CHAPTER 4:
METHOD: A DUAL APPROACH TO EXPLORING HUMAN EXPERIENCE

4.0 Introduction

The purpose of this chapter is to outline the procedural component of the study. This study design takes a dual approach to the research question, using two methods, namely, a quantitative component using a survey questionnaire, and a qualitative component consisting of a series of interviews in a qualitative study informed by phenomenology. Quantitative research is primarily focused on numbers and statistical analysis, while qualitative methods are more suited to exploring human experiences. Qualitative research is also useful for studying phenomenon or events about which little is known (Appleton 1995, p. 993). The combination of both methodologies is designed to produce the best answer to the research question, and has the capacity to strengthen the study.

The initial part of the study draws on the previous work of Armentrout (1986) and permission was obtained for the use of that study’s questionnaire. The main function of the questionnaire in this study was to discover what were the nurses’ main issues of concern, the results of which were used to structure the interviews. This chapter discusses the survey questionnaire, its format, the sample, sample size, rationale for selecting the sample, the ethical considerations, and the time frame for the questionnaires and interviews. It further discusses the qualitative component of the study and provides a step by step guide to the analysis. The data from the interviews were analysed and the results are presented in five separate chapters (6-9), with a final interpretation given in each chapter. The discussion chapter explores in detail one aspect from each theme.

Phenomenology as a philosophy and its use as a research method for the current study is briefly explored. An historical perspective on phenomenology is not included. Many scholars have explored its development in publications with phenomenology as method (Oiler 1982; Omery 1983; Benner 1984; Benner 1985; Knaack 1984; Thompson 1990; Wilkes 1991; Bartjes 1991; Taylor 1991; Taylor 1993; Taylor 1995; Benner 1994;
Darbyshire 1994) and have shown the historical time line in relation to its philosophical underpinnings. The philosophy as it relates to the current research and the work of the contemporary phenomenologist, Van Manen, whose phenomenological approach informs this work are however discussed.

4.1 The Research Question

After critical review of the current knowledge base and reflection on the experiences of neonatal nurses as they grapple with the ethical issues that arise from caring for babies of 24 weeks gestation and less, the research question was formulated.

What are the ethical issues experienced by neonatal nurses concerning the care and management of babies of 24 weeks gestation and less, and how are they experienced?

4.2 Aims of the study

The aims of the study are:

1. To identify and explore the ethical issues faced by neonatal nurses as they care for babies of twenty-four weeks gestation and less.
2. To describe the experience of neonatal nurses with ethical dilemmas that arise during their care of babies of twenty-four weeks gestation and less.

4.3 Purpose of the study

The purpose of the research was to discover and explore the ethical issues faced by neonatal nurses concerning the care of babies of twenty-four weeks gestation and less. At present only one study has examined the feelings, thoughts and beliefs of nurses about working with extremely premature babies (Armentrout 1986). In 2007 the ethical dilemmas facing neonatal nurses are substantial, at a time when available technology has been shown to make very little difference to outcomes for extremely premature babies. This effectively means that with available technologies the prognosis for extremely premature babies has not improved (Battin et al. 1998, p. 469; Hack & Fanaroff 1999, p.
Nurses consider themselves to have special insight and information about the babies that they care for (Mellien 1992, p. 130), and could contribute to the discussions related to these tiny babies (Miya 1989, p. 417; Martin 1989, p. 467-468; Miya et al. 1991, p. 256). Historically, neonatal nurses have played little part in the decision making processes that relate to life and death issues of the babies in their care. The voices of nurses are still relatively silent in this debate, although nurses constitute the largest group of staff working in neonatal intensive care units (Mellien 1992). This study provides a description of the nurses’ experience of the ethical issues surrounding the care of extremely premature babies, and aims to increase nursing knowledge in this important area of practice.

4.4 Significance of the study

The research is an innovative study that has not been previously undertaken. A substantial literature search has confirmed that this study has not been performed elsewhere. Prior to this research no precedent research in Australia which examined the research question has been undertaken. The improved survival of babies less than twenty four weeks gestation in Australia has widened the focus of concern from the risk of death to include the quality of life of survivors. The finding by Allen et al (1993, p. 1597) that only two percent (2%) of infants born at twenty three (23) weeks gestation survived without severe neurological abnormalities has pre-empted this investigation. Neonatal nurses have been shown to be more conservative about the aggressive care of infants of marginal viability than their neonatologist colleagues (Lee, Penner & Cox 1991, p. 110; Oei, Askie, Tobiansky & 2000, p. 357; Streiner et al. 2001, p. 152), and may, in turn, influence the way they view infants of extreme prematurity. This research will add to existing knowledge about neonatal nurses as they care for extremely premature babies and the ethical dilemmas experienced by them.
Little literature and research addresses the attitudes and feelings of neonatal nurses regarding the moral, ethical, legal, economic and social issues surrounding the care of infants of marginal viability. Armentrout (1986) sought to determine the attitudes, beliefs and feelings of neonatal nurses towards the management and care of fetal infants within the context of ethical, legal, economic and societal environments in the USA. Her research showed that neonatal nurses experienced ethical dilemmas in relation to the care of these babies. They experienced anger when there was a lack of proper consultation with the parents prior to the institution of life-saving measures, or when the medical staff did not consider parental wishes concerning the withdrawal of life support (Armentrout 1986, p. 23).

Substantial changes have occurred in the care of premature babies since Armentrout’s (1986) study into the management of infants of marginal viability, defined as 26 weeks gestation or less. Firstly, infants of much lower gestation are being saved. Secondly, the birth weights of these infants are much lower and, thirdly, because of reproductive technologies there are more multiple pregnancies (Evans, Littmann, St Louis, LeBlanc, Addis, Johnson & Moghissi, 1995, p. 1750) resulting in more premature infants. Extending the life of the extremely premature infant is controversial, however, the decisions associated with such treatment are complex, emotionally demanding and may have lifelong consequences for the baby and family. Unfortunately, some babies are deemed too small or immature to survive even with intensive care. Neonatal nurses need to articulate their ethical dilemmas surrounding the care of these tiny babies. Repeated exposure to ethical dilemmas could see neonatal nurses leave the profession (Severinsson 2003, p. 59) with a significant effect on staff retention.

4.5 The place for quantitative and qualitative methods in this research

Both quantitative and qualitative research methods have an established place in nursing research. It is not argued that one method is superior to the other, on the contrary, both methods are used in this study. While empiricists and qualitative researchers may differ in their philosophical assumptions and the way they collect and make sense of their data, their ultimate enterprise is the same. Both analyse their data, construct explanatory
arguments from the results and speculate on the observed outcomes (Sechrest & Sidani 1995, p. 78). It has been claimed that mixed method research offers the best opportunity to answer questions (Johnson & Onwuegbuzie 2004, p. 16) in human research.

Mixed method research is where the, “…researcher mixes or combines qualitative and quantitative research techniques, methods, approaches….into a single study,” (Johnson & Onwuegbuzie 2004, p. 17) in constructing the overall research design. Collecting multiple data sources using different strategies, approaches and methods result is a combination that is likely to result in enhanced strengths and diminished weaknesses of both methodologies (Johnson & Onwuegbuzie 2004, p. 18).

For this research, the combination of both quantitative and qualitative methods was deemed to be the most effective way to answer the research question. A full exploration of the issues was possible using both the questionnaire and the qualitative approach informed by phenomenology. Issues arising in the interviews might not have emerged if only a quantitative approach was used. The questionnaire explored the issues of concern for Australian neonatal nurses. A qualitative method informed by phenomenology was used to interpret the interviews because of the need to understand the nurses’ experiences, or in the case of this research, understand their ethical dilemmas surrounding extremely premature babies. In this research the quantitative research provided the overview or the breadth of the topic under exploration, while the qualitative research provided the insight or depth of the topic. In other words the quantitative component provided the discovery (Foss & Ellefsen 2002, p. 244), while the qualitative component provided the understanding of human experience.

It is not common practice to use a phenomenological approach and a questionnaire to elicit the information to form the basis of the interviews, however, this procedure is a valid inclusion. The hallmark of good qualitative methodology is its variability, and there should be evidence of adaptation and redesign (Horsburgh 2003, p. 309). Given the lack of specific literature on the topic under investigation, it became necessary to identify the issues of concern from the neonatal nurses themselves. It was important to find out from
the nurses what their issues of concerns were, rather than make assumptions. Allowing the nurses to document these in the questionnaire, and then discuss in the interviews their issues of concern was essential for a thorough understanding.

4.6 Data collection

This research is a mixed method study exploring the ethical issues experienced by neonatal nurses when they care for babies of 24 weeks gestation and less. Data were collected with a survey questionnaire and interviews. Neonatal nurses who were members of the Australian Neonatal Nurses Association (ANNA) were sent a questionnaire about the ethical issues related to the care of infants of less than 24 weeks gestation. It is not possible to ascertain what percentage of Australian neonatal nurses are members of ANNA. Contact was made with the executive of the state branches, and the questionnaire subsequently administered.

Following analysis of the questionnaire, an interview schedule was constructed, and twenty four (24) nurses took part in interviews. Fourteen (14) interviews were conducted, and these consisted of single interviews and focus groups.

