

**Foretelling futures:
dilemmas in neonatal neurology**
**a social science research project
2002-2004**



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Disclaimer

The research topic has especially sensitive and controversial aspects and, apart from the interviewees' views and the literature that we quote, the authors are responsible for any comments and conclusions in the project reports.

Abbreviations

EEG	Electro-encephalogram
MRI	Magnetic resonance imaging
NBAS	Neonatal Behavioural Assessment Scale (see section 1.C)
NIDCAP	Newborn Individualized Developmental Care and Assessment Programme (see section 1.C)
NICU	Neonatal intensive care units, our research was based in and mainly refers to these regional units for the most small and sick babies
SCBU	Special care baby units, mainly for the larger healthier babies where the care can be more informal and family centred.

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1. Introduction and background

'Foretelling futures: dilemmas in neonatal neurology' has been a social science research project conducted in four neonatal units from March 2002 to July 2004.

This end-of-project report has been written for the project funders, The Wellcome Trust, and for individuals who generously helped with the research. The report is also intended to be a background resource for readers who would like to know more details about the 'foretelling futures' research, the context, aims and methods, and the neonatal units and families involved in the project.

Most of the time on writing up the 'foretelling futures' research has been devoted to writing papers for academic and professional journals, for several reasons: to publicise the research to a wide readership; to try to do justice to the wealth of data that has been gathered; to use the critical peer review process to enable us to write to higher standards; through publication, to join in long-standing international neonatal discussions; to show how social science observations and analyses can be relevant to current controversies, policy and practice.

For these reasons, and perhaps unconventionally, the main part of this report, section 4, provides summaries of the journal papers that have been or are being written so far. The aim is to provide a guide to the range of findings that are emerging from the project, and to show how the papers relate together and fit into five themes: families in the NICU; babies' rights; sharing information, dilemmas and decisions; time; and knowledge. The brief summaries in this report are not given as alternatives to reading the papers, which explain issues in greater detail and with more examples that readers can interpret for themselves. Instead, the summaries are intended to encourage readers to refer to the journal articles.

Section 2 shows that the protocol raised seven exploratory research questions. We received numerous varying, complicated, and sometimes contradictory responses to these questions from the practitioners and parents and the related multidisciplinary literature, and no simple answers. The journal papers go some way towards answering some of the questions. We have much more material from the observations and interviews that could provide further answers, if we had more time for analysis and writing of papers. Because each paper separately and at some length explores answers to one or more of the research questions, we have not tried to summarise the answers into a concluding section. Instead, section 5 gives a four-page summary about the whole project and some key findings.

This report will be posted on the project webpage, which will also give details of the papers when they are published. The report begins by explaining some of the background to this multi-disciplinary project.

1.A. A social science and multi-disciplinary project about neonatal care

Neonatal care involves a wide range of disciplines: medicine and paediatrics including specialties in radiology and in babies' neuro-development, respiration, digestion, cardiology, hearing and vision; nursing; occupational, speech and physiotherapy; nutrition; pharmacology; management, administrative and technical support; social work; psychology and psychotherapy; religious support; interpreters; planners and architects. There are also the vital perspectives of the parents, besides growing interest in the babies' experiences and possible views. Research about neonatal care further involves the disciplines of anthropology, economics, ethics, genetics and a range of natural sciences, history, law, social medicine, social policy and sociology.

One aim of this project was to step back from a single-discipline perspective and to take a broader multi-disciplinary view. Research tends to reflect neonatal practice in concentrating on highly specialised perspectives. Our purpose was to see:

how the different kinds of knowledge and expertise work together to serve the babies' all-round needs;

how and why some kinds of knowledge are highly valued in the units, and other kinds are less valued;

the effects these differences can have on the babies, on the ethos of the units, and on neonatal planning and policy.

We also aimed to examine the units within their social and economic context, to see how current social trends can explain how and why neonatal care is provided in its present format, and to see what neonatal care reveals about babyhood in twenty-first century Britain.

We took four approaches to the multi-disciplinary work.

The research team involved people who have worked in psychology, sociology and ethics research, nursing, health visiting and teaching, and who have had experience of working or being a parent in neonatal units and related services.

From the first planning stages, the project has involved advisers from a range of relevant disciplines.

The multi-disciplinary advisory group discussed key issues in the research during six meetings.

We have drawn on multi-disciplinary literature resources.

Numerous research reports are published with recommendations on how to improve standards of neonatal care. And yet practitioners find it very hard to alter established practices. The response then tends to be: 'We need to do more research and larger trials before we can make any changes.' This study examines connections and disconnections between research analysis and policymaking, practical raising of standards, staff education and support. We look at underlying obstacles that prevent practitioners from providing the optimal care they aim to give. This study is therefore not statistical and does not assess outcomes. Instead, we observe, describe, analyse and explain processes.

1.B. Neonatal neuro-related development

'Neuro-related' refers here to a wide spectrum in neonatal neurology, including neurological development in the term and preterm infant, vulnerability to neuro-related problems, to physiological, behavioural, sensory, emotional or learning difficulties that may develop during childhood and may be linked to neonatal experiences. The range of disorders covers four groups.

- 1) The premature baby, from those at high risk who are born before 26 weeks gestation, to those born 32-35 weeks who are at increased risk of developing mild to moderate neuro-developmental problems (Huddy et al. 2001).
- 2) The premature baby with evidence of cerebral injury on cranial ultrasound scan, usually due to haemorrhage.
- 3) The baby born at term with severe cerebral injury, usually due to perinatal problems such as hypoxic ischaemic encephalopathy.
- 4) The baby with major congenital abnormalities.

Prognostic information relies on long-term outcome studies of premature babies. Group 3 involves studies of encephalopathic babies, using measures that include ultrasound, EEG and MRI. For group 4, there is often limited information, as there is a great range of congenital abnormalities. A very few babies are so adversely affected neurologically, that intensive life-support may be withdrawn. The more premature the baby, the greater the developmental vulnerability, especially the one per cent of very low birth weight babies born up to 12 weeks early. There is also growing concern about children born at 32-35 weeks, who may be medically healthy but at above average risk of developing mild or moderate neuro-related difficulties, including sensory, motor and speech and language problems. Brain scans show mild changes that may resolve with no effects, or else they may have mild effects that do not show until much later. Some brain scans are normal at birth, but problems arise later.

Neuro scanning and imaging and animal research have immensely increased the knowledge of fetal and infant brain development. In humans, within five months of conception, all the 80 billion neurons for the mature cerebral cortex have been formed. At peak growth times, 250,000 neurons are 'born' each minute. The cells grow, migrate (by about seven months gestation), mature, and are selectively ablated, as the infant brain develops into the fully integrated adult brain. Synapses, which communicate between neurons, develop during gestation and infancy through great 'overproduction' and, crucially, through 'pruning'. Adults may have 10^{14} cortical synapses, 40 per cent fewer than they had in infancy. Insufficient pruning is associated with learning difficulties (Fox et al. 1999; Fischer and Rose 1994; Purves 1994).

Relatively recent developments offer benefits, but can further complicate long-standing neonatal dilemmas. Modern treatments enable very small and/or sick babies to survive who, only a few years ago, could not have lived (Rennie and Bokhari 1999). When ultrasound brain scans and other diagnostic techniques provide new neonatal neurological data, the long-term effects may be unpredictable (Rennie 1997; Rushe et al. 2001). The profusion of data may complicate rather than clarify prognoses. Reports call for more long-term neonatal follow up studies, using more standardised methods (Strauss 2000; Colver and Jessen 2000). These studies tend to report deficits much more than positive aspects of the babies' later childhoods (for example, Hille et al. 2001).

Little is known about the predictions that parents might prefer to discuss, in the NICU and retrospectively.

Clinicians face hard dilemmas. It might sometimes seem kinder to protect bewildered and distressed parents from complex, alarming uncertainties. Yet recent Inquiries from Bristol (Kennedy 2001), Stoke, Liverpool and London, professional guidance (RCPCH 1997, 1997a 2000; BAPM 2000; BMA 2001 2001a; DH 2001a 2001b; GMC 1998; Kennedy 2001; Mason and Megone 2001; NSF 2004) and research evidence (McHaffie et al. 2001; Vermeulen 2004) increase ethical and medico-legal pressures on clinicians to inform parents in great detail. How can clinicians attend to parents' individual needs while also giving standard neuro-related information, partly for medico-legal reasons? Can they warn honestly about the future without implying or over-stating predictions of difficulties that may become self-fulfilling prophecies? How can they help parents to be realistic, without setting up negative tensions in the delicate new infant-parent relationships? While we were planning the project, a consultant expressed deep concern about research published in July 2001 (Huddy *et al.* 2001) that raised new doubts about neuro-development in up to one third of babies born at 32-35 weeks. He had been keen to reassure parents about these babies' futures, believing that optimism fostered positive family relationships and helped to counter the disruption which admission to NICU entailed. The EPICURE survey of babies born in 1995 has a new longitudinal report (currently in press) and was featured on a Panorama television programme (19.9.04). Forty per cent of the children born <27 weeks gestation were found to have moderate or severe difficulties by age 8 to 9 years – although 60 per cent did not.

In some cases, it is hard for practitioners to know when to respect parents' values that differ from their own. For example, parents may veto the recommended withdrawal of life support, because they believe God would not sanction it, or they feel too hopeful or sad or guilty or ashamed. This project has investigated the views of neonatal staff and parents about the questions and problems raised by neuro-related knowledge and dilemmas.

1.C The NBAS and NIDCAP programmes

A growing contribution to neonatal knowledge comes from neurobehavioural research and practice. All babies give cues about their feelings, seek for optimal conditions and try to avoid adverse ones (Als 1997 1999; Murray and Andrews 2000; Warren 2001). Their subtle behaviours may influence understanding about their best interests (Crook 1999; Goldson 1999; Kay 2000). The NBAS (Neonatal Behavioural Assessment Scale) systematically documents babies' responses to aversive and non-aversive stimuli at term, scores behaviours in six main areas, and notes the baby's strengths and the parents' comments and concerns (Brazelton 1961; Brazelton and Nugent 1995). Very preterm and ill babies can be observed systematically using NIDCAP (Newborn Individualized Developmental Care and Assessment Programme) a systematic approach to care planning based on naturalistic observations that follow the babies' progress during their early weeks (Als 1981, 1997, 1999). A recorded narrative of events shows the baby's strengths and sensitivities (not deficits) and identifies goals and recommendations for care. Both programmes have their own theoretical framework, structured format and reliability training. They aim to describe neuro-developmental behaviour and progress, and to promote mental health, through enhancing infant competence and positive parent-infant interactions, especially during the crucial first

three months. They assume that the brain is activity-dependent and that the way babies are handled, and their environment affect their early and later brain development.

'Environment' ranges from nutrition and oxygen levels, to the NICU setting, to babies' and parents' stress, and disruption to their incipient relationships. For example, babies who are extra sensitive to noise and light cannot sleep deeply, which adversely affects their energy, feeding, moods and self-soothing behaviours, and so may affect their weight and health. Light and noise levels may be far in excess of the recommended levels for adult staff in offices, and efforts to relieve these problems can lead to improvements in babies' well-being as many studies show (for example, Glass 1988, 1993; Gottfried 1985; Graven *et al.* 1992; White 1992; Lagercrantz 2003; Linn *et al.* 1985; Mann *et al.* 1986; Philbin 1999; Wolke 1989, 1995; Boxwell 2000; Symington and Pinelli 2000, 2004). Improvements are achieved both through individual 'baby-led' care programmes, and also through changes in the NICU environment, which is so unlike the filtered stimuli in utero. Research about NIDCAP and related developmental programmes, including 32 randomized controlled trials, demonstrates some benefits and 'no major harmful effects reported', with calls for larger trials (Symington and Pinelli 2000, 2004). Few neonatal staff are trained in NIDCAP or NBAS, and policies and decisions about optimal care in NICU are limited by the services and expertise available.

2. The research questions

- 1) How do contemporary neuro-related knowledge, practice and policies complicate or illuminate long-standing neonatal dilemmas?
- 2) How do clinicians identify criteria to select and manage the many related issues, when making neuro-related diagnoses, prognoses and treatment plans?
- 3) How do parents experience discussions with practitioners on these issues?
- 4) How can neuro-developmental assessments of babies support parents and inform decisions about their babies' best current and future interests, individually and at NICU policy level?
- 5) How can a multi-disciplinary advisory group led by an ethicist increase understanding of neuro-related NICU best practice?
- 6) How can all the relevant knowledge be connected into a coherent, practical framework?
- 7) What are the strengths and gaps in current knowledge and practice?

3. Methods

3.A Access to the hospitals and units

The neonatologists, nursing management, research & development, and local research ethics committee in each hospital approved the research and the researchers' access to the NICU. Two researchers were given honorary clinical contracts. There were delays, and access to one unit took a year to arrange.

3.B Informing staff and families, gaining consent, ethics

Information and consent We presented introductory sessions about the project and answered questions at NICU staff meetings. We put information leaflets (appendix 6C) and photographs of ourselves on notice boards, and gave out the leaflets to staff and parents, in order to inform as many people as possible. The two sociologists (PA, MK) wore badges labelled 'social researcher' and invited people to ask questions about the project. We tended to talk informally to parents and staff about the project in the rooms where we were observing, and we were alert to any cues that people might want us to leave the room or avoid talking to them, especially if they might be too preoccupied or perturbed to say so. Ethnographic research is very wide ranging; minor aspects of the NICUs might become highly significant. It was therefore hard to explain in advance precisely the research questions and areas of study, while asking people if they minded being observed. Formal consent/refusal can be given for specific interviews and observations, but it was harder to ensure that everyone in the Unit was aware of and agreed to ethnographic research. The researcher who was also a practitioner (JH) did the NBAS programme, as well as observations and interviews. In another unit, the practitioner (IW) did the NIDCAP sessions, one NBAS and four interviews.

