### WAITING: A CRITICAL EXPERIENCE

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A thesis submitted in fulfilment of the requirements for the degree of Master of Nursing (Research)

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February 2001

#### STATEMENT OF SOURCES

This thesis contains no material published elsewhere or extracted in whole or in part form a thesis by which I have qualified for or been awarded another degree or diploma. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution. All research procedures reported in the thesis received the approval of the relevant Ethics Committees.

#### **ACKNOWLEDGEMENTS**

With profound gratitude -

To the women who participated in this study, I owe an enormous debt of thanks for your honesty and commitment;

To my supervisor John Struhs and co-supervisor Carmel Seibold, for all your encouragement, wisdom, patience, time, and good humour;

To the library staff at Australian Catholic University Aquinas Campus, for their hard work in rounding up the myriad of journal requests and for their cheerful dispositions;

To Sharon Clarke at Australian Catholic University Aquinas Campus, for her "never say never" computer skills and help;

To my family and friends, especially my parents, for all the tea and sympathy (literally!);

And finally to Andrew whose gentle support and undying faith in my ability to finish this project sustained me through the darkest hours.

In loving memory of two very special women-

Doreen Walker 24/07/1921 - 02/06/1999

And

Patricia Clohesy 26/02/51 - 9/4/1999

#### **ABSTRACT**

Waiting: A Critical Experience.

This study explores the experiences of relatives waiting. Often relatives wait for considerably long periods, especially in critical care areas, whilst their loved one, whose health status is unknown, receives care. To explore these experiences and to understand the symbolic meaning behind the participants' stories, a grounded theory approach was utilised which is firmly rooted in the sociological theory of symbolic interactionism. A qualitative approach was employed in order to yield a rich description of the human experience often not found in quantitative studies (Jamerson, Scheibmeir, Bott, Crighton, Hinton and Kuckelman, 1996, p. 468). Similarly, the use of feminist principles to guide this study has facilitated a greater understanding of such issues as gender roles, language, power and hierarchy. Using grounded theory methodology, audio-taped interviews were conducted with six female relatives who were recruited using theoretical sampling. Simultaneous recruitment, data collection, analysis and literature review took place, as advocated and outlined by Barney Glaser and Anselm Strauss (1967).

The overarching core category discovered using this approach which epitomises the waiting experience, is the balancing of both positive and negative aspects of the four codes identified. These four codes are - mothering, trust, flustered anxiety and institutional and medical power. Each code had negative aspects, such as being denied the felt need to mother the critically ill loved one, being asked to entrust the health of a

loved one to people that relatives had never met, feelings of fluster and anxiety, and a perception that they would interfere with medial care if they were to be involved in their loved one's care. Conversely, each code could potentially have a positive aspect, such as being involved in the care of the loved one, feelings of relief once the care of the loved one was entrusted to 'professional' health care providers, affiliating with other relatives who were waiting in similar circumstances, and receiving frequent information from staff. A final model was produced that illustrates the balance that many relatives aspire to when waiting in the Emergency Department waiting room. If the balance tips in favour of the negative aspects of the codes, a negative impact on the relative's feelings of well being can result.

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## CHAPTER 1:

## INTRODUCTION

#### IMPETUS FOR THE STUDY

I heard from my sister-in-law that my mother had been taken to hospital. Apparently she had suffered a collapse, whatever that meant. I stormed to the hospital, arriving breathless at the triage desk, only to find it unattended. I reluctantly rang the "please press for attention" bell and before long a nurse whom I did not know inquired "Yes?". I inquired about my mother. Using crisp consonants and an obvious air of annoyance, she explained that the doctor was assessing her, adding that I should take a seat and that "somebody will come and get you when they're ready". She looked flushed, as if all hell was breaking loose behind those doors. I took a seat and felt a sense of annoyance with myself, and with her. I had worked as a nurse in this town for over ten years, and I knew most of the emergency nurses, I even knew the back way into the department....yet I sat, wondering what had happened to my mother. Perhaps my mother had suffered a C.V.A. or an arrhythmia? Perhaps something less sinister - low blood sugar or a middle ear infection? It seemed an age before "somebody" was apparently "ready" to afford my safe passage through to the inner sanctum of the department. Inside the department, an air of flustered business prevailed, and Fiona, a nurse I had worked with previously, informed me of all that had transpired. She apologised profusely for not realising I was waiting in the waiting room.

The above experience occurred in 1996, I remember it well, even down to those feelings of angst and anger at being made to wait; those feelings of

exclusion. I remember thinking the worst, yet hoping for the best. I remember how the time spent waiting in this 'twilight' seemed to compound my longing to see my mother, to see and make sense of this sudden crisis. I entertained the idea of accessing the department literally by the back door, but instead opted to wait, like all of the other family members in the waiting room. From this personal experience, it became more than apparent to me that people who appear calm and 'happy' waiting in the waiting room might be experiencing similar emotional turmoil to that which I had experienced.

It is never easy to be on the "other side" of health care, and through this experience and through my experience as a practising nurse in an emergency department, I became more acutely aware of how the relatives of our patients are often poorly cared for. Did they feel as I did when 'made' to wait? Is it incorrect to assume that relatives who passively wait are happy to do so? I had developed a need to understand more clearly the relatives' experiences of waiting. In other words, I had developed a desire to research this experience.

Schulamit Reinharz (1992, p. 9) defined research as "the production of a publicly scrutinizable analysis of a phenomenon with the intent of clarification". Indeed this study has been conducted in the hope that the phenomenon of the passively waiting relative is clarified and that this clarification will significantly alter the way in which nurses care for such relatives. Barney Glaser and Anselm Strauss (1967, p. 252) claim that crucial insights into a phenomenon can be gained not only via the research process, but from one's own personal experiences prior to or outside that

process. I knew the intensity of my own ambivalence as a waiting relative, torn between worry on the one hand, a splash of anger on the other, and the choice I felt I had made to passively wait. I had noted that the majority of relatives waited 'quietly' in the waiting room, and I wanted to know more about this phenomenon. I had also noted that women were more likely than men to passively wait. As a feminist, this was of great interest to me. Consequently only women were chosen as participants for this study. Furthermore, David Allen (1995, p. 176) argues that as women and as nurses we have long witnessed and participated in medical paternalism and as such, texts by women have been systematically devalued in health care settings. This study will help address this imbalance.

#### THE RESEARCH PROBLEM/THE RESEARCH QUESTION

The primary purpose of this study was to generate a theory to explain and clarify the experiences of relatives waiting for news of their critically ill loved one. To meet this purpose, a grounded theory approach was taken. The grounded theory approach generates theory from the intense analysis of data. The data in this case was transcripts of interviews conducted with waiting relatives, memoranda, and other notes I had made during the interview process.

To ensure a genuinely intense analysis of the data, Phyllis Stern (1994, p. 215) advocates the researcher enters the scene bereft of performed theory so as to ensure that observation and questioning are guided by a hypotheses generated in the field. Yet how does one identify an interesting

phenomenon worthy of study, if one has not thought about it, hypothesised about it, or indeed, as in my case, personally experienced similar phenomena? Patricia Becker (1993, p. 256) states it is naive to expect the researcher to enter the field of inquiry without a set of preconceived ideas about the phenomenon under examination. She asserts that it is only human to give meaning to the world. Similarly, June Lowenberg (1993, p. 65) contends that "most talk cannot be interpreted without extensive background knowledge of both the symbolic meanings and the social environment". I believe that my own experience as a waiting relative combined with my knowledge of emergency nursing, medical politics and hospital environments facilitated my interpretation and analysis of the symbolic meanings imbedded in the participants' "talk".

However, Becker (1993, p. 256) does warn that if the hypothesis and research problem are too well defined from the outset, data collection may be constrained and sensitivity and openness to emerging theory may be lost. For this reason, Kerri Smith and Francis Biley (1997, p. 20) recommend that the research begin with a flexible, open-ended research question, one which is broad enough to enable a thorough investigation of all facets of the phenomenon. For example, my initial research question was "How do relatives feel about being made to wait in the waiting room?". This assumed that another agent was forcing them to wait and that their free will was not a factor - something I had assumed to be true. However, reflecting on the nature of the research question, I came to realise that by using the word "feel", the question negates any thoughts or other experiences that may have taken place in the waiting room other than 'feeling'. Hence, over time,

the research question was modified and refined to - "What is the experience of waiting for relatives in the critical care arena?". As it turned out, this question was broad enough to encompass many facets of the participant's experience, some of which were very unexpected.

#### AIMS OF THE STUDY

This research is exploratory in nature, and as such, specific objectives for the study are avoided in order to remain open to, and guided by the concepts emerging from the data. However, the broad aim of this study was to identify and explore issues commonly encountered by relatives waiting in the waiting rooms attached to critical care areas - Emergency Departments (EDs), Coronary Care Units (CCUs), and Intensive Care Units (ICUs), where the health status of their respective loved one was unknown to them. Finally, by drawing together these insights and concepts, a substantive theory was constructed that represents the experience of 'the waiting relative'.

From this aim, some general objectives emerged. These were:

- 1. to explore relatives' experiences of waiting in a waiting room while separated from their loved one.
- to explore relatives' perceptions and reactions to the experiences of waiting.
- 3. to explore the impact waiting has on the waiting relatives' feelings of well-being and to explore their motivations for waiting.

- 4. to conceptualise the experiences and perceptions of the waiting relative into a substantive theory.
- 5. to develop procedures and policies that may reduce the negative impact of waiting.

A secondary aim of this study was to increase nurses' and other health professionals' awareness of the issues confronting the 'waiting relative' by disseminating the results of the study and by making recommendations based on the results.

#### DEFINING THE TERMS

To ensure the reader's full comprehension of this report, I seek in this section to define the terms used throughout this research report. In essence there are only two terms that require definition, and they are the terms 'relative' and 'loved one'.

The term 'relative' is perhaps used somewhat differently to the traditional understanding of this term. In my experience as a nurse, those people who are in some way connected to a patient but who are not related by blood or marriage, are often referred to as a "significant other", or worse, they are identified by the abbreviation "S.O.". It is somewhat degrading that such a person be referred to as an "other" as it belittles their potentially close relationship with the 'loved one'. Chris Weedon (1997, p. 171-2) argues that in patriarchal societies, knowledge and power work systematically to

marginalise women, defining us as 'other' to the patriarchal order of meaning. By refusing to use the term 'significant other', this study recognises the dehumanising effect this term may have, and the potential to reinforce medical patriarchy when it is used. Therefore, when the term relative is used, it is to describe anyone who is in a close relationship with the one receiving care. It is not used to represent those who are related by blood or marriage.

There is some justification in taking this more inclusive view of the term 'relative' as many studies that have found little difference in the responses of 'relatives' related by blood or marriage and 'significant others'. To specify, Joan Reider (1994, p. 274) found in her study of relatives waiting in Intensive Care Unit waiting rooms, that there was no relationship between type of family relationship to the critically ill patient and their the family member's anxiety level. Similarly, David Price, Anthony Forrester, Patricia Murphy and Joan Monaghan (1991, p. 186) found in their study of waiting relatives in the ICU setting that parents, spouses, adult siblings, and significant others ranked needs in very similar ways. It is therefore my belief that kinship and close relationships are not exclusive to family members, and hence the broader definition of relatives is used in this study. Similarly, the terms 'relative' and 'family member' are used throughout this study interchangeably.

In this study, the person receiving care is referred to as 'the loved one' in recognition of the importance this person has for the waiting relative, instead of using the impersonal and medicalised term 'patient'.

#### THE SIGNIFICANCE OF THIS STUDY TO NURSING

The study of the experiences of waiting relatives is highly relevant to the nursing profession for a variety of reasons. Norman Wooley (1990, p. 1402) states that if one believes in the holistic approach to care, then it is essential that critical care nurses are able to identify the specific needs of family members, and demonstrate appropriate intervention techniques with those in need of support. If we are to genuinely fulfil our obligation to provide holistic care, then it is imperative that we as nurses begin to understand the experiences of waiting relatives and care for them in an appropriate and timely manner. Furthermore, this study will expand nursing knowledge as current literature is focused on the *needs* of the waiting relative rather than on the *whole experience* of waiting. Similarly, the findings of this study are unique in that there is a dearth of Australian studies in this field.

It is noteworthy that few professional groups identify and address the needs of the relatives of the critically ill. Linda O'Neill Norris and Susan Grove (1986, p. 194-5) argue that nurses are responsible for intervening to meet the psychological needs of the critically ill and their families. At the same time they also contend that nurses often lack adequate knowledge or background to optimise such care. To address this, some North American researchers, for example Diane Solrush (1990), have advocated the appointment of other health care professionals to care for relatives.

Therefore, if critical care nurses are to maintain their professional obligation to provide holistic care and to avoid fragmentation of this care, it is essential we seek to comprehend the experiences of waiting relatives. It is my sincere hope that the theory produced by this research and the recommendations arising from the theory will indeed offer nurses techniques to better care for relatives and their loved ones.

Finally, much has been written exploring the positive effects that relatives can have on the recovery of those who are critically ill (Walters,1999, Belanger and Reed, 1997, Millar, 1980, Reider, 1994, Benner, Hooper-Kyriakidis and Stannard, 1999). If we are to provide the best care for the critically ill then we cannot ignore the impact relatives can have on the healing process. It is therefore imperative that these relatives receive the support they need in order that they can expedite the recovery of their loved one who is critically ill.

It is anticipated that this study and the resulting theory, once disseminated, will provide the basis for a change in the way nurses' perceive relatives' needs, and therefore the way in which we go about meeting these needs.

## CHAPTER 2:

BACKGROUND

BRIEFING

#### DEFINING BACKGROUND BRIEFING

In most research studies, a portion of the paper is traditionally dedicated to a review of the literature. Whilst this study conforms to this tradition, I have elected to rename this section 'background briefing' in an attempt to more accurately represent the background review undertaken during this study. Whilst it is true to say that the majority of the background briefing has been constituted from professional nursing literature, other sources of information, such as television, videos, and popular media have been invaluable sources of information.

The literature review for a grounded theory study is conducted somewhat differently to other qualitative and quantitative approaches to research in that information about the phenomenon obtained from sources other than the data is collected once the data analysis has taken place. The reasons behind this are explored further in the 'Process of Inquiry' section. However, the 'background briefing' section of this paper has been placed early on in the thesis in order to give the reader the necessary background to comprehend this study. It is not indicative of the order in which the background briefing occurred in the research process.

#### NEEDS OF RELATIVES

Nancy Molter (1979, pp. 332-9) was one of the first researchers to examine the needs of relatives of critically ill people and developed a research tool which was to be used by many other researchers after her. She developed a list of "need statements" through a literature review and by surveying 23 graduate nurses. The 45 need statements formed the basis for structured interviews of 40 relatives, 25% of whom were women, in an American ICU. Each need statement was rated by the relatives according to its importance on a scale of 1 (not important at all) to 4 (very important). Respondents were also asked an open-ended question which sought to identify any needs not previously listed. Interestingly, no new needs were identified. Molter's findings reveal that relatives ranked the need for hope and honesty regarding their loved one's condition as of paramount importance. This was followed by the need to feel that staff espoused a caring attitude, and the need for detailed information regarding their loved one's condition. Curiously, relatives frequently stated that "they did not expect the health care personnel to be concerned about them", and that they believed that the care should be solely focused on the loved one. Most of the relatives' needs in this study were perceived to be met by nurses, but there were some needs, such as information regarding treatment plans, prognosis and death that were seen as better met by physicians than nurses. Also of note was that written information, such as that given to the relatives of loved ones undergoing elective operations, was perceived by relatives as being of little use in meeting their needs. Relatives instead found that reassurance

through verbal communications with medical and nursing staff was more valuable.

Molter's need statements have been used by many other researchers in both ICU and other critical care settings. Jane Leske (1986, pp. 189-193) recruited 20 male and 35 female relatives of loved ones being cared for in a metropolitan ICU in America. They were approached within 72 hours of their loved one's admission. She used a survey design incorporating the 45 need statements developed by Molter with a further open ended item to identify any new needs not previously reported. No new needs were identified and the results of the survey mirrored Molter's earlier results. The need of relatives to feel that there was hope of recovery of their critically ill loved one was ranked first, followed by the need to have questions answered honestly. The need to know the prognosis of their loved one's illness, the need to know specific facts concerning their loved one's progress, and the need to have explanations given in terms that they comprehended were ranked as next in line of importance. Interestingly, four of top five most important needs identified by relatives related to the strong desire for information relating to their loved one.

O'Neill Norris and Grove (1986, pp. 194-199) modified Molter's needs statements, taking the number of statements from 45 to 30. Subsequently, they set out to examine the congruence between the needs of family members of relatives in ICU in America, and the ICU nurses' perception of these needs. The revised questionnaire was given to 20 family members (70% of whom were female) and 20 intensive care nurses at least 48 hours

after the admission of a loved one. The results showed that for relatives, three of the four highest ranking needs dealt with the need for information and the fourth was the need to feel that hospital personnel cared for their loved one. Nurses ranked the relatives' need for hope lower than that of the family members', and O'Neill Norris and Grove postulated that this was because nurses were reluctant to give hope in circumstances where to do so might encourage false hope. It was also found that nurses tended to underestimate the total informational needs of family members, possibly because they perceived that specific information was not needed by family members.

Zarpe, Margall, Otano, Perochena and Asiain (1997, pp. 12-6) conducted a similar study modifying Molter's instrument by reducing the needs statements from 45 to 34. These 'needs' were ranked in order of importance by 85 relatives of critically ill loved ones, and a 5 - point Likert scale was used to evaluate the extent to which the need had been met. The setting was a Spanish ICU, and the instrument was administered at least 48 hours after admission of their loved one. The gender mix of the sample was not mentioned and potential differences arising between the responses of male and female participants were not explored. The Spanish ICU in which this study was based employed an auxiliary nurse who was responsible for welcoming relatives and giving them information about the unit. This nurse also accompanies the relatives on their first visit to their loved one, and the role this nurse plays may have been a significant influencing factor on the participants' responses. The results from this study revealed that all respondents felt reassured that their loved one was receiving the best

possible care, and 99% felt they had been given explanations of their loved one's progress and care in terms they understood. Relatives identified the need to feel assured that their loved one was receiving the best care and the need for understandable explanations of their loved one's progress and care were the two highest ranked needs.

Christine Breu and Kathleen Dracup (1978, pp. 51-53) explored the issues of grief and loss experienced by spouses of loved ones in an American CCU. Their conceptual framework was drawn from the work of Hampe (1975) who had studied the spouses of terminally ill loved ones. Interviewing these spouses, Hampe came up with eight needs common to spouses going through the stages of anticipatory grief. Breu and Dracup then added another need, the relief of initial anxiety, based on their own experience with families and the interviews they conducted. They also noted that families show a high degree of anxiety and disorganisation during the loved one's first few hours in the CCU. This type of experience can be seen to parallel that of relatives whose loved ones are admitted to the Emergency Department. The results of this study suggests that the need for relief of initial anxiety is ranked the highest of the needs, followed by the need for information, the need to be with the 'patient', the need to be helpful to the 'patient', and the need for support and ventilation of their feelings. No information is given in this paper indicating the period of time that had elapsed between the interviews and the time of admission of the loved one to the CCU, numbers of participants or gender mix of the sample. Leske (1986, p. 191) states that the nature of the critical illness and the variance in the time of data collection may account for some of the differences in the rating of importance for certain needs.

Mairead Hickey (1990) reviewed eight studies from 1976 to 1990 that researched the needs of American families with critically ill loved ones. The studies were conducted by Molter (1979); Mathis (1984); Leske (1986); Spatt, Ganas, Hying, Kirsch, and Koch (1986); Rodgers (1983); Bouman (1984); Daley (1984); Dracup and Breu (1978); and O'Neill Norris and Grove (1986). Four of these studies I have outlined above. Most of these studies used Molter's instrument or a variation of it as a data collection tool. The two needs that were in the ten most important needs in all studies were to have questions answered honestly and to know specific facts regarding what was wrong with their loved one and their prognosis. After reviewing these studies, Hickey concludes that families seek honest and frequent information about their loved one's status and prognosis, and that they also require reassurance that the loved one is comfortable and receiving the best possible care.

Linda Daly (1984, pp. 231-237) used 46 needs statements based on Molter's original list as a basis for a structured interview of 40 relatives in an American ICU. They were interviewed within 72 hours of their loved one's admission and 75% of the sample were women. Like previous studies, Daly found that the highest-ranking need was for the relief of initial anxiety followed by the need for information.

Price et al (1991, pp. 183-8) again utilised a revised version of Molter's family needs instrument to survey 213 relatives of loved ones receiving care in an American ICU. The survey was given to relatives 24-72 hours after the admission of their loved one, however the gender mix of the sample was not mentioned. They found that family members need two things most - to have honest, intelligible, and timely information and to feel assured that their loved one is being cared for by competent people. They also found that environmental amenities within the waiting room and talking to others about their feelings were of lowest priority. Price et al concluded that the focus of relatives is on needs pertaining to the loved ones' welfare and that there is relative disregard of needs that pertain more to the family members' own welfare.

In discussing the use of Molter's tool, Price et al found that the respondents consistently ranked all items as "important" or "very important". Consequently, they suggest that this may be a limitation of this tool. To overcome this limitation, Price et al suggest that the development of an alternative device for discriminating amongst family needs would be useful.

Terri Simpson (1989, pp. 388-97) is similarly critical of Molter's instrument, stating that the construct validity of the instrument, despite its broad use, is only in the developmental stages. She also recommends that convergent validity should be further verified by using a variety of measurement strategies, such as observation in conjunction with the self - report instrument. Simpson concurs with Leske (1986, p. 191) that the reliability of the tool is questionable if administered at different time intervals.

However, it is interesting to note the similar findings of studies incorporating Molter's tool despite the variance in the time of administration of the tool to participants. Such similarities suggest that Molter's tool is indeed reliable when administered at various time intervals. Simpson also suggests that research incorporating Molter's instrument should be anchored in a conceptual or theoretical framework that guides the organisation and interpretation of the study. There was no mention of conceptual or theoretical frameworks in the studies reviewed for this background briefing.

In contrast to previous studies however, Wooley (1990, pp. 1402-8) frames the experience of the waiting relative in terms of a crisis theory as developed originally by Richardson (1945). The basic premise of this conceptual framework is that individuals face potential crises as part of a natural and ongoing process of maturational development and the crisis even can be viewed as either a danger or an opportunity. The dramatic and unexpected nature of a critical illness combined with inexperience in facing crises' has the potential to increase that person's vulnerability to a stressful event. This may explain why older respondents had lower anxiety levels in a crisis, as discovered by Reider (1994, p. 276) in a similar study. Reider sought to examine the anxiety levels of waiting relatives. She concluded that older respondents have lower anxiety levels when faced with a crisis, as they have had greater exposure to crises' during their lifetime. In reviewing the literature, Wooley divides the needs of the family into four main categories - initial anxieties and informational concerns, emotional support and interfamily contact, involvement with care and finally, personal needs.

Interestingly, Wooley concurs with Price et al and Molter's assessments that relatives appear least worried about their own personal needs. He argues, however, that for relatives to remain an effective means of support to the loved one and to each other, they must receive adequate rest, sleep and nutrition. Despite this need being rated lowest by many respondents in many studies using Molter's tool, it is obvious that this is indeed an important need and perhaps highlights another short coming of Molter's instrument.

Deanna Pearlmutter, Ann Locke, Susan Bourdon, Gail Gaffey and Rosalie Tyrrell (1984, pp. 173-188) suggest that the 'professional family' (defined as one in which a member or several members have professional backgrounds in, for example, health care, law, or education) have special needs. They argue that the control and independence associated with professional practice contribute to the professional families' need for structure and information during their hospital experience. Issues of privacy, feelings that the physician should be more available to them or that they should be allowed special privileges, or controlling, demanding and angry behaviour can cause staff significant stress. Pearlmutter et al state that these behaviours are borne from feelings of helplessness, anxiety, or fear. They suggest using language that makes the most sense to the individual, respecting the family member's usual role behaviours, setting limits and clarifying roles, and developing a structured plan of care that involves the family are useful strategies in relieving the professional relative's negative feelings. These strategies seem to be based on anecdotal evidence and noted positive

outcomes from the implementation of these strategies in a North American hospital. Formal research conducted by Pearlmutter et al is not mentioned.

Melissa Johnson, Susanne Heinzerling, Katheryn Mattison, Jamie McGurn, Patricia Rock and Deb Smith-McMahon (1993, p. 34) argue that although the needs of families have been identified in many studies, it is often impractical for the ED staff to meet these needs. They further argue that in the case of a death of a loved one, the family needs are best met by a professional trained in the area of crisis intervention. In reviewing a 39 item survey (presumably based on Molter's need statements, although not stated) given to ED clients, the need to keep 'patients' and waiting family members informed of progress was highlighted.

Catherine Waters (1992, pp. 107-17) contrasted the needs of families from different cultural backgrounds visiting relatives in an American ICU. She developed the Professional Support Questionnaire for Critical Care Nurses Working with Family Members (PSQ) by conducting interviews with families asking "the critical care nurse can best support me by...". The 36 item PSQ was derived from recurrent statements and revision by an expert panel. This questionnaire was administered to 90 relatives, 30 were African American (27 were female), 30 Hispanic (19 were female) and 30 white (23 were female). The participants self-identified as belonging to these cultural groups. Overall, there was a consistency across cultural groups for the five highest scoring items, four of which related to receiving information, and one that related to assuring the best care for the loved one. Again, the

lowest scoring items cross culturally related to personal needs such as food and refreshments, restrooms, and support groups.

