

Ethics and law

G158 WHAT DO WE MEAN BY THE "BEST INTERESTS OF THE CHILD"?

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Aims: To define different meanings of "Best Interest of the Child" and discuss their implications by means of a specific case example.

Methods: Ethical definitions, eg, "Best Interest of the Child" (BI of C) is a common term in medicine and law. It often assumes that all involved subscribe to a common understanding/definition. However, there are three subclassifications:

- ▶ The normative, "ideal" scenario where what is desirable for a population of children rather than individuals, eg, health policies.
- ▶ The "standard of reasonableness", an acceptable but not desirable option, eg, custody disputes or "good enough" parenting standards.
- ▶ The "threshold for intervention" where unacceptable circumstances permit state intervention, eg, removal into foster care.

Argued case example, eg, genetic testing of Looked After Children (LAC) awaiting adoption. BAAF Guidelines 2006 divide genetic testing into predictive symptomatic testing, eg, cystic fibrosis; predictive presymptomatic testing for later onset diseases, eg, Huntingdon's chorea (HC) and asymptomatic carrier status such as Duchenne muscular dystrophy. Myotonic dystrophy (MD) is classified alongside HC, although it can present in childhood and is an anaesthesia risk. Guidelines suggest that well children with family histories of MD should not offered testing until old enough to give valid consent (thereby respecting their future autonomy). Thus similar LAC awaiting adoption should not be tested as it is not in their long-term best interest. This is the normative argument against testing. The "standard of reasonableness" argument views LAC to be in different circumstances. Uncertainty about the diagnosis rather than the diagnosis itself (positive or negative) may lead to delay in permanent placement. This is not in their short-term best interest and is an argument in favour of testing.

Results: Arguments for and against testing utilise the term "best interests of the child", yet are diametrically opposed in their conclusions.

Conclusions: It is important to be aware of the different definitions of the "best interests of the child" when addressing ethical dilemmas or writing/interpreting guidelines.

G159 SHOULD PRESCHOOL VACCINATION BE MADE COMPULSORY?

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Aims: Preschool vaccination is a good example of the utilitarian argument of the "greatest good for the greatest number". The state requires parents to act in the best interests of their children and has a responsibility to intervene when children are "at risk of significant harm". Parents are not allowed to neglect their children. However, respect for individual autonomy is highly valued in liberal societies. Coercive policies override autonomy and may produce disutility in terms of the cost of surveillance and increased public opposition.

Method (ethical argument to be discussed): As preschool vaccination is safe and the state has a duty to protect the welfare of children, the wishes of dissenting parents should be overridden in order to protect children.

Results (ethical discussion): Parents leave their children unvaccinated for a variety of reasons. Active parental autonomy is exerted when they disagree with some/all vaccinations: passive disengagement is where parents do not access the health service for their children due to cultural/language/access difficulties or due to neglect. The question is whether vaccination is in the best interests of all preschool children and whether non-vaccination constitutes

"risk of significant harm". I will argue that the small but significant risks to individuals, coupled with the lack of 100% efficacy of vaccination mean that compulsory preschool vaccination cannot be defended from an ethical standpoint. However, I will argue that in order to act in the best interests of their children, parents have a responsibility to access objective health information. Provided they comply with this, they should be allowed to exert their autonomy and should not be coerced into vaccinating their children. Parents who do not engage are neglecting their children and the state has a duty to intervene.

Conclusions: Preschool vaccination should not be made compulsory because of the potential disutility; however, parents should be required to engage with health services before registering their decision. Children should not be exposed to avoidable harm (vaccine preventable infectious disease) due to neglect.

G160 TAKING A DOG WITH A TAIL AT BOTH ENDS FOR A WALK

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Drama provides an unusual and potentially powerful tool for medical students to explore controversial issues and to think "outside the box." As part of a strategy of exploring ethical issues with medical students a play concerning a possible future paediatric treatment was deliberately written and performed in front of an audience of UK medical students. The premise of the play involves Jo, an adolescent with Down syndrome and profound special needs being given at the point of death an innovative highly experimental medical treatment. This not only saves Jo's life, but allows her developmental parameters now to attain within the "normal" range. Unfortunately, as the treatment progresses and Jo starts to experience the world, she wants to stop her treatment. Jo prefers instead to be "as she was before." The play was performed in front of an audience of medical students at Birmingham University. An audience questionnaire was completed after the performance.

This presentation will draw out the ethical themes explored in the play and how the students related to them, together with filmed excerpts from the play itself. These themes include, consent, competency, respecting decisions that do not concord with clinical opinion, clarity of medical purpose and the role of parents where children are gaining competence to make their own decisions. This presentation will demonstrate the clear potential of this educational tool to enrich, and add to the repertoire of experience upon which future doctors will draw during their medical practice.

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G161 SPECIALIST REGISTRARS' TRAINING NEEDS IN CLINICAL ETHICS

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Aims: To define the training needs of paediatric specialist registrars (SpRs) in clinical ethics and to identify ways in which these needs might be met.

Methods: An online survey was distributed to SpRs. SpRs were asked whether they had received ethics training and when this had occurred. The survey also asked how often SpRs encountered ethical dilemmas, whether they felt their training equipped them to

deal with these situations and whether they had accessed support from other sources. Finally, SpRs were asked to suggest what further ethics training they required and how it might be delivered.

