Chapter 10

Summary
General discussion
Recommendations

SUMMARY

In the Netherlands every year 500 to 550 pregnancies are terminated before 24 weeks of gestation because of serious fetal abnormalities. These - mainly chromosomal - abnormalities are diagnosed through invasive prenatal diagnostic procedures such as amniocentesis or chorionic villus sampling. Additionally, an unknown number of pregnancies is terminated because of serious abnormalities diagnosed with ultrasound.

Termination of pregnancy (TOP) for fetal abnormality is a major life-event for parents and a potential source of serious short-term or long-term psychological problems on their part. In the context of trauma and bereavement, the phenomenon is a remarkable one because it is the parents' own decision to terminate an otherwise desired pregnancy (see Chapter 2 for cases).

Hardly any systematic research has been done to identify parents that are at risk for long-term psychological morbidity after such an event, that is, research based on a sufficient number of participants and on validated measuring methods. Such research is important, because it might well lead to goal-oriented and potentially intensive counselling of high-risk groups. Counselling of this type will ease adjustment and may prevent pathological grief. Such research is all the more important, because it is to be expected that further implementation of prenatal screening techniques will lead to an increase in the diagnosis of serious fetal abnormalities at an early gestational age.

Chapter 1 describes the background, outline and aims of the study. A ten-year period of interviews with parents served as the basis of two questionnaire studies. In order to determine the psychological outcome of TOP as complete as possible we opted for both a short-term and a long-term approach. For the retrospective study we sent questionnaires to women and their partners who had opted for TOP two to seven years earlier. In the prospective study parents were asked for participation at the time of hospitalization for TOP. In this study we used comparable questionnaires at approximately 4, 8, and 15 months after termination. For both studies the attending gynaecologist contacted the women and partners in question whether they agreed to being approached about the investigation. We used validated questionnaires on grief, symptoms of posttraumatic stress, depression, generalized psychological malfunctioning, and the personality dimension self efficacy. A second part of the questionnaire was especially designed for this study and contained questions about doubt and perceived external pressure during the decision period, and questions about perceived partner support. The research was conducted in 9 hospitals in the Netherlands to achieve a sufficiently high number of participants.

It was the aim of the study:

1. To get insight in the decision-making process and 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 describe guidelines, which may minimize the emotional trauma, associated with this kind of termination of pregnancy.

Chapter 2 contains the results of interviews with 40 women and 31 men six weeks and six months after the termination of their pregnancy. This was a qualitative study with partly standardized questions. The interviews were taped and transcribed at a later date. Six months after the termination, a substantial number of parents still suffered from severe emotional distress. Feelings of failure, doubt and guilt and moral and social pressure characterised their adjustment and made it more problematic. Analysis of the interviews showed that a number of factors appeared to influence the grieving process. Termination for a life-compatible disorder seemed to be more problematic than termination for a life-incompatible disorder. Insecurity about the severity and / or viability of the disorder was another problematic factor. Contrary to expectation, gestational age at termination did not make a difference as to the grieving process. Almost all parents indicated that in the case of another pregnancy, they would opt for prenatal diagnostic testing as early in the pregnancy as possible. Four of the 40 women indicated that they regretted their decision to terminate the pregnancy; in all four the severity of the disorder was uncertain to them. Many parents suffered from conflicting feelings and thoughts. Only 14% of participants wished to participate in a patient self-help group. Eighty percent of the parents indicated that their adjustment had benefited from the extensive conversations during the interviews. Fifty percent of the parents was willing to talk to fellow-sufferers in case they would be asked to do so. Such conversations only took place in a small number of cases. Parents offered the following advice to counsellors: parents need to be better informed about the nature and the severity of the disorder and the longevity of the grieving. The importance and gravity of the event should be acknowledged by the medical staff and the social environment of the parents.

Chapter 3 describes responses of 196 women two to seven years after TOP. The termination had been experienced more as a trauma than as a loss event, and the scores on grief were much better than these of posttraumatic stress symptoms. More than 17% showed pathological scores for posttraumatic stress. The most important predictors of long-term psychological morbidity were poor partner support and low level of education. Of less importance were advanced gestation age at the time of termination and a life compatible disorder. Both did, however, affect psychological outcome. In the case of a life compatible disorder women

showed - in retrospect - slightly more doubt about their decision. In conclusion, the great majority of women do well after TOP for fetal reasons. Symptoms of posttraumatic stress are the most frequent complaints.