Some of the differences that did emerge, however, related to chaplain services where African Americans rated this need much higher than Whites or Hispanics and is consistent with national figures that show most African Americans are Protestants. Interpreter services were rated much higher by Hispanics than Whites or African Americans as they are more likely to come from a non-English speaking background. A visitation by the critical care nurse once a shift to 'check out' relatives' concerns in the waiting room was ranked significantly higher by Hispanics and African Americans than white family members. Waters admits that there is no 'categorical, quantifiable explanation' for this difference, but suggests that the recurrent theme is to keep family members connected, especially ethnic-minority family members.

#### FAMILY VISITATION DURING RESUSCITATION

There has been much written about family witnessed resuscitation in the literature, with the general consensus being that it is a positive initiative for both nursing staff and relatives alike. Linda Hackley (1995, p. 584) conducted a survey of 218 nurses working throughout Sweden in Emergency Departments to illicit their attitudes toward permitting family members in the treatment room during resuscitation. The survey was constructed using a 27-item instrument, The Emergency Nurses Attitudes Toward Family Presence During Resuscitation. The highest scoring item was "It helps the family talk to the patient prior to death pronouncement", the lowest scoring

item being "I experience burnout as a result of family presence in the treatment room during resuscitation". Significant differences were noted between attitudes and level of education (more favourable beliefs were found in those with advanced degrees), positions (more favourable in advanced practice/educator nurses), and type of visitation policy (more favourable in Emergency Departments with open visitation policies). It is interesting to note that the predominant culture of the Emergency Department, as indicated by their visitation policy, has more influence over the nurses' attitude toward family witnessed resuscitation than years of emergency nursing experience or the nurses' age.

Theresa Meyer's (2000, p. 9) personal account highlights the perils of challenging the dominant philosophy of visiting rights in her ICU in America. She took it upon herself to facilitate the presence of the parents of a 14-year-old boy undergoing cardio-pulmonary resuscitation. Despite getting the 'reluctant approval' from the surgeon in charge of the resuscitation to allow the parents to be present, many of her co-workers felt uneasy. Indeed, Meyer recounts how uncomfortable the following few weeks were for her, with "powerful people in the institution" saying that she had "crossed the professional line and should be fired". Such sanctions obviously have great influence in how and to what extent family members are cared for and involved in the care of their loved one. Catherine Chelsa and Daphne Stannard (1997, pp. 64-71) used interpretative phenomenology to examine interviews conducted with 130 nurses working in American critical care units and came to similar conclusions. They found that the care of the family was influenced strongly by institutional philosophies and structures, as well as

the professional's "orientation to and educational preparation for working with families".

Mary Anne Belanger and Sandra Reed (1997, pp. 238-9) discuss the results of the introduction of family witnessed resuscitation in terms of both staff and family responses. Prior to its introduction, the staff of this small American community hospital felt that their function during the resuscitation would be impaired. They expressed fears relating to families interrupting them, their emotions being evoked, fear of legal ramifications and a fear of giving up control. A trial was conducted after protocols were drawn up and one staff member was allocated to give the family information, accompany them into the resuscitation area, answer their questions, and support them. The physicians involved the family in the decision making process. A follow-up survey was conducted a year after the trial began, and the majority of staff believed there was no impairment to their function if families were present, and staff never felt that the family "got in the way". They also revealed a strong camaraderie with resuscitations taking on a "personal" atmosphere. Of the 24 family members surveyed who had witnessed their loved one being resuscitated, all stated that if faced with a similar situation, they would again participate because they believed it enabled them to cope better with their grief process.

# RELATIVES' EXPERIENCES OF A CRTICALLY ILL LOVED ONE

Patricia Jamerson, Monica Scheibmeir, Marjorie Bott, Francis Crighton, Ruthellyn Hinton, and Ann Cobb (1996, pp. 467-74) set out to describe the experiences of families with a relative in an American ICU. They chose interactive, unstructured interviews of 20 relatives, eighteen of whom were women, to best illicit the 'rich description of human experience' not found in other quantitative methods. It is not known how soon after admission of the loved one that relatives were interviewed. A thematic analysis yielded four categories of experience - hovering, information seeking, tracking and garnering of resources. Hovering is described as an initial sense of confusion, stress and uncertainty experienced whilst family members wait to see their loved one, learn of the diagnosis, or to comprehend a prognosis. Similar responses have been noted by several other researchers, but especially by Breu and Dracup (1978, p. 51) who added to Molter's list of needs the need for relief of initial anxiety.

The next category of experience identified by Jamerson et al was information seeking, described as the active process of gathering information. This process, according to Jamerson et al, assists relatives to move out of the hovering phase. Conversely, Jamerson et al state that limited information about the loved one's status prolongs the hovering phase. This is congruent with many of the "needs" studies whereby the need for information was consistently ranked highly by relatives. Tracking is a

process of observing, analysing, and evaluating the care given to the loved one. This phase also relates to the relatives' satisfaction with the environment and care givers. Finally, the garnering of resources involves the acquisition of what relatives' perceive as needs for themselves or their family member. In response to these experiences, Jamerson et al suggest nurses can best care for relatives of loved ones by, anticipating and providing regular information about their loved one's status and care, treat families with respect, dignity, and empathy, be an advocate for family members, and provide inidvidualised, flexible visitation.

Brian Millar's (1989, pp. 31-3) anecdotal evidence suggests that relatives' fears, anger, mistrust, helplessness or hopelessness, combined with the lack of information about their loved one's illness, can create either the worst kind of behaviours in relatives or an overly passive and uncritical reaction. He argues that these attitudes are often developed during the relative's initial contact with the ICU. I believe that the same could be said about relative's initial contact with any critical care department, especially the Emergency Department. Millar agues that the unfamiliar environment coupled with the families' desire to help their loved ones, families will often conform rigidly to formal and informal rules outlined by the ICU. He believes this is attributable to the families' attempt to gain staff acceptance thereby putting 'acceptable' forms of behaviour ahead of 'felt' needs. This is congruent with Wooley (1990) and Price's et al (1991) findings that often the personal needs of the relative is ranked lowest by them. Millar conducted semi-structured interviews with relatives of loved ones visiting three Welsh ICUs. The time after admission to interview was not

mentioned, nor was the number interviewed or gender of participants. Using Molter's needs statements as a basis for the interviews, he found the need to reduce anxiety and the need for information ranked highest. In addition, he found that relatives felt the need to explain what had happened before their loved one's admission and illness, and unless this discussion occurred, relatives appeared unable to concentrate on identifying their needs.

Millar's study also provides some insight into the waiting experience as a whole. The unwillingness of relatives to be seen criticising the staff, and the tendency to excuse nursing staff as too busy to attend their needs were some of the findings gleaned from the interview approach in addition to Molter's need statements. Millar argues that a therapeutic relationship cannot be formed between nurses and relatives if the nurses are constantly changing and the continuity of care is broken. The opportunity to develop a similar therapeutic relationship with relatives may be made even more difficult within the context of an Emergency Department where time constraints limits contact with relatives, and thus the formation of such relationships.

Solrush (1990, pp.155-62) is a counsellor and back-up support professional to medical staff in an American ED specialising in trauma care, and in her experience, there are five crucial factors that impact on relatives once a loved one is injured. These include the sudden and unpredictable nature of the trauma, the relationship linking the relative and the loved one, issues of responsibility, anger and guilt, religious beliefs and, finally, the trauma sequelae. Solrush gives anecdotal evidence of how these factors impact on

the experience of relatives, and suggests that organ and tissue donation programs, and the introduction of psychotraumatology may ease their plight. The former may ease the loss when the trauma victim dies as something good and worthwhile can been salvaged from the devastation that relatives feel. Psychotraumatology workers are specially trained in handling the emotional and psychological sequelae of trauma, working with both families and staff. In terms of the family, they assist in the two-way communication between them and the medical staff, and interpret and explain information to both sides. In light of previous studies that have identified the relatives' need for information, this initiative may be one way to address this need whilst offering professional psychological support, not unlike that advocated by Johnson et al (1993, p. 34).

Reider (1994, pp. 272-9) assessed the anxiety levels of relatives of critically ill loved ones and argues that the stress and stressors faced by relatives is not as important as their corresponding anxiety state. Two tools were used, the Brief Symptom Inventory assesses psychological symptom status, and the Family Crisis Oriented Personal Evaluation Scales which measure effective problem solving attitudes and behaviours. The anxiety levels of 75 relatives, 79 % of who were female, were measured 48-96 hours after their loved one was admitted to an American ICU. The results showed that families were better able to utilise coping strategies if levels of anxiety were low and that younger relatives experienced higher anxiety levels. Interestingly, acquiring social support or mobilising family to acquire and accept help was not related to anxiety level, and there appeared to be little relationship between anxiety and type of family relationship, socio-economic

status, educational level or severity of illness of the loved one. The sudden onset of the critical illness experienced by the loved one did, however, caused increased anxiety in the family member, and Reider states that the nature of the illness as *perceived* by the relative influences anxiety more than the actual severity, which the relative is unable to ascertain. This may account for the consistent need of relatives for information as highlighted in many studies, and in some cases, Reider argues this information reduces the relatives' anxiety level. A similar assertion was made by Jamerson et al who saw information as means by which relatives can pass out of a sate 'hovering'.

Reider also asserts that the ability of relatives to absorb information is impaired when they are experiencing a high level of anxiety and suggests nurses need to assess this level of anxiety before imparting information. She also suggests that coping may be enhanced in relatives if they can contribute to the well being of the loved one, and encourages nurses to engage relatives in the care of the loved one.

Charmaine Kleiber, Margo Halm, Marita Titler, LouAnn Montgomery, Susan Johnson, Anita Nicholson, Martha Craft, Kathleen Buckwalter and Karen Megivern (1994, pp. 70-76) undertook to examine the emotional responses of 52 relatives of loved ones in an American medical and surgical ICU, and neonatal ICU. 70% of the sample were female and participants were asked to keep a journal of their feelings throughout the admission. A thematic analysis showed a "broad range of powerful emotions", although fear, worry, anger and exhaustion was common themes in the first 24 hour period. They

also reported that family members identified a caring attitude as the most support behaviour of staff, followed by the theme of providing information. It is interesting to note that exhaustion was a common theme in the initial period, and yet other studies outlined previously have shown that despite this, meeting personal needs is of lowest priority for relatives during this time.

#### OTHER SOURCES OF INFORMATION

Barbara Keddy, Sharon Sims and Phyllis Stern (1996, p. 451) quotes Strauss as saying "everything is data", including the experiences of the researcher's own life. Bowers (2000-perosnal communication) concurs stating that one should treat the data of one's own experiences as another interview, to be used comparatively. Indeed, many of my experiences have been compared and contrasted with the collected data in the process of theory development, and are discussed in the results section of this paper.

Many grounded theory studies include the analysis of popular literature, which provides an insight into how the area is conceptualised by non-researchers (Bowers, 1989, p. 53). Similarly, the press, television and fiction serve to transmit and reinforce common meanings and values (Weedon, 1997, p. 169). For this reason, I reviewed four episodes each of 'E.R.', an American drama set in a busy 'Emergency Room', 'All Saints', an Australian drama set within a ward environment, and 'R.P.A.', an Australian series portraying the real-life illness experience of people admitted to the Royal Prince Alfred hospital in Sydney. What is generally striking about all three of these television productions was the detailed realism of medical procedures performed and equipment used. Wooley (1990, p. 1405) comments that in his review of studies relating to waiting room relatives' needs, the need for information regarding specific equipment and sounds was not rated highly amongst participants. He believes that one reason for this is the growing public awareness of the critical care environment brought

about by popular television presentations that demonstrate aspects of nursing and medical care in explicit detail.

The realistic portrayal of medical and nursing care may also lend a degree of credibility to the roles of families portrayed in these television shows. In ER for example, a screaming woman was literally dragged off her husband so that the medical and nursing staff could save his life. "Just get her out!" screamed the doctor prior to charging up the 'paddles' and defibrillating the unresponsive husband (ER 1994, 'Happy New Year', volume 1.) It seemed to me that medical staff were portrayed as controlling and generally emotionally detached from those whom they care for. Nurses by comparison are depicted as being far more interested in the psycho-social aspects of caring, often holding the hands of relatives or loved ones (ER 1994, 'Into that Good Night', 'Chicago Heat' and 'February 5, 1995', All Saints 1999, screened on the 7<sup>th</sup>, 14<sup>th</sup>, 21<sup>st</sup>, and 28<sup>th</sup> September 1999). Relatives by contrast, are portrayed as a nuisance that get in the way. It is not unreasonable that the general public, in viewing these fictitious dramas, assume these roles to be appropriate and realistic, especially when the medical procedures and equipment lend a degree of credibility to the stories portrayed, be they real or fictitious.

In 'R.P.A.' the family is often depicted as being concerned and in close physical proximity with the loved one receiving care. The medical staff are portrayed as cheerful, informal, and the primary source of information for the family and loved one. The family and loved ones are very grateful for information and care received by medical and nursing staff, although it is

usually only the medical staff that is mentioned or filmed. The four episodes I watched (screened on the 6<sup>th</sup>, 13<sup>th</sup>, 20<sup>th</sup>, and 27<sup>th</sup> July 2000) all involved more or less elective surgical procedures, and none portrayed a sudden critical illness requiring emergency treatment. Interestingly enough, families would quickly vacate if doctors or nursing staff were required to perform any physical care of the loved one. Similarly, the status of medical staff was subtly reinforced by body language. Often the medical staff would be in a position whereby loved ones and relatives had to look up to see the face of their doctor whilst s/he used this height difference to look down on her/his patients. One of the surgeons addressed relatives whilst still dressed in his or her theatre attire, while others wore white coats. Again, medical staff appeared uncomfortable if the relative or loved one required psycho-emotional care. A quick pat on the shoulder whilst beating a hasty retreat and espousing a 'you'll be right' attitude was noted several times when loved ones or relatives showed signs of emotion.

The nexus of power relations between families, loved ones and medical staff was highlighted recently on a series of talk-back interviews on radio (ABC Melbourne, 774Mhz, 23<sup>rd</sup>, 24<sup>th</sup>, 25<sup>th</sup> and 29<sup>th</sup> August 2000). "Dr Paul" and John Faine conduct a weekly segment to discuss medical issues and on the 23<sup>rd</sup> invited discussion relating to inappropriate medical conduct. Many callers rang in, days and even weeks afterward with stories of medical incompetence, arrogance with an alarming amount of callers recounting stories of sexual assault. More alarming was the fact that most of these female callers had not reported the male doctors, let alone told any one else about the incident. Some callers felt a degree of guilt that they had allowed

such misconduct to occur or that they had in some way encouraged the behaviour. All of the callers felt intimidated or that the doctor "knew what was best" and was therefore beyond reproach. This seemed to be true regardless of the age of the caller. Although not conclusive, these examples illustrate the extraordinary power the medical profession still holds in the Australian community.

#### SUMMARY

Many of the studies outlined gave a gender breakdown of participants involved in the research process, whilst some did not. In spite of this, the research findings were similar between the two genders across studies. Although this research paper is based on the responses of female participants and does not intend to be extrapolated to the male waiting relative, it is noteworthy that in previous studies similarities exist between the male and female waiting relatives' experience.

Most studies have focused on the needs of waiting relatives rather than the overall experience of the waiting relative. In reviewing the studies that have addressed the needs of waiting relatives, some common themes have emerged. The need for hope has been found to be variable in its ranked importance across studies, but the need for honest and frequent information is consistently identified as being of paramount importance across most studies. Likewise, the need of relatives to be assured that their loved ones are receiving the best possible compassionate care is a highly ranked need. These may be universal across cultures, as suggested by Waters (1992) and Zazpe et al (1997), but further study is needed to

support this contention. Also of note was the consistently lowest ranking item across 'needs studies' which pertained to the relative's personal needs. Facilities such as toilets, refreshments, and waiting room amenities were of lowest priority for relatives when ranking what they perceived as important for them.

Research relating to the waiting experience of relatives as a whole, identified that relatives experienced an initial state of confusion, disorientation, stress and worry. Jamerson et al (1996) labelled this state as hovering, and this state was reflected in Breu's and Dracup's (1978) study where the need for relief of initial anxiety was of greatest importance for relatives. Reider (1994) suggests that the way in which relatives cope with this initial state is dependent on their level of anxiety rather than the level of stress they are placed under. Again, information was highlighted by Jamerson et al (1996) and Reider (1994) as a means by which this initial anxiety state can be relieved.

The involvement of family members in the care of the loved one has been emphasised in many studies as a means by which relatives can better cope with their loved one's critical illness. Although a dramatic example, studies pertaining to family witnessed resuscitation have been shown to be beneficial for both critical care staff and family members when relatives are involved in the decision making processes.

It is noteworthy that the majority of studies examining the experiences of relatives have originated in America. Whilst the Australian experience may differ in some respects, a review of popular media, both Australian and

American, reveals a common public perception of medical staff as being powerful, judgmental, and controlling, and of relatives being an inconvenience, often 'getting in the way'. This perception is reinforced in both fictional and non-fictional portrayals of medical relationships. It is also mirrored by Millar's (1989) observation that families will conform to formal and informal rules laid out by the critical care unit, even when adopting such 'acceptable' behaviour is often at odds with 'felt' needs. Similarly, many talk back radio callers recounted stories of compliance with medical procedures that they knew were unnecessary and degrading. This again is indicative of the power possessed by medical staff in Australia.

# CHAPTER 3:

# METHODOLOGY

### METHODOLOGY - AN INTRODUCTION

The methodology guiding this research is grounded theory, which has arisen from the philosophy of symbolic interactionism. Traditionally, this section of a research paper explores the philosophical underpinnings of the method used in collecting and analysing the data. However, before exploring this further, it is necessary to first explain my world-view, which arises from feminist theory. Feminists believe that researchers can never attain an objective stance and that it is necessary to demonstrate the value bases from which they come (Holloway and Wheeler, 1996, p.133). I have therefore elected to begin this chapter with an explanation of the feminist perspective to which I ascribe and which has shaped this research project.

### **FEMINISM**

Feminism is a perspective, not a research method (Reinharz, 1992, p. 240, Holloway and Wheeler, 1996, p. 141), and as such, does not offer a method by which analysis can take place. However, Keddy, Sims and Stern (1996, p. 448) consider grounded theory as a feminist method and methodology provided that the "methodologist is grounded in feminist theory". They argue that grounded theory was designed to avoid spurious objectivity and the biases of positivistic research, and was developed to allow for the voices of the participants to be heard. Furthermore, grounded theory encourages the use of feminist strategies such as intuitive feelings, hunches and the use of the researcher's own experiences and knowledge to permeate the process (Leddy and Pepper, 1993, p. 103, Keddy, Sims and Stern, 1996, p. 451,

Becker, 1993, p. 258). Such strategies would be considered a threat in traditional positivist research paradigms as they are perceived to invalidate and bias so-called 'objective', 'value neutral' studies.

Norman Denzin and Yvonna Lincoln (1992, p. 13) note that the theoretical perspective assumed by the researcher directly affects the researcher's view of the world, and as such, affects the way in which the researcher believes it should be studied and understood. The theoretical perspective that dominates this study, symbolic interactionalism, blends well with feminist ideals, and is discussed further under the heading of 'Symbolic Interactionism'.

This is a study of women in the hope of affecting social change, of providing better care for female relatives who wait in Emergency Department waiting rooms. The qualitative nature of this study also lends itself to feminist ideals.

However, it should be noted that employing a qualitative research technique does not guarantee that feminist principles have been used. Debra Jackson (1997, p. 88) notes that studies conducted within a qualitative framework, such as those employing a grounded theory technique, can be as "inherently andro-centric" as can studies from a positivist framework. Similarly, being a female researcher does not guarantee a feminist perspective as one's writing may not "challenge hegemonic norms or employ a different, resistant and specifically female discourse" (Weedon, 1997, p. 165) which is central to feminist research. It should also be noted that, whilst the term "feminism"

implies a degree of exclusivity toward men, male researchers may also operate within a feminist paradigm, as biological female sex is neither necessary nor sufficient to be a feminist (Campbell and Bunting, 1991, p. 6).

#### FORMS OF FEMINISM

There are many different forms of feminism, with traditional distinctions in the literature being made between Liberal, Socialist/Marxist, and Radical feminism, all of which seek to explore and explain the means by which women are oppressed, suppressed and repressed, with each ideology offering strategies to overcome these issues. In order to illustrate the feminist perspective used to inform this research, it is useful to briefly overview the historical distinctions between the major schools of feminist thought. Liberal feminists believe that the subordination of women stems from social and legal barriers that prevent women's entrance to, or success in, the public arena (Tong, 1993, p. 2). In terms of the Australian experience, Ann Curthoys (1994, p. 16) outlines the impact liberal feminist ideology had between the years 1913 to 1975. This period was marked by rapid changes, such as the provision for equal pay granted by the Arbitration Commission in 1972.

Socialist feminists believe gender and class play approximately equal roles in the oppression of women, whilst Marxist feminists consider issues of class plays the greatest role in defining women's status and functions (Tong, 1993, p. 39). Inherent in the Marxist-feminist view is the belief that the organisation of production is strongly influenced by patriarchy and

capitalism (Hartman, 1987, p. 111). Curthoys (1994, p. 21) contends that Socialist and Marxist feminist traditions "more or less died" in Australia at the end of the 1980s as many saw this perspective as male-centred and gender blind.

Radical feminists focus upon the exaggerated biological sex/gender system, whereby men always have the dominant, "masculine" roles and women the subordinate, "feminine" roles (Tong, 1993, p. 96). In terms of this research project, it is noteworthy that the popular media portray most medical roles as male and most nursing roles as female, as discussed in the background briefing. Indeed, all of the participants in this study recounted that the medical staff were male and the nursing staff female. Curthoys (1994, p. 21) states that other sources of oppression, such as class and race, might be acknowledged in Radical feminist discourse, but they are considered secondary to that of social differentiation. Radical feminism was developed in the 1970s, but was revitalised in Australia in the latter part of the 1980s (1994, p. 21).

Denzin and Lincoln (1994, p. 15) contrast similar differences in ideology between humanistic cultural studies and more structural cultural projects that emphasise the influence structural and material determinants, such as race, class and gender, has on individual experience. Whilst humanistic studies focus on the lived experience of the individual, as indeed my own research does, Denzin and Lincoln argue that cultural studies act as resources for "...understanding and for producing resistances to local structures of domination" (p. 15). I am hopeful that the theory I have

produced from the intense analysis of participant's experiences will be sufficiently pragmatic in application to produce similar 'resistances' to accepted hospital practices, in order to affect policy change.

Feminist poststructuralism, as defined by Weedon (1997), is based on the theories of language, subjectivity, discourse, and power relations, and is useful in understanding individual experiences whilst relating them to social power. This theory relies heavily on the exploration of social discourse, a term that can be defined as a way in which meaning is given to the world and the way in which social institutions and processes are organised (Weedon, 1997, p. 34). For example, Weedon (1997, p. 35) believes that the discursive fields of the family, the law, medicine, education, employment, the media and religion all reproduce the dominant discourse of female sexuality as being naturally passive. From this, social definitions of women's places as being 'in the home' as a wife and mother is further reinforced. Women internalise this masochistic form of femininity as this helps them psychologically accept the material structures of their oppression (Weedon, 1997, p. 39).

The reinforcement and production of various discourses is done so primarily through the use of language. Although the term discourse is representative of society structure, social institutions, modes of thought and individual subjectivity, it is language that is representative of the dominant discourse (Weedon, 1997, p. 39-40). Language is not transparent and does not label a 'real world', it is instead historically and socially located (Weedon, 1997, p. 40). In terms of this study, the exploration of the participant's language was enlightening and indicated the accepted discourses that they had

internalised. It lead to a greater understanding of their experience as a waiting relative, and of the power relations inherent in the medical system.

Patriarchy, as defined by Reinharz (1992, p. 2), is the power relations which exist that subordinate women's interests to those of men. It implies a fundamental organisation of power on the basis of biological sex, which is not natural and inevitable, but socially produced (Weedon, 1997, p. 123, Curthoys, 1994, p.22). Feminists recognise that patriarchy in not only embedded in the structure of society, but in the very construction of social relationships (Holloway and Wheeler, 1996, p. 133). Marilyn French (1992, pp. 133, 144) claims that the male dominated medical profession is largely indifferent to women's health, citing many examples of women unjustly subjected to medical dominance. This study focuses on the experiences of relatives subjected to the power of a larger, patriarchal institution and how the subordination of this group of people is subtly reinforced. The attempt to understand power in all its forms is of central importance to feminists (Weedon, 1997, p. 120), and whilst the participants in this study were all female, it is possible that male relatives waiting in similar circumstances may be subjected to similar patriarchal power relations. Furthermore, whilst the participants related their stories of male medical staff and female nursing staff reinforcing the existing power relations within the institution, it is possible, although beyond the scope of this study, that female medical staff and male nursing staff also reinforce the patriarchal power structure.

#### PERSONAL PERSPECTIVE

It is true to say that feminism encompasses "many species under one genus" (Tong, 1993, p. 1), Rosemarie Tong making further distinctions between Psychoanalytic feminism, Existentialist feminism and Postmodern feminism, all with distinctive world views. Joanne Hall and Patricia Stevens (1991, p. 17) outline the difficulty in adopting a universal lens through which to view women's experience. They suggest that researchers adopt a more generalised view. Throughout this research project I have aspired to fulfil similar principles to that which Hall and Stevens (1991, p. 19) have outlined. These include to value women and validate their experiences ideas and needs, to identify and recognise the ideological, structural and interpersonal conditions that oppress women and finally, to be instrumental in bringing about social change of oppressive constraints through the dissemination of the research results and recommendations.