4.6.1 Development of the questionnaire

The questionnaire development drew on a previous study by Armentrout (1986) in which neonatal nurses in the USA were asked about their feelings, attitudes and beliefs towards caring for fetal infants (defined as less than 26 weeks gestation). Since Armentrout’s (1986) study the lower limit of viability has decreased. There have been advances in technology that have allowed smaller and smaller infants to survive. At present with the available technology and clinical experience, the lower end of viability would appear to be 23 weeks gestation, although Japanese clinicians suggest that they can save babies from 21 to 22 weeks gestation (Oishi, Hishida & Sasaki 1997, p. 3). Given that babies of 25 weeks gestation and less are likely to have a 50% chance of survival (Allen et al. 1993; Whyte et al. 1993; Holtrop et al. 1994; Ferrara et al. 1994; Costeloe et al. 2000;
Marlow et al 2005, p.9), 24 weeks gestation and less was chosen as a condition of the study, because it could be hypothesised that nurses might experience ethical dilemmas with babies who have less than 50% survival, and of those who survive at least a 50% chance of a major disability (Allen et al. 1993; Synnes et al. 1994; Msall, Buck, Rogers, Merke, Wan, Catanzaro, Zorn 1994; McCormick 1997; Battin et al. 1998; Lui et al. 2006, p.499).

Armentrout (1986) used a 31-item Likert-type questionnaire, which explored the moral/ethical, economic/resource, jurisdictional/legal and technological issues. In addition there was a 6 item self-reporting statement. The topics in Armentrout’s study are still pertinent to the present study, however, there are major differences between the USA and Australia in relation to medical, legal and social systems, which include the provision of health care. An investigation was done to assess if Armentrout’s questions were valid in the current medical, social, legal and political systems within Australia. Firstly, the Australian legal system in relation to saving extremely premature infants was explored, followed by an examination of the Australian health care system (MEDICARE) in relation to the financial aspects of saving these infants. Each question was thoroughly examined for its ability to reflect the nature of Australian health care.

A survey questionnaire was selected because it had the advantage of gathering information on neonatal nurses’ opinions and views about caring for extremely premature infants, from a larger population, namely neonatal nurses in states across Australia.

4.6.2 The questionnaire

A questionnaire might not be commonly used when seeking answers to questions of an ethically sensitive nature. The questionnaire was chosen because I wanted to understand the experiences of Australian neonatal nurses. Utilising a questionnaire meant information could be gathered from a large population of neonatal nurses. Australia is a vast country (7,692,024 km²), the world’s sixth largest country (Australian Government Geoscience Australia 2003) with six states and three territories. Australia’s vastness
creates disadvantages for interview techniques. These disadvantages include the costs and time required for interviews. A survey questionnaire was therefore selected. Postal survey questionnaires are cheap, cover a widely distributed population group, and more importantly, avoid interviewer bias (Jacoby, Lecouturier, Bradshaw, Lovel, & Eccles 1999, p. 296). A questionnaire is considered reliable because responses are collected in a standardised manner.

The questionnaire was modified from a study undertaken by Armentrout (1986), and with her permission. A 62-point Likert-type questionnaire, with 4 self-reporting questions was developed. The questionnaire consists of six (6) sections. The sections contain different subject matters for ease of completion. Section one contains demographic information, and includes the length and type of neonatal nursing experience of the respondents. Section two is a series of statements related to how neonatal nurses manage the experience of caring for babies less than 24 weeks gestation. Section three explores the neonatal nurses’ attitudes to extremely premature babies’ survival, and the decision making process. Section four explores issues relating to the funding of health care, and neonatal intensive care units in particular, as well as social and family issues. Section five poses questions about government and legal involvement in management decisions regarding tiny babies. Section six explores the ability of new and advanced technology to solve many of the problems that are experienced in the neonatal intensive care. A copy of the questionnaire is located in the appendices (Appendix A).

Questions can reflect the philosophical issues under investigation. Open-ended questions are used when the end points of the investigation are complex and uncertain, while closed ended questions lend themselves to limited response (Lydeard, 1991, p. 86). Closed ended questions offer the respondents a choice of alternative replies, while open-ended questions have no answers and the respondents reply in their own words (Lydeard 1991, p. 86). When investigating feelings or opinions, open-ended questions are more applicable. Lydeard (1991, p. 86) emphasises that open-ended questions are easy to ask, difficult to answer and difficult to analyse, while closed ended questions are easy to ask, easy to
answer and easier to code for analysis. This questionnaire has open and closed ended questions. The most appropriate approach to analysing data gathered by a questionnaire is the generation of descriptive statistics. The questions were pre-coded for ease of data entry with the computer program Statistical Package for Social Sciences (SPSS) version 10, used for analysing the data. SPSS has the ability to generate descriptive statistics and complex statistical analyses (SPSS1999, p. iii).

4.6.3 Specifics of the questionnaire

The demographic details in the questionnaire (section 1) included;

1. Gender
2. Age
3. Religion (optional)
4. The influence of religious beliefs on ethical decision-making
5. Present working role
6. Educational qualifications, hospital programs
7. Educational qualifications, college/university based programs
8. Formal education in ethics
9. Years employed as a nurse
10. Years employed as a neonatal nurse
11. Current employment
12. Current neonatal nursing employment
13. Level of nursery in which currently employed
14. Length of experience with caring for babies of 24 weeks gestation and less

The demographic details were sought in order provide a demographic profile of those who participated in the survey questionnaire. Demographic information is important. It allows for comparison or correlation between groups.

Question 16 (section 2) contains a series of questions related to the neonatal nurses’ emotions associated with caring for babies 24 weeks and less. Not all neonatal nurses in
Australia have experience of caring for babies of 24 weeks gestation and less, therefore, only those with experience were requested to fill out this part of the questionnaire. Other neonatal nurse participants were asked to commence at Question 17 (section 3).

In addition, there were 5 open-ended questions which explored:

21. How would you define quality of life?
22. How would you determine what was in the best interest of babies of 24 weeks gestation and less?
23. Are there specific ethical issues that concern you about the care of babies of 24 weeks gestation and less?
24. Do you have any specific concerns about the long-term outcomes for babies of 24 weeks gestation and less?
25. Do you have any further comments?

A content analysis (part of Appendix B) was performed on the open-ended questions in order to determine the issues of most concern. Content analysis is a data reduction technique. The content analysis of the questionnaire sought to determine the attitudinal, behavioural, psychological, ethical and emotional states of the participants in relation to their experience of caring for extremely premature babies. A content analysis is a method of textual investigation and is particularly useful with large amounts of textual data. It can be further divided into conceptual and relational analysis. A conceptual analysis establishes the existence and frequency of concepts represented by words of phrases in the text, while a relational analysis seeks to go beyond presence by exploring the relationships between the concepts identified (Colorado State University 2007). Content analysis was useful because it allowed inferences to be made which could be supported by the other methods of data collection. A set of rules was developed to insure coding was consistent throughout the text. This allowed me to streamline and organise the coding process. Firstly the text was coded into manageable content categories. A category was considered to be a group of words with similar meaning or connotations. By reducing the text to categories the researcher can focus on patterns that are indicative of the research question (Colorado State University 2007). Five categories were established:

- Long term outcomes
• Feelings, attitudes and beliefs
• Ethical issues
• Best interests
• Quality of life

In the next step the text was coded by reading through the text and writing down concept occurrences, using words or phrases. Following this I examined the data and attempted to draw conclusions and make generalisations. Content analysis is useful to see trends that are indicative of larger ideas (Colorado State University 2007).

An advantage of content analysis was that texts and transcripts could be directly examined and the views of the neonatal nurses about caring for extremely premature infants could be readily discovered. Content analysis can be used for both quantitative and qualitative data (Colorado State University 2005b). The data from the content analysis was used to help determine the interview questions. The disadvantages in using it in this research were that it was time consuming, reductive, and had the potential to disregard the context that produced the text (Colorado State University 2005c). I recognised that these problems might exist but with two other data sources to incorporate into the final research results I hoped that I could minimise such problems.

The validity and reliability of a content analysis would refer to its stability, reproductibility and accuracy, or whether others could re-code the same data consistently over time using the same categories and come to the same conclusion (Colorado State University 2005a). I checked and re-checked the results myself, however, I recognise that this does not offer the security of independent scrutiny.

4.7 Study Population

The population under study was Australian neonatal nurses who were current financial members of the Australian Neonatal Nurses Association (ANNA) in the years 1999-2000.
4.8 Ethics approval and research ethics committee expectations

This research project was approved by the Flinders University South Australia Social and Behavioural Research Ethics Committee, Approval Number 1924 (Appendix C). The committee stipulated that only those neonatal nurses who were members of ANNA were to be included. The members of the committee accepted that organisations such as ANNA have a mandate to protect their members from unethical behaviour by researchers. Approval included the qualitative interviews with neonatal nurses. The nurses who were to be interviewed were required to have completed the questionnaire.

Arrangements were made to store the data involved in the research, completed questionnaires, audiotapes and interview transcripts, in a locked cupboard in the researcher’s work office. All participants in both phases of the study were assured that confidentiality would be maintained. The computerised data for questionnaire and text would be de-identified and each nurse coded with a number. Participation in the research was voluntary. The interview participants were informed that there would be no direct reference to them in the written thesis or any publications which emerged from the study. Interview participants were given the opportunity to read the information about the study, and to ask questions before they made their final decision to go ahead with the interview. (Appendix E) The written consent form was signed at this time. (Appendix G)

4.9 Preparing for the research process

The researcher acknowledged the necessity of having the questionnaire assessed for its content and readability. The questionnaire was pre-tested and a pilot focus group interview was undertaken. Armentrout’s (1986 &1988) original questionnaire was not pre-tested.

