Legal and ethical issues in neonatal nursing: a case study

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Abstract

Neonatal nurses regularly face complex legal and ethical dilemmas. This article discusses the hypothetical case of Jack, a two-day-old infant diagnosed with trisomy 13 (syndrome), a life-limiting condition. Jack’s prognosis is poor, and he is not expected to live past two weeks of age. The legal and ethical perspectives of withholding life-sustaining treatment in infants and children will be explored through the application of ethical frameworks, as well as statute and case law relevant to children and adolescent nursing. The article also discusses the neonatal nurse’s role, with reference to local and national guidelines.

Keywords

ethical frameworks, ethics, legal issues, legislation, neonates, neonatal nursing

THE NURSING AND MIDWIFERY COUNCIL (NMC) (2014) states that nurses must be able to recognise ethical challenges in their role and to practise in accordance with legal, professional and ethical frameworks to overcome these challenges. It is important, therefore, that nursing students gain experience of legal and ethical challenges during their education, and that undergraduate nursing courses incorporate content to encourage and support students to develop values that form the basis for professional attitudes and behaviours. Using a hypothetical case study, this article discusses ethical theoretical concepts and health and social care policy, in particular bioethics in nursing, ethical frameworks, case and statute law relevant to children and adolescent nursing, clinical guidelines on withholding life-sustaining treatment and the role of the neonatal nurse.

Case study

Jack was born at 39 weeks’ gestation and was two days old. Following genetic testing, Jack was diagnosed with trisomy 13 (syndrome) and was being cared for in the neonatal intensive care unit. Trisomy 13, or Patau syndrome, is a chromosomal disorder in which there are three copies of genetic material from chromosome 13 in each cell of the body, instead of two. Trisomy 13 causes significant medical and developmental problems that are often life-threatening (National Organization for Rare Diseases (NORD) 2007). The clinical features of trisomy 13 consist of major craniofacial, cardiovascular and central nervous system anomalies, neurological defects, low birth weight and feeding difficulties (NORD 2007). The complexity and severity of the clinical presentation of trisomy 13 can vary from case to case (NORD 2007).

Jack’s condition was considered to be extremely severe. The healthcare professionals involved in Jack’s case felt that invasive treatments and procedures would not be in his best interests, since although these would potentially lengthen his life in the short term, the treatment would be burdensome and his quality of life would be poor. The primary aim after diagnosis of a life-limiting condition in a neonate is to enable the family to spend quality time together, outside of the hospital wherever possible (ACT.
(Association for Children’s Palliative Care) 2009). It was, therefore, suggested that Jack’s parents should take him home with support from a community palliative care nurse. Jack’s parents, however, disagreed and wanted to proceed with all active treatment options.

**Ethical frameworks**

Butts and Rich (2008) described ethical nursing as the analysis of bioethical issues from a nursing perspective and suggested that ethical frameworks should be used to assist this process. Beauchamp and Childress (2012) developed four principles of biomedical ethics considered by many as the theoretical framework from which to analyse ethical situations in medicine. The four principles are (Beauchamp 2003):

» Autonomy – the obligation to respect the decision-making capacities of autonomous persons.

» Beneficence – the obligation to provide benefits and to balance benefits against risks.

» Non-maleficence – the obligation to avoid causing harm.

» Justice – the obligation of fairness in the distribution of benefits and risks.

However, Tingle and Cribb (2014) suggested that this framework is limited and there is room for individual professional judgement. Furthermore, the four principles compete with each other, with no clear emphasis on which should take precedence. This could lead to confusion, ultimately complicating decision making (Mason 2006).

**Four quadrant approach**

The four quadrant approach, first developed in 1982, provides a set of questions to follow when exploring a clinical ethics case from wider perspectives (Jonsen et al 2010). Schumann and Alfandre (2008) suggested that this approach helps to highlight areas of controversy and clarify the principles underlying the circumstances of a clinical ethics case, which should guide discussions to enable all involved, if possible, to achieve a resolution. For learning purposes, the systematic framework of the four quadrant approach permits a fuller discussion of the case study involving Jack.

The first stage of the four quadrant approach involves establishing a diagnosis, the treatment options and the prognosis. Infants, such as Jack, with trisomy 13 have a limited life expectancy. Many infants die within days and 5-10% of children survive beyond 1 year (Genetics Home Reference 2016). There is no cure for trisomy 13, and treatment consists of supportive measures to minimise discomfort and enable feeding (Barlow-Stewart 2012).

The second stage of the four quadrant approach, patient preferences, involves establishing the patient’s views and wishes. In the case study, the wishes of Jack’s parents were explored. Jack’s parents had experienced difficulties in conceiving and had been trying for more than 2 years before they had Jack. They felt strongly that they wanted their son to be given every chance of survival with both medical and surgical interventions. They wanted to proceed with mechanical ventilation and cardiac surgery to repair an atrial septal defect in Jack. Cereda and Carey (2012) found that some physicians may choose to carry out life-sustaining treatment if requested by parents, to respect parental autonomy; however, the benefits of such treatment must outweigh the high possibility of increased pain and suffering. Evidence has shown that parents must be given time to assimilate these recommendations from clinicians, or their distress levels will increase (POPPY 2009).