Reinharz (1992, p. 7) concurs with Hall and Stevens, and celebrates the differences encompassed by the term 'feminism', but concludes that self-identification as a feminist is all the definition that is needed. This interpretation of feminism goes some way in avoiding the traditional one-sided labelling of feminist researchers, and its plurality rejects the notion of a "transcendent authority" that decides what constitutes a feminist. Whilst cognisant of the broadness of this approach, it does subscribe to the principles outlined by Hall and Stevens above, and has been of great utility. The feminist approach adopted in this research project has assisted me in actively listening and encouraging women's thoughts and words. Is has also

been invaluable in uncovering the hidden meaning behind women's words in order to examine the power relations they are subjected to as women accessing health care, and how these relations are reflected in their language. Finally, adopting a feminist approach has been enormously instrumental in the formulation of the grounded theory, which I hope will facilitate the improvement in the care of female relatives waiting in Emergency Department waiting rooms.

Curthoys (1994, pp. 26-28) contends that Aboriginal and Torres Strait Islander demands are somewhat different to those within the existing feminist framework. For Aboriginal women, the anti-male style of the Australian women's movement was generally out of place, as was the attack on traditional ideas of family. Similarly, Aboriginal and Torres Strait Islander women were wary of white women who had historically been party to the processes of racism and colonialism. Whilst the participants of this study were white, English-speaking women, I am confident that the theory produced would be broad enough to be applicable to people from a variety of cultural backgrounds who may need access to the health care system. Using Reinharz' definition of feminism as a plural, multifaceted paradigm, I am aware that whilst many women are oppressed, many other women are in fact perpetrators of oppression, suppression and repression. Similarly, within the context of this research, patriarchal power relations were often noted to be reinforced by female health care workers.

The language used throughout this paper is intended to reflect the feminist ideals I hold. Speaking in the first person does not come naturally to me. I

have been educated within a positivist paradigm and writing in the first person, despite my feminist convictions, somehow lends a degree of vulnerability, of self- disclosure, which up until now I have been conditioned to ignore. Weedon (1997, p. 258) states that researchers publishing in mainstream journals are "typically forbidden" to use the first person singular voice, yet I feel it impossible to imbue the research with intuitive feelings, thoughts and experiences without owning them.

I have taken Reinharz's (1992, p. 14) lead in using other stylistic choices such as attempting to use the author's full name when first mentioned in this paper rather than the "vague, impersonal, masculinist surnames" typical of positivist research. However, whilst I have undertaken extensive searches, some authors' given names remain a mystery and have therefore been omitted from this paper. Also using such terms as participant rather than "subject" or "informer" reflects the collaborative approach used in this study. Ann Oakley (1990, pp. 40-45) argues feminist research requires us to be interactive in interviewing, approaching participants openly, thereby rejecting 'traditional' masculine paradigms where intimacy from selfdisclosure is discouraged. Similarly, Keddy, Sims and Stern (1996, p. 451) state that for the symbolic phenomenon to be interactive, the researcher and the participant must be fully involved. For feminist ideals and to understand symbolic interaction from the participant's viewpoint, an openness and honesty is required of the researcher, and thus the stylistic approach of this paper reflects these ideals.

An analysis of language used by participants can also give greater insight into the existing power relations. Weedon (1997, p. 21) states that language is the place where actual and possible forms of social organisation and their likely political and social consequences are defined and contested. Given the long history of patriarchal silencing of women, and that, according to Weedon (1997, p. 105), the most powerful discourses in our society have firm institutional bases such as medicine, an analysis of the participants' language aided in uncovering hidden meaning behind the words used. Women's language in this study reflected many times the inherent patriarchal power they were subjected to when accessing the health care system.

#### METHODOLOGY - DEFINING THE TERMS

Various methodological approaches have been used by nurse scholars to develop nursing knowledge. However, it has been argued that some inquirers fail to examine methodologies in detail, as they tend not to explore the philosophical roots that inform the research (Appleton and King, 1997, p.15). Prior to undertaking this research, I explored a variety of methodological philosophies in order to establish the best way in which to examine the experiences of the 'waiting relative'. In doing so, I found it necessary to combine feminist theory with grounded theory methodology (underpinned by the sociological theory of symbolic interactionalism).

Lowenberg (1993, P. 62), Jane Appleton and Lindy King (1997, p. 16), and Imelda Coyne (1997, p. 629) contend that there is a lack of shared meanings

and terminology in nursing research, in particular in relation to the term 'methodology'. Confusion exists in the literature with the terms 'method' and 'methodology' being used interchangeably. For example, оНН aklif; lkiHWilson and Hutchinson (1991, p. 263) initially refer to Heideggerian hermeneutics and grounded theory as methods, and later as methodologies. Similarly, Appleton and King (1997, p. 14) refer to ethnography, phenomenology and grounded theory as methodologies, whilst Phyllis Stern (1994, p. 214) refers to them as methods. Keddy, Sims and Stern (1995) argue that method and methodology are intricately woven, and so the question posed is this - what exactly is the difference between a method and a methodology?

Harding (1987, p.2) describes a method as a technique for, or way of proceeding in gathering evidence, which by themselves are not bound by a philosophical stance. As Jacquelyn Campbell and Sheila Bunting (1991, p. 3) reiterate, methods do not drive assumptions and can be used to illustrate a variety of philosophical viewpoints. A methodology, in contrast, involves a theory and analysis of how research does or should proceed (Harding, 1987, p.3). In other words, a methodological approach is more than a research method, it is both theory and method (Keddy, Sims and Stern, 1996, p.449), and is concerned with the process of gathering knowledge about what exists in the world with aims, concepts, strategies and methods (Appleton and King, 1997, p.16).

To this end, Barney Glaser (1992, p. 7) states that grounded theory methodology is itself a theory which is generated along side the substantive

theory it is generating. Furthermore, grounded theory is a methodology unto itself as it is a way of thinking about and conceptualising data (Strauss and Corbin, 1998, p. 8). Whilst agreeing with these statements, I am mindful of the symbolic interactionalist philosophy that underpins grounded theory. Similarly, I am aware of studies that have successfully combined grounded theory methodology with hermeneutics (such as the study of decision making of family care givers of Alzheimer's dementia patients by Wilson and Hutchinson, 1991). It is therefore possible for grounded theory to be a methodology that incorporates methods and can be adapted to other philosophical standpoints. Indeed Glaser (1992, p. 17) concurs, stating that grounded theory methods work 'quite well' for analysing data within the perspective of any discipline. In this area of inquiry, however, I view grounded theory from a symbolic interactionalist standpoint, and therefore find it necessary to explore this philosophy in a little more detail.

#### SYMBOLIC INTERACTIONALISM

Historically, symbolic interactionalism emerged in the mid to late 18<sup>th</sup> century, thanks to the work of philosophers such as Adam Smith, David Hume and Ferguson of the Scottish Enlightenment movement (Longmore, 1998, p. 44). They viewed society as a network of interpersonal communications that connect people, and approached the study of human behaviour from a social viewpoint rather than from a biological viewpoint (Longmore, 1998, p. 44). In the early and mid 20<sup>th</sup> century, the work of John Dewey, Charles Cooley, James Baldwin, and George Mead saw symbolic interactionalism evolve into a theoretical perspective which stresses the

primacy of society whilst acknowledging the individual as an active, creative source of behaviour (Meltzer, 1972, pp. 2-5).

More recently, symbolic interactionalism has been defined by as being the peculiar and distinctive character of interaction that takes place between human beings (Blumer, 1962, in Manis and Meltzer, 1972, p. 139). Further to this, Mead (1934, in Manis and Meltzer, 1972, p. 140) views this interaction in terms of three main tenets: mind, self and society. Blumer (1969, in Becker 1993, p. 257) outlines one of the main tenants of symbolic interactionalism is the belief that people act toward things on the basis of meaning that those things have for them. Such meaning is derived or arises out of social interaction with other people. Furthermore, Blumer explains that the derived meanings are handled in and modified through an interpretative process and by the person dealing with the things she/he encounters.

Contemporary symbolic interactionalism has seen the split into two methodological orientations. The Chicago school emphasises the self in terms of face to face interactions, whilst the Iowa school emphasises the functions of groups and role relations within them (Longmore, 1998, p. 45). In this study of the experiences of waiting relatives, I have focused on the influence role expectations have on the behaviour and understanding of these relatives. This study may therefore be seen as more congruent with the Iowa school than the Chicago school. The approach taken in this study, however, has also been modified through the influence of poststructuralist feminism which views the experiences of waiting relatives in terms of the

dominant discourse to which they ascribe. So whilst the Iowa school emphasises the functions of groups and role relations, this study also seeks to identify and explore the subtle discourses that influence the participants' responses, functions within a group, and role identity.

The framework for grounded theorists is underpinned by symbolic interactionalism (Blumer, 1969, Mead 1964, in Stern, 1994, Smith and Biley, 1997, p. 17, Wilson and Hutchinson, 1991, p.266). As implied earlier, symbolic interaction involves the study of the symbolic meaning of artefacts, clothing, gestures and language used by groups of people as they interact with each other (Stern, 1994, p. 215). Grounded theory was first 'discovered' by Glaser and Strauss who described the method in their first book 'The discovery of grounded theory' in 1967. As the name suggests, grounded theory methodology aims to generate theory through the systematic and careful analysis of data obtained through social research (Glaser and Strauss, 1967, p. 3). Generating theory from the data means that most hypothesis and concepts come directly from the data, and are systematically worked out in relation to the data during the course of the research (Glaser and Strauss, 1967, p. 6).

Research undertaken using grounded theory is therefore congruent with symbolic interactionalist methodology in that the researcher is required to view social phenomenon in light of the participant's social interaction and social context (Becker, 1993, p. 257). By constant comparative analysis, meanings are seen as social products, created and formed "through the defining of activities of peoples as they interact" (Blumer, 1969, p.5 in

Becker 1993, p. 257). Using a grounded theory methodology in conjunction with the Iowa school of symbolic interactionalism, I have attempted to discover how the participants in this study felt about 'being required' to wait in a waiting room for inordinate periods of time, and what motivated them to accept this role of the 'waiting relative'. Becker (1993) maintains that the use of such a theoretical perspective to view human behaviour necessitates the viewing of social change and problems in light of their social interaction and within their social context.

## PROCESS OF INQUIRY: GROUNDED THEORY OVERVIEW

In order to understand the decisions taken in recruitment using theoretical sampling and data analysis, it is useful to place the process of grounded theory analysis within a historical context. The central focus of grounded theory methodology is the development of theory through constant comparative analysis of data gained from theoretical sampling (Coyne, 1997, p. 625). Keddy, Sims and Stern (1996, p. 450) summarises the process as follows -

Small bibbits (or 'data bits') are extrapolated from the field notes and their properties are compared with one another and the existing literature, if any is available. As the properties become more formalised categories, we begin to link them together. We live with the data as they become part of our essence, constantly revising the analysis...and allowing our values, intuitions and hunches permeate the process.

The result sought from grounded theory is a small set of highly relevant categories with properties that are connected by theoretical codes and are integrated into a theory (Glaser, 1992, p. 42). Such theory development ensures that the theory is grounded in empirical data as opposed to a theory that is logically derived (Bower, 1989, p. 43).

Theories that are 'discovered' in this process can be ordered in their conceptual density (Stauss and Corbin, 1998, p. 23). Some theories are more abstract and can therefore have broad applicability, but are more removed from the data from which they arise. Glaser and Strauss (1964, p. 32-4)

refer to these types of theories as formal theories. Theories that are less abstract and more specific to the phenomena from which they arise are referred to as a *substantive* theory (Glaser and Strauss, 1964, p. 33). This research paper aims to produce a substantive theory to illustrate the phenomenon of waiting for female relatives in the ED setting. The theory is specific to the setting and the gender and is therefore substantive in nature.

The methods employed by researchers to produce a grounded theory have been contentious. Since the initial 'discovery' of grounded theory by Glaser and Strauss in 1967, there has been a methodological divergence of opinion occur between these two authors. Smith and Biley (1997, p. 30) suggest that this has confused researchers as to what constitutes grounded theory and subsequently, a dilution of grounded theory methodology has occurred.

Glaser and Strauss (1967, p. 5) initially suggested that there were no clear-cut procedures or definitions to describe the method of grounded theory. Instead, they aimed to stimulate other theorists to codify and publish their own methods for generating theory (p. 32). This possibly contributed to the confusion of grounded theorists as variations of grounded theory emerged. Stern (1994, pp. 213-6) contends that in some instances, data is manipulated in "any old way" and is named grounded theory with little regard to the principles first outlined by Glaser and Strauss. Conversely, Stern contends that grounded theory is both an art and a science and she therefore dismisses any description of how to perform grounded theory. A dichotomy clearly exists in the research world regarding the definition of a grounded

theory. Stern denounces attempts to clearly define the research methods needed to produce a grounded theory, yet laments the loose application of the term 'grounded theory' to studies using a variety of methods. Stern suggests that one way novice researchers can ensure their research subscribes accurately to grounded theory methodology is to enlist the help of an experienced mentor.

In my case, I learned about grounded theory over a period of years and then with the assistance of three mentors. My first mentor was Dr Carmel Seibold who introduced me to grounded theory methods in 1996, and since then I have undertaken another unit of research as a precursor to this research study, again guided by Dr Seibold. During this time I have had some limited experience in interviewing techniques and employing grounded theory methods of analysis to this data whilst being guided by Dr Seibold. My supervisor, John Struhs is also well versed in grounded theory techniques and has been invaluable in promoting a creative approach to data analysis. Finally, I attended a seminar entitled "Principles and Practice of Grounded Theory" held by Dr Barbara Bowers, Professor of Nursing at the University of Wisconsin - Madison (31/07/00, Patrick campus, ACU). Her doctoral studies used a grounded theory approach which she undertook at the University of California - San Francisco under the guidance of Strauss and Glaser themselves. As a novice researcher, I was very cognisant of the variation in approaches and often wondered if this project was 'on the right track'. I found Bowers' seminar reassuring and enlightening that this project was indeed subscribing to the grounded theory methodology outlined by Glaser and Strauss.

Perhaps in an effort to address the issue of what exactly constitutes grounded theory, Strauss and Corbin (1990) produced a book entitled "Basics of Qualitative Research: Grounded Theory Procedures and Techniques" in which descriptive steps were outlined in the process of theory generation. Much criticism ensued with Keddy, Sims and Stern (1996, p. 450) arguing that such description suggests "linear thinking" that opposes the original intent of Glaser and Strauss to provide a circular and fluid process of constant comparison to generate theory. Similarly, Stern (1994, p. 219) contends that "book learner's" research, i.e. research conducted by novices without the input of experienced mentors, is often incomplete and thin, usually getting no further than categorising the data. Glaser (1992, p. 104) goes so far as to say that Strauss changed the format of grounded theory (which they developed in their previous three books together) to such an extent that Strauss' version is a completely different methodology. Glaser refers to it as "a preconceived, full conceptual description which hits upon all the general interests of sociologists, irrespective of relevance, fit or workability". Strauss' 'general interests' are defined by Glaser as being "pet codes" that are not necessarily related to the data, but are explored by Strauss in many of his studies. Stern (1994, p. 220) states that one of the major differences between Glaser's and Strauss' approach is that Glaser asks "what do we have here?" and focuses on what is contained in the data, whilst Strauss asks "what if?" relating various 'pet codes' even if they don't appear in the data.

The thing that is most disheartening in Strauss' and Corbin's interpretation of grounded theory is the apparent disregard they appear to have for the creative, intuitive input that makes grounded theory so different from pure descriptive studies, or indeed quantitative methodologies. Glaser (1992) is critical of how Strauss and Corbin break up concepts such as coding, theoretical sampling and memos as separate entities with defined procedures. He believes it is unnecessary as it can lead to forcing of concepts on to data, and that much of what they have defined occurs in many cases far less formally. It is this kind of definition that stifles the skills, creativity and the intuitive sense. Becker (1993, p. 258) contends this necessary to make conceptual connections from social situations that appear to be quite different. I believe that creativity and intuition is central to the construction of a valid grounded theory that is true to feminist principles.

Susan Moch (1990, p. 158) outlines intuitive knowing as the immediate knowing of something without the conscious use of reason. She argues this can happen when one is open and trustful that "knowing" without "knowing how" can occur. Similarly, Glaser and Strauss (1967, p. 225) stated that a researcher knows what she/he knows, not only because of exposure to the field of study, or carefully discovered and generated hypothesis, but because "in his (sic) bones he feels the worth of his final analysis". This type of knowing, the intuition and creativity that should be instilled into the research process, is ignored by Strauss' and Corbin's version of grounded theory methodology, and certainly disregards the approach of being open and trustful, qualities that are inherent in feminist research practices. Therefore, after much study and reading, and with the help of my mentors,

I have adopted Glaser's and Strauss' approach to grounded theory as this best suits the research topic and my feminist ideals.

#### ETHICAL CONSIDERATIONS

The regional centre in which this study took place has a population of 83,000 people and supports, amongst many other health care facilities, two acute hospitals, one public, the other private. The decision to recruit from these two institutions was based primarily on convenience, although the contrast between the waiting experiences of relatives in public and private hospitals was also of interest. In order to recruit from these two institutions, ethics clearances had to be obtained from the Australian Catholic University, and each of the two hospitals. Obtaining the ethics clearance from the hospitals took three months as they were in the process of combining their ethics review boards and considerable delay occurred in establishing their inaugural meeting. However, after three months of phone calls and waiting, the research proposal for this study was considered and passed.

Obtaining an ethics approval from the University was somewhat easier and decidedly quicker, aided by a standardised application form. This, however, tended to be a double-edged sword, as such forms are made applicable to a wide spectrum of research paradigms. Questions pertaining to estimated number of participants, their gender, the age range of participants and their state of health are near impossible to answer if using a grounded theory approach. Barbara Bowers (1989, p. 49) concurs, stating that the inability to predict which participants will be sought to accomplish theoretical sampling

and how interview questions will evolve creates difficulties in writing and submitting research proposals. Similarly, Smith and Biley (1997, p. 20) state that grounded theorists cannot decide the size of the sample to be taken as one keeps sampling until saturation of categories has occurred. submitting the ethics approval form, I made the rough estimate of eight participants, but six were all that was needed for saturation to occur. I decided that participants needed to be over the age of 18 years as I felt younger participants may experience undue psychological discomfort as a result of the interview process. In so far as the interview questions were concerned, I submitted an "aide de memoir" (see appendix 3) to the ethics committees rather than set questions, as set questions would be incongruent with the theoretical sampling and question alteration which occurs in the theory generating process. The 'aide de memoir' was later altered to a more general 'interview guide' (see appendix 4) in order to give the interview as much freedom as possible for relatives to explore their experiences and raise issues that were important to them.

Once ethics clearance had been obtained from the two hospitals involved in the study, meetings were held meetings with the Nurse Unit Managers of the Coronary Care Units and the Emergency Departments of the two hospitals. In these meetings I outlined the nature of the study and its aims so that if any relatives had any questions, they could be forwarded on to me. Generally, these meetings were encouraging with general support being given to the research topic, although one Unit Manager insisted that if relatives had any questions relating to the care of their loved one they be referred to the Unit Manager. The implication that I not give information when asked

was, in my view, ethically unreasonable. This study highlights the power inherent in the control of information, and I felt that if asked, I was obliged to share what knowledge I had with the participant. I also hoped that participants would see me as an entity independent from the hospitals and as such, would be more likely to seek information from 'an outsider'. Fortunately, no participants were recruited from this Unit Manager's unit, but if they had been, I would have felt obliged to share what information I had before referring them to the Unit Manager.

After meeting with the Unit Managers, I arranged to meet staff of the Coronary Care Units at their next staff meeting. The purpose of this was to disseminate information about the study and allow them to ask questions. I have also undertaken to share the results with staff members at the completion of this study.

The letters of introduction given to relatives (see Appendix 1) outlined the participant's role in the study and included the provision to discontinue their participation at any time without giving any reason and without fear of penalty to themselves or their loved ones. This was reinforced verbally by me prior to conducting the interview. Two consent forms were signed (we could then have a copy each) after the participant had had time to ask questions and understand the study's aims, before proceeding with the interview process (see Appendix 2). The availability of two counsellors, one at each hospital, was arranged prior to the commencement of interviews in the event that participants were in need of counselling as a result of the research process. This was explained in the letter of introduction given to

participants, and at completion of the interview when participants were asked how they felt about the research process and if there were any issues with which they felt they needed assistance.

An audio-taped interview was conducted with the participant at a mutually convenient time and place, after which the tape was transcribed verbatim by me to maintain confidentiality. The locations in which interviews took place varied and ranged from hospital offices to my home. In each case the privacy of the participants was considered of paramount importance so as to enhance confidentiality. Pseudonyms were used and references to specific locations and events were deleted or disguised in the transcriptions and in the final report. The audio-tape was erased after transcription and the transcriptions and field notes stored in a locked filing cabinet in my supervisor's office at Australian Catholic University.

Participants were contacted once transcription had been completed to review the interview, being encouraged to add or delete anything they wished. By reviewing the interview, words or thoughts participants did not want to share could still be removed and points elaborated or clarified. I believe that this ensures, as far as possible, 'informed consent' on behalf of the participant. It is difficult, if not impossible to consent to words or thoughts that have not yet been formulated as is the case at the beginning of an interview. Encouraging the participants to review the interview transcripts and allowing them to amend them as they wish secures an even 'better informed' consent.

#### RECRUITMENT OF PARTICIPANTS

Initially, letters to self-selected potential participants were left in the waiting rooms of the coronary care units at the two participating hospitals. A sign above these letters read "Are you tired of waiting?". The letters were in brightly coloured envelopes to attract the attention of potential participants, with the words "An invitation" written on the outside. Inside the envelopes were letters of introduction, explaining the study and inviting the reader to contact me by phone to arrange an interview time and to nominate an appropriate location for the interview. It was hoped that, because the participants were self-selecting, they would be less likely to feel obligated to take part in the study than if I had approached them personally, especially if I had cared for their loved one. Coupled with this is the fact that my contact with potential participants, in the Emergency setting, would usually be at a time of great mental and emotional stress for the waiting relative and I did not wish to burden them more by introducing this study to them. By the time relatives collected the letters in the Coronary Care Unit, it was likely their loved one's health status would be more stable than at the initial presentation in Emergency, and relatives would therefore be more receptive to information regarding this project. Relatives from non-English speaking backgrounds and those unable to read the letters inviting participation were obviously unable to self select and were excluded from this study.

There were two problems encountered with this method of recruitment. Firstly, the letters kept disappearing from the waiting rooms yet, after two

months, nobody had contacted me to arrange an interview. Secondly, this method did not allow for purposeful or theoretical sampling. Patton (1990, p. 169) defines purposeful sampling as a way in which information rich 'cases' are targeted in order to study a phenomena in depth. Hence, the participants in this study were not chosen on the basis of their representativeness, but rather they were chosen for their expert knowledge of the phenomenon being studied. Statistically speaking, this type of sampling is non-representative, but it is informationally representative, in that the data will be obtained from participants who can stand for other persons with similar characteristics (Sandelowski, 1995, p. 181). In essence, the events, incidents and experiences are the objects of purposeful sampling, and not potential participants per se (Strauss and Corbin, 1998, p. 202), and as such, participants who could impart informationally rich accounts of their experiences waiting were sort for this study.

There have been many interpretations in the literature of what constitutes purposeful sampling. Selective sampling can be seen as one form of purposeful sampling in that it involves "the calculated decision about who and where to sample prior to the onset of data collection" (Becker, 1993, p. 255). Purposeful sampling implies that the research problem is well defined and that the participants recruited will be those who are most likely to answer the question being asked. Initially, all grounded theory studies begin recruiting participants using this technique, being guided by the purpose of the study and other constraints such as time, participant availability and researcher interest (Bowers, 1989, p. 54).

However, once the first interview has been conducted, the data can be analysed and further participants selected based on those who will be able to further shed light on the emerging codes and developing theory. Coyne (1997, p. 629) defines this technique as theoretical sampling which she identifies as a form of purposeful sampling. In order to produce a grounded theory, it is critical that data collection, coding and analysis take place simultaneously (Glaser and Strauss, 1967, p. 43, Becker, 1993, p. 256, Coyne, 1997, p. 625). Bowers (1989, p. 45) argues that sensitivity is "severely restricted" if analysis does not take place simultaneously with participant recruitment as this guides and may even change the interview questions, research questions and the research hypothesis. In turn, this can lead to changes in data collected and participants sampled.

Anselm Strauss and Juliet Corbin (1990, pp. 177-186) divide theoretical sampling into two further categories, open sampling and variational or relational sampling. Open sampling involves samples that will provide the greatest opportunity to gather the most relevant data relating to the phenomena under investigation. Relational or variational sampling, conversely, involves moving from situation to situation gathering data on theoretically relevant categories. Glaser (1992, p. 102) is quite critical of this division, claiming such techniques "fractures the concept (of theoretical sampling) and dilutes its meaning", and argues that such sampling is encompassed less formally within theoretical sampling. Coyne (1997, p. 627) concurs stating that any prescription of steps in theoretical sampling is "antithetical to the ethos of theoretical sampling" and may encourage researchers to "look for data rather than look at data".

Mindful of the concept of theoretical sampling and coupled with the lack of response to the ever-disappearing letters, it became apparent that in order to recruit participants for this study I would have to make personal contact with potential participants. While this meant additional work, it also gave me the opportunity to evaluate potential participants and select only those whom I felt would give me the best, richest and most theoretically relevant story.

Being cognisant of the significant stress relatives face when their loved ones are critically ill, I approached potential participants inside the ED, only after their loved one's medical condition was stablised, and usually just before they were transferred to a ward. I felt that approaching potential participants at this time would be less stressful for them than approaching them at a time when their loved one's medical condition was less stable. Potential participants were given a brief explanation of the study and, if they were still interested in participating in the study, a letter of introduction was given to them to be read at a more convenient time. They were told that I would catch up with them on the ward when they were next visiting, in a few days time. It was emphasised that they could withdraw from the study at any time without explanation, and without penalty, as I felt that some may not feel inclined to participate once they had read more about the study. However, of the seven people I approached, only one declined to participate after my second contact with them.

