Alderson P (2006) Parents' experience of sharing neonatal information and decision. *Social Science and Medicine* 62: 1319-1329

ABSTRACT

Background
Medico-legal consent and the consent literature concentrate on 'major' decisions, when doctors are most knowledgeable and active and patients or parents are least so. Neonatal decisions and activities where parents tend to be most knowledgeable and keen to share agency and responsibility are often seen as less relevant to parents' choices or the informed consent process.

Methods
A study of four neonatal intensive care units during 2002-2004 in southern England; observations over 18 months, and semi-structured interviews with 96 parents and 40 senior staff concerning how they shared information and decisions about care; qualitative data analysis of parents' views and responses.

Findings
Many parents wanted to use information and decision sharing to enable them to become more active in: responding to their baby; sharing in 'minor' as well as major decisions; sometimes questioning and renegotiating practitioners' decisions; advocating for their child; agreeing recorded plans; caring for the baby 'in spirit'; informing their prayers; 'walking' with their child towards an expected future.

Discussion
Greater recognition of the relevance of informed and negotiated consent to major and 'minor' neonatal decisions could encourage parents' informed agency in their baby's care and in the partnership with practitioners advised in the guidance.

Introduction

Based on research in neonatal intensive care units (NICUs), this paper reviews the related literature on decision making and consent, then outlines the research methods and reports how parents discussed ways, related to informed consent, which might increase their active involvement in their baby's care. The purpose of the paper is to contribute seldom-heard parents' views to the literature on how practitioners and parents share in making decisions, giving care and taking responsibility for the babies.

There are renewed pressures on practitioners to inform patients or parents and to request their consent to all clinical interventions.[1] [2] [3] [4] [5] [6] [7] [8] The Inquiries[9] [10] that initiated recent guidance particularly involved parents' consent to interventions on their babies and recorded the parents' heavy sense of responsibility and their desire to be respected, informed and involved in decisions. To raise standards in NICU from much usual practice up to those in the guidance is said to require 'drastic changes'.[11]

The 'Foretelling Futures' study[12] investigated the views of neonatal practitioners and parents about the ideal and actual standards of their sharing of information and decisions. This paper reports seldom-considered aspects of the consent process: parents' agency and connections between the three stages of consent. The stages are 1) sharing information, 2) negotiating, forming and signifying the decision, and 3) implementing the agreed treatment plan. The literature on consent in law, ethics and policy guidance tends to emphasise practitioners' activities when they give expert information and obtain consent in order that they may provide treatment. Patients and parents implicitly tend to be presented as relatively passive and ignorant, when they receive information and agree or refuse to receive the treatment. The psychosocial research literature on consent attends mainly to how patients recall and recount stage 1) practitioners' information giving.[13] There is little attention to the invisible activities in stage 2) of formulating consent or refusal. For major interventions, this can involve the hard work of digesting and making sense of information, relating it to embodied experiences, reflecting on the risks and hoped for benefits in the light of personal hopes and values, weighing choices and making a decision. Thinking may be informed by an arduous emotional journey, initially of dread and doubt, moving towards hope, courage to undertake risk, and confidence in the practitioners.[14][15] Nursing and social research studies record how parents take an active part in stage 3) through the many small practical aspects of health care and recovery by following medical and nursing advice. During weeks in the neonatal unit, parents become highly knowledgeable and expert, they use the technical language and carry out some nursing procedures as well as providing much of the babies' daily care. Some staff feel that some parents intervene too much when they adjust monitors or talk about information they have gained from the internet. However, the studies seldom relate these activities to the consent process, or regard them as arising from shared and negotiated decisions, or as 'major' enough to be preceded by formal decision-making. These vital matters for parents may be treated as 'minor' non-choices, routines, best practice or nursing protocols for which consent is an 'undeveloped concept'.[16] Indeed in a reversal of the law, sometimes for good reasons, parents often feel they have to ask for nurses' consent or permission to touch their child.[17]

This paper reviews how some parents consider that the stages of consent could increase their informed involvement in their child's care through greater sharing of information, and negotiations about who is responsible for the baby and in which ways. During interviews, even confident and assertive seeming parents explained how they wanted to open ways to their own more active involvement. The final section considers how NICU procedures relating to consent might be adapted to encourage this involvement.

