Parental adaptation to termination of pregnancy for fetal anomalies

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Parental adaptation to termination of pregnancy for fetal anomalies
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Parental adaptation to termination of pregnancy for fetal anomalies

Psychologische gevolgen voor ouders van zwangerschapsbeëindiging op grond van afwijkingen bij het kind

(met een samenvatting in het Nederlands)

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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 well [22]. 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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Chapter 2

Termination of pregnancy on genetic grounds: coping with grieving

Semi structured interviews with parents 6 weeks and six months after termination

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ABSTRACT

Objective: This study describes reactions of couples to the termination of their pregnancies because of a fetal anomaly. The aims were: evaluation of the counselling at our hospital, in order to formulate recommendations for improvement, to find out whether there was any need for a support group, and to see whether being able to discuss the experiences extensively might be a positive factor in coping.

Methods: Forty women and 31 men were invited to have two semi-structured interviews, 6 and 26 weeks after the termination, respectively. All interviews were recorded on tape and written out afterwards by the interviewer.

Results: Factors found to be of influence on decision-making and coping include whether the anomaly was found by chance or through directed search, whether or not the anomaly was compatible with life, how far the pregnancy had progressed, and by which method the pregnancy was terminated.

Conclusion: The feelings these couples faced were in some ways comparable to those perceived after a stillbirth or neonatal death, but the authors also encountered other, entirely different feelings. The latter include guilt, doubt, failure, and feelings of moral and social pressure. Recommendations for clinical practice are given at the end of the paper.

INTRODUCTION

The psychological consequences of termination of pregnancy (TOP) on genetic grounds was the subject of the investigation. The study was set up as a combined project of the Department of Obstetrics of the University Hospital of Utrecht, the Clinical Genetics in Utrecht, and the Department of Medical Psychology of the State University of Utrecht. Currently, when prenatal diagnosis (PND) or ultrasound reveals a severe fetal anomaly, the pregnancy will often be terminated. In Holland the number of invasive diagnostic procedures has risen sharply during the past decade as a result of extensive publicity, lowering of the maternal age limit, and an increasing number of gravidae aged over 30 years. Moreover, the types of anomalies detectable by ultrasound are still on the increase[1], and routine ultrasound scans are now generally accepted. Inevitably, an increasing number of parents-to-be are confronted with the prospect of a seriously disabled child, challenging them to choices regarding its life or death. Physicians and geneticists have done much work on the development of diagnostic techniques for detection of fetal anomalies. However, as a consequence, the confrontation with the psychological and emotional implications for the parents and their relatives is inevitable. The same counts for the medical staff involved.

Termination of pregnancy on genetic grounds is different from abortion in that it is an initially wanted pregnancy. It differs from stillbirth because the parents themselves have to decide whether the child will live or die. The literature only presents a limited number of prospective studies on this issue[2,3]. For the Netherlands, Leschot[4], and Thomassen-Brepols[5] studied the psychosocial aspects of prenatal diagnosis and its consequences.

The purpose of our study was threefold. Firstly, to evaluate the counselling of clients who had TOP on genetic grounds at our hospital, in order to formulate recommendations for improvement. Secondly, to find out whether there was any need for a support group. Finally, to see whether being able to discuss the experiences extensively might be a positive factor in coping. We will present the results of client evaluation, and discuss a number of factors that were found to be of great influence on decision-making and grieving.

PATIENTS AND METHODS

All women and their partners who had TOP on genetic grounds were invited to participate in the survey when still in the hospital. The couples were invited to have two semi-structured interviews, 6 and 26 weeks after the termination, respectively. The interviews were taken by two specially trained midwives (M.J.K., H.R. I.-K.) and a social worker of the Clinical Genetics (H.G.v S.)

The interviews were recorded on tape and written out afterwards by the interviewer.

After the first 2 years of the study a written enquiry was held to find out the interviewees' attitude towards the interviews.

RESULTS

From January 1986 until October 1990, 40 women and 31 men were interviewed. Table I gives some more characteristics of these families and the indication for TOP. Thirteen couples declined to take part. The first interview took between 1.5 and 3 hours, and the second between 1.5 and 2 hours. The clients were highly heterogeneous and we found a wide range of factors influencing decision-making and grieving.

Anomalies found by chance as opposed to directed search. In 25 of the 40 cases the fetal anomaly was found after directed search on account of patient history. In these cases, the parents had often decided beforehand to have the pregnancy terminated, should a defect be found. However, the actual diagnosis of an anomaly appears to affect this rational decision. The emotions involved often forced the parents to go through the decision-making process all over again. If the anomaly was found by chance (routine ultrasound scan, abnormal findings during prenatal visit or abnormal screening results, many patients reacted impulsively: 'Out with it, as soon as possible'. Such requests were in principle never granted; rather, it was suggested that the parents take a few days for deliberation and reflection. During this time often a change of attitude could be observed. 'All that waiting was not in vain,' a woman (number 33) told us. 'I wanted to be informed as thoroughly as possible, so that I knew this was for the baby's best and so that I could feel: I am a good mother for my baby if I decide to do this.' Another woman (number 17) who had only 1 day between the final diagnosis and TOP, said: 'The sooner the better, otherwise doubt sets in, and then I might not have gone through with it'.

The time-lapse between diagnosis and intervention varied from 1 to 10 days, with an average of 4.7 days and a median of 4.4. Two couples found their waiting period too short (2 and 3 days, respectively), 11 couples found it too long (5 $\geq$ 5 days and 6 $\leq$ 4 days), and in 27 cases the parents felt it was just right (13 $\geq$ 5 days and 14 $\leq$ 4 days).

Compatibility with life. The question whether the anomaly was compatible with life was another factor in decision-making and grieving. In the group studied, 25 defects were compatible with life; 14 were not, and one was questionable (case 4). Compatibility with life complicated the decision to terminate the pregnancy. A woman (number 13) said, 6 months after she had TOP because of spina bifida: 'Whenever I see a child in a wheelchair, I think: Those children can be very happy, too'. And a woman who had a chorionic villus sampling (CVS) on account of her age, and in whose fetus trisomy 18 was found (number 30), told us: 'This made the decision very clear for us. We do not feel we interfered with life; rather we anticipated a situation that would have arisen anyway. I would have found trisomy 21 much more difficult to cope with'.

Certainty of diagnosis of the defect or its severity. In prenatal diagnosis, some defects can be fully demonstrated, whereas others face the parents with an N% chance of a defect, as may be the case in sex-linked disorders or in DNA diagnosis.

In our study there were in total seven cases with either an absence of diagnostic possibilities or an unpredictable severity of the defect. With respect to coping, there appeared to be a world of difference between 100% proof and some uncertainty, however little. A man said (number 14): ‘But I cannot help thinking of the other possibility: that it was all right after all. Yes, that really kills me sometimes. We might have had a child now, and maybe even a healthy child at that!’

The gestational age. The duration of pregnancy was a predominant factor in decision-making: the further the pregnancy had progressed, the more difficult the decision to terminate. When asked, most but not all couples stated that in future they would opt for the earliest possible diagnosis. A woman (number 30): ‘After 2.5 months of pregnancy, emotionally it was a child to me, but a child on the way to becoming a child. I think the baby did not suffer, because it was still so small’.

Contrary to what we expected, however, we found no major differences in grieving between early and late pregnancy termination. Couples who had their pregnancy terminated at a late stage found solace in having been able to feel and see their baby, and in having pictures of it. It had become a real person to them: their child. A woman (number 33): ‘It may sound odd, but we have his picture in our room’.

The method of TOP. The method by which the pregnancy was terminated depended on the duration of the pregnancy. Dilatation and curettage (D and C) was applied up to 14 weeks gestation (10/40). Between 14 and 22 weeks the parents had the alternatives of dilatation and evacuation (D and E) (8/40), and local or parental induction of labour by prostaglandines (13/40). From 22 weeks onwards, only labour induction was applied (9/40).

Dilatation and evacuation is a swift and painless method for the patient. This is often why patients opt for this method. However, sometimes they prefer it in order to avoid the confrontation with their child.

In local or parental induction of labour the contractions are induced pharmaceutically so that the child can be delivered per vaginam. In most cases it dies during these contractions. Induction can be protracted and aggravating, even with effective pain suppression (e.g. by epidural anaesthesia). Very little is known about the fetus’ suffering in either method[6]. Nevertheless, several couples stated that their choice of the method of termination was partly determined by their idea of what would be least painful for the baby.

It is difficult for gynaecologists to give objective and honest information about these methods, and in one case it was perceived by the parents as hurting. A woman (number 25) said: ‘But I really take offence at the gynaecologist saying: ‘You do understand that the baby will come out in parts?’ I did not want to know that’. In most cases TOP by means of prostaglandin induction appeared to have a positive effect, despite the considerable emotional and physical strain, in that the couple could actively and consciously participate in the delivery, confront their baby, and have the opportunity to take pictures. A woman (number 13): ‘No, not general anaesthetics. After all, it is me who is going to deliver my child’.

Table 1. Characteristics of the patients

Case number	Reason for prenatal diagnosis	Method of prenatal diagnosis	Diagnoses	Interval between diagnosis and termination (days)	Gestational age at time of termination (weeks)	Method of termination	Interviewer
1	family history/ elevated sAFP	US	spina bifida	8	18	PG iv	mw 1
2	abnormal obstetric findings	AC	XXXXY	8	29	PG iv	mw 2
3	routine ultrasound	US	hydrocephalus	10	17	PG iv	mw 1
4	maternal age	AC	ruptured membranes	9	23	PG iv	mw 2
5	maternal age	CVS tc	trisomy 18	2	10	D&C	mw 2
6	maternal age	CVS tc	trisomy 18	3	12	D&C	mw 1
7	former affected child	AC	spina bifida	1	18	PG iv	sw
8	family history	US	anencephalus	3	16	D&E	mw 2
9	paternal age	AC	XO	4	20	D&E	mw 1
10	routine ultrasound	US	hydrocephalus/spina bifida	6	19	PG iv	mw 2
11	abnormal obstetric findings	US	anencephalus	7	25	PG iv	mw 2
12	family history	CVS tc	Duchenne's MD	4	11	D&C	sw
13	routine ultrasound	AC	trisomy 18	5	24	PG iv	mw 1
14	family history	imposs.	nil	3	15	D&E	mw 1
15	anxiety mother	US	anencephalus	5	15	D&E	mw 2
16	maternal age	AC	trisomy 21	2	17	PV iv	sw
17	family history	imposs.	nil	8	15	D&E	mw 2
18	former affected child	AC	unbalanced translocation 14/21	1	20	D&E	mw 1
19	maternal age	AC	encephalocele	2	18	PG iv	sw
20	abnormal obstetric findings	US	hydroceph./Potter's syndrome	10	28	PG iv	mw 1
21	abnormal obstetric findings	US	encephalocele	2	17	PG iv	sw

22	family history	CVS tc	hemophilia A	3	11	D&C	sw
23	former affected child	AC	trisomy 21	3	18	PG iv	mw 2
24	family history/ elevated sAFP	US	anencephalus	3	16	PG iv	mw 2
25	maternal age	AC	XYY	10	20	D&E	mw 1
26	family history	CVS tc	hemophilia A/chrom. marker	4	13	D&C	mw 2
27	routine ultrasound	AC	trisomy 18	2	21	PG iv	mw 1
28	former affected child	US	left ventricle aplasia	4	22	PG iv	mw 1
29	elevated sAFP	AC	balanced translocation 1/10 de novo	3	22	PG iv	mw 2
30	maternal age	CVS tc	trisomy 18	3	10	D&C	mw 1
31	maternal age	AC	trisomy 21	2	18	PG iv	mw 1
32	former affected child	CVS tc	XO	2	11	D&C	mw 2
33	abnormal obstetric findings	US	left ventricle hypoplasia	6	30	PG iv	mw 1
34	maternal age	CVS tc	trisomy 21	4	10	D&C	mw 2
35	maternal age	CVS ta	XYY	5	15	PG iv	sw
36	family history	US	left ventricle hypoplasia		25	PG iv	mw 1
37	former affected child	CVS tc	trisomy 21	6	11	D&C	mw 2
38	former affected child	US	Pena Shokeir syndrome	5	20	PG iv	mw 1
39	family history	CVS tc	hemophilia A	7	10	D&C	mw 2
40	elevated sAFP	US	anencephalus	7	15	D&E	mw 1

sAFP = α-fetoprotein

US = Ultrasonography
AC = Amniocentesis
CVS = Chorionic villus sampling;
tc = Transcervical;
ta = Transabdominal;

MD = muscular dystrophy

PG = Prostaglandin;
D&C = Dilatation and curettage;
D&E = Dilatation and Extraction;
iv = intravaginal

sw = Social worker;
mw 1 = Midwife 1;
mw 2 = Midwife 2;

Feelings after TOP on genetic grounds. The interviews revealed a wide range of emotions in our clients that also occur after for example, perinatal death but with a different background and emphasis.

Feelings of guilt. Feelings of guilt (12 women and four men) focused on various aspects: toward the child, since the parents had, partly out of self-interest, decided that it should not live. There was also guilt towards a previous child with a similar defect, toward one's partner in case of carrier state, and sometimes toward religion. For instance, one man (number 18) anxiously kept the event a secret from his religious community for fear of condemnation. Feelings of guilt, which occurred almost exclusively in the non-lethal defects, were among the least discussable aspects of grieving. They were rarely expressed, but now and again they did filter through. An example: a woman (number 7) had two severely defective children in a row. The first child was full-term but died 2 weeks after birth by means of euthanasia. The second pregnancy was terminated at 20 weeks gestation on account of the same defect. When asked whether she wanted to get pregnant again, she said: 'I dot not know. I cannot go on killing babies, can I?'

Feelings of failure, of genetic inferiority. The feeling of having failed (24 women and seven men) by being unable to give birth to a healthy child was prominent in many interviewees, mostly women. Sometimes their self-esteem had been severely damaged. As one interviewee (number 28) expressed it: 'I am good for nothing. I am a lousy wife, and now I am a lousy mother, too!'

Feelings of revulsion and fear. Some parents expressed fear of revulsion toward the unborn child. It was mostly women who mentioned this, and only when an external, visible defect was involved. Depending on the nature of the defect some parents developed a 'nightmare-image' of the fetus: an unrealistic image of the defective child. 'As if you were raped by the devil', is how a woman (number 20) described her feelings when she heard that her baby had hydrocephalus. For 10 days she harboured the idea that she was carrying a monster, until she was told (after having had to ask explicitly) that the baby's head would hardly deviate as to appearance and size. Knowing this did not alter the situation, but it gave her peace of mind, so that she was able to go through the delivery, see her baby, and cope with its funeral.

Some women expressed aversion or distaste for their own bodies, which, they felt, had let them down. A woman (number 20): 'I found it scary, but also dirty in a way. I felt very dirty, too'. Several women retained this aversion for their own bodies until long after TOP.

Doubts about the rightness of the decision. Doubt occurred only among clients in whose children the defect could not be shown with certainty or in whom the severity of the defect was uncertain. Four couples (number 14, 17, 29, 35) expressed serious doubts about having made the right decision. Remarkably, all these couples belonged to the group in which uncertainty of severity or diagnosis occurred. None of the clients whose children did have demonstrable defects revealed doubts about the rightness of their decision. Nevertheless in this group, too, ambivalent reactions occurred; in particular, some clients regretted the fact that the defect had been found at all. A woman (number 27): ‘For some time I felt furious, furious at medical science, those stupid ultrasound scans they make you have. For then you find out things you do not really want to know’.

Feelings of moral or social pressure to terminate the pregnancy, the feeling of not being free to make up one’s own mind. A small minority of interviewees felt a kind of obligation toward their child with a non-lethal defect, by the sheer knowledge that if the pregnancy were allowed to continue, their child would be born severely disabled. A man (number 25): ‘What do you tell the child when it is a few years old, when you have to say you already knew it had a defect?’. Some parents also felt pressure from society not to wilfully have a disabled child.

Sometimes, when discussing the diagnosis with the parents, the gynaecologist leaves the possibility of continuing the pregnancy out of consideration; this mere fact may be perceived by parents as pressure to have the pregnancy terminated. A woman (number 26) told us: ‘Far be it from me to say that the doctors talked us into it, but nobody ever said anything like: ‘Should that really be a reason for you to have an abortion?’. This particular case concerned a fetus with haemophilia A.

Contradictory feelings. Many parents expressed a contrast between grief for the death of their child, and relief that it would not have to live. As a woman (number 20) said: ‘I thought, for God’s sake do not let it be a small hydrocephalus, otherwise I may have to have it after all”. This relief would sometimes cause a taboo afterwards, a reason for not allowing oneself to grieve.

Feelings about another pregnancy. The wish for a child was stronger than the fear of another misfortune: the majority of parents in this study eventually opted for another pregnancy (30 women and 25 men). Three women (numbers 17, 21, 22) and two men (number 17 and 18) opted against another pregnancy. In general the parents were advised not to start another pregnancy too soon, in order to allow for sufficient time to grieve. However, particularly in age-related defects parents often did not allow themselves this time.

Besides longing for a (healthy) child other motives were involved, such as the ‘empty nest feeling’, as one woman described her nostalgia for a pregnancy; hoping or expecting to ‘forget’ the event by another pregnancy; or hoping to prove that they are able to put a healthy child into the world. Of all interviewees who wanted another pregnancy only one couple rejected any form of PND. This concerned patient number 4, for obvious reasons.

Different reactions in men and women. As in other situations of mourning, men frequently had reactions to TOP different from those of women. They expressed strong feelings of helplessness and of being an outsider, particularly during parturition. The latter was sometimes exacerbated by the woman-oriented attitude of the medical team. Contrary to women, men often appeared to have repressed their feelings, partly because they felt it was required of them to be a tower of strength, and partly because they had to resume their normal routine as soon as possible. In several cases this led to tensions and reproaches between husband and wife.

In general, it was women rather than men who felt the need to talk about the event more extensively and more often, with their partners and with their relatives and friends. While some women complained that their husbands cared less than they did, it was men who proved to be more afraid of another pregnancy.

Despondency 6 months after TOP. We found that 6 months after TOP 34 women and 24 men were still suffering from episodes of sadness and low spirits. It seems that the worst phase of grieving was the 3rd and 4th months. Seven women and one man needed professional help to cope with the termination, which varied from temporary outpatient care to admission (once) to a psychiatric hospital. However, six of these eight already had serious psychological or social problems prior to the pregnancy in question.

Reactions to the interviews. In the enquiry, held after the first 2 years of the study, 80% of the parents indicated that the interviews had been valuable in coping. Being able to talk extensively about the event even after a considerable period of time was perceived as beneficial. This was concordant with the oral response from the group as a whole. By contrast, there appeared to be little need of a parent self-help group or of contact with fellow sufferers. Only eight women and two men indicated a need for this. However, half of all the interviewees were prepared to talk to someone in similar circumstances, 'for the other person's sake'. Four women got to know each other this way.

At the clinic the study has influenced the daily practice from the start, both of nursing and medical staff, because of the heightened awareness of the problems involved in this issue, and because of intermediate feedback from the researchers.

DISCUSSION

Prenatal diagnosis and subsequent termination of pregnancy have far-reaching consequences for the parents involved[2-5, 7-9]. Having to decide about life and death, balancing personal interests, coping with resulting feelings of guilt, and feeling genetically inferior are aspects which may explain the serious problems these people encounter afterwards. In his study of the duration and severity of depression in women after TOP, Lloyd[10] found statistically significantly more severe and protracted episodes of depression as compared to perinatal death or abortion on social grounds. In our study we did not use psychological tests to measure the extent of depression. However, we were impressed by the severity and the intensity of the range of negative feelings after TOP. An inventory of these feelings yielded a number of factors which heighten the risk of complicated bereavement. These include: uncertainty about the fetal prognosis or diagnosis, the non-lethal nature of the defect, and serious psychological problems prior to the pregnancy.

The worst phase of grieving appears to be 3 – 4 months after TOP. The need to resume one's normal course of life conflicts with persistent feelings of grief, exacerbated by the parents' supposition that for them and for society, their grief should be over by now. The notion that they are personally responsible for this situation, since it was they who decided to terminate the pregnancy, may complicate grieving considerably.

The parents who co-operated in this study gave us a further number of valuable suggestions for counselling with regard to TOP on genetic grounds.

- After diagnosis, as few uncertainties as possible about the effects, prognosis, and life expectancy of the anomaly should be left. Also, since fantasies are always worse than reality, it is important to visualize the anomaly if possible[11,12].
- Tangible memories are extremely valuable in coping, even, or perhaps particularly, if the termination is done by D&C of by D&E.
- Information about the possibly protracted period of grieving is perceived as useful. The parents, their social circle and their employers should be sensitive towards this aspect.
- During grieving, support by means of extensive talks with a member of the medical team can be helpful[7,8,10,13].
- Advice during hospitalisation about, e.g. personally arranging and attending the funeral, whether or not to send announcements, and involving relatives or friends, can be valuable, and offers the opportunity of positive and lasting memories of the event.
- Recognition of the client's parenthood by medical staff, relatives and friends is important. For, the pregnancy was real, as was the child for whom the parents had assumed responsibility. Denial of this reality can be very painful and insulting to the parents.

The effects of intensive post-termination support are difficult to measure. However, many authors recognize its importance[3,7]. When parents were asked to participate in the study with the suggestion that it might help them to cope, many tended to refuse, whereas they were far more compliant when the emphasis was on helping the clinic. The feeling of 'We don't need any help' prevailed. Nevertheless, the majority, particularly the women, claimed to have benefited from the interviews. We found the same trend with regard to the need of a support group or contact with fellow sufferers. The great majority claim to have no need of it, whereas 50% would agree if it would help other parents in a similar situation. While our study does not patently show a need for some sort of self-help group, many authors stress its importance[2,13,14]. Possibly, when specifically asked, people hate to admit that they need help, but they may feel less inhibited when there is a patients' association or a well-known self-help group already in existence, as is the case in England and Scotland (Care and Asbah, respectively). In the Netherlands there are now tentative initiatives in this direction.

A number of dilemmas remain.

- The time-lapse between the final diagnosis and TOP. As compared to other studies[7,15], the time-lapse in our study is relatively long (mean 4.7 days). Adler and Kushnick[16] state that women perceived the waiting period as unbearable, even though in their study the time-lapse never exceeded 1.5 days. Our conclusions do not concur with this: the optimal waiting period appears to be highly individual. We now tend to go by the parents' wish. As a result, parents in the later stages of the study were given the opportunity to reconsider the planned date for TOP, and to change it if required.

- Surgical versus pharmaceutical termination. When the pregnancy has progressed to the second trimester (14-22 weeks), the parents will have to decide by which method the pregnancy is to be terminated. They will only be able to come to a balanced decision if the gynaecologist has pointed out all pros and cons. Jones[14] suggests that D&E would result in less episodes of post-termination depression, and is therefore preferable over vaginal delivery. On the other hand, the authors tend to prefer the medicinal induction of labor to the surgical method. The former offers the parents a greater opportunity to identify with the subject of their grief, which is a positive factor in coping[7,11,12]. However, our figures are too small to lend proof to this supposition, and eventually it are the parents who have to be able to make this choice.
- First or second trimester prenatal diagnosis. When prenatal diagnosis by means of CVS became possible, counsellors expected a decrease in emotional problems after TOP, because of the early stage at which CVS can be done and the considerably shorter time required for laboratory diagnosis[3,17]. However, our study does not validate this presupposition. Even if the pregnancy is terminated at an early stage, the parents have to cope with the loss of a child and the loss of an envisaged future. This does not necessarily conflict with the fact that the majority of parents opt for the earliest possible PND in case of a next pregnancy.

In conclusion, based on the study, we have decided to continue these extensive post-termination interviews because of the need for structural support and the positive feedback.

Caring for parents who have their pregnancies terminated on genetic grounds requires specific expertise, experience, time and manpower, and above all a strong involvement of all people concerned.

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Chapter 3

Long-term psychological consequences of pregnancy termination for fetal abnormality: a cross sectional study

Retrospective study in women

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ABSTRACT

Objective: We examined women's long-term psychological well-being after termination of pregnancy (TOP) for fetal anomaly in order to identify risk factors for psychological morbidity.

Methods: A cross-sectional study was performed in 254 women 2 to 7 years after TOP for fetal anomaly before 24 weeks of gestation. We used standardised questionnaires to investigate grief, posttraumatic symptoms, and psychological and somatic complaints.

Results: Women generally adapted well to grief. However, a substantial number of the participants (17.3%) showed pathological scores for posttraumatic stress. Low-educated women and women who had experienced little support from their partners had the most unfavourable psychological outcome. Advanced gestational age at TOP was associated with higher levels of grief, and posttraumatic stress symptoms and long-term psychological morbidity was rare in TOP before 14 completed weeks of gestation. Higher levels of grief and doubt were found if the fetal anomaly was presumably compatible with life.

Conclusion: Termination of pregnancy for fetal anomaly is associated with long-lasting consequences for a substantial number of women. Clinically relevant determinants are: gestational age, perceived partner support, and educational level.

INTRODUCTION

First or mid-trimester termination of pregnancy (TOP) for fetal anomalies is legally and morally accepted in many countries. Over the past decades screening and diagnostic methods have improved noticeably and, as a result, increasingly more anomalies are being detected at an early stage in pregnancy. When a severe congenital anomaly is diagnosed, the majority of couples opt for termination of pregnancy [1, 2]. This has led to an increasing number of TOPs for fetal anomalies, currently around 500 of 200.000 deliveries a year in the Netherlands. Termination of pregnancy in case of a fetal anomaly is a complex and conflicting life-event. Many women and their partners describe it as an almost inhuman decision to take [3]. Especially the fact that it is a voluntary act may interfere with normal grief responses. A number of studies have shown that gestational age, severity of the anomaly, and degree of compatibility with extra-uterine life are major factors playing a role in the decision process [1, 4-8]. Psychological consequences of the decision to terminate the pregnancy in terms of grief and posttraumatic stress, and the factors influencing these, have also been explored, but the findings are less conclusive. Our study was conducted to evaluate women's long-term psychological reactions after TOP for fetal anomaly in a large study sample. The principal aim was to identify risk factors for psychological morbidity. The relevance of this knowledge lies not only in improving patient care but also in providing essential information for the development of screening and diagnostic programs for fetal congenital anomalies.

PATIENTS AND METHODS

Data were collected on pregnancies terminated before 24 weeks of gestation, following the diagnosis of fetal anomaly, between 1995 and 2001, at the University Medical Centres of Utrecht, Amsterdam and Maastricht in the Netherlands. All centres involved with prenatal diagnosis in the Netherlands follow protocols of the scientific society, and specialists in this field frequently interact in the Working Group Prenatal Diagnosis. In the three hospitals, termination of pregnancy before 14 completed weeks is usually done by dilatation and evacuation (D&E), thereafter labour is induced by prostaglandins. Between November 2000 and December 2002, women were contacted who had had a TOP 2 to 7 years earlier. The responsible, attending gynaecologist or head of the unit at the time of the TOP sent a letter to his/her patient with information about the study and a request for participation in what was called "an extensive anonymous questionnaire study". After receiving written informed consent, anonymous, but coded, questionnaires were mailed. The ethical committees of all three hospitals had approved the study design. The principal investigator (MJK) was an independent investigator, not involved in the clinical management of the enrolled patients. Altogether 254 women were included.