The time from the loved one's admission to the interview taking place was at least 48 hours but was variable due to my wish to accommodate the needs of the participants during this hectic period of their lives.

#### THEORETICAL SAMPLING AND SAMPLE SIZE

Theoretical sampling and sample size are closely linked and in this section of the paper I have outlined the decisions made in choosing participants for this study. Whilst it is necessary to make mention of the codes uncovered, a more detailed analysis of these codes is explored under the heading of 'Findings'.

Initial participation in the study was restricted to those who were above the age of 18 years old, had been waiting longer than 30 minutes to see their loved one who was receiving care. To get the richest story, I also sought relatives whose loved ones' illness was acute requiring the services of an ED and that they had been left waiting alone in the waiting room without any support from other relatives. It was under these conditions I found it most curious that relatives waited passively in the waiting room. I also restricted participation to female relatives in line with my feminist convictions. The time from admission to time of interview was variable, from 48 hours to 92 hours. I deliberately did not interview before the 48 hours as Price et al (1991, p. 185) had reported that participants interviewed within 24 hours of their loved one's admission had difficulty in following directions.

The first participant who consented to interview was a woman in her late 70s whose husband had been admitted to the ED. I chose 'Anne' because she had remained in the waiting room for quite a while before coming in to see her husband, and because she was talkative and I suspected she would have little problem in discussing her experience with me. I was right, and after one-and-a-quarter hours, I found I had extensive data, including favourite recipes and other material not specifically related to the waiting experience. She was, however, able to furnish a rich description of her current experience with examples from another waiting experience, when her son was critically ill.

Using the grounded theory technique (outlined earlier in this chapter), codes relating to knowing staff, anger, being left out, powerlessness, and language began to emerge. The second participant I chose to interview was slightly younger than Anne. Coyne (1997, p. 626) states that theoretical sampling means selecting according to emerging categories rather than a concern for variables such as age, class or characteristics of the sample. Mindful of this, I did not ask participants questions relating to demographic data, and so only rough estimates of ages has been made. I deliberately chose a younger participant than Anne as I thought that her age might be significant in her perception of medical power relations and the way in which the language she used distanced her from any criticism she voiced of her experience waiting.

The second participant, 'Bea', was in her late 50s and, unbeknownst to me prior to the interview, is a retired nurse. Her husband had taken ill and she

was asked to "take a seat" in the waiting room where she remained for a considerable length of time. The interview, however, focused more on a previous experience waiting in a waiting room whilst her father was being treated in a metropolitan hospital ED. Curiously, despite her familiarity with the medical system, analysis of this second interview and notes uncovered similar codes to the first interview. At this point, I started to think that the experience of the waiting relative was not as dependent on the age of the participant as it was to some other factor. Consequently, I started to explore the notion of the participant's medical knowledge or exposure to medical discourse.

The third participant, 'Carol', I knew was a practising nurse in her mid-40s. It was her daughter who required medical care. As I had anticipated, Carol's participation was invaluable as she could give insights into waiting whilst having some knowledge of what care her loved one was receiving. Carol waited in the waiting room for around an hour before being 'allowed in' to see her daughter. I wondered if her perceptions of power, trust and the like were any different to the previous participant who had possibly nursed in an era when medical decisions and power were accepted by nurses and relatives alike, without question.

Similar codes were re-emerging in the analysis of this third interview as was uncovered in Anne's and Bea's interviews, furthermore, a new code of affiliation with other waiting relatives, was added. Re-examining the previous interviews, I found this code to be present there too, but memos made at the time of analysis were to the effect that this was related to

passing time and distractions. Now I began to realise that it was a code unto itself. Keri Smith and Francis Biley (1997, p. 18) argue that the analyst must return constantly to the data sources to check aspects of the emerging interpretations. Indeed, some codes, categories and memos written previously were re-written as more data highlighted certain aspects of the participant's experience. It was also at this point that I began collapsing codes, for example, 'expectations of a long wait' was included in the code of 'passive outsider', and 'knowing staff' was included in the code of 'trust'.

The forth participant, 'Dee' was in her 40s and had little experience of anything medical. Her husband had taken ill and, as with all the participants, waited in the waiting room until 'somebody was ready' to allow her to see her loved one. Again, similar codes emerged, such as trust, getting in the way, affiliation with other waiting relatives, powerlessness and being a passive outsider. The fifth participant, 'Francis', was, unbeknownst to me, another ex-nurse in her mid-60s. The circumstances surrounding her inclusion in the study was when her mother was admitted to the ED. However, Francis illustrated her story with examples from previous experiences of waiting when other loved ones were ill in metropolitan hospitals.

I was becoming more excited as similar codes and categories again emerged. It was more than just coincidence that these themes kept surfacing; I was getting closer to the essence of the experience of waiting for relatives. I had used the same interview guide for the forth and fifth interviews, and most of the data gained from these interviews fell within the existing codes and categories. Strauss and Corbin (1998, p. 292) describe how data

collection should continue until theoretical saturation takes place. Theoretical saturation means that no new data is being unearthed and that any new data adds, in only a minor way, to variations of major categories. Similarly, Glaser (1992, p. 102) states that theoretical sampling ceases when the categories are "saturated, elaborated and integrated into the emerging theory". Margarete Sandelowski (1995, p. 180) contends that, in addition to saturation, sampling should cease when the researcher "feels comfortable" that the data already collected is sufficient. By the fifth interview, in hindsight, saturation of core categories and subcategories had occurred. However, being a novice researcher, I felt that in order to be sure and to feel "comfortable", I needed to conduct one more interview. The sixth participant, 'Ellen', was in her early 50s and recounted the story of her experience of waiting when her nephew was admitted to the Emergency Department. She also told me of previous experiences of waiting when other family members required care at other hospitals. Not surprisingly, data from this interview supported previously identified codes and categories.

Part of the problem I had with stopping at the fifth interview was the concern that this was a small sample. Some of the literature did not negate this concern. For example, Morse (1994, p. 228) recommends about 30 to 40 participants needed to be interviewed and/or observed for an effective grounded theory study. Wilson and Hutchinson (1991, p. 269) claim that a sample of 20 to 30 participants is typical. My application for ethics clearance projected eight participants would be required for interviewing in order to sufficiently explore the waiting experience. The question now arose - how many participants is enough?

Clearly, the end sample size is reliant upon theoretical saturation and a feeling the researcher has that data collection is sufficient. Stern (1994, p.218) therefore concludes that a grounded theorist should never make excuses for the size of the sample because she/he continues to collect data until she/he is satisfied she/he is not hearing anything new. Bowers (1989, p. 54) states that a sample size may be very small, for example five or six. In her lecture on the topic Bowers (31st July 2000, Australian Catholic University, St Patrick's Campus, Melbourne) went further saying that one participant may be enough and that "three is plenty". This is because the analysis that takes place uncovers the shared meanings of participants and society, an assumption that underpins the methodology of symbolic interactionalism. By analysing just one interview, it is possible to conceptualise a theory that is potentially applicable to a wider audience. Furthermore, the theory can then be subjected to testing.

Sandelowski (1995, p. 183) surmises that an adequate sample size is

"...one that permits - by virtue of not being too large - the deep, case oriented analysis that is a hallmark of quantitative inquiry, and that results in - by virtue of not being too small - a new and richly textured understanding of the experience".

It was heartening to speak to other researchers at Dr Bowers' seminar, as one researcher employing grounded theory techniques stated that he interviewed nineteen participants, but could have stopped after 5 because

he was hearing the same thing over and over again. This was tremendously reassuring for me, and using the concurrent triad of theoretical sampling, coding and analysis, I had the courage to stop sampling after six participant interviews as theoretical saturation had been achieved.

## THE INTERVIEW PROCESS: THE VENUE

After making contact with potential participants for the second time, a mutually convenient time and place for the interview was arranged. Two of the participants came from outlying country areas so the most convenient time for them to be interviewed was when they next visited their loved one in hospital. A further two participants suggested an interview within the hospital setting without any prompting, stating that this would be the most convenient for them. In order to ensure privacy, and in order for the participants to feel comfortable enough to articulate their experiences of waiting without the threat offending staff, I negotiated with the respective wards in which the loved ones were now being cared for the exclusive use of their "visitor/patient lounges". A 'Do Not Disturb' sign was placed outside of the room during the interview and staff were made aware that an interview was being conducted through personal or written communication.

Despite these provisions, one interview was interrupted by a staff member who profusely apologised for the interruption and left hastily. Fortunately, at the time of the interruption we were nearing the end of our discussion, which meant that trust and rapport had already been established. Consequently, the interruption did not exert a negative effect on the

interview or the participant's perception of the interview process when she was asked about it at the close of the interview. An interruption earlier in the interview could have had a negative impact on the development of trust. As it was, I think this interruption affected me more than the participant. I felt particularly annoyed that I could not guarantee the participant's privacy despite my best efforts, and I felt wholly responsible for the interruption. In hindsight, using the hospital as a venue for interviews was not ideal. Aside from the potential interruptions, it is hard to judge how much impact such a setting has on the participant's responses, either positively or negatively. Pierre Cossette (1998, p. 1361) espouses that the place where such interaction as these interviews occur is likely to have specific meaning for one or both of the interlocutors. I did not explore the effect the hospital setting may have had with the participants, but believe that some may have felt intimidated by the surroundings or less inclined to be critical of the institution in which the interview took place. However, four participants nominated the hospital as the place to be interviewed, and, coupled with its convenience, it is conceivable that they may have felt comfortable within this setting.

Glaser and Strauss (1967, p. 226) emphasise the importance of trust between the researcher and the participant and claim that if this trust does not develop, then analysis suffers. The analysis can suffer if participants feel that they cannot be honest with the researcher for fear of negative consequences, for example, offending the researcher, or a fear or ridicule or retribution for expressing negative aspects of their experience. The data may therefore fail to reflect the experience in its entirety. I

recognise the impact that the interview setting may have on the development of trust, and on the ability of participants to see me as an independent party to the institution. In the cases of the four participants interviewed at the hospital, however, a connectedness and an honesty developed during the interview. This was born out in the transcripts, and indicates that trust development was not unduly impaired by the decision to conduct interviews within the hospital setting.

The remaining two participants were interviewed outside of the hospital setting. One participant, it transpired, lived nearby to my own house and seemed quite pleased to accept an invitation to be interviewed at my home over a cup of tea. This was the best interview I conducted, possibly because I was more relaxed in the familiar setting of my own home, and also because I had the experience of four other interviews behind me. Whilst it is important to accommodate the feelings of the participant in choosing interview settings, I now recognise that the setting may also affect the novice researcher. Feeling comfortable with the interview process and being in a setting that was personally reassuring meant that I was less concerned at the time of interview with extraneous issues and was more focused on the story the participants were sharing with me. This assisted me in achieving what Robert Park (1950, in Bowers, 1989, p. 43) suggests is a position of "marginality". This is when the researcher views the participant's world from the inside whilst maintaining the distance necessary to raise analytical questions. I believe this can only take place if the researcher has had some experience of interviewing and is relaxed in the setting of the interview.

The other participant elected to be interviewed at her place of work. It turned out to be the most frustrating of all the interviews as we were frequently interrupted and the interview was fragmented. Whilst this did not seem to affect the participant, I found it difficult to concentrate, to ask appropriate questions and keep track of what was being said. Initially, I thought that such an interview setting would be ideal in that the participant would be more relaxed in a familiar setting. However, what I had not counted on was my own reactions to this environment. Again I found it difficult to concentrate and pick up on salient points when the participant moved in and out of the room. This was in spite of my taking notes during the interview. As part of negotiating interview venues with participants in any future study, I will be sure to discuss the issues of privacy and the need to ensure freedom from interruptions as priorities in making the decision as to where the interviews will take place.

#### EASING THE POWER DIFFERENTIAL

I was mindful of a perceived power imbalance that might exist between the participants and myself. Keddy, Sims and Stern (1996, p. 452) concede that whilst the collection of data and verification of themes and hypothesis can be a non-hierarchical exercise, the education and skill of the researcher "must, in the end, be acknowledged". This implies a power imbalance between the participants and the researcher based on the skill and education of the researcher. Coupled with this is the knowledge of all the participants that I am a nurse, and in many cases, was the nurse who cared for their loved one when they were initially admitted to the Emergency Department. Indeed,

Reinharz (1992, pp. 24-6) contends that every aspect of the researcher's identity can impede or enhance the empathy needed to facilitate the development of ideas, the construction of meaning and the use of words by the participant that say what she means.

To breakdown any perceived power differential between the participant and myself, I employed both physical and mental strategies. physically, I only ever wore casual clothes to the interviews, never a nurse's It is possible that whilst some participants may have been uniform. intimidated by the nurses uniform, the uniform also associated me closely with a powerful institution. It was my aim that participants viewed me as an independent entity, and wearing casual clothes was one way to convey this. I also ensured that the seating arrangement was casual, with me seated at the same height or lower than the participant to convey the equality of our relationship and the reciprocal nature of the interview interaction. Whilst the tape recorder can be off-putting for some people, it was necessary to have it within relatively close proximity to the speakers to ensure a good recording. I found however, that once we began talking, most, if not all the participants became so engaged that the recorder was soon ignored. Eye contact was used in a non-threatening manner, but was not something I was cognisant of at the time of interview. Similarly, until the tapes were transcribed, I was not really aware of touching two of the participants in an effort to comfort them. It is probable that at the time of interview, I was far less analytical than I am presently, and such acts as touching and maintaining eye-contact were born from a genuine interest in the participant's story and well being.

Mentally, I strove to be a careful and cautious listener, and tried to hold myself in check when the interview strayed into areas outside of the waiting experience. I strove to form a connectedness with the participants which Reinharz (1992, p. 20) and Moch (1990, pp. 156-8) espouse as integral to the diminishing of boundaries and to the development of trust. Reinharz (1992, p. 36) suggests multiple interviews of participants as a way in which to build this trust further, but due to the time and budgetary constraints of this study, singular interviews of participants were conducted. However, sharing the transcription with participants and inviting their comments I think also facilitated the development of a trusting relationship between the participants and myself. Keddy, Sims and Stern (1996, p. 449) encourage the use of feminist principles when interviewing, such as an interactive dialogue which is empowering, reflective, transformative, non-hierarchical, and evolving. The richness of the data obtained from the interview process reflects the trusting, empathetic engagement and authenticity that was built into my relationships with the participants.

Often during the interview process, participants would ask my opinion of their loved one's diagnosis and precipitating factors and of the current treatment their loved one was receiving. I was grateful for the opportunity to share something of myself, to self disclose and to develop further, what Reinaharz (1992, p. 20) refers to as, a sense of connectedness with the participants.

#### LENGTH OF INTERVIEWS

The longest interview took an hour-and-a-quarter and was the first interview to be conducted. The more interviews I conducted, the more focused they became in accordance with the evolution in the interview guide. The last interview took just under forty minutes. I think too, the more interviews that were conducted, the more skilled I became in directing the discussion away from experiences that were unrelated to the waiting experience.

### INTERVIEW QUESTIONS

Each interview started with a standard opening, which was -

Cast your mind back to the period immediately after your loved one was admitted to the Emergency Department and you were asked to wait in the waiting room. Tell me what happened.

Despite the requirement of the University ethics committee to view likely interview questions (see appendix 3), a more accurate guide to the interviewing procedure was constructed after gaining ethics approval (see appendix 4). This guide consisted of broad topics that I wished to cover that may have been relevant to the participants' experiences of waiting. They did not constitute questions unto themselves and so left some leeway in guiding the interview discussion into these areas, or, more importantly, into areas nominated by the participant. However, the topics were still largely representative of the sample questions originally submitted to the ethics committee.

Glaser (1992, P. 25) contends that the researcher "never ever" asks questions directly in interviews as this preconceives the emergence of data. Similarly, Bowers (1989, p. 54) reiterates that a structured interview schedule is inappropriate for grounded theory studies. With this in mind, the only inquiry that remained constant throughout the interview process was the opening inquiry outlined above. The interviews were therefore openended and guided largely by the participant. Reinharz (1992, p. 18) explains, that open-ended interviews facilitate the exploration of the participant's views of reality and therefore allowed free interaction between the participants and myself.

The initial set of guiding topics, those topics that I thought would be relevant to the experiences of waiting, changed only slightly after the analysis of the first interview. Coyne (1997, p. 626) illustrates how the evolution of the interview topics are linked to theoretical sampling. She states that interview questions may change as categories and their relationships are identified through theoretical sampling. For instance, time perception whilst waiting was not altered and did not seem to be an issue with the first two participants, however, the ability to 'pass time' was fundamental to waiting experienced by relatives. This category, as more interviews were conducted and analysed, was eventually linked to the participant's ability to distract themselves from feelings of anxiety and concern for their loved ones. Thus the guiding topic of 'time' was used as a prompt only, and issues surrounding the participants' perception of time were freely explored.

#### ANALYSIS OF THE DATA

It has been exceedingly difficult to write this chapter in a prescribed order. Equally, it has been difficult to extrapolate the steps I took in undertaking this project, as general reading, theoretical sampling and data analysis took place simultaneously. Similarly, as each step in the research process was dependent on the other, it was difficult to decide which phase of the process to explain first. Lowenberg (1993, p. 62) is critical of nursing research manuscripts that dedicate 'a major portion' of the report defining, specifying and justifying the technical aspects of the research approach. She contends that this reinforces the tendency of nursing to feel obliged to 'prove' its scientific merit, and contrasts this sharply with the social sciences where little room is given in manuscripts outlining technical aspects of the research.

In contrast to this, Smith and Biley (1997, p. 23) contend that the usefulness of a grounded theory study can only be evaluated if all the processes of the method are made explicit. Similarly, and in lieu of the lack of structure inherent in grounded theory, Stern (1994, p. 219) states "I don't care what you do as long as you tell me about it"! Bowers (2000, personal communication) agrees and states that the methods section of a grounded theory research paper should be the largest section. With so many variations in research strategies claiming to be grounded theory, I find it necessary to outline the process I utilised in some detail.

Once the first participant had been recruited, and an audio-taped interview conducted, the interview was transcribed verbatim. Each line of the transcription was numbered to allow for ease of cross - referencing. I decided to transcribe the interviews myself for four main reasons. Firstly, it enabled a greater degree of confidentiality for the participants, as the participant's voice, name, events and location would only be know by me. Secondly, I was able to correlate the notes taken during the interview with the transcription as I listened to the tape. Thirdly, I was able to add notes relating to pauses, hesitations, nervous laughter, and other nuances that might otherwise be overlooked by 'an outsider' transcribing the tape for me. Cossette (1998, p. 1361) states that such language factors give context to the statements of the speaker and helps make them meaningful for the hearer. Finally, it immersed me in the data. It took quite a few hours just to transcribe one interview, but after this time I had started to become quite intimate with the data and with the way the women spoke, and it set me thinking about possible codes even at this early stage.

The next step was to do a line by line analysis of the transcript. From this, dominant themes started to emerge as I wrote notes to myself (memos) about the meaning behind these themes, the conditions under which they occurred, and other themes or dimensions that were possibly related. My comments were generally written in the large margin at the side of the transcript. A line from Anne's interview illustrates this process -

"But, ah, they just said to take a seat in there and we'll come for you when we want you."

## Memos I wrote relating to this line included -

"just take a seat" implies she is unimportant? Flippant remark by staff?

"when we want you" by sitting out there is she unwanted? Huge power difference, controlled by staff.

At times, the memos were rambling thoughts, at other times, single words. I also wrote memos relating to the interview process alongside the point of the transcript in which they had occurred. Red pen was used to easily identify those memos that were taken during the interview itself, and blue pen for memos made during the line by line analysis. Memos made during the interview ranged from interpretative observations such as "(participant) looks uneasy, sitting on edge of seat, using lots of hand signals" to straight observation such as "teary". I also jotted a word or phrase that would jog my memory of where in the interview and in what context these observations were made.

To classify emerging themes, grounded theorists use two terms - categories and properties. Glaser and Strauss (1967, p. 36) defined categories as themes that stand by themselves as a conceptual element of the theory, whilst a property is a conceptual aspect or element of a category. After analysing the first transcript, common themes started to emerge with some related properties. As further data was gathered, some of the original themes were in fact identified as properties of another category. The more

data I collected, the more I reviewed previous memos, codes and transcripts in order to make sense of, and integrate, the emerging theory. One mistake made in this process, however, was not dating the memos I had made. Dating the memos would have made it much easier to follow the evolution of the theory, and would have saved time as I would not have needed to revisit hypothesis and categories I had already dismissed or collapsed. In any case, the first interview gave me enough data to establish the start of some possible core categories and to direct me in choosing, by theoretical sampling, the next participant.

After analysing the second transcript using the line by line technique and by constantly asking the question "what is going on here?" of the data, similar dominant themes started to emerge. At this point, I started indexing these themes as categories. Each category was written on a manila folder and memos and pieces of transcript (identified by its corresponding line number) related to this category were copied onto an A4 sheet of paper and then filed in the folder. Using direct quotes from the transcripts is known as "in vivo coding" (Glaser and Strauss, 1967, p. 246), that is using the participants' own words to represent the code or property. I found that by using the participant's own words, it kept the developing theory grounded in the data, and thereby kept the memos, categories and properties focused upon the emerging theory. Also, some of the quotations from participants summed up the category so succinctly that they represented the category beautifully. An example of this is the property 'being with'. Many of the participants used this term, but were often unable to explain why 'being with' their loved one was so important. Rather than replace the term 'being with' with

something a little less ambiguous, but not necessarily as representative, such as the term 'touching', I have kept the original term to represent the vast array of emotion and need that the participants were expressing.

As more transcripts were analysed, previous indexing was refined. Memos and in vivo codes were reallocated to different categories and some categories were refined or combined. I wound up cutting up the original A4 sheets of paper and pasting these properties into new and different manila folders, which represented new categories derived from the refinement or combination of old categories. Whilst I recognise that writing up this study without the use of a computer would be tedious in the extreme, I deliberately chose to use a "cut and paste" approach to data analysis rather than employ the use of computer programs such as NUD.IST. I felt more comfortable and more creative in being able to visualise the theory as it took shape. I do not believe a computer program would have facilitated such feelings for the data. It made more sense to me to "cut and paste", despite being a somewhat clumsy process. Strauss and Corbin (1998, p. 278) agree, saying that paper, pencil, scissors and paste can give the researcher a different feel for the research, and may be more likely to inspire creativity than a computer screen. Becker (1993, p. 258) is especially critical of computer usage in data analysis of grounded theory studies stating that it results in flat, oversimplified descriptive results. These are exactly the sort of traps that a novice researcher can fall into and are inherent in a poorly constructed grounded theory. Using a cut and paste approach helped me to avoid a theory that was merely descriptive, and assisted me in finding the connections between the categories.

Another reason I chose not to use a computer program to facilitate the analysis was the necessity to jot down ideas and thoughts quickly. I found that ideas would come to me in the strangest places and times, and the ability to capture thoughts about the data quickly was an advantage. Consequently, I had many pieces of paper that were easily filed in the folders at a later date and proved to be far more portable than my computer. After the third interview, I started playing around with models of categories and properties to visually display the links that could be made between them. This model went through many incarnations before I settled on the one presented in this paper.

Data obtained from the participants' reviews of the transcripts was generally not very helpful. Despite my encouragement of participants to add or delete or make more explicit anything they said or would have liked to say, most participants merely corrected the grammatical errors. Perhaps they perceived that such corrections did in fact serve to make their points more explicit, however some of the nuances were lost from the transcripts once the paralinguistic features (such as the use of 'err') were removed.

#### THE LANGUAGE USED BY THE PARTICIPANTS

Language is a powerful force. It is revealing as it tells us about the people who are using the language and their own biases (Keddy, Sims and Stern, 1996, p. 450). During the analysis of interview transcripts, I took particular note of the way in which participants' thoughts were expressed, their word

choice and nuances that give added meaning to their discourse. Marjorie DeVaulat (1990, p. 108) encourages researchers to focus their analysis on conversational features of an interview, such as an indrawn breath, elongated vowels and hesitations. Many of the codes and categories uncovered in this study emerged because I took into account the subtleties of participant's expression, such as nervous laughter, pauses, and the alike. Women's language, according to Weedon (1997, p. 62) is non-linear, incoherent, and incomprehensible compared to male language with its focus on the logic of reason. For example, DeVault (1990, p. 103) suggests we respect the intentions behind women's words and learn to listen to phrases such as 'you know' as a request for understanding. Furthermore, DeVault believes that women's "often halting, hesitant, tentative talk signals the realm of not-quite-articulated experience" where standard vocabulary and language is inadequate to express women's experiences. Women also use "mmmm" more than men because it does not interrupt a turn of talk, and as such it should be recognised as a supportive utterance consistent with the ways women have been socialised (Thorne and Henry in Fisher 1986, p. 164). Whilst interviewing and analysing the dialogue of women, recognising these nuances as valid forms of expression contributed to the richness of the study and to my understanding of women's talk.

#### A WORD ABOUT THE BACKGROUND BRIEFING

The grounded theory approach to the literature review and background briefing ensures that the new theory evolves from the data itself. This is achieved by leaving the extensive reading of the literature until after the data analysis has taken place, thereby avoiding any influence of prior theoretical assumptions found in other studies (Smith and Biley, 1997, p. 19, Glaser and Strauss, 1967, p. 37). Glaser (1992, p. 32) states that once the theory is sufficiently grounded in core variables and in an emerging integration of categories and properties, then the literature review can commence. Conversely, Bowers (1989, p. 45) argues that the phases of literature review, data collection and analysis should occur simultaneously rather than as a sequence of distinct phases. In this study, the bulk of the literature review did indeed occur after data analysis had been completed. However, during the data collection and analysis phases, I engaged in general reading of topics related to the study, such as feminist theory, and I also analysed those aspects of the popular media that included references to waiting relatives.