We gave potential interviewees leaflets about the project and their rights (appendix 6C). The consent form included options for parent interviewees to consent or refuse to take part in a follow up interview at home, and also to allow researchers to see the baby's medical notes. A few parents and a practitioner did not want to be tape-recorded, and so written notes were made. Almost every parent whom we asked agreed to be interviewed, although we waited for weeks before asking some parents whose baby was having great difficulties, to avoid adding to their stress.

We offered to send parents and staff a copy of their transcript. The note with the transcript invited them to let us know of any sections which they do not wish to be repeated in discussions or reports, or which they wanted to alter or correct. All interviewees and others involved with the project were sent a short interim report in early 2004, and a short end-of-project report in the autumn 2004 with a reply slip to order a copy of the longer end-of-project report, and/or details about reports of the project when these were published. We are grateful that almost everyone concerned generously allowed us to observe them and willingly talked with us.

Confidentiality and respect This project is unusual in that, firstly, we interviewed parents while their baby was in the neonatal unit, not only later in retrospect. Secondly, we investigated parents' thinking, decisions and assessments, and not only their feelings and needs on which researchers tend to concentrate as, for example, the 250

references in McHaffie's retrospective work on parents' share in decisions about withdrawing neonatal treatment illustrate (McHaffie 2001). We were careful not to discuss interviews with other people in the units, or to refer to people in ways that might identify them. We also took care that the research would not inadvertently adversely affect relationships between NICU staff and families, or raise new doubts, fears or hopes in parents' minds. For these reasons, we did not ask to observe interviews between doctors and parents. Instead we relied on participants' views about what had been said. Reported views may differ from what is actually said. However, parents' beliefs and memories can so much influence their future life, and therefore are likely to influence the babies' futures, the main topic of our research. Also, practitioners' views on what they should say during interviews express dominant values, such as about optimal practices or acceptance of limitations, which have their own influences and validity even if daily practices differ from these views.

The transcripts were anonymised and numbered, and all names were changed before transcripts were stored on computer and printed out. Families' personal details were not kept on computers and all data were stored in lockable spaces in accordance with the 1998 Data Protection Act. At the monthly research team meetings, we avoided using interviewees' names. We also discussed any ethical problems that arose, such as examples of particular problems and incidents that we would not use in reports, in order to respect confidentiality. We aimed to avoid giving negative reports about personal incidents. If it was relevant to report problems or poor practice in order to make generalisable points, the emphasis was to be on understanding underlying pressures and difficulties and highlighting good practice. However, we also aimed to be clear about the very serious problems that some people experienced in the units.

3.C The samples, observations and interviews

Observations This study used ethnographic research methods, in the tradition of other studies of neonatal or adult intensive care (Guillemin and Holmstrom 1986; Frohock 1986; Alderson 1990; Zussman 1992; Chambliss 1996; Anspach 1996; Vermeulen 2004). This involved 18 months of generally observing daily routines in the units, the care of the babies, twice daily ward rounds, nurse hand-overs, some staff meetings, informal discussions among staff and parents, besides also talking with staff and parents. The research was planned to be based in one NICU that uses NBAS, one that uses NBAS and NIDCAP, and two units that do not use the programmes. However, we found that limited resources for developmental programmes do not allow for the programmes to be used regularly with many babies in the units. For the purposes of this study, 17 babies had one NBAS and 10 had two NBAS in one unit. Thirteen babies had NIDCAP in the second unit, and one had NBAS. Also, aspects of these programmes were provided by a speech therapist in the third unit, and by three junior nurses in the fourth. We investigated the views of parents and staff about these programmes, but were not able to do a straight comparison between units that do and do not use the programmes. The two sociologists had considered adapting NBAS and NIDCAP methods into a formal sociological version of observing babies. However we found the methods too complicated, although they were very useful in learning to observe babies more carefully and to 'read their language' of gestures, facial expressions, positioning and colouring (Brazelton and Nugent 1995; Als 1995; Warren 2001; Bond 2002; Hawthorne 2003). We reviewed how these programmes appeared to have more or less influence on the general ethos of the units (see also appendix 6A).

The families Sixteen babies in each unit (in the event 65) were selected and their parents were asked to consent to be interviewed, to allow their baby to be observed, and to agree that the researcher could talk to the parents informally when they met in the unit during the following weeks. In this qualitative study, we were not aiming for a random sample for statistical analysis, but for a purposive sample that would include as wide a range of relevant cases as possible. In examining uncertainty, a key theme in the research, we selected babies with varying kinds of potential neuro-developmental problems and with apparently different degrees of severity, from serious impairment to mild concern on the part of the staff although sometimes their parents were extremely anxious. Parents' and doctors' estimations of cause for concern did not necessarily correlate. With twins and triplets, there was usually greater concern about one child, though we included the siblings partly to review any differences between their experiences and their parents' views about them. We noted whether the babies appeared to influence decisions about their care. We involved babies with varying ethnic and socio-economic backgrounds, and aimed for a balance of boys and girls. It took several months to find the families in each unit, mainly because we waited until parents seemed likely to be ready to take part (see also appendix 6B).

We aimed to interview the parents of 20 of the babies at home, months after we had talked with them in the NICUs. However, we managed to conduct interviews with the parents of 40 of these babies, and so collected detailed longer-term data from this larger sample. The protocol also included interviews with parents of four children from each unit (16 children) when aged 4-6 years. We aimed to gain some understanding of certain parents' follow up experiences and their retrospective views about the information they had been given in the NICU, its relevance and accuracy, and whether they wanted to have been informed more or less. We selected moderately and severely neurologically impaired children for this group. All the babies' mothers were interviewed and also 16 of the fathers. We cannot form firm generalisations from these small samples, but the parents do provide a range of valuable insights in this under-researched area.

The practitioners We interviewed 40 people: 15 consultant neonatologists; 1 community paediatrician; 2 neonatal specialist registrars; 18 senior neonatal nurses; 3 counsellors; 1 interpreter.

The doctors discussed the range of neuro-related information they consider when making diagnoses, prognoses and treatment plans. The range included clinical and technical data, research evidence and other texts, personal and colleagues' views and experiences, follow up records, published guidelines, and parents' and babies' responses. The neonatal nurses spoke about their part in informing parents and sharing with them the care of the babies.

Interviews lasted between 15 minutes (two sessions) and 150 minutes, on average about one hour. A few parents took part in a series of short interviews because they had little free time, a practitioner wanted to speak to them, or else they were quite reticent, although as long as they had said they were willing to talk we thought that it was important to include a wide range of parents from articulate confident ones to hesitant quiet ones who did not speak much English. We had several informal talks with some parents about their baby's changing state and their changing views during their weeks in the units.

3.D Six advisory group meetings

The advisory group meetings drew on multi-disciplinary perspectives to review key themes in neonatal care and policy. The group included 4 neonatologists, 4 senior neonatal nurses, 8 parents, a developmental specialist, and 4 social researchers. Dr Farsides and Dr Draper, the bioethicists who facilitated the meetings, were especially interested in relating ethics to complex real-life experiences. Each two-hour meeting took a main theme and, although the group discussed topics that have been widely debated and written about, the meetings were valuable to the researchers in the varied contributions, the times when some form of consensus or disagreement emerged, and also in seeing how groups of practitioners and parents shared their views. The first meeting concerned communication and information sharing. The second meeting was about trust, especially in the health care services; how is trust defined, what does it mean, and how is it experienced by different people and groups. Meeting three was on discharge procedures, going home or transferring to another unit, follow up care for babies at home, and the part parents play at these times and in decisions about these changes. Meeting four was about uncertainty, and began with everyone being asked to mention a good aspect of uncertainty, such as when certain choices may still be open, before moving on to the anguish that prolonged and serious uncertainties can bring. Meeting five discussed care and love, parents' varying early relationships with their baby, the difficulties for mothers and fathers have in expressing intimate parental love in the public neonatal units, and the qualities of nursing care. The final meeting looked at the future of the babies and parents after they leave the NICU, and the future of neonatal services at this time of social, economic and political change in the health services.

3.E Data analysis and writing research papers for journals

We collected over 160 transcripts, with observation notes and other records. These were qualitatively analysed (Glaser and Strauss 1967; Lincoln and Guba 1985; Weber 1990; Strauss and Corbin 1998; Mays and Pope 2000) for responses to the research questions and for themes raised by the staff and parents. Methods of analysis included reading and rereading the transcripts to identify recurrent themes; identifying models of family-practitioner interactions; searching for all related illustrative examples and classifying these into types or categories across a spectrum of views; noting how people's views may change over time, and how different sources of data throw new light on to one another; noting exceptions which could challenge emerging conclusions; tracing how adults' perceptions of the babies' responses appear to contribute to adults' understandings of the babies' current and future neuro-developmental needs and experiences; reflecting on how the researchers may be influencing the data and analysis; reviewing how reliable, or at least transferable to other settings, the evidence and conclusions can be. The papers written for journals are concerned with social structures, relationships and processes, and aim to understand and explain these by examining underlying patterns and influences (Scambler 2002).

Analysis of the interviews is complicated. For example, we asked whether parents wanted to be informed about serious current or future problems for their baby, or if they would rather not be told, and if later on they thought they had been either 'over-informed' or 'under-informed' about potential problems that their baby might develop. However, their retrospective answers will be half hypothetical when the outcome was predicted, or

is either worse or better than predicted, so that many parents can speak from only one experience, not all three. People's views change over time, sometimes from not wanting to be informed into wanting to have been informed. Which view then counts as the authentic one? And everyone's views are partly contingent, depending on mood, setting, and the wording and tone of the questions. For example, a thoughtful study of parents' views after neonatal treatment was withdrawn and their baby died found that a high proportion of parents 'were satisfied with the management of their cases [and these were] in tune with most parents' needs' (McHaffie 2001: 411). The researcher carefully qualifies her conclusions, but one layer of complexity is that, after a death, people close to the deceased person need to recall and retell the event in ways that bring some comfort (Seale 1998). In that context, parents may need to believe and say genuinely that they are satisfied, because not to be satisfied would magnify their pain in futile and destructive ways. The finality of death can lead people to talk in terms that draw a close. In contrast, most babies in our study survived, and their parents were talking about how the past might affect their hopes and their baby's future. In our analyses, therefore, we have tried to be reflexive and to set the replies in context. A mother talking beside the incubator, or laughing at her baby's first steps a year later, may respond differently.

4. Outcomes: the project findings reported in papers for conferences and journals

The main outcomes from the 'foretelling futures' project are research papers written for meetings and journals. This section starts with 4A a list of presentations about the project at meetings, followed by a list of papers that have been written for journals or are nearly completed and which report the project in detail. The main part of section 4, 4A-4E, gives short summaries of the papers written for a range of academic, practitioner and policy journals, as explained in the Introduction, section 1. The quotations are taken from the interviews with practitioners and parents.

List of conference and seminar presentations and posters

- * 'Foretelling futures', presentations to staff in the four neonatal units
 - 1) to explain the project when starting to collect data
 - 2) to present findings at the end of the project (PA, JH, MK).

- * 'Foretelling futures: dilemmas in neonatal neurology: a social research project in four NICU', lecture at the International Conference on Infant Development in Neonatal Intensive Care, Royal College of Physicians, London, March 2003 (PA).

- * 'Researching interpretations of care in neonatal units', paper given to Medical Sociology Annual Conference, University of York, September 2003 (MK)
- * and to the Human Reproduction British Sociology meeting, University of Northampton in December 2003 (MK).

- * 'Information-sharing in neonatal units', poster for the Society for Reproductive and Infant Psychology Annual conference, University of Dundee, September 2003 (JH).

- * 'Who does the baby belong to?' poster abstract in proceedings of World Association of Infant Mental Health Conference, Melbourne, January 2004 (JH).

- * 'Time in the neonatal unit', paper for the Medical Sociology Annual Conference, University of York, September 2004 (PA).

- * 'User's views', lecture to the South East London Neonatal Network, October 2004 (PA).

- * 'Developmental insights in neonatal units: differences in ethos', poster for International Conference on Infant Development in Neonatal Intensive Care, London, March 2005 (JH).

List of the research papers written for journals

The titles are grouped into five themes, as follows.

4.A Families in the neonatal unit

- * Fathers in the neonatal unit (MK, JH)
(submitted to a childhood journal)

- * Belonging: Parent-baby relationships in neonatal units around transfer (JH, MK)

4.B Babies' rights

- * Are premature babies citizens with rights?
Provision rights and the edges of citizenship (PA, JH, MK)
(in press *Journal of Social Science*)

- * The participation rights of premature babies (PA, JH, MK)
(in press *International Journal of Children's Rights*)

4.C Sharing information, dilemmas and decisions

- * Parents' experiences of sharing neonatal information and decisions: consent, risk and cost (PA, JH, MK)
(in press *Social Science & Medicine*)

- * Complications within consent (PA)
(submitted to a medical journal)

- * Parents' active consent (PA)
(submitted to a medical journal)

- * Nurses and parents' consent in the neonatal unit (PA)
(submitted to a nursing journal)

4.D Time

- * Time in the neonatal unit (PA)
(versions being written for a sociology and a practitioners' journal)

4.E Knowledge

- * Knowledge and suffering during neonatal uncertainties (KE and PA)

- * Suspended futures in neonatal intensive care units (KE and PA)

- * Knowledge and information in the neonatal intensive care unit (KE and PA)

4.A Families in the neonatal unit

Fathers in the neonatal unit

Fathers may feel as deeply as mothers do about their baby, and this paper considers how the extra difficulties that fathers can experience illuminate mothers' difficulties too.