One general questionnaire contained questions on socio-demographic, medical and obstetric history, as well as questions about reproductive wishes or decisions, and pregnancies after the index pregnancy. A number of other questionnaires concerned Dutch versions of validated self-completed questionnaires. Maladaptive symptoms of grief were measured by the Inventory of Traumatic Grief (ITG), a 29-item self-report questionnaire [9] with 5-point scales and a possible total score ranging from 29 to 145. It is an expanded version of the Inventory of Complicated Grief (ICG) [10]. A cut off score of > 90 is indicative of traumatic grief [9, 11]. Symptoms of posttraumatic stress (PTS) were measured by the revised Impact of Event Scale (IES-r) [12-14]. This instrument is probably the most widely used self-report measure for exploring the psychological impact of traumatic events like violence, accidents, rape, war, and all sorts of bereavements. In our study the items of the original scale were anchored to the traumatic event of the termination, as was recommended by Horowitz et al. (1979). The 22-item scale deals with the components intrusion, avoidance, and hyperarousal in a 4-point response format with a possible total score ranging from 0 to 110. A total score of ≥ 39 represents pathological posttraumatic stress reactions (R. Kleber, personal communication, October 2004). Psychological well-being was measured with the use of three subscales of the Symptom Checklist-90 (SCL-90): depression, anxiety and somatic complaints. The norm means and SDs were 24 (9), 15 (6) and 19 (7), respectively [15, 16]. A last questionnaire was specially designed for the purpose of this study. It contained questions on perceived external pressure in the process of decision-making, perceived support, seeking of professional help, and questions about doubt or regret. All questionnaires had been first tested in a group of 20 couples with a history of TOP for fetal anomaly.

Maternal age, level of education, religion, having other living children at TOP or assessment, gestational age, method of TOP, severity of the fetal anomaly, occurrence of life events during the 2 years before assessment, time elapsed since TOP, and perceived partner support at the time of the TOP, were considered as predictors. The scores on the inventories concerning traumatic grief, posttraumatic stress, psychopathological symptoms, and feelings of doubt and regret were considered as the outcome measures.

SPSS for Windows (version 10.1, SPSS Inc., Chicago, Ill.) was used for data management and statistical analysis. Results were summarised with the use of standard descriptive statistics: counts and percentages for categorical variables, and means, standard deviations (SD), and ranges for continuous variables. Groups were compared for equivalence in baseline characteristics using the Chi-square test or Fisher exact test, as appropriate, for categorical measures and Student's *t*-test for continuous variables. Subject characteristics that showed an association with the outcome measures (Pearson or Spearman correlation coefficients where appropriate; $p < 0.10$) were considered candidate variables for further analysis. Multiple linear and logistic regression analyses were conducted to identify independent factors. All predictors except partner support were entered on step 1. Perceived partner support at the time of termination was analysed separately and entered on step 2 because it is potentially subject to recall bias. With all tests, p-values < 0.05 were considered statistically significant.

RESULTS

Between February 1 1995 and December 31 2000, 254 women had their pregnancy terminated in one of the three participating centres. Seven women could not be traced and 51 women refused participation. The results are based on the data of 196 women who completed the set of questionnaires, that is, a response rate of 79%.

(Tables 1 and 2) show the demographic and obstetric characteristics of the participants respectively. The relatively advanced age of the women at termination (mean 34.1 years) indicates a large percentage with a maternal age indication. The mean gestational age at TOP (18 weeks) reflects a relatively higher percentage of anomalies diagnosed at amniocentesis or ultrasound examination than at chorionic villus sampling. There were four sets of twins: two sets of conjoined twins, one set with both fetuses affected by Down syndrome, and a set with one fetus affected by Down syndrome (selective foeticide). None of the studied variables, including the outcome measures, differed statistically across the three participating hospitals. The 51 non-participants did not differ from the participants in duration of pregnancy at termination, assessed viability of the disorder, and proportion of Down syndrome.

Table 1. Socio-demographic characteristics of the participants. Data are presented as number, percentage, mean, SD, and range.

Participants	196	
Age at TOP (years)	34.1	SD 4.6; range 23-43
Age at assessment (years)	38.2	SD 4.9; range 25-48
Marital status at assessment		
Married / living together	185	94.4%
Divorced	5	2.6%
Single	6	3.0%
Change in marital status since TOP	8	4.1%
Religious (yes)	112	58.9%
Living children at TOP (yes)	115	58.7%
Living children at assessment (yes)	171	87.2%
Highest achieved level of education		
Low	43	22.1%
Medium	66	33.8%
High	86	44.1%
Employment (yes)	143	73.0%
Elapsed time since TOP (years)	4.1	SD 1.3; range 2-7

TOP, termination of pregnancy SD, standard deviation.

Table 2. Obstetric data of the participants. Data are presented as number, percentage, mean, SD, and range

Total number of terminations	196	
Gestational age at termination (weeks)	18	SD 3.5; range 11-24
Not likely to be compatible with survival > 6 months	79	(40%)
Chromosome anomaly	115	
Trisomy 13	4	
Trisomy 18	21	
Trisomy 21	58	
Triploidy	9	
Turner’s syndrome	7	
Other	16	
Neural tube defect	17	
Spina bifida	13	
Anencephaly	2	
Encephalocèle	1	
Meckel Gruber	1	
Neuromuscular disorder	15	
Haemophilia	1	
Uropathy	8	
Isolated cardiac anomaly	4	
Skeletal dysplasia	4	
Other isolated anomaly (hydrocephaly, omphalocèle)	14	
Metabolic anomaly	4	
Multiple malformations	14	
Method of termination		
Dilatation & Evacuation	52	(26.6 %)
Induction of labour	143	(73.0 %)
Foeticide 1 affected fetus of twins	1	(0.4 %)

The scores on grief, posttraumatic stress (and its components), and psychosomatic symptoms were strongly inter-correlated (range of R’s between 0.47 and 0.71), while these outcome measures and the feelings of doubt and regret were only poorly to moderately inter-correlated (range of R’s between 0.14 and 0.38). The means, SDs, and ranges of scores for grief were 45 (16; 29-119), total posttraumatic stress 20 (19; 0-82), depression 27 (12; 16-73), anxiety 15 (7; 10-48), and somatic complaints 18 (7; 12-48). The proportions of patients who reported feelings of regret or doubt were 8 and 10% respectively.

Table 3. Overview of statistically significant relationships between the independent and dependent variables represented by Pearson or Spearman correlation coefficients. Empty cells indicate a correlation with p > 0.05. TOP: termination of pregnancy.

	Dependent variable								
Predictor	Grief	Posttraumatic Stress Symptoms				Psych. Som. Complaints (SCL)			Doubt (no / yes)
	Total	Total	Intrusion	Avoidance	Arousal	Somatic	Anxiety	Depression	
Education (low/middle/high)	-0.194 **	-0.302 ***	-0.257 ***	-0.243 ***	-0.308 ***	-0.161 *		-0.167 *	
Maternal age at TOP (year)		-0.147 *			-0.162 *				
Elapsed time since TOP (year)							0.143 *	0.201 **	0.154 *
Gestational age (week)	0.142 *								
Lethality anomaly (no / yes)									-0.199 **
Previous children at TOP (no / yes)				0.163 *					0.171 *
Partner support at TOP ‡	-0.262 ***	-0.181 **		-0.186 **	-0.226 **	-0.143 *	-0.161 *	-0.271***	

* p < 0.05; ** p < 0.01; *** p < 0.001.

‡ : Partner support: 1 hardly to not at all; 2 moderate; 3 very much so.

Religion, having children at assessment, method of TOP, and life events: not significant.

None of the predictors was significantly correlated with feelings of regret.

Table 3 shows an overview of significant correlations between predictors and outcome measures. Level of education and perceived partner support were consistently highly correlated with the outcome measures: low-educated women and women who reported that they had experienced little support from their partners had the most unfavourable scores on the psychological inventories. Other determinants were occasionally related to the outcome measures, either significantly (Table 3) or showing a trend towards significance (not presented). None of the predictors was significantly correlated with feelings of regret. Religion, having living children at assessment, method of TOP, and recent life events were not statistically related to any of the outcome measures ($p > 0.10$). The predictors were not interdependent (range of R's between -0.16 and 0.22), except for an expected relationship between gestational age and the method of TOP ($R = 0.71$, $p < 0.0001$).

Predictors that showed a (nearly) significant correlation with the outcome measures were included in multiple regression analyses to identify independent factors. The resulting models are presented in Tables 4 and 5, with and without adjustment for perceived partner support. Grief was independently predicted by three factors: education, gestational age, and lethality (Table 4) (highest scores in low-educated women, in women with an advanced gestational age, and in women whose babies had an anomaly compatible with life). Posttraumatic stress was significantly predicted by the level of education (highest scores in low-educated women), while gestational age showed a trend toward significance (total and intrusion, p-values were 0.076 and 0.055 respectively; Table 4).

Low-educated women more often reported somatic complaints; symptoms of both anxiety and depression appeared to increase over time (Table 5). Experiencing doubt about the decision to terminate was independently predicted by advanced gestational age at TOP, presumed viability of the fetal anomaly, and the presence of living children. Perceived partner support had an independent effect on grief, posttraumatic stress (except intrusion), anxiety ($p = 0.071$), and depression (step 2 in Tables 4 and 5). Inclusion of partner support in the models increased the amount of explained variance by 2.1 to 5.3% as represented by the change in R^2, yielding an overall amount of explained variance ranging from 5.8% to 16.9% (Tables 4 and 5).

Figures 1a, b show the number of women with pathological grief (ITG) and posttraumatic stress scores (IES-r), respectively. Five women (2.6%) had pathological scores for grief (Figure 1a). Thirty-three participants (17.3%) had pathological posttraumatic stress scores (Figure 1b). In the latter group, the elevated scores were unrelated to the elapsed time since TOP, whereas the scores were negatively correlated with time in women with normal scores ($\beta = -1.78$, partial $R = -0.201$, $p = 0.012$). Compared to women with normal scores (< 39), women with high IES scores generally had a lower educational level ($\chi^2 = 13.5$, $df = 2$, $p = 0.0012$) and less often a paid job ($\chi^2 = 5.3$, $df = 1$, $p = 0.036$). In addition, they had more often sought professional help ($\chi^2 = 6.4$, $df = 1$, $p = 0.011$), felt more often that their decision had been made under pressure of the family and/or significant others ($\chi^2 = 3.9$, $df = 1$, $p = 0.045$).

Table 4. Results of multiple regression analysis for grief and posttraumatic stress. Models are presented without (step1) and with (step 2) accounting for partner support

Variable	Grief Total score		Posttraumatic stress Symptoms Total score (IES)		Posttraumatic stress Intrusion		Posttraumatic stress Avoidance		Posttraumatic stress Hyperarousal	
	β	SE	β	SE	β	SE	β	SE	β	SE
Step 1: predictors										
Education	-3.99 *	1.65	-6.70 ****	1.82	-2.42 **	0.78	-1.77 **	0.71	-2.31 ****	0.60
Maternal age	-0.43	0.28	-0.48	0.32	-0.12	0.14	-0.20	0.13	-0.16	0.11
Elapsed time since TOP	0.32	0.89	0.32	1.04	-0.20	0.44	0.01	0.40	0.52	0.34
Gestational age	0.74 *	0.34	0.69 #	0.39	0.32 #	0.17	0.21	0.15	0.16	0.13
Lethal anomaly	-5.74 *	2.46	-1.31	2.85	-0.38	1.22	-0.16	1.11	-0.77	0.94
Children at TOP	3.99	2.72	2.94	3.18	0.42	1.35	2.02	1.54	-0.49	1.05
F model	3.15 **		3.98 ***		2.79 **		3.32 **		4.49 ****	
R^2 on step 1	0.096		0.120		0.087		0.102		0.133	
Step 2: partner support	-5.91 ***	1.80	-4.47 *	2.11	-0.78	0.91	-1.75 *	0.82	-1.95 **	0.69
F model	4.36 ****		4.03 ****		2.45 *		3.44 **		4.98 ****	
R^2 on step 2	0.149		0.142		0.091		0.123		0.169	
Change in R^2 ¶	0.053 ***		0.022 *		0.004		0.021 *		0.036 **	

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; **** $p < 0.0001$; # $p < 0.10$ (trend).

¶ difference in R^2 on steps 1 and 2, and the significance of F-change.

Table 5. Results of regression analysis for somatic complaints, anxiety, depression, and doubt. Models are presented without (step1) and with (step 2) accounting for partner support

Variable	Somatic complaints		Anxiety		Depression		Doubt †	
	β	SE	β	SE	β	SE	β	SE
Step 1: predictors								
Education	-1.39 *	0.70	-0.96	0.68	-1.67	1.18	0.02	0.38
Maternal age	-0.03	0.12	-0.02	0.12	-0.31	0.21	-0.08	0.07
Elapsed time since TOP	0.33	0.40	0.69 #	0.39	1.71 **	0.67	0.17	0.19
Gestational age	0.08	0.15	0.02	0.15	0.11	0.25	0.19 *	0.09
Lethal anomaly	-0.51	1.10	-0.57	1.07	-1.84	1.83	-2.32 **	0.86
Children at TOP	1.55	1.21	0.96	1.19	2.31	2.04	1.66 **	0.63
F model	1.36		1.20		2.42 *		***	
R^2 on step 1	0.044		0.039		0.076		0.101	
Step 2: partner support	-1.12	0.81	-1.41 #	0.79	-4.22 **	1.34	-0.43	0.38
F model	1.52		1.57		3.54 ***		**	
R^2 on step 2	0.058		0.060		0.125		0.107	
Change in R^2 ¶	0.014		0.021 #		0.049 **		0.006	

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; **** $p < 0.0001$; # $p < 0.10$ (trend).

¶ difference in R^2 on steps 1 and 2, and the significance of F-change.

† logistic regression.

They also experienced feelings of doubt (χ^2 = 17.5, df = 1, p < 0.0001) and regret (χ^2 = 17.7, df = 1, p < 0.0001) more often, reported more psychosomatic complaints (t-test; p < 0.0001), and had higher scores on the grief questionnaire (t-test; p < 0.0001). A similar analysis of the scores on grief was not feasible due to the low rate of pathological scores in this group (Figure 1a).

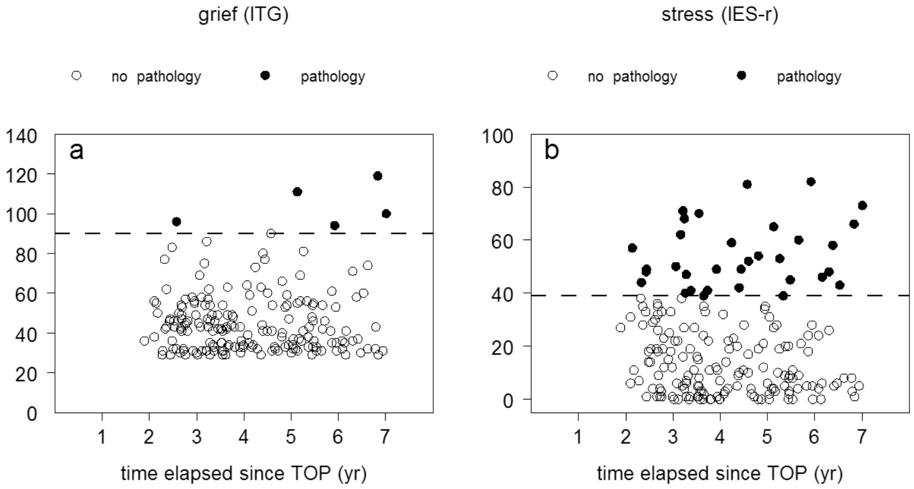

Figure 1. Levels of grief (a) and posttraumatic stress symptoms (b) in relation to the time interval since TOP. Dotted lines represent established cut-off levels (90 and 39, respectively).

Figures 2a and b show the relationship between gestational age at TOP and the scores for grief and posttraumatic stress respectively in patients with D&E or induction of labour. Patients who underwent TOP before 14 completed weeks of gestation had significantly lower scores for grief (mean 40.0; SD 10.8; n = 44) and posttraumatic stress (mean 14.1; SD 14.5; n = 44) than women terminating after 14 completed weeks: means (SD) were 46.9 (17.4; n = 150; p = 0.014) and 21.5 (20.3; n = 148; p = 0.026), respectively. In addition, pathological grief and posttraumatic stress scores were almost absent in women who had TOP before 14 completed weeks. For posttraumatic stress, the difference in the proportions of women with pathological scores before and after 14 completed weeks reached statistical significance (Fisher exact test; p = 0.041).

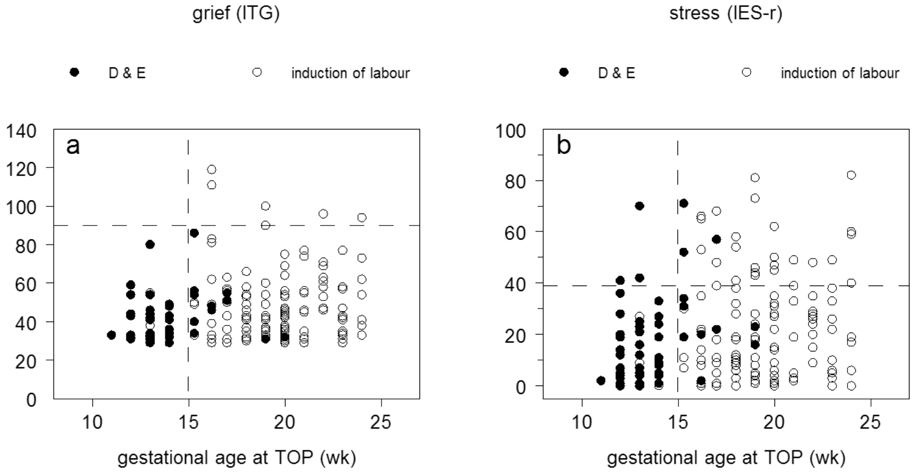

Figure 2. Levels of grief (a) and posttraumatic stress symptoms (b) in relation to the gestational age at TOP in women whose pregnancies were terminated by dilatation and evacuation (D&E) or induction of labour. Horizontal dotted lines represent established cut-off levels (90 and 39, respectively). Vertical dotted lines indicate the 14th completed week of gestational age.

DISCUSSION

In the present study we have assessed the psychological consequences of termination of pregnancy for fetal anomaly in women. The assessment took place between 2 and 7 years after the event. Large variation was found in symptoms of grief and posttraumatic stress. Women generally adapted well with respect to grief, but a substantial number of participants showed pathological scores for posttraumatic stress. Significant risk factors for poor psychological outcome were a low level of education and a low level of perceived partner support. A modest, but consistent, association was found between advanced gestational age and the level of distress. Women with pathological responses were equally distributed over the 5 years of study.

Termination of pregnancy because of fetal anomaly is a major life event for almost all women and may cause sustained psychological morbidity [17-19]. To assess the extent of this distress, we separately measured grief and posttraumatic stress symptoms. In the present study pathological scores for grief were rare (2.6%). In previous studies, grief scores after TOP varied widely. Almost all authors found evidence of pronounced feelings of grief in the first months after TOP [2, 20-26]. However, results of long-term follow up studies were less consistent [27]. In most long-term studies, it was found that overall psychological distress decreased in the first few years after the event [2, 17, 21, 22, 24, 26, 28]. Hunfeld [20] found a significant decrease in symptomatology in her four years follow-up study, but reported that about a quarter of the 29 participants still showed high levels of psychological distress at the last assessment. Kersting et al. [29] to the contrary found no significant differences between women 2 to 7 years after TOP and those 14 days after TOP with respect to the extent of grief and post traumatic stress symptoms, suggesting that there is no decrease in symptomatology with time. In our cross sectional study, the number of women with pathological outcomes on grief and posttraumatic stress symptoms was equally distributed regardless of the time elapsed after the event, which may indicate that there is no decrease in symptomatology between two and seven years after the event.

Kersting et al. [29], who also used the IES-r inventory to assess symptoms of posttraumatic stress, reported a mean stress score of 28 in 80 women, which is slightly higher than in our study. In addition, we found a relatively large number of women with pathological scores for posttraumatic stress (17.3%). Compared to these findings related to TOP, a mean stress score of 8.6 and an incidence of pathological outcome (scores > 39) of 2.8 % has been found among 285 women at 10 months after normal pregnancy and delivery [30].

Low level of education and low level of perceived partner support were the most important risk factors for poor psychological outcome. In two other studies on post termination responses, the level of education or socio-economic status showed no association with psychological symptomatology [8, 21]. Data from our institute show that there is less problematic grieving after the loss of a child in parents with a high level of education than in respondents with a low level of education [31]. In one study of normal pregnancies more adequate use of coping mechanisms was found in women with a high level of education [32]. A sufficient level of perceived partner support has been found to be related with better psychological outcome after TOP [21, 33,] and almost all referenced authors emphasise the importance of support given by the partner, other family members, and by the caregivers. Also, in our study, perceived partner support turned out to be an important predictor of adjustment to the loss after TOP. However, this finding should be interpreted with some caution: the reminiscence of perceived partner support might be influenced by current psychological well-being, in which case it is a consequence rather than a determinant of psychological well-being.

Advanced gestational age at TOP was found to be associated with more psychological distress, as evidenced by positive linear contributions of gestation to the models of grief ($p < 0.05$) and posttraumatic stress ($p < 0.10$; Table 4). In addition, women who had termination after 14 completed weeks compared with those before 14 weeks had significant higher (mean) scores for grief and posttraumatic stress and showed significantly more often pathological scores on posttraumatic stress. This result is nicely depicted by the virtual absence of pathological scores in the upper left quadrants of Figure 2. These observations, if confirmed in currently undertaken prospective studies, will support the use of early screening and diagnostic techniques. In two other studies, some effects of gestational age on the process of coping have been described [2, 21]. Gestational age and the methods of termination are strongly correlated and their effects therefore are difficult to distinguish.

We had expected that (non-) viability would strongly influence the psychological responses after TOP, but this was only partly true. Chances for live outcome influenced psychological outcome in two ways: women with a viable fetal anomaly experienced more doubt, and had a higher level of grief than women with TOP for a non-viable anomaly. Eight percent of the women reported feelings of regret and 10% reported feelings of doubt about the decision to terminate their pregnancy. These women were overrepresented in the group with high posttraumatic stress symptoms. This stresses the importance of adequate psychological support and guidance from the caregiver during the decision making process in order to avoid impulsive and not fully internalised decisions.

The current study is, to the best of our knowledge, the largest in this field. It used standardised assessment techniques and was carried out in three hospitals with a uniform policy for TOP. Termination of pregnancy for fetal anomaly is associated with long-lasting psychological morbidity for a considerable number of women. The burden of posttraumatic stress appeared to be much heavier than that of grief: on the long term, women apparently experience TOP more as a trauma than as a loss.

Although the amount of variance explained by the factors studied was generally low (< 17%), the study has provided insight in the psychological consequences of TOP. For clinical use, the following issues are of particular interest. Perceived partner support was the most important amenable factor determining long-term psychological morbidity. Counselling of partners therefore deserves more of our attention. Low-educated patients are more vulnerable and consequently need more support. Finally, the modest but in many ways significant association between advanced gestation and poor psychological outcome, stresses the importance of early prenatal screening and diagnostic tests.

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Chapter 4

Psychological consequences of termination of pregnancy for fetal anomaly: similarities and differences between partners

Retrospective study in both partners

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ABSTRACT

Objective: We examined the psychological responses to termination of pregnancy (TOP) for fetal anomaly from both men and women. The aim was to find risk factors for poor psychological outcome both for the individuals and for the couple.

Methods: A cross-sectional study was performed in 151 couples 2-7 years after TOP. We used standardized and validated questionnaires to investigate grief, symptoms of posttraumatic stress, somatic complaints, anxiety, and depression.

Results: Most couples adapted well to their loss, although several patients had pathological scores on posttraumatic stress symptoms and depression. Differences between men and women were slight. Higher education, good partner support, earlier gestational age and life-incompatibility of the disorder positively influenced the outcomes, more for women than for men. Men and women with pathological scores rarely had such scores simultaneously.

Conclusion: We emphasize the importance of equally involving both parents in the counselling because the outcomes of grief and posttraumatic stress symptoms between men and women only moderately differ and post-TOP psychopathology occurs in men as well. Good adjustment to TOP in women seems dependent on the level of support that they perceive from their partners. The intracouple results of the study suggest a mutual influence in the process of grieving between the partners.

INTRODUCTION

Nearly all research on the psychological consequences of termination of pregnancy (TOP) for fetal anomalies focuses on the mother, thereby neglecting the father. In reality the decision to terminate pregnancy is taken jointly by both parents in a majority of couples and for either of them TOP is a life event. In the few studies in which the responses of men and women to TOP were assessed, fathers did show distress compared to mothers, but less severe and less prolonged [1-3]. Only the study of White-van Mourik used standardised and validated methods. Far more studies have addressed the reactions of both parents to spontaneous perinatal demise. In these studies, fathers again showed less-severe and less-prolonged distress than mothers [4-6]. Support of the partner and/or significant others is known to be of crucial importance in adjustment to serious life events including TOP [7-10]. If we aim at giving good care to women, we cannot neglect their partners and their partners' needs. We therefore assessed the psychological consequences of TOP for women and men, 2-7 years after the event in a cross-sectional study. Responses from the women have been described in more detail elsewhere [11]. The women's adjustment to TOP was strongly dependent on the perceived support of their partners. In the present study, we examined psychological responses to TOP in both men and women in order to find risk factors for poor psychological outcome in both partners and to explore their interaction.

METHODS

Two hundred and fifty-four couples, who underwent pregnancy termination because of fetal anomaly before 24 weeks of gestation, were asked to participate in a retrospective questionnaire study. There were three participating hospitals: the University Medical Centres of Utrecht, Amsterdam and Maastricht, all in the Netherlands. The ethical committees of the hospitals approved the study design. The assessments were carried out between 2– 7 years after the event. At the time of TOP, the attending gynaecologist or head of the unit of prenatal diagnosis sent a request for participation to the woman and her partner. After written informed consent, anonymous but coded questionnaires were mailed.

Standardized and validated questionnaires on the socio-demographic situation, medical and obstetric history, and psychological outcomes were used. Maladaptive symptoms of grief were measured by the Inventory of Traumatic Grief (ITG) [12, 13], and symptoms of post traumatic stress by the Impact of Event Scale – revised (IES-r) with the subscales intrusion, avoidance, and arousal [14-17]. The presence of psychological and somatic maladaptive symptoms were assessed by three subscales of the Symptom Checklist-90 (SCL-90): somatic complaints, anxiety and depression [18, 19]. The following cut-off points were indicative of pathologic outcome: ITG ≥ 90 [12, 13]; IES ≥ 39 (R. Kleber, personal communication); SCL somatic complaints: women ≥ 34, men ≥ 27; anxiety: women ≥ 27, men ≥ 22; and depression: women ≥ 42, men ≥ 34 (95th percentile)[14]. Self-designed questionnaires were used to assess regret and doubt. The scores on the above-mentioned (sub) scales were considered as outcome measures.

