

**The Ethical Complexities of Saving Extremely
Premature Babies: A Phenomenological Study**

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Abstract

The ability to save the life of an extremely premature baby has increased substantially over the past decade. Survival, however, can be associated with unfavorable outcomes for both the baby and the family. Neonatal nurses as the main caregivers for the baby and family are witness to the highs and lows associated with caring for these tiny and fragile humans. The treatments and outcomes of these babies are a source of ethical dilemmas and moral distress in the nurses caring for them. These ethical dilemmas are a sensitive topic, and interviewing about sensitive topics can have an impact on the participants and the researcher. Interviewing on sensitive topics and how to deal with sensitive data will be explored in this case.

Learning Outcomes

By the end of this case, students should be able to

- Reflect on the potential impact of researching sensitive topics for participants and the researcher
 - Explore the use of qualitative methods, such as phenomenology, and how they can be used to explore sensitive research topics and issues
 - Consider the complexities associated with dealing with sensitive research data
 - Understand the importance of using a reflective research journal in qualitative approaches
 - Appreciate the benefits of journaling in qualitative studies on sensitive issues
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Project Overview and Context

The pursuit of science and technology and the subsequent advances in neonatal intensive care have meant that more premature infants are surviving at the extremes of human viability. Where once these infants would have died, it is now not only possible to save them, but it is commonplace in highly developed health care systems in industrialized nations. The current edge of viability relates to infants born at 23 to 25 weeks' gestation (Subramanian, 2012). A lower gestational age is associated with higher mortality and morbidity (Tomlinson et al., 2010), including a greater chance of long-term and severe morbidities (Moore et al., 2012). In contemporary neonatal practice, infants born at 24 weeks' gestation or less cause the most professional and ethical concerns for both medical and nursing clinicians. Premature infants of greater gestation have a better chance of survival and a positive outcome (Gurka, LoCasale-Crouch, & Blackman, 2010). Conversely, those infants born at 24 weeks' gestation or less who are statistically likely to have poor outcomes generate the greatest moral and ethical dilemmas in the staff caring for them (Griswold & Fanaroff, 2010). This could be because the current outcomes for extremely premature babies related to major neurological impairments have

remained stable, despite improved survival (Iacovidou et al., 2010). Importantly, infants born at less than 25 weeks' gestation, especially those born at 22 and 23 weeks, have a very low likelihood of surviving with little or no impairment (Jarjour, 2015).

Consider the Following Case

Nicholas (fictitious vignette) is a male baby born at 23 weeks' gestation and weighs 550 g. In contrast, an average full-term baby, born between 37 and 42 weeks, weighs approximately 3.2 kg. Nicholas was intubated, given surfactant to help his immature lungs, and ventilated at birth. Within 24 hr, Nicholas suffers a massive intracerebral bleed because of the tiny fragile blood vessels in his brain. It is the most serious bleed and classified as a grade IV intraventricular hemorrhage. Given the grave health state of Nicholas, his parents are informed of the potential outcomes, supported with this information, and offered the opportunity to withdraw treatment. Their history, however, of multiple in vitro fertilization (IVF) attempts means that Nicholas's family are desperate to take a baby home, and their decision is to continue treatment.

With such a premature immune system, Nicholas is vulnerable to infection, and he subsequently requires multiple courses of antibiotics over the coming days. On day 10, Nicholas is diagnosed with a patent ductus arteriosus (PDA), a remnant of his fetal circulation. The PDA is treated with a course of indomethacin; however, one of the side effects is spontaneous bowel perforation, and Nicholas is transferred to a neonatal surgical center for removal of part of his small bowel, and he requires a short-term ileostomy to rest the bowel. Total parenteral nutrition (TPN), including lipids, is commenced to provide nutrition to rest his gastrointestinal system. Long-term TPN can, however, cause liver failure.

One hundred days have now passed and Nicholas remains dependent on invasive mechanical ventilation and has developed chronic lung disease as a consequence of prematurity, ventilation, and oxygen therapy. Nicholas's eyes are checked and retinopathy stage IV is diagnosed. To maximize his remaining vision, Nicholas undergoes laser therapy. A head ultrasound shows periventricular leukomalacia (holes in the white matter of Nicholas's brain). Since Nicholas's birth, he has had over 200 painful procedures performed and 50 diagnostic tests. The medical staff explain to his parents that the Nicholas is likely to have a poor neurological outcome. The nurses are now experiencing ethical dilemmas when providing treatment to Nicholas.

