

A burden of knowledge: A qualitative study of experiences of neonatal intensive care nurses’ concerns when keeping information from parents

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Abstract

Improved life-sustaining technology in the neonatal intensive care has resulted in an increased probability of survival for extremely premature babies. In the neonatal intensive care, the condition of a baby can deteriorate rapidly. Nurses and parents are together for long periods at the bedside and so form close and trusting relationships. Neonatal nurses as the constant caregivers may be presented with contradictory demands in attempting to meet the baby’s needs and being a patient and family advocate. This article aims to explore the issues arising for neonatal nurses when holding information about changes to a condition of a baby that they are unable to share with parents. Data were collected via interviews with 24 neonatal nurses in New South Wales, Australia. A qualitative approach was used to analyse the data. The theme ‘keeping secrets’ was identified and comprised of three sub-themes ‘coping with potentially catastrophic news’, ‘fear of inadvertent disclosure’ and ‘a burden that could damage trust’. Keeping secrets and withholding information creates internal conflict in the nurses as they balance the principle of confidentiality with the parent’s right to know information. The neonatal nurses experienced guilt and shame when they were felt forced by circumstances to keep secrets or withhold information from the parents of extremely premature babies.

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Background

Babies born ≤ 24 weeks of gestation are liable to many problems associated with anatomical and physiological immaturity (Pignotti and Donzelli, 2008). Early birth means a disruption to brain development at a time when it is most vulnerable to damage. Extremely preterm babies are prone to neurological bleeding due to the fragility of their cerebral blood vessels within lateral ventricles, and such bleeds can be associated with poor neurological outcomes (Lavrijsen et al., 2005). Withdrawal of treatment is an option for those babies who have large intraventricular bleeds when the prognosis is considered to be poor (Brouwer et al., 2008). Therefore, the discovery of major neurological damage should herald timely discussions between parents and health professionals about the implications of the neurological prognosis and possible withdrawal of active treatment. Difficulties can arise when there is a delay in parents being informed, and nurses are informed about the diagnostic test results that are considered confidential to the medical team. Nurses may hold this information and have to keep it from parents until such time as the medical team can meet and discuss details with the parents. This situation of knowing, but not being able to tell, can create conflicts for nurses and make the principle of confidentiality both simple and complex.

Gunther and Thomas (2006) identified that lack of communication between physicians and families is potentially complicating to a nurse's work. Any work involving 'people work' such as nursing a sick baby and close involvement with the family is especially taxing, which is expressed as a link between emotional labour, emotional expression and suppression and burnout (Brotheridge and Grandey, 2002). When an employee feels differently from the emotion expressed, or they are hiding their emotions, they are more likely to become emotionally exhausted (Brotheridge and Grandey, 2002). For neonatal nurses, the withholding of information from parents could be considered to be part of the 'emotional labour' of nurses and having to wait on organisational processes have been shown to leave nurses tired and frustrated (Henderson, 2001).

Aim

Findings presented in this article are drawn from a larger doctoral study (Green 2007) that sought to investigate the caregiving experiences of neonatal nurses in caring for extremely premature babies < 24 weeks' gestation. The focus of this current article is the qualitative data that explored the experiences of neonatal nurses who in the course of their work are required to keep secrets and withhold information from parents of extremely premature babies.

Design

Setting and participants

Purposive sampling was used to identify participants. Qualitative data were collected during interviews from 24 Australian neonatal nurses.

To participate in the study, nurses should be fluent in speaking English; be willing to participate; be a registered nurse employed in a level 3, level 4 neonatal intensive care unit (NICU) or

paediatric intensive care unit where babies are cared for; or be a member of the newborn emergency retrieval team; and have >5 years of experience with caring for babies \leq 24 weeks' gestation.

Data collection

The single or group interviews were conducted, and the data were collected by the first author, an experienced NICU nurse.

Ethical considerations

This research project was approved by the relevant institutional research ethics committee. The sensitive nature of the topic warranted the provision of counselling for the participants; however, none of the nurses required this service.