Despite leaving the literature review until after the data analysis had been completed, a general sensitivity to the subject area was needed prior to undertaking the study. Glaser (1992, p. 28) argues that professional and personal experience combined with an in depth knowledge of the data is required to develop the sensitivity necessary to generate categories and properties. Similarly, Smith and Biley (1997, p. 19) recommend 'general reading' as a means by which one can obtain a feel for the issues at work in

the subject area. My own experience as a waiting relative, combined with my experiences as an emergency nurse and the general reading and media review undertaken throughout the data collection and analysis afforded me a sensitivity that facilitated the generation of the grounded theory.

#### **VALIDITY**

Objectivity, validity, reliability and generalisability are scientific cannons often used to judge the quality of good, positivist quantitative research. Yet these cannons are not applicable to qualitative work, indeed Strauss and Corbin (1998, p. 266) refer to such cannons as dangerous and to be guarded against by qualitative researchers. Bower (1989, p. 55), and Hall and Stevens (1991, p. 16) concur stating that reliability, which assumes replicability, is not appropriately applied to grounded theory research as the symbolic interactionalist approach assumes that meanings are constantly evolving and do not remain static over time. So how do we judge the merit of qualitative, feminist, grounded theory?

Glaser and Strauss (1967, p. 237) suggest that a good grounded theory is one that demonstrates four highly related properties - a close fit with the data, understandability, is broad enough to apply to other situations within the substantive area, and affords the user of the theory the partial control over the structure and process as situations change through time. In terms of this study, the close fit of the theory with the data has been achieved by constant comparison and extensive memo taking. Hopefully, illustrating the core categories and codes with bibits or snippets of phrases from the data

itself, and by explaining the method I used to construct this theory, you will be able to judge how well the theory and model represents the data.

Synthesising the theory from mounds of memos, notes, and data has been laborious and difficult. I felt an enormous burden of responsibility to distil the essence of the experience of waiting relatives. It also required a certain degree of faith in oneself that the categories and properties, and the choices I made in formulating them, were representative, accurate, and understandable. Understandability has also been enhanced in this project by the valuable input of my supervisor. It is hoped that the theory presented later in this paper is clear enough to be utilised by fellow health professionals to improve the care given to relatives.

In terms of generalisability, Strauss and Corbin (1998, p. 267) maintain that a substantive theory, defined as one that has been developed from one small area of investigation and from one specific population, does not have the explanatory power of a larger, more general theory. However, Bowers (1989, p. 40) explains that through a socialisation process, a shared meaning develops between individuals by learning the meanings of objects and interpreting how others act. Such socialisation not only allows us to interact in a predictable and meaningful way, it leads to increased conformity and an understanding of actions. Thus a grounded theory that is truly grounded in the data will be applicable to many situations within the substantive area because of this shared meaning, conformity, and predictable interactions. In order to do this, core categories should not be so abstract as to lose their sensitising aspect, yet at the same time they must be abstract enough

to make the theory a general guide to a multi-conditional, ever-changing reality (Glaser and Strauss, 1967, p. 242). At times I have used the participant's own words to express the category, but I have tried to be mindful of a level of abstraction that satisfies both concepts of generalisability and a close fit with the data.

This study is relatively small compared to typical quantitative studies, yet theoretical saturation was achieved, as outlined in the methods section. If saturation had not been achieved, this too would limit the theory in terms of density and variation (Strauss and Corbin, 1998, p. 292), and thus generalisability. Despite being a substantive theory, I believe this theory may be applicable to a broad range of organisations and situations. Of the participants interviewed, four of them furnished their recent experiences of waiting in a private regional hospital with other experiences of waiting came from exposure to the metropolitan hospital setting. Their experiences were remarkably similar. Also, it was heartening to conduct the literature review after data analysis had taken place, and note the similarities between the results of this study and other studies which have used descriptive statistics to examine the experiences of the waiting relative. This too suggests that the theory produced may be applicable to a wide range of It implies a level of abstraction that makes this study generalisable and easily manipulated by the user to suite the structure and process of different organisations and situations.

Yvonna Lincoln and Egon Guba (1985, pp.289-331) suggest a different set of criteria to those of Glaser and Strauss to evaluate the merits of qualitative

studies, namely applying the principles of credibility, transferability, dependability, and confirmability to establish trustworthiness. However, parallels can be drawn between these principles and those outlined Glaser and Strauss. Credibility relates to the fit of the theory with the data, transferability relates to the generalisability of the theory, but dependability and confirmability are not directly applicable to grounded theory studies. Glaser (1992, p. 29) comments that the theory developed need not be verified or validated as this is the task of verificational and replicational studies whose focus is not to generate theory but to test theory. Thus, issues of confirmability are outside the scope of this study. However, a degree of confirmability may have been obtained had the completed study been presented to participants for comment, but time and budgetary constraints prevented me from doing this. Sandelowski (1993, p. 4) maintains that "no reliability coefficient can ever adequately deal with the analytic challenges of narrative data". In terms of the dependability of a study, Sandelowski states that participants often change their story from one telling to the next as new experiences cause them to see the nature and connection of the events in their lives differently. Similarly, Weedon (1997, p. 33) and Hall and Stevens (1991, p. 24) emphasise the plurality of women's experiences and state that feminism proposes a subjectivity which is precarious, contradictory and in process. Therefore, the principles of dependability and confirmability are not as applicable to this study as a means by which to determine its merits.

Hall and Stevens (1991, pp. 16-29) argue that feminist researchers should reject the old cannons of reliability and validity, which can be seen to be

reflected in Jamerson et al constructs of dependability and confirmability. Hall and Stevens instead favour the more encompassing standard of 'adequacy' to determine the merits of a feminist study. Adequacy, according to Hall and Stevens, can be judged by several criteria including the use of a reflexive approach, using credible descriptions and explanations, developing rapport with participants, and ensuring a coherence and consensus between data sources. Also, adequacy requires a relevancy to women's issues, and honesty and mutuality with women participants, and the naming of concepts that indicates the researcher sees beyond and behind what one has been socialised to believe is there.

This study meets these criteria principally because the theory generated is grounded in the data. I have used participant's own words to illustrate some categories, and was conscious throughout the research process of the potential power differential between myself and the women I interviewed. Throughout the research process I have striven for honesty both in the interactions with the participants and in the way I interpreted and represented these women's stories.

Sandelowski (1993, p. 1) contends that qualitative researchers are in danger of making a fetish of trustworthiness at the expense of perfecting a craft and of making rigor and unyielding end in itself. Furthermore, she states -

"We can preserve or kill the spirit of qualitative work; we can soften our notion of rigor to include the playfulness, soulfulness, imagination,

and technique we associate with more artistic endeavours, or we can further harden it by the uncritical application of rules" (p. 8).

In light of Sandelowski's assertion, Glaser (1992, p. 59) is critical of Strauss' and Corbin's (1990) validation techniques of 'waving the red flag', using 'flip flop' techniques and using 'far out' comparisons to verify interview data. Glaser instead suggests "constant comparing and coding, focusing on emerging categories and properties, demystifying them, saturating them and integrating them into a theory" and is a creative process that needs no verification of trustworthiness.

To enhance the insightful analysis of a complex phenomenon, Johnson et al (1996, p. 470) suggest the use of triangulation. Triangulation is a technique used to combine two or more theories, data sources, methods or investigators (Johnson et al., 1996, p. 470). Triangulation may also occur on a number of levels and can mean very simply "more than one" (Smith and Biley, 1997, p. 26). In terms of this research project, triangulation can be said to have occurred on many levels, through constant comparative analysis and memoing, using notes and observations made during the interview process to add greater meaning to the interview data, and finally, contrasting my own experiences as an emergency nurse and as a concerned relative. I believe these many data sources and methods of analysis constitute a degree of triangulation that has assisted in producing this rich, conceptually dense and integrated theory.

#### POTENTIAL LIMITATIONS OF THE STUDY

The final theory outlined in the 'Findings' chapter, whilst broad, may be limited in its application due to the homogenous nature of the women who participated in this study. Whilst there were similarities between this study and studies drawn from more diverse groups, this research was never intended to be representative of the entire population from which the participants were drawn. However, I am hopeful that this study is, as Glaser (1992, p. 24) states, readily modifiable to new conditions, new subjects and perspectives on the same experience.

All of the participants were female in line with the feminist approach of this research. Consequently, the theory that explains their experiences of waiting is not applicable to men. Personal anecdotal evidence verifies this assertion, as typically men appear to react to the experience of waiting differently to women. For example, men appear less likely to offer excuses, as do women, for being required to wait in waiting rooms for long periods. Equally, men appear less likely than women to speak to other relatives waiting under similar circumstances. Joanne Coyle's (1999, pp. 723-31) study confirms that differences do exist in the expectations men and women have of health care services. In exploring issues surrounding dissatisfied users of health care, she noted that women, for example, were more likely than men to accuse practitioners of being uncaring. Generally, the complaints made about health care services suggested a dichotomy between women's concern with private issues and relationships and men's predisposition

towards public concerns. In lieu of such differences, this study can only be extrapolated to situations involving waiting female relatives.

Another limitation of this study may stem from the fact that all of the participants came from white, English speaking backgrounds, were literate, and were recruited from the waiting room of a regionally based Catholic Some would argue that these factors significantly limit the generalisability of the study. However, Water's (1999) and Zarpe et al (1997) studies would suggest that such factors do not necessarily limit generalisability. To elaborate, Water's study of Hispanic, African American and White American waiting relatives and Zarpe et al (1997) study of Spanish waiting relatives found little difference in their highest ranking despite their culturally diverse backgrounds. Nevertheless, differences were noted in those needs ranked as less important, in particular those pertaining to religious and chaplaincy needs. As participants for this study were recruited from a Catholic hospital, some aspects of the theory may be coloured by this. However, within the context of this study, it is hoped that core categories and codes are sufficiently abstract to allow the application of this theory to other areas of cultural diversity and religious affiliations.

The time frame in which the interviews took place varied between participants. I did not aim to interview participants at exactly the same time post admission of their loved one, as I felt it more important that interviews took place at a convenient time for the participant. Leske (1989, p. 191) suggested that participant responses can change over the passage of

time. For example, a person interviewed a week after their loved one took ill may respond differently if their loved one has recovered within that time, compared to a person interviewed at a time when the recovery of their loved one was still taking place. I also did not recruit participants on the basis of their loved one's medical diagnosis or prognosis and this may have lead to some variation in responses. For example, relatives of loved ones suffering a myocardial infarction may respond differently to relatives of loved ones suffering a mild asthma attack. Consequently, the focus of the theory may not have been as sharp as it might have ideally been.

# CHAPTER 4:

## FINDINGS

## FINDINGS: INTRODUCTION

Following the advice of Bowers (1989, p. 54), the results of this study and the discussion of these results have been placed in one section as the results are grounded in the data and to have a separate discussion section would be artificial. A summary that links together the core category with other categories and properties follows the discussion. This format has been chosen to facilitate the reader's understanding of the components of the final model and the core category even before the model is presented.

From the data, four main categories were identified - being flustered, mothering, trust in expert care and power - although it should be noted that these categories are not discrete in nature. This is not, however, cause for undue concern as such overlapping of categories is congruent with the feminist theory that has informed this project. Campbell and Bunting (1991, p. 6) reiterate that a feminist world view tends to reject exclusive categories and that women are less comfortable with absolutes than men. The result is a blurring of the boundaries of women's experiences, as is the case in the results of this study. However, for the purpose of clarity, a model is used at the beginning of each category section to illustrate the codes and their relationship to the category. Once the four categories and their codes have been explored, the overarching core category, called balancing, is explained. Indeed, it has been difficult to extrapolate the themes from each other, but I am hopeful that the resulting model accurately represents the experiences of the waiting relative.

## BEING FLUSTERED

The first category that was identified was the initial state of being flustered. Related properties included the affiliation with others waiting, feelings of anxiety and methods used in passing time. As indicated by the model in figure 1., these properties were closely related to each other and to the category and are shown as intersecting.

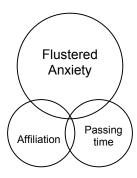


Figure 1.

"I was all churned up and upset, just trying to get my head to think straight..." Carol

The sudden onset of a critical illness of a loved one consistently left the participants in a state of flux. Often they felt that when they had finally arrived at the ED, they "couldn't think straight"; they felt flustered. Observing relatives arriving after their loved one has been taken 'through the doors' of ED, it was obvious that they are under a great deal of stress. Simple tasks such as remembering their loved one's birth date or finding Medicare or private health insurance card took on a flustered urgency and often mistakes are made. Similar behaviour and self reported feelings have

been noted by many other researchers when examining the initial responses of relatives waiting in waiting rooms (Reider, 1994, Millar, 1989, Breu and Dracup, 1978, Jamerson et al, 1996, Leske, 1986, Wooley, 1990, Zazpe et al, 1997). It is similar to the state of hovering that Jamerson et al (1996) identified in relatives waiting in the ICU setting.

The reasons behind this behaviour and self reported stress were varied. All of the women interviewed described in detail the events leading up to the admission as if they felt that this background was important for me to understand. For example, Ellen states that her initial state of being flustered was due to "...what's going on in my mind the whole time, and thinking over why, and all that sort of thing, why did it happen...". Similarly, Anne explains that "...its got terribly involved in everything that surrounds why I was at the waiting room, what I've gone through at home, and not being able to get a GP...". The need to explain the events leading up to their loved one's admission to the ED alludes to the considerable amount of anxiety the relatives had already experienced prior to their hospital presentation which in turn contributes to their flustered state. A similar phenomenon was noted by Millar (1989) who found that relatives could not concentrate on identifying their needs unless they had explained what had happened before their relative's illness.

Recounting their experiences prior to their loved one's admission may also have been a way for relatives to persuade me to view their loved one in some other context other than that of a critically ill person. I remember caring for a terminally ill man in a metropolitan ICU. He was unconscious and

completely hairless after many bouts of chemotheraphy. I had no other way of knowing this person other than through his eight siblings who kept a vigil by the bedside. By the end of my shift, the thin frame curled into a foetal position had taken on new meaning for me as I then knew about his zest for life, his musical accomplishments, outrageous parties, about his love for his family. When he passed away, I had the whole family with him, and I cried too for the man who had never spoken to me. Perhaps this is the sort of connection participants were hoping for by recounting the events leading up to their loved one's admission.

## "IT WAS FROM 6 'TIL 8" - PASSING TIME

When asked about their waiting experiences, most of the participants could recount the exact length of time they had waited. Even when recounting stories of other waiting experiences, experiences that had occurred prior to the experience being recounted in this study, the memory of the exact length of time they had waited was quite vivid. Ellen recounts from an experience waiting four years ago "I waited and waited, so it was two hours, six o'clock to eight was the time...". Despite feeling restlessness and flustered, or perhaps because of this, time seemed to take on a new dimension for the participants. It may have been one way to anchor their experience and anxiety to something more tangible in reality. Carol recalls that is was "about two and-a-half-hours before I got to see Jo". Interestingly, the time spent waiting was measured in the time it took for the participants to physically see and touch their loved one, and not the time

taken to be given news of their loved one's progress. This will explored further under the heading of mothering.

Another perspective of how time passed comes from Carol, Dee, Anne, Francis and Ellen as all described their waiting experiences as passive and 'just sitting there'. When asked about the amenities in the waiting room, such as the television, toilets, magazines and toys, most replied that they had not made use of these amenities. Francis maintains that "with all this going on in my mind, I couldn't cop on to any of that...". Of those participants that had made use of these amenities, it became apparent that they were of little use in comforting or helping pass the time. It is noteworthy that there is no clock in the waiting room and that time perception is purely based on subjective experience.

It was clear that the participants' preoccupation with the events leading up to the admission and their worry for the welfare of their loved one impairs the waiting relatives' ability to concentrate. This is illustrated in Dee's comment:

"You're sort of sitting there, you're on edge, and you're trying to read and um...that sort of, I never comprehended anything that I was reading, I was going through it and through it, and I thought...I was concentrating really on what was going on with Ed..." Dee.

Consequently, diversionary strategies employed in waiting rooms that require concentration are of little comfort to relatives. Some may argue that

watching television requires little concentration. However, despite this, Anne, Francis, Ellen and Dee all claimed not to have watched the television either as they perceived such amenities of little use in passing time. Price et al (1991), Wooley (1990) and Waters (1992) all found that waiting room amenities were rated lowest in the ranked needs of relatives. They postulate that this is because the relatives' primary focus is on the welfare of the critically ill loved one. This may be coupled with the relatives' initial state of fluster and anxiety as Bea reiterates "I was getting myself all nervous about all of that...trying to imagine what was happening in there...".

However, Francis suggests that a coffee machine would be a useful amenity in the waiting room because - "It's something to do, something to get up and do to get a coffee and walk around rather than just sitting there". Rather than employ diversional strategies that require a degree of concentration in waiting room areas, Francis has suggested a way in which people can feel more active in their waiting role, by walking around and engaging in an activity that takes less concentration than reading or television. Unfortunately, in many EDs, snack and drink machines are not encouraged as there is a potential for those seeking care to eat and drink when they may be in need of a procedure that requires them to fast. Soothing background music used in ED waiting rooms can also serve to ease the initial anxiety experienced by those who wait (Routhieaux and Tansik, 1997, p.36), although this was not mentioned by any of the participants.

#### **AFFILITATION**

"People want to share what's going on, tell you why they're there.

When you're nervous you tend to talk anyway..." Francis.

Speaking to other relatives waiting in the waiting room was a means of garnering support and a strategy employed by the participants to pass the time. Pearlmutter et al (1984, p. 175), Kleiber et al (1994, p. 75), Jamerson et al (1996, p. 472) noted a similar phenomenon in the ICU setting and claims that such informal grouping of families provides a source of support and diversion for some people. James Kalat (1990, pp. 617-20) describes the theory of affiliation as the motivation to be with others and is based on four influences – similarity, proximity, mere exposure and physical attractiveness.

In this study, the similarity with others, close physical proximity and exposure appear to be particularly active in forming relationships amongst relatives in the waiting room. As Ellen attests "I find people talk a lot to each other in the waiting room...you find people are very willing to talk". Stanley Schanchter (1959 in Kalat, 1990, p. 619) showed that 'subjects' exposed to high anxiety states showed a much stronger preference for waiting with others of similar high anxiety levels than with 'subjects' of low anxiety levels. Thus it can be concluded that people suffering anxiety, a condition that is closely associated with being flustered, may find some relief from just being with other people who share their experience, a conclusion also drawn by Pearlmutter et al (1984, p. 175). Pearlmutter et al also (1984, p. 176) suggest that people experiencing high levels of anxiety

affiliate with others who are also anxious in an effort to determine if their own anxiety level is greater or less than normal. In other words, affiliating with others who are anxious serves as a yardstick to gauge reactions.

Strauss (1969, p. 109) suggests that when the passage of status is more or less well regulated, as is the case in our current health care system, those who have gone through the recognised steps stand ready to guide and advise their successors. Anne gives credence to this theory by stating "The lady beside me was green, she'd never had to wait before...". Relatives who have been waiting for some time or who have previously experienced waiting in the ED waiting room, indeed seem ready to guide others who have never experienced such waiting. The roles taken by relatives waiting in waiting rooms are shaped by many powerful and often subtle cues, and a more in depth analysis of this phenomenon follows under the heading of 'Institutional Power'. However, whilst discussing affiliation, it is interesting to note that conformity to a passive waiting role may be encouraged and reinforced by fellow waiting relatives.

Affiliating with other relatives in the waiting room offers a degree of support, as Dee explains "but when this woman was more miserable than I was, I told her how my husband came good...". Efforts to 'cheer up' fellow waiting relatives is evidence of the support that can be garnered by being affiliated with others in the waiting room. All of the participants in this study reported that their interactions were with other women only, however. Nancy Chodorow (1993, p. 53) reported that women are especially open to a

range of "equally deep and primary relationships" and most particularly with other women and with children. Indeed, Carol stated that "There was a little baby running around...so I sort of helped her (the mother) with that". Chodorow argues that the apparent ease with which women form such relationships with other women is related to an internalisation of societal norms, and that this internalisation takes place in early childhood. Participants of this study described how easily relationships are formed with other female relatives, as illustrated by Francis - "You only have to smile at a person next to you and they'll tell you why they're there and everything!". Affiliation may also be dependent on gender similarity, an issue not addressed within the confines of this study. Long waiting periods can be broken when interactions take place within the waiting rooms. Affiliation with other relatives therefore serves as a diversionary tactic, as Carol attests "The woman beside me was busy informing me on how ill her husband was - I didn't have time to think!".

Whilst affiliation can offer support and is a means by which to pass the time, the reverse case scenario may also hold true, in that the waiting experience is perceived as more negative if affiliations are not developed. Dee recounts a waiting experience in a large metropolitan hospital ED where a much more multicultural clientele seek care -

"We just sat there, we had a cup of coffee and - well we had to go over and pay for that, not that you'd expect if for nothing- um, you know, we just sat there and listened to all these new Australians talking, I'm not racist but, you know, there was no magazines to read, there was no nothing. We just sat there".

Dee felt isolated as the other relatives waiting were of a different cultural background, "calling out in their language" and thus, Dee felt it difficult to affiliate with them. As Kalat (1990) suggests, similarity to others is one of the main influences that fosters affiliation. This study goes some way in illustrating how the similarity in anxiety level, gender and cultural background may influence affiliation behaviour. Close proximity in the form of a small waiting room and mere exposure may also help foster affiliations between relatives who previously were strangers.

# MOTHERING

The category of mothering was supported by the codes of caring, the desire to 'be with' their loved one and by contrast, being left out, and is illustrated in figure 2. The properties of caring and the desire to 'be with' their loved one was integral to the participants' expression of their mothering behaviour and desires and as such is represented as intersecting the core category. By contrast, the property of 'being left out' was at odds with the behaviour and desire to mother and care. This code is therefore not illustrated as intersecting the category. It is, however, still closely related, as it is the negative effects of being left out that impact most on the participants' mothering roles. Being left out is therefore illustrated as being related to, although not intersecting the category of mothering.

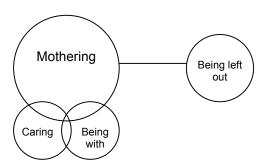


Figure 2.

"I was waiting to see that she was being treated, that she was going to be admitted, so I don't have to worry anymore, somebody else was dealing with it - I mean you worry, but the responsibility, you're passing the responsibility on to somebody else the minute you come into ED" Carol.

Women, in their roles as mothers and carers, frequently refer to their responsibility for others, and their moral duty to maintain the health of other family members (Coyle, 1999, p. 728). The mothering role that Carol fulfils is reflected in the responsibility she feels she has for the well-being of her loved ones. Bea's comments also reflect the empathetic and caring role she fulfils in relation to those who are ill -

"...and you put yourself in the position of an old man or lady, who don't know where they are, and all this noise and everything, it must be horribly frightening...the whole thing, and I think in a way like, older people tend to go back to being children in a way, and you know, reassurance helps them..."

Bea's comments are reflective of the mothering role she fulfils within her own family and the way in which this role extends to 'generalised others' who are elderly and ill. Bea's comments are congruent with Coyle's (1999, p. 728) assertion that women have been socialised to feel responsible for others. Also of note is her reference to older people reverting "back to being children" which is possibly not so much an observation of older people, as the role fulfilled by Bea in mothering caring.

Carol describes the relief similarly expressed by Anne, Dee, Francis and Ellen when handing over the responsibility for their loved one's health to the health care professionals. However, the initial relief was often replaced by a feeling of discomfort. Being isolated physically and emotionally from their loved one, and being denied a role in their care was frequently a cause of angst for the participants. Anne explains how she felt anxious when her mothering role was denied -

"I suppose I just felt he might be neglected, he might need a drink or he might just need his face wiped or, you know, silly little things and there might be no-one there to do it, that was the thing...so you know, you sort of feel frustrated, you feel you can't help".

Whilst Anne belittles the caring aspects that she could provide her loved one as being 'silly little things', being prevented from 'helping' was identified as a source of frustration for Anne. Feelings of anxiety were never identified as arising from the participant's own need to care for their loved one, rather the anxiety was usually put down to the many 'unknowns'; the standard of care their loved one was receiving, their treatment, their health status, their medical diagnosis and prognosis. Carol states she "was worried that he was getting sicker and that his (medical problem) was getting worse—that why I was so worried", and Bea expressed that it's the "not knowing whats wrong with them" that was the cause of her anxiety. However, in spite of the participants' non-recognition of their own needs, it is apparent that preventing relatives from assisting in the care of their loved ones

contributes to their overall anxiety. Whilst on the one hand, participants stated their trust in the health care personnel and equipment, on the other hand, they had to adjust to a passive waiting role in which their usual caring roles were denied. Weedon (1997, p. 33) outlines the contemporary definitions of women as mothers and states that this definition often conflicts with other subject positions we are encouraged to assume. Women are encouraged to fulfil the caring, mothering role in society, yet as a waiting relative, women are expected to deny this role and wait passively in isolation from their ill loved ones. Consequently, relatives are subjected to a range of conflicting discourses, which can therefore cause them great anxiety.

All of the participants waited passively despite the immense emotional cost, caused in part by their own need to mother their loved one. Factors influencing women's decision to wait in the waiting room in a flustered anxious state include the role expected of them by relatives, and this is explored further under the heading of 'role expectations' later in this paper. Another factor that may help explain this complex phenomena relates to the desire to guarantee the best care for the relatives' loved one who is ill, although this was never fully articulated by the participants. Millar (1989, p. 31) found that given the unfamiliar environment and their wish to help their relatives, families will often conform rigidly to the formal and informal rules of the institution. Indeed, I have often observed relatives waiting passively for inordinate periods of time and rarely do they approach the desk or request access to their loved one. Anne stated that the waiting room "was the best place for me to be", but did not elaborate on why. The concept of

relatives guaranteeing the best of care for their loved one is further supported under the heading of 'getting in the way'.

