred and terrified. You said you were fucked, finished. What were you feeling this time?

M This time it didn't actually change my mind as to the prognoses. This time, although there is more to follow ... this time it was all about the loss of my breast, ... this time! I wasn't more scarred, I remained as scarred as I had being – how scarred can you be – I was right up there ... I was just broken hearted, broken hearted to lose my breast. Absolutely broken hearted.

G and in that sense of a broken heart and fear, what did it all mean. Was it the fact that you had cancer or that you were losing your breast that you were conscious of?

M Mmmm ... Mmmmmm

G The first time you said you were thinking statistics, America, Irish women and mortality rates ... [cut off]

M Yes, yes, because the truth was my breast, and that's what I think is the ... is the bitch! of breast cancer [with strong emphasis]. I remember saying to my GP when he came to see me ' you know my great great grand daughters are going to roll around the floor laughing saying they did what to you! They cut off your breast [exaggerated high pitch voice – giggle but serious] it's a medieval treatment and they were still doing it in the early part of the century! Its appalling. And slice slice you tit off ... God its appalling when you think about it ... the 21st century, cutting off women's breast, I cannot believe it's so unsophisticated. It's appalling, and he actually thought my great great granddaughter's generation would still be having mastectomies, at the rate that cancer treatments are going on. I was confident I was still in a top teaching hospital, with an oncologist who was just back from America, but I was still going to lose my breast. And as time went by I thought the real bitch was that they do this very unsophisticated, horrible, savage treatment and still don't give you any guarantees. You know you might agree to your leg been cut off if they could guarantee that you are sorted. But they do all this [pointing to her breast] and you still don't know if you are sorted. OK lets move the clock forward, because there is yet another piece of bad news to come ... we have another piece of bad news to break to me. There I am sitting up in XXXX [hospital] mourning my breast, crying all over the place, post surgery ... I mean going down for there surgery was awful ... mmmm [silence]

G *Maise, when you were in hospital. How did people communicate with you?*

M *the nurses were fabulous. They were really fabulous ...*

G *fabulous in what way?*

M *I spent a lot of my nights out on the stairwell smoking and crying ... a lot of nights ...and the night nurse on that ward, who could only have been an infant, she was in her mid twenties ... was superb she was superb ... and looking back on it what I was getting was brief interventions, brief interventions. There is no doubt about it, I was ... and they were so skilled at it I didn't even know it.*

I had one nurse who was in with me one day doing a dressing or something, and she was trying to be my psychologist ... and she was clack handed at it and she was horrible and I ran her out of the room Everybody on that ward was fabulous, they were just great.

G *What did they do that made them so good?*

M *The young night nurse said to me 'I notice Maise that every time you get upset its when your mind races into the future and you are trying to sort thing out ...and its all future scares. So she said 'come back, come back ... come back and be here with us in this five minutes. She was a kid!, she was an infant!, she was just so skilled! [with emphasis]. And I could see that that was a kind of lifeline to stop me loosing my reason.*

She was the first person to actually bring me back into the present, you know I was fucked, I was dead and buried I was finished, I was never going to see my grandchildren. And then after the lumpectomy I wouldn't look at the scar, 'cause we remember that pretty matters and I couldn't look at it. And the young nurse who had hosed me down that morning and was changing the dressing said to me 'do you want to have a look at it?' and I said 'absolutely not, I have no intention of looking at it.' 'Mmmmm' she says, 'will I describe it to you?' and I thought you clever thing you. So she described it and that kind of took some of the big unknown out of it, by her saying to me it's that many inches by that many inches, its this red and its, its over on that side and that took a whole load of panic out of it. I still didn't look at it that day, but it really helped me to come back to the here and now, instead of running ahead into the future. So they were two very specific interventions from nurses which really helped me.

G so you were saying that post operatively you were sitting up in bed crying and going through all sorts of emotions. What role did others play in helping you come to terms with your situation ...

