

Preface

The book “Ethical dilemmas in prenatal diagnosis” is based on the contributions to the international conference “Ambivalence of the technological progress in medicine” which was held in September 2008 in Frankfurt/Main, Germany. The focus of this conference was on technological developments in the life sciences which – often tacitly – confront us with new facets of a Faustian seduction. Are we “playing God more and more, as some contemporary critical authors of modernity are claiming? Achievements in genetic research produce ethical dilemmas which need to be the subject of reflection and debate in modern societies. Denial of ambivalences that ethical dilemmas arouse constitutes a threat to societies as well as to individuals. The European study “Ethical Dilemmas Due to Prenatal and Genetic Diagnostics” (EDIG, 2005–2008) investigated some of these dilemmas in detail in a field which is particularly challenging: prenatal diagnosis. When results from prenatal diagnosis show fetal abnormalities, women and their partners are confronted with ethical dilemmas regarding: the right to know and the right not to know; decision-making about the remainder of the pregnancy and the desire for a healthy child; responsibility for the unborn child, for its well-being and possible suffering; life and death.

With this book we would like to contribute to this ongoing and demanding discussion from an ethical, psychoanalytical and medical perspective. The book presents a compilation of some of the results of the EDIG study providing an insight into the interdisciplinary nature of the research. In a sense, this book can be considered to be a continuation of the volume *The Janus Face of Prenatal Diagnostics. A European Study Bridging Ethics, Psychoanalysis and Medicine* edited by Marianne Leuzinger-Bohleber, Eve-Marie Engels, and John Tsiantis and published by Karnac Books in 2008.

Marianne Leuzinger-Bohleber, the coordinator of the EDIG study, introduces the subject-matter by giving a short overview of the research project. In particular, she highlights clinical-psychoanalytical findings and discusses protective as well as risk factors that may help medical staff identify couples who particularly need support and help during the process of having to decide on the life or death of their unborn child. Then Nicole Pfenning-Meerkötter discusses the management of such a large and complex undertaking as the EDIG research project and the challenges posed to the scientists involved.

In the following chapter, Tamara Fischmann presents empirical results of the EDIG study, focusing on distress resulting from prenatal diagnosis and related ethical issues. She describes the study design and population, as well as the impact on women of the testing process. Katrin Luise Läser scrutinizes the subjective attitudes of women towards prenatal testing by analyzing empirical EDIG data with a qualitative approach. She explores women's motives for undergoing prenatal testing and their feelings towards the process. A positive test result is a disturbing experience for women and their partners who find themselves at the limit of their emotional capabilities. Elisabeth Hildt focuses on this difficult issue from an ethical point of view studying the responses given by women to the open questions about their decision making processes.

After reviewing developments in prenatal testing, the chapter by Helen Statham and Joanie Dimavicius provides important information which may help professionals give optimum support and care to those undergoing prenatal diagnosis. In particular, a number of useful Internet-based resources for professionals and couples are presented. Astrid Riehl-Emde and colleagues summarize some 10 years of research in Germany, which has focused on collaboration between different professional groups involved with women during prenatal diagnosis. The authors suggest that although there have been definite advances, there is still a need for better coordination of information and care for pregnant women and their partners.

Anders Nordgren reflects, in his chapter, on policy frameworks for prenatal genetic counselling and the implications that empirical findings, such as those from the EDIG study, may have for informing decisions about policy. Another facet of prenatal diagnosis and genetic counselling, highlighted here by László Kovács, is the balancing of risk versus the need for certainty. His chapter analyzes differences in the practical and ethical concerns of health care professionals and of pregnant women and he suggests that ethically sound solutions have to integrate both perspectives. Dierk Starnitzke's contribution draws on his experience as speaker of the board of one of the largest institutions for disabled people in Germany. He discusses counselling with respect to termination or continuation of a pregnancy after a positive test result. Yair Tzivoni argues that a consideration of the unconscious in the decision-making process could promote a more ethical and responsible way of working through this process both for the person who has to decide and for the doctor/counsellor.

Regina Sommer then draws on the Aristotelian model of decision making in order to explain limitations in the choice a pregnant woman will make when confronted with an abnormal prenatal test result. From an applied ethics perspective, Göran Collste considers moral aspects of decision-making by drawing on four interviews with women who had been confronted with difficult choices through the information provided from prenatal diagnosis. Autonomous decision-making is also scrutinized in a clinical case vignette from Maria Samakouri and colleagues. This emphasizes the ways in which certain personality traits and past life experiences may influence decisions concerning prenatal testing. And finally, Stephan Hau poses the question 'Different cultures – different ethical dilemmas?' He highlights an ongoing public debate on ethical questions in the field of prenatal diagnosis in Sweden.

This collected volume would not have been possible without the research, effort, enthusiasm and patience of the partners of the EDIG study. We thank all those who participated in the conference and who contributed a chapter to this book, as well as the additional authors. We are particularly grateful to Helen Statham and Joanie Dimavicius for their elaborated and thoughtful English editing of the manuscripts and for stimulating discussions.

And last but not least we would like to thank all the women and their partners who so willingly agreed to participate in this study and gave us so much insight by talking to us and by completing all those questionnaires.

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