Introduction

The importance of close contact between mothers and their newborn babies has long been understood and encouraged (Klaus and Kennell 1976), and research interest in fatherhood is growing (Lewis and O'Brien 1987; Vine 1995; Freeman 2003). It cannot be assumed that fathers' and mothers' feelings about the baby differ, and when we say 'fathers' and not 'parents' we do not imply that mothers are necessarily different. Instead, we aim to draw attention to the under-researched subject of fathers in the NICU, their particular experiences and concerns, how they were perceived and treated by other people, their own reactions, expectations and self-perceptions, and their social experiences, status and relationships in the NICU setting.

Fathers in the neonatal unit

Most mothers spent more time in the units than fathers, so it was easier to speak to them, by default. Through their absences and in how they were treated by other people, fathers could seem to be less involved and less concerned. Yet the amount of time and practical care that fathers give cannot indicate the depth of their feelings and concern for their baby. Stereotypically, fathers are seen as more comfortable with the NICU technology than mothers are, however fathers described becoming very distressed too: 'It's very very frightening because you think that the little one is dying or something's happening with him, because of these alarms going off, and all of that is a bit intimidating for somebody who's not used to it.'

Fathers supporting their babies and partners

Parents mentioned wanting to 'hold back' for fear that their baby would die, and that this could be even more painful if they had grown close to their baby. Sometimes the father would be the main caregiver at this time. One of the mothers talked about her experience: 'I didn't want to get too involved; because I wasn't sure she'd make it... my husband was very much more talking to her and stroking her foot if he could. The nurses were always trying to encourage you to bond and he [my husband] was very good at that.' In relation to information sharing, sometimes fathers acted as a mediator between the staff and their partners. One of the mothers talked about hearing bad news: 'When they told me, I was really angry with them for telling me because I didn't want to be so frightened, and you resent someone who frightens you. So I said to my husband, tell them I want them to not tell me.' Fathers talked about holding back information so that they would not cause distress to their partner and other family members.

Social expectations and stereotypes of fathers

Henry's mother commented that one of the most helpful things a nurse said to her was, 'It's all right to cry'. No fathers made this kind of remark, suggesting, not that they had less feeling, but that it was harder for them to be allowed and to allow themselves to show their feelings. The social expectations of fathers may increase their distress, both through their fear of appearing weak and unmanly by showing their feelings, but also

having their hidden feelings overlooked. Fathers talked about how they may be perceived by the staff:

How people appear may not necessarily be what's actually going on internally, and my worst fault is that very often I can't be there, and people think that I don't care or that I'm just a male or whatever and they may not realise that you may actually be under an incredible amount of stress yourself.

A father described his way of coping to support others: 'We had this tragedy and the world was black. I spent a lot of time trying to be Mr Cheerful...which I didn't remotely feel, but in some way to be supportive of my wife.' A neonatologist expressed his views on fathers in the neonatal units: 'It's more difficult for them to form a relationship with the nurses... I don't think men chat about what is happening at work or their emotions, which I think puts them under more strain.' The mismatch between stereotypes and fathers' real feelings can make it harder sometimes for fathers to work with the staff. One of the male senior house officers said, 'It's a woman's world in here!' because the nursing staff are predominantly female. This raises the question about how fathers fit into the 'woman's world'.

Barriers to involvement

In addition to the barriers of social expectations on fathers, there may be structural barriers to their involvement in neonatal units. A major barrier, particularly for fathers, was lack of space and chairs near the incubator. Parents might have to fetch a chair for the mother, leaving the father standing uncertainly. Inadvertently, this arrangement strongly implied there was not room for fathers. Neonatal staff who welcomed and supported fathers therefore worked against, or in spite of, this negative message. Fathers of twins could play a fuller part, extra parenting care was needed, and when the babies were in separate cots there was more space for both parents.

Conclusion

Simply reporting fathers' relative absence in NICU, or ascribing it to male characteristics, could reinforce negative expectations about fathers in neonatal care. Instead, we have considered hidden influences, to help practitioners and parents to question and perhaps alter them. Difficulties arise mainly from culturally acquired perceptions of fatherhood. These include beliefs that mothers, more than fathers: matter to their babies; provide better care; have earlier and deeper feeling for their babies; and have more urgent emotional needs. We found challenges to these generalisations, but they can become self-fulfilling prophecies, making it harder for fathers to fit into the resulting 'women's world', and for nurses to support them warmly. The less time fathers spend in NICU, the less welcome other fathers may feel.

These beliefs and practices can change, as we observed. One NICU has five double parents' bedrooms. Some units encourage parents to read the medical notes, and attend doctors' rounds and nursing hand-overs. They make space for both parents, and try to create more private areas by rearranging furniture. They promote shared baby care, through welcoming, valuing, and respecting fathers as well as mothers.

Belonging: Parent-baby relationships in neonatal units around transfer

In this paper, parents' perspectives on the meaning of their role in neonatal units, their status, agency and contributions are discussed. These points were well-illustrated around the transfer of their babies to another unit.

The birth of a baby is usually a joyful event shared with family and friends. Once at home, there is a long period of adjustment and getting to know each other in familiar surroundings with the support of family and in the privacy of their home. This period of 'primary maternal preoccupation' (Winnicott 1956) is usually unhampered by outsiders, and parents are able to arrange the events and patterns in their life with their new baby on their own. Parents have a sense that their baby belongs to them as their baby is part of their family. Parents need for closeness and mutual exploration of their baby's characteristics is fundamental to the formation of the parent-baby and social relationship.

The birth of a preterm or ill baby who must be nursed in a neonatal unit is a very different beginning for the parent-baby relationship. Often the birth is an emergency with no warnings during the pregnancy that the baby may be preterm or ill. Parents may have expected a healthy, full-term baby whose behaviour and appearance is very different from a tiny, fragile, preterm baby or a sick baby. By tradition, hospitals are public institutions where the baby is under medical supervision and management. There is emphasis on the deficit model and need model, and patients and parents become dependant on the expertise of the staff in managing medical events. Although the primary function of a mother is to keep her baby alive (Stern 1995), this role is removed from her in a neonatal unit.

Parents with babies in neonatal units may wonder whether their baby belongs to them or the hospital. Although 'belonging' does not always refer to a personal relationship, its meaning involves a mix of powerful emotions, and is defined as: to be connected with, concern and relate to. The affix 'long' is linked to depend, desire, love (including affection, long for). Parents may feel that the nurses know their baby better than they do, and sometimes they feel that their baby knows the nurses better than they know the parents. On the other hand, parents value highly the nurse who can show caring attention to their baby and know them as a person (Killen et al. 2004). There is a link between a parent feeling that their baby belongs to them, and the development of the attachment relationship. Some parents feel they cannot have the contact they want with their babies:

I couldn't come up until the Tuesday, I just walked into the room and burst into tears, because you just don't realise it's your baby, and you're just thinking 'why us?'

And also you can't touch you know, you can't hold them and you can't feed them, you can't, you know, you can't bath them, you can't take them home directly, you can't have them beside you in your room until you go home...

[Y]ou lose out on that sort of natural bonding after you have a baby because you can't get close to them, you know, you can't feel them properly, you know, you can't cuddle them, you know...

Points discussed in this paper:

Differences in ethos

All four neonatal units in this study had a different ethos about parenting and promoting positive parent-baby relationships. There were differences in policies about environmental stimulation and the provision of programmes to support parents and listen to babies. This study was not designed to compare units, but rather to describe parent's parenting experiences and perceptions of their baby. Most parents reported that most staff were friendly and helpful, but while all units were first-rate medical units, in some, the practices and provisions were not led by the psychological needs of parents and babies. Differences were seen in the use of space, comfy chairs, number of double bedrooms, food and drink provided, as well as staff attitudes.

Communication between parents and staff

Both staff and parents made a huge effort to communicate. Some parents needed to know their baby is liked by the staff. They can worry that any rift between them and the staff might affect the way staff care for their babies. Some parents feel that their baby does not know them:

I felt that after staying in that night, I felt that Jenny didn't know me, and I felt there was no bond there and it was awful because the nurse walked in to see her at one point and she sort of went, 'Jenny, Jenny!' like that, and Jenny sort of quietened and looked, and I was like, you know...she's bonded with...

But for one parent, holding was knowing:

But I felt more that she was mine when I could hold her.

Trust

Some parents reported that the fact that they trusted the staff meant that it felt easier to leave their babies in the care of the staff:

I felt that I trusted them implicitly. I trusted them, they knew what they were doing, do you know what I mean, and that's it, and I was hands tied and there was nothing I could do, sort of thing, and I trusted them completely, and I felt that they explained to me well what was going on.

Parents worked on developing a trust in the staff which took time. For some, they felt happier when a particular nurse was on duty. When the baby was transferred to another unit, parents tended to take time to develop trust in the staff there (see below).

Parent's knowledge of their baby

Parents can be seen as contributors to knowledge about their baby, not just as learners. In the interviews, many parents described their baby's personality and behaviour in detail. Although they may not feel like experts in the medical setting of the neonatal unit, their emotional investment in their relationship with their baby make them experts about their baby. Some studies have suggested that some parents spend more time with their baby in a neonatal unit, than they might with a full-term baby. It helps parents to feel their contribution to their baby's care and recovery is valued by the staff.

Baby communication

Babies communicate their likes and dislikes by their behaviour which is their language. There are many ways to see if a baby is feeling pain, joy and fear. The NBAS and the NIDCAP are tools to assess the infant's reaction to stimulation. Parents in this study discussed their concerns about the way their baby is feeling or is handled by staff. A large number of staff may deal with a particular baby. During a stay of 49 days in a Toronto nursery, a baby was attended by an average of 71 different nurses (Minde *et al.* 1975). The baby is affected by changes in personnel and routines. Babies also tend to communicate the feelings of their parents, and if the parents feel unheard, the babies are likely to feel unheard (Cohen 2003).

Transfer

There are many pressures on neonatal units to use the cots provided, and babies are often transferred to a unit nearer their home, or to another unit for treatment if there are no cots available. In this study, there were 20 babies transferred from one unit to another. Although moving a baby closer to home is beneficial for the parents, this study highlighted the need for special preparations for this transfer, other than medical. Receiving units need to value the mother's observations of her baby's behaviour in response to his or her care. Parents were found to get used to the medical routines in the unit they have spent weeks in, but they also get used to the way the staff treat them and their baby socially and emotionally:

No, I think in [other unit] because it's a smaller unit they had more time, the consultants actually spent more time explaining things, and you were part of their...whereas here, you know, they swap every week and no one sort of, it took a while for the consultants to actually come up and actually speak to you...

Some parents felt their observations and knowledge about their baby was not respected:

I remember with the...second day she was there or something, and they done a ward round and I was allowed there because she was in a room on her own, and they was asking questions about Jenny and was asking a nurse who had been there...for a couple of hours that morning, who obviously did not know Jenny, so I was answering all the questions, and like the way they looked at me was like...who are you?...Once I'd done that, made that mistake..., every time I said something they saw it as me comparing hospitals rather than saying what my baby had liked and was used to.

Some parents are seen by staff as 'difficult' around discharge home or upon transfer to another unit. This is likely to be their effort to demonstrate to themselves and staff that their baby belongs to them and they know him/her well. But this is also linked to the growing knowledge, assertiveness and authority that parents need to feel as their baby gets better and is closer to going home. This may also be linked to the passive and dependant role parents might be playing in the neonatal unit, while 'other people' care for their baby. It is also worth considering how the baby is feeling about being transferred to another unit. The personal relationships and emotional links parents have made with staff have to be made again in the new unit.

The issues around parent's feelings about loss of control in the neonatal unit as their baby is cared for by skilful and professional staff are further discussed in this paper. For some parents, this feeling lasted when they returned home:

she was...our baby, but not ours. So she was...she felt like the hospital's baby, even after we felt that, because the community support was there. I mean...I've seen other babies in our family where mum and dad decides everything but I had to call the unit to do...to give her a little Gaviscon or, you know just...every little thing I was so cautious.'

...quite scary when first at home. In the unit, we had to ask permission to do things for Frank, and then at home it's weird because he's completely ours. In the unit we were his parents, and we didn't need help with the nappies, but we felt we did need it!

Conclusions and recommendations

Neonatal units could benefit from transfer planning that incorporates the parents' and babies' voices about their emotional needs for this transition. Designing a joint parents and staff care plan that covers feeding, timing and pacing of care, and the baby's preferences for touching, holding, positioning, light and noise, benefits not only the parent-staff relationship, but respects the parents' observations and knowledge of their baby.

4.B Babies' rights

Are premature babies citizens with rights?

Provision rights and the edges of citizenship

The first papers on babies' rights reviews the so called provision rights in the Convention on the Rights of the Child (UN 1989) – UNCRC - to see how these rights apply to premature babies and how they provide checklists for assessing neonatal care. The summary gives some of the main points from the papers.

Premature babies are the same gestational age as the fetus that, in Britain, has no rights (RCOG 1994). However, most of the rights enshrined in the UNCRC apply from birth, even when babies are born as early as 22 or 23 weeks gestation, 17-18 weeks early. These papers review how attention to premature babies' rights and citizenship illuminates dimensions of human rights and babies' interests. Babies' rights can be useful indicators of the extent to which each society respects and treat individuals as citizens with civil, political, social and economic rights. In Britain, babies have the right to life, once they have shown the potential to benefit from life-sustaining treatments. Their provision rights include access to health services and costly multi-disciplinary neonatal intensive care.

This review of babies' rights illustrates how human rights are:

Embodied, and informed through babies experiencing and sensing their bodily and aesthetic needs;

Emotional, in how the rights are respected, experienced and interpreted;

Interactive, interpersonal and gaining reality through their social and emotional context;

Political and economic, when babies' survival and the meeting of their basic needs depend on highly organised state services, or support in paying for privately provided health services. The political and economic aspects of human rights are also illustrated in many countries when babies die for lack of funded neonatal services, or even for lack of clean water and basic health care provision.