Results: 211 trainees (67% female) responded. The greatest proportion of the response (24%) was from first year SpRs and the least from fifth year SpRs (14%). Over half of all respondents agreed with the statement, "Clinical ethics and law are essential to practice and therefore education and training should be mandatory for SpRs" and 90% stated they would like further ethics training. Most SpRs had received some training, more commonly during undergraduate than postgraduate education. Almost all respondents encountered ethical dilemmas at least monthly, yet less than 10% felt their ethics teaching adequately equipped them to deal with them. Advice from senior colleagues was the most popular source of ethical support (97%); individuals with a special interest in ethics, the RCPC and the GMC were also popular choices. Over 70% of respondents identified dilemmas concerning consent and confidentiality, religious or cultural issues and end of life decision making, as practically important, with many feeling that further training was needed in relation to them. Truth-telling and involving children in decision making also featured frequently in SpR requests for further training, even though this was less commonly cited as a problem faced by SpRs. When SpRs were asked to describe actual dilemmas they faced, end of life decision making and conflicts between teenagers and their parents and the manner in which ethical dilemmas are resolved and communicated within teams all produced prominent concerns. SpRs favoured case-based discussion and online learning as methods of delivering training.

Conclusions: Respondents viewed ethical training as essential and would welcome further training relating to both the ethical dilemmas that they commonly face and aspects of practice they regard as ethically challenging.

G162 BABIES BORN AT THE THRESHOLD OF VIABILITY: SURVEY OF CONSULTANTS AND REGISTRARS IN SOUTH-EAST ENGLAND

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Background: Making decisions about the care of babies born at the threshold of viability is a challenging area of neonatal practice.

Objective: To assess key aspects of the knowledge base and decisions of consultant and middle-grade paediatricians in south-east England towards the care of babies born at 22–24 weeks' gestation.

Methods: A paper and web-based questionnaire was sent to one consultant and one middle grade doctor within each of 63 neonatal units in south-east England. Questions ascertained paediatric presence at 22-week deliveries, antenatal counselling, resuscitation according to parental requests, extent of resuscitation, perinatal death registration, guidelines and exposure to recent Nuffield¹ and Nursing and Midwifery Council (NMC)² documents.

Results: Response rate was 111 of 123 (90%). At 22 weeks' gestation, 51% of respondents would not attend the delivery. At 23 weeks' gestation, 63% would advise against resuscitation. 45% would resuscitate babies born at 23 weeks against the wishes of parents, contrary to recent guidance.¹ 41% would provide comfort care for a 23-week baby born in poor condition. On linear regression analysis, paediatricians with greater neonatal experience and older age were more likely to attend 22-week deliveries and to agree to parental requests for resuscitation. Significantly more consultants (28%) than registrars (3.5%) correctly classified perinatal deaths, had read recent Nuffield guidelines¹ (75% vs

36%) and the NMC circular² (23% vs 1.8%) ($p < 0.01$). 54% of units had written guidelines on the care of babies at the threshold of viability.

Conclusions: Consultants were significantly more likely to have read recent important legal and ethical documents and paediatricians with greater experience showed greater shared decision-making with parents. To provide support for decision making that is consistent, family-centred and according to national guidance, poor knowledge of perinatal death registration needs to be addressed and the development of guidelines for each neonatal network is recommended.

1. **Nuffield Council on Bioethics.** Critical care decisions in fetal and neonatal medicine: ethical issues. 2006. <http://www.nuffieldbioethics.org/>.
2. **The care of babies born at the threshold of viability.** Nursing and Midwifery Council. 2007. <http://www.nmcuk.org/>

G163 PARENTS' VIEWS ON THE ETHICS OF RESUSCITATION AND INTENSIVE CARE OF EXTREMELY PRETERM INFANTS

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Background and aims: Extremely preterm infants are routinely admitted for intensive care from 23 weeks' gestation, yet many do not survive or do so with adverse outcome. Many reports detail the views of medical staff on the ethics of resuscitation and intensive care of very preterm infants, but none give the opinions of parents. We asked parents who had given birth to an extremely preterm infant their views on the ethics of resuscitation and intensive care.

Methods: Postal questionnaire survey of parents of infants <27 weeks' gestation admitted to our NICU in the 3-year period 2005–07. We asked about experiences before and during their infant's resuscitation and care on NICU, and present views on the ethics of resuscitation of extremely preterm infants.

Results: 100 infants were admitted in the study period. 43 of 84 (51%) mothers consented to participate and a completed questionnaire was returned by 48 of 80 (60%) parents (27 mothers, 21 fathers; 36 parents of living infants, 12 bereaved parents). Antenatal discussion of rates of expected survival and of long-term disability was recalled by 51% and 45% of parents respectively. 68% of parents believed that doctors had been the main decision-maker about resuscitation of their baby at birth; only 31% considered this appropriate while 40% said it should be a joint decision between doctors and parents. 63% of mothers felt guilt for their preterm infant's birth. During the period of intensive care, changes in appetite/sleep patterns were reported in 75% of parents, and 71% considered the period was the most stressful experience of their life. 44% of parents said their views on having more children had since changed such that they no longer desired a further baby. Asked from what birth gestation extremely preterm infants should be resuscitated, 33% of parents stated a median minimum age of 23 weeks (range 20–27 weeks), while 67% stated that all babies merited resuscitation irrespective of gestation. 94% of parents reported that if faced with a similar situation of impending delivery at the same gestation in the future they would again ask doctors to resuscitate.

Conclusions: Despite the high mortality and morbidity and high prevalence of stress and maternal guilt associated with delivery at <27 weeks' gestation, the overwhelming majority of parents who have been through the experience said that faced with a similar situation in the future they would again want their baby to be resuscitated and receive intensive care.