Given the increasing frequency of these types of cases in practice, the purpose of our research was to explore the ethical issues faced by neonatal nurses who care for infants of 24 weeks'

gestation and less. The study design used a mixed-methods approach of both quantitative and qualitative elements to address the research question, “What are the ethical issues experienced by neonatal nurses concerning the care and management of babies of 24 weeks’ gestation and less?” The related study aims were as follows:

1. Identify and explore the ethical issues faced by neonatal nurses as they care for babies of 24 weeks’ gestation and less;
 2. Describe the experience of neonatal nurses with ethical dilemmas that arise during their care of babies of 24 weeks’ gestation and less.
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Research Practicalities

This PhD study was conducted between January 2000 and January 2008. Note that in 2017 smaller and tinier babies are now being saved, with more ethical dilemmas being experienced by neonatal nurses; this research is therefore being repeated as an international study.

A number of methodological challenges presented themselves during this research, as noted below:

1. The use of a survey questionnaire to uncover the neonatal nurses’ ethical dilemmas associated with extreme prematurity;
 2. The use of a survey questionnaire and a phenomenological approach.
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Research Design and Approach

The Place for Quantitative and Qualitative Methods in Research

Both quantitative and qualitative research methods have an established place in contemporary research, particularly when exploring complex human issues (Johnson & Onwuegbuzie, 2004, p. 16). It is not argued that one method is superior to the other; on the contrary, both methods were used in this study. Although 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 approaches analyze data for meaningful interpretations and insights, construct explanatory arguments from the findings, and speculate on the observed outcomes (Seachrest & Sidani, 1995, p. 78). That collecting multiple data sources using different strategies, approaches, and methods results in a combination is likely to enhance strengths and diminish weaknesses of both methodologies (Johnson & Onwuegbuzie, 2004, p. 18).

My (first author [J.G.]) study utilized a sequential mixed-methods design that comprised a

survey questionnaire and individual/focus group interviews informed by phenomenology. Given the complexities of the issues, this combination of approaches was viewed as most appropriate to answer this question. The questionnaire consisted of 62 closed and five open items and explored the issues of concern for a sample of 414 Australian neonatal nurses. Subsequent issues with 24 participants were explored more deeply using interviews and a phenomenological framework to understand their ethical dilemmas surrounding extremely premature babies. In this research, the quantitative arm provided the overview or the breadth of the topic under exploration, whereas the qualitative arm provided the insight or depth of the topic. That is, the survey provided the discovery (Foss & Ellefsen, 2002, p. 244), whereas the interviews provided the understanding of human experience.

Although it is not a common practice to use a phenomenological approach and a quantitative survey to elicit the information to form the basis of the interviews, this was a valid approach in this context. 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 were essential for a thorough understanding.

Survey participants were neonatal nurses who were members of our national professional association, from all states and territories in Australia. The questionnaire was modified from a study undertaken by Armentrout (1986), with her permission. A 62-point Likert-type questionnaire, with four self-reporting questions, was developed. The questionnaire consisted of six sections: (a) demographic information and includes the length and type of neonatal nursing experience of the respondents; (b) a series of statements related to how neonatal nurses manage the experience of caring for babies less than 24 weeks' gestation; (c) explored neonatal nurses' attitudes to extremely premature babies' survival and the decision-making process; (d) explored issues relating to the funding of health care, and neonatal intensive care units in particular, as well as social and family issues; (e) posed questions about government and legal involvement in management decisions regarding tiny babies; and (f) explored the ability of new and advanced technology to solve many problems experienced in the neonatal intensive care. I pretested the questionnaire for content and readability.

The qualitative component consisted of 14 interviews with neonatal nurses with more than 5 years' experience caring for extremely premature babies—eight individual or six focus groups, comprising 24 experienced neonatal nurses, from a variety of neonatal settings (perinatal,

surgical, and newborn emergency transport team) from every major center in three jurisdictions. Interview questions were based on key findings that emerged from the survey.

A qualitative approach informed by phenomenology was used to analyze the interview transcripts. Phenomenology is concerned with the study of experience from the perspective of the individual. Phenomenological approaches are based on a paradigm of personal knowledge and subjectivity, emphasizing the importance of personal experience and interpretation. Phenomenological methods are particularly effective at bringing to the fore descriptions of experiences and perceptions of individuals from their own life perspectives, thus challenging conventionality (Lester, 1999, p. 1). Phenomenology is therefore a profoundly reflective inquiry into human meaning (Van Manen, 2011a, p. 1), offering ways of understanding not offered by other research methodologies.