Contrary to the view of philosophers who deny that babies are persons (Singer 1995), many neonatal practitioners respect babies as sensitive aware persons (Brazelton and Nugent 1995; Wyatt 1998; Goldson 1999). This respect is a vital part of promoting humane and effective health care for babies and their parents in neonatal units, and of promoting their health care rights. Babies' ways of expressing their needs can help to guide adults to provide appropriate and effective care, such as when babies try to obtain comfort and avoid discomfort, and give subtle cues about their needs and optimal conditions (see section 1C). Adults can learn to 'read' the babies' language. In some NICU the babies have uterus-like soft fabric 'nests' that contain their limbs, help them relax and rest, and enable them to keep their hands near their face so that they can engage in self-soothing behaviours; light and noise are kept low, and incubators have sound and light reducing covers. In some other units, light and noise levels are high, and babies' limbs are splayed out, sometimes over loops of rough towelling. They expend energy on trying to gather their limbs together, and when they sleep they are more likely to startle and jerk awake if they are not swaddled or contained in the nests. NIDCAP, through individualized care plans to suit each baby's carefully observed needs, advises, for example, putting the cot in a position with more or less light, offering a dummy to see if the baby wants to suck it, helping babies into the position they prefer for feeding.

Provision rights include rights to education in two main ways for premature babies. High standards of neonatal care depend on highly educated clinical, technical, scientific and administrative staff. And education starts from birth with babies learning how to respond and interact with the people and events around them.

The UNCRC avoids setting babies' and mothers' rights into conflict, and instead of talking of babies' rights to breastfeed it enshrines parents' rights to education about the advantages of breast feeding. Knowing the extra advantages of breast milk for premature and sick babies, many mothers in NICU try for weeks to express breast milk and then to establish breastfeeding when their baby is strong enough. Babies' rights include the practical support that the nurses give to help mothers to breastfeed.

Children's social and economic rights include an 'adequate standard of living'. Premature birth is linked to disadvantage and to social inequalities. In wealthy but markedly unequal societies, poor people suffer from worse health than people who have an even lower income but who live in more equal societies (Wilkinson and Kawachi 1998). Britain has very unequal income levels and high rates of childhood poverty. In inner London, where three of the observed NICU were, 49 per cent of children were living in poverty (Hood 2002). Some babies in this study had to wait in the units after they were ready to go home until their parents could find a home to take them to; other families had damp, cold, noisy flats, and some were refugees and asylum seekers. During interviews it was not unusual for parents to describe the difficulties they faced in trying to ensure that their child would have an adequate standard of living.

Children who are cared for away from home have the right to 'regular review' and the units varied in how regularly the doctors met with parents to review the babies' progress together.

The paper reviews with illustrative examples the UNCRC provision rights as they relate to vulnerable premature and sick babies, and their rights as new citizens to appropriate services.

The participation rights of premature babies

The paper on the UNCRC participation rights continues the theme of the standards of care that babies need, and reviews how the babies are not simply passive receivers of care. They can be participants in the sense of reacting and interacting with the adult carers and thereby influencing neonatal practice and decisions and even policies, as the paper considered.

The research observations and interviews showed close relationships between babies and parents and between babies and some nurses. Babies born at 25 weeks gestation could recognise and react to their mother's voice. Mothers described how some babies clearly preferred being cared for by certain nurses rather than by others. The quality of life-giving care that the babies need appears to go beyond impersonal routines, and involves personal interactions between the carer and the baby, so that the care is adjusted and partly guided by the babies' sensitive subtle responses.

'Participation rights' are modified versions of adults' civil rights, with the key right:

to form and express views in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child (UNCRC article 12).

The babies were perceived by some of the adults caring for them, and by the research literature (Brazelton and Nugent 1995; Als 1999) as able to form and express views. The UNCRC does not treat children as isolated beings, but as members of families and communities, and repeatedly affirms the importance of supporting parents to enable them to honour their children's rights. Participation rights include freedoms of information, expression, thought, conscience and religion, and respect for the child's cultural background. All these vital rights enable parents to speak freely on their child's behalf and to share in making informed decisions about their child's care.

There are participation rights to a name, an identity, a nationality, to the child's contact with his or her parents and family, and to respect for the worth and inherent human dignity of the child. The research by Brazelton, Als, and others about the 'amazing' capacities of newborn and premature babies, besides evidence of the remarkable competencies of young children (Alderson 2000), opens up ways to understand babies as human beings who interact in human ways from birth, and thereby participate in human relationships. Parents and babies affect one another's moods and physiology, such as when skin to skin care releases their oxytocins and slows their heartbeat and respiration (Goldson 1999; Mattiesen *et al.* 2001) in a relationship that is social and emotional as well as embodied. Babies move between six states from deep sleep, through being awake and alert, to becoming upset and then crying. They vary in how

quickly they move between the states, and in how sensitive they are to noise and light, by startling and becoming upset, or by remaining calm. They turn towards sounds and scents that attract them and turn away from other stimuli in a 'self-actualization [that] is participation with the world and interaction with another' (Als 1999:31-5). Babies express their reactions, such as by yawning or hiccupping if they begin to become distressed, and their 'language' can be read from their facial and body movements and posture, their colouring and sounds, their breathing and heart rates. When care is timed to fit the babies' changing states, and babies can influence their care as far as possible within the busy neonatal routines, this encourages babies to enjoy human contact and to rest and sleep when they need to.

The basic participation right is the right to life. Instead of the baby's life being solely something that adults support or allow to continue, many babies appear to put much energy and concentration into surviving. Parents and practitioners spoke of some babies' determination: 'they fight and fight and you start respecting them for that...they kind of keep going and you end up feeling quite in awe of that'.

Another participation right for the child is 'to preserve his or her identity'. Babies' rights to respect for their 'cultural identity' can be evident from birth as part of their care, such as in the clothes and toys, prayer cards and other religious and cultural icons that parents bring into the units for them. Adults frequently referred to babies' differing 'personalities' and parents who sat for days, weeks and sometimes months beside the incubator or cot learned each baby's own preferences and idiosyncrasies. Whereas in some units nurses taught parents to bath the babies briskly, in other units nurses showed how the baby could set the pace of the bathing during a close participative interaction with their parents. Babies were wrapped in a sheet and gently and slowly put into the water, gradually being unwrapped as they became confident and ready to enjoy the bath. Sean's mother described how Sean enjoyed his first bath and quickly became confident: 'he practically de-gowned himself and he cried when I took him out'. When the lighting is dimmed, babies are encouraged to open their eyes and to fix, track and gaze. The eye contact powerfully encourages their parents' love, and babies too express attachment. Chima's mother said, 'Even when he is sleeping and I come in, he opens his eyes and looks around. I think he knows my smell or something.'

Babies may change their parents' plans and lives. Looking back over Henry's first months, his mother described how they had a 'tough' but also a 'wonderful' time together. Henry has Down's syndrome and his mother decided not to return to her career as she had planned, because 'he needs me'.

Sometimes, babies appeared to participate by influencing adults' decisions in the units, and even by having the 'final say'. Hannah's parents sadly agreed when she was four months old that, although the doctors would put Hannah on the ventilator again if she stopped breathing, 'if her heart was to stop beating that's her way of saying, "I've had enough. I can't cope any more"'. A short while later Hannah died. Andrew's mother said, 'I thought he definitely chose to live...he's just incredibly determined', when he survived twice against the doctors' expectations. A doctor commenting on a baby's very unexpected survival, said, 'It was extraordinary how this little body, this little soul kept winning through.' Other consultants described how 'We give them a course of treatment that we know would normally work but sometimes the babies would deteriorate anyway and would declare themselves', and how, 'I think that's even sadder when the baby takes a decision, and the baby dies in spite of everything we do'.

The paper concludes that respect for babies' participation rights is feasible, integral and indispensable to adequate neonatal care, and that babies' inalienable human rights justify and validate high standards of neonatal care.

4.C Sharing information, dilemmas and decisions

Parents' experiences of sharing neonatal information and decisions: consent, risk and cost

Several papers from the project review parents' and practitioners' practical experiences of sharing information and decision-making and of the consent process in the context of rising medico-legal and ethical standards. The papers consider how useful and realistic the standards are, and alternatives that some parents would prefer.

Background

There are growing pressures on neonatal practitioners, recorded in medico-legal and ethics guidelines, to share information and decisions with patients and with the parents of patients who are minors. Consent is supposed to be requested for 'all touching' of the patient (Kennedy 2001; Shenoy *et al.* 2003). The pressures to inform tend to come from legal, ethics and medical authorities, and from parents who believe their child suffered, and in some cases died, after parents were under-informed and misinformed. We asked practitioners and parents for their views on sharing complex, often distressing and uncertain information. We also examined how the ways in which parents share in information exchanges and in making decisions with the staff about the care of their babies, who have potential or confirmed neuro-developmental problems, can be affected by approaches that support or restrict parents' involvement in the units' daily routines. Some of the parents' preferred standards are summarised. Doctors' tendencies to emphasise distancing aspects of the consent process are contrasted with parents' tendencies to emphasise the drawing-together aspects of the process.

Emergency and routine interventions

Although the law allows doctors to give life-saving emergency treatment without needing to request consent, recent guidance advises asking for consent to all interventions. Many babies' treatment begins in emergencies when the mother may be absent, and before December 2003 the unmarried father could not give legally valid consent. When parents first arrive in the unit, some want to learn about the interventions, but others feel too shocked and distressed to listen and understand initially. Some parents are pleased when the nurse begins by giving them time to meet their baby, to touch or to see how their baby reacts to their voice, and appears to remember the sound from before birth. A mother described being shocked and sad on first seeing her tiny baby Oludayo, born at 25 weeks gestation, until the nurse told her to speak to her daughter.

She was looking so helpless and tiny, but then I say something to her and then it was so, she was moving her hands and legs so quickly and right, like trying to recognise you... 'Yes go on', [the nurse] was saying... 'this is the one voice she

known for a long time, now she can have a sense that she has not been abandoned that you are still here’.

Parents then realise how they can offer unique care to their baby, and be more than dependent learners. An initial quiet time with the baby in the NICU can be as alike as possible to the first meeting that parents and babies enjoy after a normal term birth. At first, parents are more likely to be able to absorb and respond to this experience than to receive complicated clinical explanations and requests for their permission, before they may have time to understand and reflect on the information and decide whether to consent. Parents often expressed fear of touching their fragile tiny baby, and of becoming emotionally close, which they expected would increase their pain if their child died. The nurse’s approach described above, however, introduces the baby’s views and needs, and the rewards of closer contact, and adds these into parents’ considerations of how parents themselves might be affected by contact with their baby. We need to know more about the gains and costs to parents and babies of the alternative first inductions into the NICU that emphasise either information about the technical care or else the parent-child relationship.

Respect for their consent is not a priority to many parents, when they believe they cannot refuse interventions that are emergency, or routine, or parts of complex packages of monitoring and life support systems. Emergencies quickly turn into routines that are guided by protocols and agreed best practice, when it becomes hard for parents to question these. The changing information about the baby’s transient condition can make parents feel less certain and confident about which details to question, or to accept, or to base any decisions and expectations on. Obstetricians and neonatologists might give very different prognoses. Parents gradually learn basic neonatal knowledge through sitting with their baby, talking formally and informally with staff, reading books and leaflets and, in units that encourage them to do so, hearing ward rounds and talking with other parents. Routines and rules in the unit that include or exclude parents either encourage them to talk to consultants or else discourage and deter them, and this affects parents’ understanding and their confidence to ask questions. However, by the time they understand in detail, their baby may no longer need intensive care so that consent to those procedures is no longer an issue.

Valid consent

Legally valid consent involves the person being adequately informed, having time to reflect and decide, and having a real choice to say ‘yes or no’. Parents usually feel there is no choice, and that they have to accept the medical interventions. Requests for their consent are then not only invalid, but can also increase parents’ distress and anxiety about their baby’s painful experiences, their guilt and sense of responsibility without power. It would be ‘overwhelming...too stressful’ to be asked routinely, they said. Describing scars, heel pricks and lines inserted into veins, a mother said, ‘But these were tests they had to do...No, there is no choice. You know they have to do that.’ Some clinicians agreed, such as the consultant neonatologist who commented on proposed detailed guidelines:

Your child might have a heel prick that might cause bone infection, we will put in a nasal gastric tube to feed your child but it might slip out and it might cause aspiration pneumonia...if I was a mother, ‘Do I save my child’s life or do I send her to this torture chamber that’s gong to kill them? It sounds like I am going to kill my child whatever I do’.

Varied views

Parents' views on information and consent are varied, complex, contingent and often ambiguous. They may change over time and with experience. Parents are grateful to the staff and dependent on them, they are usually anxious not to question the skill or judgement of the staff, though some parents express anger about certain practitioners' manner of informing. In retrospect, some parents are very critical that they have been 'under-informed' about future problems, others that they have been 'over-informed' about problems they did not arise. These may be the same kinds of people, and not two separate groups who either do or do not want to be told. A different group is the parents who are less critical of discrepancies between prognoses and eventual outcomes, accepting that it is not possible to predict accurately about little known futures.

A few parents said that they did not want to be told about their baby's present and potential problems, at least at first. Most parents we talked with did want to be informed, and to have procedures explained to them, and to be able to discuss these. They wanted to have the chance to question, and occasionally to choose or refuse. They therefore tended to want the staff to check with them, and not assume automatic agreement to everything, but not ask for formal consent to most interventions either.

