

Ethical decision-making regarding infant viability: a discussion

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Abstract

This paper explores the ethical complexities on who should decide to give infants born on the borderline of viability lifesaving treatment; parents or the health care professionals. It explains the legal position and highlights that the moral and ethical right of the fetus can be considered differently. Health care professionals' experiences that influence parental decision is considered. Further, parental autonomy and the difficulties they face when making a best interests decision knowing that this could cause more harm than good for their infant child and balancing any decision they make with quality of life is explored. The paper also considers barriers to an effective discussion taking place in an environment where clinical decisions have to be made quickly once the baby is born. It concludes by suggesting that it should be a joint decision between parents and the neonatal team on deciding whether to give lifesaving treatment.

Introduction

There are no universally agreed rules of health care ethics. Ethical decisions and standards tend to be linked to professional codes of practice. This paper is therefore relevant to any health care professional who is involved in the joint decision making with parents in whether to commence life-saving treatment of a baby born at the verge of viability. The paper is insightful as it gives a deep understanding of the complexities involved in this decision making and the long term consequences on the premature baby. Further, it gives a new way of thinking that causes us to re-examine the difficulties in trying to make the right decision for the premature baby.

The age of viability is defined by Breborowicz¹ as the developmental stage of a fetus where if born, it would be considered able to survive extra uterine life, and is commonly known in health care as the 'grey area'.² In the 1960s, absence of complex and sophisticated equipment and inaccuracy in assessment of gestational age meant the viable age of a premature baby was considered to be 30-31 weeks' gestation.^{2, 3} However, due to developments in medical knowledge and technology plus pioneering research, it has led to more effective resuscitation techniques. In addition, with the production of synthetic surfactant, and the provision of high quality equipment in order to administer specialized intensive care treatment^{4, 5} the age of viability has reduced to 23-24 weeks' gestation.²

Whilst this has led to a significant fall in the mortality of infants born prematurely,⁵ their sheer immaturity can lead to them requiring medical interventions which do not come without

harmful side effects.¹ For example, there is an increased risk of brain injury leading to neurodevelopmental disability, such as vision impairment, deafness, and cerebral palsy, as well as chronic lung disease^{6, 7} giving rise to concerns over their future quality of life.⁴ Within the last 20 years, it has become widely accepted practice, across countries of western culture, for decisions to provide lifesaving treatment to be heavily influenced by the seeking of parental wishes.^{7, 8} This has increased and grown due to a tendency to turn to litigation when outcomes do not meet expectations.⁷

Using United Kingdom (UK) case law and statute, this paper aims to explore some of the ethical, professional and legal dilemmas encountered, and will draw on literature from western culture to explore who should decide whether infants born on the verge of viability should be given lifesaving treatment. In this context, the term 'lifesaving treatment' refers to resuscitation at birth, and the subsequent intensive care treatment which the infant is likely to require in order to survive.

United Kingdom Legal Position

In an area of health care where law does not always provide the answers to the complex ethical issues which arise, the question that is often asked is whether interventions are morally acceptable and ethically right. As a fetus, not recognised lawfully as a person in the UK; an unborn child has very few rights if any at all, and those which it does have, exist more as moral rights than lawful ones.⁹ Subsequently, within the United Kingdom (UK) this has been a much disputed topic; mainly between legal and religious groups. Devout cultures; in particular those from the Roman Catholic religion believe that life begins at conception and that unborn children should have the same legal rights as any other person born within the UK.¹⁰ Legally, on the other hand the fetus has a very different status. Under the Convention on the Rights of the Child;¹¹ an unborn child has the right to life and protection from any harm which may cause this right to be broken. However, as can be drawn from the case of Paton v British Pregnancy Advisory Service (BPAS)¹² for the majority of other rights and laws to apply, the fetus must be born and considered a person. The Abortion Act (1967)¹³ serves to legislate the termination of pregnancy in the UK. It is one of the few laws which exists to safeguard unborn babies, albeit only until they are past the point at which they are legally considered viable, which currently stands at 24 weeks. Seri and Evans² and Fanaroff et al⁸ highlight that at the birth of a premature infant, the condition of the baby is pivotal to deciding whether lifesaving treatment is offered. Moreno,¹⁴ contributes that if an infant is born before 24 weeks' gestation and can independently maintain its heart rate and makes respiratory effort, it may still be considered viable. Lifesaving treatment should therefore be offered in these circumstances. This however, places a question over whether