The following variables were considered as predictors: parental age, level of education (low, 1; middle, 2; high, 3), being religious or not, the presence or absence of living children at the time of TOP and at assessment, gestational age, method of TOP (dilatation and evacuation; hormonal induction of labour; selective reduction), severity of the fetal anomaly, experience of life events during the 2 years before assessment, time elapsed since TOP, and level of perceived partner support (very much/much, 1; moderate, 2; none to little, 3). A critical percentage of completed questions is a prerequisite to the use of validated questionnaires. If one of the partners, or both, had not filled out the required minimum percentage of the questionnaire, the couple was excluded from the study.

SPSS for Windows (version 10.1, SPSS Inc., Chicago, Ill.) was used for data management and statistical analysis. Results were summarized with the use of standard descriptive statistics: counts and percentages for categorical variables, and means, standard deviations, and ranges for continuous variables. Groups were compared for equivalence in baseline characteristics using the Chi-square test or Fisher exact test, as appropriate, for categorical measures and Student's t-test for continuous variables. Subject characteristics that showed an association with the outcome measures (Pearson or Spearman correlation coefficients where appropriate; $p < 0.10$) were considered candidate variables for further analysis. Stepwise multiple linear and logistic regression analyses were conducted to identify independent factors. Predictors were entered on step 1 and perceived partner support was separately analysed on step 2, because it is potentially subject to recall bias. With all tests, p-values < 0.05 were considered statistically significant.

RESULTS

Of the 254 eligible couples, seven could not be traced. The response rate of the remaining couples was 79 % (n = 196) for the women and 62 % (n = 153) for their partners (all male). In 61% of the couples, both partners responded. These were included in the current study that reports on 151 couples. The women and men who participated did not differ from those who did not participate with respect to duration of pregnancy at termination, assessed viability of the disorder, and proportion of Down syndrome cases. The women who participated, while their partners did not, showed no significant differences in comparison with those who had a responding partner in demographic and medical characteristics, nor in the level of psychological distress. Table 1 shows the demographic and obstetric characteristics of the participants, subdivided in couple-shared and individual factors. Women were younger, more often not working, had a lower level of

Table 1. Obstetric and socio-demographic characteristics of the preparticipants. Data are presented as number and percentage or as mean, SD, and range

Couple shared factors	
Total number of terminations	151 (17.9); 3.5, 12-24
Gestational age (weeks)	
Method of termination	
- Dilatation and evacuation	38 25.2%
- Hormonal induction of labour	112 74.2%
- Selective reduction	1 0.6%
Not likely to be compatible	62 41.1%
with survival >6 months	
Time elapsed since TOP (years)	151 (4.1); 1.4, 2-7

Individual factors	nr of pairs	men	women	difference*	correlation	
Age at TOP (years)	151	35.6 (5.2);18-54	34.3 (4.4); 23-43	p < 0.001	R = 0.54	p < 0.0001
Children at TOP (yes)	146	44 30.1%	36 24.7%	n.s	R = 0.59	p < 0.0001
Children at assessment (yes)	149	133 89.3%	131 87.9%	n.s.	R = 0.87	p < 0.0001
Education	151					
Low		19 12.6%	33 21.9%			
Medium		43 28.5 %	50 33.1%	p < 0.05	R = 0.49	p < 0.0001
High		89 58.9%	68 45.0%			
Employment (paid job: yes)	151	143 94.7%	111 73.5%	p < 0.0001	R = 0.06	n.s.
Religion (yes)	145	69 47.6%	64 44.1%	n.s.	R = 0.35	p < 0.0001
Professional help seeking (yes)	150	24 16.0%	36 24.0%	n.s.	R = 0.44	p < 0.0001
Life events (yes)	134	54 40.3%	70 52.2%	p = 0.05	R = 0.36	p < 0.0001
Partner support	144					
(Very) much		89 61.8%	92 63.9%			
Moderate		46 31.9%	44 30.6%	n.s.	R = 0.35	p < 0.0001
None to little		9 6.3%	8 5.5%			

TOP: termination of pregnancy, *Difference between men and women tested with the paired t-test or chi-square test where appropriate.

education, and reported more life events over the previous 2 years than their partners. The perceived partner support was high and only few women and men (5.5% and 6.3%, respectively) reported that they had felt no to very little support.

Table 2 shows the levels of grief, posttraumatic stress symptoms, somatic complaints, anxiety and depression, and the presence of feelings of doubt or regret. On all these outcome measures, women had significantly higher levels of symptomatology, both as a group and as an individually within the couple, with the exception of the level of avoidance (an intra-psychic process in which the implications of the event are denied or avoided) and the presence of doubt about the decision to terminate. The levels of grief and post traumatic stress symptoms showed moderate intracouple correlation (correlation coefficients <0.40), while no significant intracouple correlation was found for the outcomes of somatic complaints and anxiety and depression (Table 2; Figures 1 and 2). The proportion of pathological outcomes was usually higher in women, but this difference showed a trend toward statistical significance only for symptoms of posttraumatic stress (Table 2). When we related the outcome measures within couples, it appeared that pathological scores never occurred simultaneously (empty right upper quadrants of Figures 1 and 2).

An overview of significant correlations between predictors and outcome measures is presented for men and women separately (Table 3). The level of education was most consistently related to problematic outcome in both sex groups: low-educated participants had more unfavourable scores on the psychological inventories. Other predictors only occasionally showed a significant relationship with the outcome measures either in both gender groups or in one group (being religious in men). Parental age, having other living children at the moment of TOP, and the presence of life events prior to assessment were statistically unrelated to the outcome measures, while the time elapsed since TOP occasionally showed a significant trend ($p < 0.10$) in either gender. The (nearly) significant predictors were included in subsequent multiple regression analyses, performed separately for men and women (Table 4a and 4b). Reported partner support was not significantly correlated with any of the predictors.

The regression analyses in women yielded that low education was related with higher posttraumatic stress scores. Advanced gestational age and presumed viability were independently associated with retrospective doubt about the decision to terminate pregnancy. The amount of explained variation on step 1 was small and ranged between 3.0 and 10.3%. Entering values for perceived partner support (step 2) showed an independent effect on grief and added somewhat to the model (delta $R^2 = 0.031$; $p < 0.05$. For none of the studied outcome measures, the total amount of explained variation exceeded 11%, with the lowest value for somatic complaints (3.0%) and the highest for doubt (10.7%).

In men, there was only one independent effect on the outcome: TOP for an anomaly compatible with life was associated with higher scores of depression.

Religion showed a trend toward significance in 3 of 6 outcome measures. Entering perceived partner support (step 2) did not add further independent effects to the model. The overall amount of explained variation ranged from 7.5% (doubt) to 11.9% (grief).

Table 2. Overview of the psychological outcome measures in men and women who had experienced termination of pregnancy. Data are presented as mean, SD, and range, or as number and percentage

Outcome measure	Men	Women	Male-Female difference[1]	Intracouple difference[2]	Intracouple correlation	Pathology [3]	
						Men	Women
ITG total (grief)	38.6 (11.4); 29-90	44.1 (16.2); 29-119	p < 0.001	p < 0.0001	R = 0.39; p < 0.0001	0.7%	2.7%
IES total (PTS symptoms)	12.8 (16.6); 0-83	18.1 (18.0); 0-82	p < 0.02	p < 0.002	R = 0.31; p < 0.0001	4.9% #	14.7%
IES intrusion	6.3 (7.0); 0-35	8.7 (7.4); 0-29	p < 0.01	p < 0.001	R = 0.35; p < 0.0001		
IES avoidance	3.9 (6.7); 0-36	5.0 (7.2); 0-34	n.s.	n.s.	R = 0.22; p < 0.01		
IES arousal	2.6 (5.0); 0-26	4.4 (6.1); 0-33	p < 0. 01	p < 0.005	R = 0.17; p < 0.05		
Somatic complaints	14.7 (5.1); 12-46	16.9 (6.0); 12-45	p < 0.01	p < 0.001	R = 0.08; n.s.	4.1%	3.4%
Anxiety	12.1 (4.5); 10-47	14.0 (6.0); 10-46	p < 0.05	p < 0.005	R = 0.01; n.s.	3.4%	4.1%
Depression	20.8 (7.5); 16-57	26.0 (11.0); 16-65	p < 0.0001	p < 0.0001	R = 0.11; n.s.	8.2%	11.0%
Regret (yes)	2 (1.3%)	11 (7.3%)	p < 0.002	p < 0.002	R = 0.41; p < 0.0001		
Doubt (yes)	7 (4.6%)	13 (8.6%)	n.s.	n.s.	R = 0.27; p < 0.01		

1 difference between men and women tested with the unpaired t-test or chi-square test where appropriate;

2 intracouple difference tested with the paired t-test; n.s.: not significant;

3 proportion of women and men with a score above the cut-off level to define pathology (see methods for definitions);
# p < 0.10 (trend).

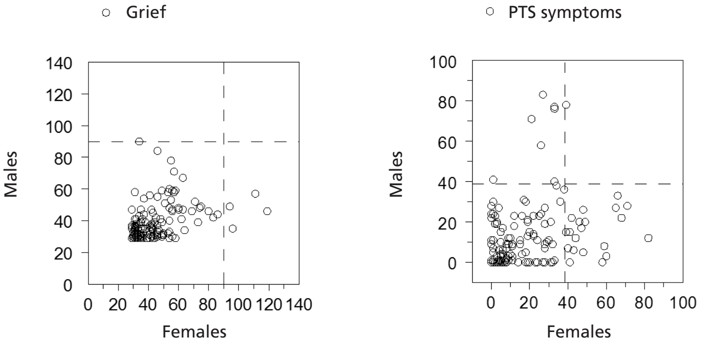

Figure 1. Intracouple relationship for levels of grief and posttraumatic stress symptoms. Dotted lines represent established cutoff levels for pathology.

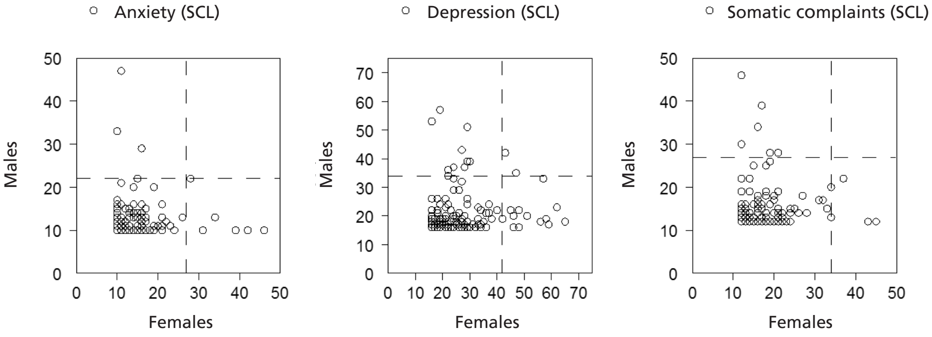

Figure 2. Intracouple relationship for levels of somatic complaints, anxiety and depression. Dotted lines represent established cutoff levels for pathology. Note the difference in cut-off levels between men and women (see methods).

Table 3. Overview of statistically significant relationships between the independent and dependent variables for males and females (n = 2x151). Presented are Pearson or Spearman (1) correlation coefficients

	Dependent variable																			
	Grief (ITG)		Post Traumatic Stress Symptoms (IES-r)								Psychosomatic Symptoms (SCL)						Doubt		Regret	
			Total		Intrusion		Avoidance		Arousal		Somatic		Anxiety		Depression					
Predictor	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀
Level of education	-0.18		-0.21 *	-0.28 ***		-0.25 **	-0.30 ***	-0.23 **		-0.26 **	-0.19 *	-0.16 *								
Religion (yes)	0.20 *		0.18 *				0.20 *				0.17 *		0.18 *		0.20 *					
Gestational age at TOP					0.16^{1} *													0.17 *		
TOP procedure	0.18 ^{1} *																			
Lethal anomaly (yes)									0.18 ^{1} *						0.18 *			0.21 *		
Children at examination (yes)	0.17 *	0.18 *												0.17 *						
Level of partner support		0.20 *								0.19 *			0.17 *							

TOP: termination of pregnancy

* $p < 0.05$. ** $p < 0.01$, ***$p < 0.001$. Empty cells indicate a correlation with $p > 0.05$.

Table 4a. Results of multiple regression analysis for psychological outcome measures in females (n = 151).

Variable	Grief ITG	Posttraumatic stress symptoms IES	Somatic complaints SCL	Anxiety SCL	Depression SCL	Doubt †
	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)
Step 1: predictors						
Education	-1.67 (1.73)	-5.59 (1.97) **	-1.21 (0.65) #	-0.77 (0.61)	-1.69 (1.18)	0.12 (0.43)
Gestational age	0.57 (0.40)	0.22 (0.44)	-0.05 (0.15)	-0.06 (0.14)	-0.20 (0.27)	0.22 (0.11) *
Lethal anomaly	3.77 (2.74)	-2.19 (3.07)	0.11 (1.03)	0.63 (0.96)	2.08 (1.86)	2.53 (1.10) *
Children at assessment	4.25 (4.00)	5.80 (4.45)	0.53 (1.49)	1.76 (1.39)	3.98 (2.71)	-9.01 (12.14)
Elapsed time	-0.35 (0.99)	-1.00 (1.11)	-0.02 (0.37)	0.34 (0.34)	1.21 (0.67) #	-0.01 (0.23)
Religion	-1.97 (2.70)	-2.04 (3.02)	-0.73 (1.01)	-0.69 (0.94)	-0.20 (1.83)	0.47 (0.68)
F model	0.99	2.16 *	0.69	0.93	1.53	*
R^2 on step 1	0.042	0.089	0.030	0.040	0.064	0.103
Step 2: partner support	4.90 (2.31) *	4.06 (2.59)	-0.15 (0.88)	0.13 (0.82)	2.34 (1.58)	0.49 (0.56)
F model	1.52	2.22 *	0.59	0.79	1.64	*
R^2 on step 2	0.073	0.105	0.030	0.040	0.079	0.107
Change in R^2	0.031 *	0.016	0	0	0.015	0.004

* $p < 0.05$, ** $p < 0.01$, # $p < 0.10$ (trend), † logistic regression.

Table 4b. Results of multiple regression analysis for psychological outcome measures in males (n = 151)

Variable	Grief ITG	Posttraumatic stress symptoms IES	Somatic complaints SCL	Anxiety SCL	Depression SCL	Doubt †
	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)
Step 1: predictors						
Education	-1.91 (1.33)	-3.44 (2.02) #	-1.16 (0.59) #	-0.69 (0.53)	-1.16 (0.91)	0.57 (0.61)
Gestational age	0.44 (0.28)	0.68 (0.42)	-0.15 (0.12)	-0.08 (0.11)	0.04 (0.19)	0.08 (0.13)
Lethal anomaly	3.67 (1.89) #	4.07 (2.87)	0.86 (0.82)	1.15 (0.74)	2.72 (1.27) *	0.58 (0.90)
Children at assessment	5.58 (3.19) #	0.72 (4.86)	-0.80 (1.39)	-0.48 (1.25)	1.11 (2.15)	-8.35 (14.38)
Elapsed time	0.04 (0.70)	-0.02 (1.06)	0.38 (0.31)	0.45 (0.28)	0.48 (0.47)	0.54 (0.31)
Religion	2.76 (1.92)	3.75 (2.93)	1.23 (0.83)	1.34 (0.75) #	2.42 (1.28) #	2.18 (1.13) #
F model	2.59 *	1.88 #	1.88 #	1.89 #	2.11 #	#
R^2 on step 1	0.107	0.080	0.079	0.080	0.087	0.074
Step 2: partner support	2.07 (1.55)	-2.01 (2.37)	0.73 (0.67)	1.11 (0.60) #	1.52 (1.03)	0.30 (0.62)
F model	2.49 *	1.71	1.78 #	2.15 *	2.14 *	
R^2 on step 2	0.119	0.085	0.087	0.104	0.102	0.075
Change in R^2	0.012	0.005	0.008	0.024 #	0.015	0.001

$p < 0.05$, ** $p < 0.01$, # $p < 0.10$ (trend), † logistic regression.

DISCUSSION

This study was set out to investigate psychological consequences of TOP for fetal anomaly separately for men and women. We tried to identify risk factors for poor psychological outcome after TOP in both sexes, and to explore the degree of concordance between partners. Previously, we have published predictors only for women [20]. The present cohort differs from the cohort described in this study, since only women whose partner also participated were included. For that reason 23% of women were excluded from the present study. The remaining group tended to have a more favourable outcome (not significant), which suggests a positive effect of involvement of the partner.

Overall, our study showed that the majority of couples adapt well to their loss without evidence of serious psychopathology. A number of respondents, however, showed TOP-related problematic responses even many years after the event. These problematic findings concerned symptoms of posttraumatic stress and depression, and, to a lesser extent, reactions of grief. Men as well as women experienced TOP more as a trauma than as a loss event. Although the scores on almost all psychological outcome measures were significantly higher in women than in men, the differences between both groups were moderate (Table 2). The proportion of pathological outcomes did not differ significantly between men and women with the only exception that women tended to have pathological levels of posttraumatic stress more frequently (Table 2). A remarkable finding is that partners never had pathological scores simultaneously (Figures 1 and 2). Although highly significant, we found only modest correlations between men and women for levels of grief and posttraumatic stress symptoms (Table 2), likely due to the number of couples showing discordant scores (Fig. 1). The same holds true for the levels of somatic complaints, anxiety, and depression, for which the intra-couple relations were not statistically significant (Fig. 2). The overall amount of variance explained by the studied predictors was relatively low (maximum 12 and 11%, in men and women, respectively). A substantial part of the determinants influencing psychological outcome positively were the same in men and in women, with high level of education and good partner support being the most important ones, followed by earlier gestational age at TOP, incompatibility with life, and having children at the time of assessment (Table 3). However, regression analysis showed that for men only lethality of the fetal anomaly was independently related with depression, with a trend for religion (Table 4b).

In general psychological research, women are described to express more symptoms of distress [21], and to express more negative emotions after stressful life events such as bereavement [5, 22] than men. Also, studies on early intrauterine or perinatal bereavement show almost consistently less-severe and less-prolonged distress in fathers than in mothers [4-6]. Our findings point in the same direction, but differences among sexes were very small. Similarly Goldbach et al. [23] showed less distress in men shortly after spontaneous loss of pregnancy, but after 1–2 years, they found nearly the same levels of symptomatology in both parents.

Prior studies based on TOP have found evidence that the grieving process is dependent on partner support [7-10]. In the current study, women in particular showed lower levels of grief and depression when they had perceived good support of their partner. This result has to be further evaluated in prospective studies, because of a possible recall bias disturbing assessments long after TOP.

The discordance in couples in which either the man or the woman showed pathological outcome levels was consistent in all measurements (lower right and upper left parts of Figures 1 and 2). It is rare for partners to exhibit a pathological level of outcomes simultaneously. Even without the use of cut-off points for pathology, which might be debatable, the empty right upper parts in Figures 1 and 2 illustrate this phenomenon. Owing to the cross-sectional design of the study, we do not know whether this discordance of pathology is a continuing factor in the couples' grieving process or the result of a time-related changing pattern between both partners. In a longitudinal study of perinatal loss by [24] similar rarely congruent scores of high distress in both partners were reported and the pattern tended to be a chronic one. The results of Vance and of the current study provide valuable information to pass on to patients who sometimes tend to blame each other for not showing the same degree of psychological distress during the coping process.

In counselling at TOP, the caregiver focuses primarily on women. On first thought, our results seem to justify this procedure, given the more problematic outcomes in women. Nevertheless, we emphasize the importance of involving both parents in the counselling. Firstly, because grief and posttraumatic stress symptoms only moderately differ between men and women and problematic grieving can occur in men as well. Secondly, because in women good adjustment to TOP is dependent on the level of support that they perceive from their partners. And, finally, because the intra-couple results in this study suggest that there is a mutual influence between the partners in the process of grieving.

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Chapter 5

Parental coping four months after termination of pregnancy for fetal anomalies: A prospective study in 226 cases

Short-term assessment in both men and women

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ABSTRACT

Objective: To assess parental consequences of termination of pregnancy for fetal anomaly and identify factors influencing psychological outcome.

Study design: A prospective cohort of 217 women and 169 men completed standardized questionnaires four months after termination. Psychological adjustment was measured by the Inventory of Complicated Grief, the Impact of Event Scale, the Edinburgh Postnatal Depression Scale, and the Symptom Checklist-90.

Results: Both women and men showed high levels of posttraumatic stress symptoms (44%-22%, respectively) and depression (28%-16%, respectively). Determinants of adverse psychological outcome were being religious, advanced gestational age, high level of doubt in the decision period, inadequate partner support, and low self-efficacy. The termination did not have an important effect on their future reproductive intentions. Only 2% of women and less than 1% of men regretted the decision to terminate.

Conclusion: Termination of pregnancy for fetal anomaly affects parents deeply. Four months after termination a considerable part of them still suffers from posttraumatic stress symptoms and depressive feelings.

INTRODUCTION

Worldwide, an increasing number of pregnant women request screening for fetal anomalies. This had led to an increase in termination of pregnancy for fetal anomalies both in the first and second trimester of pregnancy. The decision to terminate a wanted pregnancy is complex and painful for almost all parents [1-4]. Retrospective studies have shown that for a considerable part of women the psychological burden of this loss results in long-lasting serious psychological problems, even though the majority of parents ultimately adjust well [1, 2, 4-11]. In clinical practice it would be helpful to identify individuals who are most vulnerable to problematic psychological reactions in order to offer them extra support. Studies on psychological outcomes of patients undergoing termination of pregnancy (TOP) for fetal anomaly are often not based on standardized validated measurements, have a limited number of participants, or are focussed on one specific predictor. Furthermore, nearly all previous research has focussed on the mother, thereby neglecting the partner.

General bereavement research has shown that an early high level of distress is strongly predictive for later grief complications [12, 13]. We therefore investigated the early consequences of termination for fetal anomaly in a large prospective study. We assessed psychological morbidity and identified factors influencing psychological outcome in women and men, such as personality characteristics, education, prior elevated risk for anomaly, gestational age at termination, and fetal viability with life.

PATIENTS AND METHODS

From January 1999 to October 2002 three hundred women underwent termination of pregnancy (TOP) because of a fetal anomaly before 24 weeks of gestation. In three university and five non-university hospitals in the Netherlands they were approached at the time of the TOP by their treating gynaecologist, who asked permission to send a research information letter. In the information letter women as well as their partners were invited to participate in what was called ‘an extensive anonymous questionnaire study’. After written informed consent, coded questionnaires were mailed. Parents filled out the questionnaires separately. The ethics committees of all participating hospitals approved the study.

One general questionnaire contained questions on socio-demographic, medical and obstetric history. A number of other questionnaires were Dutch versions of validated self-completed questionnaires. Maladaptive symptoms of grief were measured by the Inventory of Complicated Grief (ICG), a 29-item self-report questionnaire with five-point scales and a possible total score ranging from 29 to 145 [14]. Symptoms of posttraumatic stress (PTS) were measured by the Impact of Event Scale (IES) [15, 16]. This is a widely used 15-item instrument measuring the impact of a named stressor, in this study the TOP. The scale deals with the components intrusion and avoidance in a 4-point response format (0, 1, 3, 5) with a possible total score ranging from 0 to 75 [15]. The Symptom Checklist-*90* (SCL-90) was considered to assess the level of generalized psychological malfunctioning [17, 18]. Because of the nature of the loss we also used the Edinburgh Postnatal Depression Scale (EPDS), a 10-item self-rating scale that has satisfactory sensitivity and specificity for defining post partum depression [19, 20]. Indicative of pathologic outcome were the following cut-off points: ICG: ≥ 90 [14, 21]; IES: ≥ 26 [3, 16]; SCL-90: women ≥ 204, men ≥ 170 (95th percentile), EPDS ≥ 12. We used the Generalized Self Efficacy Scale (SES)[22], a 10-item instrument which measures self-confidence as a stable personality characteristic, in which a high score reflects that an individual believes that he or she can cope with difficult demands. A final questionnaire was specially designed for this study. It contained questions about feelings of doubt or regret around the decision to terminate, questions on perceived external pressure at decision-making, on perceived support of the partner, as well as questions about reproductive wishes or decisions, and new pregnancies after the index pregnancy. The whole package of questionnaires had first been tested in a group of 20 couples with a history of TOP for fetal anomaly.

A critical percentage of completed questions is a prerequisite in the use of validated questionnaires. If one of the participants had not filled out the required minimum percentage for the underlying questionnaire (on average 90%), the person was excluded for that questionnaire.

All variables considered as predictors are shown in Table 1. The treating gynaecologist was responsible for providing diagnosis and viability scoring. Down syndrome was singled out as a separate predictor because of its frequent occurrence and because of the fact that current screening programs are directed towards Down syndrome. The scores of the inventories on complicated grief, posttraumatic stress, psychological distress, post partum depression, and feelings of regret 4 months after termination, were considered as outcome measures.

SPSS for Windows (version 10.1, SPSS Inc., Chicago, Ill.) was used for data management and statistical analysis. Results were summarised with the use of standard descriptive statistics: counts and percentages for categorical variables, and means, standard deviations (SD), and ranges for continuous variables. Groups were compared for equivalence in baseline characteristics using the Chi-square test or Fisher exact test, as appropriate, for categorical measures and Student's t-test for continuous variables. Subject characteristics that showed an association with the outcome measures (Pearson correlation coefficient $p < 0.10$) were considered candidate variables for further analysis. Stepwise multiple linear regression analysis was conducted to identify independent factors.

RESULTS

Three hundred couples were asked for participation. Seven couples were excluded: two because their address could not be traced, and five because the questionnaires were received outside the appropriate time window. One of the partners was excluded because of language barrier. Sixty-seven women and 121 partners refused participation. Two women were single. Consequently the results are based on the data of 217 women and 169 partners (all men), a participation rate of 74.1% and 58.3%, respectively. In nine cases the partner was the only responder and hence the final study describes 226 cases of termination. The non-participants did not differ from the participants with regard to the viability of the anomaly and the percentage of Down syndrome.

Socio-demographic and obstetric characteristics of the participants and other study predictors are given in Table I, with separate data for women and men, if appropriate. The distribution of 70% induction of labor versus 27% dilatation and evacuation (D&E) is due to the fact that in the Netherlands terminations beyond 14 weeks of gestation are usually done by induction of labor. Ninety-nine percent of the women and 97% of the men responded that the pregnancy was a wanted, or initially unplanned, but later on accepted pregnancy.

For all psychological measures women had significantly worse outcomes than men (Table 2). Correlations between predictors and psychological outcome for females and males are shown in Table 3. Being religious, higher gestational age, insufficient partner support, high level of doubt experienced during the decision period, perceived pressure at decision, and low level of self-efficacy, were associated with less favourable scores.