The prospect of deciding whether a child should live or die is challenging, and parents will experience feelings of guilt, loss, anger and pain. It is essential that they are supported throughout this process (Eden and Callister 2010). Palliative care encompasses not only the care of the child but also that of the family (ACT 2009). Families should be given psychological and emotional support, from the point of diagnosis through to the end of life and after death, and palliative care should include religious, pastoral and spiritual support (Mancini et al 2014). A study of parents’ views found these interventions, along with memory-making, are invaluable in the...
bereavement process (Harvey et al 2008). During Jack’s time in the neonatal unit, his parents were supported by the nursing staff and hospital chaplain, and ongoing support was to be provided by the community palliative care nurse after discharge.

Stage three of the four quadrant approach explores whether the proposed treatment will improve the patient’s quality of life. A study by Tsukada et al (2012) reported that while intensive treatment can improve prognosis, it is of little benefit to infants with trisomy 13, as in Jack’s case. Furthermore, the burdens of such treatment are considered to outweigh the benefits. Baird (2011) found that long-term mechanical ventilation is associated with increased suffering and a reduced quality of life. Trisomy 13 cannot be cured and intensive treatment, whether medical or surgical, will not alter the natural course of the syndrome.

The fourth and final stage of the four quadrant approach requires that clinicians explore any contextual factors that may affect the decision. White and Wicclair (2012) described the irreversibility of the decision as a contextual factor to be considered in clinical ethical decision making. Without invasive procedures and treatment, Jack’s condition would progressively deteriorate, ultimately leading to his death. Despite this, it was considered not to be in Jack’s best interests to carry out such treatment. Jack’s parents, however, had had difficulties conceiving and held strong religious views on the sanctity of life, both factors were acknowledged as influential in the decision-making process.

Ethical approaches and legal principles

Although life is respected and recognised to be of inherent value, there are occasions when it should not be considered sacrosanct (Royal College of Physicians 2010). A rules-based ethical approach would argue that life is fundamental and the duty should always be to treat people in all circumstances (deontological theories). However, the sanctity of life can be limited when aggressive interventions are deemed futile and the purpose of treatment is recognised to be to alleviate suffering (Mancini et al 2014). To continue with invasive life support in such cases could be argued to be prolonging the dying process and an unethical use of resources (Singer 1993). This argument supports an ethical theory that places prominence on the likely consequences of a decision (consequentialist approach). In such cases, it is necessary to facilitate a family-centred individual approach that considers the unique context and quality of life as assessed in partnership with the family (Bliss 2010). This is neither rules-based nor wholly based on consequences.

Essential documents produced by Mancini et al (2014) and the Royal College of Paediatrics and Child Health (RCPCH) (2004) emphasise the importance of unanimity between clinicians and parents in decision making (Nuffield Council on Bioethics 2006). Where conflict arises, Mancini et al (2014) suggested the involvement of a clinical ethics committee. This is a multidisciplinary group whose primary role is to support a healthcare institution in making decisions on ethical cases. However, when a resolution cannot be reached, legislative frameworks can be applied (Muirhead 2004). The legal considerations for making decisions about withholding life-sustaining treatment in infants and children are detailed in both statutory and case law (Larcher et al 2015).

The rights of children outlined in the United Nations Convention on the Rights of the Child (Unicef 2016) are embodied in the Human Rights Act 1998 (Larcher et al 2015). The most relevant rights in relation to the case study involving Jack are Article 2: the right to life and Article 3: the prohibition of torture. Withdrawing or withholding life-sustaining treatment requires a balance between the duty to protect life and the duty to prohibit inhuman treatment (Larcher et al 2015). It could be suggested that withholding life-sustaining treatment denies an infant or child’s right to life (British Medical Association (BMA) 2008).

However, this is considered to be within the law and consistent with human rights if it is in the infant or child’s best interests (RCPCH 2004).
The ‘best interests’ principle has its foundation in the Children Act 1989. This act is a central piece of legislation that provides a statutory framework for children’s services, with the aim of ensuring the welfare and safety of all children (Allen 2005). Section 3(1) of the Children Act 1989 defines parental responsibility as ‘all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property’, and includes the right to make decisions about, and consent to, their child’s medical care (BMA 2008). This is based on the concept that parental instinct will guide parents in making the right decision, although this is not always the case (BMA 2008). Therefore, there are limitations to parental rights; parents cannot demand inappropriate treatment or refuse treatment that is in their child’s best interests (BMA 2008). The overriding principle of the Children Act 1989 is that the infant or child’s welfare and best interests must be of the highest regard in all decisions concerning their upbringing.