However, seemingly very small decisions could have great life-long consequences. One example is whether to set up an antibiotic drip during premature labour associated with maternal infection, in order to prevent the baby from developing an infection that might cause severe and lasting damage. Parents could grieve for years over such omissions. They were especially perturbed if they were not informed or listened to on two main grounds. They felt humiliated at not being trusted and treated as mature rational people. And they bitterly regretted not being able to help their child as much as they would have done if they had been informed earlier, or if they had been listened to (such as the mother who requested the antibiotic drip during labour, or parents who noted early signs of sepsis and felt their warnings were not heeded promptly). Describing how he wished that the information that his daughter had cerebral palsy, together with details about practical methods of helping her, had been given to the parents months before they were informed, a father said: 'We had no idea that we could be doing anything practical. In other words, instead of having a problem that we could perhaps seek to find a solution for, we had this tragedy and the world was black.'

Parents' standards for informed consent

Many parents said they wanted the following standards for shared, informed decision-making:

- * Doctors to begin discussions by trying to find out how far parents needed or wanted to be informed;
- * Doctors to give 'bad news' sensitively and respectfully, adding positive points if possible, and giving a 'sign of concern';
- * Information that enables parents to have some control over events whenever this is realistic and practical – a decision to touch the new baby, or to hold the baby early on can be a momentous decision to parents;
- * The offer of further information and support when they are given serious major news;
- * Adequate information and time to discuss and reflect;
- * A two-way process of practitioners and parents listening and sharing information;
- * Sometimes having an intermediary or advocate to help them, even usually authoritative parents could find it hard to be 'proactive' and ask questions without help;

- * An informed firm 'bargain' between fairly equal partners;
- * Clear records of any agreements so that these could be honoured through the changing staff rotas.

The parents' interviews suggested three main reasons for giving parents information rather than withholding it. First, the more parents say they are distressed about being 'over-informed' about problems that did not develop, the more distressed the same ones might be if they had been 'under-informed'. Second, communication is interaction, and only through beginning to inform parents can practitioners learn from them and work out with parents how and when and how far they want to be informed at each session. Third, parents repeatedly linked knowledge to their power to help their child. Conversely they were perturbed if information about how they might give practical help was withheld, even in decisions as seemingly minor as whether they could touch or hold their baby.

This analytical and not statistical study cannot measure the findings or indicate the proportion or type of parents who wish to be informed. The units, the practitioners and the parents all vary. Yet besides individual examples, the research reports structures, processes and concerns that are likely to be widespread. The findings are therefore partly transferable to other neonatal units. The paper gives examples to convey something of the emotional risks and costs and the complicated context of the NICU. The research began from the view that pressures on doctors to inform parents appeared to come mainly from management for medico-legal purposes, rather than from the majority of parents. The results suggest that parents tend to want to be clearly informed; the minority who do not are likely to be in a temporary crisis. The timing, manner and content of information giving could be improved in some cases to match the standards of the best practitioners that parents tended to prefer.

Parents have to learn much implicit as well as explicit information and rules about what they may or may not do; they are unlikely to be aware of how the rules vary between neonatal units and thereby open or close their choices, such as to be present at medical rounds, or how soon they can begin to hold their baby. Our observations suggest that the more open the rules and access, the more confident parents tend to be about talking with the staff. Parents can then raise questions, vital to them for shared discussion and decision-making, which the staff may perceive as too minor to be related to formal consent.

Complications within consent

This paper continues ideas developed in the previous paper and reviews two issues in more detail: complications and contradictions within the consent process, and parents' motives for wanting to be involved in the process.

There are two main types of information relating to parents' consent. One concerns the nature and purpose of procedures such as investigations, monitoring and treatment. Junior doctors and nurses give much of this information in terms of 'this is what we are doing, and this is why we are doing it'. Parents are informed, but seldom asked for their views or their consent, and parents' questions reinforce the position of the staff as expert providers of knowledge and care. The second type of information concerns the potential effects of procedures, the risks, benefits and alternatives, the results of tests and their possible implications, diagnoses and prognoses. This more complicated and sometimes

controversial type of information is frequently left to consultants to discuss with parents. Medico-legal pressures may deter nurses and junior doctors from discussing such complications and uncertainties, so that more time is needed from consultants to discuss them.

Current medico-legal-ethics guidance on consent repeats the traditional legal concept that practitioners must request consent to all ‘touching’, but with a renewed emphasis to seem to include emergency procedures. Several agencies, Department of Health (2001), Royal College of Paediatrics and Child Health (1997, 2001), General Medical Council (1998) and neonatologists’ associations (BAPM 2000) have recently issued guidance. The guidelines might seem at first to offer clear concise steps towards achieving patients’ or parents’ informed, voluntary and valid consent. However our interviews and observations suggested that the guidance tends to set up a series of contradictions and complications, with little acknowledgement of these difficulties or information on how to deal with them. Table 1 lists some of the contradictions between medical aims and standards and real daily experiences.

Table 1. Contradictions between medical aims and standards versus common experiences of the consent process

<i>Medical aims/standards of good practice in consent process</i>	<i>Common experiences of the consent process</i>
Respect parents’ rights	What if parents want to have the right not to know?
Request consent to all touching	Many interventions are emergencies, routines, protocols, packages of care and parents cannot ask for one part of the whole life-sustaining intensive care system to be withdrawn
Encourage parents’ informed involvement	Consent tends to be based on a model of active staff and dependent ignorant parents, which implicitly discourages parents’ active involvement
Medico-legal good practice to keep full records	Can be bureaucratic and time wasting
Promote trust	Can seem defensive, mistrustful
Reduce dissatisfaction	May increase climate of litigation
Transfer legal responsibility for risk from doctor to parent	Consent may be legally invalid, if no real informed choice, so responsibility is not transferred
Explain risk, benefit	Hard to select and explain complex and

Explain risk incidence of over 2% or 'very small and rare' risks if patients are 'concerned' (DH 2001)	uncertain details Hard to tell which parents are concerned without explaining risks to them
Allow time to decide	Often rushed
Exert no pressure on decision	Hard to avoid many pressures
Consent is a choice, right to refuse (DH 2001:15)	Many decisions seem to be about necessities, not choices
Only people with parental responsibility can consent for their children	Confusion about unmarried fathers, very young mothers, grandparents, who has parental responsibility?
Traditional model of personal contract between individual doctor and patient	Team care – who asks on behalf of team?
Person asking for consent must be trained to ask	Concern about these standards deters nurses and junior doctors from being involved with consent, so there is less time with fewer staff, the consultants, to negotiate consent
Coherent, consistent, continuing information	Hard to achieve this with changing staff rotas and perceptions, and changing state of babies
Fair equal involvement of all parents	Parents have unequal needs, abilities and involvement
Model of equal doctor-parent partners	Parents initially inexperienced, ignorant, anxious, doctors are highly experienced and informed
Predict risks, outcomes, and gauge parents' likely later reactions	Often hard or impossible to predict outcomes and reactions, dealing with probabilities rather than facts
Refer to longitudinal data on future outcomes	Data may be out of date or not locally relevant
Inform to warn, prepare, support parents	Information may increase parents' stress and tensions

The paper reviews these differences and contradictions. It shows how consent is constructed to concentrate on areas where doctors are most and parents are least knowledgeable and active (position X) in table 2. In contrast, the areas where parents are most knowledgeable and want to be most active (position Y), such as feeding the

baby, are often not regarded by the staff as involving decisions and choices for parents to make. Instead these matters tend to be assumed by staff to be routines and best practice, which only ignorant or unreliable parents would question.

Table 2. Consent and areas of knowledge and action.

	Consent that relies on doctors' knowledge	Consent that relies on parents' knowledge
Consent that enables doctors' action	X	
Consent that enables parents' action		Y

Information and consent as keys to parents' action

The medico-legal model of consent assumes that skilled, knowledgeable practitioners inform the relatively passive ignorant and dependent patients or parents in order that, by signifying consent, patients/parents allow the practitioners to act. However, the parents we talked with suggested another implicit model: sharing information that enabled parents themselves to choose and also to act. The activities that they described, which also explain parents' motives for wanting to be involved, included:

- * To be able to make more informed decisions;
- * To know small details so that they could understand the bigger picture;
- * To understand how to agree to, or question, the practitioners' interventions;
- * To learn how to make informed observations and respond appropriately to their baby;
- * To know how to help, touch, care for and relate to their baby;
- * To agree clear recorded plans in an equal partnership;
- * To share in deciding 'small' matters - feeding, holding, ensuring quiet space, planning discharge;
- * To protect and advocate for their child - such as in the pacing of procedures, or asking doctors to remove an infected line sooner rather than later - and to be able to alert the staff if necessary to the child's particular needs;
- * To 'care for the baby in spirit' when they are not in the unit, 'your heart is here', so that parents rely on having regular detailed updates about their baby;
- * To inform their prayers;
- * To 'walk' with their child towards an expected future.

The paper explains these motives with examples and concludes that when serious medical decisions arise, parents usually want to share in making them. However, more often, there are 'minor' decisions that parents want to influence, but these tend to link to nursing rather than medical care. They relate to matters that tend to be decided by nursing protocols when parental choices may not be envisaged or offered. Partly through medico-legal pressures, consent is identified with doctors' rather than with nurses' interventions. Possible ways to resolve the contradictions summarised in table 1 are reviewed.

Nurses and parents' consent in the neonatal unit

This paper continues themes from the two previous papers. It reviews recent changes in guidance and policy for nurses regarding consent, from no mention of consent except in a clause on disclosing information (UKCC 1992), to an 11 paragraph section headed

'you must obtain consent before you give any treatment or care' (NMC 2002). The obstacles that prevent and inhibit nurses from following this guidance are reviewed, such as nursing's traditional roles, its relationship with medicine, the locus of decision making and control, and the complications of team work as a setting for individualistic concepts of consent. It is suggested that formal medico-legal concepts of consent fit uneasily with nursing's gendered concepts of care, need and empathy.

Much-cited books by Chambliss (1996) and Anspach (1993) on ethnographic research about intensive care nursing tend to sideline parents and their views. They illustrate a general absence of theoretical and practical interest in parents' consent in the nursing literature, as does Abdullah's article (2004) on 'Decision making in neonatal nursing: parental participation'. The article is about nurses' decisions on how to involve parents in care giving, but not about parents' own decisions. McHaffie's work (2001) on parents' experiences of decisions to withdraw care from their baby is exceptional in the literature by nurses. Nursing protocols can raise standards and increase nurses' authority, but they allow less room for parents' choices.

This paper reviews the varied parts that nurses play in parents' decision-making and consent to many aspects of neonatal care, using the example of breastfeeding. Nurses' status and responsibilities within NICU structures, policies and routines can increase or restrict parents' involvement, and thereby promote or discourage breastfeeding. The paper considers models of consent that are less defensive and legalistic than traditional models, and involve more information exchange and informal negotiation between parents and practitioners. This could increase the possibilities for more baby-centred neonatal care, which takes greater account of babies' social and emotional needs as well as their medical ones.

4.D Time in the neonatal unit

During this project about babies' futures, analysis of different understandings and approaches to time illuminated and questioned some of the pressures and structures that influence present forms of neonatal intensive care.

The aims of the neonatal unit can be summarised as follows:

- To reduce and prevent neonatal mortality and morbidity
- To promote babies' current and future health and welfare
- To encourage parental care
- To promote teaching, training, staff development and research.

The main means to achieve the aims are:

- Medical, nursing and other assessments, treatment and monitoring
- The work of collecting and sharing information, reviewing, planning, and making decisions.

The essential tools are:

- Technical, administrative, managerial, financial and domestic support.

A classic finding in sociological studies of organisations is that the tools, instead of serving the aims, tend to take over the main activity, attention and priorities, so that the

tools come to dominate and even determine the aims. Budgets, targets, and recruiting, retaining and training staff require so much time, that hard pressed managers and practitioners may have little energy left to promote primary aims. This paper discusses how an analysis of time in the neonatal unit can remind managers and practitioners of the importance of the key aims and of ways to advance these. Concepts of time pervade neonatal care and discussions. The concepts involve counted and costed Newtonian clock time, the rhythms of natural time, and individuals' elastic perceptions and experiences of social time (Adam 1995).

Medicine and nursing especially rely on clock time. For example, premature babies are 'born out of time', and stay in the time limbo of the NICU, waiting to achieve their 'term date' or sufficient maturity and health to be able leave. Correct fetal and neonatal development involves meeting milestones, marking weeks and months along a time journey towards adulthood. Babies can be admitted to units that have a spare 'cot', which is code for available nursing time. Clock time dominates routines and staff shifts (to do the bloods by 10am, the 'cares' every 4 hours). Screens and monitors display the micro-timing of the babies' bodily functions and the efforts of the staff to synchronise (time) these with optimal pacing and rhythms, such as of respiration and heart rates, by increasing or reducing the speed and volume of mechanical support. Policies and protocols prescribe the correct sequence and timing for processes such as the babies' feeding or planning their discharge. Staffing rotas, grades and salaries all indicate close connections between cost and clock and calendar time. There is also the challenge to weld the fragments of individual staff time and passing rotas into a service that provides families with continuing, consistent and expert care and information. Meanwhile, time rapidly brings changes to the condition of each baby, which further complicate attempts to provide consistent information. Nurses are particularly concerned with how to divide and share their care of (time for) the baby with the parents, and how to manage in flexible or controlled ways the parents' time in their access to the NICU and to talk with the staff. While children grow, if they have impairments, their disability is assessed in terms of time, in how slowly and how far the child lags behind average development in certain measures, though these cannot precisely indicate the child's and family's actual experiences and quality of life. There is disagreement over how to assess the progress of children who were born very prematurely by setting their age either from their actual birth date or corrected to their due birth date. New policies for managed care networks, with increased transfers of babies between units, are designed to ensure the highest use of scarce staff time, by matching each baby's need to the staff team/time with the appropriate level of expertise.

People transfer agency on to time: 'We'll wait and see what the future brings'; 'We'll improve the policies after we move into the new unit'. Time plays a powerful part in evidence based medicine, when practitioners insist that a standard that happens to be practised now must continue, and they reject proposed changes 'until there is enough research evidence'. Time stands still while the present practice continues *because* it is the present one, and not obviously more efficacious than alternatives.

