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ORIGINAL PAPER

Living in Hope and Desperate for A Miracle: NICU Nurses Perceptions of Parental Anguish

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Abstract The birth of an extremely premature baby is a tragedy, and it is only natural that the parents will rely on the spiritual and religious beliefs that guide the rest of their lives. At this difficult time, parents with strong religious beliefs will hope for divine intervention and pray for a miracle. This paper outlines the difficulties experienced by neonatal nurses when caring for an extremely premature baby whose parents hold on to hope and their belief in divine intervention and a miracle. Data were collected via a questionnaire to Australian neonatal nurses and semi-structured interviews with 24 neonatal nurses in NSW, Australia. A qualitative approach was used to analyse the data. The theme of "hoping for a miracle" was captured by two sub-themes "praying for a miracle" and "oscillating between hope and despair". For some families, the hope of divine intervention seemed all consuming, and the nurses were witness to the desperation and disappointment of families when a miracle was not forthcoming.

Keywords Neonatal nurses · Extremely premature babies · Hope · Miracle · Qualitative research · Interviews

Introduction

Technology and expertise in the newborn intensive care has advanced to the extent that smaller and more fragile babies are surviving. Such survival of extremely premature babies (defined in this research as $\leq$24 weeks gestation) comes at a cost to parents, who must balance hope for survival with hope for a good outcome. The minimum age of viability is considered to be as young as 23 weeks gestation, with the occasional survivor reported at 22 weeks gestation (Subramanian 2012). Mortality of extremely premature babies has

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improved; however, despite the best efforts of all those who care for these tiny babies, the rate of neonatal morbidity such as adverse neurodevelopmental outcomes has remained stable (Markestad et al. 2005; Stoll et al. 2010). This means that discussions between the medical staff and parents about the survival of extremely premature babies by necessity must include the risk of death and disability. When it becomes obvious that the extremely premature baby will not survive or is suffering from continued existence, discussions to cease active treatment occur and some of those with strong religious convictions will hope and pray for divine intervention and a miracle.

Background

Are there limits to what can be offered to extremely premature babies, or are their parents or surrogates entitled to expect that the baby will receive everything that neonatal medicine has to offer, even if it is futile? Futility can be defined as interventions that serve no useful purpose or are completely ineffective (Merriam-Webster Dictionary 2014). Parents of an extremely premature baby have the right to make decisions; however, autonomy-based rights are not absolute rights. Parents do not have the right to demand non-beneficial treatment, and medical staff has no obligation to provide the treatment (Dugan 1995). Futility has both medical and moral features and is therefore a value-laden term. Making judgements that treatments are futile or a particular treatment is not worthwhile could be interpreted by a family that their baby should not be alive or is not worth the effort. Therefore, futility discussions with distraught relatives are probably futile.

Religion plays a powerful role in the lives of many people; however, neonatal staff could become understandably nervous when the word "miracle" is mentioned because of the case of Baby K, widely referenced in the medical literature (Annas 1994; Hylton Rushton 1994; Bonanno 1995; Flannery 1995; Wright Clayton 1995; Post 1995; Schneiderman and Manning 1997; Perkin et al. 1997). Baby K was a live-born baby with anencephaly who spent two and a half years on life support at the insistence of her mother who was praying for a miracle (Annas 1994; Bonanno 1995). Baby K was born by Caesarean section on 13 October 1992. Anencephaly had been prenatally diagnosed, and the mother (Ms H) continued with the pregnancy hoping that the ultrasound machine was wrong. The neonatal team agreed to intubation and mechanical ventilation at birth not to ensure the correct diagnosis, but to give the mother time to adjust to the tragic and terminal diagnosis and to give her time to say goodbye (Flannery 1995). The baby with anencephaly has a functioning brain stem and is often able to sustain respirations, but lacks the necessary structures for thinking and cognition. Baby K had only a functioning brain stem which was the part of the brain responsible for the autonomic functions of the body, including sucking, swallowing, breathing, digestion, circulation, crying and avoidance of pain (Flannery 1995). She was permanently unconscious and could not interact with her environment, and because she could not suck and swallow, she was given nutrition via a tube placed in her stomach (Flannery 1995). In anencephaly, death usually comes within hours or days from respiratory failure due to the non-functioning brainstem (Perkin et al. 1997).