Data analysis

A qualitative method informed by phenomenological insights and the work of Van Manen (1990) was used to interpret the interviews because it was considered the best approach to understand the nurses' experiences of caregiving dilemmas surrounding extremely premature babies. Phenomenology is the study of experience from the perspective of the individual, making the purpose of the phenomenological approach to illuminate the specific, to identify actors in a situation or the neonatal nurses in this research.

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). The meaning units or themes were created and clustered together. Thematic analysis identifies meaningful patterns, stances and concerns and can be more illuminative than looking at words or phrases. Creating themes is an active interpretative process. Themes help the researcher to focus on the significant issues in the data (Van Manen, 1990). It is through the act of reading and writing that insights emerge (Van Manen, 2006). Significant ideas from the text were converted to a written thematic statement. For a theme to be authentic, it needs to provide an authentic understanding of the 'big picture' (Braun and Clarke, 2006: 12).

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. Data and emerging interpretations were regularly audited and validated by the entire research team.

Results

This article examines the issues facing the neonatal nurses when they were required to keep secrets or withhold information from the parents of extremely premature babies. A common scenario relayed by most of the nurses about secret keeping was related to the discovery of indicators that could lead to the conclusion of potentially poor neurological status in a baby and the possible

option for parents to consider the withdrawal of treatment. A brief background is provided to contextualise the findings for readers.

Cranial ultrasounds for extremely premature babies are a routine aspect of care and will reveal various cerebral conditions including intraventricular haemorrhage. There is a correlation between the grade of bleed and the likelihood of serious neurological sequelae (Lavrijsen et al., 2005); and so depending on the grade of a bleed, there may be a need to consider withdrawal of active treatment (Brouwer et al., 2008). It was not uncommon for the neonatal nurses to hold the knowledge of this potentially catastrophic diagnosis to themselves, for perhaps the entire length of their shift. They may even have to hand this information over to the oncoming shift. When parents arrive in the NICU, the first person they usually speak with is the nurse caring for their baby. Parents are understandably keen to be told the results of any tests. The nurses managed this situation by pretending the test results had not been reported or were still being interpreted. This evasion made the nurses feel guilty, and participants disclosed a feeling they were being deceptive and betraying the parents. The nurses expressed an empathic understanding as they put themselves in the parents' position, particularly with their knowledge of the implications of the test results.

The nurses were convinced that secrets kept from parents created difficulties and threatened the trusting nurse–parent relationship. The theme of 'keeping secrets' was comprised of three sub-themes 'coping with potentially catastrophic news', 'fear of inadvertent disclosure' and 'a burden that could damage trust'. Coping with potentially catastrophic news saw the nurses becoming aware of test results often for many hours before parents were informed. Fear of inadvertent disclosure meant the nurses were constantly on edge because they feared the knowledge could be accidentally revealed with some personal and professional consequences. This secret keeping created personal conflict for the nurses. It was experienced as a burden and one that could ultimately damage the trust between the nurse and parents.

Coping with potentially catastrophic news

The nurses found it difficult when the parents came into the NICU expecting to be given test results. If medical staff were not available, nurses would have to tell the parents that they await the arrival of medical staff to get the results of the ultrasound. The nurses were aware that potentially catastrophic news would be imparted and that the parents need to know this news as soon as possible. However, they needed to observe professional etiquette and hospital policies which meant nurses were 'not allowed to take on the responsibility of informing parents about the fact that their infant has a terrible cerebral bleed' (Nurse 10).

The nurses were empathic and realised how heartbroken the parents would feel when they were made aware of the extent of the problems and were possibly offered the option of withdrawal of treatment. The nurses had an enormous compassion for the babies and they themselves felt upset and distressed when the prognosis was so poor for a baby. They felt a sense of sadness, grief and disappointment. In recalling her own reactions to a baby with a poor prognosis, one nurse stated, 'No one could believe it. "Oh No!". Here is one we thought would do well' (Nurse 14).

