

Parental involvement in decision-making in the neonatal intensive care unit: a review of the international evidence

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ABSTRACT

The aim of this review was to establish the current evidence base regarding parental involvement in decision-making in the NICU. The review question was set as 'What is known about the process of parental participation in clinical decision-making in the NICU?' The findings of this critical literature review illustrate the process of decision-making for parents in NICU. The available evidence base was minimal. The parental role in decision-making is variable with current literature suggesting that the informed parental role, allowing parents to make the ultimate decision, is increasingly desired. Despite this there is still a requirement for medical and shared decision-making for some families. Regardless of the role parents assume it is evident that there will always be an array of emotional complexities to follow. Most feelings and emotional responses reported by parents were negative. The literature suggests several reasons for these feelings. A lack of parental knowledge and experience in NICU leading to confusion as to whether the right decision has been made alongside parents having a heightened awareness of the potential for suffering and harm for their baby. There are the added pressures of time and the weight of responsibility. The burden appears to be unequally distributed between parents. Several studies illustrate the transfer of responsibility from the father to mothers.

Keywords: decision-making; intensive care; involvement; neonate; parent

INTRODUCTION

Usually, when parents realise that they are expecting a baby it is a time of great excitement and anticipation. This is not to say that parents do not worry throughout the pregnancy. A common worry during this time is whether there is something wrong medically or developmentally with the baby, although it has been found that this anxiety becomes less significant during the third trimester of pregnancy. However, it is only when an abnormality is discovered on an antenatal scan, when labour starts prematurely, or when a problem arises soon after birth that the true reality of an adverse event begins to be contemplated.

When a baby is admitted to a neonatal intensive care unit (NICU) parents are faced with many challenges. The environment is unfamiliar and frightening and their expectations of parenthood are challenged immediately. There are many decisions to be made while a baby is in the NICU. These incorporate aspects of care such as the provision of mothers' own or donor breast milk, administration of a blood transfusion, whether to enrol a baby into a clinical trial, prescription and administration of various medications, or withholding or withdrawing intensive care treatments.

During their baby's stay in NICU, the number and complexity of decisions faced by parents will vary between families. All parents are individuals, will have different needs, and will make decisions in different ways. A significant number of studies have explored the antenatal period when women are in pre-term labour at the limits of viability or when end of life decisions need to be made regarding an extremely sick baby in the NICU. Although these are complex, distressing ethical and practical decisions for parents to consider, healthcare providers need to be well-informed about how they can improve the quality and effectiveness of decision-making for all parents who have a baby in NICU, regardless of the complexities of the decision.

As the focus of patient participation in their own care across the world changes so does the scope of parental participation in NICU. This review was undertaken to explore the current evidence base surrounding aspects of parental involvement in NICU: the parental role in decision-making, parental responses to involvement in decision-making, the impact of professional's approaches and actions, and influences upon decision-making.

PARENTAL ROLES IN DECISION-MAKING

Four aspects of the parental role in decision-making were identified: medical decision-making, informed decision-making, shared decision-making, and decision-making without options or "no decision". The latter indicated that there was effectively no decision to be made and only a single course of action was possible.

Medical decision-making

A study across four NICUs in France identified a medical decision as a decision that is made solely by doctors without any direct involvement of the parents. It was found that medical decisions were associated largely with positive feelings from parents. Parents found relief in not having to make a decision, with some feeling that ultimately they had reached the same conclusion themselves in any case. The relief of not having to make a particularly difficult decision is understandable, but parents retain a level of responsibility for their baby. Whilst they may be reassured that doctors are making the right decision for their baby, parents need to be self-assured that it was the right decision for them as a family.

There are times when doctors appear to make recommendations to parents but instead are merely seeking acquiescence. Some parents may view this as representing shared decision-making, but the reality of the situation is that the doctor has made the decision and conveyed it to the parents who have accepted the decision. That still constitutes medical decision-making. Doctors, however, viewed this as parents making the decision.

Informed decision-making

The term informed parental decision-making was used in a French study to describe decisions that were made solely by parents after receiving a comprehensive explanation regarding their baby's medical situation. It is thought that informed decision-making can build trust, allowing a patient (or their surrogate decision-maker) to become a true partner in their own care.