After a while, Baby K was breathing on her own; however, court involvement meant that if she suffered respiratory complications, she would be returned to an intensive care unit, intubated and ventilated (Annas 1994; Flannery 1995). Baby K died of a cardiac arrest on the 5 April 1995 and could not be resuscitated. The general public and the courts might have been given the wrong impression about the life of Baby K. According to Komelasky

(1993), a nurse, Baby K's mother told the courts that the baby could crawl and hear and try to stand, when in fact she could do none of these things. Baby K's mother also stated on national television that her baby knew when she visited (Hylton Rushton 1994). In response to the Baby K case, Korman (on USA Today 1993, cited in Manning and Schneiderman 1996, p. 103) stated "miracles do happen, but if we were to use that as justification for all decisions, we would be almost entirely paralyzed".

Mixed messages were probably received by Ms H, as she had requested from the medical staff that the baby be resuscitated and mechanically ventilated, during discussions prior to Baby K's birth (Annas 1994). When the attending medical staff acceded to her request, this mixed message was received by a grief-stricken mother as a hope-filled one (Green 1997). Anencephaly is a lethal condition; therefore, the medical team should have declined active resuscitation because the appropriate care for the live-born baby with anencephaly should be limited to nutrition, warmth, hydration and loving care (Green 1997). Further mixed messages may have been received when Baby K was delivered by a Caesarean section. The Caesarean section is needed to extricate an imperiled foetus and resuscitate the baby prior to it suffering irreversible neurological damage. Berkowitz et al. (1990) suggest that delivering an anencephalic infant via Caesarean section is primarily for the mother's emotional benefit, rather than medical need. Manning and Schneiderman (1996, p. 103) remind us that attempting futile treatment in an effort to achieve a miracle has never been a goal of medicine.

While Baby K's mother was praying for a miracle to restore her anencephalic baby to a normal healthy infant, the nursing staff caring for her was experiencing profound moral distress. Perkin et al. (1997) interviewed nurses who cared for Baby K and found that although the nurses showed compassion for Baby K during caregiving, they believed they were placed in the untenable position of violating their conscience which caused professional suffering and loss of integrity (Perkin et al. 1997). One nurse stated I feel anguish, hostility and resentment in providing her daily care (Perkin et al. 1997, p. 229), while another nurse with a spiritual focus stated "I am trying to discover the purpose for her suffering…the powerlessness one feels eats away at your soul" (Perkin et al. 1997, p. 229). It is noteworthy that none of the 87 paediatric intensivists, emergency department directors and ethics committee chairpersons who were interviewed by Schneiderman and Manning (1997) endorsed the treatment given to Baby K.

According to the Oxford Dictionary of World Religions (Bowker 1997, p. 644), a miracle is a "striking event brought about, usually by God, for a religious purpose, against the usual course of nature". Miracles according to Hylton Rushton and Russell (1995) are unexplainable events or actions that challenge the limits of humans and technology. Therefore, by their very nature, miracles represent a violation of the laws of nature. Hylton Rushton and Russell (1995) believe that miracles are intangible and that each person has his/her own interpretation of miracles. Traditionally, miracles have been linked with faith in God, and it is this commitment to faith that involves a "personal and existential dimension that it not refutable by reason or scientific fact" (Hylton Rushton and Russell 1995, p. 64). Miracles are theological entities, not medical entities (Stempsey 2002); therefore, efforts directed towards convincing believers that they hold irrational views in relation to their faith are likely to be unsuccessful. Stempsey (2002, p. 2) outline the problematic situation that "any wondrous occasion, even a marvellous but natural coincidence, is turned into a miracle".

Duffin (2007) trawled the Vatican's secret archives looking for the evidence of medical miracles. Duffin's (2007) illuminating work found that 90 per cent of the miracles in which hospitals are mentioned were during the twentieth century and that patients cured by

miracles had been cured by the best available medicine, drugs or surgery. The Vatican decrees that to be in a position to qualify for a miracle, best practice and up to date medicine must have been used (Duffin 2007). For a miracle to be accepted, the Vatican strives to consider the latest in medical science; "it does not want to be manipulated by the wiles of sensationalists or the aspirations of the gullible" (Duffin 2007, p. 713). Doctors, medicine and science are important to the Vatican's process for investigating miracles. Doctors are asked to explain the event scientifically, and the Doctor must declare the prognosis hopeless even with the best of treatment (Duffin 2007). The Catholic tradition also requires physicians to announce impending death and ask the family to summon the priest. Duffin (2007) emphasises that the rigorous duty of summoning the priest is built into the drama of the illness, because many of the miracles of healing have occurred in people who have received the last rites. For the Vatican, miracles occur when the patient recovers from certain death or permanent disability (Duffin 2007). It is interesting that avoiding operations recommended by a surgeon was a common form of miracle in the nineteenth century (Duffin 2007).