the UK Abortion Act remains appropriate,¹⁵ especially when taking into account law from other countries such as France, where women are only able to have an elective abortion up to the twelfth week of pregnancy.¹⁶ Moreover, it also questions, whether medical technology has advanced to the extent that it is no longer supported with appropriate legislation.

Given that once a baby is born, and is considered legally a person that is entitled to the protection of the law with its own human rights, when babies are born on the verge of viability, this marks the outset of a huge ethical debate for families and professionals alike. In particular, this arises if all of the risks associated with treatment and the long term detriment to quality of life are known and taken into consideration. Premature newborn babies; by their natural immaturity, are considered to be one of the most vulnerable groups in society.¹⁷ Whilst certain rights, such as their right to life and right to protection from harm are protected by the Human Rights Act (1998: schedule 1)¹⁸ they clearly lack the competence and ability to make decisions for themselves. Meaning, they are unable to give consent, nor exercise their right of autonomy.⁸

Informed consent

Informed consent is the process by which information about a proposed procedure is presented to a patient. It comprises thorough education about what is involved to carry out that intervention, and the benefits and risks associated. This enables the patient to make an educated and informed choice about whether they wish the process to proceed.¹⁹ An open and honest approach to the discussion of any interventions proposed is promoted by Griffith and Tegenah,²⁰ who say that this will allow individuals to give consent in a well-informed, uninfluenced and uncoerced way. Obtaining informed consent is a process which health care professionals are legally obliged to carry out; as is stated in Part 1 of the UK Nursing and Midwifery Council (NMC) Code,²¹ which details the standards which nurses and midwives within the UK must uphold in order to practice.²² The gaining of informed consent has become increasingly significant in recent years due to the development of a culture which more readily turns to litigation if something does not go as planned, than it perhaps has done before.²³ With this in mind, when babies require medical intervention; their inability to provide consent themselves means they require an advocate to promote their best interests and make decisions for them. Parents are generally thought to be the best advocates,²⁴ and are legally given the authority to make decisions and give consent on behalf of their children through the notion of parental responsibility. This was introduced by The Children's Act 1989 and 2004: Part 1(2).²⁵

The process of obtaining informed consent for the provision of life saving treatment for babies born on the verge of viability is done through parent-clinician discussions. This is of particular importance, given that the earlier the gestational age, the more likely quality of life is to be compromised by severe long term disability, thus increasing the likelihood of the requirement of demanding continuing care.³ Where possible, such discussions will involve members of the neonatal team offering information about proposed interventions, and the associated benefits and risks of these. This is in order to ensure competent understanding of the predicted outcomes, to prepare the parents for the delivery of a premature infant, and make them aware that their baby may require immediate lifesaving treatment.^{3, 26} This is also an opportunity for clinicians to ascertain parents' views on whether they want treatment to be provided, and involves informing them that depending on the condition of the baby when it is born, it may not be possible or advisable to provide treatment. Winyard⁶ criticises decision making responsibility being placed upon parents. The author highlights how this can place them in a difficult situation as they may not want to have the burden of responsibility in making the final say on something which may result in their child not surviving. This is a prospect which appears to be over-looked by the Children Acts' and equally by those enforcing this aspect of the Acts'. However, if professionals are to respect and support decisions that patients' make, and comply with Part 1 of the NMC Code (2015b);²¹ this should be considered and honoured. In doing so, it will safeguard their decision making capabilities, and also their autonomy. There are, however, several barriers to the efficacy of these discussions, which surrounding literature has alluded to.