M I had a really good relationship with the surgical team. He [the consultant] had three women with him, a reg. and the other two, and they were great 'craic'. If they were passing by my room on their way up or down the hospital, sometimes during the night, they would come in and we would have a chat.

G Do you think the fact that they were women made a difference?

M Oh absolutely, absolutely, and I wouldn't have been conscious of that at the time. But we had a kind of a rapport and yea... one of them was about to get married and she was enormously flat chested. She was telling me about going around town trying to get this bra which would give her a profile. And she said that Mr Z had given me a fold of skin on top because he knew I wanted reconstruction of my breasts, she laughed and said that I had bigger cleavage post mastectomy than she I do [giggling loudly, with her hand to her breast].

G so you could laugh at it at the time? But you were still going through tearful nights at this time also....

M Oh God I was distraught, distraught. Nothing was ever going to fix this and I just felt, please put me back the way you found me lads.

One of the doctors, one of the three lovely lassies, as I used to call them, as I was wheeled in for the mastectomy, I thought, I really thought I was putting on a brave face, I thought I was magnificent ... and she ...when I woke up in the recovery room, she was holding my hand. And she told me subsequently that I looked so [emphasised] terrified when I went in that she felt duty bound to be there with me when I woke up. So I mean I got wall to wall great care I really cannot fault them, they were all excellent, apart from the fuck up in the lab, and all the rest of it ... my neighbour who works in finance says 'it's such a slick operation, well oiled customer care, it is just so well done.' Ammm ... then they told me the final bit of bad news.

G Had you been discharged at this point?

M No I was still in ... the oncologist ... I had a very long admission this time, because I thought from the hysterectomy, I'd be better this time. ... We had builders booked to come in here [home] to have the bathroom taken out and major work done,

and I said this to Mr. Z and because they were mortally embarrassed, they said I could stay as long as I liked, so I became a kind of fixture in the ward. Ammm I ended up actually having to go to a hotel for a week when I left there because the work was still going on. So I think I was about three weeks in, but I kept going out, I went out for lunch, I went out for dinner ...I think I was a bit manic, I think I had this feeling that they can't hit a moving target – keep moving, keep moving.

And all around me, everyone kept minimising it, minimising it. All my friends, colleagues, neighbours kept telling me well you'll be fine because your so positive. As if that had anything to do with it [with emphasis & raised voice]. Two friends, locked into the way I was really feeling, a very small number of friends, a very small number...

G And what were you feeling at this time?

M [7 second silence] ... frightened and scared, on the run and afraid to stop. I look back, when I would have been talking to people similarly and I think 'Jesus Christ, did I talk to people like this too?', you know. But I think they feel an urgency, you feel an urgency to shut this down ... to shut down all this emotion [with emphasis] because its scary, so close it down and, ammm back off from it.

And I , I just needed somebody just to hear me, just to hear me [with emphasis], you know, just to hear what this was like, just to hear it and just to say 'this is shit.' That's all. The only response I needed, someone to be honest and somebody just to hear me, just to hear what this was like, just to hear it, and I actually got it from very few people. That's not to say that I didn't get barrows of flowers, stacks of cards, but I can't remember who it was said to me, at one stage, that's very different from support. But like I say I was inundated with cards and flowers, it was incredible, and people are really good and I got offers of help and all the rest of it, but not that many people who could hear you talk about it ... not that many.

The third lot of bad news! [with emphasis and moving the story on].

The oncologist came round to see me while I was still in the hospital and he gave me the further details of the second lab results. Because the tumour that she found on the margin, the little tumour, wasn't an oestrogen dependent tumour, it was a tumour called HER2¹ which is a bitch. And he stood there and he shot straight from the hip.