Natural time tends to be cyclical, unlike linear clock time. There are the babies' breathing, heart rate and oxygen saturation, and the slower rhythmical cycles of digestion and sleep-wake patterns. Relationships between babies and parents gradually deepen with time, and restful skin-to-skin ('kangaroo') contact helps their physiological cycles to slow down in therapeutic ways. The mother quoted below, for example, mentions the micro-timing of improved oxygen saturation rates, while perceiving her

relationship in terms of time and pace: 'immediately', 'beginning', 'rush', 'ended up', 'twice a day', 'always'.

I immediately fell in love with her. Immediately...At the beginning...I sort of tried to distance myself emotionally...a part of me didn't want to get attached to her, because I thought she was going to die... I was protecting myself so I didn't want to rush and have contact [but later] I ended up having kangaroo care like twice a day...so we was getting really close, you know, it was lovely, and I felt that she was my baby and I could get to know her...She was always happy with that, she was always saturating well...

The NICU inevitably disrupts family time and timing, so that a central therapeutic task is the constant effort to reduce timed disruptions and to promote the slower family time, as far as is compatible with effective and often rushed clinical care. Just as babies move constantly between approaching and withdrawing (Als 1999), parents could feel ambiguous about becoming closely involved with their baby or self-protectively distancing themselves, as the mother quoted above has described. Commenting on the way the nurses in one unit did not proactively encourage parent-baby contact, one mother described her sense of urgency and how she asked to have earlier contact.

It would be impossible for me to wait four weeks before touching him as some parents say they do. How could you build a relationship with your child? When you take him out and cuddle him, the mother or the father, you are fully involved, he calms right down.

Babies rest and relax more easily when they are dressed in soft clothes and hats, with cotton 'nests' and blankets that absorb sounds (Als 1999; Warren 2001) whereas, in some intensive care and high dependency areas, babies lie undressed with possibly only a rough towel loosely looped round them, their warmth maintained by the incubator. It is easier for parents to lift babies out of incubators and cots in the first type of NICU. However, much nursing time is needed to ensure that clean clothes, nests and blankets, suited to each babies' size, are always available. This is one example of how policies dominated by costed clock time may preclude allocating nursing time to this task, whereas attention to natural time and the effects on the babies' cyclical body rhythms and on the relationships between parents and babies would appreciate the value, as well as the cost, of nursing time devoted to providing the clothing. Many parents bring in clothes and blankets, but this also takes up nursing time, to ensure that they are used and not lost.

Decisions about the best use of nursing time relate to the third time-scape, social time. Social time may pass too quickly for practitioners trying to fit numerous tasks into the day. Time passes far too slowly for parents. It is extremely stressful, when perceptions and experiences of time are markedly out of synch with clock time, and when people in contrasting time scales are trying to understand one another. Time links to perceptions of social status, such as the moral and legal time barrier that babies move through at birth when suddenly they acquire human rights. There is uncertainty about which time zone premature babies are in and whether they primarily have the needs of a fetus or of a term baby. Status and authority link to time in terms of people's age and how long they have worked in their profession and in the unit. This can complicate efforts to hold equal discussions between people with long or short records of experience, and the complications are explored in the papers.

To recognise that time is not a single entity, and to see differences between clock, natural and social time-scapes, although these overlap, can help practitioners and policy makers to perceive when problems are under or over connected and attributed to clock time. People may blame inexorable lack of clock time rather than altering their use of time. They may acknowledge and try to reduce very painful mismatches between the pace of costed clock time and the value of natural and social time, especially for newborn babies and their families. Time can be seen as a complex flexible shared resource, that may be negotiated in ways that open or close parents' share in contributing to and influencing the babies' care. Valuing the present moment can help to promote aims over the means and tools in the NICU, such as by supporting ways to increase babies' 'quality time' when they sleep deeply or are calmly awake and alert. Clock time in scientific neonatal care contributes to life-sustaining treatment, monitoring and healing, although it needs to be held in balance with the healing that promotes and restores babies' natural rhythms and self-regulation in resting or feeding.

This project on 'foretelling futures' reports practitioners' and parents' views about predictions of babies' future health and abilities, which are often framed as sets of variables that may or may not prove to be accurate. The project also considers explanations about how the neonatal present and predicted futures are perceived and constructed, by looking at 'webs of causation' and risk factors and underlying explanatory processes (Scambler and Higgs 1999; Scambler 2001; Brown *et al.* 2000). Two papers on time will develop this analysis.

4.E Knowledge

The three papers on knowledge are based on the interviews with 40 practitioners. Like the previous summaries, they outline ideas, which are more fully analysed and have more extracts from the interviews in the full journal papers. The first paper examines how practitioners help parents to cope with uncertainty and suffering.

Knowledge, suffering and uncertainty

Practitioners' responsibilities include enabling parents to cope with medical uncertainties about the past, present and future, and to work through processes that help them to accept and live with future outcomes. During interviews, practitioners frequently discussed the limits of medical knowledge and of data, for example, from brain scans, to inform doctors' understanding of the current and potential future state of the baby's brain and neuro-development. Babies often made unexpectedly better or worse progress, and uncertainty may continue for years when mild or moderate learning or behavioural difficulties do not show definitely until children are at school.

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. At times, practitioners have to persuade parents to readjust their expectations of the child's future, not only in

order to make a definite decision about treatment, but also in order to be able to accept whatever the future brings. This more open kind of partly helpless acceptance of a nebulous future, possibly of severe impairment or early death, can be harder for parents and practitioners to understand and achieve than informed decisions about definite neonatal interventions, when the adults have some sense of control and active hope.

Relative helplessness links to suffering, which means to undergo or to bear, in contrast to the comparative security of agency and some freedom to act and control one's circumstances. When they cannot prevent or cure disease or disability, practitioners partly share the position of patients, of the babies and parents who have to endure suffering. Some practitioners also described their ambiguities and uncertainties about whether the hoped for benefits of treatments and investigations exceeded the harm and pain they could cause, and they discussed how neonatal care could be more sensitive to the babies' needs. Doctors could feel a sense of professional as well as personal failure when babies died or were severely impaired (Christakis 1999, 2003). Practitioners also tended to feel a moral responsibility in how they might affect the present and future relationships between babies and parents, and the babies' future welfare, when they warned parents about the babies' impairments or likely future problems. Sometimes the duty of care to comfort and support parents could complicate the duty to inform parents honestly and to involve them making hard decisions. Occasionally, the staff felt forced to continue to care for a baby whose parents, against their advice, refused to consent to withdrawal of life support. These staff sometimes felt a 'humanitarian angst', similar to the uncertainty experienced by people who give medical aid during wars and other complicated emergencies. There is ambiguity about when to intervene or not intervene, and the traumatic realisation that they cannot do good without also doing harm (Kleinman *et al.* 1997; Anderson 1998; Weiss 1999; Fox 2003). There is the added awareness that giving painful treatment to babies now might increase their potential future suffering.

Non-intervention entails either withholding or withdrawing treatment. One Dutch NICU takes the view that treatment must be withheld from babies born <26 weeks gestation (Vermeulen 2004), but this involves several major problems. Parents are likely to hear of exceptional cases of babies born at 23 weeks who have survived unimpaired (the latest EPICURE report in press includes one example, for an earlier EPICURE report see Wood *et al.*, 2000) and the parents may therefore have lasting bitter regrets. The initially untreated baby may survive in a sufficiently viable state until the staff feel morally bound to provide care, but by that time the baby may have sustained injuries that might have been prevented if treatment had started earlier. Many practitioners argue that babies born around 28 or even 32 weeks used to be thought not viable, but are now comparatively easy to care for, so that setting arbitrary age limits will prevent medical progress that one day could ensure the healthy survival of babies born <25 weeks gestation. The suffering of individual babies today may partly be vindicated by the general benefit to future babies through the skill and knowledge gained by caring for today's borderline babies. Others reply that the care is too experimental with too much suffering for babies and parents in neonatal units, and for some children through subsequent years, to justify the few successful cases. The 'foretelling futures' project does not aim to adjudicate or resolve these arguments, but instead reports, with examples, how practitioners and families try to deal with the arguments and the consequent suffering in everyday practice. Somehow practitioners have to respond to individual families' needs and also to wider general social values.

Neonatal practitioners described uncomfortably holding two positions in 'a sort of greyness', which continues the prenatal pro-choice and pro-life positions after birth, when doctors are guided by parents' seeming preference either to accept or reject their impaired or potentially impaired baby. While the prognosis is still uncertain, doctors conduct more investigations in the search for certainty, or they maintain uncertainty and speak of 'watching and waiting', 'only time will tell'. The balancing of probabilities and uncertainties while supporting parents draws on clinicians' intellectual and emotional capacities (Bursztajn *et al.* 1990). There is a spiritual dimension in healthcare, in the work of finding meaning in suffering and the compassionate sharing of parents' need for hope (Fox 2003: 261-5). Talcott Parson's concept of 'ritualised optimism' can be distinguished from hope derived from faith or spiritual beliefs.

Moral dilemmas involve irreconcilable opposites, so that although practical decisions must be made, the responsible adults also have to tolerate ambivalence about the potential dual effects of their interventions. This involves a kind of suffering that practitioners share with the parents, because although both have unique capacities to help the baby, they are also both relatively helpless as to the baby's future survival and quality of life. For most parents this will be a new experience that requires them to learn very quickly, whereas doctors are experienced and have been trained for uncertainty (Fox 1957). The capacity to live with uncertainty is perhaps something that parents most need help with, and is a main way in which some doctors are able to help them. This 'soteriological' humane medicine that involves the transforming of suffering, and the reducing and containing of anxiety may 'irrupt' into the rational-technical-scientific sphere, and doctors often report these times as professionally the most satisfying moments when they can combine intellectual excitement with 'a passionate engagement with the primal forces of sickness and suffering' (Good 1994: 85). Paradoxically, the extremes of modern high-technology medicine can especially call on practitioners' traditional qualities of humanity summarised as 'bedside manner'. By contrast, work which calls only on one or other of these capacities can lead to doctors and nurses experiencing either boredom or burnout (Ehrich 2000).

A sister referred to both capacities when describing the qualities in doctors that parents find most helpful: 'the human approach, parents value technical skill and knowledge, and they value doctors who are human. Most parents see them as demi-gods who know all and have power to bring things into existence. But as well as being good clinically, they like doctors to sit with them and talk to them as a person'. A consultant found 'constant strain and worrying' most tiring and stressful with loss of control in routines: 'the labour ward not having enough resources, and having to transfer babies out, the pressures we're under from management about overspend and things like that, those are the two things that I find killing, not the diagnoses...' which call for extra intellectual and emotional activity. A sister described these as 'exciting' challenges.

[Y]ou have to grow within [your] specialty and so things that you found particularly challenging years ago you won't find a challenge anymore, because you've sort of been there and done that a bit [...] ¹ I no longer get a high level of anxiety when I'm asked to go to labour ward [...] when you've not had a lot of experience, you have palpitations [...] Now I won't say it doesn't bother me because really, you know, it is a very important thing that you're doing, but you don't have the same degree of anxiety because you can second guess what is actually going to

¹ [...] denotes words omitted by author.

happen. [...] What generates anxiety mainly is fear of the unknown [...] We had 27 week twins delivered, one that we knew had a severe congenital abnormality, and [...] I was more than happy to go over [to the labour ward ...] it's still exciting to be involved in those sorts of things, because you think, you know, whilst you can anticipate what is going to happen, you never really know until the baby's here.

The two sources of tension between scientific-technical skills and also humane interpersonal capacities, between responses to individual and also to general needs, require sophisticated responses from the practitioners, individually and collectively. The interviewees expressed concerns that the great advances and techniques of medical science can be potentially ambiguous and even dangerous tools, without the valuable personal qualities, knowledge, judgement and compassion that they described.

Suspended futures in neonatal intensive care units

This paper continues selected themes from the previous paper in greater detail. How can neonatal practitioners help parents to inhabit the present when the future and sometimes the past are so uncertain?

Predicting uncertain futures

Rather than attempting to speculate on the babies' possible futures and optimal ways to support their development, the 'foretelling futures' study aims to examine who takes responsibility for the future, and to uncover underlying, sometimes taken-for-granted processes on 'how the future is created, constructed, contested, colonised and consumed, how it is materialised, managed and mastered' and how risks are played against potential benefits (Adam 2000). This involves seeing how people predict the future. Brown *et al.* (2000) found that predictions tend to concentrate on technology and pay little attention to human relationships or social inclusion or 'the life world' (Scambler 2001). Predictions made by different interest groups may favour or 'lock in' promising outcomes and thereby 'lock out' other possibilities. The future is actively constructed through competing present claims. Dominant ones promote excitement and faith in medical advances and 'break throughs', which make it harder for neonatal staff to contain parents' rising expectations, although the staff also promote this faith in partly experimental endeavours, and are more likely to discuss how to conduct an intervention rather than whether to do so. Competing claims in debates about the gestational age when a premature baby begins to become viable, and is entitled to neonatal care, and can have a prospect of a reasonable life provide one example of how futures are constructed and contested.

The limbo of the uncertain present

People living through crisis are often told to live 'one day at a time', but parents in NICU cannot fully inhabit the 'now'. They do not know if today is one of many days in their baby's eventually healthy life, or perhaps one of only a few days in their baby's short life, with magnified significance for every event and moment in it.

People can't celebrate that they have a child. They dare not. Someone might go out after two or three months and buy a little pair of booties and the baby becomes ill, and they put them away and think, 'I shouldn't have done that'. [...] I

think a lot of parents haven't even allowed themselves a normal relationship with their child, because they think their child will be taken away (neonatal counsellor).

