

Foretelling futures: dilemmas in neonatal neurology

a social science research project 2002-2004

Recent medical, legal and policy developments and guidance increase demands on neonatal practitioners to provide highly scientific, cost-effective and also humane services. Practitioners are urged to provide full and frank information to parents. The 'foretelling futures' research project investigated in four neonatal intensive care units (NICU) the views and experiences of staff and parents about sharing information and the care of babies who have uncertain neuro-developmental futures. Observations and interviews with the parents of 80 babies and with 40 senior practitioners are reported in a series of papers. A few of the key findings are summarised here.

- Rising expectations that extremely premature and sick babies should survive unimpaired exert pressures on neonatal staff to provide highly scientific, cost-effective and also humane services. These aims partly conflict, and they pose dilemmas and hard choices for practitioners and parents, which are addressed in a variety of ways.
 - Practitioners are required to obtain consent before 'all touching' of the patient. Much neonatal care, however, does not fit the traditional individual doctor-patient models of consent. Parents are often consulted on matters when they believe there is no choice and not consulted on matters that they do want to influence.
 - There is growing interest in how babies' own responses inform effective care. From birth, babies are entitled to the rights in the 1989 UN Convention on the Rights of the Child (UNCRC), including the right to form and express views. The rights enshrine and endorse high standards for neonatal care. Babies show how human rights for people of all ages are embodied and expressed through personal interactions.
 - Fathers may feel as deeply as mothers do about their baby. The extra difficulties fathers often have can illuminate problems that many mothers also have.
 - Parents vary in how they feel their baby belongs to them or to the unit. Transfer between units and the days before discharge can increase their ambivalence. We review ways to promote baby-parent attachment and the sense of belonging.
 - Counted and costed clock time, which regulates efficient NICUs, can conflict with the natural timing of babies' cyclical body rhythms. Awareness of both forms of time can help to increase efficiency and effectiveness in neonatal care.
 - Unknown futures destabilise present understandings and relationships. Doctors' responsibilities include enabling parents to cope with uncertainty and to arrive at decisions through processes that help them to accept and live with the outcomes.
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Neonatal dilemmas

Rising expectations exert pressures on neonatal staff to provide highly scientific, cost-effective and also humane services. These aims partly conflict, when there is doubt whether it is in the child's best interests to survive, and when respectful compassionate care requires time that could be spent on other responsibilities. Through observations and interviews, this qualitative study investigated how four neonatal teams shared information from doctors, nurses and other practitioners, and from parent and babies. The teams varied in the credence they gave to knowledge from different sources. The research project papers (summarised below) review effective ways in which practitioners and parents shared discussions and responsibilities and resolved problems within tight time and resource limits.

Complications with consent

Practitioners are required to obtain consent before 'all touching of the patient'. However, neonatal care often begins during emergencies, the parents may be absent, procedures may be seen as essential, or agreed best practice, or integral to packages of interventions provided by large teams of staff. For these and other reasons, traditional models of consent often cannot apply. Parents tend to prefer to be asked for their consent only when this can be legally valid: when they are properly informed, have time to reflect and a real choice, and when their views are respected. Parents are often consulted when they believe these conditions do not apply, and they are often not consulted on matters that they would like to share in deciding, such as details about their babies' care. Current guidelines on consent might seem to provide clear steps for all staff to follow, but they pose puzzling contradictions between ideal and actual practice. Papers for journals about this project review the contradictions, parents' views about consent, and the nurses' roles in informed consent.

Babies' rights

From birth, babies are entitled to all the UNCRC rights. The Convention's respect for the worth and dignity of every member of the human family shows how babies can be treated as persons and rights holders. Children's and babies' internationally agreed rights enshrine and endorse high standards of neonatal care. The protection and provision rights cover babies' needs, welfare and best interests. The so-called participation rights are more controversial. Can babies form and express views? Programmes from Boston USA show how it is possible to 'read babies' language' and their quite clearly expressed preferences, and to plan more sensitive and effective care guided by these readings.

In consequence, in some units, lighting and noise levels were lower, and babies were clothed and covered and loosely swaddled. Rather than starting parents' first inductions into the NICU with details about the technical care and requests for consent, the staff would make time for the first meeting between the baby and parents. One mother, for example, described how when the nurse suggested that she talk to her baby born at 25 weeks gestation, the baby wriggled excitedly showing that she recognised and remembered her mother's voice from before birth. From the start, neonatal staff can emphasise the family's helpless dependence on the NICU technology, or else their unique human relationships.

Empirical research about babies' rights offers new insights into how human rights for people of all ages are expressed through personal interactions of respect and care, especially for the person's body, besides rights being political, economic and civil matters. The care relates to parents' as well as babies' welfare, such as in allowing parents access to the unit and comfortable amenities. Babies' rights are useful indicators of how each society respects its citizens. The costly high quality neonatal care expresses a high regard for babies, but some of the causes of premature and multiple births, that lead to the need to stay in the NICU, relate to serious social problems faced by many children today.