Factors have been identified that can influence the response rate of questionnaires. Questionnaires considered by the respondents to be salient or important, public health surveys (Goyder 1982, p. 551), and government sponsored questionnaires have high
response rates. Certain groups of individuals are more likely to return questionnaires; these being students, employees and military personnel (Heberlein & Baumgartner 1978, p. 451). The length of a questionnaire and its subject do not seem to affect the response rate (Heberlein & Baumgartner 1978, p. 453; Herzog & Bachman 1981, p. 559). The importance of the topic under investigation for the nurses could influence their choice to complete the questionnaire.

4.9.1 Validity and reliability

Validity refers to the degree with which a study accurately addresses the concept the researcher is attempting to measure, or the study’s success at measuring what the researcher set out to measure (Colorado State University 2005d). Internal validity refers to the rigor with which the study was conducted. This rigor takes into account the study's design, the care taken to conduct measurements, and the decisions related to what was measured. External validity refers to the extent to which the results of a study are generalisable, recognising that the qualitative component will not be and should not be generalisable (Colorado State University 2005d). Reliability is the accuracy of the measuring instrument, and refers to the extent to which an experiment, test, or measuring procedure yields the same result if another researcher were to conduct the research (Colorado State University 2005e).

In this research validity was established through an initial review of the literature to establish the issues of importance in relation to the care of extremely premature infants. Each of the questions was thoroughly researched to ensure that it was appropriate for Australian neonatal nurses, recognising that the context of health care delivery in Australia differs from many overseas countries.

The reliability of this study was established by using a pilot group to test the questionnaire. The reliability of the study could also be measured through stability reliability or test re-test reliability, where over time, the questionnaire could be used again. In theory, to test the stability, the questionnaire could be repeated on the same
respondents at a future time, the results could be compared to give a measure of stability (Colorado State University 2005f).

4.9.2 Bias

Bias, or systematic error refers to defects in the design, conduct of the research, analysis or interpretation of the data, which produces results or conclusions that differ systematically from the truth (NHMRC 2001). Bias occurs when there is unacknowledged or unknown error created during research question choice, sampling, measurement or procedure. This includes errors in methodology, statistical analysis and interpretation. Errors related to statistical analysis occur when inappropriate statistical methods are used (NHMRC 2001). Bias is more likely to occur when there are two or more groups and there is determination of difference between the groups. Bias in this study has been minimised, as there is only one group of nurses. The purpose is not to determine the difference between groups, but to get a picture of the whole.

Selection bias is a distortion of data that arises from the way that the data are collected. It is hoped that selection bias has been minimised in the quantitative component by including all participant’s questionnaire data, including outliers. Non-intentional sampling bias might have occurred in several ways. Firstly, accessing only neonatal nurses who are members of ANNA might produce different results from those neonatal nurses who were not members of ANNA. Secondly, members of professional organisations might give more consideration to ethical and philosophical issues surrounding their practice, possibly being one of the reasons that they joined their professional organisation. I also recognise that the omission of a specific sub-group of neonatal nurses makes the sample non-random and could be open to error, however, members of ANNA as participants was specified by the ethics committee.
4.9.3 Bias, validity and reliability in a qualitative study

There is a key difference between bias in quantitative and qualitative research. Quantitative researchers attempt to eliminate bias, while bias is explicitly acknowledged by qualitative researchers. The potential for bias exists in qualitative studies, however, it can be minimised through rigorous study design (NHMRC 2001). Bias refers to errors in research design, conduct and interpretation. Quantitative research stresses objectivity. Qualitative research operates on the premise that total detachment on the part of the researcher is unattainable as the researcher is an integral component of the whole process and product (Horsburgh 2003, p. 307). Cutcliffe and McKenna (2004, p. 129) suggest that bias in qualitative research is both necessary and purposeful. It is their belief that deliberate bias stems from the decisions made in relation to which literature to access, choice of setting and selection of participants. There needs to be acknowledgement that bias exists. In qualitative research samples are chosen purposefully rather than randomly. Purposeful sampling attempts to select interview participants according to the criteria determined by the research process (Tuckett 2004, p.53). Purposeful sampling can also be thought of as selection bias. Selection bias has occurred in this study, as I chose neonatal nurses who had cared for extremely premature babies to participate in the interviews, because the qualitative research process is one of discovery rather than testing of hypotheses.

Deliberate bias occurs as qualitative researchers are part of the research, yet separate from it, and they strive to maintain subject-subject position (Cutcliffe & McKenna 2004, p. 129). Deliberate bias can also occur because of the interest of the researcher in the research topic (Corben 1999, p. 55). Reflexivity is acknowledgement by the researcher that his/her actions and decisions will impact upon the meaning of the phenomenon under investigation. Through reflexivity the researcher realises he/she is an integral part of the world under investigation and that neutrality and detachment in relation to data collection, analysis and interpretation are impossible (Horsburgh 2003, p. 308).
Validity is the degree to which the results represent reality. If reality is subjective this could have implications for the validity of the study because the data gained in an interview is always second hand. The interview participants have already interpreted their experience to some extent, particularly if they saw the experience as distressing or traumatic. Koch (1999, p. 23) confirms this by stating, “the inquirer cannot come to grasp the mind of the participant. Nor can the inquirer recover the past as it actually was”. Interpretation of the event by the participant prior to telling the interviewer could be one way in which the ego is protected.

One of the hotly debated topics in qualitative research is related to whether rigor can or should be measured or even quantified. Koch and Harrington (1998, p. 883) speak of the preoccupation of qualitative researchers with methodological rigour, which is seen as a legacy of the positivist epistemology. Rigour is part of the validity of the qualitative study, however rigour deals specifically with how a research paradigm’s ontology and epistemology inform the interpretative methodology which is used to answer the question (Koch 1996, p. 177). Validity in a qualitative study is about trustworthiness. The trustworthiness of the study is confirmed in three ways: firstly, if the researcher describes and interprets the informants experience. It is about the richness of the description, and this lends credibility to the study. Secondly, readers consider the study is transferable to another context, and are able to follow the decision trail of the researcher. This decision trail establishes the dependability. Thirdly, the researcher shows how interpretations were arrived at, which is the confirmability of the study (Whitehead 2004, p. 513).

Reliability is the extent to which random variations might have influenced the results. If a study is reliable it should be able to be reproduced, however given the experiential nature of a qualitative study informed by phenomenology this might not be possible. Sandelowski (1993, p. 1) emphasises that two researchers faced with the same research task will produce different accounts due to their individual philosophies. If the findings of research are created via the interaction of the interview participant and the researcher, then different researchers will yield different truths.
4.9.4 Pre testing the questionnaire

To assess the validity of the questionnaire it was pre-tested by twelve (12) clinicians working within the neonatal intensive care, and three (3) academics. Those who pretested the questionnaire included Neonatologists (2), Nurse Academics (3), Clinical Nurse Consultant (1), Clinical Nurse Specialists (7), and Registered Nurses (2). Those undertaking the pretest were asked to point out any problems that they had with the wording or clarity of the questions. The questionnaire was revised in light of the comments made by those who undertook to pretest the questionnaire. For example, the question on the nurse’s religion was made optional as several of the pre-testers believed that asking about religious beliefs might be unacceptable to the neonatal nurses.

An attempt was made in designing the questionnaire to keep the language simple. Two nurses, however, who pre tested the questionnaire found difficulty in the wording of some of the questions. They observed this could have been due to the philosophical nature of the questionnaire. Several questions were rewritten.

4.10 Dissemination of the questionnaires to the participants

Following approval by the ethics committee a post office box at a suburban mail sorting centre and a reply paid service was organised. A letter was written to each of the neonatal nursing associations/organisations in each state of Australia. Each organisation was provided with the envelopes sealed and postage stamped that contained the questionnaire, letter of introduction from supervisor, (Appendix E), a reply paid envelope, and a letter of support for the research (Appendix H). The organisation addressed the letters and mailed the questionnaire to their members. All completed questionnaires were returned to the researcher in the reply paid envelope. They were opened by the researcher.
4.10.1 Informing neonatal nurses about the research

Two to three weeks before the questionnaires were posted, a visit was made to all the neonatal units in Sydney NSW to speak about the research detailing its aims and to encourage those members of ANNA to complete the questionnaire. The specifics of the questionnaire were not mentioned during these sessions. A letter of introduction from the researcher’s supervisor, part of Flinders University ethics requirements (Appendix E) was included with the questionnaire. The secretary and the professional officer of ANNA at the time wrote a letter of support for the research (Appendix H) which was also included. The President of ANNA at the time, included support for the research in her “Message from the President” on the ANNA website (http://www.anna.org.au).

4.11 Response rate

At the time of the study there were 760 members of ANNA. Of these 414 questionnaires were returned, a response rate of 54.4%.

4.12 Time frame for the study

The time frame allocated for the collection of all data, including questionnaires and interviews was six months. The study began with the quantitative phase, and because the questionnaires went out very close to the Christmas period, two months was allowed for the return of the research, from the end November 1999 to January 2000. The data was analysed during February 2000, and the interviews commenced. All interviews and transcriptions were completed by June 2000.

4.13 Comments from the respondents about the questionnaire

Generally the feedback from the respondents about the research and questionnaires was extremely positive. I did not specifically ask for feedback, however several respondents
believed the questionnaire was difficult to answer, although perhaps it was not the questionnaire itself, but the thoughts and feelings that the questionnaire provoked.