Aim

Findings presented in this paper are drawn from a larger mixed method doctoral thesis (Green 2008) that sought to explore the caregiving experiences and ethical dilemmas of neonatal nurses caring for extremely premature babies 24 weeks gestation and less. Findings pertaining to the burden of keeping secrets and the difficulties associated with caring for extremely premature babies have been published previously (Green et al. 2014a, b). The focus of this paper is on how neonatal nurses understand and manage the situation of medical futility when the parents are hoping for divine intervention and a miracle.

Design

In the first stage of the study, Australian neonatal nurses (n = 414) who were members of a national neonatal nursing organisation were surveyed using a self-completed questionnaire. In the second stage of the study, following data analysis with SPSS, purposive sampling was used and data were collected through semi-structured interviews with 24 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. NSW has the largest number of neonatal intensive care units and neonatal intensive care beds. This meant that every neonatal intensive care unit in NSW and the ACT was represented. There were eight single interviews and six focus groups.

It is important to note that the questionnaire asked about the religious beliefs of the nurses; however, some chose not to answer that question, while others stated they were associated with a particular religion, but had no specific religious beliefs. The questionnaire had room for participants to comment on their experience and issues of concern.

A qualitative method informed by phenomenological insights and the work of Van Manen (1990) was used to guide this study. Phenomenology is concerned with the study of experience from the perspective of the individual, making the purpose of the phenomenological approach to illuminate the specific, to identify phenomena through how they are perceived by the actors in a situation or the neonatal nurses in this research.

Van Manen (1990, p. 9) considers phenomenology to be the study of lived experience, and if authentic should ask the question "what is this or that kind of experience like".

Fundamental to Van Manen's (1990) phenomenological approach is the belief that reflecting on the lived experience cannot occur while the person is still living it; therefore, it is the retrospective reflection of the person who has lived through the experience that needs to be captured by the researcher.

Phenomenological research should be seen as a dynamic interplay among four important procedural activities (Van Manen 1990). The first is turning to a phenomenon of interest and investigating it. Van Manen (1990) emphasises that the experience should be investigated as it is lived rather than how it is conceptualised. Themes should be discovered, and the essential themes should be reflected upon and the description of the phenomenon should be provided through writing. Writing is a key part of the method. (Van Manen 2006). The identification and interpretation of the nurses' accounts of their experience of caring for extremely premature babies was achieved through thematic analysis and reflective processes.

Setting and Participants

In the first stage of the study, the 760 neonatal nurses who were members of a neonatal nursing organisation in Australia were invited to participate in a self-completed questionnaire. Four hundred and fourteen neonatal nurses returned a questionnaire, representing a response rate of 54.4 %. Following data analysis with SPSS, the second stage involved a purposive sampling was used to identify interview informants. Qualitative data were collected from 24 neonatal nurses in New South Wales (NSW) and the Australian Capital Territory (ACT). The duration of the interview was between 60 and 90 min and was recorded using audio tape. The full interviews were transcribed prior to in-depth analysis to identify major themes.

The criteria for participant selection were: registered nurse, currently employed in a neonatal intensive care unit or paediatric intensive care unit where neonates are cared for or members of the newborn emergency retrieval team. They required greater than 5 years experience with caring for babies $\leq$24 weeks gestation. They needed to be willing to participate and agree to have their interview audio taped.

Data Collection

The data were collected by the first author, an experienced NICU nurse. The questions asked during the semi-structured interviews were based on findings from the questionnaire and explored the nurses' experiences of caring for infants of $\leq$24 weeks gestation.

Ethical Considerations

This research project was approved by the relevant Institutional Research Ethics Committee, and all ethical processes were adhered to. Informed consent was obtained from the interview participants, who were given the option of asking questions for clarification. 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. Due to the sensitive nature of the topic, counselling was made available to interview informants if required, although none of the nurses reported requiring this service.

