

Chapter 1

Introduction and outline of the thesis

INTRODUCTION

The expanding use of prenatal diagnosis and improvements in prenatal screening lead to an increasing number of fetal abnormalities diagnosed in early pregnancy. While the majority of parents who have opted for prenatal diagnosis will be reassured that their child does not have the anomaly the test was aimed at, some parents will be confronted with the diagnosis of an anomalous fetus. Therapeutic options are limited and these parents will have to decide whether they will continue the pregnancy and have a severely handicapped child or a child that will die soon after birth, or whether they will terminate this otherwise desired pregnancy. In the Netherlands this complex and painful decision is currently made 500 to 550 times a year ¹.

From the literature we know that once a severe fetal anomaly has been diagnosed, most pregnancies (87 – 94%) are terminated ²⁻⁴. Apart from the ethical questions these developments have also mental health implications. What happens to couples who opted for a termination of the pregnancy (TOP)? They decided on their own loss of pregnancy. Their initial ‘bliss’ is replaced by something that threatens their happiness. At the same time they are in control and have to decide about subsequent events. For most of the parents it is a difficult and often lonely decision.

Blumberg and colleagues were among the first to investigate 15 couples after TOP in 1975 ⁵. They were surprised by the high incidence of depression as an immediate response to the termination. According to the authors, neither abortion on social grounds nor spontaneous loss of a desired child due to intrauterine death nor loss during childbirth did show a comparable incidence of depression. They argued that the active role of the parents in the decision-making and the responsibility inherent to this event explained the more serious depression. But they concluded: “most families elect a termination and its concomitant emotional trauma as an alternative to the even more burdensome birth of an ill or handicapped child”. In the Netherlands, Leschot and Verjaal were the first to pay attention to the consequences of TOP for genetic reasons ⁶. They found a high incidence (31%) of depression long after the termination in a study of twenty women. Since then quantitative and qualitative studies have increased our knowledge of consequences of TOP for genetic reasons ⁷⁻¹⁹. The results of these studies vary greatly. Researchers found that shortly after the termination 20% to 67% of women have levels of depressive or posttraumatic stress symptoms indicative for pathology ^{7-9, 12, 15, 20}. Some studies have shown that the psychological burden of trauma and bereavement of this kind of loss results in long-lasting (\geq one year) serious mental problems for a considerable part of women ^{8, 9, 15, 19-21}, even though the large majority of parents adjusts well. Nearly all authors concluded that TOP should be seen as a major life-event. Limitations of most studies are the small samples, the non-standardized and non-validated measuring methods and the fact that almost all studies are focussed on the mothers only ^{5, 10, 19}.

Loss and grief are integral parts of life and the majority of people is able to adapt well²². When it comes to health care it is important to identify individuals with more than a common vulnerability to bereavement complications. Previous research on general perinatal bereavement has shown that pre-loss mental health is an important predictor of grief after pregnancy loss^{23, 24}. As TOP for fetal reasons is relatively rare, all studies in this field lack pre-TOP assessments of mental health or vulnerability factors of the responders. A partial solution to this problem may be measurements of personality dimensions, with validated and stable instruments. Another aspect hampering research in this field is the great number of participants needed to identify influences of external factors. This may explain why little research has been done into factors that are predictive of problematic mourning after TOP.

From 1986 to 1995 a project was undertaken at University Medical Centre Utrecht (UMCU), which combined research as well as patient care for parents who were hospitalized for TOP following the diagnosis of a fetal anomaly. Aim of the study was to investigate the psychological consequences of TOP. It was a joint project between the Department of Medical Psychology (Utrecht University), the Department of Genetics (UMCU) and the Department of Obstetrics (UMCU). Parents were interviewed six weeks and six months after TOP. The interviewers, two midwives and one genetic social worker had received a tailor-made training for the purpose of these long and semi-structured interviews. The conversations were taped and subsequently transcribed. Hundred and twenty-nine couples were interviewed and the results of the first forty conversations were published (Chapter 2).

This lengthy research period laid the foundation for the main study that will be described in this dissertation. To re-examine the issue in a larger cohort with more robust instruments, questionnaires were developed with the knowledge and experience acquired in the interviews with these “pioneer” parents.

The main study started in 1996. The study design was based on the following:

1. Given the very specific character of a loss in which parents themselves have taken an active part (namely: in a way parents themselves have ‘caused’ this), it may well be possible that there are complications, which only arise in the long term. Therefore, we opted for both a retrospective and a longitudinal study in order to achieve the best understanding of the psychological consequences of TOP.
2. For the measurements we used postal questionnaires with standardized methods and validated instruments allowing for the results to be compared with other studies in this field.
3. Because of the large number of participants required, we cooperated with several other hospitals.
4. Both the women as well as their partners were involved in the study. The same questionnaires were used for the partners (in this study all of them men) in

order to assess parental interaction and potential differences between men and women.

5. Given the complex process of bereavement, we used a wide scale of psychological measurements, including ones relating to depression and posttraumatic stress.
6. The survey focussed on beneficial and detrimental factors in the grieving process after TOP.
7. Because of the lack of pre-TOP assessment, vulnerability for pathological coping was measured by the instrument of generalized self-efficacy (GSE), a stable personality characteristic in which a high score reflects that an individual believes that he or she can cope with difficult demands.

AIMS OF THIS THESIS

1. To get insight into the decision-making process and in the short and long term psychological consequences for parents of the termination of a pregnancy for fetal anomaly.
2. To identify factors influencing psychological morbidity.
3. To compare the reactions of women and men and assess the interaction in the couple.
4. To formulate guidelines, which may minimize the emotional impact associated with the termination of a pregnancy.

THESIS OUTLINE

We conducted the following studies:

Chapter 2. In a qualitative study 40 women and 31 men were interviewed to explore specific psychological sequelae of TOP for fetal anomalies.

Chapter 3. A retrospective study was conducted in 254 women 2 to 7 years after TOP, in order to get insight in the long-term psychological consequences of TOP and in potential risk factors for maladjustment.

In chapter 4 also the partners were addressed. Differences between men and women as a group were studied, as well as patterns of intra-couple reactions.

In Chapter 5 reactions of both men and women are described 4 months after the termination, in which in addition to the variables of the retrospective study, the personality characteristic self-efficacy was included. This prospectively obtained cohort included 226 cases of TOP.

In Chapters 6 and 7, the longitudinal results of the above named cohort are presented up to 15 months after TOP. In Chapter 6 we describe the course of adjustment of 147 women, and in Chapter 7 we addressed 90 couples for psychological consequences of TOP and investigated intra-couple reactions and their implications.

In Chapters 8 and 9, two aspects of the issue of TOP are discussed separately. In Chapter 8 we describe perceived pressure as reported by the parents in the period of decision-making and in Chapter 9 we describe aspects of the decisional process in 71 women who terminated their pregnancy because of Down syndrome.

Chapter 10 contains considerations, a summary and recommendations for clinicians.

Finally, we added an Appendix in order to give an overview of TOP in broad perspective, based on the results and experiences of the three populations studied.

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