Stepwise multiple regression analysis was conducted to identify independent factors in females and males (Tables 4a and 4b, respectively). Down syndrome, procedure of TOP, number of previous living children, and perceived pressure had no significant contribution to the models. Lower parental age, having a religion, and advanced gestational age (step 1), poor partner support (step 2), much doubt during the decision period (step 3), and high scores of self-efficacy (step 4) showed to be independent predictors of negative psychological outcome. The amount of explained variance in the outcome measures varied between 12% and 22% for women and between 18% and 30% for men.

Six percent of women (N=13), and one percent of men (N=2) experienced feelings of regret when asked four months later. Most of them indicated to have these feelings only occasionally, but 4 women and one man did really regret their decision to terminate. We also addressed the issue of a possible future pregnancy. Six percent of women and 9% of men indicated that they would refrain from a next pregnancy for fear of another anomalous child. This was not related to parental age, gestational age, viability of the anomaly, or Down syndrome in the index pregnancy. Of the parents who opted for a new pregnancy, 92% would again undergo prenatal diagnostic testing and 3% would definitively reject such tests. After the TOP, 27% of women and 21% of men had sought psychological support.

Twenty-seven percent of women and 6% of men indicated the need for a support group or contact with parents with the same experience, whereas only one percent of women and men actually had made use of this possibility at that time.

Table 1. Obstetric and socio-demographic characteristics of the participants and psychological predictors. Data are presented as percentage or as mean, SD, and range. TOP: termination of pregnancy.

Couple shared factors			
Total number of terminations	226		
Gestational age (weeks)	17.6 (3.7); 12 - 24		
Prior elevated risk (%)			
maternal age	42.9		
genetic / other	17.7		
No prior elevated risk screening / accidental	39.4		
Method of termination (%)			
dilatation & evacuation	27.4 *		
medical induction of labour	69.5		
selective reduction for anomaly**	3.1		
Viability (%)			
viable anomaly	50.9		
nonviable anomaly	34.5		
uncertain	14.6		
Down syndrome (%)			
viable	37.2		
nonviable (due to other anomalies)	1.8		
Individual factors	**women n = 217**	**men n = 169**	**difference #**
Age at TOP (years)	34.8 (4.6); 19 - 44	37.0 (5.3); 26 - 56	p < .0001
Education (%)			
low	16.7	16.7	
medium	39.8	26.8	p < .02
high	43.5	56.5	
Religious (yes; %)	58.7	51.2	ns
Children at TOP (yes; %)	64.5	59.9	ns
Time elapsed since TOP (weeks)	15.0 (2.8); 9 - 26	15.1 (2.6); 10 - 24	ns
Doubt in decision period (yes; %)	38.9	31.0	ns
Perceived pressure (yes; %)	14.3	10.7	ns
Partner support (%)			
(very) much	85.1	91.6	
moderate	12.6	7.2	p = .053
none to little	2.3	1.2	
Generalized Self-Efficacy (GSE)	30.8 (5.0); 15 - 40	33.1 (4.8); 10 - 40	p < .0001

* n = 7 after 14 wk, ** multiple pregnancies, # difference between men and women tested with the unpaired t-test or chi-square test where appropriate.

Table 2. Psychological outcome measures in women and men 4 months after termination. Data are presented as mean, SD, and range.

Outcome measures	Cut-off level		Scores in women	Scores in men	Female-male difference[1]	Pathology women[2]	Pathology men[2]	Fisher test
	women	men	N = 217	N = 169				
Grief (ICG)	≥ 90	90	59.0 (20.4); 29-109	47.8 (16.6); 29-114	p <.0001	9.7%	2.4%	p <.005
Posttraumatic Stress Sympt. (IES)	≥ 26	26	25.1 (15.2); 0-71	16.9 (12.6); 0-57	p <.0001	44.0%	21.6%	p <.0001
General Psych. Malfunct. (SCL 90)	≥ 204	170	145.6 (53.1); 90-361	121.5 (36.6); 90-268	p <.0001	13.8%	10.8%	ns (.44)
Post Partum Depression (EPDS)	≥ 12	12	8.4 (5.6); 0-25	5.5 (5.2); 0-20	p <.0001	28.2%	15.8%	p <.005

1 difference between the groups of men and women tested with the unpaired t-test

2 proportions of women and men with a score above the cut-off level to define pathology; difference tested with the Fisher exact test.

Table 3. Overview of statistically significant relationships between predictors and psychological outcome measures for females (n=217) and males (n=169). Presented are Pearson correlation coefficients and levels of significance. TOP = termination of pregnancy. Empty cells indicate a correlation with p > 0.05.

	Grief (ICG)		Posttr. Stress Symptoms (IES)		Gen. Psych. Malfunct. (SCL 90)		Post Partum Depression (EPDS)	
Predictor	♀	♂	♀	♂	♀	♂	♀	♂
Age at TOP	-.17 .015		-.14 .049		-.14 .041			
Religion (no=0, yes=1)	.16 .020	.25 .001	.17 .013	.25 .001		.25 .001		.24 .002
Gestational age	.21 .002	.29 .0001	.16 .019			.27 .0001		
TOP procedure (D&E=1, med ind=2)		.23 .003				.16 .049		
Prior elevated risk (no=0, yes=1)								-.15 .049
Viable anomaly (no=0, yes=1)		-.18 .022						
Down syndrome (no=0, yes=1)		.21 .006				.19 .016		
Children at TOP (no=0, yes=1)	-.19 .006		-.23 .001					
Partner support (low=1, middle=2, high=3)	-.20 .004	-.20 .009	-.15 .033	-.16 .037	-.32 .0001	-.30 .0001	-.29 .0001	
Doubt decision period (no=1, very much =5)	.33 .0001	.27 .0001	.21 .0001	.30 .0001	.22 .001	.32 .0001	.24 .0001	.16 .048
Perceived pressure (no=0, yes=1)	.20 .003			.15 .050	.17 .010			
GSE - self-efficacy	-.28 .0001	-.23 .003	-.17 .011		-.34 .0001	-.24 .002	-.33 .0001	-.30 .0001

Note: elapsed time since TOP, new pregnancy at assessment, and level of education: not significant.

Table 4a. Results of multiple regression analysis for psychological outcome measures in females (n = 217).

Females	Grief (ICG)	Posttr. Stress Symptoms (IES)	Gen. Psych. Malfunct. (SCL-90)	Post Partum Depression (EPDS)
Variable	β (SE)	β (SE)	β (SE)	β (SE)
Step 1: predictors				
Age at TOP	-0.63 (0.30) *	-0.41 (0.23) #	-1.41 (0.80) #	-0.08 (0.08)
Religion	5.81 (2.79) *	4.68 (2.14) *	9.09 (7.59)	1.15 (0.79)
Gestational age	1.22 (0.38) ***	0.64 (0.29) *	-0.07 (1.03)	0.16 (0.11)
F model	7.37 ****	4.98 **	1.68 N.S.	1.96 N.S.
R^2 on step 1	0.098	0.069	0.024	0.028
Step 2:				
Partner support	-10.11 (3.11) ***	-5.81 (2.42) *	-37.07 (8.34) ****	-3.81 (0.88) ****
F model	8.42 ****	5.36 ****	6.44 ****	6.38 ****
Change in R^2	0.046 ***	0.028 *	0.090 ****	0.085 ****
R^2 on step 2	0.144	0.097	0.114	0.113
Step 3:				
Doubt decision period	3.60 (1.07) ***	1.36 (0.85)	7.49 (2.85) **	0.83 (0.30) **
F model	9.39 ****	4.86 ****	7.03 ****	6.77 ****
Change in R^2	0.047 ***	0.012 N.S.	0.036 **	0.033 **
R^2 on step 3	0.191	0.109	0.150	0.146
Step 4:				
Self-efficacy (GSE)	-0.81 (0.27) **	-0.36 (0.22)	-2.54 (0.72) ****	-0.29 (0.08) ****
F model	9.31 ****	4.30 ****	8.13 ****	8.20 ****
Change in R^2	0.031 **	0.008 N.S.	0.049 ****	0.056 ****
R^2 on step 4	0.222	0.117	0.199	0.202

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; **** $p < 0.0001$; # $p < 0.10$ (trend).

Table 4b. Results of multiple regression analysis for psychological outcome measures in males ($n = 169$).

Males Variable	Grief (ICG) β (SE)	Posttr. Stress Symptoms (IES) β (SE)	Gen. Psych. Malfunct. (SCL-90) β (SE)	Post Partum Depression (EPDS) β (SE)
Step 1: predictors				
Age at TOP	-0.12 (0.24)	-0.03 (0.18)	-0.04 (0.52)	-0.02 (0.08)
Religion	8.18 (2.43) ***	6.31 (1.91) ***	17.29 (5.46) **	2.50 (0.81) **
Gestational age	1.29 (0.33) ****	0.49 (0.26) #	2.53 (0.75) ***	0.19 (0.11) #
F model	9.03 ****	4.97 **	7.53 ****	4.34 **
R^2 on step 1	0.144	0.086	0.124	0.077
Step 2:				
Partner support	-8.69 (3.65) *	-5.58 (2.87) #	-29.41 (7.96) ****	-1.99 (1.21)
F model	7.96 ****	4.46 **	9.29 ****	3.79 **
Change in R^2	0.024 *	0.016 #	0.067 ****	0.012 N.S.
R^2 on step 2	0.168	0.102	0.191	0.089
Step 3:				
Doubt decision period	2.69 (1.01) **	2.68 (0.79) ***	7.27 (2.19) ***	0.46 (0.34)
F model	8.75 ****	6.23 ****	10.39 ****	3.38 **
Change in R^2	0.051 **	0.065 ***	0.060 **	0.010 N.S.
R^2 on step 3	0.219	0.167	0.251	0.099
Step 4:				
Self-efficacy (GSE)	-0.72 (0.24) **	-0.26 (0.19)	-1.64 (0.53) **	-0.32 (0.08) ****
F model	9.04 ****	5.52 ****	10.70 ****	5.66 ****
Change in R^2	0.041 **	0.010 N.S.	0.045 **	0.084 ****
R^2 on step 4	0.260	0.177	0.296	0.183

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; **** $p < 0.0001$; # $p < 0.10$ (trend).

DISCUSSION

This paper reports on the short-term impact of TOP for fetal anomaly on the psychological health of parents and on factors influencing the process of coping. It is well documented that an initially high level of distress is one of the best predictors of long-term maladjustment to bereavement [12, 13, 23]. Therefore, identification of determinants in early adjustment after TOP is important.

Four months after termination of an initially wanted pregnancy, both men and women showed high levels of posttraumatic stress symptoms and depression. Men as well as women experienced TOP apparently more as a traumatic than as a loss event, which is in agreement with our retrospective study [3]. Nearly one in three women scored above the pre-determined cut-off points for post traumatic stress and depression. This is in line with results of other short-term studies using similar instruments [6,7]. By way of comparison, three months after a normal delivery, pathologic PTS symptoms (IES, >26) were only found in four percent of the mothers [24]. In this prospective study men and women considerably differed in outcome: men showed less negative responses in almost all measures. Nevertheless, still 16 to 21% of men fulfilled the conditions for pathology in depression and PTS symptoms.

When assessing the individual determinants of adverse psychological outcome, having a religion and more advanced gestational age appeared to be moderately important predictors for both parents. Inadequate partner support was highly associated with poor psychological outcome in women but only moderately so in men. High levels of doubt in the decision period was a strong predictor for both parents. Low levels of self-efficacy was also a strong predictor for both parents in grief, psychological distress and depression, but interestingly, self-efficacy was not significantly related to posttraumatic stress symptoms in either sex. These predictors combined accounted for 12 to 22% of explained variance in women and for 18 to 30% in men.

Both in this study as well as in our retrospective study [2] we found advanced gestational age at TOP to be a significant negative predictor. Because in the Netherlands termination beyond 14 weeks of gestational age is usually done by medical induction, the predictor method of TOP was strongly confounded with gestational age. However, recently Burgoine et al. demonstrated no significant difference in grief resolution among women who terminated a pregnancy for fetal anomaly by medical abortion or by a surgical abortion at equal stage of pregnancy [6]. For men, this may be different (Table 3). Altogether, these findings stress the importance of early screening / diagnostic tests and the possibility of timely TOP in case of anomalies.

The predictor self-efficacy contributed highly to all outcome measures, except for post traumatic symptoms. This is in line with the study of Hunfeld et al., who found that the personality characteristic ‘personal inadequacy’ (which can be considered as a low level of self-efficacy) was the most important determinant for perinatal stress and grief reactions [8].

The predictors viability, no prior elevated risk for fetal anomalies, and Down syndrome versus other conditions were not linked to worse outcome in women and rarely so in men. This is in contrast to our expectations since Down syndrome is a viable condition, varying from mild to severe and subject to controversy regarding termination or otherwise. These results are especially important because Down syndrome is the single most frequent indication for TOP and most current prenatal screening techniques are specifically directed at the identification of this syndrome.

Although TOP appears to be a traumatic event, it is reassuring that only a few patients regretted their decision. Moreover, TOP does not seem to have an important effect on their future reproductive intentions, nor on their willingness to opt for prenatal testing. In other words, in a society without much pressure on the decision process of the parents, TOP for fetal reasons is well accepted [25].

To terminate an initially wanted pregnancy for fetal anomaly deeply affects parents, and four months after TOP a large part of them still suffers from depressive feelings and symptoms of post traumatic stress. Adequate information and active counselling of both men and women around the termination may diminish long-term adjustment problems. This may include information regarding severity and prognosis of the fetal anomaly, options for continuing pregnancy, problems that might be expected after the TOP, and the existence of specific support groups. Easily accessible psychological assistance should be provided, in particular for those who are estimated to be at risk for problematic coping on the basis of their individual characteristics or for patients who are exhibiting symptoms of maladjustment. It is the responsibility of the medical professionals to provide tailor made care before, during, and after the process of termination.

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Chapter 6

Psychological well-being after termination of pregnancy for fetal anomaly: A longitudinal study in women at 4, 8 and 15 months after the event

Longitudinal study in women

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ABSTRACT

Objective: To assess maternal impact of termination of pregnancy (TOP) for fetal anomaly and to identify factors influencing psychological outcome.

Study design: Prospective study with validated instruments and measurements on three time points: 4, 8 and 15 months after the event.

Results: More than 40 percent of women did not show at any time point reactions above the threshold for pathology. High levels of posttraumatic stress symptoms four months after TOP were a signal for maladjustment later. Other important predictors of persistent disturbances were low self-efficacy, doubt during decision making, and lack of partner support. Lack of knowledge about the disease was associated with doubt.

Conclusion: Clinicians should focus on giving more information about the disease at counselling and the partner should be actively involved in the process. The availability of professional help and support groups should be discussed more explicitly.

INTRODUCTION

Many studies have demonstrated that termination of pregnancy (TOP) for fetal reasons can be considered as a major life event[1-14]. Characteristic psychological reactions include depressive and problematic grief reactions. There is no consensus neither about which women are at risk for problematic coping. We therefore designed a prospective study with a large cohort of patients who terminated pregnancy for fetal anomaly using standardized and validated inventories. The overall aim of the study was to give clinicians instruments to improve and tailor their care for patients after termination of pregnancy.

PATIENTS AND METHODS

Women who underwent termination of pregnancy (TOP) because of a fetal anomaly before 24 weeks of gestation were approached at the time of the TOP by their treating gynaecologist. Three university and five non-university hospitals in the Netherlands participated. The study was conducted between January 1999 and October 2002. The ethics committees of all participating hospitals gave their approval. The women were asked permission to be sent a research information letter. In that letter they were invited to participate in what was called 'an extensive anonymous questionnaire study'. After written informed consent had been obtained, coded questionnaires were mailed at about 4 months (T1), 8 months (T2), and 15 months (T3) after TOP.

One questionnaire contained questions on socio-demographic, medical and obstetric history. A second series of questionnaires were Dutch versions of validated questionnaires. Maladaptive symptoms of grief were measured by the Inventory of Complicated Grief (ICG), a 29-item self-report questionnaire with 5-point scales and a possible total score ranging from 29 to 145 [15 16]. Symptoms of posttraumatic stress (PTS) were measured by the Impact of Event Scale (IES) [17, 18]. This is a widely used 15-item instrument measuring the impact of a named stressor, in this study TOP. The scale deals with the components intrusion and avoidance in a 4-point response format (0, 1, 3, 5) with a possible total score ranging from 0 to 75 [17]. The Symptom Checklist-90 (SCL-90), was considered to assess the level of generalized psychological malfunctioning [19, 20]. Because of the nature of the loss we also used the Edinburgh Postnatal Depression Scale (EPDS), a 10-item self-rating scale that has satisfactory sensitivity and specificity for assessing post partum depression [21, 22]. The following cut-off points were considered as indicative of pathologic outcome: ICG: $\geq$ 90 [15], IES: $\geq$ 26 [9,23]; SCL-90: $\geq$ 204 (95th percentile); EPDS $\geq$ 12. We also used the Generalized Self Efficacy Scale (GSE) [24], a 10-item measure which assesses self-confidence as a stable personality characteristic, with a high score reflecting that an individual believes that he or she can cope with difficult demands. A last 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, all to be answered on a 5-point scale:
1 ('very much'); 2 ('much'); 3 ('moderate'); 4 ('hardly' or 'poor'); and 5 ('not at all'). Dependent on the response rates, these categories were later recoded for statistical reasons to form new parameters (see Table 1).

A critical percentage of completed questions is a prerequisite for the use of validated questionnaires. If a woman had not filled out the required minimum percentage for a questionnaire (90% on average) she was excluded for that questionnaire.

The treating gynaecologist was responsible for providing diagnosis and viability scoring. Down syndrome was singled out as a separate predictor because the majority of programs for prenatal screening and diagnosis focus on this disease. All variables considered as predictors, either assessed at T1 only once or on each of the three occasions, are shown in Table 1. The total scores on the inventories for complicated grief, posttraumatic stress symptoms, psychological malfunctioning, and post partum depression at 4, 8, and 15 months after termination were considered the outcome measures.

SPSS for Windows (version 12.01, SPSS Inc., Chicago, Ill.) was used for data management and statistical analysis. Results were summarized with the use of standard descriptive statistics: counts and percentages for categorical variables, and means, standard deviations (SD), and ranges for continuous variables. Groups were compared for equivalence in baseline characteristics using the Chi-square test or Fisher exact test, as appropriate, for categorical measures and Student's t-test for continuous variables. Multilevel analysis (mixed model option) was used to identify variables that had an independent effect on the time course of the outcome measures. Fixed effects were considered for all predictors and random effects for elapsed time and participants. Stepwise logistic regression analysis was conducted to identify independent factors in subgroups of participants.

RESULTS

Three hundred women were invited to participate and 217 of them completed all questionnaires at T1, a participation rate of 72.3%. Subsequently, 178 and 153 women participated at T2 and T3, respectively. A total of 147 women completed the questionnaires on all three occasions. The attrition group, i.e. women who filled out the questionnaires at T1 but not at T2 and/or T3 (n = 70; 32%), differed from participants (n = 147) in that it contained more terminations in early gestation and more terminations by dilatation and evacuation, but the psychological outcome measures at T1 were similar. The non-participants at T1 did not differ from the participants with regard to the viability of the anomaly and the proportion of fetuses with Down's syndrome.

Subject characteristics are presented in Table 1. The women were generally at advanced age, well educated, and all had a male partner. TOP was performed by means of dilatation and extraction between 12 and 15 weeks of gestation (mean 13 wk) or by induction of labor between 14 and 24 weeks (mean 19 wk), showing only a small overlap in age range which is due to the Dutch policy as to the application of either method. New pregnancies were increasingly reported as the study progressed. Seventeen percent of women indicated that they had had severe feelings of doubt and 12 percent had perceived pressure in the period of decision making. Partner support was generally perceived as excellent or sufficient and less than 5% of women reported no support at all; the response categories 'moderate-poor' and 'not at all' were combined in further analyses. The scores on the GSE inventory were similar on all occasions and showed extreme intra-individual stability over time ($p = 0.99$).

The four psychological outcome measures were fairly inter-correlated on each occasion. The R-values ranged from 0.59 – 0.74 at T1, from 0.65 – 0.79 at T2, and from 0.37 – 0.74 at T3 ($p < 0.001$ for all relationships). The lowest R-values were consistently found for the relationship between the IES- and SCL-scores. All outcome measures declined steadily with time (Fig. 1; Table 2). For each measure, the values at T2 were significantly lower than those at T1 and so were the values at T3 when compared with the T2-values.

The effects of predictors (Table 1) on the outcome measures were analysed using multilevel analysis. Level of education, having living children before TOP, the TOP method, estimated viability of the unborn, Down syndrome, and perceived pressure at decision making had no significant contribution to the models. The variables of statistical importance and the final models are summarized in Table 3. Being religious and being at advanced gestational age at TOP were associated with higher scores on grief and posttraumatic stress symptoms, while the presence of a new pregnancy at T2 or T3 was associated with lower scores on SCL only. Women who experienced (very) much partner support showed lower scores on all outcome measures. On the other hand, higher scores on grief and psychological malfunctioning were found in women who had had serious doubt as to their decision regarding TOP. Self-efficacy was an important determinant of psychological functioning after TOP in each model, with poor self-efficacy related to higher scores on the outcome measures.

In the next step of analysis we investigated whether women with initially high scores on the outcome variables (distress) continued to have high scores at follow-up and whether others showed late onset of distress. On each of the three occasions, a woman's score on a particular questionnaire was classified as pathological or normal (see Methods for cut-off levels to define pathology). The women were then categorised according to whether they: 1) were distressed for the first time at either T2 or T3 ('late onset'); 2) remained distressed, i.e. were distressed at T1 and on at least one subsequent occasion; 3) were not currently distressed but had been so on at least one previous occasion ('no longer distressed'); or 4) were not distressed at T1 and continued to be non-distressed ('not distressed'); (adapted from Boyle et al., 1996) [26]. Figure 2 shows that the proportions of women with pathological scores for ICG and SCL were initially relatively low, but not for the IES and EPDS. As the proportions of 'no longer distressed' women increased with time and only a minority of women displayed late onset of distress (for IES and EPDS in particular, mainly at T2), most women had a normal score at T3. This demonstrates that the majority of women adapted well to their loss. In addition, 43% (IES) to 88% (ICG) of women were not distressed at T3 and had not been previously ('never distressed'). For all outcome measures, the distress rates declined over time with the largest reductions to occur from T1 to T2, but the change did not sustain between T2 and T3, except for IES (Fig. 2). If a woman had a score in the pathological range at T1 she had a fair chance of being distressed subsequently (Table 4). One in three (33%) and one in five (22%) women were consistently distressed for IES and EPDS, respectively, and the figures were even higher if their score at T2 was disregarded.

The decrease with time in number of distressed cases (Fig. 1) did not permit the identification of variables that could differentiate the 'remain distressed' and 'late onset of distress' subgroups from the 'never distressed' subgroup. As an alternative, we calculated the lower (P0 – P25) and upper (P75 - P100) quartiles of the outcome measures on each occasion. The numbers of women with high scores at T1 who continued to have high scores at follow-up and of women with delayed onset of high scores (T2 or T3) were larger, which allowed logistic regression analysis. The women who consistently had a score in either the lower or upper quartiles for the outcome measures were compared (Table 5). High levels of grief were associated with having a religion and having had serious doubts as to termination in the decision period, while having a religion and poor partner support were predictors of high scores on posttraumatic stress symptoms. Psychological malfunctioning was predicted by three variables, but none of these attained statistical significance. High scores on the EPDS were associated with poor partner support and serious doubts in the decision period. Interestingly, in this analysis the effect of self-efficacy on the psychological measures showed only a trend towards significance. The overall results did not change when GSE-scores were entered on step 1 and the other variables on step 2.

Low self-efficacy appeared to be the only determinant of late onset of high scores (T2 or T3) for all measures: ICG (β = -0.45, n = 18, p = 0.013); IES (β = -0.43, n = 22, p = 0.002); SCL (β = -0.16, n = 21, p = 0.056); and EPDS (β = -0.18, n = 29, p = 0.023), as compared to the 'always low score' subgroups (n = 14 to n = 21). The GSE-scores were on average 3 points (SCL, p = 0.050) to 7 points (IES, $p < 0.001$) lower in the 'late onset' subgroups.

As doubt was repeatedly ascertained as an important determinant we looked into factors associated with doubt during the decision period. Those with possible clinical relevance were the number of previous pregnancy losses ($p < 0.001$), lack of intra-couple consensus about the decision ($p < 0.0001$), doubt about the correctness of the diagnosis (p = 0.011), and lack of knowledge about the disease (p = 0.009).

Table 1. Maternal demographic, obstetrical, and psychological data at inclusion (T1) and subsequently where appropriate. The total number of participants with measurements on three occasions was 147. Data are presented as proportion (%) or as mean, SD, and range. TOP: termination of pregnancy.

Age (y)	35.0 (4.4); 19-44
Education (%)	
Low; Middle; High	15.1; 37.7; 47.2
Religious (yes; %)	59.6
Children before TOP (yes; %)	62.6
Gestational age at TOP (wk)	18.0 (3.5); 12 - 24
TOP procedure (%)	
Dilatation & Extraction; Induced labor	20.1; 79.9
Viability (yes; %)	55.6
Down syndrome (yes; %)	37.4
Elapsed time TOP – assessment (weeks)	
T1	14.6 (2.4); 10 – 22
T2	35.4 (2.7); 32 – 50
T3	65.5 (3.3); 58 - 78
New pregnancy (yes; %)	
T1	3.4
T2	34.1
T3 (or baby)	56.5
Psychological measures	
Doubt in decision period	
(very) much; moderate / hardly; not at all (%)	17.0; 45.6; 37.4
Perceived pressure in decision period (yes; %)	12.2
Perceived partner support	
(very) much; moderate / poor; not at all (%)	
T1	83.6; 13.0; 3.4
T2	75.9; 19.3; 4.8
T3	78.9; 16.2; 4.9
Self efficacy (GSE)	
T1	31.0 (4.8); 15 - 40
T2	31.0 (5.0); 17 - 40
T3	30.9 (4.9); 12 - 40

Table 2. Psychological outcome measures in 147 women 4 (T1), 8 (T2), and 15 (T3) months after termination of pregnancy. Data are presented as mean (SD), and statistical significance is indicated after Bonferroni correction for repeated measurements.

Outcome measure	T1	T2	T3
Grief (ICG)	58.8 (19.6)	54.0 (18.2) *	50.1 (16.5) *, $
Posttraumatic stress symptoms (IES)	25.2 (14.2)	21.4 (15.1) *	15.5 (12.4) *, $
Psychological malfunctioning (SCL)	144 (50)	128 (39) *	121 (33) *, $
Depression (EPDS)	8.3 (5.7)	6.9 (4.9) *	5.3 (4.4) *, $

* : $p < 0.001$; tested vs T1 values, $: $p < 0.001$; tested vs T2 values

Table 3. Overview of results of multilevel modelling for the total sample ($n = 147$ women). Presented are estimates (± standard error) of predictors and the level of significance of their contribution to the models. Note that estimates must be read as regression coefficients for continuous variables, and as change from outcome measure (constant) relative to the reference category for categorical variables.