Families in the NICU

Fathers may feel as deeply as mothers do about their baby. The extra difficulties that fathers can have may illuminate problems that many mothers also have. Fathers are liable to feel uneasy about: expressing their feelings and asking for emotional support; having to spend much time away from the unit; believing that their absence may be interpreted as lack of concern for the baby; trying to fit into the 'women's world' of the nurseries; having to support

their partner by 'being strong'; and trying to counter unhelpful social expectations about masculinity and fatherhood. The paper reviews fathers' views about some of these difficulties and barriers and suggests ways towards overcoming them.

Parents vary in how soon they feel that their baby knows them, and belongs to them rather than to the staff. The four NICU have very high levels of medical expertise, but differ in how actively they promote parents' involvement in their babies' care, and in the trust between staff and parents, and the space provided for families. The transfer of babies between units is increasing. It can be hard for parents to adapt to routines in a second unit, and also to accept nurses' authority when the baby is nearly well enough to go home. The paper reviews parents' views, and ways to promote the practical and emotional experiences of belonging between parents and babies.

Time in the neonatal unit

Efficient NICUs rely on well-managed, counted and costed clock time. Clock time is connected with the *means* of neonatal work: the clinical assessments and treatments; the work of collecting and sharing information; making reviews, plans and decisions; managing the *tools* of technical, administrative, managerial, financial and domestic support. However, instead of serving the primary *aims* of the NICU, the means and tools can overtake and even paradoxically undermine these aims. The aims include reducing mortality and morbidity, and promoting babies' health and parents' care for their babies. The aims involve respecting the natural timing of babies' mindful bodies and cyclical rhythms, nurturing babies' ability to manage their own breathing, digestive and sleep-wake patterns, encouraging parents to relate to their baby in synchronised dyads that respond to the baby's changing state and needs. Clock time can conflict with the babies' natural timing and rhythms. The paper analyses parents' and practitioners' views about time and considers how awareness of different time-scapes can help them to resolve conflicts between time-scapes.

Knowledge and uncertainty

The present takes its meaning from and shapes the meaning of the past and future. Unknown futures destabilise present and past understandings and relationships. Parents and practitioners cannot understand what a scan of a baby's brain haemorrhage really means in isolation, it must be read as a longer-term complex consideration of possibilities for the child's future. Meanwhile many parents have to cope with painful ambiguity about who the baby is and might be, how to relate to the baby, and how long the relationship might last, from a few days to many years. Practitioners' responsibilities include enabling parents to cope with these uncertainties and to work through processes that help them to accept and live with the outcomes. If decisions have to be made when there is great uncertainty, the process of deciding with respect and care for the baby can be as important as the eventual conclusion and outcome, in helping to reconcile parents now to the future and also in later years retrospectively to these deliberations when they are memories.

Practitioners described when some things cannot be said, such as if there might be litigation, and when they have to be cautious in interpreting information, in warning about the future and about possible risks, and in trying to give consistent details to parents that accord with their colleagues' accounts. Working at the edges of what is technically and socially possible, in what they say and do, or do not say, neonatal staff help to shape broader social, political and ethical debates about the value of life and the human status of very premature babies.

Society delegates unpalatable decisions to doctors, which they have to manage, such as questions about which babies can have access to health and social care and life support, and the social acceptance of severely impaired children. The research reports review practitioners' and parents' views about how uncertainty is managed and the hardest decisions are made. Their discussions show that along with ever increasingly sophisticated technology, science and clinical skills, the traditional qualities of compassion, optimism, acceptance and forbearance are still vital aspects of neonatal care.

The 'Foretelling Futures' Project

The research project's questions

- * How do relatively new treatments, diagnostic techniques, neurological and neuro-behavioural knowledge, and ethical guidance complicate or illuminate long-standing neonatal dilemmas and prognostic methods?
- * How do clinicians select, evaluate and manage the many neurologically-related issues, when making diagnoses and prognoses, and discussing treatment plans with parents and NICU staff?
- * How do parents experience these discussions?
- * How do babies' neuro-behavioural responses inform NICU care?
- * How can multi disciplinary insights increase understanding of neuro-related NICU practices and prognoses?
- * What are the strengths and gaps in current neonatal knowledge and practice?

Aims

To discover more about fairly new cross-disciplinary developments and the views of neonatal staff and parents, in order to provide coherent research based information intended to help to raise standards of care and information-sharing in baby units everywhere.

Methods

Multi-disciplinary literature review; six multi-disciplinary advisory group meetings; ethnographic observations in four NICU; interviews with 40 senior neonatal staff and with the parents of 80 babies who had confirmed or potential neuro-developmental problems, in the NICU and, for some, later at home; detailed studies of babies' responses; qualitative data

analysis; writing of a series of research reports for journals and conferences.

Ethics

Four research ethics committees approved the project; posters and leaflets informed staff and parents about the project and about their rights; interviewees gave their consent; research transcripts, records and reports were anonymised and babies' names were changed.

Outcomes

Fourteen conference/seminar presentations/posters. Detailed end of project report. Eleven journal papers in press or in progress (by October 2004).

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To download the full report: <http://www.ioe.ac.uk/ssru/reports/foretellingfutures.pdf>