This notion of partnership in decision-making is problematic since in these situations parents make the decision independently albeit after being provided with essential information by medical staff. The term 'partner' suggests the sharing of responsibility for the decision. The literature on informed decision-making often confuses informed decision-making with shared decision-making. Both provide parents with sufficient information to allow them to come to a decision about their baby's management. However, informed decision-making is focused on providing parents with this information and then allowing them to make an independent decision without undue influence from the medical and nursing team.

When parents experienced informed decision-making, most described the experience as 'complex', 'neither chosen nor rational' and 'solitary'. They reported feeling mixed emotions and not having the ability or the desire to make rational decisions. These terms are difficult to appreciate especially when describing a decision as not 'chosen'. There are contradictory opinions between what doctors want to do (make a decision and then gain parental acceptance) and how parents feel a decision should be made. One mother explained how a neonatologist had told her that no parent should make an end of life (EOL) decision, but it should never be done without their acceptance. The results suggest a distinct orientation away from informed parental decision-making into medical decision-making. Removing this element of choice from parents may lead to acceptance of a decision that they are not yet ready to make, adding further to an already complex and distressing situation.

Shared decision-making

Shared decision-making has been advocated as the most appropriate approach to decision-making for most parents. Despite this, most of the available evidence supports informed parental decision-making. Decisions in the NICU are often made in times of poor outlook or desperation. Then the parents may feel unable to express an opinion or to make treatment decisions, so working in partnership with healthcare professionals to reach an agreed decision might be less stressful and more effective in reaching a decision. Overall the shared decision-making approach was perceived most positively by parents, allowing them to express their feelings whilst sharing the responsibilities with an expert health professional. The medical professional remaining non-directional in the encounter is vital, offering an honest, clear explanation of the situation and risks before expressing a professional perspective on the available choices.

PARENTAL RESPONSES TO INVOLVEMENT IN DECISION-MAKING

Three parental responses to involvement in decision-making were identified in the literature: thoughts about the future, emotional response and feelings, and risk versus benefit.

Thoughts about the future

Five categories of decisions that could be made by parents were identified; all showing contemplation of the future: the ethical decision as the decision that was never a choice, the ethical decision as looking for a way out, the ethical decision as thinking and feeling oneself through the consequences, the ethical decision as indecision, and the ethical decision as something one falls into.

The decision that was never a choice

When parents are presented with treatment options there must be a potential benefit for each treatment, albeit sometimes only a small benefit, otherwise it would not be given as an option. Conversely, no treatment options may be given: only a suggestion to withdraw treatment. In these situations, it is suggested that no real choice exists for the parent except to continue and let their baby have a chance of life. Contemplation of negative future impacts such as their child having severe disability was shown but was not viewed as a reason for withdrawal of treatment.

The ethical decision as looking for a way out

This type of decision was explained as a decision that cannot be made immediately but requires an amount of information for parents to exclude uncertainty. In an ideal situation, all decisions would be made with the luxury of time and information. As with the previous category parents were shown to respond through contemplation of the future for their baby. One set of parents described how they needed to go away from NICU for a long walk and discuss the situation between themselves. They discussed the prospect of raising a child with a severe disability and how much they were prepared to live with. Ultimately, they made an intermediary decision to base their final decision on the result of a further investigation: *'What about if we ask for a head ultrasound to confirm that she does not have a brain bleed? 'Cause if she had had a brain bleed, we were not going to go on with it.'*

The ethical decision as thinking and feeling oneself through the consequences

Parents explored the outcomes for their baby contemplating what the future may be and, as in the second category, whether they would be able to cope with a disabled child. The contemplation of the future is not only the practicalities of caring for a disabled child but, for these parents, imagining their baby in their home.

The ethical decision as indecision

Parents who also had other children expressed an initial indecision. As well as contemplating the future for their baby, they also have the lives of the other children to consider. It is here that responsibility of a parent is explored. As well as responsibility for their baby there is also a responsibility for the lives of the other children.