What cannot be known now destabilises present and future meaning. The meaning of today is emergent, contingent on the baby's tomorrow. An ultrasound scan doesn't mean anything in itself. It may record past haemorrhages and changes in the brain, which might still be occurring though they are not yet visible on the scan. Its full meaning can only be known certainly through future events, although parents hope that the scan can tell them something about the future. How do the staff give uncertain news without making promises or raising undue hopes?

This paper reviews the use of accounts, photographs and drawings to explain possible brain damage in attempts to lend the uncertain future a slightly more tangible reality in the present, and to help parents to find meaning in each day. Predictions of the babies' futures, envisaging what these might or should be like, in a sense construct and 'perform' versions of the future strategically to help to manage the present in different ways. Predicted futures of new technologies often turn out to be inaccurate when they fail to take account of social contexts (Geels and Smit 2000). For example, the staff frequently deplored the lack of therapies and social support to follow up neonatal care and enable babies to live more fully the life that neonatal technology has salvaged. Predictions about lack of support also led to cautious accounts about the babies' futures and the overall value of neonatal care after extremely premature birth.

Individual decisions were seen as having two important societal implications: the babies' survival may influence society's future economic and social policies, and there is a lack of societal consensus on how unpalatable decisions should be made about extremely premature or sick babies, and about the social acceptability of severely impaired children, which leaves doctors and parents individually to have to grapple with hard choices within contradictory social values.

I think until society makes some decisions that life is not for everybody 90 years, that comes down to parents and staff learning that. It is a societal thing, not just our ward. We as a society have to make a decision and maybe look at some of these babies. Parents think with their prayers everything is going to be ok, or with all our care the baby is going to be fine [and...] it's ok to carry him around and change his nappies now, but at 10 years of age when his family life and parents' relationship has completely broken down [...sighs] we have more disabled kids as a result of neonatal care, behavioural and learning difficulties, mobility (neonatal sister).

Through delegating such decisions to doctors, society expects doctors to arbitrate and to persuade colleagues and parents to accept choices about which babies can have access to limited health and social care and life support. The longstanding severe shortage of staffed neonatal cots could be seen as political pressure, exerted deliberately or inadvertently, to force doctors to be more choosy about whom they will save. The shortage also makes economic decisions appear to be medical ones about which babies are most likely to benefit from services. The paper reports practitioners' views about how uncertainty is managed when 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.

Practitioners often emphasised to parents that they too are uncertain about the future, and are not withholding information, but also have to wait and see. There is a play of time with uncertainty. The past and future cast shadows and suspend the ability to live knowingly in the present. One influence is the projected futures of foretold medical and social scenarios awaiting the baby, which are used rhetorically and strategically (Billig 1991). They are used in subtle ways to influence how people can live with and cope with present uncertainty, make decisions and prepare for the future (Michael 2000). For example, there is talk of 'miracle' babies and managed optimism, or forms of realism and pessimism. The invoked futures may be based on the medical model of impairment, or the social model of disability that takes greater account of enabling or disabling circumstances (Oliver 1996). There is concern that projected negative futures may determine the present and future through becoming self-fulfilling prophecies (Christakis 2003).

I think it's very important not to be too negative about their children. I think it is extraordinary the emotion that you feel for your child, and I don't think it is actually very helpful to constantly have people giving you negative information (consultant).

Practitioners who have worked in neonatal units for decades remember how rapidly past practices and the expectations of very premature babies' futures have changed, which casts further uncertainty on present policies and prognoses. The future is always out of reach and makes currently accepted knowledge questionable.

I can remember babies that I looked after in the late '60s and early '70s. You cared for them with great love and attention, and they died. I know that they wouldn't have died now, because they would have been just straight forward run of the mill sort of babies really, but at that stage they were the ones that were really on the edge of viability. We hadn't got the knowledge. We perhaps did things to some babies that in retrospect were pretty horrendous, but at the time we thought it was the best thing. I'm sure there must be things [...] that we do now that we think are absolutely the bees knees, in 20 [...] or even 50 years time people will think 'however could they have thought that that was a good idea?' But you don't deliberately do some things that are unsafe do you? You do what at the time is the best with what you've got (sister).

The constant pushing back of boundaries brings new uncertainties when clinical interventions are partly experimental efforts in the historical endeavour to keep reducing morbidity and mortality and to enable smaller babies to survive. The endeavour alters what it means to be a viable human being with human rights. Paradoxically, while babies born from 22 weeks gestation are gaining a higher chance of receiving neonatal treatment, ultrasound fetal scanning is revealing more conditions for which termination of pregnancy may be offered, so that the survival of the fetus right up to 40 weeks is becoming more provisional. Debates about the level of neonatal viability, when treatment should be either offered or withheld, partly revolve on whether extremely premature babies truly exist or else are in some form of suspended time limbo, having lost their fetal past before they could achieve a human present. The debates were coloured by the practitioners' reported memories of how former patients succeeded or failed in realising medical hopes for their future.

We can only exist and think in the present, but we 'manage' in the present by 'deploying representations of the past and future' (Michael 2000:21). Interviewees repeatedly discussed how the meaning of today or yesterday, including the meaning of the effects of clinical interventions, is emergent (Paget 1988) and depends on the baby's tomorrow. Neonatal staff therefore to some extent have to try to keep parents thinking in the now, and to prevent them from thinking too confidently about the future, or thinking about what might have been. The encouragement continued in some cases after babies went home.

I always say to them, just enjoy the baby as she is at the moment, don't worry too much, obviously they will worry about it, don't get me wrong, but I always say just enjoy, you know, being at home and get to know her, see how she is first before you start planning on what may or may not go wrong, unless they categorically have been told, because I think parents always have hopes, don't they, on the whole, and they always hope the doctors are going to be wrong, don't they? (community liaison sister).

Parents of 40 of the 80 babies in the 'foretelling futures' study gave follow up interviews months later, and were asked questions about possible continuing effects on the babies of their NICU experiences. However, the longer term effects seemed to be felt by the parents rather than the babies. Some parents anxiously guarded their children, for example from infection, in ways that suggested that these parents felt that their babies' 'normal childhood' was still 'on hold', a limited and partly suspended present constrained by anxious uncertainties about the future.

Knowledge and information in neonatal intensive care units

Despite medico-legal guidance that parents must be fully informed, practitioners discussed occasions when certain things could not be said, as well as what could be said or must be recorded. Three kinds of NICU communication are reviewed in this paper. The first kind is talk that is legitimised in NICU custom and practice, for example, when staff try to give consistent details to parents that accord with their colleagues' accounts. The second kind involves 'tricky' talk or topics, and staff describe using caution in interpreting information and warning about the future and possible risks. The third kind is communication that must be recorded in official documents, whether or not it is spoken about. This paper considers in more detail the theme in the previous paper that when 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.

In district general hospitals junior doctors have more responsibility, but in the specialised NICU junior doctors and nurses leave much information giving to the consultants. They set the content and extent of information, make prognoses, explain investigation results, convey risk and uncertainty and, as far as it is feasible and humane to do so, encourage parents to look into the future. A consultant explained an example of what would not be said.

If there's dilatation and then that's ongoing to the point where they'd need a shunt then ... then you're talking long term developmental problems, but you see we wouldn't talk about that with them, the impact that potentially ... we would say there's dilatations, grade 3, again we can't really tell you necessarily what the

outcomes are, but this child may need a shunt if the ventricles continue enlarging, erm ... the developmental outcome may, you know, be poor, because we can't tell because we can't. Erm ... that's very generally the view here. If they were then to go on and need a shunt, then to consent for a shunt we don't really say that in the next 5 years your child may need 22 operations to revise this shunt, you know, we don't go on to tell them potentially what the long term problems are of shunts and things like that. [...] [W]e just go ahead, we get them to consent to a shunt, but we're not saying that we are potentially creating problems here for you and this child for life, you know, infections, shunt revisions, blockages, we don't explain all that [...] [W]e tell them now the immediate impact of having a shunt put in, and the benefits of having a shunt put in and the potential initial problems, you know, it could get blocked ... it could get infected, but we don't say that's ongoing for the next ... for how ever long your child's got to live or requires the shunt.

Another consultant described managing hope.

I think that [...] you have certainly got to be careful not to dampen all hope and enthusiasm for the outcome of a patient because some parents go off in a big way when you tell them bad things about their baby and there is always an element of not knowing except for the few percent of patients when you really do know, if a baby is going to do well I am uniformly and 100% optimistic at all times, because to be anything else would be entertaining thoughts that you weren't sharing with the parents.

Nurses also used silence and caution, as described above in an earlier paper. Practitioners described warily keeping records.

I think people are generally more litigious, and we have been educated to be more defensive, and it means you do extra tests, and spend more time writing notes. You do worry that you are going to end up being sued or suspended (consultant).

[S]ometimes parents can be termed difficult parents, but it's such an awful time, they're so overwhelmed [...] one of our parents who swore that she was not told about the possibility of baby being brain damaged [...] when the baby was about a year old and not doing things that you would expect a one year old to do [...] and] another lady [...] again refused to hear anything negative and again I had to say to her, 'You must let the doctors know that you are hearing, you're understanding what they say', but even then she swore that she did not hear, they did not say, fortunately they had then taken to documenting what they had done (sister).

Practitioners were also wary when parents believed that obstetric problems during labour had led to the baby's injuries, and in some cases they had observed the problems occurring.

I think we are more aware of (medical legal concerns), erm [...] particularly with the link with obstetrics and some of the difficult deliveries that come through to us, and I think that would probably encompass the babies that present with encephalopathy and some of them do end up as complaints and require an investigation. [...] we are usually trying then to optimise things for the baby, and

I don't feel concerned or any more concerned about our practice and medical legal problems. I think we are much more aware of writing down conversations [...] because I think from that point of view I am slightly more aware that people tend to ... or seem to complain more or can complain more (consultant).

Some practitioners were uncertain how frank to be with parents about limited resources, such as when babies had to be transferred between units when it was not in their own best interests but was a matter of resource management. Another example was when babies were not given enough individual attention because of lack of staff time, in the view of parents and/or the staff. The paper reviews discussions about staff feeling they should advocate for patients at such times, and how they believe trust between staff and parents is affected by strains and awkward silence about limited resources. This is another example of how economic pressures can be converted into personal responsibilities carried by practitioners in how they decide to allocate resources and how they decide to explain the problems to parents or try to conceal them. The paper develops the theme from earlier papers that, 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.

Section 5

The summary report is printed on the next four pages

As explained in the introduction, because each paper explores answers to one or more of the research questions separately and at some length, we have not tried to summarise the answers into a concluding section. Instead, section 5 gives a four-page summary about the whole project and some key findings. We will print many copies of this 4-page report for widespread distribution.

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.

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 within 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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For further details, see <http://www.ioe.ac.uk/ssru/projects/neonatalfutures>

6. Appendix A. Details about the four neonatal units in the study

	(1)	(2)	(3)	(4)
Total number of babies admitted per annum to NICU	404 incl 24 readmiss	c 334	567 incl 148 readmiss	510 incl 106 outborn transfers
Average length of stay in days	30	--	20	--
Number admitted < 28 weeks	42	40	147	40
28-37	170	147	222	244
> 37	192	147	198	226
Number <1000gm	52	35	43)	50)
1000-2500 gm	148	145	206) 419	196) 503
> 2500 gm	204	154	170) 148 readmis not incl	257) Plus 7 unrecorded
Discharged to: Postnatal ward	--	174	--	--
To NICU/SCBU/paediat/surgical	--	56	--	--
Home	--	87	--	--
Deceased	--	17	--	--
Available cots in IC	10	8	12	12
HD	8	6	6	6
SC	7	8	12	4
Transitional care	4 (8 if all have twins)	6	42 postnatal beds	20 dedicated ward next to NICU
Staff: FTE				
Consultants	5	4.5	4	6
SPR (Registrars)	4	5	6	6
SHOs	6	6	6	8
Research	2	0	4	1
Number of vacant medical posts	DK	0	2	DK
Nurses: FTE				
H Grade	3 (-1)	1	5	3
G Grade	10 (1)	9	11	7
F Grade	10 (3)	14	5	12
E Grade	17 (22)	14	16	18
D Grade	18 (-1)	6	26	
C Grade (NNEB)	5 (1)	4	1	4
B Grade			8	
A Grade	3		1	
Agency			16	
Research		0	0	1
ANNP	2 (0)		(2 H grade)	
Community/HV	1 (0)	2	1	2
Number of funded nursing staff	94			
Number In Post nursing staff	69	50	74	47
Number of vacant nursing posts	25	16	DK	15
Reception/Secretaries/Ward Clerk	3	2	3	3

Cleaner	1	1	2	2
Ward assistant		1.25		
Positive touch	0	0.4	0	As required
Psychologist	0	0	0	2 hours per week.
Social Worker	1	0.1	0	As required
Occupational therapy	As required	1.5	As required	As required
Physio	1	0.1	As required	As required
Speech	1	As required	0.05	As required
Chaplains	Anglican, RC, Free Church, Muslim & Jewish	As required	As required	As required
Audiology	1	Routine as required	As required	1
Radiography	Team	As required	As required	As required
Pharmacy	1	0.25	daily ward round	< 0.5
Counsellor	1	2 (0.3 FTE)	0	1 (0.5 FTE)
Technician	1	1	As required	0.25
Dietician	1	0.4	0.4	0.5
Breast feeding support	weekly breast feeding workshop	0.5 + 0.5 ITU nurse	counsellor based in maternity unit	drop-in feeding clinic
% babies went home mainly breastfeeding	--	76%	--	--
Psycho support				
For babies	NIDCAP	NIDCAP, NBAS, positive touch;	none;	Brazelton;
For parents	weekly support gp & indiv counsellor;	weekly support gp with parent counsellor	referred to psycho-therapist in another unit if required;	counsellor; support gp on a need basis;
For staff	counsellor & Oasis	weekly gp with staff counsellor	none	not in formal way
Parent and baby rooms in/near unit				
Single beds	0	1	1	0
Double beds	2	2	1	5

Transition care ward	4	6	0	15
Kitchens for parents	Yes, fridge, kettle, microwave, sink	Yes, fridge, kettle, microwave, sink	Yes, sink, coffee machine	Yes, fridge, kettle, microwave, sink
Food provided for parents	--	Drinks, spreads, bread, biscuits, meal tokens	None	Sand-wiches for BF mothers
Baths	0	0	0	0
Showers	1	1	1	2
Toilets	1	3	2	2
Beds occupied by parents in past week	14	14	DK	DK
Help granted in past month for parents' travel	Info not available	confidential info	DK	DK
How often was an interpreter/link used in month	4	DK	DK	2
Are parents allowed/not allowed/encouraged to stay during ward rounds	allowed to listen to info about own baby	allowed, not encouraged	not allowed	Not allowed during principal ward round
Other arrangements for parents	weekly appt list with specialist registrars			
When was Unit opened	1930s	DK	1968	DK
Upgraded/ reopened	1966/1980s	1990/1997	1988/2002	1983/1996/2003
Annual Budget:	£4.6 m	-	£2.6 m	-

6. Appendix B.

The 65 babies whose parents were interviewed in the neonatal units

Parents of the other 15 children were interviewed 4-6 years after their children had been in the NICU.

