



When a baby has an abnormality: a study of parents' experiences
Helen Statham, Wendy Solomou & Josephine M Green

The 1st volume of the report of this study is now available.

Detection of fetal abnormality at different gestations: impact on parents and service implications was funded by the NHS (R&D) Mother and Child Health Initiative. Volume 1 presents the experiences, views and feelings of 467 women and their partners over the 14 months after they had had a serious abnormality confirmed during pregnancy or after birth.

The report (358 pages) focuses on parents' feelings after a prenatal diagnosis, whether that is followed by termination or a continued pregnancy, and after a postnatal diagnosis. Quantitative and qualitative data are presented describing

- o the care received by parents in different situations
- o how care is co-ordinated
- o satisfaction with care during diagnosis, in hospital and after the termination or birth
- o the relationship between mood after a termination and obstetric, social and personal characteristics
- o the perceived advantages and disadvantages of prenatal diagnosis

Full details of the contents can be found on the following page.

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If you would like to purchase a copy of Volume 1 of the report, please print out the current page and complete the form below. Return it with a cheque made payable to the University of Cambridge to Sally Roberts, Centre for Family Research, University of Cambridge, Cambridge, CB2 3RF UK

ISBN: 0 9512312 6X Price including postage: UK £20; Europe £22; Rest of the world £25

Volume 2, which presents the study of health professionals' experiences, will be available shortly.



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Introduction: Background to and aims of the study.

Methodology: Research design, recruitment, measures of emotional well being and satisfaction and data analysis.

Response rates and sample characteristics.

Parents' experiences of the process of prenatal diagnosis: The diagnostic process, quantitative and qualitative analysis of satisfaction with the diagnostic process.

Termination of pregnancy: Personal, social and obstetric characteristics of parents who terminated pregnancies and relationships between independent variables.

Care in hospital for parents who terminated their pregnancy: Satisfaction with care, location for and methods of termination, staff support.

Care after leaving hospital for parents who terminated their pregnancies: Satisfaction with post-termination care, what parents would have liked and problems after a termination.

Determinants of emotional well being after a termination: Changes in emotional well being over time and relationship between mood and personal, social and obstetric characteristics including gestation, method of termination, previous and subsequent reproductive history, and social support.

Satisfaction: some methodological considerations: What people are scoring, expectations retrospective ratings and how satisfaction relates to mood.

Emotional well being after a termination and the impact of taking part in a longitudinal study: a comparison between women who took part in the longitudinal and retrospective study.

Ongoing pregnancies after a diagnosis of fetal abnormality: Characteristics of women and their pregnancies, parents' accounts of an ongoing pregnancy and antenatal care.

Postnatal diagnosis of abnormality: Characteristics of the parents, babies and births, being told that there is something wrong and satisfaction with getting the diagnosis.

Care in hospital for women who had babies: Characteristics of the births and post-natal care for parents.

With hindsight: The advantages and disadvantages of a prenatal diagnosis.

Emotional well being after the death of a baby with abnormalities: a comparison between parents whose baby died and whose pregnancy was terminated.

Discussion: Methodological issues, the findings and the organisation of maternity care.

Bibliography.

Appendices: Study participants and participating hospitals; data collection tools; sample recruitment and characteristics; *Lancet* letter: perceived pressure; Decision making: a discussion paper; ARC [SATFA]; Random Effects Modelling; comparative data for parents who joined the retrospective study and longitudinal study after termination; how the baby died. 358pages.