¹ HER2 (human epidermal growth factor receptor 2) is a protein found on the surface of cells that, when functioning normally, has been found to be a key component in regulating cell growth. However, when the HER2 protein is altered, extra HER2 protein

G *where were you at the time he came to see you?*

M *I was in bed, he was on my left, he came in and I remember he blocked my window (funny the things that go through your head), ahh ... this guy is a scientist, he has not graduated with bedside manners ... and I was in a private room. You know when I was first admitted they put me in a semi private ward with three other women. And the first night the team came around and started to talk in front of the other patients [tilting her head forward and raising her eyebrows, leaning forward on the chair, smiling] and I said, 'ladies and gentlemen we are going to go somewhere else,'*

G *You said that to the team ...? [joining in with her slight giggle]*

M *Of course I did, of course I did. There was no way no way I was going to give all my history with a curtain, which is a pretend sound-proof room. No I took them out and we actually went out onto the stairwell, and that's where I gave them my history. I wasn't going to do it in a public ward. I'm very stroppy and I'm doubly stroppy when I am frightened ... and I was very frightened. I also felt thought that I had to send out very strong signals to these people that I was a 'compus-mentus' adult, I brought in photos of Jack and the children and put them on the locker beside me. I wanted these people to know, very clearly I have a family at home that needs me, you must save me, you must [with emphasis]. I got up and washed and dressed and put on my make-up every morning, so it was unusual that your man [oncologist] found me, I'd say I was dressed but lying on the bed. But I really needed to send out the right signals, I know all the sociology studies ... tramps get a very different treatment in A&E to women who are brought in in fur coats, and I knew all this stuff and I was going to send them our powerful signals, this is a serious woman you are dealing with here, take her seriously, treat her very carefully.*

G *... so the scientist came in, the oncologist ...*

receptors may be produced. This over-expression of HER2 causes increased cell growth and reproduction, often resulting in more aggressive breast cancer cells. HER2 protein over-expression affects approximately 20% to 30% of breast cancer patients. Women with HER2 over-expression may not be as responsive to standard breast cancer treatments, including certain regimens of [chemotherapy](#).

*M ... the scientist came in and shot straight from the hip and I had ... actually he slagged me first, he asked me to give him a walk around all the bouquets in the room, and like I say it was wall to wall flowers, and I said, well that's the chief executive of XXXX, and that's the managing director or XXXX, and that the chief executive of XXXX. And he said to me 'I'm glad to see the tax payers money is been spent wisely.' And I said these people would have paid for these personally, I am personal friends with these people.
Anyway he tells me about this fucking HER2 ...*

G Did he explain what that meant to you ...

M ... yes he did ...

G ... and you understood what ...

M ... yes, oh I had no trouble understanding it. He was very clear, he was crystal clear. It was the worse prognosis, much greater chance of reoccurrence, and when it came back it was [click of her finger] it was very aggressive, da-da-da da-da-da, it was horrible. And there was no hand holding this time, like there was from the surgeon, no breast care nurse there with the tissues ...

G ... was there anybody else there ...?

M No, no. Just him and me.

G ...so nobody else heard what was said?

M No, nobody only me ... [4 seconds silence, looking down at the floor].

Ammm, mmmm and it took me a long time to get myself up off the floor after it. That was the final insult [with emphasis].

You have violated my body. You have done all this awful stuff to me and NOW YOU ARE TELLING ME I have this! [said great emphasis, standing out of her chair, voice very angry. She thumps the table with her hand on the last word] Fucking HER2 – I though oestrogen dependent take Tamoxifen, yea yea yea, but HER2! Percentages and all the rest of it ... I was devastated ... and I didn't tell many people ... this last bit of the diagnosis. I didn't tell the kids. I remember talking to Sally about this, and Sally said, 'it's not that you are never going to tell them, it's you may not feel able to tell them now.' And I still haven't told them. Ammm and not many people know it. And since I have attended a conference in the States on Cancer, but went 'mitching' the day they were talking about breast cancer – who needs it [smiling].

And low and behold, the next day someone starts talking about statistics and HER2. I couldn't believe it, I nearly went through the floor, because you'd never hear about HER2.