“It has been interesting and thought provoking filling in this questionnaire.” (Q/A 339)

“I have only nursed a few of these babies, and this questionnaire has made me feel I need to think about it more deeply.” (Q/A 394)

“A very valuable study…the questionnaire made me really think.” (Q/A 77)

“This questionnaire has stimulated some self reflection and self disclosure as I’ve attempted to work out my own values and thoughts.” (Q/A 82)

Those who pre-tested the questionnaire suggested it would take half an hour to complete. Several nurses commented that the questionnaire took more time than this, although these nurses stressed this was because the questionnaire prompted them to think more deeply than they otherwise would have done.

“Q/A a bit long.” (Q/A 81)

“Your questionnaire was very thought and emotion provoking. I found it took longer than ½ hour to do – in order to give justice to your questions (2 hours).” (Q/A 160)

4.14 The use of the questionnaire

Questionnaires lack the ability to probe into the behaviours of those being researched. Questionnaires are more appropriate for extensive, rather than intensive analysis. The format of this questionnaire with its philosophical questions might have improved this situation. The interviews were used to explore in depth the major issues, which emerged, from the questionnaire. Therefore, the use of both questionnaire and interviews was confirmed as the most fitting way to explore the issues, and answer the research question.
Sample size for the questionnaire was important because a bigger sample size was more likely to represent the neonatal nursing population. Seven hundred and sixty questionnaires were sent to neonatal nurses in Australia, and 414 returned. Given the nature of the questionnaire and the time of year, three weeks before Christmas, this was a good response for an Australian study.

4.14.1 Advantages of the questionnaire

Surveying all members of ANNA using a questionnaire provided an Australia wide perspective of ethical issues experienced by neonatal nurses. This is the first study of its kind. Researching neonatal nurses in one state in Australia would not have given an overall picture of ethical issues confronting neonatal nurses in the other states in Australia.

Although the questionnaire was not designed to examine at the deepest level the neonatal nurses’ thoughts, feelings and emotions, many of the nurses took the opportunity to write in greater depth about issues concerning them about caring for such tiny babies. Many of these comments were negative, and included stories of babies that the respondents had cared for in the past. A number of the nurses used the back of the pages to discuss their issues of concern. Fifteen percent of the nurses stated that it was useful to be able to write down their thoughts on the subject. These unexpected comments were included in the content analysis. This decision could be criticised because not all respondents made comments.

4.14.2 Disadvantages of the questionnaire

The main difficulty with questionnaires distributed on a large scale is ensuring an adequate response rate. The questionnaires for New South Wales were posted the week before Christmas; such timing may have contributed to a lower response rate. Reminder notices in with each state’s Neonatal Nurses Association newsletter were placed in order to remind the nurses to answer the questionnaire.
Contact details of the members of ANNA were not supplied nor was access to the mailing lists. Those who had not returned their survey could not be identified. To send out the full number of reminder notices in order to remind those who had not returned the questionnaire was deemed not feasible.

4.15 The qualitative component

The qualitative component of this study consists of interviews with neonatal nurses. Twenty four (24) neonatal nurses were interviewed and fourteen (14) interviews were undertaken. The participants were from a number of neonatal settings (perinatal, surgical and the newborn emergency transport service) in Sydney and Newcastle in NSW, and Canberra in the Australian Capital Territory (ACT).

A qualitative, interpretative approach was chosen for this second part of the research in order to explore and gain an understanding of the nurse’s experience with ethical dilemmas in the care of extremely premature babies. Qualitative research stresses the importance of subjectivity, or that which comes from a thinking subject, and claims that the foundation of factual knowledge comes through human experience. A qualitative approach is useful for providing rich and detailed descriptions of previously unexplored directions of inquiry. Qualitative methods focus on human beings within their own social and cultural context (Morse 1991, p. 120). This interpretative study sought to describe and understand the experiences of the neonatal nurses and their ethical dilemmas.

The interpretative approach suggests that reality is subjective, and built on social and historical contexts. Reality is the “...state of things as they are, or appear to be, rather than as one might wish them to be” (Collins 2001, p. 1248). Reality, therefore, changes over time, place and circumstance. Sarantakos (1998, p. 10) suggests that “reality is not ‘out there’ but in the minds of people; reality is internally experienced, is socially constructed through interaction and interpreted through actors, and is based on the definition people attach to it.” For example, the nurses’ experiences with negative outcomes of extremely premature babies might influence their beliefs about whether these babies should be
saved. Reality for the neonatal nurses was subjective, as what they see and experience has already been interpreted by them. Oiler (1992, p. 179) suggests “…people live forward. They know what it is to have lived through only by looking back”. This is how the nurses made sense of their experiences. Accessing data about experiences from individuals can be problematic even under the best circumstances (Sechrest & Sidani 1995, p. 80). Memory loss, the importance of the event for the person concerned, and the repression of threatening situations, can all contribute to the difficulty of accessing data from personal experience narratives (Smith, 1992 p. 101).

In interpretative research the participants’ perspectives are sought, and it is through the recounts of the participants that the researcher is able to gain an understanding of their lived experience. Participants and researchers are able to share this experience. Knowledge of the neonatal nurse’s world, revealed by the research, can be gained through searching, describing and documenting the meaning as accurately as possible.

4.16 The interviews

Twenty four nurses were interviewed and 14 interviews were performed over a three-month period.

4.16.1 Recruitment for interviews

A purposeful sampling technique was used to identify the participants. The nurses who were interviewed were either known to the researcher (1), or recommended to the researcher by either Clinical Nurse Consultants (CNC) (12) or Clinical Nurse Educators (CNE) (11) from the perinatal or surgical centres. The neonatal nurses were initially approached by the CNC or CNE about the possibility of being interviewed. If they agreed the researcher was given their contact details. All the neonatal nurses who were interviewed had completed the questionnaire. The questions used were based on the significant findings of the questionnaire.
4.16.2 Venue for the interviews

The interviews occurred in several places, in the participants’ own homes (5), the interviewer’s home (4), or a quiet room away from the neonatal unit at the participant’s hospital of employment (5). Home interviews can be problematic, because of unwanted interruptions or participant inhibition in the presence of their family and friends. Those nurses with partners and families organised to be interviewed when there was no one else at home.

4.16.3 The inclusion criteria for interview:

The criteria for inclusion in the study was determined according to the qualifications and experience of the participants. Participants needed to be:

(1) Registered Nurse

(2) Current employment in a level 3 or level 4 neonatal intensive care unit or paediatric intensive care unit where neonates are cared for, or members of the newborn emergency retrieval team.

(3) Substantial, greater than 5 years, experience with caring for babies less than 24 weeks gestation and less

(4) English speaking

(5) Willing to participate and have the interview audio taped

4.16.4 Emotional protection of the interview participants

When undertaking research using interviews it is important to achieve an ethical standard. The potential good arising from the research is considered with the potential harm done to the neonatal nurses by participating in the research (Smith 1992, p. 99). In researching sensitive topics considerable thought is needed about the issues related to self disclosure for the participants. The participants stated they were comfortable with self disclosure. The ethics approval from the Flinders University required the availability of a counsellor if the interview participants became distressed during their interviews as they recalled sensitive situations. A professional counsellor was organised, and the
participants advised of this availability. None of the interview participants required this service.

4.16.5 A pilot focus group

The skills of the interviewer and how he/she evokes the respondents to recall stories and descriptions of events have a direct impact on the quality of the data obtained (Sorrell & Redmond 1995, p. 1117). In order to practise the interview technique and improve interviewer reliability, several neonatal nurses agreed to participate in a pilot focus group. The nurses were assured that their participation was confidential, that any information, that could identify them, their colleagues or the institution in which they were employed would be deleted in the transcriptions. All focus group interview participants signed the consent forms. The interviews were taped using a tape recorder. Following this focus group, feedback from the participants about the interview was sought. Their comments affirmed the approach for further interviews. On reflection I realised that I spoke frequently during the pilot focus group interview, seeking clarification on certain points. I noticed that my words could influence a participant’s train of thought. Care was taken in the interviews to minimise my input.

4.16.6 Conducting the interviews

Personal interviewing of the participants allowed the interviewer and each interviewee to meet in a face-to-face situation. Visual contact is important because the interviewer is able to see the interviewee’s face and observe the body language that the questions provoke. A major advantage of face to face interviewing is that the researcher can put the interviewee at ease. The researcher can also take the opportunity to clarify any ambiguous or unclear questions. In the interviews I aimed to be facilitative, sensitive to language being used, and to extend my enquiry into what had not been anticipated (Britten 1999, p. 2).
Engagement occurred with the nurses during the interviews. Tea, coffee, cakes and biscuits were provided for the interviews by the participants or the researcher. It seemed that when food and drink were provided the formality of the interview was modified, becoming more relaxed and open. The nurses were prepared to talk freely about their experiences of caring for extremely premature babies. The content of the discussions covered many areas, and some accounts were highly emotional. A number of issues remained unresolved for these nurses. Although the role of the interviewer is not to produce catharsis (Smith 1992, p. 102), the interviews held a cathartic quality.

Neonatal nurses from all the major centres in NSW and the ACT, that provide care for extremely premature infants, took part in the interviews. The original plan was to interview neonatal nurses at two perinatal centres and one children’s hospital in Sydney, NSW. The plan was revised to include nurses from every major centre in NSW and the ACT. Approximately half the membership of ANNA live and work in NSW, therefore, interviewing nurses from all centres would increase trustworthiness. Interviewing nurses from across NSW and the ACT provided accounts from a diverse group of neonatal nurses.