Mothers' ages ranged from 17 – 41 years, mean age 31 years
44 babies were born by caesarean section, 3 by forceps, 18 by vaginal birth.
33 boys, 32 girls,
43 had no older surviving siblings, 1 set of triplets, 3 sets of surviving twins

Babies' gestational age at birth

	%
23-25weeks	18.5
26-31weeks	41.5
32-35weeks	21.5
36-42weeks	18.5
Total	100.0

Birth weight in grams

	%
<1500	67.2
1500-2499	14.0
2500+	18.8
Total	100.0

Overall days in NICU 12 – 290 days (includes 21 transfers out to other units)
mean number of 68 days, 8 babies not recorded

13 babies had NIDCAP (20%), 18 babies had NBAS (28%)

10 babies transferred into NICU other than from the labour ward in the same hospital,
8 postnatal transfers, 1 home birth, 1 from postnatal ward

17 had feeding tube in at discharge (27%)
7 discharged on oxygen (11%)

Babies' ethnicity

34 White (52%)
16 Black African or African-Caribbean (25%)
2 Asian (3%)
6 Mixed race (9%)
7 not stated (11%)

44 had ventilation (68%), 18 had surgery (28%)
14 had surgery in same hospital, 4 were transferred elsewhere

List of surgical procedures

anal stretch and rectal biopsy
close hole in heart
broviac line
gastroschisis repair
gastrostomy
hernia repair
Hickman line
laparotomy
liver biopsy
For necrotizing enterocolitis
PDA ligation
pleural aspiration
pulmonary artery band
remove left kidney,
remove liver cysts
Rickham reservoir

Babies' diagnoses

acidosis
adrenocortical insufficiency
agenesis of corpus callosum
albinism
anaemia
bilateral cataracts
bilateral hydrocele
bilateral pleural effusions
bilateral purencephalic cysts
bilateral ventriculomegaly
undescended testes
bilateral periventricular leukomalacia
bone disease
bradycardia
chronic lung disease
coagulopathy
congenital abnormalities

conjugated hyperbilirubinaemia
cranial haemorrhage
distal ileostomy
Down's syndrome
epilepsy
exomphalos
gastroschisis
gastro-oesophageal reflux - GOR
haemorrhagic disease of newborn
hyaline membrane disease - HMD
hydrocephalus
hypercalcaemia+hypertension
hyperglycaemia
hypoglycaemia
hyponatraemia
hypotension
hypoxic-ischemic encephalopathy - HIE
infections
inguinal hernia
intrauterine growth retardation - IUGR
intraventricular haemorrhage - IVH
jaundice
necrotizing enterocolitis - NEC
nephroma
occipital infarct
patent ductus arteriosus PDA
pneumonia
pneumothorax
polycythaemia
polycystic kidneys
possible left parietal infarct + right
prematurity
pulmonary stenosis
pulmonary haemorrhage
respiratory distress syndrome RDS
rickets of prematurity
retinopathy of prematurity - ROP
seizures
tachycardia

6 Appendix C. Information leaflets for 1) parents and 2) practitioners

Printed on coloured paper and folded to A5 leaflets

Letter heads

Thinking about the future

A social research project, March 2002 - February 2004

Research team: Margaret Killen at this hospital, with Priscilla Alderson, Inga Warren and Joanna Hawthorne who are researching in other baby units.

This leaflet is being given to parents so that, if you meet me, you will know something about what I am doing. I hope that you will not mind me being around, observing the routines and talking to people. Please feel free to ask me about the research at any time. I am also asking 20 parents if they might help me by taking part in tape-recorded interviews.

Why is the research being done? When a baby needs intensive care, parents often say that they live from day to day – that there is too much to think about now, without looking further ahead. Yet parents also often wonder about how being born early, and having intensive care, might affect their baby's future.

Doctors can do a growing range of tests, such as brain scans. But what the results mean, in terms of how the baby will develop, is not always clear. It is not easy to share complex, uncertain knowledge.

There is also new knowledge about how babies react to having intensive care and how they express their needs.

Recent reports advise that doctors must tell parents as much as possible about their baby's condition and treatment, and about the likely future effects on their child.

What are the research aims? We aim to find out more about these fairly new developments, and to compare how they affect families and staff in four baby units. What do parents think are the best ways for them to become informed and involved in their baby's care? How do they want to talk about their baby's condition and treatment and likely future? Parents' views could help to improve standards of care and information sharing in baby units everywhere. The research will also look at how the many kinds of knowledge about babies' care and brain development fit together. How can babies' medical needs be balanced well with their emotional and social needs? A multi-disciplinary group will review these questions in the light of related research reports and anonymous reports from this study.

How will families be affected by the research? There will be general observations. I will ask 16 parents in the Unit to take part in one or two formal tape-recorded interviews lasting about an hour.

I will ask five of these families, whose baby stays in the baby unit for some weeks, if I can talk to them regularly. I may ask to meet you or telephone you later at your home.

I will also interview four parents of older children who once stayed in the Unit.

Four baby units are taking part in this project, involving 80 parents and babies, and 32 staff who will also be interviewed.

The main research questions for parents

* The kinds of ways of sharing information about their baby's future that parents find helpful, or not helpful.

* The kinds of support that parents find help them to care for and feel close to their baby in intensive care.

* What parents think about the ways their baby feels and reacts.

* How parents, doctors, nurses and other people involved with the baby share ideas about the best ways to care for and treat each baby.

Parents' rights. Do you have to take part in the research?

No. It is for you to decide. Whether you help us or not, you and your baby will still go on having just the same care.

The general observations If you do not want me to talk to you or observe near you, please let me know and I will move away. You may want to ask a nurse to tell me. I know that parents want to be left alone sometimes.

The tape-recorded interviews You will have time to ask questions, and time to decide if you choose to do an interview or not. If you agree, I will ask you to sign a consent form.

During the interview please tell me if you want to stop, or have a break, or opt out of the research. If you don't want to answer some questions, just say 'pass'. You do not have to give me any reason.

There are no right or wrong answers. It is your own views on your baby's care and future that matter. I will ask for your permission to see your baby's medical notes.

If you wish, you can have a copy of your typed interview transcript, and you can tell me if you want any words changed or taken out.

The research team will see the notes and transcripts, but we will respect your privacy

- We will keep all our research tapes and records in a safe lockable place and treat all data according to the Data Protection Act (1998).

- We will make sure that if we repeat your comments to anyone else, and publish them in research reports, that you cannot be identified.

The five families I hope that five of the 20 parents will agree to talking to me informally over some weeks, if their baby is likely to stay in the unit for some time. All the same rights will apply to them.

Will doing the research help parents and babies? I hope you will enjoy talking to me. Yet the main point of doing the research is to collect and report knowledge that will help parents, babies and staff in neonatal units everywhere.

Could there be any problems for parents who help with the research? Most people enjoy talking about their views, but some people might feel worried or upset when talking. If this happens, I will stop the session if they want to, and I can put them in touch with someone who could help them, if they wish.

As this is not medical research and I will not touch the babies, there is no risk of physical harm, but I have to let you know that if anyone did feel that a parent or baby had been injured and wanted compensation, the indemnity costs would be covered.

The research results We will send everyone who helps us a short report in Spring 2004, with details about how we can send you longer reports if you would like to see them.

Funds The Wellcome Trust Bioethics Programme is paying for the research costs, part-time salaries for three of the researchers, and a contribution to each baby unit for the time and support given by the staff.

The research is based at the Social Science Research Unit, Institute of Education, University of London.

If you would like to have more details please contact me, Margaret, [address, telephone, email] or [name and contact details of consultant neonatologist].

We will give you a copy of this leaflet and your consent form to keep. This project has the support of [consultant's name] and his colleagues, and has been reviewed by the hospital Local Research Ethics Committee, project no. 02/0006. Leaflet version 3, summer 2002.

Thank you for reading this leaflet and helping us to find better ways to care for babies and their families

Letter heads

Thinking about the future: dilemmas in neonatal neurology

A social research project in four NICU, March 2002 – Feb 2004

The purposes of this leaflet are:

- to inform all staff in the four NICU concerned, about this project;
- to ask the staff if they are willing to help informally with the research, such as by allowing us to observe their work, and by answering occasional questions;
- to enable the staff to tell parents or new colleagues who enquire about the project how to obtain further details;
- and to invite four neonatologists and four neonatal nurses in each NICU to take part in a tape-recorded interview lasting about an hour.

Background Fairly recent developments increase pressures on practitioners and families in NICU, offering new benefits but also complicating neurologically-related ethical dilemmas. New treatments enable babies who are more small and sick to survive. Diagnostic techniques such as scans reveal neurological evidence but the future implications are not always clear. There is growing knowledge about neonatal neuro-development, and of methods of charting babies' responses and ascertaining their preferences. Recent Inquiries and Guidelines urge that parents should be more involved, and require practitioners to share complex, distressing and uncertain information with parents and take account of their varying cultural beliefs and values.

The research aims to investigate these 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 and what are babies' neuro-behavioural responses to NICU care?
- * How can multi disciplinary insights - medical, nursing, parental, neuro-developmental, sociological, psychological, ethical and religious - increase understanding of neuro-related NICU practice and prognoses?
- * What are the strengths and gaps in current knowledge and practice?

Benefits This research aims to discover more about these fairly new developments, the multi-disciplinary research literature and about the views of staff and parents to provide coherent research based information intended to help to improve standards of care and information-sharing in baby units everywhere.

Research methods

- * A wide-ranging, question-raising, multi-disciplinary literature review on the spectrum of meanings, research reports and practices relating to neonatal neurology.
- * Ethnographic observations and in-depth interviews, in 4 NICU, with 16 neonatologists, 16 neonatal nurses, 64 parents in the Units, and 16 parents whose babies have been in NICU, to produce descriptive analyses of methods with which staff and parents manage and share neonatal neurological-related information and ethical dilemmas.

- * Detailed studies of 10 babies with neurological or potential neuro-developmental problems, using adapted Brazelton methods (at two other Units, not University College).
- * Six multi-disciplinary advisory meetings with neonatal staff to discuss the anonymised research data, led by an ethicist.
- * Qualitative and quantitative data analysis and writing of research reports to answer the research questions.
- * Designing of a subsequent systematic analysis and grading review of the neonatal neurological-related literature by a clinician.

Risks, discomfort Most people enjoy talking about their views, but some staff might feel anxious about some of the topics we discuss with them. Our aim is to find supportive ways of tackling common dilemmas. As this is not medical research there is no risk of physical harm, but we have to let you know that if anyone did feel that they had been injured and wanted compensation, the researchers' indemnity costs would be covered.

Researchers Priscilla Alderson PhD, Professor of Childhood Studies and Margaret Killen RGN RHV BA Research Officer (Institute of Education, University of London), Joanna Hawthorne PhD, Neonatal Developmental Research Psychologist, (NICU, Rosie/Addenbrooke's, Centre for Family Research, University of Cambridge), Inga Warren Dip COT, MSc, Neonatal Developmental Specialist (Winnicott Unit, St Mary's Hospital). Margaret will be the researcher at University College.

Rights of all staff and families affected by the research

We aim to avoid being in the way, or to take up too much staff time, or to ask questions at busy and stressful times. We will move away if people seem to want us to leave, without waiting to be asked.

We will respect your rights:

- * to ask us to move away, without needing to give a reason;
- * to refuse to help us, or to answer certain questions;

- to take time to decide whether to agree to be interviewed;
- to have the research notes and tapes kept in a safe lockable place, and all data kept according to the Data Protection Act (1998);
- to see a transcript of your interview and to tell us if you want any words changed or deleted;
- to be kept informed about the research and publications, if you wish;
- to have your privacy respected – we will make sure you cannot be identified if we repeat your comments to other people and when we publish research reports.

Funds The Wellcome Trust Bioethics Programme is paying for the research costs, part-time salaries for three of the researchers, and a contribution to each NICU to recognise the time and support given by the staff.

The four neonatologists who support this project are:

Professor John Wyatt, University College Hospital, London
 Dr Janet Rennie, King's College Hospital, London
 Dr Jag Ahluwalia, Rosie/Addenbrooke's, Cambridge
 Dr Karena Ghaus, St Mary's Hospital, London

If you would like to have more details please contact Margaret Killen at [address, telephone, email] or [consultant's name and contact details].

Ethics approval This project has the approval of the Trust's Local Research Ethics Committee, project no. 02/0006. Leaflet version 3, Summer 2002.

Thank you for reading this leaflet

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