Participants also alluded to the belief that their presence in the waiting room may be of assistance to their loved one's recovery on a less physical level. Given their relative physical isolation, participants could not articulate the potential benefit to their loved one derived from their presence in the waiting room. When asked why she waited in the waiting room and not elsewhere, Dee replied "I couldn't go anywhere else, because...I'd feel like I'd left him". Frances elaborates further stating "I couldn't really wait at home, because Mum is frightened and had nobody else, and she's old and physically handicapped and she really needs somebody there...". Frances implies that, despite being separated from her mother, her mother is still cognisant of her presence and that Frances' presence in the waiting room was of benefit to her mother.

Despite accepting the passive waiting role in an unfamiliar, high-tech environment, many participants still felt that they could be of assistance in caring for their loved one. Ellen illustrates this by stating "Sometimes you can help the staff by just being there, keeping them (the loved one) quiet". This may be due in part to the notion of caring as a moral duty that is embedded in participant's perceptions of women's roles (Coyle, 1999, p. 726). The positive support participants perceived they could provide staff in caring for the loved one can be illustrated by Bea's comments -

"Yeah well, I think the thing is you know, you can see how busy they are...but you just feel what if he gets off the stretcher and breaks a leg, or you know, you know that they are, um, restless and upset, you know they're likely to get off the stretcher then you think that that's just the end of all ends! And if I could just sit with him, it would calm him down".

The language of the women is also reflective of an alliance with the staff, united in the common goal of caring for their loved one. In reference to the importance of information about her loved one, Dee refers to her loved one as a health professional might - "And like, you can reassure your patient...and you must be informed to make them more comfortable..."(italics added). Interestingly, Dee does not have any previous medical experience. It is possible in Dee's case that in her role as carer, she perceives her loved one as a patient and herself as a legitimate health care provider. Coyle (1999, p. 726) noted that the notions of 'caring' as a moral duty was similarly embedded in the female respondent's perceptions of women's roles in her study.

The overwhelming focus for all the participants in this study was the welfare of their loved one. They made personal sacrifices in the hope of optimising the care their loved one was receiving. This included waiting passively in the waiting room when their 'felt' need was to fulfil the caring role, and denying or hiding their emotion from their ill loved one. Francis, when explaining how she felt about not getting the information that she wanted stated -

"And that's what made me so cross, was that if somebody didn't insist, they would've been swept aside...I was very, very, very cross, I never told my husband...in fact I'm still cross about that and that was ten years ago!"

Anne, Francis and Ellen highlight the personal toll exacted by being excluded from the care of her loved one and also the efforts she had made to comfort and protect her loved one from her own anguish and emotional state. Anne comments in relation to informational needs that "...it (loved one's medical condition) was never explained, and I got very tearful which I never try to be, I try to kid (my loved one) that err, he's not as serious as he makes out to be...". Hiding her own emotional state from her loved one is indicative of what Weedon (1997, p. 92) states is an approach to traditional family life that is governed by norms of 'selflessness'. Selflessness of waiting relatives was also illustrated in Wooley's (1990) and Waters' (1992) study where waiting room amenities and personal comfort was rated as the lowest priority when relatives were asked to rank their needs.

In separating relatives from their loved ones, the mothering and caring roles that they might otherwise have fulfilled, are denied and can contribute to the flustered state described earlier.

### "THEY DIDN'T NEED ME AT ALL..." - BEING LEFT OUT

"Well, you're going to be called for when we need you. You're told.

Just wait there and we'll call for you when we need you. Well, they didn't need me at all, they never called for me...they should have been sensible enough to give them my side of the story" Anne.

Prior to presenting to the ED, the participants fulfilled the role of carer and in doing so, all of the participants had hypothesised as to the cause of the illness in their loved one. Ellen believed that "a lack of sleep brings on his (her loved one's) condition", and Bea wondered if her loved one's medical condition was "actually caused by the other medication". It was a source of frustration that participants could not share their unique insight and what they thought was invaluable information with the staff caring for their loved ones.

Participants felt that by ignoring their input in providing information about events leading up to their loved one's illness, health professionals are similarly dismissive of the role relatives play as health care providers in the home. Being denied this input was seen as "stupid" and potentially detrimental to the overall care of their loved one. Ellen explains -

"Oh, just to have been allowed to stay with him all the time, and hear what the doctor said, and me tell him that I know what's gone on, because Joe clams up. He's very um...er...well, you know, they'll say to him how are you? and he'll say Oh good thank you!"

In spite of the belief that their knowledge is invaluable in planning care for their loved ones, participants did not volunteer their theories regarding their loved one's health status unless they were specifically asked by staff. It is possible that participants felt intimidated and feared ridicule from health professionals if they had volunteered their theories. (This notion is explored in greater depth under the heading of "Power".) However, having built a rapport with participants during the interview process, participants appeared grateful to use me as a resource to ascertain the extent to which their theories and diagnosis were valid.

Whilst the participants saw their lack of input as potentially detrimental to the care of their loved one, it may also be of detriment to their own well-being. Feelings of anxiety and anger were well articulated, although this was never attributed to the renunciation by health professionals of the roles relatives perform as legitimate providers of health care. However, Leta Holder, Juanita Peavy and Catherine Summerlin (1987, p. 6) report that families frequently feel left out and unimportant to their loved one and to staff, and that this can contribute to the anxiety levels relatives experience. Conversely, Reider (1994, p. 278) found that coping may be enhanced in families if they can contribute to the well-being of the family member.

All of the participants elected to passively wait in the waiting room rather than go home or ask to see their relative, and all emphasised the importance of seeing and being with their loved one in person. The reason behind participants' need to be with their loved one was poorly articulated however. Dee tries to explain by saying -

"And I'd probably want to go to look at him and say, well that's fine and go back (into the waiting room). But then its not that I distrust anyone, its just, um...I don't know what it is..."

Relatives experience a dichotomy between the need to trust staff, which is discussed later in this paper under "Trust", and the need to reassure themselves by seeing their loved one. Carol illustrates this dichotomy further by stating "I just wanted to see that she was still breathing - but I knew if she wasn't breathing you would've told me...".

None of the participants could articulate why it was so important for them to be in close physical proximity to their loved one. "Being with" a critically ill loved one is a consistently high ranking need of families in many studies (Simpson, 1989, p. 391, Reider 1994, p. 278, Breu and Dracup, 1978, p. 53). None of these studies offer an explanation as to why relatives need to be in close physical proximity to loved ones, however. All of the participants made it abundantly clear that the need to see their loved one does not stem from a distrust of staff. From the literature and my own experience, the need of

relatives to be with critically ill loved ones is influenced by three main determinants.

Firstly, being with their loved one may be a way for relatives to gain information. Jamerson et al (1996, p. 471) believed that the desire to 'be with' a critically ill loved one was part of a tracking process whereby visual reassurance of the loved one's status is provided by the ability to see and observe the care given. A similar sentiment was reiterated by Francis when she stated "Well, I was waiting to see him because he was suffering (symptoms) and because he was so ill, and I wanted to see what was going on". Patricia Benner, Patricia Hooper-Kyriakidis, and Daphne Stannard (1999, p. 300) contend that family access not only facilitates family connection but also provides relatives with visual cues and other information concerning their loved one's condition. Carol states that she "wanted to see that she (Carol's loved one) was comfortable, that she was a lot better, and that you'd given her all the treatment...". Carol's statement is significant as it illustrates the kind of information that Carol expects to glean from seeing her loved one in person.

A second determinant that influences relatives' need to be with their loved ones relates to the connection that exists between loved ones and their relatives. Bea explains "But anyways, they invited me to come in and sit with him and I felt good then, really good". Bea did not state that her 'feeling good' was related to the satisfaction of informational needs, or any other factor. She simply felt good because she was again connected with her loved one. Waters (1999, p. 114) in her study of culturally diverse waiting

relatives states that a recurrent theme noted in participant's responses is the need to keep family members connected, especially ethnic-minority family members. Hilary Graham (1985, p. 38) describes how women's roles as carers and health providers involves giving time, attention and affection to those in her charge. This may be part of the drive behind the participants need to see their loved one, to show concern and affection, and to be connected.

Finally, given that the participants' focus has always been on the care and welfare of their loved ones, physical contact is seen as a way to reassure their loved ones. Bea explains "I think because of the likes of dad, at his age, there was somebody...he felt more comfortable because one of us was there...". Similarly, Ellen and Francis express how their presence might 'calm down' their loved one, especially when their loved one is ill and in a foreign environment such as an Emergency Department. Belanger's and Reed's (1997, p. 239) anecdotal evidence of family witnessed resuscitation found that loved ones were encouraged to 'continue the fight for survival' and were very much aware of their relative's presence. Personal anecdotal evidence suggests that loved ones are indeed reassured when visited by their relatives.

The need to reassure their loved one is again indicative of the type of behaviour congruent with the mothering role which many of the participants felt compelled to fulfil. It is noteworthy that this phenomenon is not isolated to participants with nursing backgrounds. Anne, Dee and Ellen all demonstrated the need to care and reassure their loved one despite not

having a nursing background. This perhaps is more illustrative of women's socialisation, than a phenomenon typical of women from a nursing background.

## IN SAFE HANDS - TRUST IN EXPERT CARE

Trust is the category illustrated by figure 3., and encompasses the properties of relief and knowing staff, excuses offered by participants if criticisms are made and disowning language to distance participants from criticisms. The category of trust is shown in the model as being intersected by relief as they are closely related. The properties of making excuses and disowning language is also related, but is the result of the participants' unwillingness to jeopardise this trust. These properties therefore do not intersect the core category of trust.

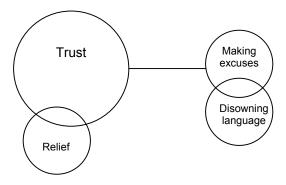


Figure 3.

"Well, I was worried because he had previously (medical condition) over the years, but the main thing was, I knew he was in safe hands. But there's always the thought because the doctor said it could be (another medical condition), and you sort of think well, what if this happens or that happens, but then I knew if something happened, they'd come and get me" Ellen.

A dichotomy exists in the experiences of the participants. On the one hand they are flustered, anxious, unable to think straight, and worried about the health status of their loved one. On the other, all of the participants recounted experiencing a degree of relief once their loved one was finally in receipt of 'expert' care. As Bea states "You girls can look after him much better than I could!". Not only was their loved one perceived as being better cared for by health professionals, 'expert care' also relieved the participants of the responsibility for their loved one's health, as outlined under the heading 'Mothering'.

Participants' feelings of relief were closely related to the belief that their loved one is in receipt of expert care, and the trust participants placed in staff and the technology associated with modern critical care. Dee recounts - "I suppose I felt comfortable because I knew that all these machines were going to pick up and do...their jobs". Dee clearly defines the relationship between her feelings of relief and the trust that she places in the 'expert' care her loved one is receiving. Benner et al (1999, p. 304) states that even in more routine circumstances, separating a critically ill loved one from the family requires a great deal of trust on the part of the family.

Many of the participants knew the staff members caring for their loved ones. Being one of only two EDs in a regional centre, most participants had had previous experiences with the institution and its staff, and many had based their feelings of trust on familiar faces, environment or routine. Carol reiterates this by stating - "I reckon I'd feel more stressed if I was

at another hospital...because I don't know the set up and I don't know the people over there".

Many studies have highlighted the strong need of relatives to feel that their loved one is being cared for in an empathetic and compassionate manner (Simpson, 1989, p. 391, Coyle, 1999, p. 726, Price et al, 1991, p. 185, Waters, 1999, p. 110, Leske, 1986, p. 193). This is evidenced by Anne's earlier quote that she could provide the "silly little things" that nursing or medical staff couldn't or wouldn't provide, and also indicates the high standard of care that she hopes is fulfilled for her loved one. Relatives may feel that by knowing staff, by having some sort of connection with them, their loved one would receive more personal and compassionate care. Anne maintains that "If you have a personal contact, then its pretty good". Knowing and trusting staff may go some way to relieving the relative's state of fluster by augmenting their trust in the care that their loved one is receiving. However, simply knowing staff does not guarantee relatives will trust them, as Carol points out, when asked why she was reluctant to leave her loved one in the care of staff -

"No, because I knew who was on (laughs)! First of all I did ask who was on, which doctor...I asked (the receptionist) who was on and she said, ah, Dr X had just left, I said good, and said Dr Y was on and I already knew you were on and (other nurse) was on, so I really didn't have any worry"

Although Carol knew Dr X, she did not trust him, and trusted Dr Y more. Knowing staff may be a doubled edged sword, as Carol's trust in the care her loved one was receiving would have been significantly reduced had Dr X been the treating doctor. Similarly, Carol's feelings of flustered anxiety would have almost certainly been increased.

Knowing and trusting staff, or having some prior connection with them also made it easier for relatives to address their own needs, such as the need for information, as Francis explains -

"Dr Z, because I knew him, it was quite easy to ask a couple of things, but I wasn't quite as game to ask any thing to that first doctor because I didn't know him. He didn't even tell us who he, oh well he didn't tell me who he was, but there again, he probably told Joe, you know, who he was, but I just sat there 'cause I didn't know him at all..."

Not being 'game' to ask questions of some staff, whilst feeling more confident with those with whom a prior connection existed, indicates that whilst relatives trust staff to care for their loved ones, they feel more at ease when they actually know the staff. In any case, three of the six participants responded that they felt it easier to get information from staff members that they knew than from those they did not.

In many cases, the relatives have no other choice but to trust staff to care for their critically ill loved one. Dee states "If you don't know the hospital, you just don't know, you know, what they might be doing", indicating the

degree of mistrust and anxiety that may be produced as a result of this lack of trust. Bea found it difficult to articulate why not knowing staff was a problem, stating "No, I'm sure you can trust them probably, I'm probably not confident enough...see I don't know!". This too may contribute to the flustered state of the relative as they are being asked to entrust the life and well being of their loved one to people they have never met. In Zarpe's et al (1997) study of 60 Spanish relatives waiting in ICU, the most positive aspect of the Unit noted by the relatives was the personal treatment they had received. Given that it is impossible for relatives to know staff in every institution, and that trust is integral to allaying to some degree the initial flustered state of relatives, a connection is needed between the 'health care professionals' and relatives left waiting in the waiting room.

Participants were often required to abide by the decisions made by health care professionals in relation to the participant's loved one, in good faith. However, having been excluded from the caring and planning roles, some medical decisions come as a surprise to relatives, as Anne describes - "I've got to accept this now (loved one's admission to ICU), it must be the best thing". Anne's statement again reflects the dichotomy faced by waiting relatives. They are isolated physically by being required to wait in the waiting room, and are not consulted or, as appears in Anne's case, not given the information required to allay their anxious state. Instead, Anne is being asked to trust the judgement of people she has never met. Sue Fisher (1986, p. 30) states that women have been socialised into believing that "the doctor knows best" and will act in her best interests ever since the male medical profession gained dominance in the 19<sup>th</sup> century. Her statement

that it "must be the best thing" is as though she is trying to convince herself of this "fact".

Relatives value a 'personal touch' and this may include sharing information and consulting relatives and love ones before decisions are made. Carol stated that "It was wonderful to find somebody (staff member) you know and ah, she would tell (loved one) exactly what his blood pressure was and how things were". Benner et al (1999, p. 323) concludes that the development of trust and rapport or connecting with a family is central to offering family support. I believe it is also central to relieving the initial flustered state. Valuing relatives' input regarding the decisions made that effect the health and well-being of the loved one has also been found to enhance the relatives' ability to cope (Reider, 1994, p. 278) and possibly move out of the flustered state.

Jamerson et al (1994, p. 472) found that nursing skills such as communication, and treating people with dignity and respect were equated with competency by participants in their study. Believing in the competency of staff lead to feelings of trust in their ability to care for their loved one and as such, may go some way in relieving the relatives' initial flustered state. Carol illustrates this point when stating "Because I knew who was on and could trust them, I really didn't have a worry". It is interesting to note that 'to be reassured that the best possible care was being given to my relative' was a consistently highly ranked need in many studies (Waters, 1999, p. 110, O'Neill Norris and Grove 1986, p. 198, Price, 1991, p. 185, Zarpe et al 1997, 14). This indicates how imperative the establishment of a

therapeutic and trusting relationship with relatives is in order to relieve some of the anxiety experienced by waiting relatives.

"IT WAS SO BUSY, BUSY, BUSY!" - MAKING EXCUSES

"You had to call (another nurse) in that night, it got busy outside after Jo's arrival. So I mean, you know, takes up time too, you're busy, you can't always go out to the relatives all the time..." Dee.

Anne, Bea, Dee, Ellen, Frances and Carol all offered excuses as to why their needs and care as waiting relatives were neglected by staff. Usually, these excuses related to how busy the ED was at the time of admission of their loved one, as Ellen testifies - "Perhaps if they came out a bit more readily and said something, I don't know, I may be expecting too much, because I know that you're busy".

Weedon (1997, p. 34) states that not all discourses are of equal weight or power, and that some will account for and justify the appropriateness of the status quo. Within the context of this study, one can assume that the status quo in relation to waiting relatives is that they wait passively in the waiting room for a length of time that is determined by medical personnel. What is interesting is that one would assume that the more powerful discourse, that being the medical institution, is not the one defending the status quo in this study. Relatives, whose role is far less powerful than that of the medical institution, defend the status quo by making excuses for long

waiting times, poor information dissemination and consequently, offer excuses for the anxiety they experience.

Rather than pick fault with the institution or staff, all of the participants pointed to either personal short-comings or factors that were beyond the control of the staff or institution as reasons for them being required to wait. Personal factors that relatives point to as contributing to their anxiety included being, as Dee states "a nervous person anyway", or as Francis declares she is "impatient at the best of times". All participants believed that when the department was busy, the needs of the relatives were of secondary consideration for staff and that this was understandable and acceptable, as Carol reiterates, "And it depends on how busy Emergency is, if its busy, you can wait". Ellen recounts how she was reluctant to interfere with the care being provided by health professionals and concludes - "I just felt too scared to ask him anything, because I knew he was busy".

Millar (1989, p. 32) also noted the phenomenon of relatives offering excuses when their needs were not met. In Millar's study, excuses such as the nurses are too busy or that they are simply relieved that everyone was doing their best for their loved one were used. It is true that when the department is busy, the primary focus of staff is on those who are critically ill, and the care of relatives is often neglected. But is this ideal? Rather than criticise working conditions and staffing levels, or explore ways in which their needs can be met even during 'busy' times in the ED, relatives saw their neglect very much on a personal level, and were quick to excuse individual staff members for it. This may be partly due to the fact that women have

been shown to be more concerned with private issues and relationships rather than public concerns, which is traditionally the predisposition of men (Coyle, 1999, p. 730). Participants of this study saw their neglect on a micro level, and not as part of a wider, organisational issue.

#### DISOWNING LANGUAGE

Language differentiates and gives meaning to assertive and compliant behaviour and teaches us what is socially accepted as normal (Weedon, 1997, p. 73). The normative behaviour of the waiting relative is examined under the heading of 'role performance', but suffice to say at this point that part of this role is generally not to criticise the institution nor those who work in it. Consequently, when participants were critical of their care, they couched the criticism in terms that distanced them from it. Bea waited for three and a half hours in the waiting room whilst her father was being cared for in a metropolitan ED. Her use of qualifying language to soften the criticism of the long wait is typical of all the participants' language when she stated "It's a long wait, but um, you know, I suppose you do expect it in a way..." (italics added). Another example of softening language comes from Dee when she attempts to voice her criticism regarding the lack of information waiting relatives are given, stating "Yeah, I just sort of, I think it was appropriate, but just maybe, just the once, or twice even, if the reception girl sort of said something perhaps...".

The use of qualifying and softening language may indicate the reluctance to challenge the trust participants had placed in staff or the gratitude

participants may have felt for the expert care provided by staff. Coyle (1999, p. 724) cites many studies that highlight the barriers that exist in expressing dissatisfaction with the health care system. They include the stigma associated with complaining, the fear of being labelled a nuisance and feelings of gratitude that may prevent people from complaining. With this in mind, it is little wonder that participants used language to soften their criticisms, distance themselves from owning the criticism by speaking in generic terms, or following a criticism directly with a compliment.

Also, in making excuses for their needs not being met, the participants are portraying themselves as being understanding of factors perceived to be outside the control of the individual. Dee comments "Perhaps if they came out a bit more readily and said something, I don't know, I may be expecting too much, because I know that you're so busy". Dee's informational needs were not met, but rather than criticising staff outright, she identified that a factor outside of staff control, i.e. the business of the ED, contributed to her poor care. Allsop (1994 in Coyle 1999, p. 724) noted a similar phenomenon in reviewing letters of complaint to the National Health Service in the United Kingdom and believes such "complaint worthiness" helps them feel justified in their compliant by showing their good character.

Intensifiers such as "such a lovely day", tag questions "isn't it" and qualifiers "this may sound crazy but" are less forceful modes of expression and displays patterns of weakness and uncertainty (Fisher, 1986, p. 164). Many times the participants used 'you know', and 'sort of' during their interviews, such as Carol - "I think, you know, everyone's individuals, and everyone sort

of relaxes at different things..." (italics added). This is again reflective of the role participants perceived as appropriate for them, as women waiting passively in a waiting room, and as women not complaining.

## INSTITUTIONAL POWER

Participants' perceived power imbalance is the category illustrated in figure 4., and is supported by the codes of being a passive outsider and getting in the way, and the need for information, reassurance and confidentiality. By compiling to the dominant medical discourse, participants believed that they 'got in the way' and thus complied with a passive outsider role. These properties are therefore shown to intersect the institutional and medical power category. However, participants identified that a lack of information, reassurance, and confidentiality were also related to institutional and medical power, but these codes participants were more openly critical of. They are therefore illustrated as being related but not intersecting.

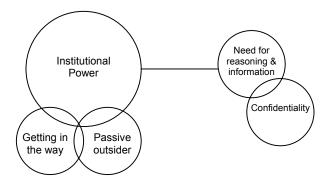


Figure 4.

In an effort to understand the roles taken and accepted by women waiting, it is useful to have some background knowledge of the power relations that exist within the hospital and ED environs. According to Gerth and Mills (1953, in Manis and Meltzer, 1972, p, 200), an institution is -

"An organisation of roles which means that the roles carry different degrees of authority so that one of the roles- we may call it the 'head role'- is understood and accepted by members of other roles as guaranteeing the relative permanence of the total conduct pattern".

In this study, the term institution can be seen to refer to both the hospital's authority and the institution of medicine, which plays a powerful role within the hospital. As a representative of the institution of medicine, doctors were often identified as occupying the 'head role' by the participants. All of the participants described medical staff as male and the nursing staff as female. It is thus problematic, and beyond the scope of this research to ascertain whether the power relations within the hospital setting is based purely on the gender of the person occupying the head role or whether this power is derived from a patriarchal structure of authority. In other words the participants' interpretation of institutional power may have been altered if the treating doctor was female, and for that matter, the nurse was male.

Dee stated that "I'm sure it would be he (doctor) that makes people wait" underscoring the power she perceived medical staff possessing. Anne's comments are also interesting and indicative of the power she perceives medical staff possessing as she states "If somebody was a nuisance - they'd be silenced and not allowed to upset the doctor and his patient anymore" (italics added). Not only does Anne perceive medical staff as being bad tempered, she also implies that her loved one has now become the property of the medical staff, using the terms "his patient".

The 'head role' held by medical staff was reinforced by their behaviour.

Ellen explains -

"I just felt, um, you know, he (the doctor) was very business like, um, but I'm not taking away that he didn't do the right thing...but I just felt very...I suppose intimidated probably is the word, I just felt too scared to ask him something"

The 'business like' manner of the doctor reinforces the head role he/she fulfils, and Ellen appears intimidated by the doctor's rather remote approach to caring. Despite feelings of intimidation, Ellen appears grateful for the care offered, as indicated by her comments that the doctor 'did the right thing'. However, such faint praise can also be viewed as an attempt by Ellen to excuse the doctor's business like behaviour and that Ellen is willing to accept the behaviour because the doctor occupies the head role and is beyond reproach. Francis implies that her loved one also accepted the doctor's head role status, and that such status is reinforced by the behaviour of the doctor -

"And then we had the Specialist who just strides past you and everything else, and calls the patient by their Christian name, which people my (loved one's) age are not used to straight away, yet she didn't mind...(but) they're not used to things being very informal"

Francis indicates that behaviour that would otherwise be unacceptable to her loved one, that is to be called by her Christian name upon first meeting someone, is accepted by her loved one when it comes from a doctor. Similarly, Carol comments that "I think the manner (of the doctor), it comes into the power and you know, you walk in as the big boss". Carol confirms that the power held by medical staff excuses and reinforces types of behaviour by that would otherwise be unacceptable to relatives and loved ones.

The fictional portrayal of doctors' roles invariably reinforces the status of doctors in the head role. Often performing heroic life-saving procedures, their white coats flapping and stethoscopes swinging as they strut down corridors, medical staff in the ED are portrayed as powerful, judgmental, and pressed for time (ER, 1994-5, volumes 1 and 2). Bea mirrors this belief in her comments regarding relatives visiting their loved ones in the ED - "I have no doubt over the years they've found some people that are very upset and, err, the doctors just don't want to mess around with that, delay procedure". The participants' views of the roles medical staff and waiting relatives fulfil closely mirror the portrayal of these roles in the popular media

Benner et al (1999, p. 294) states that caring for distressed family members, by convention, has not been the traditional style of coping with time-sensitive and high-demand lifesaving interventions. Such tradition has also served to reinforce the powerful roles that nursing staff occupy within the ED. Carol states that "Took them nearly half an hour to get permission"

to go in there, it was the charge sister or sister in charge that gave permission to go in" (italics added). Whilst nurses were seen by participants as holding a certain amount of power, Francis explains that nurses do not exercise their power in the same way -

"Power and authority probably rests with the medical staff although it's still there in the nursing staff, but its not thrust at you in the same was as it is with the medical staff"

Leske (1978, p. 53) found that many spouses in her study were reluctant to "bother" nurses with questions and, therefore, did not voice their concerns. However, one wonders as to the degree relatives may feel intimidated by 'busy', perhaps 'business like', nurses in a similar way that Ellen felt intimidated by medical staff. Reluctance by participants in this study to 'bother' nurses was justified by the participants' apparent understanding that the nurses were so busy (discussed in this paper under the heading of 'Excuses').