	Grief (ICG)	Posttraumatic stress symptoms (IES)	Psychological malfunctioning (SCL)	Depression (EPDS)
Constant	56.2 (3.4); $p < 0.0001$	27.9 (2.4); $p < 0.0001$	150 (6.6); $p < 0.0001$	10.1 (0.6); $p < 0.0001$
Elapsed time (wk)	-0.17 (0.02); $p < 0.0001$	-0.20 (0.02); $p < 0.0001$	-0.41 (0.07); $p < 0.0001$	-0.06 (0.01); $p < 0.0001$
Religion (yes)	5.9 (2.59); $p = 0.024$	5.4 (1.9); $p = 0.006$	$p = 0.19$	$p = 0.13$
Gestational age (wk)	0.65 (0.37); $p = 0.085$	0.63 (0.27); $p = 0.020$	$p = 0.42$	$p = 0.85$
New pregnancy (yes)	$p = 0.34$	$p = 0.57$	-13.3 (5.3); $p = 0.014$	$p = 0.42$
Partner support				
1. (very) much ¶	-3.9 (1.6); $p = 0.018$	-5.0 (1.6); $p = 0.002$	-11.6 (4.1); $p = 0.005$	-2.0 (0.6); $p < 0.0001$
Doubt at decision				
1. (very) much #	11.3 (3.9); $p = 0.005$	n.s.	13.1 (7.7); $p = 0.091$	n.s.
2. moderate #	5.6 (2.8); $p = 0.045$	n.s.	11.0 (5.7); $p = 0.057$	n.s.
Self-efficacy at T1 GSE)	-0.55 (0.18); $p = 0.002$	-0.35 (0.16); $p = 0.025$	-2.1 (0.4); $p < 0.0001$	-0.29 (0.05); $p < 0.0001$

¶ : compared with reference category 2 (‘moderate-poor’ and ‘not at all’ combined); # : compared with reference category 3 (‘not at all’).

Table 4. Continuing pathology on two subsequent occasions (T2, T3) in women with scores in the pathological range on the first occasion (T1). Presented are numbers of women involved. Distress rates at T1 are expressed as percentage of total sample (n = 147). Rates of continuing distress are expressed as percentage of the number distressed at T1.

Pathology	Grief (ICG)	Posttraumatic stress symptoms (IES)	Psychological malfunctioning (SCL)	Depression (EPDS)
Cut-off level	≥ 90	≥ 26	≥ 204	≥ 12
T1	n = 14; 9.5%	n = 67; 45.6%	n = 18; 12.2%	n = 41; 27.9%
T1, T3, not T2	n = 3; 21.4%	n = 24; 35.8%	n = 6; 33.3%	n = 13; 31.7%
T1, T2, and T3	n = 2; 14.3%	n = 22; 32.8%	n = 3; 16.7%	n = 9; 22.0%

Table 5. Results of logistic regression analysis for women with a high score (P75 – P100) on the outcome measures on each of 3 occasions compared with women who repeatedly had a low score (P0 – P25). Indicated are the numbers of cases for subgroups of the lower and upper quartiles, respectively.

Predictor	Grief (ICG)	Posttraumatic stress symptoms (IES)	Psychological malfunctioning (SCL)	Depression (EPDS)
	β (SE) (n = 21 vs 23)	β (SE) (n = 17 vs 18)	β (SE) (n = 17 vs 17)	β (SE) (n = 16 vs 18)
Step 1:				
Religion	2.85 (1.02); p = 0.005	2.19 (0.85); p = 0.010	1.98 (1.02); p = 0.052	1.98 (1.02); p = 0.054
Gestational age	0.16 (0.15); p = 0.29	0.11 (0.12); p = 0.38	0.01 (0.14); p = 0.99	0.01 (0.14); p = 0.97
Partner support	1.94 (1.31); p = 0.14	3.05 (1.35); p = 0.008	2.33 (1.24); p = 0.059	4.48 (2.06); p = 0.020
Doubt in decision period	- 1.83 (0.71); p = 0.010	-1.02 (0.68); p = 0.14	-1.47 (0.79); p = 0.060	-1.68 (0.69); p = 0.042
R^2 on step 1	0.432	0.403	0.377	0.478
Step 2:				
Self efficacy (GSE)	-0.17 (0.10); p = 0.080	-0.12 (0.11); p = 0.29	-0.21 (0.11); p = 0.053	-0.20 (0.12); p = 0.088
p model	< 0.0001	< 0.0001	< 0.0001	< 0.0001
R^2 on step 2	0.478	0.425	0.465	0.528
Change in R^2	0.046	0.022	0.088	0.050

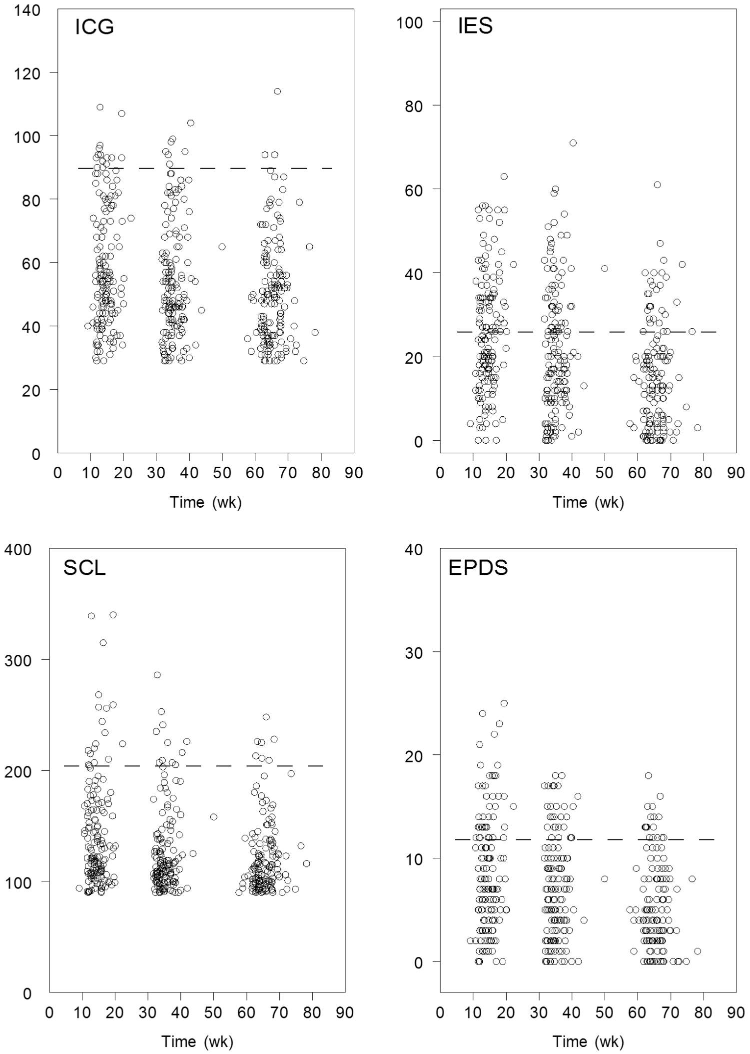

Figure 1. Distribution of raw data for each of the four psychological outcome measures: grief (ICG), posttraumatic stress symptoms (IES), psychological malfunctioning (SCL), and depression (EPDS). Dotted lines represent the cut-off levels to define pathology.

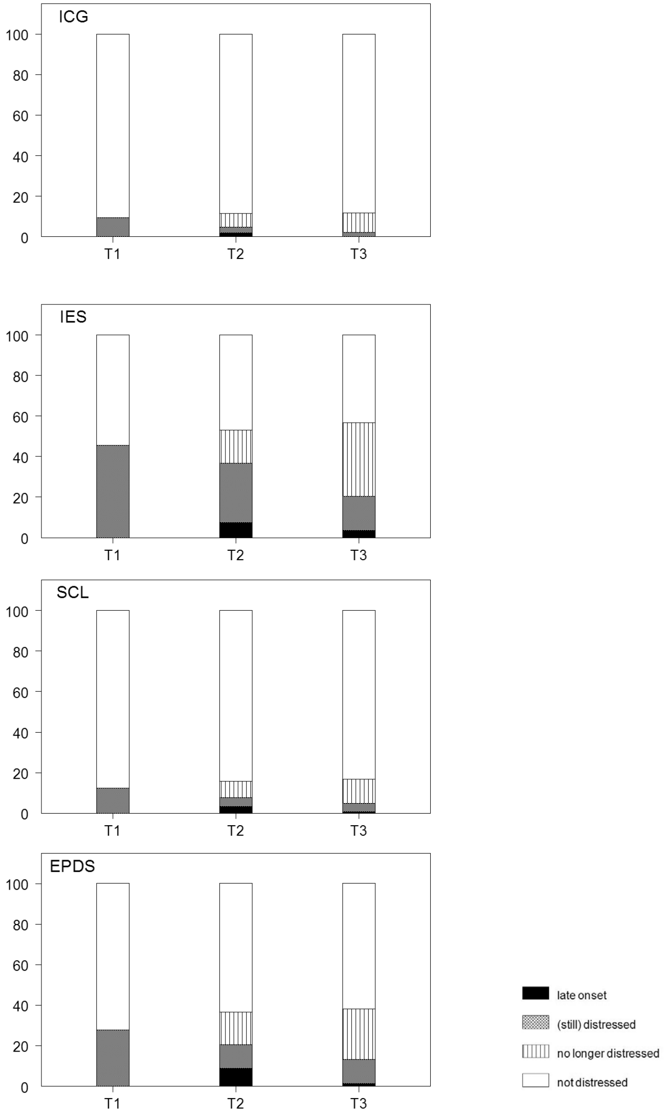

Figure 2. Patterns of continuity and change (resolution, pathology onset) for four psychological measures in women with normal and pathological scores on the first occasion (T1).

DISCUSSION

In this study we report on 147 women who each responded three times to sets of questionnaires designed to assess psychological well-being after genetic termination of pregnancy 4, 8, and 15 months after the event. More than 40 percent of women did not show any reactions above the threshold for pathology, neither in grief, nor in posttraumatic stress symptoms, nor in postpartum depression or generalized psychological malfunctioning scales. Those women who did show pathology mainly had abnormal scores in the posttraumatic stress reactions and mainly at the first measurement. There was a clear improvement over time for all the women for all outcome measures.

Persistent problematic or pathological adaptation was well predicted by early pathological reactions: 30% and 20% of women with abnormal scores at the first assessment for posttraumatic stress and depressive reactions, respectively, also had abnormal scores at the third assessment. Counsellors, therefore, should especially be alert on early problematic reactions. Late onset of problematic adaptation did not occur frequently, but if so it was predicted by low self-efficacy.

The aim of our study was to find predictors of pathological reactions. We had expected that lethality of the fetal condition would be important. This was not the case. Secondly, we had expected that gestational age and method of termination would be paramount. This was only true to some extent. The most important predictors of persistent disturbances were low self-efficacy, considerable doubt during decision making, lack of partner support, being religious, and advanced gestational age. Self-efficacy was for obvious reasons not measured before the event. The fact that self-efficacy scores remained stable at all three measurements for the whole group as well as at the intra-individual level strongly suggests that the first measurement can be considered as a pre-termination of pregnancy measurement. High levels of posttraumatic stress symptoms on the first occasion were a signal for maladjustment later on.

Doubt during the decision period was associated with previous pregnancy loss, doubt or lack of knowledge about the diagnosis or the disease, and lack of consensus with the partner. The results could mean that whenever an anomaly is found extensive counselling by a professional counsellor given to both partners simultaneously is indicated. Forty-four percent of women have elevated levels of posttraumatic stress symptoms 4 months after the event. This is a high percentage and confirms that termination of pregnancy is a major life event and should be considered as such, not only by those involved in the care of patients, but also by family, friends and employers. Secondly, we demonstrated that problematic reactions diminish over time in most patients. Our study is unique in that it covers a large number of patients, with a high response rate and in that posttraumatic stress symptoms and grief have been studied separately.

So, how do these data help to improve our clinical care? The key words are reassurance, encouragement, and reinforcement. Reassurance that being trauma-stricken, grieving, and having depressive symptoms after termination of pregnancy is normal. Encouragement that the majority of people come to terms with this impact full event, but that it needs time, often up to more than a year. Reinforcement especially of the partner by involving him as much as possible in all the events. But also reinforcement of women who show a lot of doubt at the time of decision making. Explicitly discussing the reasons for doubt will possibly help some of them. Referral for professional help might be useful in others. The same applies to women who show signs of distress at the post termination check up visit. Much can be gained through preventive measures, like providing patients adequate knowledge about the disease at hand. Prenatal tests should not be undertaken without at least discussing the disease or disease groups that the tests are aimed at. Likewise there is lack of information amongst patients about the existence of support groups and networks and the ways to access these. Our study strongly suggests that even in centres that have intensively focussed on care for patients who have had termination of pregnancy there are still possibilities for improvement.

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Chapter 7

Psychological functioning in couples after termination of pregnancy for fetal abnormality: the impact of early intra-couple discordance

Longitudinal study in couples

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ABSTRACT

Background: Serious and enduring psychological problems in women after termination of pregnancy (TOP) for fetal abnormality are well established. However, little is known about psychological adjustment to TOP in men. The impact of within-couple discordance for psychological measures on long-term mental health has never before been studied.

Study design: Longitudinal prospective study. Self-completed questionnaires on grief, posttraumatic stress symptoms, generalised psychological malfunction, depression, and a number of other topics were obtained from 90 couples 4, 8, and 15 months after TOP. Data was analyzed for within-couple effects to identify risk factors.

Results: 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 partners (denoted as discordance). Discordant couples compared with consistently concordant couple s were predicted by lower self-efficacy in women compared with partners and by intra-pair disagreement about the amount of support they received from each other.

Conclusion: Within-couple discordance (female score exceeding male score) for psychological functioning 3 – 4 months after TOP is a risk factor for serious and enduring mental problems in the female partners.

INTRODUCTION

Several studies have provided compelling evidence of serious and enduring mental health problems in women following termination of pregnancy (TOP) for fetal abnormality.[1-13] However, much less is known about the impact of such loss on psychological responses in men and on couples' adjustment to TOP. This is surprising, as TOP in almost all cases is truly a couples' issue: both partners face the loss of a (usually wanted) baby and experience the distress and life alterations associated with that loss.

In a recent study of psychological functioning in bereaved couples 2 – 7 years after TOP, we reported that females compared with their partners displayed more grief and posttraumatic stress symptoms, that partners' scores correlated well, and that simultaneous occurrence of partners' scores in the clinically pathological range was virtually non-existent.[3] However, because of its retrospective character, the study provided no information about the trajectories of psychological adaptation over time, neither in individuals nor in couples. In addition, despite the fair correlations between partners' psychological outcome measures, the latter often showed poor correspondence within couples.

The present prospective longitudinal study aims to address some of the mentioned limitations. Psychological malfunctioning was assessed three times over a 15-month-period in 90 couples who underwent TOP for fetal anomaly. Attention is given to patterns of continuing pathology and to intra-couple discordance for psychological outcomes and its risk factors. This knowledge is useful for the early identification of couples at risk for long-term psychological problems both for clinicians and in health policy.

PATIENTS AND METHODS

This study was conducted in three university and five non-university hospitals in the Netherlands between January 1999 and October 2002. All local ethics committees granted approval of the study. Women who underwent termination of pregnancy (TOP) because of a fetal anomaly diagnosed before 24 weeks of gestation were approached at the time of the TOP by their treating gynaecologist. The women and their partners (all male) were asked permission to be sent a research information letter in which they were invited to participate in what was called 'an extensive anonymous questionnaire study'. After written informed consent had been obtained coded questionnaires were posted out. They were returned at about 4 months (T1; mean 14 wk, range 11 – 22 wk), 8 months (T2; mean 35 wk, range 32 – 50 wk), and 15 months (T3; mean 65 wk, range 59 – 72 wk) after TOP. Partners were requested to fill out the questionnaires separately.

One questionnaire contained questions on socio-demographic, medical and obstetric history. A second series of questionnaires were Dutch versions of various validated questionnaires. Maladaptive symptoms of grief were measured by the

Inventory of Complicated Grief (ICG), a 29-item self-report questionnaire with 5-point scales and a possible total score ranging from 29 to 145.[14,15,16] Symptoms of posttraumatic stress were measured by the Impact of Event Scale (IES).[17,18] This is a widely used 15-item instrument measuring the impact of a named stressor, in this study TOP. The scale deals with the components intrusion and avoidance in a 4-point response format with a possible total score ranging from 0 to 75.[17] The Symptom Checklist-90 (SCL-90), was considered to assess the level of generalized psychological malfunctioning.[19,20] Because of the nature of the loss we also used the Edinburgh Postnatal Depression Scale (EPDS), a 10-item self-rating scale that has satisfactory sensitivity and specificity for assessing post partum depression.[21,22] Indicative of pathological outcome were the following cut-off points: ICG: ≥ 90 [14,16] ; IES: ≥ 26 [9,23] ; SCL-90: women ≥ 204, men ≥ 170 (95th percentiles); EPDS ≥ 12.

The Generalized Self Efficacy Scale (GSE)[24], a 10-item measure, was used to assess self-confidence as a stable personality characteristic; a high score indicates that an individual believes that he or she can cope with difficult demands.

A last 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, all to be answered on a 5-point scale: 1 (‘very much’); 2 (‘much’); 3 (‘moderate’); 4 (‘poor’); and 5 (‘not at all’). Dependent on the response rates, these categories were later recoded for statistical reasons to form new variables (see Table 2).

The treating gynaecologist was responsible for providing diagnosis and viability scoring. The total scores on the inventories on complicated grief, posttraumatic stress symptoms, psychological malfunctioning, and post partum depression at 4, 8, and 15 months after termination were considered the outcome measures. Couple-shared variables (Table 1) and the intra-pair discordance for partners’ age, educational level, religiosity, doubt and perceived pressure during decision making, and perceived partner support at T1 were considered predictors (Table 2).

SPSS for Windows (version 12.01, SPSS Inc., Chicago, Ill.) was used for data management and statistical analysis. Results were summarized with the use of standard descriptive statistics: counts and percentages for categorical variables, and means, standard deviations (SD), and ranges for continuous variables. Groups were compared for equivalence in baseline characteristics using the Chi-square test or Fisher exact test, as appropriate, for categorical measures and Student’s t-test for continuous variables. Trends over time were evaluated with one-way ANOVA for repeated measurements. Stepwise logistic regression analysis was conducted to identify independent factors in subgroups of participants.

RESULTS

Three hundred couples were invited to participate; 217 women and 160 of their partners returned the questionnaires at T1. Couples were lost to follow-up mainly due to a high attrition rate in males, such that full data of 90 couples was available for the present investigation.

Couple-shared characteristics and individual variables for partners are presented in Tables 1 and 2, respectively. All couples lived together either in wedlock (75.6%) or unmarried (24.4%) and remained cohabiting during the study period. Males compared with females had more often a full time job (as it is common in the Netherlands), were older, and had higher scores on self-efficacy (GSE on all occasions. The scores on GSE remained stable over time both in males and females. Level of education and the response categories of religiosity, doubt and perceived pressure in the decision period, and perceived partner support did not differ between females and males and showed fair intra-couple relationships, except for partner support on two occasions (Table 2).

On each of the three occasions, females had higher scores than males on all outcome measures and the couples' scores were fairly correlated (Table 3; Figs. 1 - 4). The psychological measures declined during the study period in either sex ($p < 0.0001$ for all time courses). The proportions of females and males with a score in the pathological range (distress), according to predefined criteria (see Methods), were similar for ICG and SCL on all occasions, but differed statistically for IES and EPDS (Table 3). However, for couples the incidence of having a pathological score together was markedly lower, especially when compared to the distress rates in females. The distress rates in females and males and the rate of simultaneous distress decreased steadily over time (Table 3). The latter is illustrated by the clearing of the upper right quadrants in the graphs for posttraumatic stress symptoms from T1 to T3 (Fig. 2).

Table 1. Couple-shared variables for partners who underwent termination of pregnancy (TOP). Data is presented as proportion or as mean (SD) and range for 90 couples.

Duration relationship (y)	8.8 (4.8); 2 - 22
Living children at TOP (yes; %)	62.2
Parity (%) 0; 1; ≥ 2	 28.8; 35.6; 35.6
Gestational age (wk)	18.3 (3.5); 12 - 24
TOP procedure (%) Dilatation & Extraction Induced labor	 17.0 83.0
Viability (yes; %)	51.1
Elevated risk (yes; %)	67.8
Down syndrome (yes; %)	40.0
New pregnancy (yes; %) T1; T2; T3 (or baby)	 3.3; 33.3; 53.9

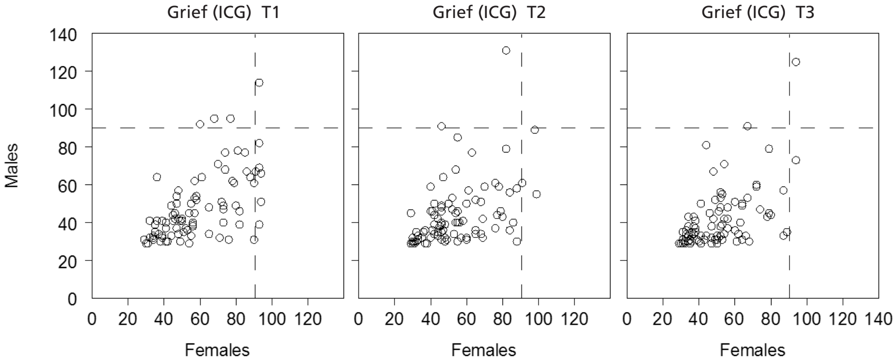

Figure 1. Relationship of partners' scores on complicated grief (ICG) on each of three assessment occasions (T1: 4 months; T2: 8 months; T3: 16 months). Dotted lines represent cut-off points to define psychological pathology (distress).

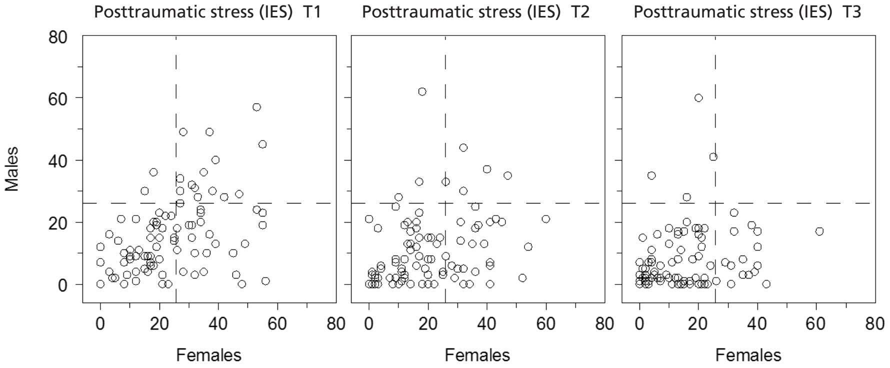

Figure 2. Relationship of partners' scores on posttraumatic stress symptoms (IES) on each of three assessment occasions (T1: 4 months; T2: 8 months; T3: 16 months). Dotted lines represent cut-off points to define psychological pathology (distress).

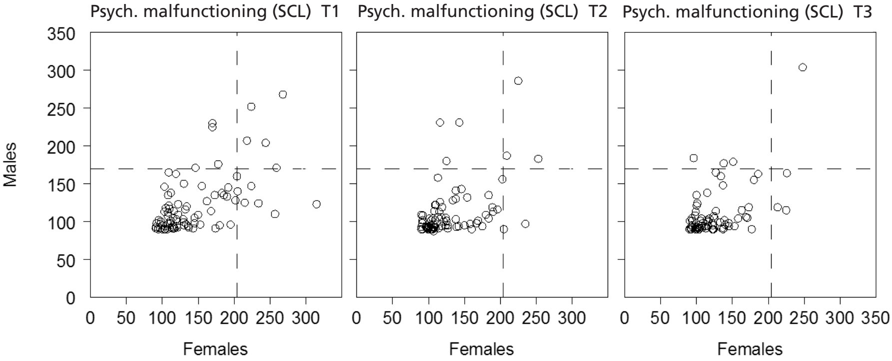

Figure 3. Relationship of partners' scores on generalised psychological malfunctioning (SCL-90) on each of three assessment occasions (T1: 4 months; T2: 8 months; T3: 16 months). Dotted lines represent cut-off points to define psychological pathology (distress), which were different for women and men.

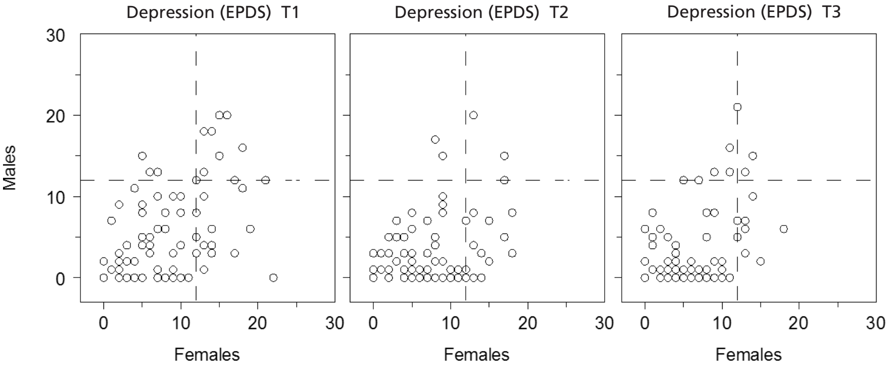

Figure 4. Relationship of partners' scores on the Edinburgh postnatal depression scale (EPDS) on each of three assessment occasions (T1: 4 months; T2: 8 months; T3: 16 months). Dotted lines represent cut-off points to define psychological pathology (distress).

To study patterns of continuing pathology, scores of partners on a particular questionnaire were classified as pathological for both (B); pathological for the woman only (F); pathological for the male only (M); or as normal for both (N). For each outcome measure, this resulted in categorization of the couple into one of 64 possible combinations when all three occasions were considered. In view of the results of our retrospective study (ref.), combinations that represented alternating patterns of change between the partners over time, such as BFM, FMF, or MFM, were of particular interest. However, there was no evidence of specific patterning for any of the outcome measures.