Data Analysis

The qualitative analysis was guided by Van Manen's (1990) framework. The text from the interviews was examined carefully and systematically. The formal analysis consisted of line-by-line analysis, the construction of themes and the interpretation of the nurses' experience from the interview data in keeping with Van Manen (1990). Creating themes is an active interpretative process. Themes help the researcher to focus on the significant issues in the data. The meaning units or themes were created and clustered together. Benner (1994) has emphasised that thematic analysis identifies meaningful patterns, stances and concerns and can be more illuminative than looking at words or phrases. Significant ideas from the text were converted to a written thematic statement.

Rigour

Rigour or trustworthiness is an essential part of the validity of the qualitative study. Guba and Lincoln (1989) argue that rigour is established through credibility, transferability and dependability, and a study is considered to have faithful description when co-researchers and readers when confronted with the experience under study can recognise it. In order to ensure integrity of the data, data and emerging interpretations were regularly audited and validated by the entire research team. A decision trail was provided to establish the rigour and trustworthiness of the study. It consisted of returning to the original text to ensure all conclusions were firmly grounded in the data.

Results

This paper outlines the difficulties experienced by neonatal nurses when caring for an extremely premature baby whose parents hold on to hope and their belief in divine intervention and a miracle. There were no specific questions in the questionnaire or asked during the interviews that pertain to the topic of hope and miracles. The semi-structured nature of the interviews allowed this issue to emerge. The theme of "*hoping for a miracle*" was captured by two sub-themes "*praying for a miracle*" and "*oscillating between hope and despair*". The theme "*praying for a miracle*" saw a mother praying for a miracle after being given the heart-breaking news that her extremely premature baby would not survive, and the medical team considered the withdrawal of life support to be a better option for the baby than survival. The nurses witnessed hope and despair in the parents of extremely premature babies, and at times, the parents seemed to be "*oscillating between hope and despair*". For some families, the hope of divine intervention seemed all consuming, and the nurses were witness to the desperation and disappointment of families when a miracle was not forthcoming.

The nurses considered that the use of the word miracle was not realistic. The nurses believed that how the babies survive could be explained; therefore, they were not miracles. They also understood that although some of these extremely premature babies survived intact, many more suffered from lifelong physical and mental disabilities. 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 hoping for a miracle has been explored in more detail below.

Praying for A Miracle

The nurses stated that they had never witnessed a miracle. One nurse said "*I have seen some amazing things in NICU, but I have never seen what I would call a miracle; something that defies explanation*" (Nurse 8). Yet, it was the understanding of the nurses that parents with a strong belief in religion would hope and pray for a miracle.

It was the nurses' experiences that parents began to pray for a miracle when the condition of the baby was considered to be poor, or there were discussions about withdrawing life support. The nurses spoke of situations in which treatment was not withdrawn because the family were hoping for a miracle. One nurse explained:

> It [baby] probably wouldn't even be able to do anything, and would probably be a baby for the rest of his life if he survived. And there was this mother saying, "God will send me a miracle". (Nurse 16)

Claims of miracles were likely to engender negative responses in the nurses, especially those who did not hold strong religious beliefs. The nurses said that they did not know how to respond to the mother's belief in a miracle despite a dismal prognosis for the baby. The nurses all stated they knew that religion played an important role in the lives of many families in the NICU. They also understood that while the free exercise of religion needed to be considered in the light of parental autonomy, parental autonomy could not be absolute. The nurses, who held to a Christian-based philosophy, but not necessarily strong religious beliefs, found it difficult to comprehend what could be done to a baby in the name of religion. They realised many parents drew hope from religious beliefs and could anticipate divine intervention. It was also their understanding that parents who expected a miracle were unlikely to be swayed by medical science.

Several nurses realised that praying for a miracle was about hope, and as one nurse stated "the most difficult issue is knowing the path that many of these babies will travel down…Dealing with parents in the early days of their baby's life…To balance giving them hope and taking away all hope is hard". (Nurse 14) The nurses did not want to take away the parent's hope; however, they also recognised that a baby's best interests could be denied in waiting and hoping for a miracle. The nurses all believed the needs of extremely premature babies were not served by being kept alive at all costs. They stated they were also aware that there is no requirement in Australian law for neonatologists to provide futile care. They believed too that parents did not have the right to request futile treatment. Yet, a definition of futility eluded most of the nurses who were interviewed.

