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Using Principlism to resolve the ethical dilemma of withdrawing treatment from a neonate diagnosed with Spinal Muscular Atrophy

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Abstract Neonatal nursing can be a very rewarding career. However, neonatal nurses are often caring for very ill babies and difficult decisions may need to be made. This paper explores one of the most challenging aspects of neonatal nursing; the withdrawing of treatment from a neonate. A case study has been included of withdrawing from a neonate born with Spinal Muscular Atrophy type I. Confidentiality has been maintained throughout, in accordance with the Nursing and Midwifery Council (2008).

To assist health professionals make these difficult decisions, ethical frameworks can be applied. Beauchamp and Childress (2009) advocate using four ethical principles to assist clinicians in the decision making process; beneficence, non-maleficence, justice and autonomy. This paper will introduce the reader to these principles and explain how they can be applied to neonatal nursing.

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Introduction

This essay will discuss the strengths and weaknesses of the moral theory of Principlism in relation to an ethical dilemma. A vignette focusing on a moral problem is included. The moral problem to be discussed is withdrawal of ventilation from a neonate. In accordance with the Nursing and Midwifery Council's (2008) Code of Professional Conduct, pseudonyms have been utilised throughout to protect confidentiality.

Within the neonatal intensive care unit (NICU), some babies may receive aggressive treatments to sustain life 'at all costs' in expense of quality of life (Longden, 2011). Many babies that would have died a few decades ago are now surviving birth. However, these babies can have multiple health issues and complexities to overcome. Clinicians are often accountable for and actively treating neonates whose chance of survival is minimal (Warrick et al., 2011). This can result in clinicians facing the ethical dilemma of whether to treat or not and knowing when to stop.

A quote by Clarke (2000) succinctly captures this ethical dilemma:

> "Advances in medical knowledge and technology have made it increasingly difficult to decide when there is a medical duty to sustain life and when treatment no longer serves any useful purpose and ought to be stopped." (p.758).

Caring for compromised neonates is emotionally demanding on health professionals and relatives (Wiggs, 2011). It is also costly when there is a limited amount of resources. When these babies appear to be suffering and not gaining from treatment it can be kinder to withdraw life sustaining technologies. Clinicians need to recognise when treatment is futile to ensure their patients receive the correct care (Warrick et al., 2011).

Mohammed and Peter define futility as:

> "Providing inappropriate treatments that will not improve disease prognosis, alleviate physiological symptoms or prolong survival" (2009, p.292).

Within the United Kingdom, there are five permissible reasons in neonatology to consider withdrawal/withholding of treatment; babies diagnosed as brain dead, babies in a persistent vegetative state, babies born with no chance of survival, babies with no purpose which means babies born with severe physical/mental impairments and babies considered to be in unbearable pain (Royal College of Paediatrics and Child Health, 2004).

These guidelines exist but it is still a challenging decision to decide to withdraw treatment from a neonate. This is because the future is uncertain and the neonate cannot offer their opinion. No-one knows if the neonate finds it a burden (Lindemann and Verkerk, 2008). In addition, acknowledging futility in children can be difficult as it is hard to accept a baby will not be able to reach maturity. Withdrawal of life support is one of the most difficult and challenging decisions for clinicians (Wiggs, 2011). This is because it means stopping a treatment which is sustaining life.

The clinicians and parents caring for the neonate have to decide which action is best for the infant. To do this they need to consider the current and future benefits and burdens of a baby's life (Wilkinson, 2011). However, determining which action is correct is fraught with difficulties. Continuing to treat may prolong life but it may be an unbearable life full of suffering. Conversely, withdrawal from ventilation may end a baby's suffering but also their life.

This essay will discuss the complexities of such a scenario. To assist clinicians to make these decisions moral theories can be applied. Deciding whether something is morally right or wrong can help make the decision. This essay will analyse how moral theory such as Principlism can be utilised to debate the ethical dilemma.

The moral problem

Joanne and Stephen were expecting their first child. The pregnancy had proceeded well and they were very happy prospective parents. Joanne had decided against anomaly testing throughout her pregnancy as she was religious and believed "whatever baby God gave to her would be a blessing". Her pregnancy progressed normally.

At 38 weeks, Joanne went into labour. Joanne's labour was long but free from complications. The baby, a boy appeared healthy when born. Joanne and Stephen decided to name him Alfie. Joanne and Alfie were transferred to the labour ward, late in the evening. During the night, Alfie deteriorated. He developed symptoms of respiratory distress. He was grunting and his breathing was laboured.

Alfie was assessed by the paediatrician and it was decided he should be transferred to NICU. Joanne was reassured by the midwife and attending doctor that it was not extraordinary for newborn babies to require a little assistance. The multi-disciplinary team (MDT) reassured Joanne and Stephen about Alfie's prognosis. The MDT was