The time frame between the staff finding out the results and the parents finding out may be relatively short; only a matter of hours, but for the nurses, '... they're the longest hours' (Nurse 15). Knowing of the situation and withholding information for even a short period of time created difficulties for the nurses as the parents would attempt to engage the nurses by asking questions. The nurses were acutely aware of their own body language and concerned that parents may have been observing them closely, trying to read their responses. The nurses feared that definite

behaviour changes could potentially arouse suspicions in the parents, so they monitored their behaviour and reactions, worried they might seem avoidant or detached in the face of intense parental questioning and their own sadness at the fate of the baby. These became further dimensions of stress for the nurses. One nurse expressed her concern that parents were alert to and able to pick up on non-verbal cues and clues, '... they know when you're keeping something from them, because they've either known you for six hours or six days, so they can tell ... they can read things off your face or off your demeanour that something is wrong' (Nurse 15). In recalling her experience of being told not to say anything about the test results in front of the parents because the neonatologist had not yet had time to talk to them, one participant stated:

Those parents knew something was wrong. Everybody went really edgy and stilted with conversation. The parents had been here for a long time. Nobody went over and had a chat with them like they normally did. The atmosphere changed, they knew something was wrong and nobody would tell them because we had our hands tied. (Nurse 19)

The nurses knew that when the news was finally delivered, it would hit the parents hard. At that time, the nurses all understood their role was to help the parents, '... you're there to look after the baby and pick up the pieces when they [the parents] all fall apart' (Nurse 17).

Fear of inadvertent disclosure

It was clear that the nurses believed that fear of inadvertent disclosure made them behave differently with and around the parents. The nurses feared unintentionally disclosing information to the parents verbally. In addition to fearing, they might say something, they also feared disclosure through body language. They tried to suppress thoughts of the information they held and this generated anxiety that they would reveal the secret.

One nurse explained the tension:

You're very guarded and you have to watch everything you say because if they don't know and then it slips out you really feel bad because then they're upset and you create big problems. (Nurse 12)

Keeping secrets from parents troubled the nurses because they believed parents had the right to know everything about their baby and that such knowledge should be imparted in a timely manner. Whilst accepting the direction about keeping such information as confidential until the medical staff were able to meet with the parents, the nurses were none the less in a problematic situation.

This issue was associated with who is authorised to give information to parents. In the current study, the nurses' role in communication was limited to re-explanation of information already provided by medical staff. Thus, in this situation, the nurses believed that they were caught in the middle between the medical staff and the family. One nurse told of a situation in which she accidentally disclosed some information to parents, and she tried to extricate herself. However, the issue of parental trust later surfaced when the parents found out that the nurse had not been completely honest with them. This nurse explained her anxiety:

I think I said something which let the cat out of the bag but then I quickly covered it up. 'Oh, no, I've got you confused with somebody else', but then later it comes out and it's really hard, because they say 'Well you knew, why didn't you tell us?' And you say 'Well I'm not at liberty to tell you.' It's really

hard because you know what's going on, but they don't know, and they've got to wait for the consultant to actually tell them. (Nurse 12)

The narratives were replete with evidence of the distress and conflict the nurses experienced when keeping information from parents. For one nurse it, '... makes you feel sick to think that you are hiding information ... information that they should have' (Nurse 19). The length of time it took the neonatologist to speak to parents had a real bearing on how the nurses coped with holding the information. One nurse disclosed that it could sometimes be, '... 4 or 5 days down the track' (Nurse 19) before the medical staff can meet and discuss details with the parents. For parents of very premature babies four to five days is a very long time. During that period they are likely continuing to be very hopeful and even thinking that every day that passes means their baby is getting better and stronger.

A burden that could damage trust

Being asked to withhold information from parents was experienced as a professional burden. The 'burden' refers to the physical and psychological consequences of acting deceptively or being evasive.