Several nurses tried to disentangle the word care from treatment, hoping that parents did not think that withdrawal of treatment was synonymous with withdrawal of care or total abandonment of their baby. The nurses acknowledged that parents needed time to spend with their baby and to be able to hope for a positive outcome or divine intervention. Parents spending time might mean a baby was kept alive longer than necessary. Yet, the nurses were troubled and conflicted when they perceived a baby was, "…in pain and suffering unnecessarily and it really should have treatment withdrawn" (Nurse 10). The nurses were caught between the baby suffering and the needs of the parents. For the nurses, "…the dilemma is never solved until the baby dies" (Nurse 19). They did, however, understand the parent's needs:

> We have a lot of happy mothers and fathers who probably have never had baby, and have been happy to have one [baby] for 12 h or 2 days or 3 weeks, even though

> they've seen the writing on the wall. They've been happy to have that baby for that period. (Nurse 14)

The nurses emphasised that life support was not withdrawn before parents had come to the realisation that nothing more could be done. This realisation was important for the parents, and one nurse stated:

> We've never actually withdrawn treatment until the parents are ready and they've decided that there's nothing else that can be possibly done. We've done everything. We've waited those extra few days, prayed for a miracle. It's not going to happen. (Nurse 20)

Some parents, according to the nurses, never came to this realisation, and the baby died on life support, instead of being held by its parents. The nurses all spoke of being deeply saddened by this outcome. The nurses experienced difficulty understanding why parents would not permit their baby to die. Conversely, they understood that making this decision might overwhelm the parental coping mechanisms.

The nurses understood the need for parents to hope and pray for a miracle; however, whenever a situation arose it was deemed that the baby's outcome would be extremely poor, or the baby was on a dying trajectory, the nurses experienced moral distress. This moral distress occurred because the nurses believed the baby should be allowed to die in peace and with dignity. The moral distress was great, and one 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)". Another nurse described how the situation affected her:

> I have seen a 23–24 weeker given full resuscitation and full treatment at parent's insistence when the baby was obviously in very poor condition, and appeared to be suffering greatly, only to die on the ventilator. This situation distressed me greatly. (Q response 199)

One nurse stated "the babies seem so vulnerable and the treatment so very invasive it is quite distressing caring for them". (Q response 316). Caring for these babies could overwhelm the emotions of the nurses. One nurse emphasised that she was "always left angry. Depressed after nursing these babies only for them to die 6–10 days [after birth] from infection. Dreadful way to die, awful for the parents to watch this" (Q response 41).

Oscillating Between Hope and Despair

The nurses understood that hope for a miracle was probably related to parental desperation and despair. Praying for a miracle might be important for parents. The nurses all spoke of their frustration when parents prayed for a miracle.

It was the experience of most nurses that parental hope was heightened when parents were given unrealistic expectations of what neonatology could offer tiny babies. These nurses attempted to temper this hope with the realism that the baby might not survive. This realism was explained by one of the nurses:

> Especially if you've brought it [baby] around [from labour ward] and they've [parents] been hyped up by the obstetrician that the baby is going to survive, when you know that it's not necessarily going to be. You don't want to take away all their hopes, but at the same time you want to be a little bit realistic. (Nurse 17)

The nurses all knew it was unrealistic to believe every baby, let alone extremely premature baby, could be saved. There were suggestions that they felt they had failed when they were unable to live up to the parents' expectations of them.

The nurses were all convinced there were some parents who could not "let go" (Nurse 12). They understood the ties that bind a family, but they could not understand the relentless pursuit of life by the parents. They wondered whether the obligations created by loving and meaningful interactions, even in the short time their baby had been in existence, could be easily relinquished.

The nurses could all see that those who hope and pray for a miracle held deep religious beliefs. The nurses understood that hope was important for the parents. The nurses explained that trying to get the parents to really hear and understand what was happening to the baby in the course of treatment was challenging for the team. The parents' continual hope or optimism in the face of a poor prognosis was difficult for the nurses. One nurse explained:

> I found it very difficult…she [mother] was just so optimistic and we kept having to say to her "No. No, No, No, this, this and this." She'd just bounce back up like she didn't hear you… You're saying things and they shut off because they don't want to hear what you're saying, unless you're saying what they want to hear. (Nurse 16)

This nurse found herself in a quandary. She did not want to shatter this mother's hope, but she wanted her to understand the current reality as it stood for the baby. This nurse was attempting to transform the mothers' hope into something that was grounded in reality. It was the understanding of several nurses that some parents could be too hopeful and unreasonably optimistic, and when they were presented with bad news, they responded with denial.

