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What is This?



# It's agony for us as well: Neonatal nurses reflect on iatrogenic pain

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## Janet Green

University of Technology, Sydney, Australia

## Philip Darbyshire

Monash University, Australia; Flinders University, Australia; Philip Darbyshire Consulting Ltd, Australia

## Anne Adams and Debra Jackson

University of Technology, Sydney, Australia

#### **Abstract**

**Background:** Improved techniques and life sustaining technology in the neonatal intensive care unit have resulted in an increased probability of survival for extremely premature babies. The by-product of the aggressive treatment is iatrogenic pain, and this infliction of pain can be a cause of suffering and distress for both baby and nurse.

**Research question:** The research sought to explore the caregiving dilemmas of neonatal nurses when caring for extremely premature babies. This article aims to explore the issues arising for neonatal nurses when they inflict iatrogenic pain on the most vulnerable of human beings — babies  $\leq$ 24 weeks gestation.

**Participants:** Data were collected via a questionnaire to Australian neonatal nurses and semi-structured interviews with 24 neonatal nurses in New South Wales, Australia.

**Ethical consideration:** Ethical processes and procedures set out by the ethics committee have been adhered to by the researchers.

**Findings:** A qualitative approach was used to analyse the data. The theme 'inflicting pain' comprised three sub-themes: 'when caring and torture are the same thing', 'why are we doing this!' and 'comfort for baby and nurse'. The results show that the neonatal nurses were passionate about the need for appropriate pain relief for extremely premature babies.

**Conclusion:** The neonatal nurses experienced a profound sense of distress manifested as existential suffering when they inflicted pain on extremely premature babies. Inflicting pain rather than relieving it can leave the nurses questioning their role as compassionate healthcare professionals.

#### Keywords

Extreme prematurity, moral distress, neonatal nurses, pain, qualitative research

Corresponding author: Janet Green, Faculty of Health, University of Technology, Sydney, PO Box 222, Lindfield, NSW 2070, Australia.

Email: Janet.Green@uts.edu.au

## Introduction

Most healthcare professionals go into their careers to help heal, and their professional identity can be built on healing as an ideal. Inflicting physical and psychological pain on human beings is antithetical to nursing; the role of the nurse is to relieve pain and suffering, yet at times the nurses are required to inflict pain as part of the therapeutic regime. Indeed, Fagerhaugh and Strauss found that inflicted pain was very common and a considerable number of nurses worked with patients in pain, and inflicted pain on patients as part of their care regime. Despite this, according to Madjar, there is inadequate attention paid to the problem of inflicted pain in medical and nursing literature.

# **Background**

The profession of nursing was founded on the moral obligation to care for others. In fact, Neville stated 'being a nurse is, in itself a moral endeavour. Almost every decision a nurse makes has moral dimensions' (p. 128). The failure of nurses to live up to their moral obligations results in moral distress, and every episode of moral distress is assumed to leave moral residue. The concept of moral distress has been explored by many nursing scholars. Jameton originally defined moral distress as 'painful feelings and/or psychologic disequilibrium that occurs when nurses are conscious of the morally appropriate action a situation requires but cannot carry out that action because of institutionalized obstacles' (p. 6). When a nurse's sense of what is correct and their action is constrained and decisions are made, often by others, that are contrary to the ethical principles they base their professional careers on, they experience a violation of their ethical principles resulting in moral distress. Therefore, 'moral distress occurs when nurses are unable to translate their moral choices into moral action' (p. 161). This article will outline what happens to neonatal nurses when they experience the moral burden of inflicting pain on extremely premature babies (defined in this research as ≤24 weeks gestation), and how they reconcile their role of carer with inflicting pain.

The seminal work of Fagerhaugh and Strauss<sup>3</sup> has provided insights into the infliction of pain by nurses. While other scholars<sup>1,8,14–20</sup> have highlighted the difficult paradox of nurses inflicting pain as part of therapy, the work of Fagerhaugh and Strauss,<sup>3</sup> even in 2014, continues to be the most comprehensive analysis of the causation of pain by nurses and the endurance of pain by patients. In the study by Fagerhaugh and Strauss,<sup>3</sup> the nursing staff considered inflicted pain to be a secondary consideration because it was considered a by-product of the monitoring, diagnostic and therapeutic interventions required for patient care. This view justifies the infliction of pain in order to achieve treatment, leading Fagerhaugh and Strauss<sup>3</sup> to accept the legitimacy and inevitability of inflicted pain. Madjar<sup>4</sup> suggests that it might be tempting to make the conclusion that inflicted pain results from insensitive and uncaring staff. Perry<sup>21,22</sup> found a high degree of stress in nurses who performed painful procedures. Madjar<sup>4</sup> asserts that it would be difficult for nurses to inflict pain, but emphasised that nurses are free to leave the situation of inflicting pain, however the patients are not in a position to leave.

