

Deciding for imperilled newborns: medical authority or parental autonomy?

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Abstract

The ethical issues around decision making on behalf of infants have been illuminated by two empirical research studies carried out in Scotland. In-depth interviews with 176 medical and nursing staff and with 108 parents of babies for whom there was discussion of treatment withholding/withdrawal, generated a wealth of data on both the decision making process and the management of cases. Both staff and parents believe that parents should be involved in treatment limitation decisions on behalf of their babies. However, whilst many doctors and nurses consider the ultimate responsibility too great for families to carry, the majority of parents wish to be the final arbiters. We offer explanations for the differences in perception found in the two groups. The results of these empirical studies provide both aids to ethical reflection and guidance for clinicians dealing with these vulnerable families. They demonstrate the value of empirical data in the philosophical debate.

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Introduction

The withholding and withdrawing of intensive invasive treatment is now an accepted part of neonatal practice.^{1,2} In referring to *invasive* procedures we exclude intensive compassionate and nursing care: this should never be withheld and a series of court cases has underlined the importance of this distinction.³

An extensive literature exists on treatment limitation, much of which has been reviewed elsewhere.^{4–7} It is, however, “hard to imagine a topic about which so much has been written, yet so little is actually known”.⁸ Much of what is known derives from surveys of professionals’ attitudes and opinions, reports from individual neonatal nurseries or senior doctors, accounts from families of their personal experiences, and publicised legal cases. The recent production of two official medical publications setting out guidelines on the subject^{1,2} demonstrates that the topic is of on-going concern to clinicians. These sources all provide a certain kind of information or opinion but must be interpreted with caution.

In areas of ethical sensitivity, both empirical and philosophical research is needed to inform the debate.^{8–11} When it comes to withdrawal of treatment

from neonates, volumes have been written on the philosophical components, but as yet there is little sound empirical work to illuminate the reality of decision making. Empirical research has the capacity to identify and describe important ethical issues, to see how they are resolved in real life, and to assess the consequences of current management.¹⁰ Such research must, however, be rigorous, and meet essential criteria if it is to add to understanding: it must address the real moral issues, conceptualise those issues appropriately, arrive at justifiable conclusions, and address all the significant components of the issue.^{10,11} There is currently a paucity of work which meets these standards.

As part of an effort to rectify this, the question of who does in fact make decisions on behalf of newborns, and where responsibilities lie, has been the focus of a programme of research within the Institute of Medical Ethics for the past seven years. Numerous publications advocate involving parents in decision making, but what happens in practice? Are parents really sharing decision making or are neonatologists practising a form of benevolent paternalism?⁵ Do parents experience the guilt which staff believe they will?^{4,5} Though purporting to be attending to the best interests of the family, are doctors actually reducing the power of the parents by “protecting” them from taking responsibility? By manipulating the situation in this way are they ensuring that what they think to be right for the child is what happens?

Elsewhere detailed accounts of the design, methods, quantified results and in-depth analysis have been presented.^{4,7} The authors are very conscious of the huge literature in this area, the many arguments and counterarguments, and the potential to expand on so many points. However, this paper focuses on a) the reality of decision making and b) the importance of empirical research in areas of ethical sensitivity. We limit our attention here to the points which contribute to our principal arguments and refer the interested reader to our more detailed reviews of the literature and expansion of these issues.^{4,7}

The research

Two projects were carried out sequentially. Ethical approval was obtained for the research which involved parents.

SETTING AND SAMPLE

The first stage of the inquiry was an investigation into the thinking and practices of 176 doctors and nurses working in six large neonatal intensive care units (NICUs) throughout Scotland. At their own request all consultants were given the opportunity to participate. The remaining 155 respondents were selected by the researcher to ensure a representative sample of all grades of doctors and nurses. All the in-depth, face-to-face interviews were conducted by the first author (HMCH), and were audiotaped. Semi-structured schedules were used to guide thinking and topics under investigation focused on the law, policies and practices, factors influencing decision making, conflicts and tensions, and the involvement of parents.

The second stage of the inquiry investigated the perceptions of 108 parents of 62 babies for whom there was discussion about withholding invasive treatment. Three regional NICUs formed the study units. All parents who met the eligibility criteria over a period of two calendar years were invited to participate. The infants all had a medical prognosis of either early death or impairment severe enough seriously to limit potential quality of life, and included the three main categories of imperilled infants: premature delivery, congenital anomalies and perinatal asphyxia. All of them died. Two taped, in-depth semi-structured interviews were conducted by the same interviewer (HMCH) with the parents at three (59 families) and 13 months (50 families) after the death. Interviews (usually in their own homes) covered the parents' whole experience from conception to the present time and included their subjective assessment of their personal involvement and management at each stage, as well as their opinions relating to decision making and withholding of treatment.