Determining an infant or child’s best interests regarding end of life care is challenging and involves weighing up the benefits, risks and burdens to the infant or child and the family (General Medical Council 2010). The GMC (2010) states that authoritative clinical guidance must be used to determine what treatment may be in their best interests. Many of these cases conclude that there is no breach of Article 2 (the right to life) of the Human Rights Act 1998, and Article 3 (the prohibition of torture) is upheld by not imposing oppressive treatment (Nuffield Council on Bioethics 2006).

Role of the neonatal nurse

Neonatal intensive care nurses will regularly face complex clinical, ethical and legal dilemmas in their role (Monterosso et al 2005). The National Association of Neonatal Nurses (NANN 2006) states that nurses have a crucial role in ethical decision making, since they are in a unique position to understand both the infant’s medical condition and the values, beliefs and wishes of the family. Furthermore, neonatal nurses are required to implement decisions made about the provision, withdrawal or withholding of medical treatment (NANN 2006). The Nuffield Council on Bioethics (2006), therefore, suggests that nurses should be directly involved in all decision making. NANN (2006) acknowledges that nurses need ongoing education and training in nursing ethics and bereavement support to enable them to contribute to effective decision making.

A study by Monterosso et al (2005) indicated that neonatal nurses considered their primary role in ethics cases as advocating for the best interests of their patient. The NMC (2015) places prominence on the nurse’s role as the patient’s advocate, stating that nurses must act as an advocate for those in their care.
and the vulnerable. Nurses are trained to provide life-prolonging treatment, so they may feel internal conflict when they are involved in the withdrawal or withholding of care (Brykczynska and Simons 2011). Despite this, neonatal nurses must avoid a paternalistic attitude and remain non-judgemental when advocating for the best interests of the infant and family (Kenner and Lott 2007). Advocacy requires nurses to use skills such as courage, assertiveness, confidence, negotiation and communication (Kenner and Lott 2007).

The complex nature of ethical decision making means that professions often develop ethical codes to aid practitioners through the process (Dahnke 2009). The International Council of Nurses (ICN) (2012) Code of Ethics outlines the fundamental principles for ethical conduct in nursing. In relation to the case study involving Jack, the code states that nurses should promote an environment in which the rights of the patient and their family are upheld and respected, provide sufficient and accurate information on related treatment, advocate for equity, and demonstrate professional values such as integrity and compassion (ICN 2012).

The therapeutic relationship between clinicians and patients is the foundation of nursing. In intensive care units, however, conflict between patients, relatives and practitioners is commonplace (Kelly 2006). The therapeutic relationship between clinicians and patients is the foundation of nursing. In intensive care units, however, conflict between patients, relatives and practitioners is commonplace (Kelly 2006). Nursing staff should attempt to manage and resolve conflict as it arises to prevent the negative effects it can have on patients and the nursing team (Vivar 2006). Others have identified that the two predominant approaches to conflict resolution used in the nursing profession are competing and compromising (Losa Iglesias and Becerro de Bengoa Vallejo 2012). Competing is described as a negative approach to conflict resolution in which the individual seeks to outdo their colleagues, often to the detriment of others. Compromising aims to identify a mutual solution (Losa Iglesias and Becerro de Bengoa Vallejo 2012). While there is no single strategy that should be used, collaboration is the preferred approach, since this requires the nurse to recognise areas of controversy and identify a solution incorporating the perspectives of both parties (Vivar 2006).

Acknowledging the lasting implications of the decision and reassuring the parents that nurses too have the infant’s best interests at heart can help to resolve conflict on neonatal units (Muirhead 2004). Ultimately, it is often a matter of the approach used; although legal interventions are sometimes necessary, the prospect of a judge determining the infant’s treatment is an alternative that is best avoided (Muirhead 2004).

Outcomes
No legal proceedings were necessary in Jack’s case. After several lengthy conversations, Jack’s parents were in agreement with the clinicians that life-sustaining treatment would be withheld in Jack’s best interests. Jack’s condition was stabilised and he was taken home by his parents 3 days later. The nurse’s role in planning for discharge home was to liaise with community teams and provide medical training for the parents to care for Jack at home (ACT 2009).

Conclusion
Neonatal nurses and children’s nurses will encounter ethical and legal dilemmas throughout their nursing careers. Ethical frameworks should be used to approach ethical dilemmas in patient care and assist in the decision-making process. Wherever possible, parents and practitioners should mutually decide on the most appropriate treatment; however, when conflict arises, legal frameworks can be applied. The fundamental legal perspective in relation to children and young people is that the best interests of the child must be paramount. Although parents have overall responsibility for their children, practitioners have a right to challenge parents’ decisions if they believe they are not in the child’s best interests. Nurses should therefore be aware of relevant legislation and health and social care policies to be able to apply them in their practice. The primary role of nurses in these cases is to advocate for the infant or child and the family, and to ensure that their rights are upheld and respected.

KEY POINT
‘The therapeutic relationship between clinicians and patients is the foundation of nursing. In intensive care units, however, conflict between patients, relatives and practitioners is commonplace’ (Kelly 2006)
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