Methods

The 'foretelling futures' study observed practitioners', parents' and babies' experiences and interactions in four NICU in southern England over 18 months. Eighty babies with definite or potential neuro-developmental problems, whose parents gave consent, were selected through purposive sampling for a range of neuro-developmental conditions and socio-economic and ethnic backgrounds. Semi-structured tape-recorded interviews were held, with their consent, with 40 experienced practitioners, and the mothers of the 80 babies and 16 of the fathers, mainly about how they all shared information, decisions and care of the babies. This study was unusual in interviewing parents in the NICU, as well as later at home, and in investigating their reasoning, rather than their feelings or needs. Babies' names are changed to protect confidentiality.

Observation notes and transcripts were read and reread and analysed qualitatively by content for emergent themes.[18] Esmé's parents drew attention to one such theme: parents' agency in relation to the informed consent process. During their interview, after reporting seriously adverse experiences with information and consent, Esmé's father said emphatically that he wanted to be informed so that he could 'know what to *do*', as if to reclaim agency. Parents' interview transcripts were then reanalysed and their references to types of agency relating to or arising from the consent process were coded as sub-themes, and they provide the subheadings below. The sample is too small to support generalisations about how many parents wish to be involved in various ways. 'Some' or 'many' indicate approximate preferences when responses were varied.

Findings: information and consent as keys to parents' action

Decisions were broadly of two kinds: *clinical matters* when the practitioners were most active and expert, and *parenting matters* when parents, because of their close continuing contact and involvement with their baby, soon became most expert, such as in cleaning, feeding and comforting their child. With their demanding responsible new identity of parenthood, parents found it hard passively to watch their baby being cared for, and described desiring to be active in the following ways.

To observe, care for and relate to their baby

Oludayo's mother described her joyful surprise when a nurse told her to talk to her baby on first seeing her. Born at 25 weeks gestation, Oludayo wriggled excitedly on hearing her mother's voice, and the nurse said: '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'. The nurse transformed the mother's role from dependent learner into a partner who could give unique parenting care to her baby. 'Intensive care' tends to be regarded as medical, nursing and technical care, whereas parents also give intensive parenting care.

Some parents described their distress when they learned incidentally from a nurse or another parent that they could have been touching or caring for their baby for the past days or weeks, and it seemed that staff had assumed that they already knew or were not ready. Although some parents wanted to wait, others greatly valued practitioners' gentle encouragement to touch their child. Parents discussed matters, such as timing the first contact, in contradictory ways: as major to them, described with intense delight or pain, but also as too 'minor' a matter to be recognised as a negotiable decision. Much depended on each nurse's own view or on parents' courage to ask.

To understand details within the bigger picture

Parents learned through listening and observing, talking with staff and other parents, reading literature and the internet and, when permitted, reading the notes and hearing ward rounds. They felt this learning was part of their responsible care giving and often wanted to discuss their concerns more with the staff. For example, through watching for weeks, parents saw how clinical matters could overlap with ordinary everyday parenting matters. If hand washing is inadequate it can lead to infection and eventually the potential need for major surgery. Parents related wanting to remind some staff to take more care with hand washing between touching each baby. Some parents were the first to recognise the 'slow insidious onset'[19] of necrotizing enterocolitis because they were so intimately aware of their baby's subtly changing states. They explained how they thought their initial concerns should have been attended to earlier and taken as credible.

To review options and make decisions

Parents appreciated regular reviews with a consultant about their baby 'from head to toe, everything that is going on', connecting together the many tests and treatments and discussing their pros and cons.