Informed consent was sought and included the provision for a participant to withdraw from the study at any time. All participants signed the consent form (Appendix G). The participants who agreed to be interviewed were informed that they could choose not to answer any questions and that they could terminate the interview at any time. None chose to withdraw. The participants were given a letter of introduction that explained the process of interviews (Appendix F). The interviews were audiotaped. Following each interview the audiotapes were coded and transcribed with all nuances, such as laughter, crying and body language noted. During the interviews I noted what was happening to the participants at the time. For example, one nurse told a story and had tears running down her cheeks, although she did not make a crying noise. Haggman-Laitila (1999, p. 16) recommends marking such notes because transcribed discussions cannot include all that is meaningful and that written notes may help with the interpretation of the experience. The interviews took between one and two hours.
4.16.7 Focus groups

The focus group interview is a qualitative research method for exploring ideas within a group context (Nyamathi & Shuler 1990, p. 1282; Kingry, Tiedje & Friedman 1990, p. 124; Dilorio, Hockenberry-Eaton, Maibach, Rivero 1994, p. 175; Asbury 1995, p. 414; Goss 1998, p. 30; Burrows 1998, p. 3). Focus groups use the interaction of the group to produce data and insights about the research (Kitzinger 1994, p. 103; Cote-Arsenault & Morrison-Beedy 1999, p. 280; McLafferty 2004, p. 187). Focus groups in this research were thought to facilitate talk, because other neonatal nurses were present who might have had similar experiences in caring for infants 24 weeks gestation and less. The focus groups were very relaxed and informal, and the participants were not required to talk about issues they would rather not.

Focus group participants have common or shared experiences (Goss 1998, p. 31) and were neonatal nurses who had experience with caring for infants of 24 weeks gestation and less. They had all completed the original study questionnaire and were members of the ANNA. In each focus group there were between two to six neonatal nurses and the researcher. The numbers were kept small so that all participants would have the opportunity to share their insights. In both the single interviews and the focus groups the main findings of the questionnaire were discussed by the participants.

4.16.8 Sampling for interviews

In qualitative research the type of sampling is determined by the methodology and the topic under focus. Generalisability is the key issue that differs in quantitative and qualitative research. Qualitative research employs non-probability sampling which means that the findings are not generalisable, but apply to the particular population under study (Higginbottom 2004, p. 11). Qualitative research aims to reflect the diversity in a given population (Barbour 2001, p. 1115), therefore a sample in qualitative research should be those diverse individuals who can provide data on the area under investigation. In qualitative research informed by phenomenology research samples are always purposive,
and can be very small in size. In this study there were 14 interviews and 24 interview participants. There were eight single interviews and six focus groups. There is no specific number of focus groups or single interviews required. The goal according to Goss (1998, p. 30) is to include as many groups as required to answer the research question. In qualitative research informed by phenomenology a homogenous sample is required in order to reveal what an experience means to a particular group.

4.16.9 Participating neonatal intensive care units

Nurses from every major centre in NSW and the ACT (Australia), providing care to extremely premature babies, has been included in this study. Twenty four female neonatal nurses from ten neonatal intensive care units in NSW and the ACT were interviewed. Nurses from the paediatric and neonatal emergency transport service (NETS) were also included.

4.16.10 The interview questions

The questions used for the interviews are listed. They were constructed from the issues that arose from the questionnaire, the content analysis of the philosophical questions and other issues that emerged. For example, 22 percent of the nurses wrote in the comments section of the questionnaire that if they were in labour at 24 weeks gestation they would not want their baby treated. One respondent stated, “...every neonatal nurse I know would go bush rather than go to a tertiary centre if they were in prem labour with a pregnancy of 24 weeks gestation or less” (Q/A 106) (see footnote). This unsolicited information became the basis for one of the questions. Time was also allowed for unstructured conversation.

The interviewer and interviewee both participate in phenomenological interviews

In Australia the term “go bush” is colloquial language which refers to leaving the city and going to the remote outback wilderness. In this context there are no facilities capable of saving extremely premature babies.
(Higginbottom 2004, p.10). It is important that the participants describe their experience, rather than interpret it (Sorrell & Redmond 1995, p.1120). In the interviews some unstructured conversations that encourage the respondents to tell their stories are necessary. Questions are designed to uncover meaning. Higginbottom (2004, p.10) suggests probing questions such as, “What does this mean to you”? Questions that sought meaning of events were included.

Phenomenological questions seek to reveal how things appear in human consciousness. Questions were developed by asking the nurses about their experience, its meaning and context. A philosophical question challenges what is normally thought, and can be deliberately provocative.

Questions with an ethics orientation consider what is good or bad and right or wrong, while values questions explore the value of a thing that is allocated by an individual. Phenomenological, philosophical, challenging and value laden questions were included in the interviews in order to gain a full view of the nurses’ experience.

- Very few positive feelings emerged in the results, only challenged, concerned, discouraged and depressed feelings were given. Can you explain this? What does this mean to you?
- Some neonatal nurses wanted to shield the parents from decision making. Can you explain this? What does this mean to you?
- How is it different caring for babies of 24 weeks gestation and less for those neonatal nurses who are parents?
- 24 weeks gestation seems to be a definite cut-off point for the nurses. Why is this?
- What would the nurse do “hypothetically” if she went into labour at 24 weeks gestation?
- Knowing something about the baby that the parents do not know seems to be problematic for the nurses. What is your experience?
- Some couples seem to be desperate to have children. What is your experience?
- The nurses believed that, if resuscitated, these tiny infants should not be ventilated with minimal support for the first 24 hours to determine if they will live or die. Instead they should be given maximal care. What do you believe? What does this mean to you?
• The nurses believed that full disclosure of the potential prognosis and the results of the outcome studies should be conveyed to the parents prior to the delivery of infants less than 24 weeks gestation and less. What do you believe?
• The nurses believed that treatment should not be instituted in infants of 24 weeks gestation and less if the parents request non-intervention. Should the parents be able to make this decision?
• The nurses believed that tiny infants with a poor neurological prognosis would be better off dead. What does this mean to you?
• The nurses believed that all infants with a poor neurological prognosis would not be better off dead. Why is there a discrepancy between the nurses believing that tiny infants with a poor neurological prognosis would be better off dead, and yet the same could not be said for all infants with a poor neurological prognosis? What is your experience?
• The neonatal nurses do not seem to be concerned with the cost of NICU for 24 weeks gestation infants. Does cost not play a part? How does this affect the care you give?
• The nurses believed that the value of human life should not be measured in dollars and cents. What is your belief?
• The nurses believed that family disruption and dysfunction occurs frequently with babies of 24 weeks gestation and less. Can you talk about your experiences with the families of tiny babies?
• The nurses believed that the law should not require initiation of treatment in infants of 24 weeks gestation and less. Does the law have a place in these decisions?
• The nurses believed that hospitals should have policies governing the management of infants of 24 weeks gestation or less. What do you believe?
• The nurses believed that a combination of parents, doctors and nurses as decision makers. What do you believe?
• The nurses believed that neonatal nurses should be involved in decisions related to the continuation / discontinuation of care for infants of 24 weeks gestation and less. What is your belief?
• The nurses believed that the development of ethical guidelines would make these difficult treatment decisions much easier. Do you agree with this, and what is your experience with ethics committees?
• The nurses believed that when making decisions for infants of 24 weeks gestation and less, quality of life must be a critical factor to be considered. How would you define
quality of life? Could you give examples of what you believe to be acceptable and unacceptable quality of life?

- The nurses believed that future technology would only add to the dilemmas in relation to infants of 24 weeks gestation and less. Will the technology of the future make things more difficult?

In addition, questions based on the themes that emerged from the content analysis of the open ended questions in the questionnaire were posed in the interviews.

- The nurses spoke about their experience of the lack of honesty of some medical staff. Can you speak about your experience?
- The nurses spoke about the personal morals and religious beliefs of some medical staff in decision making. Can you speak about your experience?
- The nurses spoke about being left to care for babies of poor prognosis when no one will make a decision. This caused distress for the nurses. What is your experience of this?
- The nurses spoke about being initially hopeful, but became very concerned when catastrophic complications occurred. Can you talk about your hope and optimism in relation to babies of 24 weeks gestation and less.
- The nurses believed that parents should be the ultimate decision makers. Should parents have this right?
- For the nurses there was a concern about experimentation on tiny babies who cannot give consent. Is experimentation an issue, and could you give any examples?

4.17 The philosophy of phenomenology

Phenomenology is concerned with the study of phenomena. It is descriptive in its pure form, and does not attempt to explain the reasons for events. Phenomenology differs from ontology, which is the study of existence and being, and is interpretative. Phenomenology seeks truth and logic about human existence, occurring through critical and intuitive thinking (Jones 2001, p. 65). Discovering the nature of human experience and what it is to be is the purpose of phenomenology. Phenomenology is the study of things as they appear in our
consciousness, the meanings things have in our experience, and is experienced from the subjective or first person point of view.