G *Were you back at work at this stage?*

M *Yea, it was in 2003. Your man was talking about a meta-analysis that has been done and that the HER2 studies, the ... he ... [quietly] the he said that the prognosis given to women with HER2 tumours was in fact far too pessimistic [raising her voice on the last word and starting to laugh]. That was a good few years, and good few years and I had lived with mine, what he [oncologist] had told me, and still not quiet the par.*

G *Maise, can I bring you back to the room and the oncologist having just given you that information about the tumour and the prognosis. What can you remember of how you were feeling?*

M *No ...[mumbles to herself] ... no can't remember much, shocked ... on the floor ...terrified. No one knew, only me, he told me and now no one else knew this bit. I had to tell Jack ... I was getting used to having to tell him all the bad stuff. And I remember saying to one of my friends, I can't do this one, I just can't do it ... I've used all my energy, it's gone ... I'm just now finished, I'm wiped out. I'd used loads of adrenaline to get through everything that had happened, and I thought, the reservoir is empty ... there's nothing left. And she said to me [Sally] 'You're not going to have to do this one on your own. We're all with you ... And another thing that was helpful, that was said to me was that ...my, a close friend of mine who is a doctor and who once worked with my GP ...he came into see me and I can still see where he was sitting and I poured all this out, about HER2 and everything terrified I was ... and he said to me ' I've only got one thing to say to you, in all of this Maise, we don't know everything.' Now, if a neighbour or my sister had said to me they don't know everything that would have meant nothing to me, I would have rubbished that, but for as illustrious as him to say that meant a lot to me. God knows I really didn't have a lot to hang on to at that stage, but I held onto that.*

G *what was it about that, that meant so much to you*
...

M *... loosing me breast, loosing my breast.*

G ... I mean what was it about what he said that meant so much to you ...?

M it was about hope. I suppose it was about a bit of hope. Although he didn't, it wasn't expressed as 'be hopeful' ... I suppose he was saying, you know, this isn't final, this is not the final word.

G Maise, that's the first time you have used the word hope this afternoon.

M Oh I'm a bit of a pessimist, I really am.

G Did you feel, when the third news was given that that was the hope taken ...

M Yes, mmmm, that's exactly what I felt. This was it, there was no hoping. Yea ... I suppose he was the first to offer me some hope again, yea, yea ... [8 seconds silence, looking over to a chair on the patio]

I suppose I had gone from sitting out on the patio thinking this is going to turn out to be a brief flirtation with cancer; I had been on a bit of a rollercoaster, most of it going downwards, ... Ammmm, would I have been any different if it was all told to me on the same day, I'm not sure.

But did he, did he give me ... I suppose he did ...although on the day I didn't feel hopeful when he said it, I suppose I just felt less panicked, you know, because I did feel very panicked, very panicked and terrified.

G Where was Jack in all of this ...?

M Poor Jack [giggling]. I felt so bad for Jack, I really did. Because here was Maise been showered with bowers of flowers, anything Maise wants, Maise gets, and ... this was as big a loss for him as it was for me. I felt that very acutely, and also, anytime anything goes wrong in this house, all that emotional type work that women do, it's very much me, I'm the sorter, you know. And here he was with the sorter falling apart at the seams. So who sorts him?

I had always thought that he would do badly with illness and that was a huge disservice to him, you know what I mean. Funny enough when I was in XXXX after the hysterectomy, he was having problems with a project at work. He had lost data, and he was coming in to visit me and going on about his lost data. And here I was flat on my back after the hysterectomy with my breast lump, thinking I was so right about this man. He can't cope, he can't cope ... who care about the fucking data – I lost my womb

and might lose my breast – so what about data. But that very quickly changed when it all, when it all became real and apparent. You know – when he realised what was really going on here. No one helped him in the hospital, he had to do that for himself.

One of his friends knew a guy whose wife had had cancer and he and Jack had coffee together one day. And I never heard what transpired during that conversation and I never asked. But I do believe that was really helpful, really helpful. Because I would come back again to the thing that I was the person who would always fix it and I still can't be the person who fixes it. Because he can't tell me how awful this all was for him without laying a trip on me, you know... so he carries his bit and I carry mine.