To identify factors that could differentiate couples discordant for a psychological outcome from couples with concordant scores (see Figs. 1 - 4), we calculated the intra-pair discrepancy as the difference in score (largest minus smallest) divided by the largest score multiplied by 100. Couples were considered discordant if the intra-couple difference was > 25% for ICG, > 50% for IES with a minimum difference of 10 points, and > 25% for SCL (not performed for EPDS, because of the narrow range of possible scores). Further analysis was restricted to couples with the woman's score exceeding that of spouses, as the opposite occurred too infrequently (n = 3 to n = 6 on each occasion). Couples with discordant scores at T1 and on at least one subsequent occasion were then compared with couples that consistently had concordant scores. The predictors (see Methods) were evaluated for their possible effect on intra-couple discordance with the use of logistic regression. Adjusted odds ratio (OR) and 95% confidence interval (CI) are presented for factors that were of statistical importance. Couples discordant for grief underwent TOP at more advanced gestational age than concordant couples (19.4 ± 3.4 wk vs 17.1 ± 3.5 wk; OR 1.24; 95% CI 1.03–1.49; $p < 0.05$), had less often living children before TOP (41.7% vs 72.2%; OR 4.17; 95% CI 1.43–14.82; $p < 0.05$), and tended to disagree more often on the mutually perceived amount of partner support (30.7% vs 9.3%; OR 4.37; 95% CI 0.93–8.48; $p = 0.063$). In addition, the women in the discordant group scored on average 3.8 points less than their partners on self-efficacy (GSE) at T1, as opposed to an intra-couple difference of 0.3 points in the concordant group (Table 4; $p < 0.05$). This effect lost significance after adjustment for the other variables (OR 0.92; 95% CI 0.83–1.01; $p = 0.079$). Couples discordant for posttraumatic stress symptoms (IES) were independently predicted by the intra-couple difference in GSE-scores at T1 only (OR 0.88; 95% CI 0.78–0.98; $p < 0.05$) (see Table 4 for mean values). Intra-pair discordance for scores on generalised psychological malfunctioning (SCL) was independently predicted by disagreement about mutually perceived partner support at T1 (37.5% vs 0% in the concordant group; OR 6.03; 95% CI 2.48–18.55; $p < 0.05$), and the intra-couple difference in GSE-scores at T1 (OR 0.85; 95% CI 0.74–0.98; $p < 0.05$; Table 4).

Table 2. Individual factors for partners. Intra-couple comparisons were performed with paired t-tests, chi-square (Fisher) test, and Pearson correlation. Data is presented as mean (SD) and range or as proportion.

Variable	Females	Males	Correlation (R; p)
Age (y)	35.7 (4.0); 26 - 44	38.0 (4.9); 26 – 50; ****	0.61; ****
Education (%) Low; Middle; High	9.0; 37.1; 53.9	12.4; 23.6; 64.0; ns	0.47; ****
Employment (%) Full time; Part time; Unemployed / other	37.8; 42.2; 20.0	95.6; 3.3; 1.1; ****	0.15; ns
Religious (yes; %)	57.5	52.9; ns	0.40; ****
Doubt in decision period (%) (very) much; moderate / hardly; not at all	14.6; 47.2; 38.2	14.6; 44.9; 40.5; ns	0.53; ****
Perceived pressure in decision period (yes; %)	15.6	14.4; ns	0.35; ***
Perceived partner support (very) much; moderate / poor; not at all (%)			
T1	88.9; 10.0; 1.1	91.1; 6.7; 2.2; ns	0.15; ns
T2	77.8; 18.9; 3.3	90.0; 8.9; 1.1; #	0.28; **
T3	83.1; 12.4; 4.5	91.1; 6.7; 2.2; ns	0.11; ns
Self efficacy (GSE)			
T1	31.0 (4.9); 17 – 40	33.1 (4.6); 10 - 40; **	0.14; ns
T2	31.3 (5.0); 17 – 40	33.6 (4.6); 11 - 40; ***	0.05; ns
T3	30.9 (5.0); 12 – 39	33.7 (4.4); 19 – 40; ****	0.24; *
Regret as to decision (yes; %)			
T1	8.9	1.1; ns	--
T2	6.7	1.1; ns	--
T3	6.7	1.1; ns	--
Doubt as to decision (yes; %)			
T1	11.1	3.3; #	--
T2	8.9	1.1; *	--
T3	6.7	4.4; ns	--

* : $p < 0.05$; ** : $p < 0.01$; *** : $p < 0.001$; **** : $p < 0.0001$; # : $p < 0.10$ (trend); ns : not significant

Table 3. Psychological outcome measures for partners. Intra-couple comparisons were performed with paired t-tests, chi-square (Fisher) test, and Pearson correlation. Data is presented as mean (SD) or as proportion.

Variable	Mean value (SD)			Pathological score (%)		
	Females	Males	Correlation (R; p)	Females	Males	Simultaneous
Grief (ICG)						
T1	58.2 (19.0)	48.1 (17.5); ****	0.59; ****	10.0	4.4; ns	1.1
T2	53.3 (18.1)	43.8 (16.7); ****	0.47; ****	3.3	2.2; ns	0
T3	50.2 (16.6)	41.3 (15.7); ****	0.54; ****	2.2	2.2; ns	1.1
Posttraumatic stress symptoms (IES)						
T1	24.7 (14.4)	16.1 (12.4); ****	0.43; ****	44.9	19.1; ***	16.9
T2	20.4 (14.1)	11.1 (11.5); ****	0.30; **	32.6	9.0; ***	5.6
T3	14.9 (12.9)	7.7 (10.0); ****	0.25; *	18.0	4.5; **	0
Psychological malfunctioning (SCL)						
T1	145 (49)	122 (39); ****	0.57; ****	14.5	10.8; ns	6.0
T2	128 (38)	111 (35); ****	0.45; ****	6.0	7.2; ns	3.6
T3	122 (34)	108 (32); ****	0.56; ****	4.8	4.8; ns	1.2
Depression (EPDS)						
T1	8.1 (5.4)	5.5 (5.6); ****	0.45; ****	28.9	15.9; *	13.3
T2	7.2 (4.8)	3.2 (4.2); ****	0.34; **	21.7	6.0; **	3.6
T3	5.6 (4.5)	3.2 (4.5); ****	0.50; ****	14.5	9.6; ns	3.6

* : $p < 0.05$; ** : $p < 0.01$; *** : $p < 0.001$; **** : $p < 0.0001$; ns : not significant

Table 4. Self-efficacy in couples concordant and discordant for the psychological outcome measures. Presented are mean (SD) intra-couple differences (scores of females minus those of males).

	Grief (ICG)		Posttraumatic stress symptoms (IES)		Psychological malfunctioning (SCL)	
	Concordant (n = 35)	Discordant (n = 24)	Concordant (n = 28)	Discordant (n = 19)	Concordant (n = 33)	Discordant (n = 18)
Self efficacy (GSE)						
T1	-0.3 (5.9)	-3.8 (6.8); *	-0.8 (4.6)	-4.7 (6.8); *	-0.7 (4.5)	-4.9 (8.3); *
T2	-0.1 (5.6)	-4.3 (8.3); *	0 (6.4)	-5.3 (5.6); **	0.5 (5.9)	-5.5 (7.4); **
T3	-0.6 (4.6)	-5.5 (7.0); **	-1.3 (4.7)	-5.2 (7.5); *	-1.9 (4.6)	-5.4 (6.1); *

* : $p < 0.05$; ** : $p < 0.01$; unpaired t-test.

DISCUSSION

The present study shows similar trajectories of psychological functioning after termination of pregnancy in women and men, although the women had consistently higher scores than their partners on all psychological outcome measures. The outcome measures declined with time in both sexes and the fall-off from T1 to T2 and from T2 to T3 seen in women kept pace proportionally with that in men (Table 3). In addition, partners' scores were well correlated, which means that when one partner obtains a particular score (or is distressed) the other is likely to respond in a similar manner. However, it is important to note that observations made for women and men at a group level as described above do not necessarily imply correspondence within couples. R-values indicate the strength of a relation between two variables, not the agreement between them. Our data show many couples with considerable lack of agreement in score among the outcome measures (Figs. 1 – 4). Instead of looking for factors that may explain high scores in individual partners as is usually done, we sought to identify factors associated with intra-couple discrepancy above a certain level. Lower self-efficacy in women than in partners at T1 was found to be a risk factor for these women to also exhibit (much) higher scores than their partners on grief, posttraumatic stress, and generalised psychological malfunctioning both at T1 and on at least one subsequent occasion. If partners were not congruent as to the amount of support they received from each other at T1, this was also a factor associated with consistently more psychological problems in women compared with their partner. Advanced gestational age and having living children at TOP were associated with more grief in women than in partners in this study. Other factors previously found as predictors of poor psychological functioning in women[2,3], including religiosity and doubt about termination in the decision period, did not play a role at the couple level.

Although termination of pregnancy for fetal anomaly affects the couple as a unit, it may trigger (latent) personality characteristics differently between partners. Self-efficacy is generally considered a personality characteristic. The women in the couples discordant for the outcome measures had lower self-efficacy than their partners, while the males in the concordant and discordant couples had comparable levels of self-efficacy (Table 4). While partners of couples who were consistently concordant for psychological functioning appeared to be overall harmonious, the discordant couples were characterized by difficulties in females to adjust to the burden of their loss. Whether this is true for couples in which the males had the higher scores awaits further study in a much larger study sample.

It is concluded that within-couple discordance for psychological functioning 3 – 4 months after TOP is a risk factor for serious and enduring mental problems in the female partners. This is important for clinicians and care givers in counselling and thereafter. Counselling, therefore, should preferably be done with both partners present.

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Chapter 8

Is there pressure from society to terminate pregnancy in case of a fetal anomaly?

Perceived pressure in the decision making

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ABSTRACT

The increasing use of prenatal screening techniques will undoubtedly lead to more terminations of pregnancy for fetal anomalies. In many societies such terminations are at stake and there is doubt whether parents take such decisions autonomously. In two large cohorts of Dutch patients we assessed the patients' perception of pressure experienced during the decision process regarding termination or otherwise. Pressure from society was perceived by approximately 6 percent of the parents. The vast majority of participants (83-92%) had felt no pressure at all. Participants, who indicated to have perceived pressure from others, had more unfavourable psychological outcomes.

INTRODUCTION

Prenatal diagnosis enables couples to terminate pregnancy in case of fetal chromosomal and/or morphological anomalies. The increasing use of prenatal screening will undoubtedly lead to more diagnoses of fetal anomaly and hence more terminations of pregnancy for this reason. The decision to opt for prenatal testing and to terminate pregnancy in case of anomalies should be the decision of the parents only, and pressure is to be avoided. In many societies, terminations are at stake and there is doubt whether parents take decisions autonomously. Termination of pregnancy is a complex decision that may lead to long-term psycho-emotional morbidity [1,2]. We could not find any studies (on the effects) of perceived pressure during the process of deciding for termination for fetal anomalies. Therefore, we assessed to what extent and from whom parents perceived pressure, and whether such pressure affected psychological well-being later on.

PARTICIPANTS, METHODS, AND RESULTS

We investigated perceived pressure at decision-making in the context of two large questionnaire studies on psychological sequelae of termination of pregnancy for fetal anomalies. The studies were conducted in three university and five general hospitals in the Netherlands. One study was retrospective, and involved couples who had made the decision to terminate pregnancy 2 to 7 years earlier; the other was a prospective study in couples who were recruited before termination and were assessed on average 4 months after termination. Men and women filled out questionnaires individually. Altogether 79% of the women and 62% of the men participated in the retrospective study and these figures were 74 and 58%, respectively, in the prospective study. The questionnaires were mainly directed at the psychological outcome and factors that helped coping with the loss. Three of the questions addressed explicitly the perceived pressure during the process of decision-making. The results are shown in Table 1. Most participants (83-92%) indicated that they had experienced no pressure during decision-making. Results of the retrospective and prospective studies were concordant. Women who indicated that they had experienced pressure in their decision-making process showed more signs of complicated grief [3] ($p = 0.003$) and depression [4] ($p = 0.005$) at follow up. For men these differences were not significant. Moral values of society had played a role for approximately 6 to 7% of women and less for men. These included the belief that handicapped children were not respected enough in society and the fear that society would blame the parent for having a handicapped child. Pressure from religion was rare. Three to 7% of participants had felt pressure from the medical staff. Perceiving pressure from the staff should clearly be differentiated from being influenced during an essentially non-directive counselling process [5]. We addressed this issue separately. Sixty percent of all parents indicated that their gynaecologist had had a substantial influence on the decision. The same holds true, to a lesser extent, for other medical professionals. However, it was the partner who had the highest influence on the decision (79-88%).

Table 1. Perceived pressure during decision-making for termination of pregnancy.

	Retrospective study 2-7 years after termination		Prospective study 4 months after termination	
	Women	Men	Women	Men
Number of participants	196	153	217	169
No perceived pressure	83%	92%	86%	89%
Perceived pressure*				
Family / friends	4%	1%	4%	2%
Medical staff	7%	5%	5%	3%
Religious community	1%	1%	1%	1%
Moral values of society	7%	1%	6%	5%

*More than one answer possible

DISCUSSION

The present study shows that in the Netherlands the vast majority of couples that decide to terminate pregnancy because of a fetal anomaly do so on their own account without perceived pressure from society. Pressure at decision-making should be avoided, if only because of the negative association with complicated grief and depression at follow up in these women. The percentage of perceived pressure from medical staff and society found in this study are low (1-7%). We should continue our efforts to keep these figures low through careful wording during consultation with patients, as well as in publications or in media outlets.

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Chapter 9

Maternal decision to terminate pregnancy in case of Down syndrome

The decisional process in case of Down syndrome

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ABSTRACT

Objective: This study explores decisional processes regarding termination of pregnancy because of Down's syndrome and aims to identify possibilities for improving counseling.

Study design: Seventy one women completed questionnaires four months after termination of pregnancy for Down's syndrome, including motivations for the decision, reasons for doubt, perceived influence and/ or pressure at decision-making and satisfaction with the received healthcare.

Results: Child related motivations to the termination were the most frequently mentioned, but almost all women indicated also motives of self-interest. Twenty-one percent of women reported much doubt. Perceived influence of the medical staff was substantial, but most women felt that they had not been put under pressure. Satisfaction with the caregivers was high.

Conclusion: Women acknowledge that self-centred motives play an important role. Medical caregivers are amongst the most important persons for women who decide to terminate pregnancy because of Down's syndrome.

INTRODUCTION

Improved screening techniques and strategies for identifying fetal anomalies have led to a more widespread use of Down's syndrome (DS) screening and diagnosis, and to an increased number of terminations of pregnancy (TOP) for DS [1]. It has been shown that after a diagnosis of DS 85 to 95% of the women decide to terminate pregnancy [1-4]. Little is known about the process of parental decision-making and available data are either casuistic or based on small numbers [5-8]. Recently, Skotko published the results of a postal questionnaire study in 141 mothers who continued their pregnancy after prenatal diagnosis of DS before 24 weeks of gestation [9]. The aim of that study was to describe the counseling process and to identify points for improvement. It was suggested that similar data on women who decided to terminate pregnancy because of DS would be a welcome addition to the literature (Commentary, AJOG; March 2005, p 3A). We conducted such a study in 71 women to get insight into psychological, social, and moral aspects of this decision and to suggest possibilities for improving health care and counseling

SUBJECTS AND METHODS

The study is part of a longitudinal study in 217 women who had their pregnancy terminated for various fetal anomalies. The current study focuses on 71 women who terminated their pregnancy because their baby had DS without anatomic anomalies incompatible with life having been ascertained. The latter was judged important as decisions to terminate pregnancy may be different in lethal versus non-lethal fetal conditions. Compatibility with extra-uterine survival was assessed by the treating physician. Women were recruited prospectively, from January 1999 to October 2002 just before or during hospital admission for termination of the pregnancy. Eight Dutch hospitals participated and it was always the attending physician who explained the study and requested participation. The ethics committees of all participating hospitals had approved the study design. Four months after termination, the women filled out extensive standardized questionnaires, that had been designed with the help of responses given to open ended questions in a previous study in 40 couples [10] and were tested in a pilot group thereafter.

Variables studied were socio-demographic and medical characteristics, motivations for the decision to terminate, possible reasons for doubt during the decision period, and levels of perceived influence and pressure of the social circle and the medical attendants. We further assessed satisfaction with the medical support before, during and after the procedure, and with the information given. Finally, we investigated possible feelings of regret on the decision and intentions for future pregnancies. The questionnaires included categorical measures (yes/no and 5-point scales) and continuous variables. For the 5-point scales, ranging from 1 (very much) to 5 (not at all), the answers to possibilities 1 and 2 (very much and substantial) were considered as positive outcome and then expressed as a percentage.

SPSS for Windows (version 10.1, SPSS Inc., Chicago, Ill.) was used for data management and statistical analysis. Results were summarized with the use of standard descriptive statistics. Groups were compared using the Chi-square test or Fisher exact test, when appropriate.

RESULTS

Of 104 women who had terminated their pregnancy because of DS, 80 women agreed to participate (77%). Nine women were excluded because of lethality or likely lethality (4 and 5 cases, respectively) caused by additional fetal anomalies. The results are therefore based on data of 71 women. Socio-demographic and obstetric characteristics of the participants are given in Table 1. All partners were male and two women were single. The study group was highly educated and at relatively advanced age. The latter is due to the policy in the Netherlands at the time of this study: serum or ultrasound screening for DS was not routinely offered to pregnant women. Therefore, maternal age > 36 years was the main indication for invasive prenatal diagnosis.. The distribution of 76% induced labor, versus 21% dilatation and evacuation is due to the fact that terminations beyond 14 weeks of gestation were usually done by induction of labor. All but two of the respondents described their pregnancy as a formerly wanted (from the beginning (77%), accepted and welcome (20%)) pregnancy.

Table 1. Obstetric and socio-demographic characteristics of the participants. Data are presented percentage or as mean, SD, and range.

Number	71
Age at TOP* (yr)	37.9 (3.0); 30-44
Education (%)	
Low	14.3
Medium	38.6
High	47.1
Religion (yes; %)	55.7
Gestational age (wk)	17.9 (3.2); 12-24
Method of diagnosis (%)	
Chorionic villus sampling	36
Amniocentesis	64
Method of termination (%)	
Dilatation and evacuation	21.1
Induction of labor	76.1
Selective reduction	2.8
Prior elevated risk total (%)	83.1
maternal age	77.5
genetic / other	5.6
No prior elevated risk: screening or accidental	16.9
Children at TOP (yes; %)	74.6

*TOP: termination of pregnancy

Table 2 addresses motivations to terminate pregnancy. Women indicated to what extent various motivations had played a role in their decision towards termination. In the questionnaire, the questions referring to the various motivations were listed randomly. Afterwards, we grouped them into two categories: 1) motivations relating to the unborn child's interest, 2) motivations relating to the woman's own interest, the relationship with her partner, or the interest of other children. Child related motivations scored highest: 45 to 92% of the women recognized themselves in one or more statements. All women had filled in at least one child-related motivation. Concern for the welfare of the other children in the family was named by 73 % of respondents. Statements related to self concern or concern about the partner were recognized as applicable by 6 to 64 % of women, issues about burden scoring highest, issues about finances or societal blame scoring lowest. All but one of the women had filled in at least one self- or family-related motivation

Table 2. Motivations for termination of pregnancy. Presented are the percentages of the 71 women who agreed (very much – substantially) to the statements in two categories (more than one answer possible).

Related to the infant	%
The child would never be able to function independently	92
I considered the anomaly too severe	90
I considered the burden for the child itself too heavy	83
I worried about the care of the child after my/ our death	82
I considered the uncertainty about the consequences of the anomaly to high	78
I thought the respect for handicapped children in our society is too low	45
Related to the respondent/family	%
I considered the burden too heavy for my other child(ren)	73
I considered the burden too heavy for myself	64
I did not want a handicapped child	63
I thought I would be unhappy of having this child	61
I considered the burden too heavy for my relationship	55
I was afraid of regretting afterwards if I would have this child	45
I thought it would obstruct my career too much	23
I would feel imperfect (lower self esteem) having a handicapped child	11
I acquiesced in the wish of my partner to terminate the pregnancy	11
I considered the financial burden too high	6
I was afraid to be blamed for continuing the pregnancy of a handicapped child	6

Levels of doubt during the decision process to terminate or to continue pregnancy were also assessed with a 5-point scale. Thirty-five percent of the responding women indicated that they did had had no doubt at all in taking the decision to terminate, whereas twenty one percent indicated to have experienced high levels of doubt (very much or substantial). The latter group had a more advanced gestational age ($p < 0.05$) and showed more feelings of regret ($p < 0.05$) four months after TOP than women with no doubt at all. In Table 3 the various reasons for these feelings of doubt are described, listed in order of occurrence. The most frequent reasons were conflict between reason and emotion, guilt about ending their child's life, and disagreement with the partner. Four women (6%) indicated to have current feelings of regret about the termination. Three of these only experienced this occasionally and one really regretted her decision.

Table 3. Reasons for doubt at the decision to terminate the pregnancy. Presented are the percentages of women who agreed (very much – substantially) with the statements. (more than one answer possible)

	%
My reason was in conflict with my feelings	49
I had the feeling of killing a child	43
My partner and I disagreed	38
The severity of the anomaly was uncertain	14
The consequences were incalculable for me	14
I felt cached off guard	13
It conflicted with my religion	7
My knowledge of the anomaly was insufficient	6
I was afraid of the procedure/ complications of the termination	6
I had doubt about the diagnosis	3

Perceived influences from the various contacts during the decisional process are shown in Table 4. The partner, gynecologist, family/ friends and geneticist where contacted most frequently. The perceived influence during the period of decision-making was highest for the partner (74%) and ranged between 18 and 45 % (from low to high) for primary health care providers, medical specialists and social workers, family/friends and religious counselors. Separately we asked the women whether they had perceived pressure during the decision process. Altogether 9 of the 71 responders (13%) felt they had experienced any pressure. The perceived pressure had its origin in 'values of society' (n = 6), religious society (n = 3), family or friends (n = 2), and medical staff (n = 1) (more than one answer was possible). Furthermore, thirty percent of all women indicated that they had to defend their decision to other persons.

Table 5 shows the percentage of women who had contacted various groups of health care providers before, during, and in the months after TOP, and in case of contact, the proportion of women who evaluated the quality of this contact as 'very much' or 'substantially' satisfying. Gynecologists, geneticists, nursing staff, and social workers were judged most positively by participants. Additionally, women's satisfaction with the kind of information given in the successive stages of the process was assessed. The information given about the procedure of prenatal testing was felt as satisfying by 91% of responders, about the diagnosis of DS by 89%, and about the procedure of the TOP by 83%. The information regarding the period after TOP scored lowest (68%). The counselors in 66% of cases addressed the possibility of continuing pregnancy. Women, who indicated that the option of continuation of pregnancy was not raised, appeared to be the ones who had reported less doubt during the decision process, as compared to the ones who indicated that both options were discussed (p = .002). Eighty-nine percent of women indicated to have received information about the possibility of professional psychological help and 40% had actually made use of this possibility. Thirty percent of the women stated that they would have appreciated to have had contacts with other parents with a DS diagnosis, but only one of them really had had such a contact. Eight percent of the women indicated that they did not dare to embark on a new pregnancy for fear of recurrence.

Table 4. Perceived influences from external contacts on the decisional process. Presented are the percentages of women who had contacted the various groups or persons in the decisional period and, in case of contact, the percentages of women who judged the influence of these persons on their decision as 'very much' or 'substantial.

	% contacted	**% that perceived influence as 'very much' or 'substantial'**
Partner	97	74
Gynecologist	97	33
Family /friends	84	37
Geneticist	70	42
Social worker	51	37
Family doctor	46	25
Midwife	40	18
Other persons with comparable experience	25	25
Religious counselor	16	45

Table 5. Satisfaction with the support of caregivers before, during and in the four months after TOP. Presented are the percentages of women who had contact with specific caregivers and, in case of contact, the proportion of women who evaluated the quality of this contact as 'very much' or 'substantially' satisfying.

	Contacted %	**Satisfied %**
Gynecologist	99	88
Nursing staff	97	88
Family doctor	80	74
Geneticist	68	88
Midwife	62	71
Social worker	59	88
Religious counselor	28	58

DISCUSSION

Termination of a wanted pregnancy following an adverse diagnosis in the unborn child is a major life event [11-14]. Grief for the – self chosen- child loss is often associated with conflicting feelings of relief, guilt, doubt, loss of self esteem, and moral bewilderment [6, 10, 14-17]. In the current study, we focused on aspects of the decision to TOP in 71 prospectively recruited women whose fetus has been diagnosed with DS.

Four months after termination, child related motivations to terminate pregnancy were predominant, but self and family related motivations played an important role too. Doubt about the decision to terminate was mainly related to the conflict between reason and emotion, feelings of guilt about ending a life, and disagreement with the partner. There were high levels of satisfaction with the information received about the procedure of prenatal testing and the implications of a child with DS. The decisional process was influenced most by the partner and much less by (health) caregivers or family and friends. Because being influenced should be clearly differentiated from the feeling of pressure during an essentially non-directive counseling process (Clarke, 1997), we addressed the latter item separately. Pressure (as a negative connotation of influence) was felt by a low percentage of women, with 'values of society' as the most frequent origin (8%) and pressure by medical staff in only one of the 71 women. In a retrospective study and in our total prospective cohort 'pressure' was felt by 17 and 14% of women, respectively [18]. Others found a percentage of sixteen percent[19]. Satisfaction with the support by the most intimately involved caregivers was high.

Skotko (2005) performed a unique questionnaire study in the United States, 0 - > 20 years (mean 4.4 years) after the prenatal diagnosis of DS in 141 women who had decided to continue their pregnancy [9]. Although satisfied with the care, the majority of respondents expressed frustration with the information and counseling process: test results of diagnosis had not always been conveyed in person, there was a perceived lack of information on DS, and a lack of referral to DS support groups. The women of our cohort were generally more positive about counseling and support, which might be due to the fact that both gynecologists and geneticists are more familiar with TOP in case of DS than with a continuation of the pregnancy. It may also be due to the fact that our study concerned more recent data. Also Skotko found a higher satisfaction among women who had more recent experiences The latter study covers a long period from 1982 till 2002 whilst our study was restricted to terminations between 1999 and 2002. In our population the given information regarding the period after TOP was considered suboptimal. This also parallels Skotko's findings and is clearly a challenge for improvement of care.

The following findings from our study may have implications for clinical practice.

1) In the decisional process the partner has a key role: his reported influence on the decision appeared to be by far the most important one. In motivations relating to TOP more than 50% of women mentioned fear of (too) heavy burden on their relationship. Disagreement with the partner was mentioned as a reason for doubt by 38% of the women, and 11% of them indicated to have acquiesced in

their partners wish to terminate. Therefore, it is essential to involve always both partners in the counseling.

2) The responses women gave concerning causes of doubt demonstrate the complex and conflicting aspects of the decision. The percentage of women with high or considerable level of doubt in the decision period was relatively large (21%). Data on this subject is lacking in literature. It may well be that this group is extra vulnerable to maladjustment. Caregivers should be attentive to this phenomenon and should offer psychological assistance in case of difficulties in decision-making.
3) It is standard practice of non-directive approach always equally to discuss both options of continuing and termination the pregnancy in counseling of fetal anomaly In the current study only 66% of women indicated that they had been counseled regarding both options. This does not seem correct, but is likely to reflect the clear decision to terminate pregnancy in part of the women. We found a strong association between the assertion of the women that this option to continue pregnancy had not been discussed and their lack of doubt at decision-making ($p = .002$). One may wonder if the option to continue pregnancy in women with no doubt at all should be discussed as thoroughly as in the other women.
4) In the literature on decisional processes following adverse prenatal diagnosis, the level of uncertainty about the precise manifestation of the disorder in the child is an important determinant [3, 19]. Especially DS is characterized by a large diversity of expression which cannot be ascertained prenatally. Although only 14% of the interviewed women mentioned uncertainty as a cause of doubt, addressing this issue explicitly and discussing the questions in detail might contribute to better coping.
5) Our results as well as those of Skotko show that support groups or contact with other parents in similar situations is an underused and maybe undervalued way of helping those clients.
6) Almost all women stated that self-interest had played a role in their decision to terminate a DS pregnancy. Self-interest may sometimes lead to feelings of guilt. Possible feelings of guilt should definitively be mentioned and discussed during counseling. And, if clearly present, persistent and interfering with daily functioning, psychological assistance is indicated.
7) Norms and moral values of society did play a role of considerable importance. Thirty percent of the women indicated that they had had to defend their decision to TOP one or more times. Almost half of them had the opinion that in nowadays society there is a lack of respect for handicapped people (reason of doubt at decision making, Table 2). And, finally, the factor ‘values of society’ was most frequently named as cause of perceived pressure. Clinicians should emphasize to the mother/ father that whatever decision they make, a considerable part of their social environment may have negative comments on their decision as they probably also would have in case the opposite decision would have been made.