Discussion

This discussion has two elements, where both hope and belief in a miracle are considered. Hope can be defined as "a multidimensional life force characterised by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant" (Dufault and Martocchio 1985, p. 380). Hope involves a realistic assessment of the threat, the realisation of its severity and the implications for the person involved (Morse and Doberneck 1995). Hope entails the envisioning of alternatives and setting of goals, while bracing for possible negative outcomes. If the assessment of threat is realistic, the negative outcomes are not ignored. Uncertainty contributes substantially to parental optimism and hope, meaning where "there is room for error there is room for hope" (Baergen 2006, p. 483). The determination to endure is part of the hope cycle (Morse and Doberneck 1995). During this time, the person will seek out supportive relationships, including family, friends and spiritual comfort. It is not uncommon for individuals to pray to get through a possible life-altering event where the outcome is uncertain (Epner and Baile 2012). Hope is clearly important for parents, and the nurses in the current study saw the parents clinging onto to hope. Perhaps the nurses did not understand that when the parents lost hope, they lost everything.

One's faith in a higher power and divine intervention often becomes increasingly important during times of stress, duress and vulnerability (Epner and Baile 2012). The nurses understood that hope for a miracle was probably related to parental desperation and despair. Parents have been found to oscillate between hope and despair (Sallfors et al.

2002). Despair might trigger hopefulness, as people hope when facing significant negative events (Morse and Penrod 1999). The hope for divine healing or divine intervention is important to those who reject quality of life principles for sanctity of life ones (Post 1995). Post (1995) emphasises that in many narratives of healing, faith plays an important part, and even if belief in a miracle invites instant dismissal, the fact remains that some believers regard the narratives of healing as literal truths. Religious followers believe that God and hope are intertwined, and it is through hope that parents of extremely premature babies are helped to mobilise their resources to cope with the illness, even if such hope is seen as false by others.

Claims of miracles engendered negative and unvoiced responses in the nurses. That is unvoiced to the parents, lest their views damage the nurse/parents relationship, but voiced to the author. The nurses experienced inner conflict and were emotionally affected when parents hoped for a miracle. Contemporary nurses are taught to be culturally sensitive and to be supportive family advocates (Linnard-Palmer and Kools 2004), yet how does one advocate for something they have no belief in, and do not understand? Hylton Rushton and Russell (1995) suggest the nurses may interpret the hopes for a miracle as maladaptive, denial of reality and irrational. It could be extremely difficult for the caregiving team to support parental belief in a miracle. Religious beliefs may prevent parents from accepting the serious nature of their baby's condition. Having to deal with the potential loss of a baby may threaten the parental relationship with God. Hylton Rushton and Russell (1995) suggest that parents wonder how God could have allowed this to happen to their baby, and while they struggle to hold on to their baby, they also struggle to hold on to their religious convictions. Death may therefore represent a confrontation for parents. Not only did they fail to protect and nurture their baby, but death may call into question the fundamental beliefs on which they base their entire life. The nurses in the current study seemed helpless and sad when parents prayed for a miracle. As already stated, the nurses had not witnessed a miracle, but what they had witnessed was parental disappointment when the miracle did not eventuate, with statements like "another set of disappointed parents" (Nurse 11) and "yet another disappointed family" (Nurse 6). It seemed that the nurses might not have understood that for parents to admit, a higher power was unable to provide a miracle thta might make them question their religious beliefs. This might be too confronting for parents at this time.