Sean's mother was exhausted from travelling to the NICU everyday and expressing breast milk for months. She wanted Sean to be strong enough to breastfeed. Within two days he had a retina test, a blood transfusion and his vaccinations. His mother agreed to these interventions but wanted them to be spaced out to help him to conserve his strength. She said that she could have controlled the timing if he had been at home, and that she was not consulted enough in the unit. She eventually gave up expressing milk when Sean continued to be too weak to breast feed. Parents believed they had uniquely comprehensive continuing insights that could inform clinical decisions.

Parents prefer to be involved in making hard major decisions[14 20] and suffer if they are excluded.[21] They do not want their consent to be assumed, but neither do they want to be asked when treatment is presented as essential and 'there is no choice'. As parents gave more care when babies moved out of intensive areas, paradoxically, they were less involved in making decisions because they had less contact with consultants, the people who mainly shared (albeit major clinical) decision making with them. For example, many parents disagreed with one NICU's discharge protocol, that babies must be on 4-hourly feeds before they could go home. They said they preferred flexible feeding times, and could establish these far more easily at home, also that their baby was too small, or weak, or became too bloated to cope with 4-hourly feeds. They felt many nurses should be more willing to discuss rather than impose nursing decisions that overlapped with parenting ones.

To respect recorded decisions

Parents valued records of decisions, linking consent stages 2) and 3), to ensure that these were remembered and carried out through changing staff rotas. Drawings, photographs and written care plans were fixed to cots and incubators to encourage consistent care, such as about babies' preferred feeding positions. Danny had three abdominal surgical investigations and great difficulties with feeding and regurgitation. His mother, who had a daily 2-hour bus journey, after months gave up trying to express milk, on the understanding that he would have fortified expressed breast milk. Instead he was given formula and his vomiting increased. His mother thought that the staff did not listen to her, and wished she had continued trying to express milk, and could have a more equal share in ensuring that decisions about Danny were recorded and kept.

A notice on one baby's cot, written by his mother and a baby support specialist, implied difficulties in ensuring that all the nurses remembered and cooperated with decisions about his tube feeding in which clinical and parenting decisions overlapped.

> My mummy's milk is very, very precious. I need every drop she can make and it is hard work for her. My mummy and daddy mix all my portions with
>
> - the right amount of gaviscon (1/4 sachet per 100 ml)
> - the right amount of fortifier (2 pk per 100 ml)
> - the right amount of milk which they adjust each day as I grow.
>
> My correct daily portions are ready for me in the fridge. There is no need to do anything except warm them up for me. Please be careful not to waste any.

To be advocates

Parents mainly learn from and usually agree with the staff. It is difficult for them to question decisions critically because they respect the staff and tend to dread jeopardising delicate practitioner-baby-parent relationships. However, sometimes they feel they must question clinical decisions. Shortly after the arrival of a new team of junior doctors, one mother heard one of them arranging with surgeons for removal of an infected line to be delayed for five days until after a bank holiday. After five months in the NICU, the mother knew the risks of delay and, in a rare example questioned the doctor and asked for the line to be removed earlier, although the baby died the next day.

It could be hard to question decisions about one baby, and harder to question general routines. For example, parents read on the internet about clinical and parenting advantages of skin-to-skin 'kangaroo' care[22] but then found that some nurses rejected these reports and discouraged the care on grounds that expert reports refuted, such as that babies get too cold and tired.

Yejidi when aged 6 months still weighed about 4 kg. Her mother longed to help Yejidi to sleep deeply and gain energy. She asked the night staff not to wake, change and weigh the babies and put cold fresh sheets on the cots. Despite help from day nurses and a care plan on Yejidi's cot, the practice continued. Parents watched their baby frequently startling awake when the cot was under bright lights and next to a washbasin with rustling paper towels and a bin with a squeaky lid. Some parents felt that interrupted sleep affected major clinical outcomes by reducing babies' abilities to feed, gain weight and resist infection, but they usually felt unable to ask about these minor matters.