“Method” in Action

Practical Lessons Learned

Reflective Journaling During the Research Process

When I (J.G.) started on this research training journey, I was convinced by my supervisors that keeping a reflective journal would be a helpful adjunct to the interview transcripts, supporting my creative, professional, and personal development. I recognized journaling has many purposes, but I decided my journal would be a tool for thinking, reflecting, and articulating using description and narration. When reflecting on the transcripts, I documented in the journal what I thought I had missed, should have asked, and would still like to know. The journal therefore provided me with an opportunity to have the whole experience recorded and reflect on my process of learning.

Sharing Shared Experiences—Notes From My Research Journal

We find a comfortable area and we exchange pleasantries. I know most of these nurses. Those I do not know personally, I know by name. Neonatal intensive care in Australia is a small specialty, and most experienced nurses know each other or of each other. I know that these nurses have been caring for extremely premature babies for many years. They have extensive experience. I am grateful they have consented to talk to me. I seek to walk in their shoes. I want to understand what caring for extremely premature babies is like for them.

My (J.G.) experience as a neonatal nurse and a researcher brings me to ask them about their experiences. I have always been interested in the ethical issues surrounding neonatal care, particularly those associated with extreme prematurity. Having studied bioethics, I wanted to

formalize my thinking and reading into a scholarly inquiry that could reveal the ethical complexities of caring for extremely premature babies.

I know how to start, but I have no idea how it will finish. This study is large, with a questionnaire and qualitative investigation. Setting limits has been difficult, but essential. I want to know about the experiences of ethical dilemmas with extremely premature babies, from the nurses who have experienced them. It is not common practice to use a questionnaire, interviews, and qualitative investigation, but I want the whole story. I tell myself that the study is rigorous and manageable and that in Van Manen's (1990, p. 36) words, "... lived experience is the starting point and the end point." The lived experience of the neonatal nurses became central to the research.

I travel, sit, listen, and talk in many different places. I travel across Sydney, to Newcastle and to Canberra. I go to the nurses' own homes, they come to mine. I go to the neonatal nursery of their employment and to neonatal intensive care units (NICUs) I have not visited before. The nurses are proud of their practice and units. Each NICU is different, each excelling at something. This excellence is what I am shown. The nurses are generous with their time, refreshments, tea, and coffee. As they talk, they give of themselves. There is nervous energy as they describe the issues that cause them to soul-search.

The nurses have completed the questionnaire and are aware there will only be one interview. I want to know about their experiences of ethical dilemmas when caring for babies of 24 weeks' gestation and less, and 24 nurses in 14 interviews agreed to tell me. These nurses are pragmatic; they have to cope in the NICU. They know that participating in interviews about a difficult topic can bring them to revisit distressing incidents. They are prepared for this and say they believe in the importance of the research. No one has ever asked them about their experiences before.

Reflections on the Interviews—Notes From My Research Journal

I mentally prepare myself for the interviews. I physically prepare the space. It needs to be conducive for talking. I check that the recording device is working. I am careful. Batteries are changed before every interview, although this may not be necessary. I do not want any mishaps with recording. The nurses are informed that the interviews will be audiotaped and that they can discontinue at any time. They sign the consent form. They know I will arrange formal debriefing and counseling for them if necessary. They explain that if they could not cope with all that they have been through, they would have left neonatal nursing. I nod in agreement; this is something that I also know. I will myself not interrupt, but sometimes clarification is necessary. It is their words which are important, not mine. For much of the interview, I am

engrossed in their stories. I ask about their ethical dilemmas and their experiences of ethical distress. I put to them the main findings of the questionnaire. Sometimes they are surprised by these findings or nod their head in agreement, their eyes wide in recognition. Mainly they agree and smile. I encourage them to talk about their experiences. They seem to make each word count.

I am taken aback by their openness and their bluntness. I am grateful for the rich data. I had not expected such richness. Some stories are extraordinary, offered by these ordinary nurses who have been placed in extraordinary situations. I am told that I am getting the full story because as a neonatal nurse I will understand. I wonder how such experiences could allow them to keep going. They do not dilute their experience. I have asked for their experiences, they tell me. For many of them, this is an opportunity to tell their story. I wonder how the nurses help the parents in their ordeal, when they themselves are traumatized by their experience. They cope, they say they have to, and ask what choice they have. They are regularly asked whether they want to talk to professionals about their experiences. They choose to talk with their colleagues, those who understand, and not those they believe could not understand. For these nurses, those who have experienced similar situations will understand.

