

## Book reviews

### Life, Death and Decisions: Doctors and Nurses Reflect on Neonatal Practice

H E McHaffie and P W Fowlie, Hale, Cheshire, Hochland and Hochland, 1996, 294 pages, £13.95.

A lot has been written, and there is a lot of talking, about withholding and withdrawing the treatment of severely damaged neonates. Hazel McHaffie has listened to the concerns of doctors and nurses who are themselves involved in the decision-making process in this often heart-rending area of medical practice and nursing. The result of this attention to reality is presented in this book *Life, Death and Decisions: Doctors and Nurses Reflect on Neonatal Practice*, written by Dr Hazel E McHaffie, a nurse researcher with the Institute of Medical Ethics at the University of Edinburgh, and Dr Peter W Fowlie, Senior Registrar in Paediatrics, at Ninewells Hospital and Medical School in Dundee. The book reports on a research project funded by the Scottish Office Home and Health Department during two years of study. An executive summary, consisting of an A4 brochure of 28 pages helps to gain an overview - but is no substitute for the excellent reading the book itself provides.

McHaffie and Fowlie present first a well-written chapter on the current debate about withholding and withdrawing treatment. In this chapter the legal dimension is addressed as well as a short historical overview presented; further, the background and perspectives of the conflicts are discussed as experienced by midwives, nurses and doctors. The arguments currently employed in bioethical discussions are carefully spelled out, touching on topics such as: saving and preserving life; the value of human life; the question of personhood, and benefits and burdens

in regard to caring for severely handicapped or mentally impaired infants. In this chapter an overview is given of the types of life-and-death-decisions that have to be made in neonatal intensive care units (NICUs); the problems to do with prediction and the development and use of scoring systems are addressed. The question of euthanasia is touched upon and the role of parents is discussed. A wealth of literature is reviewed and incorporated into this section and the rationale for the specific approach in McHaffie and Fowlie's study is clarified.

The aim of the study is described as being "to explore thinking and practices among doctors and nurses in relation to decision making in Neonatal Intensive care Units in cases where withdrawal or withholding of treatment are possible options; to do this with special reference to ethical reasoning, perceived dilemmas, sources of conflict and productive working practices."

The authors state their overall objective to be: "to identify practices which facilitate appropriate decision making relating to the care of neonates, minimising tension and conflict amongst the caregivers and family members involved".

The study is then introduced and its method briefly described, as well as the procedure of entering the field of neonatal intensive care practice. The data for this study were gained by in-depth interviews with doctors, midwives and nurses of all grades in NICUs throughout Scotland.

For readers looking for guidance as to the research procedure and details of analytic steps this chapter (chapter 3) is rather short and leaves a number of questions open. Chapters 4 to 14 then deal thoroughly with the subject matter as it arises from the interviews. These chapters are structured according to topic areas and present a full picture of the multidimensional problems to be dealt with when caring for and treating very sick and thus

vulnerable babies. Included are chapters on: The Law; Current Policies and Practices; Impairments and Disabilities; Roles and Responsibilities, Conflicts and Tensions, and Paternal Involvement in Decision Making.

In each chapter data are presented, interpreted and linked again to important literature, in a substantive discussion section which is then summarised for quick reference. The presentation of interview extracts gives this book a special richness and veracity. Here we hear the various voices of people really involved with the lives of babies and their families. We get a well-structured and clear picture of what is going on in real-life situations: how people argue about their wishes and fears; about their own vulnerabilities and pains, and about how they deal with such situations. We get a closer understanding of how nurses and doctors experience their involvement with patients and their respective families and how they live through these experiences.

In the concluding chapter (chapter 15) the issues of concern are drawn together by summarising sections such as: The babies concerned; The decision; The process (of timing events connected with the withdrawal or withholding of treatment); The parents' needs; The team; The problem of uncertainty. The reader is moved between facts that emerged from the data and the abstract deliberation of ethical questions. Much information is conveyed but never in a teaching tone or solely at an analytic level. The mix between reality and philosophising is compelling and helpful for those who have to teach ethics, lead discussion groups on medical or nursing ethics, or serve on ethics committees. But also, and not only marginally, those readers who carry responsibility where severely ill babies (and for that matter any terminally ill persons) are cared for and treated—or not treated—will gain a better understanding of their

own involvement in decision-making processes.

A list of recommendations leaves practitioners and administrators, as well as politicians, ample food for thought, which, it is hoped, will contribute to easing difficult situations where decisions have to be lived through.

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## Antenatal Screening and Abortion for Fetal Abnormality: Medical and Ethical Issues

Edited by David Painton, London, Birth Control Trust, 1997, 96 pages, £20.