4.17.1 Phenomenology as a research method

A qualitative approach informed by phenomenology was used for the qualitative component of this research. Phenomenology is but one qualitative approach to qualitative research. Others include ethnography, hermeneutics and symbolic interactionism (Lester 1999). The approaches differ in relation to the type of questions asked, the philosophical underpinnings and the final product (Ploeg, 1999, p. 37) including the research findings. A phenomenological approach rather than another qualitative approach was chosen for this research because phenomenological research seeks to describe rather than explain lived experience. It is not the intention of phenomenology as a research method to generate theories, but provides insight into the lived experience of the phenomenon (Corben 1999, p. 57). Phenomenology is effective at bringing to the fore the experiences and perceptions of the neonatal nurses from their own perspectives, and challenging their structural or normative assumptions (Lester 1999). I knew that with my neonatal nursing experience that it would be difficult to start the research without preconceptions or bias, but because of that experience I as the researcher wanted to be visible in the research as an interested and subjective participant, rather than a detached observer (Lester 1999).

Phenomenology is the study of human phenomena, and seeks to reveal the meaning and essence of a particular phenomenon (Higginbottom 2004, p. 11). Discovery of the essence of the phenomenon or what makes something what it is, is the ultimate purpose of this type of research (Bartjes 1991, p.248). Essence is the most essential meaning in a particular context (Kleiman 2004, p. 8). Phenomenology is also the study of the lifeworld (Van Manen 1990, p. 9). Lifeworld is the world in which the individual lives and is generally taken for granted. In this study it is the subjective and meaningful experiences of neonatal nurses as they cared for the smallest and most fragile of all human beings. Lived
experiences when described reveal the immediate, pre-reflective consciousness one has regarding the events that the person has lived through (Kleiman 2004, p.8). The phenomenon under investigation in this qualitative study informed by phenomenology is the neonatal nurse’s experience of ethical dilemmas when caring for babies less than 24 weeks gestation. This study uses phenomenology to extrapolate the nurses’ intersubjective meanings, the interpretation of which illuminated the phenomenon. The neonatal nurses, in giving detailed and rich understandings of their experiences of the ethical dilemmas have allowed the phenomenon to be described and understood.

Phenomenology can be described as a philosophical approach (Omery 1983, p. 50), a method (Oiler 1982, p. 178), an attitude (Knaack 1984, p. 108), and a way to approach life. Phenomenology is a way of viewing others, ourselves, and everything that comes into contact with our lives (Bartjes 1991, p. 248). It seeks to describe human experience as it is lived (Oiler 1982, p. 178), thereby seeking to understand to know and understand the truth about that experience.

Phenomenology is therefore based on the meanings that human beings form out of their interactions with the world, or in the case of this research, the meanings that the neonatal nurses make out of their experience of ethical dilemmas associated with caring for babies of 24 weeks gestation and less. Phenomenology, as used in this research, seeks to gain descriptions of the way the world of the neonatal nurse is experienced, the nature of his/her conscious knowing, and the structures of his/her lived experience in relation to ethical dilemmas associated with caring for extremely premature babies. Phenomenology does not seek to isolate the research participants’ immediate experience, rather it “…considers historical change, transformations, gains, losses, temporality and context” (Benner 1994, p. XV).

When undertaking research, several attributes are required of the phenomenological researcher. The capacity to experience the phenomenon as if it were their own, has been
suggested by Swanson (1990, p. 62) as one of the most important aspects. The data in a phenomenological study must be collected in such a way that allows the phenomenon to exhibit itself.

A phenomenological study should serve as a mirror to the lived experience of its informants and as a looking glass for those who read it: The reflection should be recognisable (Swanson 1990, p. 62).

There are no prescribed procedures in phenomenological research. Phenomenology is not a rule-bound process whereby every step the researcher takes is dictated. This study is informed by the work of Van Manen (1990, p. 30) who holds that in a phenomenological study there is no method, only tradition. This means that while there is a philosophical framework, there is no specific research technique or procedures that need to be followed. The researcher is required to transform what is seen, said or heard into an understanding of the participant’s original experience. The researcher will not experience the experience of the participants, therefore relies on the participants’ accounts to gain an insight into their world. Van Manen (1990) does, however, offer practical strategies for using phenomenology in human science research, and has provided a valuable framework to explore the nurses’ experiences of ethical dilemmas.

4.17.2 The different philosophical views of phenomenology

Edmund Husserl (1859-1938) is credited with developing the phenomenological movement, following expansion of the original work of Franz Brentano (Wilkes 1991, p. 233) and Carl Stumpf (Jones 2001, p. 65). Brentano’s contribution to phenomenology was the notion of intentionality, which means that human consciousness is directed towards a purpose (Jones 2001, p. 65). There are three major schools of phenomenological philosophy that have been used in nursing research. The first is the phenomenology of Husserl, and is referred to as eidetic descriptive phenomenology. The second is Hermeneutic enquiry guided by Heidegger, and is referred to as interpretative
phenomenology or Heideggarian phenomenology. The third is the Dutch School which includes the work of Max Van Manen and is a combination of descriptive and interpretative phenomenology (Dowling 2004, p. 32).

Fundamental differences exist between transcendental and interpretative phenomenology. Sukale (1976, cited in Taylor 1995, p. 68) concluded that the basic difference between the philosophies of Husserl and Heidegger came down to their different interpretations of the “world”. There seems to be a world with two levels, the levels of the natural world on the surface, and a level below. Heidegger was concerned with being in the world, which was the world on the surface, while Husserl was interested in the world below. Husserl was interested in epistemological questions of knowing, and recognised experience as the ultimate foundation of knowledge (Draucker 1999, p. 361). Husserl introduced the concept of life-world (lebensweld) or lived experience. The ultimate structures of consciousness were essences, therefore for Husserl, phenomenology seeks to describe human experience, where the essence and meaning of that experience are discovered. For Husserl, things existing in thoughts were real (Jones 2001, p. 66). Therefore, consciousness, which is the relationship between a person and the world that they inhabit, was important to Husserl. Phenomenology was therefore seen as the study of phenomena and how it appears through consciousness. The phenomenology of Husserl acknowledges how the person has dealt with his/her experience, but his interest lay in what happened outside his/her awareness and articulated thought. In Husserlian phenomenology, the researcher should seriously question what is ‘taken for granted’ (Husserl 1970, p. 113). For Husserl, phenomenology was about deconstructing experiences, which render them accessible to scrutiny (Jones 2001, p. 66). The meaning of that human experience is important. Husserl emphasised that the way to access the phenomenon was ‘…through reflective description of it in the person’s own words” (Jasper 1994, p. 310).

The phenomenological method includes bracketing, analyzing, intuiting and describing. Analyzing is a process of applying investigative procedures that open up the data to full description. Intuiting is the “…investigator’s experience of living the phenomenon ‘as if’, as if it were his or her own” (Swanson 1990, p.
62). If the reader is directed to an understanding through his or her own experiences, a convincing description has occurred. Koch (1999, p. 25) believes that for this to happen, “...the work needs to be readable and alive”. Bracketing is the suspension of all biases and beliefs regarding the phenomenon (Kleiman 2004, p. 8) and is peculiar to Husserlian phenomenology. Bracketing does not refer to forgetting everything that the researcher knows about the phenomena, but refers to restraint by the researcher when making judgements (Jones 2001, p. 66). The data must be collected without the researcher imposing their own understanding and constructions. In this sense, bracketing is the concerted attempt to put aside preconceived ideas, while not denying their existence (Wilkes 1991, p. 233).

In the Heideggarian or hermeneutic tradition it is understanding that is important, whereby an understanding of the meaning of human experience is sought. Heidegger’s interest lay in ontology or how we live in the world, and the temporal issues of being-in-the-world, time, life experiences and authenticity. Heidegger’s (1962) work brought the traditional phenomenology and existentialism together, resulting in hermeneutics. Fundamental questions related to Being were important to Heidegger, and human Being (Dasein) was essential in addressing problems of being. Hermeneutic phenomenology seeks to understand what it means to be a person in the world (Draucker 1999, p. 361), or being-in-the-world, and is highly suited to answering ‘what’ and ‘how’ questions about human issues and concerns (Whitehead 2004, p. 514). Rather than putting aside previous experience, attitudes and beliefs, they are examined and explicated rather than suspended (Koch 1996, p. 197).

Heidegger is responsible for the concept of the “hermeneutic circle” (Dowling 2004, p. 35). In hermeneutics the researcher is located in the hermeneutic circle. The hermeneutic circle describes the dialectic movement between the whole and the part (Whitehead, p. 513), where the circle moves continually from the parts to the whole, whereby the whole also says something about the parts. Hermeneutics is about shared understanding, or more precisely shared understanding about language, as this is the medium in which we
express ourselves. Prejudice in hermeneutics refers to our openness with the world. It is this prejudice that determines our judgements, values and perspectives of the world. Acknowledging the awareness of these prejudices or forestructures is important. According to Koch (1999, p. 26) “…the critical self-consciousness of the interpreter, his/her own historicity (background) along with that of the texts/participants are brought into the hermeneutic circle”.

Gadamer used the concept of horizon to consider how understanding and comprehension occurs. Horizon is defined as, “…the range of vision that includes everything that can be seen from a particular vantage point” (Gadamer 2000, p.302). Horizons are formed by personal, social, cultural and religious spheres. Horizons are forever changing, and time and events should be considered to be horizons, in that they are not fixed. The vantage points or beliefs of the individual, of viewing the horizon would also change depending on where one was standing. In hermeneutical research it is hoped that there will be a true merger, or fusion of horizons, of the vantage points of the researcher and the participants with the goal of better understanding (Draucker 1999, p. 363).