The nurses tell me they love caring for sick babies. During the good times, they could not imagine doing anything else. In the bad times, they would choose another career. They talk about working as a cleaner, check out operator, or even a gardener. They admit they do not always enjoy looking after extremely premature babies because it brings anger, frustration, conflict, and anxiety. Knowing what can happen to the babies is draining. Being helpless to prevent it is seen as a torture. Distancing to prevent themselves being traumatized is their way of coping. They understand this strategy may not be the best way to deal with the situation, but they cannot help themselves. They need to protect themselves. To come back to the NICU day after day, they need this protection. The nurses believe they are realists, and survival is essential. Todd (1995, p. 3), a neonatal nurse reflected, "I view our club as one of survivors of an unnamed war, of a war that was never declared because it is ongoing and will never end."

These nurses see tiny babies as miniature human beings with specific needs and wants. The babies are respected by the nurses. They work hard to save lives and have hope for positive outcomes. Hope is held until an intracerebral bleed is diagnosed. Hope then diminishes and reality sets in. The nurses want the best for the baby and family. Knowing that death is inevitable, the only option is not something they can talk about freely. It is as if there is secret business in neonatal nurseries when death is likely. It is not something to be shared. They wonder who would understand. All too often, the media portrays these babies as miracles, but the nurses do not see them as such. Miracles are not part of these babies' existence, but

heartache and suffering are. The stories are overwhelming at times.

There are experiences that are hard for the nurses to recall. They sigh, they cover their faces with their hands as if to hide, and they cry. They apologize and make jokes. They talk of their powerlessness and helplessness. They also talk of power. These nurses are not powerless in the traditional sense. They have power, although most of them do not recognize this. They talk of being embarrassed and avoiding parents who bring a severely impaired baby back to the nursery for a visit. They feel guilty and ashamed when they hide from the parents. They know that survival can mean disability, but this forced acknowledgment is sometimes too much for them. They understand success, but they know that for these babies this is often impossible. They talk of feeling guilty about those babies who survived in a damaged state. They hope for success, but for some it never comes. Advocacy comes at a price for these nurses. To advocate is to put oneself in a vulnerable position and experience conflict for the benefit of another. Yet they do this time and time again. I wonder at their courage. Most times they think they do a good job. I thank these nurses for their generosity, their time, for allowing me to borrow their experience, and see things as they do. I leave with the thought that very few people will ever know their world.

Interviewing With Sensitive Issues: Practical Lessons Learned

Dealing With Sensitive Data

The spoken words from the data presented some problems. Many times, the words used by participants were sensitive and sometimes disturbing to read, particularly as a novice researcher. The life and death of extremely premature babies is of course a sensitive topic. Sensitive topics have the potential to arouse emotional responses (Cowles, 1988, p. 163). Data are considered sensitive if their emergence renders them problematic for the researcher, the researched, or the dissemination of the data (Lee & Renzetti, 1993, p. 5). Sensitive data in this story pertain to those statements that could cause people to be hurt or offended if taken out of their context. The context of a research situation becomes important. A literature search looking for clues how researchers manage sensitive data found that although sensitive topics are reported extensively in the literature, very few authors have specifically examined these issues or, more importantly, how they are handled (Dickson-Swift, James, Kippen, & Liamputtong, 2006, p. 853). The work of Lee (1993) and Lee and Renzetti (2003) were illuminating for me because most discussions related to the ethical issues of dealing with sensitive data such as informed consent and confidentiality. Clearly, these matters need to be considered. When we as researchers enter the private world of participants, evoking strong emotions and pursuing thoughts that may have been hidden (Cowles, 1988, p. 163), a practical approach to dealing

with emotional responses and decisions about data that might be too personally or professionally sensitive was not to be found. Alty and Rodham (1998, p. 275) call the practical difficulties when dealing with sensitive data “the ouch! Factor,” and others have also highlighted the impact of sensitive data on researchers (e.g., Corbin & Morse, 2003, p. 349; Dickson-Swift, James, Kippen, & Liamputtong, 2007, p. 327; Johnson & McLeod, 2003, p. 421). It was also heartening to note that Lowes and Gill (2006, p. 587) found interviews on sensitive topics did not cause distress to the participants but were a medium through which they could express their thoughts. My interview participants took the opportunity to tell their story; however, it was made clear that I was getting the complete story because I was a neonatal nurse and I would understand; therefore, this is one benefit of being an insider—a neonatal nurse with substantial clinical experience.