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 very 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 DS proved to be a profoundly difficult decision for a substantial part of women. More data about reasons for doubt and motivations for the ultimate decision to terminate pregnancy may be beneficial as well for the mother as for the medical caregivers.

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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.

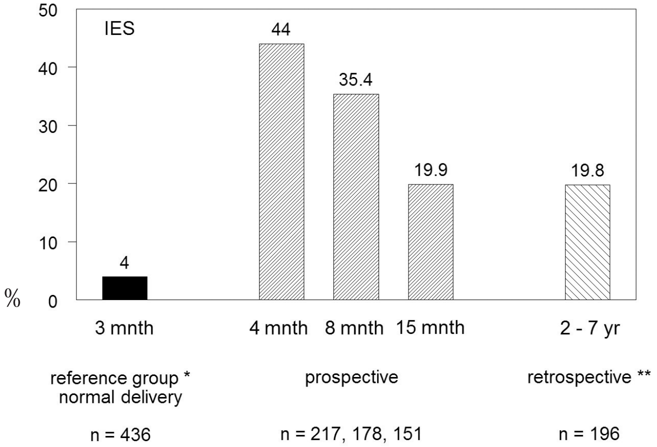

Figure 1. Percentage of women showing pathological level of posttraumatic stress symptoms (Impact of Event Scale -IES- in the months and years after TOP. Cut-off point for pathology > 26. * Reference group: E. Olde 3, ** IES-R recalculated into IES.

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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Samenvatting

Summary in Dutch

SAMENVATTING

Sinds ongeveer 30 jaar is het mogelijk om al vroeg in de zwangerschap een afwijking bij het ongeboren kind op te sporen. Dit gebeurde aanvankelijk door middel van vruchtwateronderzoek en later ook de vlokkentest. Een beperkt aantal, voornamelijk chromosomale, afwijkingen kon hiermee worden gediagnosticeerd. Aanvankelijk kwamen alleen zwangeren met een verhoogd risico op grond van leeftijd of voorgeschiedenis in aanmerking voor prenatale diagnostiek. Een van de redenen hiervoor was dat deze methodes om een afwijking bij de foetus op te sporen tegelijk ook een klein risico op verlies van de zwangerschap met zich meebrengt. Inmiddels is er een enorme vooruitgang geboekt in medisch diagnostische mogelijkheden. Met de ontwikkelingen in de echoscopie kwamen er steeds meer methoden voor het opsporen van aangeboren afwijkingen bij. Sinds eind 2005 worden alle zwangeren in staat gesteld echoscopisch onderzoek van hun ongeboren kind te laten doen op een tijdstip waarop aangeboren afwijkingen herkenbaar zijn. Een derde ontwikkeling was de opkomst van de zogenaamde risicoschattende prenatale testen, op dit moment bestaand uit een echoscopische foetale nekplooimeting en bepaling van de concentratie van specifieke hormonen en eiwitten in het moederlijk bloed. Een risicoschattende test is een test waarbij men geen diagnose stelt, maar waarmee men wel kan achterhalen hoe groot de kans is dat het ongeboren kind een bepaalde afwijking of ziekte heeft. Wanneer deze kans veel groter is dan gemiddeld, wordt diagnostisch onderzoek aangeboden in de vorm van een vruchtwaterpunctie of een vlokkentest. Daarbij kan met zekerheid worden vastgesteld of het kind wel of niet een chromosoomafwijking heeft. Op dit moment heeft elke zwangere toegang tot deze risicoschattende testen zij het dat dit soms nog voor eigen rekening is.

Bijna geen enkele afwijking die vóór de geboorte gediagnosticeerd kan worden is te behandelen. De diagnose van een ernstige afwijking bij het ongeboren kind stelt de ouders daarom voor een uiterst ingewikkeld dilemma. Ouders moeten kiezen voor leven of dood van hun eigen, tot dan toe meestal zeer gewenste kind. In ongeveer tweederde van de gevallen gaat het om een afwijking waarmee het kind in principe wel zou kunnen leven. Een probleem hierbij is dat de ernst van de afwijking vaak niet nauwkeurig te voorspellen is. Het inschatten wat deze afwijking voor het kind zelf zou betekenen is daarmee uiterst ingewikkeld, net als het inschatten van wat een kind met deze afwijking aan draaglast voor de ouders en het gezin zou opleveren. In Nederland besluiten ongeveer 95% van de ouders tot het laten afbreken van de zwangerschap wanneer bij hen in een vroeg stadium van de zwangerschap een ernstige afwijking van het kind wordt gediagnosticeerd. Volgens de laatste berekeningen bedraagt het aantal zwangerschapsbeëindigingen na een dergelijke afwijkende uitslag momenteel 500 tot 550 per jaar.

In vergelijking met het grote aantal onderzoeken dat gedaan is naar het ontwikkelen van prenatale testen, blijft onderzoek bij de moeder c.q. de vader naar de psychische gevolgen van het afbreken van een zwangerschap op grond van een afwijking van het kind daarbij achter. Er is inmiddels wel een aantal onderzoeken die inzicht geven in de problematiek van ouders die deze keuze maakten. Dit onderzoek berust echter grotendeels op kleine aantallen met vaak niet gestandaardiseerde en gevalideerde meetmethoden. De resultaten van de onderzoeken vertonen onderling grote verschillen. Wel zijn bijna alle auteurs het erover eens dat een dergelijke zwangerschapsbeëindiging als een ingrijpende levensgebeurtenis moet worden beschouwd. Het afbreken van een aanvankelijk gewenste zwangerschap is een bijzondere vorm van verlies. Normaliter is verlies en de daarop volgende rouw iets wat mensen overkomt. Rouw na een zwangerschapsbeëindiging is echter deels verlies na een zelf genomen besluit. Uit de literatuur blijkt dat een niet onaanzienlijk aantal vrouwen nog lang na de zwangerschapsbeëindiging negatieve psychische gevolgen hiervan ondervindt. Onderzoek naar welke ouders een verhoogd risico hebben op een problematische verwerking en wat risicoverhogende factoren hierbij zijn, is nog nauwelijks gedaan. Opvallend is ook dat bijna alle onderzoek op dit gebied is gericht op de zwangere in plaats van op beide ouders.

Ruim 18 jaar geleden werd in het Universitair Medisch Centrum Utrecht begonnen met een onderzoek dat tegelijk een vorm van patiëntenbegeleiding was. Het berustte op gedeeltelijk gestructureerde interviews. Met 129 ouderparen werden twee zeer langdurige gesprekken gevoerd. De resultaten van de eerste 40 gesprekken worden beschreven in Hoofdstuk 2. Deze bijna 10 jarige onderzoeksperiode diende als basis voor het vervolg onderzoek, bestaande uit een retrospectief en een prospectief gedeelte, dat in de daaropvolgende hoofdstukken beschreven wordt.

Het vervolgonderzoek was volledig schriftelijk. Er is een uitgebreide vragenlijst ontwikkeld op grond van de ervaringen, opgedaan in de gesprekken met de ouders van het eerdere onderzoek. Om inzicht te krijgen in de psychische gevolgen van een dergelijke zwangerschapsbeëindiging, werd gekozen voor zowel korte als lange termijn onderzoek. In beide onderzoeken werd zoveel mogelijk door de behandelend arts zelf contact opgenomen met de vrouwen. Hierbij werd toestemming gevraagd om de vrouwen en hun partner schriftelijk te mogen benaderen voor uitleg en voor verzoek tot deelname aan het onderzoek. De desbetreffende gynaecoloog / arts voorzag de onderzoekers van informatie over de aard en de ingeschatte levensvatbaarheid van de foetale afwijking. Inclusiecriteria waren: zwangerschapsafbreking op grond van een afwijking bij het kind, het voldoende beheersen van de Nederlandse taal en een zwangerschapsduur onder de 24 weken.

Om mogelijke verschillen tussen de partners zichtbaar te maken en de interactie tussen man en vrouw te bestuderen waren de vragenlijsten voor de partners (in deze studie zijn dit uitsluitend mannen) identiek aan die van de vrouwen. Daarnaast werd er gebruik gemaakt van bestaande gevalideerde vragenlijsten naar rouw, depressie, persoonlijkheidseigenschappen, etc. Deze zijn veelvuldig in ander onderzoek gebruikt zodat de uitkomsten kunnen worden vergeleken met uitkomsten van ander studies. Het onderzoek werd gedaan in negen Nederlandse ziekenhuizen. Het retrospectieve onderzoek gebeurde bij mensen die twee tot zeven jaar geleden een zwangerschap hadden laten afbreken. Voor het prospectieve onderzoek werd aan ouders bij de opname voor de zwangerschapsafbreking om medewerking gevraagd. Bij deze laatste groep werden op drie verschillende tijdstippen (namelijk 4, 8 en 15 maanden na de zwangerschapsafbreking) gestructureerde vragenlijsten afgenomen. We wilden onderzoeken welke ouders meer dan anderen negatieve gevolgen hiervan ondervinden en nagaan of er factoren zijn die de kans op een problematische verwerking vergroten. Daarnaast wilden wij de reacties van de moeders vergelijken met die van hun partners en mogelijke patronen of verbanden zoeken in de onderlinge verwerking. In totaal hebben 542 vrouwen en 420 mannen aan deze drie onderzoeken deelgenomen.

In **Hoofdstuk 1** wordt het doel van dit proefschrift uiteengezet, namelijk het beantwoorden van de volgende vragen:
1. Hoe verloopt het proces van zwangerschapsbeëindiging op grond van een gevonden afwijking bij het kind en wat zijn de psychologische gevolgen hiervan voor de ouders op korte en lange termijn?
2. Zijn er factoren te identificeren die van invloed zijn op de verwerking?
3. Zijn er verschillen in de verwerking tussen mannen en vrouwen, en is er een patroon van interactie te vinden in de verwerking?
4. Zijn er klinische aanbevelingen te doen naar aanleiding van dit onderzoek teneinde het verwerkingsproces adequaat te laten verlopen?

In **Hoofdstuk 2** worden de resultaten beschreven van gesprekken die destijds werden gevoerd met 40 vrouwen en 31 mannen, zes weken respectievelijk een half jaar na de zwangerschapsafbreking. Het betrof een voornamelijk kwalitatief onderzoek met gedeeltelijk gestandaardiseerde vragen. De interviews werden op de band opgenomen en later uitgewerkt. Wat het meest opviel was de intensiteit van de rouw en de ernstige depressieve klachten van de ouders, ook een half jaar later nog. Gevoelens van falen, twijfel, schuld en ondervonden morele en sociale druk kenmerkten en bemoeilijkten de verwerking. In de interviews kwam een aantal factoren naar voren die het rouwproces leken te beïnvloeden. Het afbreken van de zwangerschap voor een niet met het leven verenigbare afwijking leek minder problematisch te zijn dan een afbreking voor een wel met het leven verenigbare afwijking. Onzekerheid over de ernst van de afwijking was een bemoeilijkende factor. De duur van de zwangerschap bleek in tegenstelling tot wat we hadden verwacht geen verschil uit te maken. Wel gaven bijna alle ouders aan bij een eventueel volgende zwangerschap zo vroeg mogelijk prenataal diagnostisch onderzoek te willen laten doen. In vier van de 40 zwangerschapsbeëindigingen gaven de ouders aan spijt van hun beslissing te hebben en in al deze gevallen was ofwel de diagnose of de ernst van de afwijking onzeker geweest. Veel ouders hadden last van conflicterende gevoelens en gedachten. Slechts bij 14 procent van de deelnemers bleek er behoefte te zijn aan een patiënten zelfhulpgroep. Tachtig procent van de ouders gaven aan dat de uitvoerige gesprekken in het kader van het onderzoek waardevol waren geweest bij de verwerking. De helft van de ouders bood aan met lotgenoten te willen praten wanneer daar behoefte aan zou zijn, wat in een klein aantal van de gevallen ook gebeurde. Door de ouders gegeven adviezen voor de counselers waren: betere voorlichting over de aard en de ernst van de afwijking, informatie over de lange duur van rouw, en erkenning van het belang en de zwaarte van deze gebeurtenis door zowel de medische staf als de sociale omgeving.

In **Hoofdstuk 3** worden de resultaten beschreven van 196 vrouwen die twee tot zeven jaar tevoren een zwangerschapsafbreking hadden ondergaan. De vrouwen beleefden de zwangerschapsafbreking meer als een ingrijpende gebeurtenis dan als een verlies, wat bleek uit het feit dat de uitkomsten van de metingen naar rouw veel gunstiger waren dan die van de metingen naar posttraumatische stress symptomen. Ruim 17 procent van de vrouwen bleken op de vragenlijst voor posttraumatische stress symptomen een uitslag te hebben die boven de algemeen aanvaarde grenswaarde ligt.

De belangrijkste voorspellers voor problematische verwerking waren weinig ervaren steun van de partner en een lager opleidingsniveau. Minder belangrijk maar wel met een duidelijke invloed op de psychologische uitkomsten waren de duur van de zwangerschap ten tijde van de afbreking en een in principe met het leven verenigbare afwijking van het kind. In dat laatste geval was er ook iets meer twijfel bij de vrouwen over de juistheid van hun genomen besluit. Geconcludeerd wordt dat zwangerschapsbeëindiging om foetale redenen voor een niet onaanzienlijk deel van de vrouwen langdurige problematische consequenties heeft. De overgrote meerderheid van hen blijken deze gebeurtenis goed verwerkt te hebben.

Hoofdstuk 4 beschrijft bovengenoemde uitkomsten voor zowel de vrouwen als hun partners (allen man). De onderzoeksgroep bestond uit 151 paren die twee tot zeven jaar tevoren een zwangerschapsafbreking hadden ondergaan. Wij zochten naar verschillen in verwerking tussen de mannen en de vrouwen en naar mogelijke typerende interacties in het paar. Evenals in het onderzoek van alleen de vrouwen hadden verreweg de meeste paren de zwangerschapsafbreking goed verwerkt. De mannen scoorden op alle psychologische vragenlijsten iets beter dan de vrouwen. Het verschil was echter niet groot. Zowel bij de mannen als de vrouwen bleken uitslagen boven de grenswaarde voor pathologie voor te komen en alleen bij posttraumatische stresssymptomen bleken vrouwen significant vaker een hoge / pathologische uitslag te hebben. Een hoger opleidingsniveau, een minder ver gevorderde zwangerschapsduur en een afwijking die niet met het leven verenigbaar was waren factoren met een positieve invloed op de verwerking. Bijzonder was dat er in de paren slechts zelden man en vrouw tegelijkertijd een problematische verwerking hadden. Geadviseerd wordt om beide ouders zo veel mogelijk samen te betrekken bij de counseling.

In **Hoofdstuk 5** worden de resultaten beschreven van 217 vrouwen en 169 mannen die vier maanden nadat zij de zwangerschap hadden laten afbreken een schriftelijke vragenlijst hadden ingevuld. Uit rouwonderzoek blijkt dat mensen die in de eerste periode een problematische verwerking vertonen een verhoogd risico hebben op langdurige en ernstige problematiek. Wij onderzochten daarom of wij deze potentiële risicogroep konden identificeren. Ook in dit onderzoek zagen we het fenomeen dat een zwangerschapsbeëindiging om foetale redenen door ouders meer als een traumatische gebeurtenis wordt ervaren dan als een verlies. Zowel mannen als vrouwen scoorden op de vragenlijsten voor posttraumatische stresssymptomen en post partum depressie vaak boven de grenswaarden voor pathologie (respectievelijk 22 en 44%, en 16 en 28%). De verschillen tussen de mannen en de vrouwen waren in deze prospectieve studie groter dan in de retrospectieve studie. Voorspellende factoren voor problematische verwerking waren: het hebben van een religie, een verder gevorderde zwangerschapsduur, een hoge mate van twijfel in de periode van de besluitvorming, onvoldoende steun van de partner en een lage score op de lijst van zelfredzaamheid. Geconcludeerd wordt dat voorlichting over een mogelijk moeilijke eerste periode zinnig is en dat eventuele verwijzing voor psychologische ondersteuning laagdrempelig moet zijn.

In **Hoofdstuk 6** worden de psychologische reacties beschreven van 147 vrouwen aan de hand van metingen 4, 8 en 15 maanden na het afbreken van de zwangerschap. Respectievelijk één op de drie en één op de vijf vrouwen met een uitslag boven de grenswaarde voor posttraumatische stress symptomen en depressie bij de eerste meting, bleek een persisterende hoge uitslag te hebben. Het percentage vrouwen dat bij de eerste metingen normaal scoorde en later hoog, was daarentegen gering. Meer dan de helft van de vrouwen scoorde op de psychologische vragenlijsten geen enkele keer boven de grenswaarde voor pathologie. Risicofactoren voor meer problematische verwerking waren een lage score op de persoonlijkheidsdimensie zelfredzaamheid, twijfel in de besluitvormingsperiode en weinig steun van de partner. Naast de conclusies uit de vorige hoofdstukken, blijkt uit deze studie het belang van uitgebreide en duidelijke voorlichting over de ernst van de afwijking. Ook het doorverwijzen voor psychologische ondersteuning in geval van een grote mate van twijfel in deze periode is aan te bevelen. Vrouwen met hoge scores van psychologische distress in de eerste periode blijken een duidelijk verhoogd risico te hebben op een ernstig problematische verwerking 15 maanden na de zwangerschapsbeëindiging.

Hoofdstuk 7 gaat over het verwerkingsproces van 90 vrouwen en hun partners 4, 8 en 15 maanden na de zwangerschapsafbreking. De vrouwen bleken op alle vragenlijsten een meer ongunstige uitslag te hebben en vergeleken met de retrospectieve studie was in deze prospectieve studie het verschil in pathologische uitkomsten tussen de groep mannen en vrouwen groter. Een groot verschil in psychologische uitkomsten tussen het paar bij de eerste meting, met ongunstiger scores bij de vrouw, blijkt voor vrouwen een risicofactor te zijn voor ernstige en langdurige problematiek.

De mate van ondervonden druk bij het nemen van de beslissing tot het afbreken van de zwangerschap is in zowel de retrospectieve als de prospectieve studie onderzocht. In **Hoofdstuk 8** beschrijven wij in hoeverre en door wie ouders aangaven te zijn beïnvloed bij het nemen van hun besluit. Het merendeel van de ouders (83 - 92%) gaf aan dat zij geen enkele druk hadden ervaren. De grootste mate van druk werd ervaren vanuit de maatschappij en in het contact met de medische behandelaars. Er was een samenhang tussen de mate van druk en de verwerking: hoe meer druk was ervaren, hoe problematischer de verwerking bleek te zijn.

Hoofdstuk 9 gaat over het besluitvormingsproces bij de diagnose Downsyndroom. Downsyndroom neemt een aparte plaats in bij de problematiek van zwangerschapsbeëindiging. Bijna alle prenatale testen zijn op deze afwijking gericht. Over het afbreken van de zwangerschap bij een diagnose van Downsyndroom wordt zeer wisselend gedacht. Vier maanden na het afbreken van de zwangerschap in verband met Downsyndroom vulden 71 vrouwen een enquête in met vragen over dit besluit. Van die vrouwen gaf 21 procent aan dat zij behoorlijk getwijfeld hadden bij het nemen van het besluit. Vijfendertig procent van de vrouwen echter gaf aan geen enkele twijfel te hebben gehad. Bij de motivaties tot de afbreking werden door alle vrouwen een of meer redenen genoemd die te maken hadden met het belang van het kind, maar tegelijk gaven ook bijna alle vrouwen redenen aan die met hun eigen belang te maken hadden. De invloed van de medische behandelaars in de besluitvorming was groot, in tegenstelling tot de mate waarin bij de contacten met de medische behandelaars druk was ervaren (1%). De vrouwen waren in het algemeen tevreden over de counseling. De voorlichting over de periode na de afbreking en over het bestaan van zelfhulpgroepen of lotgenotencontact werd minder positief beoordeeld. Dertig procent van de vrouwen gaf aan dat zij zich een of meerdere keren hadden moeten verdedigen voor hun besluit om de zwangerschap af te breken. Zwangerschapsbeëindiging bij Downsyndroom is voor een niet onaanzienlijk deel van de vrouwen een moeilijke beslissing, waarbij de partner een grote rol speelt. Naast de door de vrouwen ervaren normen van de maatschappij, lijken eigen tegenstrijdige gevoelens en motieven het besluit om de zwangerschap af te breken te bemoeilijken.

In de **Appendix** tenslotte wordt een algemeen overzicht gegeven van het proces van zwangerschapsbeëindiging. Daarin zijn naast de resultaten van het huidige onderzoek ook ervaringen van de onderzoekers en citaten van ouders opgenomen. Tevens worden de klinische consequenties besproken die uit deze studie naar voren zijn gekomen.

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LIST OF CO-AUTHORS

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Appendix

Deze Appendix is een herziene versie van een al bestaand hoofdstuk, getiteld 'Begeleiding bij zwangerschapsbeëindiging op grond van afwijkingen bij het kind' uit het boek 'Sterven, Uitvaart en Rouw' (red. van J. van den Bout en E. van der Veen) geschreven door M. Korenromp, L. Christiaens en G. Visser [1]. De bedoeling destijds was om de problematiek inzichtelijk te maken voor de diverse groepen hulpverleners.

In deze versie zijn de belangrijkste resultaten van de drie onderzoeken uit het proefschrift opgenomen: 1) het voornamelijk kwalitatieve onderzoek middels gesprekken met ouders 6 weken en een half jaar na de zwangerschapsafbreking, 2) het retrospectieve onderzoek bij ouders die 2 tot 7 jaar geleden een zwangerschap hadden afgebroken en 3) het longitudinale onderzoek bij ouders 4, 8 en 15 maanden na de afbreking. Ook zijn er citaten van ouders en ervaringen van de onderzoekers in opgenomen.

Sommige van de in de Appendix gebruikte resultaten en aantallen kunnen afwijken van die van voorafgaande artikelen, omdat voor ieder artikel een specifieke groep is gekozen. Zo kunnen in een bepaald hoofdstuk alleen die ouders aan bod zijn gekomen die aan alle drie de metingen meewerkten, in plaats van de grotere groep ouders die maar één of twee keer de enquête hadden ingevuld.

In totaal hebben 962 ouders aan de onderzoeken deelgenomen.

Het afbreken van de zwangerschap op grond van afwijkingen bij het kind: ervaringen van ouders en klinische consequenties.

CASUS

Meneer en mevrouw V. besloten na een relatie van acht jaar dat zij toe waren aan een kind. Het duurde drie jaar voordat de zwangerschap een feit was. Mevrouw V. was op dat moment 35 jaar. De zwangerschap verliep de eerste maanden voorspoedig. Na bijna 23 weken werd mevrouw V. naar het ziekenhuis verwezen voor een echoscopie. De baarmoeder leek aan de grote kant voor de duur van de zwangerschap. De uitslag viel niet mee: er bleek sprake te zijn van te veel vruchtwater en mogelijk was er bij het kind een hartafwijking. Voor de definitieve diagnose moesten ze naar een academisch ziekenhuis. Daar werd de volgende dag het vermoeden van een ernstige hartafwijking bevestigd. De gynaecoloog die samen met de kindercardioloog het echtpaar hierover inlichtte, was zakelijk, maar ook duidelijk. Het bleek te gaan om een afwijking waarvan de ernst niet exact te voorspellen was: er was een reële kans dat het kind de eerste weken niet zou overleven; als het dat wel zou doen zouden er minimaal drie operaties nodig zijn, met per operatie 50% kans op overlijden bij de ingreep. Indien de baby deze operaties zou overleven dan was de kans op blijvende handicaps groot. De zwangerschap was inmiddels bijna vijf maanden; het kind bewoog volop. Meneer en mevrouw V. waren begrijpelijkerwijs zeer ontdaan. Mevrouw huilde alleen maar en haar man vroeg: ‘Ja maar wat nu, wat moeten we nu doen?’ Zij moesten, zeiden de artsen, gaan nadenken of ze de zwangerschap door wilden laten gaan of niet. Dit moest op korte termijn besloten worden want na 24 weken mag men in Nederland een zwangerschap niet meer afbreken. Ze maakten een afspraak voor twee dagen later. Dan zouden ze het besluit bespreken. Thuisgekomen tuimelden tegenstrijdige gedachten over elkaar heen.

> ‘Dit wil ik niet. Het moet weg. Ik wil geen ziek kind.’
> ‘Blijf van mijn kind af! Het is ons kind.’
> ‘Ik heb ook zoveel gerookt, terwijl ik weet dat dat niet goed is.’
> ‘Dit kunnen we ons kind toch niet aandoen.’
> ‘Wat moeten we ons leven lang met een gehandicapt kind.’
> ‘Maar dat is toch gewoon moord, dan vermoord ik het toch eigenlijk.’
> ‘Als ik er maar niets van hoef te merken.’
> ‘Wat ben ik voor een moeder, dat ik zo kan denken.’
> ‘Ze hebben het vast verkeerd gezien.’

De huisarts stond die avond voor de deur: hij was gebeld door de gynaecoloog. Hij had duidelijk moeite met het idee dat ze de zwangerschap misschien zouden laten afbreken. Maar voor de V.’s was het een steun dat hij langs kwam en ze konden veel vragen aan hem kwijt. Slechts enkele vrienden en haar ouders werden ingelicht; zijn ouders zouden om geloofsredenen vrijwel zeker tegen de beslissing zijn. Want nog dezelfde avond was het besluit gevallen: ze zouden de zwangerschap af laten breken. Ze belden de gynaecoloog. Ze wilden niet meer wachten; dan ook maar zo snel mogelijk. Wel wilden ze nog één keer een echo laten maken, voor alle zekerheid. Het kind bleek via een 'normale' bevalling op de wereld te moeten komen; een andere oplossing was er niet. Ook geen narcose. De gynaecoloog hield een verhaal over afscheid nemen van het kind en er bewust mee bezig zijn.

In het ziekenhuis viel hen op dat er, in tegenstelling tot wat ze gedacht hadden, erg open met alles werd omgegaan. Alsof het om een weliswaar verdrietige, maar verder gewone bevalling ging. Er werd hen aangeraden het kindje een naam te geven, aan te raken, bij zich te houden en het eventueel te begraven. Het was een jongetje, Stephan noemden ze hem. Hij werd dood geboren. Van de uren daarna hadden ze foto's, dat ze hem vasthielden en dat hij in een mandje werd gelegd. Hun beste vrienden waren naar het ziekenhuis gekomen en hadden hem gezien.