4.17.3 Van Manen’s human science

The work of Van Manen borrows from both descriptive and hermeneutic phenomenology. Van Manen’s hermeneutic phenomenology as a method is unique and valuable for nursing research. Its aim is to explain the meanings of every day existence, or to explore the lifeworld (Van Manen 1990, p. 9) of the participants under investigation. Phenomenology does not claim to demonstrate statistical relationships or frequencies among variables, associated with quantitative research. It does not focus on social opinions or the frequency and occurrence of certain behaviours. For Van Manen (1990, p. 29) phenomenology is a human science. Phenomenological research could be said to be a scientific or systematic quest for an understanding of what it is to be human. Therefore, it is the study of humans and their experiences within their world. It is scientific in that it is systematic, rigorous, explicit, self-critical and intersubjective (Van
Manen 1990, p. 11). Phenomenological human science is the systematic use of questioning, reflection, focusing and intuiting as genuine modes of enquiry. Phenomenology is self-critical as it continually reflects on the strengths and shortcomings of the approach. The inter-subjectivity becomes evident through the validation of the phenomena by others, described as the phenomenological nod.

For Van Manen (1990, p. 9) an understanding of phenomenology can only be accomplished by “actively doing it”, therefore active enquiry will reveal the nature of the human experience. Van Manen (1990) offers a phenomenological approach that utilises phenomenological, hermeneutic (the theory and practice of interpretation), and semiotic (approach to writing and linguistics) sources. The foundation of phenomenology according to Van Manen (1990, p. 7) is linked with his defining statements about the method. Phenomenological research, the study of lived experience, asks the question “what is this or that kind of experience like” (Van Manen 1990, p. 9). Phenomenological research offers the explication of phenomena as they present themselves to human consciousness. Consciousness is the only access that human beings have to the world, and it is by virtue of being conscious that we have an established relationship with the world. Reflecting on the lived experience cannot occur while the person is still living it, therefore in phenomenology it is retrospective reflection or an experience that the person has already lived through that is of interest to the researcher. Phenomenology is the study of lived or existential meanings. It attempts to interpret these meanings to a degree of depth and richness. Phenomenology differs from other research methods because it does not aim to look at the meaning in specific cultures, social groups, historical periods or individual’s life history (Van Manen 1990, p. 11).

Phenomenological research, as human science attempts to articulate through the text the structures embedded in lived experience. In addition, phenomenological research is the attentive practice of thoughtfulness. According to Van Manen (1990, p. 12) thoughtfulness characterises phenomenological research and is
associated with wonderment about what it means to live a life. Phenomenological research therefore is a search for what it means to be human. For Van Manen (1990, p. 12) researching lived experience illuminates “what it means to be in the world”, but more importantly its ultimate aim is the “fulfillment of our human nature: to become more fully who we are” (Van Manen 1990, p. 12). Phenomenological research therefore, is about questioning the way we experience the world, and wanting to know the world in which we live as human beings.

4.18 The decision trail

Decisions taken by the researcher should reflect the theoretical framework of the methodology (Whitehead 2004, p. 512). These decisions will affect the rigor and trustworthiness of the study. The researcher should leave a clear decision trail from the beginning of the study to the end. The decision trail should be provided in such detail to enable the reader to interpret the meaning and context of the topic under research, and expose the reader to the process (Horsburgh 2003, p. 308). This means that although the reader may not share the author’s interpretation, they should be able to audit the means by which it was explicated. Journal writing and taking notes during the interviews is part of the decision trail, as it helps to keep the context of the situation for the participants. Things that are inaudible in the interview like vocal intonations, facial and physical expressions, body language and gestures can be noted and included when examining the transcriptions.

The use of phenomenology as a research method led me to recognise the influences that I brought to the study and the possible impact of these when the data was generated. I have been a neonatal nurse for 19 years at the major children’s hospital in Sydney, Australia with many years of experience with caring for babies of 24 weeks gestation and less. The last eleven have been when extremely premature babies have required surgery. In my experience extremely premature babies requiring surgery have a high mortality and morbidity.
Prior to the commencement of the study it was my belief that keeping extremely premature babies alive might not be in their best interest. Having not seen any of these babies survive without severe disabilities, it was hard to imagine how families would or could cope when the baby was taken home. I believed that a profoundly disabled baby would devastate a family to such an extent that it could not function in anything that resembled a normal manner. I have seen babies in institutions and it was not the existence that I had mapped out for them. I have hidden from parents who came back to the nursery to show off their baby and I am not proud of my behaviour. In these circumstances I did not know what to say to the parents, partly because I felt a sense of responsibility for the outcome. I now understand they were not looking for answers, just familiar faces that had cared for their baby during its hospitalisation. Many personal lessons have been learned along the way. The most important is the realisation that in giving the best quality care possible, I can accept those things over which I have no control.

In approaching this study it was impossible to put aside 19 years of neonatal nursing experience. I could not listen to the nurse’s stories about extremely premature babies, as if I had no previous dealings with tiny babies. Bracketing is not concerned with forgetting everything that the researcher knows about the phenomena under investigation, it is about “reading the transcripts with an attunement to the factual content of the words and the actual experiences of the participants” (Whiting 2002, p. 61). It was the nurse’s experience that I sought, not mine. During the research process I tried to put aside my preconceived ideas about babies of 24 weeks gestation, their treatment and outcome. This was a hard task as I, too had experienced ethical dilemmas when caring for these babies. Hermeneutic phenomenological research recognises the influence of the researcher on the conduct of the research, therefore it relies on the self awareness of the researcher to record any influences (Whitehead 2004, p. 514). The researcher is an active participant in the research process not just a passive recipient or producer of knowledge (Draucker 1999, p. 362). During the course of the research I kept a journal. In a hermeneutic enquiry the journal serves to locate the researcher in the research process (Koch, 1998, p. 1184). The journal outlined processes, interactions, thoughts, feelings and my experiences, noting my thoughts about my part as interviewer and researcher. Prejudices or my value
positions were also acknowledged, as were the ethical issues that concerned me as a neonatal nurse. Koch (1996, p. 176) suggests that maintaining a reflexive journal is essential if the researcher is to get into the hermeneutic circle. There were times when I believed I was in the “hermeneutic hole” as elucidated by Wolfe (2000, p.36) rather then in the hermeneutic circle. During this time I experienced difficulty understanding and interpreting the text by considering parts rather than the whole.

Journaling by the researcher can improve the study’s trustworthiness, because the strengths and limitations of the methodology can be explored, and Whiting (2004, p. 517) suggests that journal entries can reveal ways in which the researcher participates in making data. Reflexivity is important in this process, because it is the critical gaze turned inward by the researcher (Koch 1998, p. 1184). An example occurred when I had finished the interviews and I was in the early phase of analysis trying to locate themes when a 24 week gestation baby was admitted to the NICU where I was working. This baby had a grade IV IVH with hydrocephalus and was admitted for the insertion of a ventriculo-peritoneal shunt. Following discussions with the parents, who stated they had not been told what the likely outcomes would be for their baby, withdrawal of treatment was offered to the parents. I remember looking at the baby and feeling no hope for its future or survival. I felt sorrow for the baby and the parents. This experience was the catalyst for a long period of reflection, and my experience of caring for this baby made the nurses conversations during the interviews even more real.

4.18.1 The benefits of being an insider

In this research there were advantages of being an insider, a neonatal nurse with many years experience. The nurses spoke of their innermost feelings and stories were replete with a richness that could never have been anticipated. I asked the nurses about this and several of them explained that they would only tell, what they called their “horror stories” (Nurse 6) about extremely premature babies, to someone who worked in the area. While I recognise there could be nurses who would only speak to an outsider, there
were advantages in that the nurses would tell their stories to someone who had an understanding of the problems related to caring for extremely premature baby. Several nurses said that they felt safe telling me, because they knew that I would understand their stories, and the contexts in which they occurred. Not being judged was important to the participants. Several participants mentioned that they would never tell distressing stories of this nature to a researcher from outside the world of neonatal care. I felt privileged that they would share their innermost thoughts and feelings with me.

A research study will not get started without a modicum of passion, and while passion provided the motivation and sustainability for the research, I recognise that being an insider might lead to conceptual blindness and an unwillingness to consider alternate possibilities (Krantz 1995, p. 92). Yet, I also recognised that for me as a researcher to enter the hermeneutic circle, I needed to have a practical sense of the NICU within which the phenomenon is situated. Nurse researchers undertaking action research can also be immersed in their organisation of employment. I adopted the view that any challenges associated with being an insider afforded the opportunity for personal and organisational learning (Coghlan & Casey 2001, p.674).

4.19 Analysis and interpretation

A number of steps were taken in the analytic and interpretive process. Analysis requires a prolonged period of reflection. The first step is to get valuable data. The participants need to relate their experiences and tell their stories in sufficient detail. The lived experience is given in the nurses’ stories. When I asked my participants to tell me their stories I knew I needed to accept them as their reality. According to Koch (1999, p. 25) these stories are their constructions of their experiences and how they make sense of the world. Stories are more likely to be told when there is an openness on the part of the researcher to allow the participants to speak, and the researcher to be ready to listen. It is the researcher’s readiness to listen that inspires participants to relate their experiences (Kleiman 2004, p. 13). How the participant relates experience lends insight into the meaning the experience had for the participant.
The entire interview transcripts were read following the interviews to get a global sense of what was emerging. Listening and re-listening several times to the interviews and reading the transcripts gave the researcher the initial ideas about the data. This first naive interpretation is probably more like a qualified guess (Wiklund, Lindholm & Lindstrom 2002, p. 118), where the researcher gets a sense of how the respondents experienced the ethical dilemmas. The transcripts were read within a framework of phenomenological reduction. Phenomenological reduction in the case of this research was an attempt to be open to the nurses’ stories, not bracketing in its true sense, and to withhold existential claims, which is where the researcher considers what is given as it is given, as presence, or phenomenon (Kleiman 2004, p. 12). As a researcher I attempted to avoid abstraction and generalisations and “strip away the theoretical or scientific conceptions and thematizations that overlay the phenomenon… which prevents one from seeing the phenomenon in a non-abstracting manner” (Van Manen 2002b).