Barriers

There are many reasons why babies are born prematurely, however in most cases, labour starts naturally; ²⁷ unexpectedly and very quickly.²⁶ Donohue et al.²⁸ highlight that the time from the start of labour to the birth of a premature baby is usually less than 72 hours. This means that by the time the woman arrives at the hospital, she is already in established labour. This presents barriers to an effective discussion taking place, as compromise to the time available may mean clinicians are be unable to provide the necessary depth of information required to allow quality informed consent to take place; ^{9, 28}. It can also cause parents to be deprived of time to fully consider their wishes. In addition to this, Allen et al.⁴ as well as more recently Douglas and Dahnke²⁹ have highlighted how this can mean discussions are held in the delivery room. This is an environment which they state is not conducive to effective communication as it is busy and impersonal. It is an inappropriate place for holding life changing conversations, which may result in families making one of the most difficult decisions they will ever have to make;^{30, 31} Hallström and Elander²⁴ draw

attention to the way in which parental ability to make decisions with consideration of their child's best interests is hindered by stress and anxiety, which may already be considerable, yet added to by feeling pressured into making decisions quickly, in a busy clinical environment.

Hurst³⁰ like Mercurio³² has raised further criticisms through concerns about professional morals and attitudes, and their influence on parental decision-making. They suggest that clinicians' previous experiences impact on the content and presentation of discussions. Although neither proceeds to say exactly how they may be affected; Hurst³⁰ states that this removes the right of parents to come to an impartial decision and in effect, denies them of their autonomy. This suggests that this may cause information to be extracted and presented in a biased way.

When considering how these barriers may be overcome, Dougherty and Lister³³ and Turrill and Crathern³⁴ are among authors who recommend that in order to ensure the obtaining of legitimate informed consent, procedures should be carefully explained, using language that parents are easily able to understand. Further, information should be given in small quantities; allowing the decision maker to ask questions and to consider their options without the influence of professional bias or coercion. Dougherty and Lister³³ and Turrill and Crathern,³⁴ also highlight the importance of a calm environment to conduct effective communication. Despite this, when applying these recommendations to a situation where the birth of a premature baby may be imminent, it becomes apparent that implementing them into practice may be difficult due to the barriers which are presented being unavoidable. If this is the case, parents may be provided with little, or no information regarding the treatment their baby may require, or the consequences associated with this.²⁸ This places a question over whether it is appropriate for parents to decide whether their baby should receive lifesaving treatment; albeit jeopardising their ability to exercise their autonomy.⁹

Autonomy

The concept of autonomy is one which has been derived from the study of ethics, and refers to a person making decisions for themselves. It is a process believed to be influenced by culture through its basis on an individual's values and beliefs.⁹ Within health care, it has become a requirement of all nurses and midwives on the NMC register to promote the autonomy of any individual gaining access to health care (NMC, 2015b).²¹ It involves patients taking control of their treatment, encouraging them to express their wishes concerning proposed interventions.³⁵ In doing this, where parents are the decision makers, the delivery of family-centred care is also enabled.

In order to allow parents to make fully autonomous decisions, Part 1 of the NMC Code (2015b),²¹ with Hendrick⁹ and Griffith and Tegnah,²⁰ highlights the importance of health care professionals ensuring informed consent is obtained through the provision of relevant and factual information. This is so parents can make justified and informed decisions. If this is done thoroughly, professionals should be able to confirm that parents have the appropriate knowledge, and judge whether they have the capacity to make decisions on behalf of their child. Following this, they must honour the choices parents make and recognise that this may mean that treatment offered maybe refused.^{9, 20} Professionals' respect for patient autonomy exists to preserve their human rights³⁶ and is concerned with Schedule 1, Part 1, the Convention: Rights and Freedoms of the Human Rights Act (1998),³⁷ which enforces people's right to their own opinion, to make their own choices and to have decisions they make respected by others. It is therefore a concept lawfully held in high regard, making the practice of it of paramount importance.²⁰

