

# Caring for a child or young person with severe illness



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## Introduction

This assignment will reflect on and critically study an incident from a clinical setting whilst using a model of reflection. This will allow me to analyse and make sense of the incident and draw conclusions relating to personal learning outcomes. The incident will be described and analysed, followed by the process of reflection using Driscoll's Reflective Model (2000) as it facilitates critical thinking and in-depth reflection which will help me to accumulate learning objectives for the future. To comply with the Nursing and Midwifery Council (NMC) (2015) Code of Conduct, confidentiality will be maintained therefore the individual will be known throughout as Ben.

Reflection is defined as a process of explaining and expressing from our own experiences and helps to develop and improve our skills and knowledge towards becoming professional practitioners (Jasper, 2003). I have chosen to use the Driscoll's Reflective Model (2000) as a guidance as it is straightforward and encourages a clear description of the situation which will allow me to look at the experience and identify how it made me feel, asking what was good and bad, and what I can learn (Sellman and Snelling 2010). Wolverson (2000) includes this as an important process for all nurses wishing to improve their practice.

## What?

Ben was born prematurely following an emergency caesarean section, whereby he received prolonged resuscitation and suffered severe hypoxic-ischaemic encephalopathy (HIE). According to Boxwell (2010), infants with severe encephalopathy have a 75% risk of dying with coma persisting, or <https://assignbuster.com/caring-for-a-child-or-young-person-with-severe-illness/>

progressing to brain death by 72 hours of life. There was a realisation that continuing treatment may be causing Ben harm in that it was unlikely to restore his health or relieve suffering. Boxwell (2010) further states that survivors of HIE carry an almost certain risk of poor neurological outcome. It is these times when consideration must be given to withholding and/or withdrawing treatment, subsequently re-orientating treatment to compassionate care. I was informed by my mentor that there would be a multi-disciplinary team (MDT) meeting to discuss and justify the decision to withdraw treatment.

I was invited into the MDT meeting by my mentor to both witness and actively participate in the discussion if I felt confident enough. The MDT consisted of two paediatricians, a paediatric registrar, the neonatal sister, and myself, a paediatric student nurse. The Royal College of Paediatrics and Child Health (RCPCH) (2004) suggest that all members of the health care team need to feel part of the decision-making process in that their views should be listened to. At the time, I was hesitant to contribute due to my knowledge, understanding and experience surrounding the clinical and ethical matter. However, I was reassured that greater openness between disciplines will facilitate better understanding of individual roles and enhance the sense of responsibility (RCPCH, 2004).

We considered what was legally permitted and required, but also at what was ethically appropriate. In considering quality of life (QOL) determinations, it was important to refer back to the ethical foundation involved with surrogate decision making, which is the standard of best interest. Some professionals argued that Ben had no prior QOL on which to  
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base a judgment. The Children Act (1989) provides an overall statutory framework for the provision of children's welfare and services but makes no specific provision concerning withholding or withdrawing treatment (RCPCH, 2004). It does however state that the welfare of the child is paramount which is further supported by The United Nations Convention on the Rights of the Child (1989). Article 3 under this legislation states that actions affecting children must have their 'best interests' as a primary consideration (RCPCH, 2004).

The NMC (2015) framework governs the maintenance of standards of practice and professional conduct in the interests of patients, acting as a guide to ethical practice within nursing. The principle of non-maleficence is one of the hallmark principles of ethics in health care which prohibits healthcare professionals from doing any action that will result harm to the patient. Also paramount, is the goal to restore health and relieve suffering, promoting good or beneficence. In the principle of beneficence, nurses are obliged to protect, prevent harm and maintain the best interest for patients (Beauchamp & Childress, 2001). Those involved needed to be confident in their ability to understand the ethical dilemmas they faced, and had to ensure they were aware of the underlying ethical principles to support their contribution to the discussion.

The decision to withdraw life sustaining treatment should be made with the parents on the basis of knowledge and trust, but ultimately, the clinical team carries the responsibility for decision making, as an expression of their moral and legal duties as health care professionals. It is not uncommon for parents to feel indecisiveness, shame or guilt about the decision to palliate their

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neonate, particularly when the outcome of the neonate's condition is uncertain (Reid *et al* , 2011). However, the final decision to withdraw intensive care was made with the consent from both parents, and this was clearly recorded in his clinical notes, together with a written account of the process and factors leading to the decision.

### So What?

Parents impending the loss of their infant experience a complex emotional reaction to their situation, typically one of anticipatory grief, shock and confusion (Gardner and Dickey, 2011). They may also experience feelings of profound loss, related not only to the imminent loss of their child but also to a loss of their expectations, aspirations and role as parents (Gardner and Dickey, 2011). Parents are fundamental in the decision-making processes around neonatal palliation and as it is they who will be the most significantly affected by these decisions (Branchett and Stretton, 2012), neonatal EOL care places a particular focus on caring for parents. Developing a flexible, transparent and family-centred care plan is essential, and so that their preferences are met, parents should take a key role in this process (Williamson *et al* , 2008). Spence (2011) recommends that a holistic approach is taken to clarify the family's wishes, desires and needs in order to effectively advocate for infants.

Whilst most parents wish to be involved in decisions and planning around EOL care for their baby, some may find this responsibility overwhelming (Williams *et al* , 2008). Despite this, we exposed the parents to a range of options which they synthesised in order to make the best decisions for their

family. However, it was important for the neonatal nurse and I to realise that highly emotive situations can often cause significant deficits in parents' ability to comprehend and process such information (Williams *et al* , 2008). As competent nurses, it is our responsibility to provide nursing care that advocates for our patients' rights in life and death, showing respect and dignity towards them and the family. We advocated for Ben by protecting his rights, being attentive to his needs, ensuring comfort and protection, and by participating in the ethical discussion to ensure a collaborative perspective of ethical negotiation (Spence, 2011).