ANALYSIS

Data were entered onto a computer under pre-determined variable names, with scope for unlimited values to accommodate the full range of qualitative responses. The software package SPSS was used for analysis. A randomly selected 10% (staff) and 12% (parents) of the taped interviews were checked by a practising paediatrician and a further 10% by a clerical assistant (staff) or a student in medical ethics (parents). These checks revealed a high level of accuracy of coding and demonstrated that three different people heard and understood what the respondents said in the same way.

The findings were discussed with members of an Institute of Medical Ethics (IME) working party, to examine the contribution of empirical data to the philosophical debate. This present paper has arisen largely out of these discussions. For the purposes of brevity the empirical research will be referred to as the IME studies.

What is the nature of the decision making process?

In essence there are two distinct phases to the decision to stop invasive intensive treatment. The first

relates to the actual determination: whether or not to treat. Facts form the foundation of any good moral decision. What do we know? What could we know? The implications of these facts must then be ascertained and considered, and a moral judgment made. A minority of consultants act alone but most discuss the options with colleagues and attempt to establish a consensus, which may be absolute or a majority view. This consensus is then taken to the parents. It may or may not include a recommendation from the medical team. The extent of involvement of parents in the actual decision varies but, if they are to take any responsibility for the choices, it is at this point that their opinions are sought. The timing of their involvement will vary with the changing fortunes of the baby, the urgency of the need to decide, the consultant's perceptions and preferences, and the family's tolerances and resources. Once that decision is made, the second phase involves guiding parents through the withdrawal and dying process.

Two other functions accompany this process. One is that of facilitating a healthy grieving process for the parents, with minimal regrets. The other is to preserve the integrity of the medical team, enabling them to continue to function effectively.

Who does decide?

Whilst doctors usually seek the opinions of colleagues or specialists, and parents occasionally discuss the issues with family, friends or ministers of religion, the IME research has shown that the actual decision is made by the medical team with or without the parents. Just who shoulders the ultimate responsibility was a question we set out to investigate. We found that staff in NICUs think it would be too weighty a burden for parents to bear alone: only 3% of doctors and 6% of nurses thought parents should take the ultimate decision. The majority think that parents should be involved, however, with 58% of doctors and 73% of nurses advocating a joint approach to the actual decision making.

When we asked the parents who they felt had in fact decided in their case, we found that 56% perceived the ultimate decision to have been theirs. This 56% was made up of 42% who believed they alone had accepted this responsibility, and 14% who said it had been their joint decision with the doctors. However, it should be noted that all those who felt they had themselves decided had relied on the doctors for information, most had been given advice, and some a recommendation. A further 7% of those who did not take the decision themselves, subsequently wished they had done so.

It has been said that the decision to withdraw treatment would constitute too great a burden for parents,^{4,5} so we pursued this idea with respondents. Though the parents recognised the magnitude of the decision, the majority nevertheless saw it as part of parental responsibility. Of those 56% (60 parents) who believed they did themselves decide, only one father said it had been too burdensome

and even he thought it was theoretically right that parents should accept this responsibility.

Events during the critical hours and days around decision making gather a momentum of their own and it seemed possible that parents might later experience regret when they had more time to reflect on what had happened. As many as 83% of the 59 families subsequently thought the right person had decided. By thirteen months later, 98% of the 50 families felt the decision itself had been right. Lingering doubts on both counts related to the lack of concrete evidence of a poor prognosis and the distressing nature of the dying process.

We have then, two key results which form the empirical basis for our ethical discussion: the majority of doctors and nurses believe the ultimate decision should not rest with the parents because it is too weighty a responsibility for them to bear; but the majority of parents believe they *should* accept this responsibility. Furthermore 56% of our respondents felt they *did* and that they were capable of doing so without adverse consequences. We look first at these two distinct groups of people involved in a crucial decision affecting the life of a patient who cannot speak for him or her self. What do they each bring to this task?

What experience and authority do doctors bring to decision making?

The experience and authority of the medical team is a vital factor in the process. Experience generates personal confidence in one's own judgment and prognosis, and over time consultants become authorities on the subject. Not only will their experience with other similar cases influence their recommendations, but their skill as communicators and their ability to present a well reasoned case will directly influence the parents' perceptions of what is done. They are not only the purveyors of facts but also of arguments.