4.19.1 Conversion of interview data to text

Following the interviews I listened to the audiotapes, and they were transcribed by a transcriber. The transcriptions noted pauses for stress related humour, laughter, tears and even exasperation as the nurses related their experiences. The interview transcriptions were meticulously checked by the researcher for their accuracy. There was a substantial use of jargon by the participants, and several of the transcripts needed to be amended by the researcher because of the jargon. In conducting interviews, checking transcripts and re-reading them, the researcher became familiar with the data.

In addition, by listening to the interviews several times I became immersed in the nurses’ experiences, their voices and words became familiar as they recounted their experiences of caring for extremely premature babies. The interview transcripts were read again slowly and the data was segregated into meaning entities. The formal analysis at this time consisted of line-by-line thematic analysis, the construction of themes, and the interpretation of the nurses’ experiences from the interview data. Van Manen (2002c) states:
Phenomenological themes are not objects or generalizations; metaphorically speaking, they are more like knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes. Themes are the constellations that make up the universes of meaning we live through. By the patterns and light of these themes we can navigate and explore such universes.

Creating themes is an active interpretative process. Themes help the researcher to focus upon the significant issues in the data. It is through the act of reading and writing that insights emerge (Van Manen 2006, p.715). Throughout the interpretative process I actively tried to create thematic meaning by writing and rewriting, which developed the interpretation (Crist & Tanner 2003, p. 203). Phenomenological inquiry should not be separated from the practice of writing (Van Manen 2002a). Phenomenological reflection is the experience of writing (Van Manen 2006, p.720). Van Manen (2002c) suggests that analysing thematic meanings of lived experience “… is a complex and creative process of insightful invention, discovery and disclosure. Grasping and formulating a thematic understanding is not a rule-bound process but a free act of ‘seeing’ meaning”. The thematic aspect of the text was important, however the mantric aspect or the imagery of language, was considered just as important (Van Manen 1991, p.346).

4.19.2 The meaning found in text

Text is defined as the original words of something that is written or printed (The American Heritage Dictionary of the English Language 2004). Text in phenomenological research serves three purposes. Firstly, it is the data on which the findings are based. Secondly, the text is a source of meaning and understanding as the language reveals the experience of the phenomenon. Thirdly, text is how the findings are communicated (Flick 1998p.2 9). Van Manen (1997, p. 368) suggests that phenomenological text should be thoughtful, and “…reflects on life while reflecting life”. Text, as a source of meaning in qualitative research can appear in many forms, and is not solely based on the printed word. Text allows the interpreter the opportunity to see things in a different way, which
allows the researcher to orient him/her self in other ways of the world (Wiklund, Lindholm & Lindsstrom 2002, p. 115). The text in this study was printed words taken from the participant’s accounts and their behaviours. Van Manen (1997, p. 345) suggests that good phenomenological text helps us “…see something in a manner that enriches our understanding of everyday life experience”.

Living with the data, watching and acknowledging its evolution, and analysing it at macro and micro levels over an extended period of time brought me into the hermeneutic circle. The experience of repeatedly reading and re-reading the transcripts and listening to the interviews meant that the researcher had a high degree of confidence in the text as an accurate portrayal of the nurse’s experience. Unclear or ambiguous text was identified. Any problems or misconceptions in the transcripts were corrected when the researcher asked the interviewees whether the transcript was an accurate portrayal of what they had discussed. All nurses confirmed the validity of the transcripts via a telephone or face to face conversation. The nurses who lived in Sydney were seen face to face, while those who lived out of Sydney were telephoned by the researcher.

I begin to understand in a different way what the participants have told me and what the text has revealed. This understanding is derived by my personal involvement as the researcher in the process of interpretation. This was the ‘fusion of horizons’, where different vantage points came together. Koch (1996, p. 176) states “the process leading to fusion of horizons is more like a posture, or way of conducting yourself, a willingness to open yourself to the standpoint of another so that you can let their standpoint speak to you, and let it influence you”.

4.19.3 Thematic statements

The identification and interpretation of the nurses’ accounts of their experience was achieved through thematic analysis and reflective processes. Thematic analysis identifies meaningful patterns, stances and concerns, and is more important than looking at words or phrases (Benner 1994, p. 115). The text from the interviews was examined in a careful
and systematic way. Significant ideas from the text were converted to a written thematic statement. Each thematic statement became an accurate interpretation of the meaning in the nurse’s words.

The nurses’ stories held accounts of their experience of caring for extremely premature babies. These accounts were structured to form the whole, or a full description of the phenomenon. During this time I undertook a systematic search for alternative and divergent themes and rival patterns within the data. The purpose was not to disprove the alternates, but to ensure that a labeled theme was strong (Whitehead 2004, p. 514). For example I had only interviewed four nurses when I was struck by the amount of conflict that seemed to be experienced by the nurses. Conflict seemed to be experienced in every aspect of caring for extremely premature babies. There were times when conflict in the data seemed to be palpable. It seemed that many of the nurses had experienced profound, significant experiences that continued to influence how they managed conflict. Conflict remained prominent with each subsequent interview.

4.19.4 The accumulated themes

Reflection on the thematic statements, coupled with the comparisons across all interview texts meant theme patterns emerged. For example, by the end of the third interview it became clear that many of the nurses had experienced similar situations that caused them to experience ethical distress when caring for extremely premature babies. Much of the textual data contained statements related to conflict between the nurse and the medical staff. A theme, tentatively labeled ‘living with conflict’ was identified. Later this theme was renamed “dealing with awfulness”. Supporting thematic statements were collected together under this heading. Other themes were similarly identified and named. In some instances the participant’s original words formed the thematic statements. Participant’s own words were used when there was no way of improving the supporting thematic statement. One such example was the phrase, “banging our heads against a brick wall”, which became an authentic description of the frustration, anger and powerlessness of caring for an extremely premature baby.
In reviewing the early themes, some were refined and modified, while others required only final adjustments to the final wording of the themes. A process of collating the thematic statements within each theme gave structure to the themes, allowing main ideas to be grouped together. Those that were grouped together were labeled dimensions of the theme. These dimensions served as discrete organisers for the theme chapters. They vary in number and are labelled. For example in the theme, “it’s all about this baby”, one thematic statement was, “desperately seeking parenthood”. Dimensions were named, “the biological imperative to become parents” and “the desperation of wanting a child”.

4.19.5 Making meaning

The final step was to subject the thematic findings to further reflection and analysis. A hermeneutic description was sought to uncover a further layer of meaning. Further reflection occurred. I attempted to establish the meaning in the nurses’ stories. In reading the transcripts I posed the analytical questions to the data “What is it to be the neonatal nurse who experiences ethical dilemmas surrounding the care of babies less than 24 weeks gestation”? and “What are the nurses telling me about the experience of ethical dilemmas when caring for babies of 24 weeks gestation?”

A description of what it was to be the neonatal nurse who experiences ethical dilemmas when caring for extremely premature babies was written as it emerged, each description an essence of the phenomenon. A good description according to Van Manen (1990, p. 39) will reveal essence, which is the inner essential nature. The essence should reveal everyday expressions of being. The final interpretation should, as Benner (1994, p. xviii) suggests, illuminate the world of the participants. It should articulate what the participants have always known, but were often unable to put into words.

4.19.6 The written account

The aim of the written account is to allow the reader to understand what it is for the nurses to experience ethical dilemmas when caring for extremely premature babies, and
to share the understanding that has been gained. In the written account I have illuminated my comprehension of the text and the way in which I have made my interpretations. The phenomenological writer according to Van Manen (2002d) “does not present the reader with a conclusive argument or with a determinate set of ideas, essences, or insights”. The phenomenological writer aims to “orient the reader reflectively to that region of lived experience where the phenomenon dwells in recognizable form” (Van Manen 2002d). The written account of the research is directly linked to the validity and reliability of the study. Quotations are used to support the researchers claim, but context is important. Quotes taken out of context are just that, so the context must be set with the quotation. It is difficult to know which quotes or how much of the quote to use, but for this work I have given attention to a range of quotations to support the theme that I was discussing at the time. Some of the quotations are lengthy but they maintain the context of the information presented.

4.20 Conclusion

This chapter has discussed the rationale for the research methods that were used to answer the research question. The questionnaire was adapted from the work of Armentrout (1986). Following analysis of the questionnaire, interviews with experienced neonatal nurses were undertaken. The investigator conducted the interviews, and the ethical tenets related to the ethics approval related to researched subjects, were observed and respected. A phenomenological framework was used to interpret the data, which entailed a thematic analysis and a search for a phenomenological description. The interpretation process consisted of several stages and has been explained. A decision trail was provided to establish the rigour and trustworthiness of the study. I have confidence in the meticulous method of data collection, analysis and interpretation in both phases of the study. Four themes were constructed from the data, and they will be discussed in a separate chapter (6-10). The following chapter contains the results of the questionnaire that were taken into the interviews.