The ethical decision as something one falls into

Moving on from considering the future, parents discuss their situation after making a decision and reliving it. One mother shares the impact it has had on her life. The decision itself has left the parent responding in a negative way. Feelings of distraction, exhaustion and deliberation are expressed. Although a parent may 'fall into' a decision through lack of time, there is the possibility of, amidst information processing and parental contemplation of the future, a sudden arrival at a decision can be achieved unexpectedly. Attention was drawn to the falsity of the idea that decision-making is a rational, emotional and deliberative process based on the baby's best interests when, in reality, it seems to be more abstruse and problematic.

Emotional response and feelings

Several studies identified parents' feelings of ambivalence towards their baby whilst in NICU. Parents are entitled to feel joy after the birth of their baby regardless of the situation, but, understandably, there will be many other feelings and emotions impeding the ability to make sense of the situation.

Most parents described having to make a rushed decision which led to irrationality. It was not only a lack of time that contributed to an irrational choice but also the lack of adequate and understandable information. Some parents described difficulty in making sense of the information provided therefore leading to an inability to reflect rationally. The parent's emotional state during the time of information provision can impair understanding. Parents may be overwhelmed (and in some accounts crying uncontrollably) so that information that is provided cannot be retained. In the early stages of admission, the parental concept of reality is impaired, causing a lack of understanding as to what is happening in NICU. It may not be that parents are incapable of making the right decision for their baby but rather that they have specific needs that require identification before their decision-making processes can be facilitated.

Feelings of guilt have been expressed by mothers when involved in a shared decision-making process. Health professionals have the opportunity to share the burden of parental decision-making and thereby to protect parents from unnecessary self-doubt and guilt. The same study identified that over half of the parents who were interviewed had experienced feelings of guilt after their baby's death, with the majority of these having made an informed parental decision. Nonetheless, guilt feelings were largely felt regardless of the type of decision made. Even years after their baby's death, some parents were still trying to rationalize the actions that had been taken, re-creating reasons as to why that particular decision was the best course of action. These thoughts may be related in part to an individual parent's moral stance such as doing what they felt was best for everyone involved or simply following their conscience regardless of how the situation was managed. This phenomenon cannot be generalized to all parents who have made a decision resulting in their baby's death and may not necessarily occur in parents who have a strong belief that it was, for instance, 'God's will'.

Other than feeling guilt for the death of their baby, parents also expressed feelings of guilt for the absence of a meaningful relationship with their baby during their short life, their inability to help and protect the baby, or their lack of presence at the time of the baby's death. It is apparent that regardless of the decision made, many parents feel an element of guilt when reviewing both the chosen decision and the alternative option. Guilt is a commonly experienced emotion regardless of the decision made. It is suggested that a parent may feel guilt towards a decision made but also for not making an alternative decision. Grief was ultimately associated with end of life (EOL) decisions and did not appear as a factor in studies discussing other types of decisions. Regardless, grief is not only associated with death, and parents may experience grief simply by having a baby in NICU, grieving for the 'normal' birth and baby that they never had. Alleviation of some of this guilt may be achieved through encouragement of bonding through skin-to-skin contact and involvement in the baby's day-to-day care.

Agreement of parents and doctors over a particular decision provided feelings of comfort and security for parents. Although parents are responsible adults capable of making many decisions

in life, the evidence suggests that they gain comfort in the doctor's approval of their decisions in NICU. Clearly this is a positive response. However, there will be scenarios when parents and doctors cannot come to an agreement. The baby's best interests need to remain paramount whilst supporting parents through the decision-making process. Risk versus benefit: although some studies have discussed parental contemplation of the future, they have not explored explicitly how parents weigh up the risks and benefits for their baby when making a decision. The parental response both emotionally and purposefully is complex. The literature identified that as well as having emotional responses that are out of parental control they also experience a psychological response that allows contemplation of the impact of their decision. A lack of time in combination with this uncontrollable emotional response appears to cloud the sense of understanding, though there is a suggestion that this could be a transient state, and clarity may overcome this with time. Unfortunately, in some situations time is not a factor that can be exploited. Overall, the emotional responses of parents appear to be mostly negative.