There is a burden because until they're told, you've got to skirt around it ... the parents might wonder why there was some hope in your speech before, suddenly you've gone negative. They must be guessing that we know something that they don't. There is a burden of knowledge. (Nurse 24)

The negativity in the nurses' speech could be a way of preparing the parents for the sad news that was to come and the enormity of the ramifications of that news. This is an example of emotion work where the nurse attempts to modify, alter or create the expression of emotions. Even when the nurses attempted to control their emotional state, there were times when the length of time the nurses held onto the secret became unbearable for them, and the nurses tried to persuade the medical staff to speak to parents in a more timely manner. The despair of the nurses was evident as explained by one nurse:

Who's going to talk to these parents? ... You're banging your head on the wall trying to get the doctor to talk to the people and that seems to be the biggest hassle. (Nurse 9)

An additional burden came through the nurses' belief that their need to be evasive on some occasions represented a real threat to the parent–nurse relationship. The nurses were committed to the belief that ensuring the best possible quality of the parent–nurse relationship was essential for optimal baby care. They worked hard to establish an optimal therapeutic relationship with parents and did not want anything to jeopardise this relationship. The nurses understood the relationship between secrets and power, with the person holding the secret being seen to have more power.

Nurses also had the concern that when parents' perceived staff were holding back information, they would wonder what else they were not being told. The participants believed trust was a core component in the relationship between the parents and nurses, and one nurse stated 'I think the parents have to trust the nurses, because they're actually looking after the babies, otherwise they wouldn't go home at night' (Nurse 16). However, they knew trust could be damaged through non-disclosure, or the deliberate withholding of information.

You're made to feel guilty that you're not being totally honest and that's a burden. ... You think that if they find out later that you haven't been honest, then you've lost their trust. (Nurse 20)

Discussion

Communication between physicians and nurses can be complicated, with Mathews (1983) suggesting that problems such as withholding information emerge because of the differences in ideology between the two professions about communication, the control of information, what ought to be communicated, who owns the information and who is authorised to give the information. Social change, consumer rights and the right to access public and health-care information means that contemporary nurses are taught that it is their obligation to keep patients (or in the current study) the parents informed (Mathews, 1983). Fletcher (1980) emphasised that for patients no news is not good news, absence of news just gives them reason to be fearful. The same thing could apply to the parents of extremely premature babies, but in this situation it may create hope of an outcome that is just not possible.

Confidentiality is a basic legal and ethical tenet in nursing practice and is defined as 'the ethical principle or legal right that a physician or other health professional will hold secret all information relating to a patient unless the patient gives consent permitting disclosure' (Barrett, 2007: 6). It has a strong association with the words secret, private and trust (Ellenchild Pinch, 2011). In this context, as with other health-care contexts, a complex nexus exists between confidentiality, secrets, silence and voice in the health-care system (Jackson et al., 2011), and this can be detrimental to patients and their families as well as sometimes burdensome to health-care personnel.

Secret keeping is a psychological process that requires deliberate behavioural and mental control. Freud (1905: 94) highlighted the difficulty of keeping secrets when he stated 'no man can keep a secret. If his lips are silent, he chatters with his finger-tips; betrayal oozes out of every pore'. A secret is the intentional concealment of information that is important to the person from whom it is withheld (Margolis, 1974). Secret or secrecy usually relates to information and has a negative connotation (Ellenchild Pinch, 2011). Dufresne and Offstein (2008) suggest that in relation to secrets, ignorance and awareness exist on the same spectrum; however, access to information or awareness of privileged information is about power. Reis et al. (2007) have drawn attention to the life cycle and toxicity of secrets that have been sanctioned under the guise of confidentiality.

The efforts put into keeping a secret prompts a preoccupation with the secret; and the more important the secret, the greater the desire to tell it, and the greater the fear of its revelation (Margolis, 1974). It seems that in relation to the nurses and secrets, the more effort put into hiding the secret, the more likely the secret will be revealed. Secrets tempt the secret holder with revelation, yet the consequences of revelation can be troubling. Margolis (1974) suggests that the intrapsychic consequences of the silence of secret keeping can be devastating. The distress provoked from secret keeping and withholding information can prompt avoidance behaviours (McCorley et al., 2005), or in the case of this research, the nurses attempt to maintain open engagement with the parents, but fearing they may be acting in an avoidant way in an attempt to avoid inadvertent disclosure.