To contribute to the neonatal community

Much as they appreciated support from the neonatal staff, many parents also valued mutual help between parents, and in parent support groups. Some neonatal teams encouraged parents' friendships, others discouraged them, to protect confidentiality. Senior doctors and nurses were influential and, in the encouraging NICUs, they set examples of empathic care, invested in counsellors, staff training, support and team meetings, and expected high welcoming standards from all colleagues including receptionists. They listened to parents' views; one unit gave evaluation forms to every parent and reviewed the replies at monthly meetings. The more or less supportive policies were based on beliefs and decisions about staffing, appropriate use of staff time, the status of parents and the welfare of babies, but the decisions were seldom seen as matters for staff and parents to discuss and renegotiate. Records from the past of NICUs that excluded parents[23] [24] show how parents' present involvement is associated with generally more humane practices.

To 'care for their baby in spirit'

The parents were intensely preoccupied with their baby[25] but many had to be absent to care for their other children or to go to work. They spoke of mentally caring for their baby 'in spirit': 'when you are not in the unit, your heart is here'. They therefore relied on nurses' reports about the baby by telephone and on their return to the unit, and appreciated being told 'every little detail'.

To inform their prayers;

Some parents described their mental care for the baby, and their sense of being supported, as prayer. They wanted their prayers to be as detailed as possible about the baby's problems and progress. 'I thank God they told me, because I talk to my God, that's the only person I can talk to.'

To 'walk' with their child towards an expected future.

Parents longed to have some knowledge and control over the direction that their child's life, and therefore their own life, might take so that they could adjust, plan, prepare and, in a sense, consent to their future. This related to another tension between clinical and parenting matters, because the knowledge would entail doctors explaining what Lucy's mother termed the abstract 'horror' of serious diagnoses with many medical details of their practical effects. She accepted this was partly impossible. Doctors 'don't control the universe they simply interpret a very small corner of it, they can't really tell us with all honesty what's going to happen.' Yet she still wished she had had some warning about Lucy's severe impairments.

While most interviews were held during the children's first year, with 16 children who had serious problems interviews were conducted when they were 4-6 years old. Their parents talked about the kinds of information and discussion they experienced or had wanted to experience in the NICU and afterwards. The extra demands on these parents when caring for their children illustrated how highly informed and skilled the parents had to become, and the importance of respectful partnerships with practitioners from the start. For example, Benedict's mother had several thick files of letters and notes recording his contact with many specialists. The problems treated included: needing to be tube fed for a year until he was fit for his temporary stoma to be reversed; vomiting for four years because the tube feeding preventing the pyloric sphincter from closing, and other feeding problems; allergies; chronic lung disease requiring extra oxygen for months; intermittent glue ear and significant speech and language difficulties; delayed walking until 20 months, and other needs for physiotherapy, occupational therapy, the services of the child development centre and learning support; teachers' concerns that he was developmentally delayed and over-dependent. These concerns had to be unravelled from the effects of prematurity (birth at 25 weeks gestation), illness and surgery and in extensive correspondence with schools, Benedict's parents insisted that he was not below average ability. His mother said, ‘We had to deal with hundreds of people, some people don’t know what they’re talking about…I kept saying to myself, you know, “There’s nothing wrong with him, there’s nothing wrong with him, he’s just been very ill”.’ She was grateful to a junior doctor in the NICU who said to her, ‘“This is going to be a long haul”. And no one ever said that in the Unit and she was right.’

To be respected as actively responsible
Parents thought that practitioners who consulted them demonstrated respect for parents’ responsibilities. Esmé’s father commented: ‘I feel that the child is yours, you have the right to know…without mincing words and everything is clear-cut, you know where you are…you know what to do, what to expect.’

Discussion: implications for policy and practice

I have got rather stuck here and would value your thoughts on these notes that need plenty of sorting and editing.

The ethical-legal model of consent implicitly assumes an informed active practitioner who considers ‘major’ decisions with and a somewhat passive and ignorant patient or parent. This paper examines the rarely researched topic of parents’ views about ‘minor’ and routine decisions, in matters about which they can be relatively expert and which for parents and babies may have major implications. It also examines how parents connect consent, the process of sharing information and decision making, with their active caring of their child. Paradoxically, parents are asked most often to consent to clinical interventions (X in table 1) when they tend to be least knowledgeable or active, and less often to Y decisions in which they can be expert.