The ability to translate pain into suffering is a complex issue, and it has long been thought, although now heartily disputed, that newborns are not able to feel pain.<sup>23</sup> Newborn physiology related to pain has previously suggested that the neonatal central nervous system was not sufficiently mature for the perception and localisation of pain.<sup>24</sup> Although infants lack complete myelinisation which slows down the velocity of the impulse,<sup>24</sup> this is offset by the shorter distances that the impulse has to travel. It has now been determined that by the end of the second trimester, infants possess both the anatomical and neurochemical capacities to experience pain.<sup>25</sup> Expression of pain through behaviour is the neonate's only form of communication. Behaviours that indicate pain include facial grimacing, crying and agitation. Physiological responses to pain in the newborn result from the activation of the sympathetic nervous system and include increases in the

heart rate and respiratory rates, elevated blood pressure, desaturation, dilated pupils, cyanosis and palmar sweating.<sup>25</sup> Newborns are considered to be defenceless and vulnerable requiring a very high level of advocacy, beyond that which is needed for most patient groups.

## Research design

#### Aim

The findings presented in this article are part of a larger mixed-method doctoral thesis<sup>26</sup> that explored the ethical issues and caregiving experiences of neonatal nurses who cared for extremely premature babies of 24 weeks gestation and less. There have been other publications from this research. Findings pertaining to the burden of keeping secrets and how neonatal nurses have to keep information to themselves<sup>27</sup> and the difficulties associated with caring for extremely premature babies, who at times look more like a foetus than a human baby,<sup>28</sup> have been published previously. The focus of this current article is the qualitative data that explore how neonatal nurses reconcile inflicting pain on extremely premature babies in order to save their lives.

#### Data collection

Australian neonatal nurses (n = 414) were surveyed using a self-completed questionnaire in the first stage of the study. SPSS was used for data analysis, and in the second stage, purposive sampling was used and data collected through 14 semi-structured interviews with 24 neonatal nurses from the state of New South Wales (NSW) and the Australian Capital Territory (ACT).

The questionnaire was modified with permission from a study undertaken by Armentrout.<sup>29</sup> The literature was scrutinised to determine the current issues of concerns surrounding the provision of care to extremely premature babies. The questionnaire was a 64-point Likert, paper-based survey that sought to explore the attitudes and the legal, ethical, social and technological issues experienced by neonatal nurses when providing care to extremely premature babies. It also looked at the demographics, age and the number of years of experience with caring for extremely premature babies. There were open-ended and closed-ended questions. It is important to note that the questionnaire did not ask questions about pain and extremely premature babies, as the original research was not about pain; however, it had room for participants to comment on their experience and issues of concern about caring for extremely premature babies. It was clear that the issue of pain was significant because at least 50% of the respondents included statements about pain when they completed the questionnaire.

In this study, the data were collected by the first author (J.G.), an experienced neonatal nurse. There were 14 interviews and 24 interview participants. There were six focus groups with between two and six neonatal nurses, and eight single interviews. The interview questions were constructed from the significant issues that arose from the questionnaire, the content analysis of the open-ended philosophical questions from the questionnaire and other issues that emerged during the interviews. The interview questions explored the nurses' experiences of caring for babies of  $\leq$ 24 weeks gestation. The interviews were semi-structured, and time was also allowed for unstructured conversation. The interviews occurred in different locations: the interviewer's home (4), in the participants' own homes (5), or a quiet room away at the participant's hospital of employment (5). The duration of the interview was between 60 and 90 min. The full interviews were transcribed prior to in-depth analysis to identify major themes. This article utilises the qualitative data that were generated during the questionnaire, the interviews, and the insights gained from a phenomenological analysis using the framework of Van Manen.  $^{30}$ 

## Setting and participants

Participants included Registered Nurses who were currently employed in a level 5 or 6 NICU or paediatric intensive care unit where neonates are cared for, or members of the newborn emergency retrieval team. The nurses required greater than 5 years' experience with caring for babies ≤24 weeks gestation. They needed to be English speaking, willing to participate in the research and agreed to have the interview recorded. Extremely premature babies can be critically ill, especially in the first week of life, and they require the most skilled and experienced nursing staff to care for them. Therefore, those nurses with 5 years or more experience with caring for extremely premature babies were considered to be the most appropriate interview subjects because of the richness of their experience.

#### Ethical considerations

A participant information sheet was provided to the questionnaire and interview participants. Verbal and written consent was obtained from the interview participants with the option of asking questions for clarification, and the right to withdraw. Confidentiality for all participants was assured. The names of the interview participants were not included on the transcripts, and the data were secured in a locked drawer. This research project was approved by the Flinders University of South Australia Social and Behavioural Research Ethics Committee (Approval Number 1924). Due to the sensitive nature of the topic, counselling was made available to participants if required, although none of the nurses required this service.