And he was talking about two of his cousins whose wives are both very ill and how tough the husbands were finding it all, and ammm he was talking about how difficult it was, and I said mmm, 'Jesus, Jack you served your own time when I was ill' – this was only then night before last. And he said 'tell me about it.' And that's as far as we ever got to talking about it. Because I am not strong enough about this to hear Jack's pain. I can't do it, I cannot do it, and I was very conscious of that with the kids hurting about it and with Jack hurting about it. They are going to have to sore each other, or sort themselves, or ... I just cant do it for them this time, I can't fix this one for them.

G Do you think it might have been different if Jack had been there for the third episode of bad news?

M No. No ...ammm, because I am convinced that having cancer is very singular. It's your diagnosis and it is a very solitary experience. Nobody can help you through this one, nobody knows what it is like to walk the cancer path.

G So what about the actual experience of hearing the diagnosis? Earlier you mentioned how Jack seemed to be sitting far away from you on that first experience of being given the cancer diagnosis ...

M Yea...[smiling] I'm sure he wasn't that far away. It just felt like he was ... it felt like I was on my own. I really needed someone to hold my hand, I badly needed it. And I just had a flashback to the night I when my son was born and everything went pare-shaped at the last minute, and he had to be a forceps. And the next day the consultant told me that he never allowed husbands to be there during a forceps, but he said to me [laughing] you had such a grip on that mans hands that I knew there was no way I could get his outside the door, there was no

way I could separate you. And he was bloody right...[laughing again].

G So Maise, terms of the whole experience, what sense can you make of it ...?

M I can't make any sense of it ... I really can't, and I've been to all the talks, read all the books and all the rest of it, and ... patients are supposed to go on this journey of benefit seeking and benefit finding, and I have talked to these women who say it was a wake up call and that they now take the time to smell the roses and ... [short giggle] I cannot find benefit in this. I ...[silence 4 seconds] I wasn't smug about my life before, I felt that I was a very fortunate person, I have worked hard at establishing a happy family, I felt enormously guilty. I felt that I had I had set off a hand grenade [with emphasis] in the middle of this happy family, yes I did, I did. And look for the benefits in that? I cannot, I cannot see how there could be any and I think the treatment is a violation of your body, chemo sucks ... I knew that I was a strong willed resolute person and that I had a lot of inner resources I don't think I needed cancer to tell me that. I knew that I was blessed with my friends, I was very conscious of that. I didn't need ... I didn't need cancer to tell me that. I remember when I had the chemo. A friend of mine was having it at the same time and we would go for lunch afterwards. And she said cancer was the best thing that ever happened to her, and I said tell me why. She said it is after giving me weeks off work, I used to have showers every morning that lasted 2 minutes if I was lucky, now I have showers that can go on as long as I like. And we had both lost our eyelashes and I was telling her how I was using an eye pencil to fake it and she laughed and said she was able to experiment with eye make-up, she said I think it's the best thing that's ever happened. And I remembered I talked to Sally about it and I said 'Am I missing something here? ...am I missing something?' and Sally said 'Maise, she's a sad bag if she needs cancer to a long shower in the morning, use eye make up and have a few weeks off work.' But I have been to lectures with big shot psychologists brought over from England and the States and they talk about the patient journey and how until you find the benefit in all of this your journey isn't resolved, and all the rest of it and if your unresolved then you are a basket case. Well then I am a basket case [with emphasis and laughing heartedly]. I cannot see any benefit in this.

G Do you think you are still on a journey ...?

M I think the whole thing is an obscenity.