Best Interests

When parents are required to take the place of decision makers for their children, the NMC Code (2015b: Part 1)²¹ makes it the responsibility of any professional on their register to ensure that when any decisions are made, the welfare of the child remains at their fore-front; requiring them to ensure parents have decision making capacity. This is also in accordance with the Children Act (1989).²⁵ Although no specific reference to the provision of life saving treatment in infants born on the verge of viability is given; Part 1, Section 2 of the Act (1989)²⁵ seeks to ensure that any decisions made have the child's best interests at their forefront. Defining best interests in such fragile lives with indefinite prospects of survival however, is difficult.^{3, 15} According to the Children Act (1989: Chapter 41, Part 1, Section 1),²⁵ consideration of a child's best interests involves taking into account their physical, emotional and educational needs, and promoting well-being in each of these areas. However, given the way in which the provision of life saving treatment to neonates can cause detrimental effects to their long term development, it is evident that interventions provided by the neonatal team could be interpreted as a failure to act in the child's best interests. For this reason, alongside Hallström and Elander,²⁴ the Nuffield Council on Bioethics³ promotes that where children lack ability to make decisions for themselves, parents are most likely to act in the best interests of the child. This is due to the inextricable link between the caring capabilities of parents and the long term welfare of the infant. Through this, it is highlighted that defining best interests is inherently a question of values; relying on parents as decision makers defining their own concepts of the term.³⁸ However, it raises a question over whether the provision of life saving treatment is in the promotion of the best interests of the infant or the parents.

Quality of Life

Another factor which also appears to be a dominant consideration when determining whether or not lifesaving treatment should be provided to extremely premature infants is quality of life. This is a phenomenon which is commonly considered in conjunction with the concept of best interests, and is pivotal to the decision making process for infants at the verge of viability. The definition of quality of life is one which has been built upon, and contributed to in parallel to the development and modernisation of the abilities of medical interventions. In 1997, the World Health Organisation (WHO) described it as a broad concept which is associated with an individual's comprehension of the values and culture which they live by; in relation to their aspirations. WHO further said it is directly influenced by the individual's physical, psychological and social well-being. It is measured through assessment of an individual's ability to achieve optimum physical, emotional and social function. Boss et al³⁹ stated that if it is to be safeguarded, professionals must pay attention to how proposed medical interventions may cause these to be affected. When applying this to premature infants; it becomes apparent that judging quality of life can be very difficult. Neonates not only have limited ability to express their feelings, meaning they are unable to apply their own perspectives; but they are also too immature to allow recognised measures to be used^{3, 39}. Due to the high chance of surviving premature babies being affected by long term disabilities,²⁶ it is also difficult to determine long term quality of life, as the extent of a child's disabilities may not become evident until months following discharge, when they may fail to meet their developmental milestones^{3, 26, 39}. With this in mind, when deciding whether to provide lifesaving treatment, Boss et al³⁹ advise that premature infants' quality of life should be measured in terms of their future family life. This should include information about parents' perceptions of how they plan to cope with a potentially severely disabled child holding significant value. If this is to be respected, it would seem apparent that the most appropriate people to decide whether or not lifesaving treatment should be provided to infants born on the verge of viability are the parents of the child. It is however, important for developments to be made to enable the definition and measurement of quality of life in premature infants, in order that care provided is in infants' best interests.³⁹

Ethical Issues

If parents are unable to inform the neonatal team of their wishes, or if they do not want to give consent, at the delivery of an infant at the verge of viability, medical staff are required to decide whether or not they should provide treatment.^{7, 20} Parental inabilities to make decisions can be caused by a lack of capacity, which may result from there being a lack of time for consultations to take place prior to the birth of the baby, as previously discussed. This may also be hindered if the baby is born outside of the clinical environment

or if the mother is of ill health herself and requires an emergency general anaesthetic to deliver the baby, for example. In such situations, the term deontology describes the way in which professionals are faced with huge moral dilemmas in which professional obligations, formed from legal dimensions and professional codes, are said to exist to assist establishing what is right and what is wrong.^{40, 20} This combined with personal morals, and a fear of litigation, can cause consequences to decisions made.^{9, 20}

One of the principles that guides professional decision making is beneficence, which describes the obligation to do good.³⁸ For health care professionals, it is enforced by the NMC Code (2015b);²¹ making it a moral and professional duty to ensure that decisions made, and interventions carried out are in the patient's best interests, in order to safeguard their well-being.^{9, 20} Defining beneficence in relation to specific interventions, however is difficult; especially in the context of the provision of life saving treatment at the birth of an infant on the verge of viability. This is because benefits are subjectively determined; meaning what is thought to be beneficial to one person, may not be for another.^{36, 20} In this situation, when all that may be known is the gestational age of the baby; professionals must weigh up the condition at birth with the infant's right to life and the 30 to 50% chance of survival with moderate to severe disability.⁷ With the fear of litigation being an increasingly significant factor to consider, it is demonstrated how beneficence places a great burden and responsibility on professionals, and raises concerns over whether lifesaving treatment is offered in the best interests of the baby or the family.