However, there are potential dangers here too. Experience may dull a clinician to the need constantly to reappraise what is being done. Recommendations may become self-fulfilling prophecies. Dr A may withdraw assisted ventilation from a succession of babies with severe intraventricular haemorrhages. They all die, and Dr A therefore recommends compassionate care for the next baby who presents in the same way. Dr B, however, may continue to treat these babies and have the occasional survivor.

Furthermore clinical authority is inevitably fallible. Many opinions are based on probabilities and there are few certainties. Experiences differ and lead to different conclusions and recommendations. These may not always be right for a given family. Sometimes predictions prove to be inaccurate. One family in our research recalled being told three times that when successive treatments were withdrawn their child would die. When these forecasts proved wrong the parents lost trust in medical expertise and as a result the child's eventual death took them by surprise.

What experience and authority do parents bring to decision making?

The experience and authority of parents is of a very different nature. Their experience is one of personally suffering during this process. Such suffering accords a certain form of authority, and the opinions of the parents in the IME study about the wisdom of treating imperilled infants must therefore carry special weight. They themselves drew attention to the very real difference between their own previous theoretical positions and the views they now held, to the wisdom that had come from experience, and the sadness which accompanied wisdom. A previously militant pro-life supporter now acknowledged areas of uncertainty. Young parents lamented their lost youth and innocence: they were now permanently separated from their peers, and could not regain their carefree approach to life. Older parents recognised that they could never again approach pregnancy or birth with unalloyed joy: they now knew indisputably that there were no guarantees of a happy outcome.

However, whilst most of these particular parents felt they had gained in maturity, experience does not necessarily result in increased understanding. Idiosyncratic circumstances may make it ungeneralisable to other situations or other people. Some parents may emerge with quite erroneous ideas. In order to make sense of their experience, one couple in the IME research, for example, concluded that doctors and social workers had colluded to kill their baby, perceiving them to be unfit parents. The fact that doctors had struggled for many hours to keep their extremely premature infant alive until the mother could be found, counted for little in their assessment of the facts since they had not witnessed this desperate activity.

An additional form of authority accrues simply from the position of being a parent to this child. Parents have a unique responsibility for their own children and throughout Europe they are held to be legally accountable for making decisions on their behalf.¹² Parents in the IME study intuitively considered that decisions about treatment limitation were part of this duty and right.

Contemplating tragic outcomes, watching a baby die, burying their own child; these are extraordinary experiences for young people to live through. The learning curve is steep. Clinicians report that in their experience parents demonstrate an impressive ability to understand the issues and weigh up the consequences for their own child. The parents' lack of subsequent guilt or doubt seems to underline their confidence and their capacity to bear this burden.

Why do perceptions differ?

It is apparent from both our research and clinical practice that in any given case the doctors and the parents may have differing perceptions of who actually made the decision regarding treatment withdrawal. Why is this?

First, interactions influence thinking and reactions. Each participant is likely to be influenced by

what they pick up from the other in this intense exchange of information. But at this time not only are emotions turbulent, but there has often been little chance to forge relationships or discover basic philosophies of life or expectations; for 63% of our respondent families discussion about withdrawing treatment took place within the first week of life, and for 22% it was within the first 24 hours after delivery. Some things must be taken on trust but there is considerable margin for misinterpretation.

Second, the parents may not be aware of the previous team discussions or decision making process. When they come to parents to discuss the options, consultants have usually already obtained a sense of the preference of the medical team. But if they are in truth consulting the parents, the decision is still an open one; the parents have an opportunity to take a different line. Some strong-minded parents do and a few persist in doing so. It seems perfectly reasonable that the parents do perceive themselves as having the deciding voice since action is not taken until they have declared their opinion. It could well be that in other cases where a decision is reached without any disagreement, those parents too perceive the decision to be open when it is discussed with them. Their vote seems to be the casting one to them, although the medical team may feel they had themselves already decided and the parents simply concurred with their choice.

Third, there is an imbalance of knowledge and experience. Our empirical data show that both medical staff and parents are very aware of this fact. Even in families where at least one partner is him or herself a health care professional, participants are conscious of this divide. Parents are therefore reliant upon medical information to form a considered opinion and the level of this awareness might colour their perception of just who ultimately took responsibility.

Fourth, it could well be that, in saying that they personally decided, parents were assuming medical involvement. To some extent people do make assumptions about the role of doctors. It is taken for granted that they diagnose disease, order treatments, assess benefits and burdens and likely outcomes, and determine management. Many parents indeed added riders that though they did take responsibility, they based their decision on the information and advice of the medical team.