The National Association of Neonatal Nurses (2015) suggests that palliative care should include comfort measures, such as kangaroo care, an ongoing assessment of pain using an appropriate pain assessment tool and written care plans to manage discomfort, pain and other distressing symptoms such as seizures using the least invasive effective route of administration. As the parent's wished to be present at time of death, the neonatal nurse prepared the family for what they would observe as life-sustaining treatment was discontinued. This included informing them of gasping and other noises, colour changes, and stating that Ben may continue to breathe and have a heart rate for minutes or hours. This is an fundamental aspect of palliative care, and provides the family with the opportunity to ask questions.

However, a study conducted by Ahern (2013) stated that nurses often express anxieties surrounding how to support parental grief and how to prepare them for the imminent death of their infant. Parental preferences were also assessed, including whom they wish present, whether they want to

hold the infant, and whether they wished to participate in any rituals or memory-making activities.

Although my mentor took the lead role in planning the infant's EOL care, my contribution focused on memory-making activities. Although this is often nurse initiated, making memories is increasingly recognised as an aid in parental coping and grieving (Schott, Henley and Kohner, 2007). However, McGuinness, Coughlan and Power (2014) reported that rather than physical keepsakes, parents and families instead appreciated other actions and gestures that demonstrated respect for their needs, including having time alone with the infant and being encouraged and supported to provide care to their baby. I asked the parents if they would like photos to be taken, and although parent's declined photography, I offered to take some to keep in the medical records in case they decided they would like them at a later date which they appreciated (Mancini et al, 2014). Despite this, the parents were acceptant of the offer to keep items that were related to Ben's care, including his wristband, blankets and hat.

Throughout planning Ben's EOL care, the effectiveness of the therapeutic relationship in meeting the family's needs was achieved by showing empathy, and by doing so I obtained the individuals trust, and respect. Carl Rogers (1961) has influenced the shift from a task- to a person-centred and holistic view of nursing care, with the adoption of Rogers' 'core conditions' (Bach and Grant, 2005). Rogers identified unconditional positive regard, genuineness and empathy as necessary conditions for helping someone change effectively through a good therapeutic relationship. This was achieved through both proficient nursing knowledge and utilising <https://assignbuster.com/caring-for-a-child-or-young-person-with-severe-illness/>

interpersonal communication skills. According to Jones (2007), there is little research in nursing literature that discusses interpersonal skills, particularly in nursing education. There is also a critique that nursing education is often removed from the realities that students experience during their clinical practice (Bach and Grant, 2005). I felt confident and assured that my interpersonal skills would bring positivity throughout a very difficult time, helping them through the grieving process. I acknowledged that both parents appreciated my forward-thinking and empathy towards the current situation. Being empathetic during this situation required my ability to be understanding not only of the parent's beliefs, values and ideas but also the significance that their situation had for them and their associated feelings (Greenberg, 2007).

Egan (2010) identifies certain non-verbal skills summarised in the acronym SOLER that can help the nurse to create the therapeutic space. I did this by sitting facing the family squarely, at a slight angle; adopting an open posture; leaning slightly forward; maintaining good eye contact, without staring and presenting a relaxed open posture. To enhance the communication through these skills, I used active-listening skills to ensure a successful interaction through techniques that facilitated the discussion. I did this by using sounds of encouragement, demonstrating that I was listening and assimilating the information provided by the parents. This was also done by summarising, paraphrasing and reflecting on the feelings and statements. Effective use of reflective skills can facilitate exploration, build trust, and communicate acceptance and understanding to the individual (Balzer-Riley, 2004). Geldard and Geldard (2005) state that it is often the paralinguistic



elements of speech rather than what is actually said that betray true feelings and emotions.

Now What?

As EOL approached, Ben was extubated on the neonatal unit and transferred to the bereavement suite whereby my mentor continued to provide one-to-one care. I was not present throughout the final palliative care phase as I wanted to respect the family's privacy. At this point, I held emotions of helplessness, sadness and anxiety, therefore I took some time to reflect on what had happened. It is important that nurses recognise and confront their own feelings toward death so that they can assist patients and families in EOL issues (Dickinson, 2007).

Nurses often experience sadness and grief when dealing with the deaths of patients, and without any support, can suffer distress (Hanna and Romana, 2007). Debriefing is a beneficial intervention designed to help nurses to explore and process their experiences. Irving and Long (2001) suggest that debriefing demonstrates a significant reduction in stress and greater use of coping strategies through discussion in a reminiscent fashion to let their feelings out. Through reflection, I have come to the realisation and understanding that patient death is an integral part of nursing practice in palliative care settings. I have recognised that support from all members of the MDT have positive implications for nursing students coping with stressors associated with patient death.

Furthermore, the experience helped me learn the importance of both verbal and non-verbal communication. As an aspiring nurse, I have to continuously <https://assignbuster.com/caring-for-a-child-or-young-person-with-severe-illness/>

improve my communication skills because I shall be interacting with more varied patients in the future. I have also been able to utilise my knowledge of ethical principles in relation to withdrawing treatment, thereby integrating theory into practice.

## Conclusion

To conclude, the care that patients receive has the direct potential to improve through reflective practice. Becoming a reflective practitioner will help me to focus upon knowledge, skill and behaviours that I will need to develop for effective clinical practice. Reflection helps to make sense of complicated and difficult situations, a medium to learn from experiences and therefore improve performance and patient care.

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