Non-maleficence is another ethical principle; often used in conjunction with beneficence,⁹ which the NMC Code (2015b, Part 3)²¹ obliges professionals to practice in accordance with. It is described by Beauchamp and Childress³⁸ as the professional duty to protect patients from harm. When taking into account the long term hospitalisation and care that the majority of surviving extremely premature infants are likely to require, it becomes evident that based on this, an obligation to practice non maleficently may make professionals more likely to withhold treatment. Although clinicians' extensive knowledge and previous experience may mean this is justified as the most ethically satisfying decision; it could be interpreted that this causes professionals to make a judgement on the child's long term quality of life. A notion which Boss et al³⁹ highlight is best judged by parents; thus causing concern about the appropriateness of sole professional decision making.

Justice is a third principle which shapes decision making, placing duty on health care professionals to treat seekers of medical attention with fairness and equality;^{9, 36, 3, 20} thus promoting consistent but individualised, and relative care. When neonatal teams are

required to decide whether to provide lifesaving treatment however, their ability to practice in a just way could be compromised as it may be perceived as unfair to commit a baby to the discomfort resuscitation can cause³ and the subsequent long term intervention that the baby is likely to require. From this point of view, when lifesaving treatment is provided, this may be interpreted as deviance from professional obligation; thus demonstrating how the decision making process may be influenced by the duty to conform to governing contracts. In addition to this, clinicians' legal obligation to protect the infant's right to life adds further burden and complexity to the decision making process, as this could be perceived to conflict the principle.

Offering a slightly different perspective; Mercurio,³² along with Seri and Evans² highlight how the notion of self-fulfilling prophecy can be created from neonatologists' previous experiences. It can make professionals more likely to provide treatment if they have witnessed the survival of an infant born on the verge of viability before; suggesting that this sets a level of achievement which may cause the condition at birth, and the likelihood of long term health implications to be overlooked. When taking this into consideration, along with the way in which professional obligation to ethical principles appear to influence the decision making of clinicians, and in some cases subsequently cause the best interests of the infant to be neglected, it becomes apparent that the nature of such commitments may mean that members of the neonatal team may not be the most appropriate people to decide whether infants should receive lifesaving treatment. It is reassuring therefore; that deduced from their studies, Seri and Evans² and later Arzuaga and Meadow,⁴¹ found that parental perspective holds significant value in the professional decision making process. In situations where parents are unable to decide, however, it has been shown that clinicians are placed in a difficult situation; and are left with no option but to make a decision based on what they think may be best for the family as a whole. This is often within a short space of time following assessment of the condition of the infant at birth.

Conclusion

It would appear, when taking into consideration the ethical and legal principles discussed above, that there is no simple answer to whether parents or members of the neonatal team should decide to proceed with, or withhold lifesaving treatment when an infant is born on the verge of viability. Given the extensive knowledge and experience of specialist professionals in this field, and the inextricable link between parental values and their capabilities to cope with the emotional and physical demands of a child who, if survives, may have vast and comprehensive care needs, it would seem most appropriate for this to be a joint decision between parents and the neonatal team. Further, it a decision that should be given

considerable rationalisation. It may also be advisable for parents to be educated in the eventuality of a premature delivery in the antenatal period so that a more efficient communication process could be enabled, and parents could be allowed the necessary time to consider what they may want to happen should they be placed in this position. This would also reduce the burden on professionals when parents are unable to make decisions at the birth of the baby, by reducing the likelihood of parents turning to litigation because professionals have not acted in a way they would have preferred.

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