Chapter 4 deals with the same population as described in chapter 3, but now also includes their partners (all of them men). The cohort consisted of 151 couples two to seven years after TOP. We investigated possible differences in adjustment between men and women and intra-couple interactions. The majority of the couples adapted well to the termination of the pregnancy. Men scored slightly better on psychological questionnaires than women, but the differences between men and women were moderate. Pathological scores occurred both in men and women and only in the case of posttraumatic stress symptoms did women do worse. High level of education, early gestational age and TOP for a life-incompatible disorder positively influenced outcome. It was remarkable that men and women rarely experienced long-term psychological morbity simultaneously. We emphasize the importance of equally involving both parents in the counselling.

Chapter 5 describes the results of a prospective study in which 217 women and 169 men filled out a questionnaire four months after TOP. Literature about loss has shown that people who are highly distressed in the first period have a higher risk of serious and long-term problematic adjustment. In this study we tried to gain insight into this potential risk group by identifying parents who were highly distressed in the early post-TOP period and in the factors causing this distress. Just as the foregoing study, this study showed that parents experience termination for fetal anomaly more as a traumatic than a loss event. The differences between men and women were larger than in the retrospective study. Pathological scores in men and women on posttraumatic stress symptoms occurred in 22% and 44%, respectively. Predictors of problematic adjustment were: religious beliefs, more advanced gestational age, high level of doubt during the decision-making process, insufficient partner support, and low score on the self efficacy questionnaire. We recommend that parents receive information about the post-TOP period, that psychological support is easily accessible to them and that they are referred in case of problematic adjustment.

Chapter 6 describes the psychological reactions of 147 women on the basis of measurements 4, 8 and 15 months after TOP. Four months after termination 46% of the women showed high levels of posttraumatic stress symptoms and 28% post-partum depressive symptomatology. These percentages fell with time and were at 15 months 20% and 14%, respectively. High levels of posttraumatic stress symptoms and depressive symptoms in the first months after TOP were a signal for maladjustment later. Important predictors of persistent disturbances were low self-efficacy, doubt during decision-making, and lack of partner support.

Apart from the conclusions from the previous chapters, these data strongly suggest the importance of adequate counselling regarding the severity of the fetal

anomaly. Moreover, parents should be offered psychological help in case of high level of doubt in the decisional period, and in case of serious distress after TOP.

In **Chapter 7** psychological reactions of 90 women and their partners were studied at 4, 8, and 15 months after TOP. To our knowledge this is the first study in which psychological outcome after TOP was investigated longitudinally in both partners using validated instruments. Trajectories of psychological adjustment to TOP were comparable in women and men at a group level. At the couple level, females often had much higher scores on psychological measures than their partners. Discordant compared with consistently concordant couples were predicted by lower self-efficacy in women and intra-pair disagreement about the amount of support they received from each other. Women of discordant couples had also a less optimistic life orientation and were less satisfied with their relationship. Within-couple discordance for psychological functioning (female score exceeding male score) in the first assessment is a risk factor for serious and enduring psychological problems in the female partners.

In both the retrospective and the prospective investigations we studied the amount of pressure experienced by the couple at the time of decision-making regarding TOP. The data on perceived pressure are presented in **Chapter 8**. The great majority of parents (83-92%) indicated that they had not experienced any pressure during the decision making process. If pressure was felt, the most prominent sources were moral values of society and pressure by medical professionals. There was a correlation between the degree of pressure and adjustment: the more pressure the parents felt, the more problematic the adjustment turned out to be.

Chapter 9 concentrates on the decision making process in case of a life-compatible Down syndrome. Society has highly divergent views on TOP for this disorder. Seventy-one women filled in questionnaires on their decisional process regarding TOP for Down syndrome, four months after the actual termination.

One-third of the women indicated that they had had no doubts at all about their decision to terminate their pregnancy, but 21% had had serious doubts. When motivating their decision for TOP, all the women mentioned the child's interest, but at the same time nearly all women also mentioned that their own interest had played a role. Medical professionals had a considerable influence on the decision making as opposed to the pressure parents experienced in contacts with them (1%). Eight percent of women reported pressure at decision from society and 30% indicated that they had had to defend their decision once or on a number of occasions. The women were generally positive about the counselling they received. They were less positive about the way they were informed about the post-TOP period and self-help groups or contact with fellow-sufferers. TOP in the case of Down syndrome is a difficult decision for a considerable number of women in the course of which their partners play an important role. Apart from the pressure exerted by social norms, their own ambivalent feelings and motives

seem to make their decision about TOP a difficult one.