THE IMPACT OF PROFESSIONAL APPROACHES AND ACTIONS

Increased knowledge and experience of parental experiences of decision-making does not lead to generalization, only acknowledgement of the complexities faced by parents and how each may deal with situations in different ways. Professionals need to develop the ability to meet the information needs of parents whilst recognizing when parents show a lack of engagement with important decisions and reconsidering the professional approach.

Keep it simple and be consistent

Notably, parents expressed a desire for an expert and completely honest explanation rather than a detailed account. It seems that the depth of information is not what parents seek to aid their decision but a factual and easy to understand explanation which provides clarity. The importance of the use of simple language and minimal terminology was stressed in several studies, together with translation and repetition if necessary.

Parents found consistency of information to be reassuring. A lack of consistent information may provide parents with an impression that either the doctors cannot come to an agreement between themselves about the right course of action or that they do not have the required knowledge to guide that decision-making process. This in turn can lead to confusion and loss of trust.

Parents gave clear indications of how their experience could be improved. They discussed the need for a trusting relationship between parents and professionals, characterized by kind, non-judgmental approaches to their participation. Healthcare professionals should at the very least deliver this element of care consistently to all patients and their families. Parents wish to be able to express emotions that are difficult to deal with, to be spoken to with respectful language such as always calling the baby by their name, and to be offered a frank, clear explanation of the situation. Consistency between professionals was also found to be reassuring. It is clear that parents were not being unreasonable in their demands for how they should be treated during such an exceptionally difficult time. They did not demand any input that should be beyond the capacity of any trained healthcare professional.

EXTERNAL INFLUENCES ON DECISION-MAKING

Mothers may shoulder more of the burden

Parents' beliefs as to what they ought to do for their child will have a significant influence on how they make a decision, and families in NICU will have different structures and dynamics. Although the concept of best interests of the baby should be at the forefront of such decisions, extended complexities such as parental coping ability and the effects on other children and family members have been explored. These are influences over which professionals have little, if any, control.

Some fathers felt that mothers should have more influence over the decision-making process than fathers especially over the care of the baby as this would affect mothers more. It was also found that the final decision was usually made by the mother. This was not always beneficial, often leaving the mother feeling upset and worrying whether she had made the right decision, negating the benefit of shared decision-making with doctors. This could be construed as fathers offloading

some of the responsibility onto the mother while she may be appreciative of his opinion and support during this time.

Several studies identified parental perception of their baby's suffering as a significant influence on their decision-making. Parents that were considering enrolling their babies into research studies also discussed the concept of harm. If they perceived their baby to be well and progressing they were more likely to enrol them into a study. Some trials were perceived to hold more risk than others. For example, parents perceived a blood transfusion study to involve more risk than a ventilation study. This was attributed to parental knowledge. It was found that the more knowledge (or even pre-conceived ideas) that were held by parents, the more risk they saw in the decision. Despite this, they were enabled to appreciate benefits, too, allowing them to make a more informed decision. An increased perception of risk would not be a justifiable reason to withhold information from parents.

The literature identifies that parents are influenced by each other, by doctors and extended family members. It also suggests that the weight of their parental responsibilities and the perception of suffering and harm are also significant influences upon their decision-making abilities. It is questionable why fathers might feel that mothers should take ultimate responsibility for making the decision. It might be that their level of involvement is inadequate, leaving them to feel they are neither entitled nor equipped to play a more active role in the decision. The inclusion of fathers is as important as that of mothers. This may be more challenging due to fathers' extra responsibilities while the mother remains in hospital such as running the house, caring for other children, bringing provisions to the hospital and going back to work. However, this emphasizes the need for active efforts on the part of health professionals to communicate with both parents. This can be compounded further for unmarried parents who have not yet registered the birth, leaving the father without any legal parental responsibility.

CONCLUSION

The findings of this review illustrate the process of decision-making for parents in NICU. The available evidence base was minimal. The parental role in decision-making is variable with current literature suggesting that the informed parental role, allowing parents to make the ultimate decision, is increasingly desired. Despite this there is still a requirement for medical and shared decision-making for some families. Regardless of the role that parents assume, it is evident that there will always be an array of emotional complexities to consider.

