

Attitudes and perspectives of healthcare professionals on resuscitation decisions for infants born at the threshold of survival: a rapid review and reflection

C4ME SUPPLEMENT

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Background

Resuscitation of infants born 22-25-weeks gestational age is one of the major ethical dilemmas in neonatal medicine. (1) Survival rates of these infants have improved in recent decades. (2) However, long-term neurodevelopmental outcomes have not seen the same improvement. Children surviving extreme prematurity remain at a high risk of a wide range of disabilities. (3) Increased survival may come at the cost of long-term disability.

Ambiguity regarding resuscitation decisions is particularly high in the "grey zone" between 22- and 25-weeks gestational age. Neonatal health-care professionals (HCPs) are required to make complex decisions between resuscitation and end-of-life care. (4) Little is known about how these decisions are made. Personal opinions, attitudes and the philosophy of HCPs impact heavily on practice and therefore it is vital to understand what factors influence the resuscitation decisions made by doctors, nurses and midwives. (4, 5) Various studies have explored this but there has been little effort to provide a comprehensive overview of the area. The aim of this study was to provide a review of the attitudes of doctors, nurses and midwives surrounding decisions to resuscitate infants born at the threshold of survival.

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Methods

The literature was comprehensively searched using MEDLINE, PsycINFO, Scopus and CINAHL. Three categories of key words were identified: types of HCPs, resuscitation, and gestational age.

Titles and abstracts of papers were screened using pre-defined eligibility criteria. Full texts of selected studies were then screened. Published studies were included if they measured the attitudes of doctors, nurses or midwives pertaining to the decision to resuscitate infants born between 22- and 25-weeks gestational age. Quantitative studies were excluded if they had fewer than 100 respondents or a response rate of less than 60%. Non-English language papers were excluded.

Data were extracted using a standardised piloted form. Due to the heterogeneity of included studies, a narrative synthesis was conducted. To identify key factors influencing resuscitation decision-making, results and discussion sections were analysed for patterns and trends to give a textual summary of the recurring themes.

Quality of cross-sectional studies was assessed using the STROBE checklist. (6) Qualitative studies were assessed using the CASP qualitative checklist. (7)

Results

607 papers were identified, of which 21 papers were eligible.

The main factors identified as influencing decisions were parental wishes, infant outcomes, infant condition, and guidelines and legislation (Figure 1).

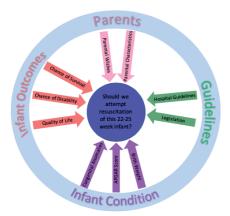


Figure 1: Model of Factors Influencing Resuscitation Decisions

Parental wishes were highly influential. Many studies reported that HCPs would consider parental preferences with regards to resuscitation. However, a few studies reported that parental wishes were not considered during decision–making.

The perceived outcomes of infants – including survival and long-term disability – were considered important when making resuscitation decisions. HCPs were less likely to resuscitate an infant they considered to have a low chance of survival or a high chance of disability.

HCPs were found to underestimate survival rates and overestimate rates of long-term disability. More accurate estimates were associated with a greater willingness to resuscitate.

Lack of guidelines and legislation arose as a key issue leading to uncertainty and inconsistent thresholds for resuscitation between respondents.

Quality of Included Studies

The main quality problems were a lack of thorough descriptions of outcomes and variables, and poor controlling of confounding and bias.

Discussion

This rapid review identified factors influencing resuscitation decisions at the limits of survival. It is significant that a minority of studies reported little consideration of parental wishes. The principle of shared decision–making (SDM) with parents is grounded in the ethical value of acting in the patient's best interests. (8) Barring some exceptions, the complete non–involvement of parents disregards the patient's autonomy.

SDM is a well-known tool in adult medicine but it has additional barriers to implementation in neonatology. (8) More work is needed to identify the specific barriers and facilitators to the implementation of SDM in neonatology.

Many studies found that HCPs poorly estimated outcomes. HCPs may make highly important decisions on the basis of incorrect outcome estimates. Obsolete outcome data and poor accessibility and dissemination of data may explain these misconceptions. (9) More work is needed on how to regularly disseminate up-to-date outcome data directly to clinicians.

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Finally, the review highlighted the paucity in formal guidelines. Lack of guidelines leads to inconsistencies in practice and lack of consensus among HCPs. (10) The sheer amount of literature on this subject must be streamlined into concise and evidence-based recommendations for clinicians, by the relevant official bodies.

Lessons Learnt

This project was conducted with the Welsh Government, where my supervisors work. As this was my first project, in hindsight, my expectations of research were very different to the realities. Initially, I struggled to envisage my project. As my supervisor often said, conducting any research can sometimes feel like "wading through treacle" — particularly at the beginning, when the structure is vague, undefined and a little intimidating. Over time, however, I developed my project through reading and discussions with my supervisors, and soon I had a plan. The treacle was feeling much smoother.

However, we later realized that, logistically, I was unable to access the required database and the project needed to be overhauled. This felt frustrating as I had worked hard to develop it. The treacle felt thicker than ever.

Although this was a setback, looking back, the original project was overambitious. The new plan – a review – was more feasible and useful to the field. Also, while at the time, I felt my work had been futile, the reading I had done and notes I had made were still relevant. This particular experience, and the project generally, developed my ability to deal with setbacks – which are common within research. For future projects, I plan to be more prepared and adaptable to changes. Not only is problem-solving useful in research, but it is, of course, highly applicable to clinical practice.

Being involved with "real-life" research and work in government has given me unique firsthand experience and undoubtedly provided me with a skillset that I would otherwise be without – and can now continue to develop. I also have a wider understanding of the ripple effect of research – not just clinically but also on wider policy.

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