Finally, the Appendix gives a general overview of the process of TOP. It contains a presentation of the results of the current research and parents' quotes and describes experiences of the researchers. The appendix also contains a discussion of the clinical consequences emerging from this study.

CONCLUSIONS

- Parents experience termination of pregnancy for fetal anomaly more as a traumatic than a loss event.
- Psychological distress following TOP is initially higher in women than in their partners, but long-term outcome does not differ greatly.
- Parents with problematic adjustment in the first period after TOP have a higher risk of psychological morbidity in the long term.
- Although most parents adapt well to TOP a significant number (about 19 percent) keep long-term posttraumatic stress complaints.
- Factors leading to long-term psychological morbidity are: inadequate partner support (mainly for women), low level of self efficacy, high level of doubt in the decision period, perceived pressure at the decisional process, more advanced gestational age, having a religion, a fetal anomaly presumably compatible with life, and a low level of education.
- For most of the parents, the termination did not affect their future reproductive intentions, and regret about the decision was rare.

GENERAL DISCUSSION

Posttraumatic stress reactions dominated psychological outcome following TOP. Almost half of the women and a considerable number of men showed high levels of posttraumatic stress reactions four months after TOP. Such reactions occur transiently in many people in the first period following a major life-event. The complaints may persist, though, and have serious long-term problematic consequences. Research on the consequences of other major life-events shows that people with such reactions in the first period run the risk of serious and long term psychological morbidity [1, 2]. One of three women from our cohort, who had scores above the cut-off point for posttraumatic stress symptoms 4 months after TOP, ended up having long-term posttraumatic stress symptoms.

The figure shows the percentage of women with pathological levels of posttraumatic stress symptoms in the months and years after TOP. This figure was made by combining the results of our prospective and retrospective study and includes data of quite another study on women three months after a normal birth [3]. The percentage of women with pathological scores fell progressively with time until

15 months after TOP, after which it appeared to stabilize, at a level about five times higher than in the women after a normal birth.

Parents need to be informed about the difficult first period after TOP and about the risk of long-term psychological distress, but also about the fact that most people adapt well. The possibility of psychological support should be pointed out to them, as well as the existence of patient self-help groups. The partner's role in the adjustment is very important and both partners should, therefore, be equally involved in counselling.

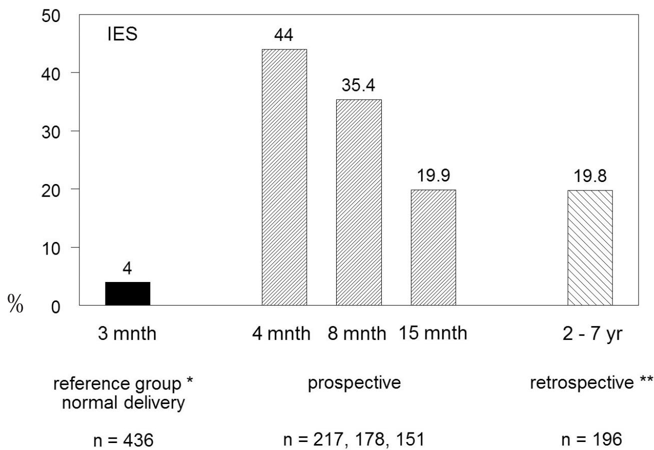

Figure 1. Percentage of women showing pathological level of posttraumatic stress symptoms (Impact of Event Scale -IES- in the months and years after TOP. Cut-off point for pathology > 26. * Reference group: E. Olde 3, ** IES-R recalculated into IES.

Up till now, grief research has not validated the positive effects of routine referral for psychological support [1, 4]. An explanation could be that people have a strong recuperative capacity which may be damaged by such a policy of referral. However, people who have a high risk for adverse outcome and those who ask for help do benefit from such a support [1, 4]. Our results indicate two reasons for referral: a high level of doubt during the decisional period and serious psychological distress in the first period after TOP. Outpatient visits in the months after TOP should be arranged, to enable doctors to signal early symptoms of psychological morbidity and refer people for professional support. Moreover, patients should be encouraged to contact caregivers in case of psychological problems. This does not only hold for the attending gynaecologist, but also for the primary healthcare providers. Our data have shown that the latter are less involved with the whole process of TOP, whereas they are the ones who usually know the couple best.