The majority of feelings and emotional responses experienced by parents were negative. The literature suggests several reasons for these feelings. Lack of parental knowledge and experience in NICU can lead to confusion as to whether the right decision has been made, alongside parents having a heightened awareness of the potential for suffering and harm for their baby. The added pressure of time and the weight of responsibility, particularly for the mother, with several studies illustrating the transfer of responsibility from the father, was an unexpected factor.

The experience level of doctors clearly had an influence on their response to and management of decision-making situations, with increasing experience encouraging greater influence by parents. Experience can come only with time, however some doctors spoke of lack of formal communication training or exposure to decision-making situations. Those doctors who had experienced this exposure felt unsupported and lacked feedback on their practice, leading to misinterpretation of parental responses. This in turn has led to inadequate identification of parental needs and impairment of the development of a trusting relationship.

The latest evidence suggests that parents still seek an element of care which is not currently being provided. This is a worldwide problem due to the limited availability of data on parental experience of participation in decision-making in the NICU. It is essential to discover what parents across the world desire and what they experience currently in order to improve practice. This can be done only through increased research with parents of babies in the NICU, assessing their desires and experiences of participation and how this can be amended in practice in order to improve their experience. It is clear that there is a significant need for further research to be undertaken in order

to establish how doctors and nurses in NICU can facilitate parental participation in making clinical decisions. Once there is a clear evidence base for this topic, changes can be made in practice to improve long-term outcomes for the families.

FURTHER READING

Albersheim SG, Lavoie PM, Keidar YDI. Do neonatologists limit parental decision-making authority? A Canadian perspective. *Early Hum Dev* 2010; 86: 801e5.

Bailey SM, Hendricks-Munoz KD, Mally P. Parental influence on clinical management during neonatal intensive care: a survey of US neonatologists. *J Matern Fetal Neonatal Med* 2013; 26: 1239e44.

Boss RD, Hutton N, Donohue PK, Arnold RM(. Neonatologist training to guide family decision making for critically ill infants. *Arch Paediatr Adolesc Med* 2009; 163: 783e8.

Caeymaex L, Jousseleme C, Vasilescu C, et al. Perceived role in end-of-life decision-making in the NICU affects long-term parental grief response. *Arch Dis Childhood Fetal Neonatal Edition* 2013; 10: 1e7.

Caeymaex L, Speranza M, Vasilescu C, et al. Living with a crucial decision: a qualitative study of parental narratives three years after the loss of their newborn in NICU. *PloS One* 2011; 6: 1e7.

Dowling D, Shapiro J, Burant CJ, Elfettah A. Factors influencing feeding decisions of black and white mothers of preterm infants. *J Obstet Gynecol Neonatal Nurs* 2009; 38: 300e9.

Einarsdottir J. Emotional experts. *Med Anthropol Q* 2009; 23: 34e50.

Fairhurst N. A qualitative study examining parental experiences and aspirations regarding participation in decision-making in two neonatal intensive care units (online). Available at: <http://usir.salford.ac.uk/id/eprint/48554/>.

Hoehn KS, Wernovsky G, Rychik J, et al. What factors are important to parents making decision about neonatal research? *Arch Dis Child Fetal Neonatal Ed* 2005; 90: F267e9.

Howell E, Graham C. Parents' experiences of neonatal care [online]. 2011. Available at: <http://www.pickereurope.org/wp-content/uploads/2014/10/Parents-experiences-of-neonatal-care....pdf>.

Jollye S. An exploratory study to determine how parents decide whether to enrol their infants into neonatal clinical trials. *J Neonatal Nurs* 2009; 15: 18e24.

Kavanaugh K, Moro T, Savage T, Reyes M, Wydra M. Supporting parents' decision making surrounding the anticipated birth of extremely premature infant. *J Perinatal Neonatal Nurs* 2009; 23:159e70.

Provoost V, Cools F, Deconinck P, et al. Consultation of parents in actual end-of-life decision-making in neonates and infants. *Eur J Paediatrics* 2006; 165: 859e66.

Van Manen MA. On ethical (in) decisions experienced by parents of infants in neonatal intensive care. *Qual Health Res* 2014; 24ss:279e87.