The measure of a sensitive topic is not a measure of its social or theoretical significance, yet frequently research on sensitive topics addresses some of society’s most pressing social issues and policy questions (Lee, 1993, p. 2). In the case of this research, it is a social issue surrounded by taboo—the life and death of the most vulnerable human beings. These sensitive data created technical problems such as what do I do with it and do I even report it!—problems which could not be dealt with in any simple way. My thesis was therefore laden with emotions that inspired feelings of sadness and desperation that at times were overwhelming for me as a researcher. Exploring the issue of sensitive data on the “researcher” was therefore a kind of self-help and therapy for me, and I found that other researchers also struggled with sensitive data.

The purpose of qualitative research is, however, to search for meaning, which meant the first thing I had to do was to step back from the data and ask myself “what was in their hearts when they said” If I took the data at face value, I would have found the nurses to be uncaring and callous; therefore, it was essential that I expose the layers and uncover the latent meaning in their words.

My participants spoke of severely disabled babies having the capacity to burden their parents and the community. They spoke about withdrawal of life support as an alternative to severe disability. Even in these times when people with disabilities are understood to have rights and special services, the nurses believed their extensive experience had led them to question medical interventions and its outcomes. These nurses are not uncaring or indifferent to the needs of disabled children. In fact, they spoke passionately about the need for financial and social support for the families of those babies who survived with some impairment.

A Moral Dilemma for Me as the Researcher—My Reflections

As a researcher, I worried that the nurses' words would be taken out of context. I experienced a type of inertia and did not want to continue. I procrastinated, I felt unable to move. There was inner conflict; I worried how the general public and specialist groups would perceive these findings. I consider leaving out the data but I cannot. This is the nurses' story, not mine. I asked them to tell me their innermost thoughts and they did. They trusted me. They have seen so much pain, suffering, and tragedy. I am expected to tell their story in an authentic way. As Van Manen's (1990, p. 98) words echo, "... participants of the study often invest more than a passing interest in the research process in which they have willingly involved themselves." I am, therefore, the interpreter and conveyer of their experience. I pondered that only qualitative researchers could understand my anxiety. My supervisors are sympathetic, but the problem remains mine. It is as if I cannot deal with the answers I should never have posed the questions. I know, however, that these reflections on experiences are not to be sanitized to make them more palatable. I ask myself, how does one report such sensitive data, be faithful to its meaning, and yet not intimate that neonatal nurses are insensitive and uncaring. This was the hardest part and one that I grappled with even at the end.

Using Phenomenology—My Reflections

Using phenomenology as a research method is a reflective experience. Reflexivity requires that I as the researcher be aware of my contribution to the construction of meanings throughout the research process. It involves reflecting on how my own values and experiences have shaped the research and how the research affected and possibly changed me, as a person and as a researcher.

Van Manen (2011b) suggests that the phenomenologist is like an artist and an author who attempts to use words to evoke some aspect of human existence in a linguistic image. As the researcher is not separate from the research in phenomenological inquiry, I will recount an experience that I had caring for an extremely premature baby. This experience could be as Van Manen (2011c) suggests my momentary gaze through the crevices. The narrative is a memory and presents an experiential window on which my reflection is possible and meaning can be found. Experience, knowledge, and wisdom are gleaned from memory. I look back and am able to re-live the experience.

Not long ago, I was given the opportunity to care for a 24-week gestation baby who I will refer to as Daisy (fictitious vignette—and a not uncommon scenario). Daisy was 8 days old when she was referred to the surgical NICU where I work. On day 6, Daisy suffered a grade IV intraventricular hemorrhage which had extended into her ventricles. The clinical notes stated this had happened rapidly, so she was referred to the neurosurgeons for possible surgical

management. Daisy was on full intensive care support. Following a magnetic resonance imaging (MRI), the full extent of the damage was realized; there was very little brain tissue to be seen. Daisy's parents had been given the news and had opted for withdrawal of treatment the next morning. I was assured by the nurse present at this meeting that the information was given with sensitivity and compassion. Withdrawing treatment the next day would give friends and relatives time to arrive to support the parents. Daisy would also be christened at that time.