## Data analysis

The need to understand the nurses' experiences of caregiving dilemmas surrounding extremely premature babies meant that a qualitative method informed by phenomenological insights, and the work of Van Manen, was considered the most appropriate way to interpret the interviews. This is because phenomenology, the study of lived experience, asks the question what is this or that kind of experience like (p. 9). Trundamental to the phenomenological approach of Van Manen is the belief that reflecting on the lived experience cannot occur while the person is still living it; therefore, the researcher needs to capture the retrospective reflection of the person who has lived through the experience.

The text from the interviews was examined carefully and systematically. The formal phenomenological analysis consisted of line-by-line analysis, the discovery and construction of themes, and the interpretation of the nurses' experience from the interview data in keeping with Van Manen.<sup>30</sup> Themes do not emerge; creating themes is an active interpretative process and helps the researcher identify the significant issues in the data. Braun and Clarke<sup>31</sup> suggest that for a theme to be authentic, it needs to provide an accurate understanding of the 'big picture' (p. 12). The nurses' stories held accounts of their experience of caring for extremely premature babies, and these accounts were structured to form the whole, or a full description of the phenomenon.

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. Validity in a qualitative study is about trustworthiness. The trustworthiness of the study is confirmed in three ways: first, if the researcher describes and interprets the informants' experience. It is about the richness of the description, and this lends credibility to the study. Second, 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. Third, the researcher shows how interpretations were arrived at, which is the confirmability of the study. Data were collected by the first researcher, and all data and interpretations were regularly audited and validated by the co-authors. The first author provided a decision trail to ensure all conclusions were firmly grounded in the data.

# **Findings**

This article outlines the existential suffering of neonatal nurses as they inflict pain and witness the suffering of extremely premature babies as part of the caregiving required to save the baby's life. It is important for readers to understand that these results about inflicting pain relate only to extremely premature babies, and not all babies. While no neonatal nurse wants to see pain inflicted on any baby, the vulnerability and fragility of these tiny babies, coupled with their potential for a poor outcome, make them a group worthy of special concern by neonatal nurses.

The theme 'inflicting pain' offers an understanding of how nurses cope with inflicting pain on extremely premature babies. The theme of 'inflicting pain' was further divided into three sub-themes: (a) 'when caring and torture are the same thing', (b) 'why are we doing this!' and (c) 'comfort for baby and nurse'. The first theme 'When caring and torture are the same thing' is about how the nurses reached a point when they could no longer bear to inflict pain on extremely premature babies, and they considered their actions more in keeping with torture than therapy. The second theme 'Why are we doing this!' is when the nurses feel conflicted about participating in painful therapeutic procedures, because they believe that the baby will no longer derive benefit from intensive care. The perceived hopelessness of the baby's situation and the helplessness of the nurse are emphasised in this theme. The nurses were emphatic that babies required pain relief, and the third theme 'comfort for the baby and the nurse' emphasised how important it was for the nurses as professionals that a baby was pain free. As there are two data sources in the results, the results of the questionnaire are represented as '(Q response number)'. The interview transcripts are represented as '(Nurse number)'. The theme of inflicting pain has been explored in more detail below.

It is clear that inflicting pain on premature infants was an issue that caused much philosophical pondering and soul searching in the nurses, and one nurse stated,

I am more disturbed with each year passing... I am also very worried about infants being subjected to multiple and repeated invasive and painful procedures during the course of their treatment. (Q response 288)

# When caring and torture are the same thing

Extremely premature babies require intensive and extensive treatment. There were times in carrying out care when the nurses inflicted pain on these tiny infants. The hope for a good recovery for the infant meant the nurses could cope with inflicting pain; however, when hope was no longer an option, the nurses came to believe their efforts to care for the baby were like torture of the baby and began to view themselves as torturers. The nurses began to fear performing repeated procedures on the baby.

It was overwhelming for the nurses to feel they were hurting the baby. For these nurses, continuing to inflict pain on a baby who would ultimately die was considered by them to be 'torture' of the baby, and their part in that torture was anathema to how they perceived their role as a nurse — as being to take away pain, not inflict it. Continuing to inflict pain in what they considered to be torturing the baby was, they believed, unacceptable and a personal agony. They could not reconcile their role of carer with acts of torture. Philosophical questions arise about the effects on a nurse when they see themselves as a carer who becomes a torturer. One nurse explained,

It concerns us a lot, too. Those babies are still going to need reintubating with a tube. They're still going to need some long lines replacing...blood taken. No one wants to torture a baby just for no good reason because it's going to be a futile outcome. (Nurse 20)

Another nurse spoke of her difficulty:

All those body systems that aren't developed means they're going to have so much intensive treatment to get them through. They're going to go through so much pain and their parents are going to suffer along with them. It's going to be, I think, agonising for the baby. (Nurse 17)

For one nurse, consideration of the benefits and burdens imposed by treatment was essential. She stated,

[The baby] should not be put through all the torture unless there is an absolute guarantee that they would be without . . . disabilities. (Q response 139)

The nurses considered that at times they were torturing the baby, yet they understood the parents needed time to come to terms with the inevitable death of a baby:

That's what it's like, isn't it? It's like torture you think the baby is going through. If it's from a parent's perspective, the parents aren't quite ready to stop ..., and so you continue for a few more days ..., I know it's really cruel and really tortuous. (Nurse 19)

The nurses all held strong beliefs about what should happen when they believed the baby was being tortured. One nurse stated,

What you have to remember deep down... you are pulling this tube [ETT] out because being dead has to be better than being alive. That's how it evens up. Being dead has to be more pain free, peaceful, than what we're actually doing. It's cruel. (Nurse 19)

There were times when the nurses could not accept what they had to do to the baby in the name of treatment. When they believed the baby was being kept alive without consideration of its humanity, the nurses came to believe that continuing to care would take an emotional and physical toll on them as thinking, feeling human beings. The nurses learnt to protect themselves by distancing themselves from ethically troubling situations.

# Why are we doing this!

There came a time when the nurses could no longer perform painful procedures and they started to voice their concerns to the medical staff, but mostly to their nursing colleagues. This was the result of having to perform procedures on a baby, who they believed was not deriving any benefit from remaining alive. One nurse spoke of her inner turmoil:

It is frustrating. Especially if you have to resuscitate them a few times. You're doing cardiac massage and you're thinking, 'What are we doing this for?' But you know that's what you have to do. Then you think, 'Well, why should we do this? (Nurse 16)

The nurses experienced high anxiety in these instances when they did not want to keep treating the baby. One nurse stated, '... maybe we should just say "This baby has gone. There's nothing we can do about it" (Nurse 16). Another nurse emphasised, 'I think we should be able to say as nurses that we don't agree with this, and we don't want to have a part of it' (Nurse 17). Clearly, the nurses experienced profound moral distress. They were in turmoil because '... even though you are sedating them, you wonder how much suffering they're going through' (Nurse 18).

It was very clear that painful procedures could be justified while there was a chance of a positive outcome, but when '... there is little chance of the baby surviving, why do we do these things to them?... It's cruel. It's heart rending' (Nurse 21). The nurses struggled with performing procedures when they saw

"... the grimacing and the drawing away, and still we do terrible things to them" (Nurse 23). The inner dialogue of one nurse revealed rationalised thinking:

I guess I compensate a lot by thinking, 'Well they're probably brain dead anyway'. Well, I guess, I just keep telling myself, you hope that they're brain dead. (Nurse 23)

There was a sense of despair when the nurses were convinced a baby should be allowed to die. This despair was about powerlessness. What is revealing is that in order for the nurses to get to this stage of despair, it suggests there is something in nursing and the NICU environment that needs immediate attention. The major source of overwhelming distress for the nurses was knowing their role was one of relieving pain and suffering, yet, not being able to provide the care that is fundamental to the nursing role. This overwhelming conflict could result in distancing and avoidance behaviours.

## Comfort for the baby and the nurse

The relief of pain and suffering is the domain of the professional nurse. It was important that the baby's pain was adequately managed, and the baby was made as comfortable as possible. In discussing the importance of pain relief such as morphine, when treatment was withdrawn and the receiving palliative care, the members of a focus group said,

It's a comfort thing and not just for the babies sometimes. (Nurse 21)

Sometimes it's a comfort thing for us too, because we know that we've done everything we can possibly do. Now we're going to let this poor little baby die, but at least we're going to give it a chance to die peacefully, rather than be in agony. (Nurse 21)

It's traumatic for everyone. (Nurse 22)

It's agony for us as well. (Nurse 21)

While the morphine was important for the baby, it held symbolic importance for the nurses. Several believed morphine was consoling for them and the family because they did not have to witness the baby's suffering. Observing a baby suffer might emphasise their powerlessness in a fundamental role of nursing, the relief of pain. A baby could live for several days following the withdrawal of treatment, and several nurses stated they became anxious because of witnessing the parent's and distress. The nurses seemed to count every breath as life faded from the baby.