Table 1. Consent to major clinical X and 'minor' parental Y decisions

Consent that relies on:	Doctors' knowledge	Parents' knowledge
Consent that enables: Doctors' action	X	
Parents' action		Y

A reviewer criticised this table as too muddled and confusing. He argued that there is a need for more dialogue between staff and parents, shared decision making, respect and systems that promote empathy. I would argue that consent can involve and promote these things as well as transparency. He said maybe the paper should raise the idea of broader interpretations about consent and we could list pros and cons and invite debate. He wanted a closing section on practical recommendations and good practice.

A nurse reviewer thought the first draft presented parents as too passive whereas she found many parents were assertive and confident sometimes too much so. I agree that many nurses find that, but wonder if the minority of assertive parents stick out memorably, and also that parents start from such a difficult lowly position – in some units - that it is hard for them to contribute we without either complying fully with staff requirements or else seeming to speak out of turn. The context can make their requests seem confrontational and challenging especially when they speak on matters that they believe are primarily parental and the staff assume are primarily clinical.

We could discuss the broad overlap between clinical and especially nursing with parental concerns and how they lead into and affect one another in the short and long term.

Barbara wrote a letter explaining, among other things, the importance of respecting babies' rights, questioning and being conscious and constantly reminded of the potential very long term impacts (including possibly exacerbating or reducing later morbidity) and possible links between stress on the baby and later concentrating and cognition. Although many people will say no links have been adequately demonstrated, we could say that when evidence is missing cautious conservative practice is advisable in the sense of conserving baby friendly environments and stimuli (Als + Goldson)

We might mention the role of the baby's advocate who is closely involved with medical and nursing teams but stands a little apart form them and so can mediate between the adults in either the clinical teams or parent/families and their separate and overlapping concerns. The challenge for the mediator is to maintain the trust and confidence of the staff and of the parents balanced with an independent position.

I started the original discussion section with:

Minor routines and protocols are actually hidden decisions.

By law, children cannot be treated without parents' permission/consent[26] [27]except in emergency or on the authority of te court. In practice: 1) neonatal staff requested consent to major interventions but seldom to routine or 'minor' interventions when parents could be most expert; 2) parents needed practitioners to permit many parenting interventions; 3) consent was used to enable practitioners to proceed but seldom for parenting procedures; 4) consent involves explicit informed negotiation of options, trust and responsibility for risks; 5) without a consent formula for discussing parents' activities, and unless there was leadership from confident senior doctors and nurses, neonatal staff could be uncertain and nervous about involving parents.

This is not to propose legalistic contractual approaches to minor decisions. However, there could be greater awareness of three questions. When can routines and protocols become explicit questions to negotiate with parents? When should seemingly minor, often nursing or parental, matters be connected with major medical concerns? When can anxieties about risk and trust in small daily matters usefully be negotiated between parents and staff?

Psychological/counselling services can help individually and generally with the anxieties. Practical management is also necessary to ensure adequate resources, staff training and support to help all practitioners to encourage parents' contributions at the level that some NICU achieve.

Questions. Do we want to suggest that consent could be interpreted and applied more broadly? Is its potential relevance as a formula for discussing the attendant risks and anxieties when sharing responsibility for the babies? Could parents in future have more share in deciding the topics and methods of consent? Should we discuss parents' dependence in practice for many of their activities, on practitioners' permission, and the tensions this sets up with the law?

ACKNOWLEDGEMENTS

I am grateful to the families and neonatal practitioners who helped with the study, to researchers Joanna Hawthorne and Margaret Killen, the project's Advisory Group, the four local research ethics committees for their approval, and the Wellcome Trust Bioethics Programme for funding project no. 066458 'Foretelling futures: dilemmas in neonatal neurology, 2002-2004, for details about the project and related papers on consent see http://www.ioe.ac.uk/ssru/projects/neonatalfutures

REFERENCES

---

[1] World Medical Association. 1964/2000 *Declaration of Helsinki.* Fernay Voltaire: WMA.