In general, results from the retrospective and prospective study were remarkably similar. There were only a few differences:

1) Psychological distress following TOP was considerably higher in the women than in their partners shortly after termination, but long-term outcome did not differ greatly. This is likely due to the fact that the women themselves did undergo the termination.
2) A life-compatible disorder was in the retrospective study associated with a higher level of psychological morbidity. In the prospective study during the first 15 months after TOP we did not find evidence for this. The difference might be due to the fact that relatively shortly after TOP the termination is experienced as a major provoking event irrespective of the underlying disorder, whereby only after some years, reflections on the viability are allowed.
3) A higher level of education resulted in better outcome on the long run, but did not protect against short-term morbidity. While in the short term emotions may have been dominant, long-term coping benefits from a higher education. A longer follow-up of our prospective cohort, for instance till about four years after TOP, could reveal if the differences between both cohorts are persistent.

At present prenatal screening techniques are increasingly implemented. Regarding chromosomal anomalies this holds especially for nuchal translucency measurement and early biochemical testing. Implementation of screening tests in the general population will result in the diagnosis of fetal anomalies in an a-priori low risk group. According to our study, this will not affect adjustment. Also termination for Down syndrome did not negatively affect parental outcome, as compared to TOP for other anomalies. The increase in medical tests is likely to result in an earlier diagnosis of anomalies than in the present study. Earlier diagnosis may have a positive effect on adjustment, since in both of our samples we found that a shorter gestational age at TOP was an independent factor for a lower level of posttraumatic stress symptoms. Such an association has only been demonstrated in a few other studies [6-8]. In our population we could not distinguish between earlier stage of pregnancy at TOP and method of TOP since these two were closely linked. However, recent data from others have indicated that the method of TOP, either medical or surgical, had no effect on psychological outcome [9]. Finally, as a result of implementation screening techniques, maternal age will likely be lower than in our population, as will be education. Our data as well as those of others have shown that this is likely to have a negative effect on adjustment [10-11].

Table 1. Percentages of women who had perceived pressure at decision-making, who regretted TOP, who did not dare to embark into a next pregnancy, and who would opt again for prenatal diagnostic testing.

Study	Number of persons	Perceived pressure at decision making		Regret decision TOP		No new pregnancy because of this TOP	PND testing again
		From society	From medical staff	Much	Occasionally		
4 Months post TOP	217	6%	5%	2%	4%	6%	93%
Down syndrome T1	71	8%	1%	1%	4%	8%	92%
Retrospective Study	196	7%	7%	3%	5%	5%	96%

Termination of pregnancy for a fetal anomaly is a major life event. The decision for termination has to be made by the parents alone. However, the parents definitely need to be informed extensively about the severity of the anomaly. They should be allowed under the circumstances enough time for a careful evaluation of the positive and negative consequences of TOP. This all to prevent regret and long-term psychological morbidity. In our studies we have addressed issues such as perceived pressure during the decision-making process, regret of the decision to terminate pregnancy and thoughts about a next pregnancy. These data are summarised in Table 1. Perceived pressure has been infrequent and so was regret. This also appears to be reflected by a positive attitude of parents toward a new pregnancy. These data are reassuring as to the counselling that these parents underwent. However, the results of our studies also show that we still could do better.

The questions asked to the women in this study were sometimes confronting and painful. Yet, especially these questions led to recognition and were mentioned by many respondents as positive for coping. The women completed the questionnaires in a remarkably open and self-consistent way. Termination of an initially wanted pregnancy after diagnosis of fetal anomaly proved to be a profoundly difficult decision for a substantial part of women.

RECOMMENDATIONS FOR CLINICAL USE

- Parents need to be informed about the risk of serious psychological distress in the first period after TOP, but also about the fact that most people adapt well on the long-term. The existence of patient self-help groups must also be pointed out to them.
- The partner's role in the adjustment is very important and therefore both partners should be equally involved in counselling.
- Clinicians should give extensive information as to the severity of the fetal anomaly.
- Parents should be offered psychological help in case of a high level of doubt in the decisional period and, in case of serious distress in the first period after TOP.

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