Nurses are moral beings, and moral distress resulted when they were unable to live up to their moral obligations. Jameton (1984, p. 6) 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 institutionalised obstacles". A violation of ethical principles results in moral distress. This occurs when a nurse has a sense of what is correct; however, their actions are constrained and decisions are made by others that are contrary to their professional ethical principles (Corley 2002). Hylton Rushton (2006, p. 161) states that "moral distress occurs when nurses are unable to translate their moral choices into moral action". It would be a mistake to think that nurses can give physically and emotionally without it having detrimental effects on them. The existential suffering of the nurses relates to their ability to demonstrate respect for human beings, or in the case of this research an extremely premature baby (Hylton Rushton 1994). The nurses showed compassion, and compassion implies sensitivity to another's suffering and the subsequent desire to relieve that suffering (Raholm and Lindholm 1999). It is through compassion that it is possible to know that others suffer (Cassell 1991). Every episode of moral distress is assumed to leave moral residue on nurses

(Hardingham 2004), and multiple episodes of moral distress are significantly related to emotional exhaustion and can lead to burnout (Meltzer and Huckabay 2004).

Communication between families and staff has been found to be problematic in the NICU (Biasini et al. 2012). An often-heard comment is "if physicians and the family would have communicated more effectively in the beginning…this dilemma would never have arisen" (Dugan 1995, p. 228). When it comes to parents' belief in miracles, the issue might not be about communication. Faith in divine intervention might increase the person's confidence in a positive outcome (Penrod 2001). Avery (1998) proposed that parents may view one chance in a million worth taking, and they may believe that a miracle will happen. Parents need accurate prognostic information in order to make well informed decisions; however, it needs to be understood that the factual approach is ineffectual when families are highly emotional and not receptive to logic and facts (Epner & Baile 2010). Widera et al. (2011) suggest that belief in a miracle is common, in the general population but not health professionals, and in the USA, belief in miracles is considered an important determiner of how decisions are made at the end of life. Manning and Schneiderman (1996, p. 10) stated that in the "past when people sought a miracle they went to church and prayed to God, now they go to the hospital and demand it of the doctor".

When a mother hopes for a miracle, it could be rooted in her love for the baby and the pain of imagining life without the baby. It could also reflect distrust in the medical establishment. Zier et al. (2009) found that 64 % of people were reluctant or unwilling to believe physician's futility predictions. One-third believed that God was capable of miraculously healing regardless of the extent of the illness. These people were more likely to request prolongation of life support despite a poor prognosis. Boyd et al. (2010) found that for 20 % of surrogates, a faith in God overrode any other prognostic information. It becomes clear that religious beliefs and belief in a miracle can trump a physician's opinion. Further evidence shows that even as early as 1995, Schneiderman et al. found that approximately half of the ethics committee consultations occurred because families were in pursuit of a miracle, and the medical teams believed the treatment would be futile.

Sadly, there are no real answers to this dilemma. Hauerwas, a theologian and ethicist, makes the argument that modern medicine involves a sense of tragedy and must necessarily fail because success commensurate with the desire of sustaining all life is impossible (Hauerwas et al. 1977). Perhaps, what should be learnt from people who pray for divine intervention is that as frustrating as it might be for the nurses in the current study, the parents will not be swayed by science. The nurses might not have understood that parents who are unable to acknowledge the reality of their baby's situation are unlikely to give up on treatment. The best that can happen in this tragic situation is that the neonatal team pay greater attention to spiritual beliefs which can foster a negotiated and mutually acceptable plan of care, without burdening the baby with prolonged existence. To withdraw treatment over the objections of the parents would leave the parents with a huge distrust in the healthcare system, creating a situation where no one really wins. It is clear that research into the issue of parental hope and praying for a miracle is crucial to ensure that parents are not left feeling disenfranchised by the healthcare system. A qualitative approach would be preferred as it would seek to understand the feelings, values and perceptions that underlie and influence parental behaviour and their belief in a miracle.

The nurses stated that they did not know how to respond to a mother who was praying for a miracle. The nurses could benefit from clinical supervision, which is a process of professional support and learning in which the neonatal nurses are assisted in developing their practice through regular discussion time with experienced and knowledgeable colleagues in the multidisciplinary team. Reflection is important, because the nurses could

think back on clinical experiences to provide a deeper understanding and/or identify areas for further improvement (Brunero and Stein-Parbury 2008).

Conclusion

Belief in miracles and divine intervention is common and might play an important role in the decision-making process of parents with an extremely premature baby. The nurses understood that the parents hoping for a miracle was about hope, desperation and despair. The moral authority of parents to decide the fate of their extremely premature baby is not a simple matter, but it is made all the more difficult when they face difficult choices in the face of tragic situations.

Conflict of interest There was no conflict of interest associated with this study.

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