Does this mean that parental autonomy is an illusion?

Our respondents have clearly shown that they wanted to be given the opportunity and means to take responsibility for treatment limitation decisions. The majority wished to make the final decision themselves. Given the imbalance of power, experience and authority, were they in reality deciding or is this an illusion created by the practices NICU teams have adopted? To what extent is trying to persuade, a form of respect for parental autonomy and to what extent is it an attempt, albeit benign, to *overcome* parental autonomy?

Parents have to rely on the medical staff for the facts. In providing a perspective for parents to facilitate *their* choices, doctors may exclude information which they believe to be irrelevant to the decision making process, but in so doing they may select information which strengthens the professional recommendation. In order to give parents the scope to make their own unaided decision it would be necessary that teams present all available information in an impartial way, not just the raw facts but the arguments to back up the case for and against each possible course of action. In the perception of both the medical team and the parents, these facts are commonly presented with guidance or a recommendation as to the preferred medical option. Is this a form of manipulation of parents? If it is, this is not necessarily a negative interpretation. Even though they may not have recognised these influences, the majority of the parents in our research were satisfied with both the decision and the process.

There are rare occasions where parents do not choose options which concur with medical recommendations. This tension may go in both directions, with parents wanting treatment either to be continued or to be withheld against advice. Many doctors take the view that where staff *or* parents wish intensive care to continue, the appropriate response is to carry on with the invasive therapy at least in the short term. We found no medical respondent who would agree to stop treatment simply on the request of a parent where continued treatment might be of benefit to the child. A number of consultants emphasised the fact that they would never mention possible withdrawal of treatment unless they were themselves convinced of its medical appropriateness in this case. There is then an inbuilt weighting towards the authority of the doctors rather than the autonomy of the parents.

For 68% of parents there was no warning of coming problems. They had simultaneously to get to grips with news of a tragic development and the possibility of impending death. To have to make considered assessments with critical consequences at such a time is an awesome task. In these sensitive and immediate situations, doctors are not looking for impulsive reactions or ill-considered beliefs. They want parents to go through a careful deliberation on the basis of accurate information, to understand the likely consequences, and to balance the burdens and benefits. By going to the parents with the full authority of a confident professional consensus, however, they may be unduly influencing the parents' decision.

Is empirical research of value in this sensitive area?

Our second focus in this paper relates to the importance of empirical research to philosophical debate and ethical understanding. We believe this programme of empirical research fulfils a number of functions with respect to this issue.

CHALLENGES AUTHORITY AND EXPERIENCE

It allows clinicians to see how practice varies, and to assess what they themselves do against various outcome measures. For example, it exposes differences in the extent of involvement of parents, in the administration of opiates, and in the timing of recalling families for bereavement visits.

ILLUMINATES UNDERSTANDING OF THE REALITY OF ETHICAL DECISION MAKING

Most clinicians have not themselves been through the experience of losing a neonate. In providing a distilled view from parents who have, these results provide a form of surrogate experience. The combined voice of so many families gives professionals an idea of how their service is perceived and received. For example, it reveals how doubts may arise if parents are given no concrete evidence of a poor prognosis, and how distressing they find it when they are given false reassurances or conflicting information, or when babies' deaths are protracted.

HIGHLIGHTS IMPORTANT PHILOSOPHICAL QUESTIONS

In detailing real-life experience, the research helps to raise awareness of the underlying important questions and the ethical implications of various practices. For example, it leads to reflection on important questions: who should take responsibility for the decision? What is the relationship between parents and professionals in making these decisions? Would it be right to make the decision professionally but to deceive the parents, however benignly, into thinking they had taken responsibility when in fact they had been manipulated into choosing a certain course of action?

EXPLORES THE LIMITS OF TOLERANCE AND ACCEPTANCE

The considered opinions and explanatory arguments of people who have experienced the reality, help to set the boundaries around accepted practice and define grey areas which need further discussion and clarification. For example, our inquiry raises questions of how much opiate it is legitimate to give and whether it is acceptable practice to withhold hydration and nutrition.

GIVES INSIGHTS INTO WHAT CONSTITUTES GOOD PROCESS

This research makes no effort to produce prescriptive guidelines but rather provides a forum within which clinicians can be helped to develop sensitive, individually tailored care. For example, it reveals the range of parental opinion when it comes to decisions about where they should be accommodated during the baby's life, who they find supportive, and whether they want to see the body again before the funeral.