The nurses attempted to use thought suppression to deal with knowledge of the baby's diagnosis. Thought suppression is the conscious process of trying to avoid certain thoughts. Thought suppression occurs when a person with a secret is reminded of the secret by the presence of the audience from whom the secret is being kept (Lane and Wegner, 1995). In this study, the need for secrecy is heralded by the arrival of the parents into the NICU. At this time, the secret keeper (nurse) tries to think of something else to talk about in the presence of the person from whom the knowledge is to be kept (parents). The secret keeper struggles to prevent thoughts of the secret and show any outward expression by acting normally. Thus, the nurses attempted to guard against the non-verbal expression

of the secret. Unfortunately, thought suppression makes thoughts hyper accessible, thus making the secret intrude into the consciousness. This intrusion of the secret causes preoccupation with the secret (Wegner et al., 1987) and renewed efforts at thought suppression; therefore, it is natural that the secret keeper would fear unintentional revelation (Lane and Wegner, 1995). It is of little wonder that the nurses feared they could inadvertently reveal the secret.

Emotional labour is the management of feelings to create a publicly observable and desirable emotional display (Hochschild, 1983) and is essential for jobs that involve people work (Brotheridge and Grandey, 2002: 17). Conceptualisations of emotional labour associated with employment requires nurses to hide, fake or suppress felt emotions. When jobs require frequent and long contact with people, employees have a greater need to regulate their emotional displays, and longer interactions have been associated with burnout (Morris and Feldman, 1983). The nurses in the current study experienced emotional labour as a state of disconnectedness related to the timing of the delivery of information from consultant to the parents. Martin (1980) has described the requirements of front-line workers to be calm and dispassionate in the face of human misery. It is clear that emotional labour is a 'front-line phenomenon' (Mann, 1999). Lawler (1991) noted that nursing work would be virtually impossible without the professional face, and Lewis (2005) found the neonatal nurses in her study were highly skilled and active emotion managers who were able to move actively between different forms of emotion management.

Emotional dissonance occurs when employees are required to express emotions that are not generally felt and is positively correlated with emotional exhaustion (Zapf, 2002). For the nurses this equates to trying to maintain cheeriness when they feel sad and devastated by the news of a catastrophic cerebral bleed in the baby.

Deception is the act of deceiving. Deception is defined as a deliberate verbal message that does not reflect the person's actual opinion (Zuckerman et al., 1979). Deception and emotional labour are linked because of the emotional work required to maintain the deception. Research has reported that nurses routinely utilise vague responses, evasion of the truth, half-truths, denial and deception by omission when dealing with patients (Tuckett, 2004). Kendall (2006) found that the nurses in her study were strongly opposed to withholding information from patients. It was also difficult for the nurses to maintain deception, and they feared the distressing consequences when the deception was uncovered. Nurses in Schrock's (1980) study practised deception because they believed they were coerced into doing so because of institutional policy's or a doctor's order. Despite the passage of time since Schrock's work, this could equally apply to the nurses in the current study, as nurses are frequently requested by others to conceal or manage the truth.

It is difficult to know whether parents perceive staff withholding information from them. Perhaps the nurses in the current study were correct that parents could read things off their face and their demeanour. Facial expressions associated with honesty have been found to be significantly more pleasant (Zuckerman et al., 1979). Although written more than three decades ago, in suggesting parents knew something was wrong when the nurses behaved oddly, or differently, or evaded or ignored questions, the work of Quine and Pahl (1986) validates the concerns of our study participants. Similarly, Tuckett (1998: 299) suggested that 'not telling or avoiding the question is not lying; but it could be conceived as dishonesty'.

Conclusion

Sometimes there is delay between diagnostic results being available and parents being informed of results. Inner conflict and distress can occur when neonatal nurses face conflicts in their

obligations towards parents and medical staff. Having to decide between truth telling and keeping secrets and deception represents a clash of principles. The neonatal nurse and parent relationship is based on mutual respect and trust, and being secretive could have deleterious effects on their relationship with the parents. Whilst the demands on the neonatologist and the unpredictable nature of the NICU can make for a difficult situation for all parties, a coordinated response and discussion of the ramifications of diagnostic results is essential.

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Conflict of interest

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