The nurses needed to know that the baby was not in pain and suffering. It was intolerable for all the nurses to think a baby was suffering, especially since the long-term effects of pain on babies are now known. The nurses were very knowledgeable about neonatal pain, and one nurse stated,

I believe that they suffer. They have the physiology. I know the researchers said that babies don't suffer pain because the nerve tracts aren't myelinated. Don't tell me that 24 weekers don't suffer. Just because they don't remember it and they don't have the language skills to remember pain, doesn't mean that they don't suffer. It's just that they can't communicate. (Nurse 12)

Even so, with all that is known about neonatal physiology, pain receptors and the pain response in neonates, these nurses encountered some medical staff who did not believe that babies could feel pain. One nurse explained,

It's amazing... you have all these talks [lectures] that babies do suffer pain but it's taking forever for the doctors to realise this. They don't give anything [pain relief]. You say, 'Hey I want to give some morphine', then they'll just say, 'No'. 'It'll drop their blood pressure'. So what? (Nurse 18)

It is clear that there is a delicate balancing act of giving narcotic pain relief that would not risk further damage, and the potential side effects. Several nurses could not accept that the side effect of morphine, hypotension, was a valid reason to withhold pain relief, especially if the baby was going to die. The nurses believed a baby could be overwhelmed by pain and suffering. One nurse reflected, '... the baby suffering, even though you are sedating them, you wonder how much suffering they're going through' (Nurse 18). The nurses wanted infants to be free from pain and were passionate about this outcome.

Pain and suffering in a baby affected the nurses. They all wanted to treat the baby with respect, and the degree of pain and suffering inflicted on tiny babies could be seen to have a profound effect on the nurses. When the baby's pain became too overwhelming for the nurse, this was when the nurse would distance themselves from the situation, at least emotionally:

When parents refuse to 'give up' for whatever reason or when a decision is being made by parents which is prolonged and taking too long... The suffering imposed on the infant affects me as a nurse caring for the infant when I feel that the infant should die with dignity. (Q response 47)

The nurses recognised that parents were important in the decision-making process; however, they were extremely concerned about what would happen to the baby when the considered baby's life was being prolonged.

[It concerns me] when parents believe so strongly in life at all costs that they are unwilling to withdraw ventilatory support on a long term 24/40 when it is obvious that the infant will eventually suffer a prolonged and possibly painful death. (Q response 63)

For these neonatal nurses, their mandate was to prevent, or at the very least, minimise pain and suffering in babies. One nurse stated.

I look at the pain that we inflict on them, even for the short time that we keep them alive, before we decide that there's no hope. We do create a lot of distress. There's no doubt about it. (Nurse 13)

Caring for a baby in pain threatened the professional esteem of the nurses, being at odds with a fundamental goal of nursing, which is to alleviate pain and prevent suffering. The nurses learnt to cope, in part, with inflicting pain on babies. Knowing they were harming a baby in trying to save its life represented a dilemma. Several used rationalisations; however, a time came when they could no longer believe their own rationalisations and were forced to admit to a different reality. They spoke of leaving neonatal nursing and finding a job that did not require the soul searching and philosophical questions about the nature of human suffering.

#### Discussion

The nurses experienced difficulties when their nursing care inflicted pain on extremely premature babies. At times they could not reconcile hurting and caring. Lantos<sup>33</sup> sums it up when he writes, '... there is nothing morally neutral about a NICU. NICUs are horrible, wonderful places. They are the best and the worst of pediatrics. They save many lives and they cause much pain and suffering' (p. 238). The nurses believed there were times when their acts were tantamount to torturing an extremely premature baby. Torture can be defined as the intentional infliction of severe physical pain, mental anguish as punishment, a very painful

or unpleasant experience, or something that causes agony or pain.<sup>34</sup> The primary goal of any nursing treatment is the care of the patient; it is not the infliction of pain or torture; however, it can be considered a consequence of care. The tension is that the nurses knew that they weren't torturing the baby, by definition, or purposely inflicting pain, but they knew there were times when the very treatment provided to the extremely premature baby could be extremely painful, and the nurses believed that such pain could be agonising for the baby if the appropriate pain relief measures were not instigated. The word 'torture' has also been used by other nursing scholars. Nurses in a study by Gill<sup>35</sup> believed at times 'treatment is tantamount to torture' (p. 262), while a nurse in Catlin's<sup>36</sup> study stated, 'I frequently felt we were torturing the child just doing daily care' (p. 744). The nurses in the current study had to perform procedures on the babies that caused the nurses distress, as did the nurses in Archibald's<sup>37</sup> study.