PROVIDES A YARDSTICK FOR WHAT OTHER PARENTS THINK

It offers some guidance as to what other parents in similar circumstances felt was right in their case.

This may be set alongside other evidence such as legal determinations, professional guidelines, survey opinions, or anecdotal accounts. For example, it identifies those factors which helped parents in particular situations to reach a decision to stop treatment, and the reasons why they did or did not elect to have an autopsy performed.

OFFERS A COMPREHENSIVE PICTURE

In its comprehensive reporting, it provides an authoritative, unbiased account free of sensationalism from both sides of this experience.

Does our research illuminate what *ought* to be done?

Both in law and in ethics, parents do, in most cases, have the authority to decide about their children's welfare. It is evident from our findings that the majority of parents want to be included in decision making about treatment limitation, and they appear to have the capacity to take on the role of final arbiters without adverse sequelae. It can be concluded then that parents ought to be given the *opportunity* to take this responsibility even though a significant number of our respondents declined to do so, indicating that they should not be *obliged* to make the ultimate decision themselves.

Our findings provide a framework within which what ought to be available can be assessed. It is highly relevant to know that parents find a protracted death distressing, and that nurses are extremely distressed if feeding and hydration are withheld from infants. But by also identifying idiosyncratic preferences the research cautions against checklists and rigid guidelines. The couple who left before the baby died because in their culture blue ears signified the end of meaningful life remind us that death and involvement mean different things to different people. The fact that several parents felt they had had insufficient evidence of a poor prognosis should alert staff to the need to provide parents with convincing signs. The sum of these individual accounts therefore tells us that a flexible package of care tailored to specific need ought to be provided.

But at a more global moral level there is no simple answer to the fundamental issues relating to limitation of treatment: what ought we to do in these kind of situations? Within what moral framework ought we to be operating? The voice of experience, as expressed in our study, does take us part way in that it illuminates the issues. It tells us what those people with considered views and knowledge of the lived reality, who are representative of the populations to be found in our NICUs, think we ought to do. But a moral judgment is still required. There can be no one authoritative voice. How ought we to balance these voices and claims against others? The distress of parents, or of individual doctors and nurses, must be set against the possibility of saving the child's life. The concerns of those who must implement decisions have to be set against those who must bear the burden of the decision for the rest of their lives.

Although the majority opinion amongst parents is that invasive treatment should be withdrawn sooner than it currently is, they do not always understand the time it takes to be sure that further treatment would be futile.

Furthermore, the voice of experience has to be set into a wider context. What is relevant and appropriate today may not be in ten years time or even tomorrow. The social consequences of limiting treatment or of actively hastening deaths must be considered. Against the wish of a parent not to have a baby's life prolonged, must be set the consequences to a doctor of facilitating a dignified death, and the effect of specific practices in treatment limitation on the integrity of the team and the wider profession. Changes to the law inevitably have effects on other rights, duties and liberties.

Knowledge acquired from this research then brings us closer to what we ought to do because it sheds light on the important issues and aids ethical reflection, even if it cannot of itself provide a resolution of the issues. New facts are available. But knowing what ought to be done is always an ideal, and we can only approximate towards it. The voice of experience and of authority is one factor amongst many. It weighs more heavily now it has been heard, and it brings us closer to that ideal.

Conclusion

These decisions are amongst the most difficult of any which have to be made in NICUs. The IME studies provide rich insights into the reality of treatment withdrawal. The findings show that both staff and parents believe that parents should be involved in treatment limitation decisions on behalf of their babies. However, whilst many doctors and nurses consider the ultimate responsibility to be too great for families to carry, the majority of parents believe that they should accept that responsibility, and that they have the capacity to do so without adverse sequelae.

Whoever ultimately decides, judgments must be made. As Warnock has said: "Ethics is a complicated matter. It is partly a matter of general principles, or even rules ... but largely a matter of judgment and decision, of reasoning and sentiment, of having the right feeling at the right time, and every time is different".¹³ All those involved are fallible human beings whose beliefs, preconceived ideas and misperceptions may not be conducive to a good moral decision on behalf of a baby. We can learn from the experiences of others.

Concluding his discussion of the place of empirical research in medical ethics, Hope has observed that: "The results from empirical medical ethics may help to enrich the subject of philosophical medical ethics: parents can learn from their children".⁹ Our empirical data illuminate issues of autonomy and paternalism, of ethical reasoning and of responsibility. But philosophical understanding can also shed light on clinical practice and

assist medical teams in the provision of yet more sensitive care. Parents and children can learn each from the other, and indeed learn together.

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