The unit I work in is purely a surgical NICU attached to a major Children's Hospital. Admission of an extremely premature baby so young is a rare event. During the course of the evening, I came to know Daisy's parents who were both in their late 30s. They had two other children, and all children had been conceived using IVF. Daisy's parents were philosophical, and although incredibly sad, they indicated they had started grieving her loss following the initial hemorrhage, as they had been told to prepare for the worst. As family members started arriving around 6:00 p.m., I did not see much of them for the rest of the evening.

Daisy was tiny at 550 g. She was nursed in an incubator. It was not difficult to provide care for her even though she was so small. What was difficult was providing care to a baby who was non-responsive. Daisy was unconscious, so she did not open her eyes or interact in any way. I did not even see her eyes, and she made no spontaneous limb movements like stretching. When I picked her up to change her position, she appeared limp and lifeless. I made sure she was comfortable and her morphine infusion made her pain free. I hoped it made her pain free, as many indicators used in neonatal pain scores are negated when the baby is unconscious. I dressed her in a tiny colorful dress. In the unit, a group of volunteers make beautiful christening gowns for babies who will be christened in the NICU. The gown is given to the family as a memento. I managed to find a gown for Daisy, but as it was sized to fit a 1000-g baby, I knew it would be a bit big.

Caring for Daisy was not an ethical challenge. The reality is that I believed withdrawing treatment was the right thing to do. I reflected that I would have experienced an ethical dilemma if treatment was not to be withdrawn. I imagined her lying in the incubator in an unresponsive state and imagined a better future for her.

I didn't feel so sad for Daisy, but I felt sad for her parents to be denied a future with Daisy. I admired their bravery at making this hard decision. It was hard not giving parents hope because I think that buoying parents with hope is what neonatal nurses do well. Giving hope helps keep parents going. The only hope I could offer them was a peaceful death. As I watched Daisy, I thought of some of the nurses' stories about their caregiving dilemmas, and I think I got off lightly. I am told by the nurse who was with the family when support was withdrawn that

Daisy died in her mother's arms.

Conclusion

Balancing hope and reality was the overarching qualitative description of the nurses' experience of the ethical dilemmas in caring for babies of 24 weeks' gestation and less and was the ultimate finding of this research. When the life and death of an extremely premature baby hangs in the balance, nurses hope for the best and expect the worst. Our participants focused equally on these practical constructs of hope and reality, balancing between these two emotional states. Importantly, nurses (and other clinicians) have to deal with the ups and downs of the family's emotions during this difficult and often protracted time. Their main function was to also assist parents to maintain hope while preparing for reality. Parents could experience hope as an emotion, experience, or need. It is only natural that parents would hope for a positive outcome for their baby; however, false hope or the hope based around an unlikely outcome was not seen as helpful by the nurses. These nurse participants therefore strove to ensure that parents understood the possible reality and to prevent reality blindness. These nurses in being professionally aware, compassionate, and highly competent practitioners continued to seek balance between hope and reality.

From my perspective as an experienced neonatal intensive care nurse and a researcher-in-training, the ethical challenges were to be true to the data and to be courageous enough to let the nurses' stories be told in a meaningful and compassionate way.

Exercises and Discussion Questions

Consider how the author's experiences and approaches to this sensitive research (including journaling) might apply to your own research and/or practice as a nurse.

How you will approach a sensitive research topic that is likely to create emotional difficulties for you personally. Use the topic of quality of life as a starting point: for example, if you believe that quality of life is more important than biological life, yet your participants relay experiences where elderly/pediatric/neonatal patients are maintained on life support following severe brain injury and damage without the prospect of what you consider to be a meaningful future.

Interview a colleague about an issue that would/could be considered sensitive (e.g., age, gender, sexuality, a life-altering experience). Establish a level of safety and trust. We suggest doing this over refreshments in a safe and private space:

1. In preparation and as you decide on the topic, do some research and determine the five most important issues that come from your basic literature search.

2. Write five open-ended questions—these will give the participants an opportunity to talk about their innermost thoughts and for you the researcher to uncover more than is on the surface.
3. During your questions, observe the body language and any hidden communication of the participant—document what you see, hear, and observe in your journal.
4. During your questions, be aware of what is happening for you as the researcher—thinking, feeling, understanding, body language, and emotional intelligence—and document in your journal
5. Think about the sensitive data that you have obtained—try and uncover the meaning of what has been said in the interview. Consider the following:
 - What makes the data sensitive?
 - Is there anything in the data that could offend anyone?
 - How will you report it?

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