G *The concept of the journey ...?*

M *I think cancer is an obscenity. The treatment is barbaric and medieval and I cannot see myself ever reaching a day where I can say I am glad that happened to me, that I thought me important lessons about life. I cannot ever see that happening to me, I just can't. In the whole thing I think that I was fortunate to have met really professional people, caring people. And I think that's what I expected, amm I had high expectations of them, and they didn't let me down. And I kind of set it up by been washed, dressed, made up, photographs and all the rest of it ...you see I had a feeling at the beginning ... I kind of knew and I made a decision very early on that I could crawl under the duvet and howl, and I felt that if I did that I would never come out from under the duvet, or I could put on the lipstick and go. That didn't stop me crying, I cried oceans, I cried and cried and cried and can still cry. I can still cry about it. I sent a Christmas card to the breast care nurses saying 'have you both developed rust in your shoulders from all the crying I did on you?' I cried in front of my clinically scientific oncologist and I banged the table one day when I was having a tirade and I said '... and I want my tit back!' [said very loudly, with action, emphasis and laughter]. He sent his nurse down afterwards to tell me that he wanted me to see a psychiatrist. And I said 'Because I cried! That's because I cried... surely it is legitimate to cry. I felt like crying so I cried.' And she said, 'well he thinks your very upset ...' Too right I felt upset and I was entitled to be upset. And I was still 'bawling' and I said to her, 'Tell me this, am I the only patient who has ever cried in front of Dr XXXX?' and she said 'Yes.' And I thought Jesus Christ there's self control. She said she suspected a lot of them are holding themselves together until they get out to the car and then let go and bawl their eyes out. And I said, 'If I feel like crying in from of him I will cry in front of him and wont apologise for it and I wont go and see a psychiatrist.'*

G *Are you a fighter?*

M *Oh God I really am, I really am. I fought all the way through this cancer, I really did, I really did. I had murder with the breast care nurses about the bras. They produced these surgical bras and I said they were like something your granny would wear. And they said these are the best bras and I asked why were the straps so wide! And they said for extra support, but I said you don't need extra support – you've got less breast! And your meant to have a soft prosthesis before you get the real one. But to shut me up they gave me the real prosthesis straight away. And they said they had just had a woman up from the west of*

Ireland and she was given her bra and prosthesis and she went out of here feeling like a million dollars. And I said I may sound ungrateful but these are ugly bras and I wouldn't wear such an ugly thing breast or no breast [laughing].

G Can I bring you right back to the stair well in the hospital, to the nights when that nurse challenged you to stay in the present and not be running off in fear in the future. What was it that made her stand out in your memory as significant?

M She saw me. She saw me totally, not a lump or a breast – she totally saw me and engaged with me as a person in my own right.

But I knew how it could be, I did medical sociology and knew how it could be will illness. But I wasn't going to let that happen to me – I was not willing to become invisible I was me and that's who they had to deal with. I knew the signals I had to send out. I'd like to think that they'd have been the same with me if I had been a more passive patient and hid under the duvet, but I knew how it could be and I made sure it wasn't. I didn't talk to the other patients, I wanted to be on my own. Even when I went for chemo, I walked onto the ward saw them all hooked up and chatting and I thought this is one club I do not want to be a member of. And I asked the nurse if I could have it on my own and she said that's no problem and so I had it on my own. Eventually I did find my old friend there and then would sit in the day room and look like a groupie.

The GP and Jack insisted eventually that I go and see a psychologist, because I was crying so much. And I think I terrified her.

G Sounds like you think everybody wanted you to stop crying?

M Oh for sure. For sure. You just don't cry, you don't cry. But sure I think there'd be something wrong with you if you didn't cry after all that. And I thought I wanted to cry, so I cried. But Dr XXXX tried to send me to the psychiatrist, and the GP and Jack sent me to the psychologist.

Now I have to admit that I had this notion that I should live alone while I was doing chemo, and I go back again to the hand grenade going off in the family. And I really felt that I should move into a flat or something, and be on my own and do it on my own. I suppose I felt a bit like a wounded animal, with wounds to cover ... amm everybody except for Luke [Maise's son] looked at me with terrified eyes, sad eyes, terrified eyes. Luke wasn't a bit frightened, he was just himself.(silent pause 4 seconds – no eye contact, staring out into the garden)

Would you like another coffee?

[There was a sense that Maise had come to the end of her story. Her body language and tone of voice gave the impression that she was tired and wanted to end the session. I accepted the offer of coffee and we chatted informally about her garden and it was clear that she had moved the conversation on. I accepted this and went with her in the dialogues]