There came a time when the nurses could no longer care for a baby, especially if they believed they were inflicting unnecessary pain or causing the baby to suffer. Even as early as 1986, Gustaitis and Young<sup>38</sup> suggested this could be because nurses and medical staff have different roles and ways of relating to the baby:

How often have I heard a neonatologist say, 'I have to give this kid a chance to live. I have to give him an opportunity. The baby will decide for us'. A nurse, on the other hand, is more likely to say 'I cannot stand to see this pain any longer. I cannot, in light of my own integrity, continue to inflict pain, and deny this baby the dignity of a human being in the process of dying'.<sup>38</sup> (p. 57)

The boundary between healer and torturer can blur, or even vanish for nurses.<sup>39</sup> Analogies can be drawn between common acts of torture and common acts of nursing; however, there is usually a differentiation between nursing acts and torture.<sup>14</sup> Although the nurses believed themselves to be torturing the baby, there was never a suggestion that they intentionally inflicted pain on the baby. A comparison can be drawn between torture methods and what happens as part of treatment in the NICU. The infliction of pain and suffering is unintentional, yet it nevertheless occurs. Pain can occur from multiple skin lancing for blood tests, and burns can occur from the technology used to measure oxygen tension or saturation in the blood. There is exposure to bright lights, sensory overload and deprivation of social contact. The placement of breathing tubes and intravenous cannulas to administer fluids all compound to give the impression that the baby is part of a futuristic experiment. The following quote from Harris Williams<sup>40</sup> considers treatment from the premature baby's perspective:

The morning after the night when I was prematurely ejected from my mother's womb during a violent tempest...I awoke to find myself in many pieces, pinioned to the incubator floor, with my several senses separately trapped in distinct forms of torture: my eyes shut against the insufferable brightness, my mouth scorched by dryness, my skin scratched by roughness, the sensitive mucosae of my nose crudely pierced by foreign tubes...Only pain made any link between my senses so that I could recognise they were all functions of myself, me. (The Ugly Duckling, 40 p. xvii)

The nurses learnt to distance themselves from ethically troubling situations such as the pain and suffering of the baby. Historically, the good nurse was the one who had the ability to hide emotional reactions and to cultivate an air of detachment, or professional distance. The good nurse was the one who could give and receive pain stoically. Nurses use different techniques to help them endure what they had to do to the patient. These strategies include nurses distancing themselves from the patient's pain, engaging with the patient's pain, seeking social support and finally reconstructing their role as carer. Distancing is an attempt to place a physical distance between the nurse and the patient's pain. For the nurses in Nagy's study, this included taking time out, having a brief or extended break from the unit, having a break from carrying out painful procedures, having another nurse look after the patient, having a tea break, going home at the end of the shift and having a holiday.

Distancing helps nurses continue working, and not face physical and emotional burnout. The distancing strategies used by the nurses in Nagy's<sup>15</sup> study included emotional detachment by switching off, tuning out, not dwelling on the pain, accepting the inevitability of pain, deliberately not trying to think of the patient as a person or focusing attention on the procedure rather than the patient and his or her pain. Distancing was effective when the nurse could focus his or her attention on the long-term benefits of the procedure to the patient.<sup>15</sup> Structuring the painful procedure, so that nurse could maintain the control, was seen as another way of distancing. This strategy prevented the nurse from being overwhelmed by the patient's pain.

Engaging with the patient's pain is an effective method of coping with inflicting pain for nurses.<sup>15</sup> The nurses in the current study came to a stage with a particular extremely premature baby where they could no longer engage with the baby's pain. Distancing oneself as the nurse from the patient's pain has its costs. Constant exposure to patients in pain contributes to nurses becoming less sensitive to the patient's pain and also less sensitive to the patient's need for pain relief.<sup>15</sup> There was no evidence in the current study that the nurses were becoming less concerned about inflicting pain. The reverse seemed to be true and they displayed anger at inflicting pain. Nagy<sup>42</sup> found neonatal nurses' feelings about pain alleviation were tied with personal responsibility. When the nurses in the current study were unable to fulfil their expectations of themselves at relieving the baby's pain, their disappointment in themselves was evident.

The nurses in the current study did not experience disembodiment. Disembodiment could prevent the nurses becoming overwhelmed by what was happening to the baby. Embodiment refers to the idea that nurses are fully present to the patients and their situations. Alternatively, disembodiment is the dissociating of one's consciousness from one's body. To disembody is where nurses separate themselves from their body while inflicting pain. <sup>14</sup> During disembodiment, one cannot be truly aware, or present to the suffering of others. 43 As many nursing procedures require nurses to participate in acts that inflict pain and suffering, they frequently disembody so that they will not suffer while their patients are suffering. The ability to disembody in this context is necessary for nurses to be able to tolerate the realities of what is happening with their patients. 14 Disembodiment can be problematic. Disembodiment by nurses serves to more easily deny the pain and suffering of others. 14 It also allows the pain and suffering of patients to be less real than if the nurses were vulnerable to the same pain and suffering. While disembodiment can be a powerful protector for nurses, patients are at their most embodied when they are in pain and suffering. 43 It is difficult to know whether this concept of embodiment applies to extremely premature babies. They can feel pain; however, the total experience of pain within the lived body is still being debated. To justify the aggressive treatment required to save the extremely premature babies' life, and the infliction of pain, Whittier<sup>39</sup> suggests nurses must consider the non-likeness of the infant to self and use a compensatory hyper-personification of the baby as 'another' (p. 224).