Nurses were seen by the participants as powerful, but they were also seen to defer to the power of medical staff. Both Anne and Dee recounted how access to their loved ones was denied by nursing staff purely on the grounds that "the doctor hasn't examined (their loved one) yet". Similarly, Jeanne Quint (1965, p. 128) found evidence in her study that nurses were expected to support physicians in their decisions to withhold or to give particular kinds of information to relatives and people who are ill, thus reinforcing the status of 'head role'.

Whilst nurses are seen to hold a degree of authority, both Linda Daly (1984, p. 234) and Jamerson et al (1996, p. 471) found that relatives put more store in the information given to them by medical staff than nursing staff in the ED. Daly found in her study that most of the perceived needs of relatives were met by physicians, including the need for relief of initial anxiety and the need for information. Jamerson et al found that although nurses who supplied information were valued for their knowledge and consideration by the relatives, families also wanted conformation from the physicians regarding their loved one's health status. Bea concurs with this assertion, stating "Dr Specialist sort of gave us the most information yesterday, which is his job to do that I suppose...". Interestingly, Molter's (1979, p. 338) study found that it was not merely a case of who relatives trust to give out accurate information, but more what sort of information relatives seek from whom. Molter found that informational needs about treatment and prognosis were sought from physicians whilst most other needs were met by nurses.

The perception of power held by medical staff is also reflected by the wider community, as evidenced by talk-back callers to a recent radio programme (John Faine morning programme, ABC Melbourne, 23-5, 29 August 2000) reporting medical misconduct. Most of the callers knew that their male doctor's behaviour or treatment was unethical or negligent, yet all complied and very few thought to report the misconduct to the Medical Practitioners Board. Instead, and in order to not upset the dominant discourse, many of the women blamed themselves and felt guilty as such a break down in role

performance could not be blamed on the failure of the 'head role'. This is also reflective of women's roles. Weedon (1997, p. 39) claims that the 'naturalness' of women to defer constantly to the interests of men and children is a result of oppression through the internalisation of a masochistic form of feminism which assists women psychologically to accept material structures of their oppression. Women are not only required to be passive, but are also expected to make excuses for aberrations in usual role performances.

Fisher (1986, p. 39) claims that sexist attitudes about women are embedded in the institution of medicine, are perpetuated by predominantly male professors and influence medical practices. In relation to this study, the women themselves, through a process of socialisation, also reinforce and internalise the dominant discourse, by excusing the behaviour of medical staff and expecting them to fulfil the 'head role'.

Strauss (1969, p. 79) claims that status forcing, such as forcing relatives into accepting a passive role, is governed by rules introduced by agents or agencies that are certified or certify themselves to carry out the status placement. The institution of medicine and the hospital itself can be seen as the certified agents in this study who force the passive status of waiting relatives. Weedon (1997, p. 35) concurs, stating that the dominant discourses of female sexuality, which is defined as naturally passive, can be found in social policy, medicine, and elsewhere. In this study, status placement seemed to be accepted by all of the participants. This is evidenced by the excuses made for long waiting periods, poor information

dissemination and other aspects of the roles relatives conformed to, and the behaviour of medical staff that was expected and accepted by relatives.

## THE PASSIVE OUTSIDER - WOMEN'S ROLES

This paper has already explored the mothering and caring roles displayed by the participants, and the way in which discomfort and anxiety is augmented by denying women these roles, whilst encouraging the passive acceptance of the institutional authority. Weedon (1997, p. 118) argues that through education and socialisation, girls are endowed with specific perceptions of their identity and potential, and whilst this appears 'natural', such perceptions are the product of diffuse forms of power. Whilst they are denied the mothering and caring roles, women are none the less expected to be passive and thus, despite the anxiety derived from being physically and emotionally isolated from their critically ill loved one, all of the participants accepted the role of passive waiting.

Weedon (1997, p. 120) believes women are capable of resistance by reflecting upon the discursive relations which constitute her and society, and as such, are able to choose from the options available to her. However, it is my belief that such reflection is more difficult in times of great personal angst and fluster, and that it is easier to conform to roles that feel 'comfortable', despite their social construction. The fact that few of the participants ever approached the desk or demanded information may reflect an inability or unwillingness to examine the discursive relations or indeed to act against them. Despite her belief that women have many options available to them to resist this discourse, Weedon (1997, p. 94) does concede that often the individual is unaware that she has a choice. On reflection, Francis concludes that she "probably wasn't allowed to stay" with her loved one

inside the ED and therefore waited passively in the waiting room, unaware that there may have been other options open to her.

Strauss (1969, p. 79) outlines the subtle way in which role performance is encouraged. He states that it would be incorrect to assume that all forcing is an entirely verbal, name calling matter, rather, passage may be forced by gesture or lack of gesture. In terms of the waiting room, there are many subtle cues to encourage the relative to assume a passive role. Michel Foucault (1981, p. 86) suggests that power is tolerable only on condition that it mask a substantial part of itself and that its success is proportional to its ability to hide its own mechanisms. Notwithstanding the pressure of affiliating with others waiting under similar circumstances (as discussed earlier), the physical layout of the waiting room subtly reinforces the power of the institution. The height of the reception desk not only obscures the view of the receptionist so as it is difficult to get his/her attention, its height may also serve to make the waiting relative feel smaller in stature. The door into the main department in activated by a key card and reinforces the power of those in possession of the card. Full-length glass runs at the back of the chairs with many people passing by it which may also be unsettling for relatives who may be attempting to garner resources. Having worked in a variety of critical care departments and hospitals, similar characteristics can be noted. Some have one-way glass, others a grill between themselves and the triage nurse, and still others an impersonal doorbell to ring if the reception desk is unattended. In my experience as a waiting relative, it took quite a deal of courage to ring this bell when the reason for doing so was, in my own mind, not important.

Meltzer (1972, p. 18) suggests that human beings respond to one another on the basis of the intentions or meanings of gestures. Such gestures are symbolic and are interpreted by the participant as something that stands for the entire act. One of the most persuasive gestures that relatives are encouraged to interpret is conveyed by the receptionist who, once the relative is separated from their loved one encourages them into a passive waiting role. Anne recalls the receptionist saying "sit down and wait there and they'll call you when they want you", a strongly persuasive statement that encourages relatives to fulfil the passive waiting role.

The efficiency and control exercised by the staff was seen by all of the relatives as a source of comfort as participants expected staff to conform to a set role. It enhanced their relief and bolstered their trust in the care that their loved one was about to receive. Dee recalls her relief brought about by staff complying with the roles she expected of them -

"I think probably the attitude of the person (staff members), the way the person behaves, the way the documents are done, it won't be very long, somebody will be out so see you in a moment, and er, everything is under control, which is good..."

By compiling too, with the expected passive outsider role, participants may have felt more at ease. Meltzer (1972, p. 19) argues that any distinctly human act necessarily involves symbolic interaction, role taking, and meaning,

and as such participants may have found that complying to their expected role was almost unavoidable, if not comforting.

Conversely, conforming to this passive role may still be seen as source of anxiety and discomfort. 'Felt' needs, such as to be with their loved one, was ignored in favour of more 'acceptable' forms of behaviour, such as sitting quietly in a waiting room. Millar (1989, p. 31) postulates that relatives may be attempting to gain the staff's acceptance by conforming to their expected roles at a time of great personal discomfort. Considering the primary focus of the participants was on the welfare of their loved one, endearing themselves to staff members may be another means by which relatives can contribute and ensure the best possible care for their loved one.

The language used by the participants was reflective of the power relations and roles they experienced as a waiting relative. Weedon (1997, p. 116) claims that to speak is to assume a subject position within discourse and to become subjected to the power and regulation of the discourse. Anne claims that "The doctor didn't even tell me who he was", and it possible that it had not occurred to Anne to ask the doctor for his name due to the assumption of the 'passive relative' role.

## THE FLIP SIDE

According to Symbolic Interactionalist theory, we can be relied upon to keep our social places because we learn to be more or less sensitive to interactional cues and because we apply and obey certain rules of interaction (Strauss, 1969, p. 76). However, the consequences of not conforming to these subtly enforced power relations inherent in the health care system are many and varied. Weedon (1997, p. 87) believes that forms of subjectivity which challenge the power of the dominant discourses at any particular time are carefully policed.

Francis outlines the difficulty she had in refusing to accept the passive relative role, stating -

"So I said well I'd like to see the doctor now, and she said no, he's too busy, so we had a bit of a discussion and said oh well, he can just come out for two minutes, so I did persist, I fought as nicely as I could"

Francis recounts an episode that occurred some five years earlier where her son had taken critically ill in a metropolitan hospital and her endeavour to illicit information from medical or nursing staff required her to 'march up to the desk' indicating the aggression needed to challenge the dominant power structure. However, whilst Francis refused to accept the passive outsider role, she still felt bound by convention where women are seen as passive and as such she felt she had to 'fight nicely'. Weedon (1997, p. 2) claims that being a woman calls for particular qualities thought to be "naturally female"

such as patience, emotion and self-sacrifice, and Francis' comments reflect these qualities.

Francis further states "And that's what made me so cross, was that if somebody didn't insist they would have been swept aside", indicating the tenacity required to challenge the dominant medical discourse. Other sanctions exist when relatives do not conform to their expected roles. Chesla and Stannard (1997, p. 70) found that nursing staff in an American ICU often perceived requests for access or information as a struggle for control rather than an expression of helplessness, anger of fear. Consequently, sanctions such as denying the relative access to their loved one was instituted by the nursing staff.

In my own experience, relatives who request information, frequent access or different care for their loved one are often labelled 'demanding' or 'difficult' due in part to the dominant institutional discourse which dictates that care given by medical and nursing staff is beyond reproach. Limiting their access into the ED certainly does occur, as does the distancing both physically and emotionally of the relative from the nursing staff. Pearlmutter et al (1984, p. 178) outlines the 'special needs' professional families have owing to their high expectations for cure and care and their control and independence associated with their professional practice. She suggests setting limits on 'inappropriate requests', which are judged to be 'inappropriate' by medical staff. It is clear that such sanctions exist to reinforce the dominant medical discourse.

## GETTING IN THE WAY

"I can understand that if you haven't got a lot of room and you are having a busy day with twenty or thirty trolleys, where are all the relatives going to fit?" Francis.

When asked why they think they were made to wait in the waiting room, all of the participants described the burden that they could potentially place on the staff if they were to wait with their relative. Whilst many participants alluded to the believe that they could have been of assistance in caring for their loved one, as discussed under 'mothering', they also 'understood' why they were made to wait in the waiting room. Carol claims that "the anxiety may transmit from a person who doesn't know what is happening to the patient!", but Dee, Bea, Anne, Francis and Ellen all agree that relatives simply "get in the way". Bea explains "I appreciate the nurses are busy, they don't want somebody like me wondering in, having to be told where to go, getting in the road of other people..." (italics added). Clearly, Bea's self deprecating language represents the power relations she perceives as appropriate within the ED setting.

In many respects, participants believed that access to their loved one may in fact be detrimental to their loved one's care as it might obstruct the staff's access to the loved one. But where did this belief come from? Benner et al (1999, p. 300) states that commonly cited rationales to limit family access includes space limitations and healthcare provider's performance abilities. Some of the participants recounted past experiences with medical staff

that reflected and reinforced this dominant discourse. Anne recounts "And, err, Mr Specialist would come along and say "clear the room!" and his father who had sat with him the whole day had to just get out of the room, you know". Dee concurs stating "When Dr Specialist came to see my husband, he asked me to wait outside!". Such is the power that medical staff wield that these demands were met, albeit begrudgingly, by Anne and Dee who complied and left the room as requested.

Popular media portrayals of relatives in the ED setting has also served to reinforce the view that relatives 'get in the way'. Relatives are often depicted as hysterical and irrational and obstructing the heroic work of medical and, to a lesser degree, nursing staff (E.R. 1994-5, volumes 1 and 2). Michele Lonsdale (1997, p. 126) contends that similar media representation reinforces long-held assumptions. In a review of popular media, Wooley (1990, p. 1405) found a growing public awareness of the critical care environment brought about by popular television presentation. In essence, popular media has probably served to reinforce the participant's view that their presence inside the ED was detrimental to care of their loved one.

In contrast to this fictional representation of relatives, a study by Bleanger and Reed (1997, p. 239) examining family witnessed resuscitation found that staff never felt the family 'got in the way'. However, it must be noted that one staff member was allocated to care for the relatives and had no other responsibilities. As discussed in future recommendations, such staff allocation could have a substantial impact on the care received by relatives.

## INFORMATION CONTROL AND THE NEED FOR ASSURANCE

"Well I think if people have to wait a long time, its better if they're given some bit of information to keep them going while they're waiting.

But I understand people are different, and they need some information, especially if its something serious..." Ellen.

Rosemary Pringle (1994, p. 208) states that power and knowledge are integrally linked and mutually dependent. The power of the medical and nursing staff is related to the knowledge and information that they possess. However, it is imperative that this knowledge is shared with relatives to optimise their emotional wellbeing. In many recent studies, the need for information regarding their critically ill loved ones was ranked very highly on a scale of importance by waiting relatives (Jamerson et al 1996, Waters, 1999, Reider, 1994, Wooley, 1990, Zarpe et al 1996, Price et al, 1991). Similarly, participants of this study outlined how important information was to their own wellbeing, as Bea explains -

"As long as you know what is going on, and people come and say to you now look, we're busy, he's (loved one) unconscious but as soon as we get him stabilised, we'll come and tell you...and I think that as long as you know that, you sort of feel alright. But if they don't come and tell you anything, or anyone comes and tells you, you sort of feel, you know, lost...".

Jamerson et al (1996) and Reider (1994) outline the detrimental effects of withholding information from relatives. They claim that it serves to prolong the state of fluster and decreases the ability of the relatives to cope with the anxiety caused by their loved one's critical illness. Anne's comments lend weight to this contention -

"And when I go in, I sat myself on a chair and they start to get the bed ready to move off! And er, I said "what's going on?" "Oh, he's going to the ward" I said "WHAT?! What for?", I said, "I thought I'd be taking him home!" Well then I burst into tears, behind his (loved one's) back..."

Anne had been waiting in the waiting room without knowing about the care her loved one was receiving or without knowing her loved one's health status. Consequently, the admission to hospital of Anne's loved one came as a shock to her and exacerbated her initial state of anxiety and fluster. Ellen similarly describes the consequences of being denied information about her loved one when she commented "I was really quite nervous, still left in the darkness of what was really happening".

In numerous studies, including that of Coyle (1999), Hickey (1990), Jamerson et al (1993) and Kleiber et al (1994), it has been shown that relatives who have been physically isolated in the waiting room without information have reported high levels of anxiety. Part of the reason for this anxiety may be attributed to an anticipatory grieving process. Wooley (1990, p. 1404) claims that those who fear the death of a loved one begin an anticipatory grieving

process prior to the actual loss and that serious illness and hospitalisation could precipitate an "overwhelming threat to an individual's emotional stability". Furthermore, relatives may believe that their loved one is more critical than they are in reality if information is not forthcoming. In an attempt to gain what information they can, relatives may misinterpret events, as Bea explains -

"The nurse was talking really softly (to the receptionist) but I couldn't hear what she was saying, and that sort of makes you feel like, you know, there's something really serious or what, and that sort of makes you feel really nervous"

Similarly, Dee and Anne recounted how, without information about their loved ones, they tried to "imagine what was happening" inside the ED and that this made them feel "upset" and "anxious". Carol used auditory cues in an effort to glean information about the wellbeing of her loved one -

"I sort of thought maybe it isn't anything, and err, but then later on I could hear the machine beeping, and really that was going through my mind that there is a problem, but I had no idea how bad a problem it was"

Waiting relatives who have not been given accurate information, try to make sense of their loved one's critical illness by using whatever means are available to them, such as auditory cues and observing staff behaviour. Relatives can misinterpret staff behaviour or comments and may therefore

have a different perception of their loved one's health status than really exists. Bea recounted how a nurse came to the reception desk and "was talking very softly - I couldn't hear, makes you feel like there's something really serious and makes you feel real nervous". Thus, withholding information can lead to a further escalation in the waiting relatives' anxiety and flustered state. Simpson (1989, p. 391) noted that the degree of severity of illness perceived by the family is significantly related to the need to see patient frequently. As discussed earlier under the heading of 'unfinished business', being in close proximity to their loved one can also provide relatives with the information they are seeking, and may lend credence to the phenomena described by Simpson.

Participants in this study were universal in their praise for the care given to them and their loved ones, but all were critical of the lack of information they were given when waiting in the waiting room. When information about their loved one was not forthcoming, participants again made excuses for staff, such as Dee who commented "I mean I suppose I'm the sort of person...I don't ask a lot of questions". This statement suggests that Dee partially blames herself for the lack of information disseminated to relatives waiting in the waiting room, implying that if she had been a more inquiring type of person, information would have been more forthcoming. Both Anne and Carol cited legal reasons behind staff's reluctance to share information with relatives. Anne states that staff may be "scared of someone saying well the doctor said this or nurse said that and found out this wasn't quite right. You know, there's a stupid amount of defamation going on...". Similarly, Carol asserts that a nurse can "get into terrible strife

if she tells someone something and it turns out to be wrong and then they head off and go to a lawyer".

A discussion exploring the politics behind information control is beyond the scope of this paper. However, Quint (1965, p. 119) suggests that nurses deliberately move rapidly and perform tasks efficiently so that such an atmosphere with primacy given to life-saving actions provides a "useful out" when relatives are seeking information that is not forthcoming.

Relatives in a flustered or anxious state have an impaired ability to process information that is given to them. Bea had difficulty recalling what a doctor had told her about her loved one when recounting the experience, and similarly Francis stated "I've got no idea what she (the nurse) said, I couldn't tell you". Aside from an inability to recollect the information, the potential exists for the information given to relatives to be misconstrued when they are experiencing high levels of anxiety. In lieu of this, many studies have advocated the repetition of information in lay terms and reframing the information until an understanding, which can be tested, is reached (Hickey 1990, p. 414, Breu and Dracup, 1978, p. 53, Wooley, 1990, p. 1405, Reider, 1994, p. 278). In my experience, however, such repetition and reframing is rarely done in the ED, perhaps because the care of the loved one occurs within a short time frame.

This paper has demonstrated the negative impact withholding information can have on the wellbeing of waiting relatives. Conversely, Francis, Ellen, Carol and Anne highlight the positive effect information about their loved

one has on their wellbeing, equating receiving information with a feeling of reassurance that "everything is under control". Jamerson et al (1996) contend that 'information seeking' was a way in which participants in their study moved out of their initial flustered state which they termed 'hovering'. Indeed, Dee states she "would have been quite happy to wait as long as you had the reassurance" and Anne "felt much better once the nurse came out and talked to me". From my own experience as an ED nurse, waiting relatives appear more relaxed once information about their loved one has been shared.

#### CONFIDENTIALITY

Participants who were given information about their loved one raised the issue of confidentiality because of the informal way in which information was given to them in the waiting room. Carol explains -

"I don't want anybody knowing my business - she probably wouldn't want anybody to know either...I think giving some information could be done somewhere else, you've got people giving out information while other people are sitting right next to you...that shouldn't happen"

Similarly, Ellen states "And if there's more than you there, then you really don't like talking in front of other people...". The apparent disregard for relatives' right to privacy is again another indicator of how little thought is given to the wellbeing of waiting of waiting relatives by staff.

However, in some of the critical care areas I have worked there have been 'family rooms' designed for confidential consultation and information sharing with relatives, but often they are not used. Part of the reason perhaps lies in the fact that these rooms are often some distance away from the treatment areas and staff shortages limit the ability for one staff member to be away long enough to share the information effectively. Another reason may lie in the low priority staff assign to relatives' needs, including the need for privacy. More often than not, information is given in low murmurs over the desk in the waiting room, and family rooms are used for grieving relatives who need space to cry.

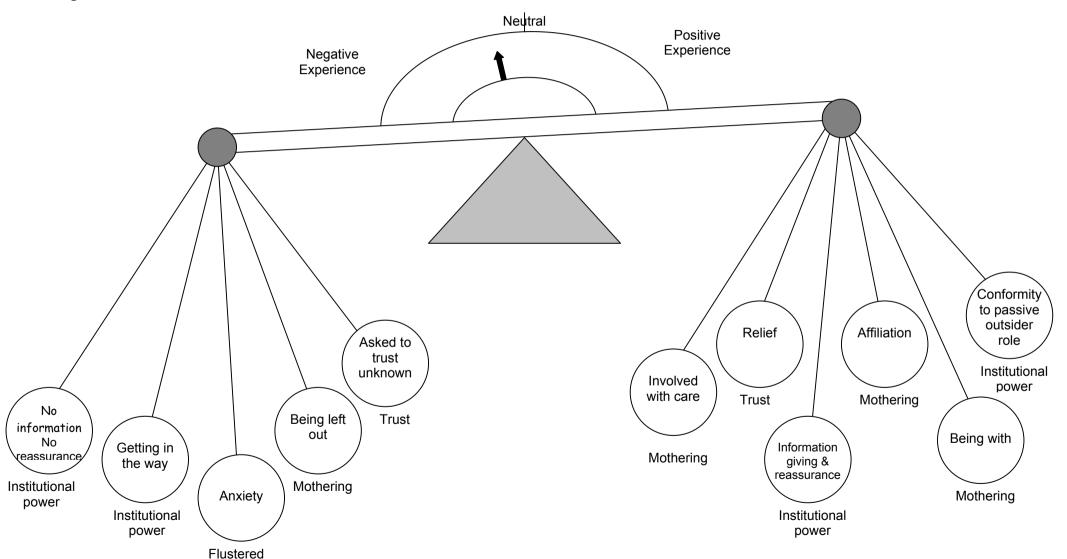
## BALANCING

The core category that links all other categories and properties together is that of balancing. Relatives frequently highlighted many positive and negative aspects of the other categories, but to maintain their own mental well-being, they strove to strike a balance between the impact the categories and their properties had on them. The final model constructed to represent the experiences of the waiting relatives is depicted in figure 5 on page 156.

The model intends to illustrate that the core category of balancing represents the labile positive and negative experiences of waiting relatives endure, and not the degree in to which the positive and negative experiences impact on waiting relatives. A shortcoming of the model is the inference that the positive aspects of a category are viewed by the relatives as being of equal weight to the negative aspects of a category and that the negative aspects of the categories are equally weighted. This is not necessarily the case. For example, the negative aspects of a category may effect the wellbeing of an individual far more than the positive aspects of that category. Similarly, a negative aspect such as 'being left out' may impact on an individual's wellbeing far more than 'being asked to trust the unknown'.

## WAITING - A CRITICAL BALANCING ACT

Figure 5.



Relatives of critically ill loved ones are often experiencing emotional turmoil when they are requested to wait 'outside' in the waiting room. I have attempted to discuss the various aspects of the participant's experience in discrete terms, but in reality a fluidity of emotion exists that is difficult to illustrate. Many of the participants describe the dichotomy of emotion and roles that they endured whilst waiting. To this end, I have illustrated the experience of the waiting relative as being akin to a balance of well being that can be altered according to the positive effects of some codes being weighted against the negative effects of the same or different codes. It should be noted, however, that all of the participants, whilst exploring some of the more positive aspects of the waiting experience, generally found that the over all effect of waiting was a negative one.

Whilst grappling with their own discomfort and anxiety, the sharp focus of all the women in this study was on maximising the well-being of their loved one. Negative experiences were seen as trivial and excusable if they were perceived to be of assistance to their loved one directly or indirectly, by assisting staff to care for their loved one.

Denying participants a direct role in the care of their loved one by physically isolating them in the waiting room was identified as a source of anxiety. Whilst these women accepted the role of mothering and caring outside of the hospital setting, they were now expected to give this role up and 'leave it to the experts'. However, whilst this may be a source of anxiety, it also provided a degree of relief in that the burden of responsibility for the critically ill was now transferred to these 'experts'.

Role and status enforcement was also contradictory in the effects it had on the participants' feeling of ease. The women of this study were all subjugated to fulfilling the role of a passive outsider whilst the institutions of medicine and the hospital played a dominant and powerful role. Some participants were consoled by this, it is what they have been socialised to expect and during periods of great anxiety and fluster, such conformity provided comfort to them. Similarly, comfort was derived from affiliating with other waiting relatives who understood and shared the feelings of fluster and anxiety. However, role and status forcing was also identified as a source of frustration. All of the participants felt that they had something to offer in caring for their loved one, whether it be articulating important information about their loved one's health, or simply participating in the care that they had provided prior to attending the hospital.

Trust was another issue that was a source of ambivalence for the participants. On the one hand, they placed a great deal of trust in the staff and their abilities to care for their loved one, and that this was comforting to them. On the other hand, some participants indicated that they had little choice but to place the care of their loved ones into unknown hands. This was a source of stress for some of the participants. It was interesting to note that those who had had previous experiences with the hospital or with staff felt a greater degree of comfort than those without such knowledge. A familiarity with staff or with the environment appeared to impact favourably on the participants' ability to trust, and as such, was a source of consolation for them.