This review is written on the 30th anniversary of the Abortion Act 1967, a time of heightened debate on the subject, and within days of the publication of the Royal College of Obstetricians and Gynaecologists' report on fetal awareness.

Although abortion for fetal abnormality accounts for only 1-2% of the total, this book reports the proceedings of a symposium held in September 1996, under the auspices of the Birth Control Trust, to consider the ethics of, and good practice relating to, screening for fetal abnormality and subsequent management of the pregnancy should an abnormality be suspected or diagnosed. The Trust is strongly in favour of the woman having the options of antenatal diagnosis and of abortion if the fetus proves to be abnormal. Readers will not find much to challenge these views within this book.

In the opening chapter, Professor Raanan Gillon argues that the fetus is not a person and therefore not entitled to the moral respect we accord one another. As a result he is able to adopt a self-confessed liberal attitude to abortion. He considers that the developmental dividing lines enshrined in law - viability and birth - are not good criteria for deciding intrinsic moral rights; neither is the concept of sentience, which produces only an obligation not to inflict unnecessary pain. At one stage he admits to a con-

tinuum of development towards full personhood. One wonders if there are not duties owed to the fetus concomitant to its position on this spectrum. If there are, what other duties may conflict with them and how much weight should be given to each at a particular time?

Some who accept abortion solely because the pregnancy is unwanted have reservations when it is requested on the grounds of fetal abnormality, perhaps because of a fear of condoning eugenics or of giving an impression that those who are disabled are somehow being devalued. Although Professor Gillon dismisses any logical connection, some debate on the reasons for aborting such pregnancies might have been apposite.

Professor Richard Lilford introduces an intellectual model with which we might assess screening nationally. As an example, he invites us to consider 100,000 pregnancies being screened for Down's syndrome. After 80,000 triple tests (often used as an initial screening for Down's syndrome to decide whether to have amniocentesis) and 3,000 amniocenteses (2,960 of which will be negative) the number of babies born with Down's syndrome will be reduced from 100 to 60 and 30 normal fetuses will have been aborted as a complication of the procedure. He concludes that the programme provides the community with a considerable net gain. Your reviewer finds the consideration more challenging than he might care to admit.

Dr Sue Atkinson describes the concepts of need, demand and supply; the influences affecting decision-making and the use of resources; the disparity of services offered within and between districts; the lack of continuity when a separate medical team has the contract for terminations; the introduction of tests before proper appraisal (nothing new in obstetrics and gynaecology), and the inadequacy of counselling. Little wonder the Chief Medical Officer has set up a committee on screening to select the most cost-effective programmes.

Three chapters relate to problems at the level of the individual. Dr Jenny Hewison, a psychologist, presents the doctor-patient contradiction in screening - the doctor determined to find if anything is wrong and the mother hoping to prove that all is well. There are problems of compliance, of adequate information-giving and of explaining results based on probability. Many obstetricians have dealt with those who have declined a

triple test but who didn't seem to realise that it was impossible to perform a scan, which was either requested or clinically indicated without observing abnormality. Full disclosure to a woman, maintaining her trust, without increasing her anxiety or bringing unhappiness at a time when joy is a path which is individual and must be trodden subtly.

Cathy Warwick describes excellent initiatives undertaken at King's College Hospital to ensure that midwives are adequately prepared, through workshops and an information package, to provide information, support and counselling before and after investigations are carried out.

Joanie Dimavicius is the director of an organisation whose name, Support Around Termination for Abnormalities, conveys the gist of her chapter. Information must be clear, accurate and consistent, while the support must extend to both parents and staff.

We are then reminded that it falls to the doctor to interpret such words as the Abortion Act as "substantial" and "seriously (handicapped)" when referring to the risk and the effect of fetal abnormality. Should this be in the doctor's discretion? There is agreement that while discretion is permitted, a list of conditions would prove unworkable.

Two gynaecologists report the practice of fetocide, at gestations beyond 15-18 weeks, since "it is appropriate that there is no sign of life at abortion". There is no discussion of whether this is to prevent fetal suffering or a potential charge against the doctor involved should the live-born baby die.

Mr Ian MacKenzie demonstrates the efficiency of newer abortifacients in reducing abortion time and side effects. The working diagnosis could be confirmed in 99% of cases. The late Mr Eric Jauniaux describes minimizing the pain and duration of the procedure by emptying the uterus using instruments, under general anaesthesia, even up to 22 weeks. The fetus is likely to be delivered "in fragments" (Mr David Paintin's words, not mine) prohibiting viewing by the parents or examination by a pathologist, yet this method was chosen by 90% of patients offered it or a medical procedure in this study and accounts for over 75% of elective second trimester abortions in the USA.

Finally, Dr Pamela Johnston compares the roles of the generalist and specialist obstetrician, the former coordinating the seamless delivery of