Schroeder<sup>14</sup> suggests that only the nurses' conscious attempts to maintain embodiment makes the infliction of pain part of caring, which is differentiated from an act of torture. Disembodiment can serve to stifle the moral conscience of the nurse.<sup>14</sup> Embodied nurses recognise and associate wholly the experience of others.<sup>43</sup> Remaining embodied is more likely to make the nurse consider the purpose and need for continuing painful procedures, and whether the outcome is congruent with the means. The nurses in the current study remained embodied, were attuned to the baby's pain and demonstrated critical thinking in relation to their actions.

The nurses in the current study perceived their role as relieving pain, not inflicting it. Nurses, whose attempts at cure also entail potentially painful procedures, have to come to terms with what they do to their patients. A 'burns' nurse in Tisdale's study<sup>44</sup> stated, 'I never get bored... but what I get tired of is causing pain' (p. 122). Another 'burns' nurse in Tisdale<sup>44</sup> stated, '... your helplessness is palpable. Your job is to cause more pain' (p. 123). Maeve<sup>43</sup> explored how nurses learnt to live with patients who were suffering and dying. Nurses were accustomed to being asked 'How can you do that?' and they often asked themselves the same question. All meaningful relationships are ordeals, and being in a relationship with a patient, no matter

how old or how small, results in the nurse sharing each of their patient's experience. This sharing includes the pain and suffering.<sup>43</sup>

Core role reconstruction is aimed at reconciling the incompatibility between a nurse's core image of self as a reliever of pain, and the necessity of inflicting pain. For the nurses in Nagy's<sup>15</sup> study, core role reconstruction was a coping attempt, which allowed the nurse to view nursing as not exclusively concerned with relieving the pain of their patients. The nurses who were effective in doing this reached the conclusion that '... caring for patients sometimes meant hurting them and that hurting patients was so much a part of being a nurse that there was no alternative but to work out ways of coming to terms with it' (p. 1433).<sup>15</sup> As Dind<sup>45</sup> stated, '... hurting is part of the job' (p. 81). It is unclear whether the nurses in the current study achieved core role reconstruction because they seemed unable to reconcile care with hurt. On the other hand, the nurses saw themselves as other than an inflictor of pain. Perhaps the key is inurement, or the transformation of perception, as suggested by Rentmeester, <sup>46</sup> where the nurse habituates himself or herself to the patient's pain through the process of self-awareness, self-reflection and a willingness to examine the basis of their experience of moral distress.

Fagerhaugh and Strauss<sup>3</sup> suggested that because the infliction of pain was needed as part of treatment, the nurses in their study considered the prevention of pain and pain relief was given a lower priority. This is not the case in the current study, and in fact, the reverse was held to be true with nurses exhibiting a level of desperation to ensure the baby had adequate pain relief. The nurses were all passionate that babies have the right to receive pain relief. Most spoke of the problems in getting some medical staff to order pain relief medication for babies. It has been many years since the seminal work of Anand and Hickey<sup>24</sup> exploded the myth that neonates do not feel pain, and a plethora of literature has been published on the topic of neonatal pain since that time. It is clear that babies of 24 weeks gestation are capable of feeling pain as cortical and thalamic connections are complete.<sup>47</sup> It was the understanding of all the nurses that pain is harmful to the premature baby and was linked to an increased morbidity and mortality. 48 When the premature baby is in pain, the resources required for growth and healing are diverted into coping with the stress response. This stress response produces increases in heart rate, respiratory rate, blood pressure and intracranial pressure. There is a possibility of intracranial haemorrhage resulting in brain damage. During the stress response, arterial oxygen saturations are reduced, adrenal hormones are released and there is impaired functioning of the immune system. 48 Many nurses spoke of their medical colleagues fearing that morphine will decrease the baby's blood pressure. Simons et al.<sup>49</sup> found that even in premature infants, morphine has minimal effects on blood pressure and is not associated with negative outcomes.