Physical isolation from their loved one was itself a cause for anxiety in participants. Denying access to their loved one limited the information the participants might have otherwise gleaned from such contact, restricted the opportunities the participants had to reassure their loved one with their presence, and finally, prevented the participants reaffirming their affection and connection with their loved one. Personal angst felt by participants was modulated however, by the overriding desire to procure the best care and treatment for their loved one. Many stated that whilst they perceived their input into caring for their loved one was potentially valuable, they also believed that their presence inside the ED could be detrimental to this care. Participants believed that "getting in the way" of 'expert' carers would compromise the care their loved ones were receiving.

The one issue that was clearly related to the comfort and feelings of well-being in the waiting relatives, however, was the sharing of information. Information regarding the health status of their loved one was closely associated with feelings of reassurance. Information and thus reassurance was imperative to the relief of initial fluster and anxiety. A similar finding was made by Jamerson et al (1996) in their study of relatives waiting in an ICU setting in America. Withholding information lead to increased anxiety levels and a continuation of the flustered state. Participants on the whole were not critical of their experiences as waiting relatives, however all suggested that mechanisms that disseminated information more readily should be instituted.

Differences in background medical knowledge and experiences seemed to have little effect on the experiences of the participants as a waiting relative. Interviewing the women with nursing backgrounds uncovered the same categories as those from non-nursing backgrounds. However, Francis and Bea, both ex-nurses, recounted their attempts to gain information and access to a loved one on previous occasions in other hospitals and discussed the difficulties they faced in not conforming to the 'passive outsider' role. Despite their knowledge, all of the women conformed to the roles expected of them as waiting relatives. They were also selfless in their pursuit of securing the best care of their loved one. Despite their own needs - for reassurance and information, to be with their loved one, and to exercise a caring role - the women of this study conformed to the passive outsider role expected of them by the institution. It seemed that the participants were only willing to act outside of their expected roles if they perceived that the care of their loved one was sub-standard. Challenging the forced role and status placement might be borne out of an unsustainable anxiety level. It may also be due in part to the fact that, by conforming to the passive outsider role, women are not contributing to the care of their loved one as they might have done if staff were trusted as competent. The participants' lack of concern for their own needs was also illustrated by their apparent disinterest in the waiting room amenities and facilities of physical comfort.

## CHAPTER 5:

# CONCLUSIONS

## CONCLUSIONS

"I really don't think you can treat a patient on their own, you've got to treat the relatives as well, in a way, on the one hand, because they're very much a part of it all" Bea.

Bea highlights the important and inextricable role relatives play in the care of a loved one who has taken ill. It is hoped that by investigating the waiting experiences of relatives separated from their seriously ill loved ones, relatives will be included in the care processes instituted by nursing and medical staff.

In formulating a substantive theory and model, figure 5 (on page 157) illustrates the dichotomy that waiting relatives endure whereby some aspects of the waiting experience can impact positively on their feelings of wellbeing, whilst other aspects are negative in their impact. In order for healthcare professionals to care more effectively for waiting relatives, our energies should be directed toward strategies that enhance these positive aspects. Such strategies include involving relatives in the care process, offering information and reassurance, allowing relatives to 'be with' their loved one where ever possible, and fostering a trusting therapeutic relationship. By being cognoscente and maximising the positive aspects of waiting, we also limit the negative impact that is experienced by waiting relatives when these issues are neglected.

This study offers a greater insight into the experiences of waiting female relatives in the Emergency Department setting, and this is a starting point from which we can modify our approach to enable us to be more holistic in our care of critically ill loved ones. It should be noted, however, that whilst this model and theory may be readily adaptable to other settings, this study has been conducted in an Emergency Department setting only. I think it would be possible to utilise this theory in other critical care areas, however, as under these circumstances, the health of the loved one is similarly critical and the stresses faced by waiting relatives are comparable. However, further studies are required to ascertain if this theory is applicable to all critical care areas.

Similarly, the theory and model in this study was produced as a result of analysing women's experiences of waiting, which may be of variance to the experience of male waiting relatives. Therefore, this study cannot be extrapolated to the male population.

This study has set out to explore the relative's perceptions and reactions to this experience of waiting and I believe that the substantive theory and model produced as a result of this enquiry has produced a frame of reference for understanding the experiences of waiting relatives.

In addressing the final aim of this study, to develop procedures and policies that may reduce the negative impact of waiting, the following subchapter may be instructive although not definitive in its recommendations. In this regard, I believe that this study has not fully achieved this final aim.

## TURNING TO THE FUTURE

Meeting the needs of relatives has traditionally been informally addressed with no one staff member being assigned this responsibility. Wooley (1990, p. 1407) argues that specialisation can sometimes result in fragmented care with individuals becoming responsible for certain aspects of care. Within the ED setting, nursing and medical care is often focused on the immediate physical care of loved ones, although, as portrayed in the popular media, nurses are more often concerned with psychosocial-emotional care of people. In spite of this, the participants of this and other studies have illustrated the belief that the medical staff most often met the majority of their needs. In this regard, however, Francis disagrees –

"(Nurses) understand much more the way the person's reacting, and I think on the whole, they also react to the way the relatives are reacting, they've, you know, already gauged the way they are behaving, they sense very quickly whether that person is nervous or - and the doctors don't seem to notice in the same way, they are really more interested in treating that patient and getting them better, and not, you know, relatives..."

If we are to seriously engage in the holistic care of those who are ill, then the responsibility for ensuring the wellbeing of waiting relatives rests with the nursing staff. Yet there appear to be many barriers preventing nurses from caring for relatives. Waters (1999, p. 107) describes how, despite the

many studies that have outlined the needs of the waiting relatives, most nurses in critical care settings continue to delay, forget or avoid interactions with family members (Walters, 1999, p. 107). Part of the reason for nurses' apparent disregard for relatives' needs has been alluded to in the literature. Solrush (1990, p. 160) describes the reputation of ED nurses as being "hard bitten" and "unfeeling", but justifies this by stating that if nurses are too sensitive or empathetic, they will be unable to perform effectively and will suffer too much personally. Belanger and Reed (1997, p. 238) found that staff feared family witnessed resuscitations as it was perceived that it may interrupt their performance, cause emotional discomfort and may have legal ramifications. Quint (1965, p. 122) goes so far as to suggest that nurses deliberately "look busy" to make it difficult for those in our care to initiate conversations, let alone to voice fears and needs, as the burden of care is too great. It appears that tradition, convention and misinformation discourage nurses from engaging in and caring for relatives.

This study, like many others, highlights the needs of waiting relatives for reassurance, information, and the need to be with their critically ill loved one. Wooley (1990, p. 1403) claims that combinations of stressful events tend to have a cumulative negative effect on the mental health and impair that individual's ability to cope effectively. If we as nurses are to limit the negative mental and emotional impact, the flustered state and the anxiety experienced by waiting relatives, we must address the issues raised in this study. However, there are many barriers presented to us as individuals to effectively care for relatives and meet these needs. One of these barriers

is the overall unit culture, as illustrated by Meyers (2000, p. 9) who advocated for the relative's presence during a resuscitation and faced professional criticism and the loss of her job. From personal experience, I have worked with a number of medical staff who 'disapprove' the presence of relatives being 'allowed in' to see their loved one. It is a powerful barrier. Fisher (1986, p. 169) claims that without policy changes, the delivery of health care will still function to support the status quo. A way to change the dominant culture and policies is through education.

Weedon (1997, p. 136) argues that it is in the universities, in state cultural institutions, in publishing, and in all branches of education that critical practices are established, reproduced, and challenged. To change the status quo, and to reach nurses who are currently practising policies of exclusion of relatives, I intend to submit this report for publishing in an Australian journal of nursing, along with these recommendations. Fisher (1986, p. 169) claims that in order to affect social change, consumers of health care need to be taught to take more responsibility for their health and to be more assertive during medical encounters. It is unclear how this goal can be achieved, considering the dominant medical discourse, the sanctions that exist if this discourse is challenged and the popular media reinforcement of traditional health care roles. However, a similar assessment could have been made about women's roles prior to the feminist movement. It is not enough to "think outside the square", relatives need to be encouraged, perhaps through a media campaign, to challenge the dominant discourse.

Student nurses need to be educated to also "think outside the square", to understand the positive impact a holistic approach can have on those for whom they care and on their relatives. Nursing education should also address the issue of trust. Nurses must realise the trust that is placed in them by people who are ill and their relatives, and the negative affects that a lack of trust precipitates. Methods by which this trust can be bolstered include being empathetic, giving relatives the opportunity to be listened to, and reassuring relatives that their loved one is receiving the best care they can provide. Such strategies need to be emphasised in nursing education as implicit in caring for relatives. It is hoped that through my supervisor, the recommendations from this study may be implemented in the education of nurses. Holder et al (1987, p. 6) outlined an innovative method for students to appreciate the needs of relatives by having students initiate conversations relatives in waiting rooms around a hospital. Holder et al claims that students are quick to identify the helplessness families experience when waiting and wondering. Such experiential learning is an ideal way to gain insight into the needs of the waiting relative and the nursing interventions that might assist relatives to meet these needs.

I concur with Benner et al (1999, p. 324), who asserts that the biggest factor that influences the nursing care of relatives in the ED is one of inadequate staffing and a lack of time. Often there is barely time to care for loved ones on a physical plane, let alone taking a holistic approach, and as such, caring for relatives becomes a 'luxury' that can only be indulged when the department is very quiet. This lack of care is not only detrimental to

relatives, but is also a source of frustration for nurses who feel they can't provide the care that is needed.

Pearlmutter et al (1984, p. 173) offers a bizarre viewpoint stating that economic constraints placed on the health care system necessitates increased family involvement, so that relatives can participate in the actual care of the loved one. Whilst the involvement in the care of loved ones can be comforting and reassuring for many relatives, they should never be placed in an obligated position, and to do so would only increase their anxiety and flustered state. I recall caring for a woman of Vietnamese background in a metropolitan ICU after she had had her coronary bypass surgery. Her relatives spent most the "late shift" with her and kept asking many, many questions, so many in fact that I was starting to believe that they didn't trust my care, despite my explanations and reassurances. However, when the "night shift" nurse arrived and I began 'handing over', the palpable angst and worry of the relatives was soon dissipated and replaced with joyous laughter. It transpired that in Vietnam, the responsibility to care for their ill loved ones over night fell to the relatives, and despite the high-tech gadgetry, wires and critical illness, they had assumed that this was the case in Australia too. We cannot rely on relatives to be involved in the care of loved ones because of fiscal imperatives. The anxiety and fluster it would cause is all too obvious, be it in a critical care setting or a nursing home. Instead, relative involvement in care should be based on the needs of the relative and of the loved one only.

Financial constraints and short staffing seems to be endemic in the Victorian health care system at present. By contrast, it is interesting to note that studies that have addressed the highest ranked needs of relatives for reassurance and information had all employed another person to specifically meet these needs. Belanger and Reed (1997, p. 238) outline their protocol for family witnessed resuscitation in an American hospital where a single staff member was appointed to stay with relatives to answer any questions about all that occurred. Solrush (1990, p. 156) espoused the benefits for both relatives and staff of employing counsellors versed psychotraumatology in an American ED. Similarly, Pearlmutter et al (1984, p. 176) advocates a psychiatric clinical nurse specialist in American hospitals to foster the inclusion of relatives as an integral part of the health care team. Zarpe et al (1997, p. 13) describes the position of an 'auxiliary nurse' who welcomes and imparts information to relatives in a Spanish ICU. Finally, Johnson et al (1993, p. 35) illustrates the positive effects that a volunteer liaison officer has had one allying the relatives' anxiety in an American ED by disseminating information. However they do note that despite the volunteer liaison program, families need periodically to speak directly with the professional staff and that talking to the liaison cannot take the place of this interaction.

A more relevant example of how to address the need for reassurance and information of relatives waiting in an ED comes from the Royal Perth Hospital. They have created a position called the "ED Liaison Nurse" whose primary responsibility is to "provide a communication link between the relatives and the Medical/Nursing staff" (Terry Jongen, Clinical Nurse

Specialist. See Appendix 5.). Satisfaction surveys have shown that this role is benefited both nursing staff and relatives. The success is due in part to the fact that the role is fulfilled by a professional nurse, not a volunteer or another health professional whose sphere of knowledge may be isolated from the relatives' whole experience. Leske (1986, p. 189) claims that critical care nurses are in an ideal position to help families cope with critical illness in an adaptive manner. However, the shrinking health budget has meant that nurses have had less time to care for relatives. Whilst appointing a nurse specifically to address the needs of relatives, namely to be reassured and to be informed, may fragment holistic care, relatives' needs are at least being acknowledged and addressed. It also ensures that somebody is taking responsibility for caring for relatives whereas unclear lines of responsibility may contribute to the poor care relatives are currently receiving.

Relatives valued a 'personal touch'. Nurses caring for relatives should be aware of the individual needs that each family member has, and that there is no set formula for caring for relatives. Pearlmutter et al (1984) for example, outlined how 'professional' relatives may have the need for very specific information regarding their loved one whilst non-professionals may be reassured by generalities. Also, in recognition of our multicultural heritage, Australian nurses need to be aware of the cultural differences that will impact on the care that they give loved ones and their relatives. Waters' (1999) study of African American, White American and Hispanic relatives found that there were minor variations in their needs, but the over arching desire of all these relatives was to remain 'connected' to their loved one. The employment of a 'nurse liaison' position to keep them informed of

their loved one's health status would certainly go some way in achieving this objective.

Changing ED policy and culture to allow relatives to periodically visit their loved ones would also strengthen the connection between them relatives and their loved ones. 'Being with' their loved one was highlighted in this study as being a strong desire of relatives. However, confidentiality was also identified as an important issue for relatives receiving information in the waiting room. Considering that inside most EDs, the only thing separating one loved one receiving care from the next is a curtain, it is very difficult for staff to maintain confidentiality under such circumstances. Therefore, visitation by relatives should be recognised as important, but limitations on the time spent inside the ED should be limited so as to ensure the confidence of other loved ones receiving care.

In terms of sharing information, many studies have posited the difficulty relatives have in processing information whilst in a state of fluster and anxiety (Hickey, 1990, p. 414, Reider, 1994, p. 278, Wooley, 1990, p. 1405, Price et al, 1991, p. 187). Both medical and nursing staff should be cognisant of this and recognise that information may need to be repeated or reframed at a later date. Also of note was Molter's (1979, p. 338) finding that written instructions, which one might assume to be useful if verbal information is not being understood, to be of little value in meeting their needs.

## **FUTURE STUDIES**

Benner et al (1999, p. 329) claims that the family's involvement in providing care can promote the loved one's healing and comfort. Indeed, this has been alluded to in many studies (Waters 1999, p. 115, Millar, 1989, p. 32, Belanger and Reed, 1997, p. 239). A more complete picture of the impact that separation has on families might include an analysis of how this separation affects the wellbeing of those who are critically ill. In my experience, loved ones are often concerned for the welfare of their relatives left waiting in the waiting room and that this worry could indeed impact on their recovery.

A study of the male relative's experience of waiting may also shed a different light on this topic. Personal anecdotal evidence suggests that men are less likely to conform to the 'passive outsider' role that is expected of women. However, it should be noted that most of the other studies outlined in the literature review included men in their samples, and similar needs were identified.

The differentiation by the participants between institutional power and patriarchy was not clearly defined. This was in part due to the fact that the medical staff that the relatives had contact with were all male. Future studies may produce greater insight into whether or not the discourse described by the women in this study emanated from a patriarchal or a gender dominance, particularly when the medical staff are female.

The participants of this study were white, literate, English speaking women recruited from a Catholic hospital. Despite an extensive literature search, studies of waiting relatives from differing cultural backgrounds were almost non-existent. Being a multicultural community, research into the experiences of relatives from various cultural backgrounds could be useful in tailoring the care nurses give to waiting relatives.

This study has explored the experience of the waiting relative and has uncovered some common themes and needs that are currently not being met. As already discussed, the reasons why these needs are not met are many and varied. However, one of these reasons pertains to the dominant unit culture and staff attitude towards visiting relatives. In order to challenge the dominant discourse, it is first necessary to examine the rationale behind such beliefs. More research is needed to examine medical and nursing staff's attitudes toward relatives, and in particular visitation rights of relatives, in order to clarify the issues and to dispel long-held, inaccurate assumptions. Karin Kirchhoff, Elizabeth Pugh, Rosemary Calame and Nancy Reynolds (1993, p. 243) studied the attitudes and beliefs of 70 American critical care nurses and concluded that any attempt by administrators to alter visiting policies without acknowledging and/or altering nurses' attitudes and beliefs would be unsuccessful. When taking into account the influence medical discourse has on the behaviour of nurses, I hasten to add that research into the attitudes and beliefs of medical staff is also necessary if we are going to challenge and improve the care that relatives currently receive.

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## APPENDIX 1



TITLE OF PROJECT:

WAITING: A CRITICAL EXPERIENCE.

NAME OF RESEARCHER:

Amber van Dreven.

Dear Sir/Madam

#### EXPLANATION OF RESEARCH:

Relatives of critically ill patients are often asked to "wait outside" in waiting rooms whilst the patient receives care, especially in emergency departments. It is not uncommon for relatives to wait for extended periods of time without news of their loved ones, let alone seeing them in person. The purpose of this study is to describe this experience from the relatives' perspective, with a view to improving the care relatives receive from nursing staff.

To achieve this purpose, this study aims to -

- Conduct an audiotaped interview with you of approximately 1 hour's duration, asking you to reflect upon your experience of waiting whilst the health status of your loved one is unknown.
- Conduct a subsequent interview with you once the first interview has been transcribed. In this interview you will be requested to check the transcription for authenticity, and to amend or delete anything you so choose. This should take approximately 30 minutes.

Participation in this research should take a maximum of 2 hours of your time.

#### POSSIBLE RISKS AND INCONVENIENCE:

1. Confidentiality.

To ensure your confidentiality, the following steps will be taken:

- a. All audiotapes will be erased immediately following transcription by myself.
- b. Transcribed interviews will use a pseudonym (alias) and direct reference to specific events and locations that may otherwise identify you will be erased or disguised in the transcription and final report.
- A mutually agreeable time and location for interview will be arranged in order to minimise the inconvenience of participating in this research.

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AQUINAS CAMPUS 1200 MAIR STREET BALLARAT VICTORIA 3350 AUSTRALIA
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TELEPHONE (61+3) 5337 3100 FACSIMILE (61+3) 5337 3105

 Recounting your story of waiting may produce or revisit a time of great stress for you. Should participation in this research cause distress, two professional counsellors are available to help. At Ballarat Health Services – Base Hospital Campus, Bev Pratt can be contacted on 5320 4828, pager number 913. At St John of God Health Care – Ballarat, Judy Ellison can be contacted on 5331 6677, pager number 501.

If you decide to participate in this research project, have questions pertaining to the research, or would like further information, do not hesitate in contacting me on -

Amber van Dreven

0417 119 838

Or my supervisor -

John Struhs 5336 5300 Head, Department of Nursing Practice Australian Catholic University 1200 Mair Street Ballarat 3350.

In the event that you have any complaint about the way you have been treated during this study, or a query that I or my supervisor have not been able to satisfy, you may contact –

Chair, University of Research Projects Ethics Committee C/- Office of Research
Australian Catholic University
412 Mt Alexander Road
Ascot Vale VIC 3032
Tel: 03 9241 4513

Fax: 03 9241 4513

This study has been approved by the University Research Projects Ethics Committee at Australian Catholic University as well as the Ethics Committees of Ballarat Health Services – Base Hospital Campus and St John of God Health Care – Ballarat.

If you agree to participate in this study, you will be asked to sign an Informed Consent Form after I have explained it to you when we meet in person. You are, however, free to withdraw your consent and discontinue participation at any time without giving a reason and without prejudice.

Thank you for your time, I look forward to hearing your story.

Amber van Dreven

# APPENDIX 2.



# TITLE OF RESEARCH PROJECT: WAITING: A CRITICAL EXPERIENCE

NAME OF	RESEARCHER:	Amber van Dreven.	•
Ť		(the participant)	
I			
agree to par	dicipate in this activity, reali-	sing that i can withdraw at any time.	
I agree that research data collected for the study may be published or provided to other researchers in a form that does not identify me in any way.			
NAME OF	PARTICIPANT	(block letters)	
SIGNATUE	RE		
DATE			
NAME OF	RESEARCHER	(block letters)	
SIGNATUI	RE		
DATE			

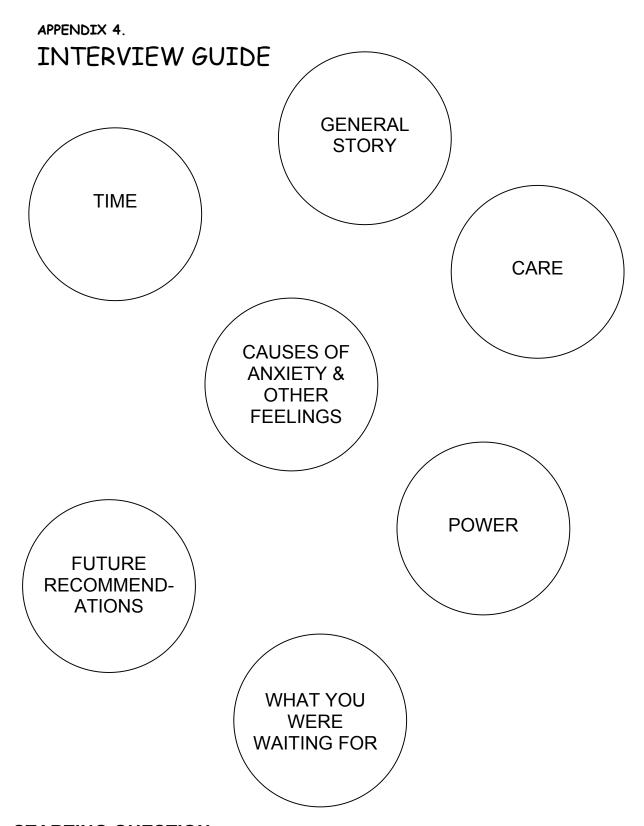
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# APPENDIX 3.

# AIDE DE MEMOIR

Cast your mind back to the period immediately after your loved one was admitted to the Emergency Department and you were asked to wait in the waiting room. Tell me what happened...

- 1. What were you waiting for?
- 2. How did time perception alter, if at all?
- 3. Describe what you found 'stressful' whilst waiting in the waiting room.
- 4. Comment on the care you received or would have liked to receive.
- 5. Explore what allayed your stress.
- 6. Of what use is information about your loved one?
- 7. Explore the issues of power and authority you encountered as a relative waiting.
- 8. Why did you wait?
- 9. Describe any unresolved feelings relating to this experience.



### **STARTING QUESTION**

Cast your mind back to the period immediately after your loved one was admitted to the ED and you were asked to wait in the waiting room. Tell me what happened ...

#### APPENDIX 5.



ref:TJ::bak

2 August, 2000

Ms Amber Van Dreven 24 Durham Street BALLARAT 3350 VICTORIA



Wellington Street Campus
Box X2213 GPO,
Perth 6847
Western Australia,
Telephone: (08) 9224 2244
Facsimile: (08) 9224 3511
T.T.Y. Line: (08) 9224 7016

Shenton Park Campus, 6 Selby Street, Shenton Park 6008 Western Australia Telephone: (08) 9382 7171 Facsimile: (08) 9382 7351

Dear Amber

Dr Gavin Leslie has passed on your inquiry to me regarding our "ED Liaison Nurse" position.

I will attempt to answer your questions.

The position evolved from a time when we had permanent triage nurses, about ten years ago. These permanent triage nurses would have the "Friends of the Hospital" (a group of volunteer helpers) do various errands and so forth.

As our department became busier and these permanent triage nurses retired, the use of the "Friends" decreased. However, the tasks were then taken on by the nursing staff. Consequently, their workload increased and so did complaints. At this time, a very senior nurse from another area of the hospital was on light duties and as a part of these light duties, she was asked to evaluate the triage role. At this time we were planning our new waiting room and changing our triage process.

The results of the evaluation indicated that there was justification for a nurse to act as a liaison during the busy hours of 1600 – 2330. This was approximately around 1993. Consequently our FTE was increased by 0.5 FTE to partly fund this. If we were short staffed, the position was not filled for the shift. This adhoc arrangement continued until 1994/1995.

On completion of the new waiting room, triage now had a central area. Previously there were two triage points. One located at the front for the "walking wounded" and one inside for the ambulance cases. Now, all cases were triaged by the one nurse which proved to be an enormous workload. Triage waiting times increased along with security incidents.

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We applied for and received further funding to employ extra staff. Triage is now covered seven (7) days a week by one Triage Nurse and one Triage Liaison Nurse. The role of the Triage Liaison Nurse is to provide a communication link between the relatives and the Medical/Nursing staff. They regularly do rounds of the waiting room, feeding information back to friends and relatives. They also encourage friends and relatives to visit prn. The Triage Liaison Nurse supports the Triage Nurse when he/she is busy and will triage patients prn. They also act on behalf of bereaved relatives.

There have been satisfaction surveys conducted by my counterparts, but I have not been able to locate them. Funding is via our salary budget and we receive no extra funding from special sources.

Staff are very happy with the role and are allocated to the role for the whole shift. There are certainly other roles that they would rather not do. I am not aware of any other hospital that has a similar position.

As a part of the training for both the Triage Nurse and Triage Liaison Nurse role, staff attend a Triage Study Day and a Behavioural Emergencies Study Day. I would suggest that something relating to grief counselling would also be useful. The former Clinical Nurse Specialist, Ms Rosy Drimatis would also be able to provide more background and perhaps a copy of the presentation case she has completed on this issue.

Rosy is at the Health Department of Western Australia and may be contacted on her E-Mail address rosalia.drimatis@health.wa.gov.au

I hope that the above information will prove useful to you, meanwhile, I will continue to try and locate the survey results.

Yours sincerely

Terry Jongen

Clinical Nurse Specialist Emergency Department

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