[2] Department of Health. *Reference guide to consent for examinations or treatment; seeking consent, working with children.* London: DH, 2001.

[3] RCPCH - Royal College of Paediatrics and Child Health. *Withholding or withdrawing life saving treatment in children: A framework for practice*. London: RCPCH, 1997.

[4] Royal College of Paediatrics and Child Health. *Safeguarding Informed Parental Involvement in Clinical Research Involving Newborn Babies and Infants.* London: RCPCH, 2000.

[5] *National Service Framework for Children, Young People and Maternity Services.* London: DH. DfES, 2004.

---

[6] MacDonald H, and Committee on Fetus and Newborn, American Academy of Pediatrics. Perinatal care at the threshold of viability. *Pediatrics,*2002; 110,5:1024-7.

[7] General Medical Council. *Seeking patients' consent: the ethical considerations.* London: GMC, 1998.

[8] British Medical Association. *Consent, rights and choices in health care for children and young people.* London: BMA: 2001.

[9] Kennedy I. *Learning from Bristol. Report of the public inquiry into children's heart surgery, 1984-1995.* Cm5207. London: Stationery Office, 2001.

[10] Redfern M. The Royal Liverpool Children's Hospital Inquiry Report. London: The Stationery Office:2001.

[11] Shenoy S, Archdeacon C, Kotecha S, Elias-Jones A. Current practice for obtaining consent in UK neonatal units. Bull Med Ethics. 2003; 188:17-19.

[12] Alderson, P. Ehrich K, Hawthorne, J, Killen M and Warren I. (2004) Foretelling futures: dilemmas in neonatal neurology. London: Institute of Education. http://www.ioe.ac.uk/ssru/reports/foretellingfutures.pdf

[13] J. Sugarman, D. McCrory, D. Powell, A. Kransy, B. Adams, B. Ball and C. Cassell, *Empirical research on informed consent (adults) Hastings Centre Report* (New York: Hastings Center, 1999 29,1: supplement pp s1-42).

[14] Alderson P. *Choosing for children: parents' consent to surgery.* Oxford: Oxford University Press, 1990.

[15] *Nuremberg* Code. 1947. http://ohsr.od.nih.gov/guidelines/nuremberg.html.

[16] Aveyard H. Informed consent prior to nursing care procedures. *Nursing Ethics,* 2005; 12,1:19-29.

[17] Lupton D and Fenwick J 2001 They've forgotten that I'm mum, *Social Science & Medicine*, 53:1011-1021.

[18] Strauss A, Corbin J. *Basics of qualitative research.* London: Sage, 1998.

[19] Rennie J, Roberton N. *A manual of neonatal intensive care.* London: Arnold: 2002: 384.

[20] McHaffie, H. (2001). *Crucial Decisions at the Beginning of Life*. Abingdon: Radcliffe Medical Press.

[21] Delight E, Goodall J. Babies with spina bifida treated without surgery. *BMJ*. 1984; 297:1230-3.

[22] Such as www.bliss.org.uk and see also Goldson, E. (Ed) *Developmental interventions in the neonatal intensive care nursery*. New York: Oxford University Press, 1999.

[23] Anspach R. *Deciding who lives: fateful choices in the intensive care nursery.* Berkley: University of California Press, 1993.

[24] Chambliss D. *Beyond Caring: Hospitals, Nurses and the Social Organization of Ethics*. Chicago: University of Chicago Press, 1996.

[25] Winnicot D W. *Babies and their mothers.* London: Free Association Books, 1988.

[26] Confirmed by the European Court of Human Rights ruling in Glass v United Kingdom [2004] 1 FLR 1019.

[27] Bridgeman J. Caring for children with severe disabilities. *Int. Journ. Children's Rights,* 2005; 3, 1:99-119.