Fagerhaugh and Strauss<sup>3</sup> found that at times the nurses in their study tended to focus on the technical aspects of care and the immediate situation. There were times that the nurses in the current study became so overwhelmed by what they were doing to the baby and what was happening to the baby that they also focused on the technical issues. The care was described by one nurse in the current study as, '...mechanical...baby doesn't have to say thank you, they just keep living' (Nurse 18). Distancing or moving themselves to the 'emotional periphery' (p. 153) allowed the nurses to function and yet not be there. Even though the nurses were distressed, they managed to provide technically perfect care to the baby. One nurse stated,

They're still looking after the baby to the best of their capabilities, and the baby still is perfectly looked after, and looks nice and comfortable on the bed. (Nurse 15)

The nurses provided care in an automatic way and this was protective for them. They provided care to the baby and emotional support to the family; however, the essential part of what made the nurse a complete person was missing from this interaction. Perhaps, the essential element is a vital core without which it was like caring for, without caring about. This is not to say that the nurses did not care about the baby, but when

they experienced powerlessness and existential suffering, they concentrated on the technical aspects, thus preventing their emotions from overwhelming them. Caring required an investment of emotions, and the nurses in such situations were unable to commit themselves, whereas detachment allowed them to continue to function.

Loewy<sup>51</sup> suggests that suffering contains an element of hopelessness as well as a sense of being without power to change the events one fears or knows will happen. Hylton Rushton<sup>52</sup> confirmed this and suggested that the existential suffering of nurses relates to their ability to demonstrate respect for other human beings. Compassion implies sensitivity to another's suffering, and the subsequent desire to relieve that suffering.<sup>53</sup> Cassell<sup>54</sup> suggests that it is through compassion that it is possible to know that others suffer, and the compassionate observer correctly reads the behaviour of the sufferer. Therefore, putting ourselves in the place of another, we can begin to understand his or her suffering. Human beings and caring individuals understand others to be in pain because of the distinctive expression, gestures and behaviours that virtually everyone knows to be characteristic of someone in pain.<sup>54</sup> However, the ideas, beliefs or conceptions used to interpret perception virtually always contain expressions of value, and it is only natural that staff employ their own values to interpret the suffering of others. Nurses are then able to read the changes in behaviour of the sufferer because they know they might suffer in the same circumstances. Human beings empathise with the feelings of the sufferer, and it is true that others are often insensitive to the suffering of others. As Cassell<sup>54</sup> suggests, 'suffering exists, makes itself known, and warrants relief' (p. 31).

It is clear that the neonatal nurses are carrying vicarious stress. This is the stress that results when people take on the burdens of other people. <sup>55</sup> In this case, it is the pain and suffering experienced by the extremely premature baby. This stress is not new. Even as early as 1960, Menzies <sup>56</sup> acknowledged the inherent and unavoidable stress associated with the realities of caring. What is new is the level of involvement, because historically there has been a change from detachment and distancing to intimacy, commitment and involvement. <sup>58</sup> Carrying vicarious stress could lead to psychological overload and chronic impotent anger because nurses are unable to solve problems. <sup>55</sup> Detachment from the situation is sometimes necessary; however, debriefing, stress reduction and management techniques could help neonatal nurses achieve a balance between engagement and detachment.

Neonatal nurses could benefit from some education about the realities of caring. Education might help them understand that human need is infinite, and they can only give their best. The education could benefit the nurses if it focused on professional distancing, because distancing as a strategy is associated with better mental health for nurses.<sup>57</sup> It would be useful if the neonatal nurses gave themselves permission to care for themselves with as much intensity as they care for the babies and parents. In order to give to others, they need to nurture themselves in ways that replenish their hope and optimism.

It can be hypothesised that nursing theorists have inadvertently set contemporary nurses up for failure. The literature on caring can be said to avoid current nursing reality in which ethical dilemmas are commonplace. It is difficult to know whether the notions of nursing in the caring literature are congruent with the ethical complexities of the NICU. The nurses in the current study showed signs of internalising the caring ideal, without fully understanding the dichotomy between ideal care and realistic care. <sup>58,59</sup> The literature on caring seems to forget the dark parts of nursing. Menzies suggests that nurses carry '... out tasks which, by ordinary standards are distasteful, disgusting and frightening' (p. 98). Publication of the dark aspects of nursing is essential. The not-so-nice realities and complexities of current nursing practice need to be revealed. Ethical dilemmas continue, but with burgeoning technology, their effect on the nurse is extensive.

#### Conclusion

The nurses in this qualitative study expressed their concern at what they had to do to the baby in order to save life. They described themselves at times as torturers, or what they did to the baby as torture, but there

was never the intentional infliction of pain. There seemed to be the differentiation of how they considered the requirements of their job; this is what we do, but this is not who we are. This has international implications because enduring is about dealing with the realities of neonatal nursing practice. For the nurses, it was a difficult, painful part of their practice. They did not like this part of the work but they endured because they are pragmatists. It would be a mistake to think that nurses can give physically and emotionally without it having detrimental effects on them. It could be argued that during these times, the nurses were not fully productive because they provided physical care only. While it is the ethical ideal, it might be unreasonable to suggest that every nurse was fully emotionally available to patients and families throughout every shift. In order for the nurses to stay productive in the NICU, they need to come to terms with the nature of nursing care that is involved.

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