Weer thuis, ging alles al snel weer bijna als vanouds. Aan een aantal mensen vertelden ze alleen dat Stephan dood geboren was; anderen wisten wat er precies was gebeurd. Iedereen was vol medeleven. Het woord abortus viel nooit; een enkeling merkte op dat ze toch ook blij moesten zijn dat hun zo'n ongelukkig kind bespaard was gebleven. Blij waren ze niet. Ze waren ouders geworden van een jongetje en hadden besloten dat hij niet zou leven. Ze hadden dit gedaan voor hem, maar gedeeltelijk ook voor zichzelf.

1. ZWANGERSCHAPSAFBREKING OP 'GENETISCHE' INDICATIE IN NEDERLAND ANNO 2006

Verdriet en rouw horen bij het leven. Zelfs zeer ernstige gebeurtenissen worden over het algemeen goed verwerkt [2, 3]. Dit geldt ook voor de meeste ouders die hun zwangerschap laten afbreken nadat er een ernstige afwijking bij het kind is geconstateerd. Toch blijkt een niet onaanzienlijk deel van de vrouwen (in dit onderzoek 17 – 19 %) nog lang negatieve gevolgen hiervan te ondervinden (hoofdstuk 3) [4]. Maar wie van de ouders hebben nu precies een verhoogd risico op een dergelijke problematische verwerking en wat zijn factoren die het risico hierop verhogen? Daar is nog maar weinig onderzoek naar gedaan. Opvallend is dat bijna alle onderzoek op dit gebied is gericht op de zwangere, terwijl de partner evengoed zowel medebeslisser als 'medegetroffene' is. Uit de bestaande literatuur blijkt dat bijna alle ouders het beëindigen van een zwangerschap in verband met afwijkingen bij het kind als een ingrijpende gebeurtenis ervaren [5-15].

In Nederland worden er 500 tot 550 zwangerschappen per jaar afgebroken nadat er een ernstige afwijking bij het kind is geconstateerd. Slechts 5 procent van de ouders besluiten in geval van een ernstige foetale afwijking de zwangerschap te continueren (Jaarverslag Werkgroep Prenatale Diagnostiek 2003). Net als in de landen om ons heen zet de ontwikkeling op het gebied van prenatale diagnostiek en screening ook in Nederland door. Het is onderdeel geworden van de normale verloskundige zorg. Zwangerschapsbeëindiging op 'genetische indicatie' zal hierdoor niet alleen vaker voorkomen, maar kan daarmee ook voor iedere aanstaande ouder een te maken afweging zijn. De wettelijke grens voor zwangerschapsafbreking in Nederland is gesteld op 24 weken.

Het besluitvormingsproces dat aan de zwangerschapsbeëindiging voorafgaat, maakt dat de verwerking bij deze vorm van verlies al begint voordat de afbreking daadwerkelijk plaats vindt. Begeleiding van deze ouders is een multidisciplinair gebeuren. Het behoort evenzeer tot de verantwoordelijkheid van de huisarts, de verloskundige, de gynaecoloog en de verpleegkundige, als tot die van de maatschappelijk werker, de psycholoog, de pastor, de uitvaartbegeleider en soms ook de psychiater. Van deze begeleiders hebben er velen niet of nauwelijks met deze problematiek te maken gehad. Zo komt in de gemiddelde huisartsenpraktijk een zwangerschapsbeëindiging in verband met foetale afwijkingen slechts eens in de negen jaar voor (uitgaande van 4533 praktijken in 2005 (Nivel), terwijl het vaak juist de huisarts is die langdurig met het rouwproces van de ouders wordt geconfronteerd.

Rouwproblematiek bij zwangerschapsbeëindiging op grond van foetale afwijkingen is binnen de thematiek van trauma- en verliesverwerking bijzonder: ouders maken zelf de keuze om een doorgaans zeer gewenste zwangerschap af te breken. Rouwen over een zelf gekozen verlies: het lijkt een tegenstrijdigheid. De aanvankelijk 'blijde verwachting' verandert in een bedreigende toekomst. Toch houden de ouders hierbij zelf de regie in handen. Zij moeten een beslissing nemen over leven of dood van hun kind. Het is een eenzame beslissing. Voor het intensieve en langdurige rouwproces dat hier vaak op volgt, kan de omgeving soms moeilijk begrip opbrengen. Ze hebben het toch zelf gewild en ze hebben er toch een heleboel verdriet mee kunnen voorkomen? Soms ook wordt het genomen besluit de ouders kwalijk genomen (hoofdstuk 9) [16].

2. DE PERIODE VAN PRENATALE DIAGNOSTIEK

2.1 Ouders

Ouders die de zwangerschap op genetische indicatie laten afbreken zijn vanuit verschillende uitgangssituaties aan het diagnostisch traject begonnen. De ouders die op grond van hun familie anamnese een verhoogd risico op een foetale afwijking hebben, zullen soms bewust of onbewust nog geen sterke band met het kind aan-gaan, hoe gewenst de zwangerschap ook is. Deze ouders kennen het ziektebeeld en de draaglast ervan van zeer nabij. Zij hebben meestal al lang tevoren een besluit genomen over wat te doen als de testuitslag niet goed zou zijn. Zo vertelde een vrouw: 'Ik voelde de vlokkentest als een begin van het verraad.' Veel ouders laten echter prenataal onderzoek of screeningstesten ter geruststelling doen en staan van tevoren nauwelijks stil bij de mogelijkheid van een slechte uitslag [17].

> Dat dóe je gewoon, het was ook het eerste waar de huisarts over begon toen ik wist dat ik zwanger was.'

Naarmate prenatale testen gewoner worden en routinematig aan alle zwangeren worden aangeboden, zal de confrontatie met een afwijkende uitslag harder aankomen. Het duidelijkste zien wij dit wanneer bij een routine echoscopie of een zogenaamde 'pret-echo' een ernstige afwijking wordt gevonden. Toch blijkt uit ons onderzoek, in tegenstelling tot wat wij hadden verwacht, dat het voor de verwerking geen verschil maakt of de ouders al wisten dat zij een verhoogd risico op afwijkingen hadden of dat de afwijking onverwachts via echo of screeningstest aan het licht kwam (hoofdstuk 5 en 9)[16, 18].

2.2 Hulpverleners

Of het nu gaat om een risicoschattende test (screenings-test) zoals een nekplooimeting of om diagnostiek in de vorm van vruchtwateronderzoek of vlokkentest, op de hulpverlener rust de taak ouders te wijzen op de mogelijkheid van een afwijkende uitslag en op de gevolgen hiervan. Bij de voorlichting moet ook plaats worden ingeruimd voor emotionele afwegingen rond beslissingen over leven en dood en voor relevante overwegingen rondom leven met een handicap.

In de praktijk merken wij dat de keuze voor prenataal onderzoek vaak meer berust bij de vrouw dan bij de partner. Het lijkt alsof de vroege zwangerschap toch meer haar verantwoordelijkheid is. In het counselinggesprek is het belangrijk om beide partners hierbij te betrekken. Wanneer de uitslag niet goed zou zijn, is medebetrokkenheid van de partner essentieel. Het is een kind van hen beiden en de ouders zullen gezamenlijk tot een besluit moeten komen. Bovendien blijkt uit de onderzoeksresultaten van deze studie dat steun van de partner een belangrijke rol speelt in de verwerking.

3. DE BESLISFASE

3.1 Ouders

Wanneer ouders te horen krijgen dat hun kind een ernstige afwijking heeft, is de reactie hierop mede afhankelijk van de reden waarom zij het onderzoek hebben laten doen. Vooral bij onverwachte bevindingen is er vaak een reactie van ongeloof, afgrijzen, angst en afkeer. Deze reactie kan razendsnel worden omgezet in de wens niets meer te maken te hebben met het kind; hetzelfde kind waar men vlak van tevoren nog met veel liefde aan dacht. Vrouwen beschrijven soms monsterachtige beelden. Later schamen zij zich hiervoor of voelen zich er schuldig over. Een vrouw vertelde: ‘We hebben het er nooit over gehad, maar ik merkte dat mijn man er ook last van had. Zijn arm lag ‘s nachts niet meer op zijn gewone plaats op mijn buik.’ Vanuit deze negatieve en ambivalente gevoelens is het moeilijk een weloverwogen beslissing te nemen.

De motieven en twijfels die de ouders beschrijven in deze periode van de besluitvorming is afhankelijk van de soort van de afwijking. Nagenoeg alle ouders (99%) gaven een of meerdere motieven aan die te maken hadden met het belang van het kind. Wanneer het ging om een levensvatbare afwijking gaven 93 procent van hen ook motieven die te maken hadden met hun eigen belang. Wanneer het ging om een niet levensvatbare afwijking was dit slechts in 60 procent het geval. Als belangrijkste twijfels bij het nemen van het besluit werden het dilemma tussen gevoel en verstand (35%) en het gevoel een kind te doden (32%) het meest genoemd. Het feit dat ook eigen belangen een rol spelen in het nemen van het besluit, kan schuldgevoel opleveren. Voor een aantal ouders blijkt dit een beletsel om te kunnen of mogen rouwen. Een vrouw schreef in de nacht voor de opname een brief aan het kind.

> ‘Ik nam afscheid van haar en schreef over mijn onmacht, waarom het zo had moeten zijn. Ja, gewoon een beetje om vergiffenis gevraagd.’

Een andere vrouw:

> ‘Hoe kan ik verdriet hebben? Je was heel welkom, maar op het moment dat je niet goed was, was je niet welkom meer. Zo ligt het wel.’

En een man zei:

> ‘Ik was erg bang dat het levend geboren zou worden, dat het pas later dood zou gaan. Dan zou ik me twee keer een moordenaar voelen.’

Wat het besluit zo moeilijk maakt voor de ouders is dat het een keuze is tussen twee kwaden. Zij moeten een afweging maken tussen het laten afbreken van een gewenste zwangerschap of het behouden van een kind dat waarschijnlijk een zware last is voor de rest van het leven van het kind zelf en van dat van de ouders. Naast onzekerheid en mogelijk schuldgevoel is het vooral de druk van een extreem grote verantwoordelijkheid.

Wanneer de ouders eenmaal tot hun besluit zijn gekomen de zwangerschap af te breken, vinden zij de wachttijd tot aan de opname vaak moeilijk. Achteraf zeggen velen er baat bij gehad te hebben. De tijd wordt gebruikt voor bezinning en voorbereiding op wat gebeuren gaat en daarmee wordt een begin van het aanvaarden van het verlies gemaakt.

Er zijn ouders die een kind hebben met een bepaalde ernstige afwijking en bij een volgende zwangerschap moeten besluiten of ze onderzoek laten doen naar deze afwijking. Voor een aantal van hen is dit een ingewikkelde en beladen keuze. Want met de keus voor het onderzoek lijkt als het ware het bestaansrecht van hun gehandicapte kind in het geding te komen.

3.2 Hulpverleners

Voor de verwerking van de ouders is het belangrijk dat zij kunnen terugkijken op een zorgvuldige besluitvorming. Begeleiding in deze fase begint bij het meedelen van de diagnose, de aard en de prognose van de afwijking en de medische en andere gevolgen ervan. Vaak worden naast de gynaecoloog nog andere deskundigen geraadpleegd. Een klinisch geneticus of maatschappelijk werker van een genetisch centrum kan completere voorlichting geven over wat een bepaalde afwijking inhoudt en wat de mogelijkheden van opvang en begeleiding zijn, dan een gynaecoloog, verloskundige of huisarts. In onze studie heeft 60 procent van de ouders een gesprek gehad met een klinisch geneticus en 34 procent met een maatschappelijk werker. Ook een gesprek met een arts die is gespecialiseerd in de afwijking van het kind, of met een groepsleider van kinderen met de betreffende aandoening, kan ouders informatie geven om hun beslissing te funderen.

De mogelijkheid de zwangerschap voort te laten bestaan en een kind met een bepaalde handicap te krijgen moet altijd als een duidelijke optie besproken worden. Maar tegelijk is het goed zich te realiseren dat er ouders zijn die geen enkele twijfel hebben bij het nemen van het besluit om de zwangerschap af te laten breken. In ons onderzoek was dat het geval bij 35 tot 40 procent van de vrouwen die een uitslag van Down syndroom hadden gekregen. Vijftien procent van de vrouwen zeiden daarentegen ernstige twijfels te hebben gehad in deze periode (hoofdstuk 9) [16]. Omdat uit het onderzoek blijkt dat veel twijfel bij de besluitvorming is gecorreleerd met een slechtere verwerking zou men ervoor kunnen kiezen deze ouders te verwijzen voor psychologische ondersteuning (hoofdstuk 5) [18]. In een aantal ziekenhuizen is het regel dat alle ouders die voor de beslissing staan in verband met een foetale afwijking wel of niet de zwangerschap af te breken, worden bijgestaan door een daarin ervaren maatschappelijk werker of psycholoog. Dit wordt door het merendeel van de ouders als positief en steunend ervaren.

De hulpverlener heeft de lastige taak de ouders te steunen in welke beslissing zij ook nemen, en moet zich tegelijkertijd onthouden van directieve adviezen. Hoe meer deze moeilijke beslissing de geheel eigen beslissing van de ouders is, hoe minder kans er is op twijfel of spijt achteraf. Sommige ouders voelen zich hierdoor in de kou staan: zij willen een oordeel van de behandelaar horen. Een vrouw zegt hierover:

> ‘Ik neem aan dat het heel professioneel is, maar niemand in het ziekenhuis zei ook maar één keer iets van: ik geef jullie groot gelijk, ik had het ook gedaan. Daar had ik zo’n behoefte aan.’

De hulpverlener staat voor een dilemma: in hoeverre mag je sturen met het doel te helpen. Mag een begeleider bijvoorbeeld zeggen: zo’n afwijking als deze, dat is voor het kind toch ook geen leven? Een dergelijke opmerking steunt en troost de ouders op dat moment, geeft hun als het ware een legitimatie voor het besluit de zwangerschap af te breken: de dokter vond het ook. Om inzicht te krijgen in de beïnvloeding en de eventuele effecten daarvan hebben wij vier maanden na de zwangerschapsafbreking de ouders gevraagd of, en zo ja in welke mate, zij in hun besluitvorming waren beïnvloed door hun medische behandelaars. Omdat counseling van deze ouders zónder enige invloed op de besluitvorming niet denkbaar is, hebben wij de deelnemers ook gevraagd of zij zich in de gesprekken onder druk gezet voelden. Het bleek dat de mate van invloed in de periode van de besluitvorming groot was (van de gynaecoloog 60%), maar dat de mate waarin de ouders druk hadden ervaren beperkt (3 tot 7%, hoofdstuk 8) [19].

De hulpverlener kan door de afwijking zo tastbaar en duidelijk mogelijk te maken, de realiteitsbeleving bij de ouders op gang brengen. Deze realiteitsbeleving is niet alleen belangrijk voor het goed kunnen nemen van een besluit, maar ook om in een later stadium het verlies beter te kunnen aanvaarden. De besluitvorming moet in alle rust kunnen gebeuren, zodat er geen definitieve stappen worden gezet op momenten dat verwarring overheerst. Met name wanneer de ouders afschuw over of angst voor het kind voelen is tijd nodig om het nieuws van de afwijking en de consequenties daarvan in ware proporties te kunnen overzien. Het kind met een afwijking moet als het ware eerst weer het eigen kind van voordien worden, voordat er afstand van kan worden gedaan.

Hulpverleners kunnen geneigd zijn eventuele schuldgevoelens bij de ouders te ontzenuwen. Door deze gevoelens echter te durven laten bestaan kunnen ouders gesteund worden. Het weerspreken van schuldgevoel, bedoeld om te troosten, kan als onbedoeld gevolg hebben dat ouders zich onbegrepen en eenzaam voelen.

Een zwangerschapsafbreking vanwege gevonden afwijkingen bij het kind komt in de praktijk van huisartsen en verloskundigen betrekkelijk zelden voor. Uit het onderzoek blijkt dat tevredenheid over de steun van huisartsen en verloskundigen iets achter blijft bij die van de verpleegkundigen, gynaecologen en genetici, die veel vaker met deze problematiek te maken hebben (hoofdstuk 9) [16]. Zowel in de periode van de afbreking en de periode daarna, als bij een eventuele nieuwe zwangerschap is begeleiding van deze ouders soms moeilijk.

Een vraag is in hoeverre de betrokken hulpverlener patiënten kan begeleiden bij het nemen van beslissingen wanneer hij of zij zelf op morele gronden niet achter de zwangerschapsafbreking staat. Dit laatste speelt vooral bij het Downsyndroom en bij sommige geslachtschromosomale afwijkingen. Onze ervaring is dat ouders in een dergelijk geval niet zelden veranderen van behandelaar. Moet men, bijvoorbeeld als huisarts, openheid over eigen twijfels geven en doorverwijzen naar een collega? De verwerking duurt tenslotte vaak lang en de gebeurtenis kan lange tijd een weerslag hebben op het algemeen welbevinden van de patiënt.

4. DE OPNAME IN HET ZIEKENHUIS

4.1 Ouders

Bij de ingreep zelf, het laten afbreken van de zwangerschap, zijn er diverse factoren die de verwerking bemoeilijken. Ondanks het feit dat het hun eigen besluit was, betekent dit voor de ouders toch vooral het einde van een gewenste zwangerschap. Erkenning dat zij hier verdriet over hebben, is belangrijk. Een man zegt:

> ‘Ik schreeuwde bijna tegen de zuster: ”Begrijp dan toch: ik heb net mijn kind verloren”.’

Een andere problematische emotie is kwaadheid. Deze emotie is problematisch omdat het zo onlogisch lijkt. Het was toch de eigen beslissing? Kwaadheid zal bij een genetische zwangerschapsbeëindiging gemakkelijk op zichzelf gericht worden. Dit kan destructieve gevolgen hebben voor zowel de ouder zelf als voor de onderlinge relatie. Met name geldt dit wanneer het gepaard gaat met een daling van het gevoel van eigenwaarde, zoals vooral vrouwen dat in deze situatie beschrijven.

De laatste verwarrende emotie is opluchting, de opluchting dat het is ontdekt, dat de zwangerschap afgebroken kon worden, dat het voorbij is, dat er geen gehandicapt kind in de toekomst zal zijn. Ruim 60 procent van de ouders geven aan dat zij ook een gevoel van opluchting ervaren hadden. Vooral vrouwen kunnen het hier moeilijk mee hebben. Een vrouw zei:

> ‘Wat ben ik voor een moeder, dat ik blij was dat de zwangerschap afgebroken mocht worden?’

4.2 Hulpverleners

De zwangerschapsduur heeft consequenties voor de methode van de zwangerschapsbeëindiging. Op dit moment is er vóór de veertiende week in de meeste ziekenhuizen de keuze tussen een curettage of medicamenteus opwekken van uterusactiviteit. Na de veertiende week wordt er meestal een inleiding gedaan, een medicamenteuze -met prostaglandines- opgewekte geboorte. Een enkele keer wordt bij een zwangerschap van meer dan veertien weken gebruik gemaakt van de zogenoemde Finksmethode. Daarbij wordt onder narcose de foetus gefragmenteerd en vaginaal verwijderd. De methode is voor de moeder snel en pijnloos, over pijnervaringen bij het ongeboren kind wordt wisselend gedacht [20, 21]. Na de ingreep kunnen de ouders het kind niet meer zien. Deze methode is voor veel artsen zelf emotioneel beladen en onaangenaam. Eerlijke uitleg aan de ouders over de procedure is confronterend en daarom moeilijk. Dit alles maakt dat deze keuze in Nederland vaak niet aan de ouders wordt voorgelegd, tenzij andere methoden om medische redenen niet goed bruikbaar zijn.

Het is goed om ouders te waarschuwen dat bij een ingeleide bevalling het kind met tekenen van leven geboren kan worden. Een aantal mensen ziet daar erg tegenop. Bij de vrouwen met een medicamenteuze inleiding bleek het kind in 26% van de gevallen nog geleefd te hebben. Bijna de helft van deze vrouwen beschreven dit als een positieve ervaring terwijl 29% van hen hier moeite mee hadden gehad. Ouders moeten ook voorgelicht worden over het feit dat de afwijking van het kind vaak uitwendig nog niet zichtbaar is, zoals bijvoorbeeld bij Downsyndroom, en dat vaak uitwendig het geslacht nog niet goed te zien is.

Tien procent van de vrouwen geven als een van de redenen van twijfel bij de beslissing aan dat zij bang zijn voor de ingreep of de bevalling. Voorlichten over het feit dat door de huidige medicatie het inleiden bij zwangerschapsafbreking niet echt te vergelijken is met een ‘normale’ bevalling, maar als lichamelijke gebeurtenis tussen het krijgen van een miskraam en een bevalling in zit, kan wellicht iets van de bovengenoemde zorg en twijfel wegnemen. Goede pijnstilling is vanzelfsprekend en met de huidige medicatie is de duur van de inleiding verkort tot één of een enkele keer twee dagen.

Bij de verwerking van een ‘genetische’ zwangerschapsbeëindiging speelt nog een andere complicerende factor een rol, die overigens ook geldt bij een doodgeboorte of een miskraam. Normaal gesproken zijn intense herinneringen aan degene die is overleden kenmerkende aspecten van het rouwproces. Bij een zwangerschapsafbreking hebben de ouders nauwelijks herinneringen aan het kind [17]. Bij een curettage kunnen de begeleiders als het ware herinneringen creëren als steun voor later. Ze kunnen bijvoorbeeld een kopie maken van het afwijkende karyogram (chromosomenpatroon) of van de brief naar de huisarts, of een extra echofoto van het kind. Bij een inleiding van een verder gevorderde zwangerschap lijkt het goed om, net als bij andere gevallen van sterfte bij de geboorte, de bevalling en de dood van het kind zo bewust mogelijk mee te maken. Dat is de reden dat men de ouders probeert te betrekken bij het hele gebeuren: door het kind te zien en/ of vast te houden, door het een naam te geven en te laten begraven. Ook als het gaat om een kind met ernstige zichtbare afwijkingen wordt dit aangeraden. Het kan twijfels over de genomen beslissing wegnemen. Bovendien voorkomt de confrontatie met het afwijkende kind dat ouders later last krijgen van spookbeelden; spookbeelden in de vorm van nachtmerries of fantasieën, die meestal gruwelijker zijn dan de werkelijkheid. De meeste ouders blijken hier achteraf tevreden over te zijn; echter in 13 procent van de gevallen had men toch achteraf spijt van deze keuze. Dit toch aanzienlijke aantal mensen moet ons aan het denken zetten. Hulpverleners moeten zich realiseren dat bovengenoemde theorieën over realiteitsbevordering niet altijd opgaan. Het niet geconfronteerd willen worden met het kind kan een - legitieme - vluchtreactie zijn. Het kan ook gebaseerd zijn op het feit dat het ongeboren kind in de beleving van de ouders nog niet echt een persoontje was. Het gevaar bestaat dat alle positieve aandacht voor rouw en rouwrituelen omslaat in een vorm van druk. Mensen hun eigen keuzes laten maken en hun eigen copingstrategie te laten kiezen, blijkt soms moeilijk. Zo zegt een man over het gesprek vóór de opname:

> ‘Ik had het gevoel met een verkoper te praten: een bevalling, afscheid nemen, met alle voordelen daarvan. Je moet oppassen voor modetrends. Wij wilden gewoon een operatie en verder niks.’

Het omgaan met genetische zwangerschapsbeëindiging als betreft het een ‘normale’ doodgeboorte, doet recht aan het gevoel van verdriet dat de ouders hebben. Maar het gaat voorbij aan de complexiteit van een dergelijk besluit met alle dilemma’s en tegenstrijdigheden. Een vrouw schrijft:

> ‘Ik vind zwangerschapsafbreking geen ‘verlies’. Het is wel degelijk een zelfgewilde dood van je eigen kind. Dat is snoeihard om te beseffen en soms nauwelijks te hanteren. Maar als je voldoende legitieme argumenten kunt geven waar je zelf achterstaat en die je naar de buitenwereld durft uit te spreken is verwerking van het gebeurde gemakkelijker dan dat je het ziet als een verlies, zoals een verlies van een ongeboren kind. En je komt, naar mijn mening, niet in het reine met jezelf als je door buitenstaanders (hulpverleners) geen ruimte krijgt om ronduit te mogen zeggen: ‘Ja, ik heb mijn kind laten sterven. En het was goed zo.’

5. OBDUCTIE EN CHROMOSOMAAL ONDERZOEK TER BEVESTIGING VAN DE DIAGNOSE

Obductie of pathologisch onderzoek van het kind is in veel gevallen belangrijk. Pas wanneer de afwijking duidelijk is, kan mogelijk een uitspraak worden gedaan over de kans op herhaling bij een volgende zwangerschap. Ouders hebben vaak moeite met obductie. Wanneer een arts obductie adviseert, doet hij/zij dit uitsluitend in het belang van de ouders en niet omwille van de wetenschap. Ooit moeten ouders beslissen of zij weer opnieuw zwanger willen en durven worden. Daarbij kan de diagnose van de afwijking van dit kind doorslaggevend zijn. In een aantal gevallen kan dan in een volgende zwangerschap gericht onderzoek worden gedaan. De brochure van de VSOP (Vereniging Samenwerkende Ouder- en Patiëntenorganisaties) over obductie na overlijden bij kinderen is bij deze problematiek goed bruikbaar.

Chromosomaal onderzoek is wenselijk vanwege kwaliteitscontrole en voor het “sluiten van de cirkel”. Om chromosomaal onderzoek te kunnen doen is weefsel (liefst kraakbeen) nodig, wat meestal wordt verkregen uit een teentje of vingertje omdat dat de grootste kans op een succesvolle kweek geeft. Als ouders daar te veel moeite mee hebben kan een huid fasciebiopt uit de oksel of een navelstreng of placentabiopt van foetale zijde een goed alternatief zijn. Het is moeilijk om dit aan ouders te vragen en het belang ervan uit te leggen. Een van onze gynaecologen doet dit als volgt:

> ‘We kunnen alleen maar zeggen dat deze slechte uitslag bij uw kindje zeker is en dat we geen fouten of verwisselingen maken, omdat we altijd, als ouders dat goed vinden, de chromosomen van de kinderen na afbreken van de zwangerschap hebben geverifieerd.’

In onze studie hebben 81 procent van alle ouders zich akkoord verklaard met dit bevestigingsonderzoek en van de ouders met een uitslag van Down syndroom zelfs 99 procent.

6. HET ROUWPROCES

6.1 Ouders

Als de ouders eenmaal thuis zijn, zal de omgeving een grote rol spelen in het verwerkingsproces. De mate waarin deze omgeving bij het hele proces betrokken was, is vaak bepalend voor de steun die de ouders kunnen verwachten. Hoe vroeger in de zwangerschap de afbreking plaatsvond, hoe groter de kans is dat de omgeving er nog niets van wist. Dat kan een nadeel zijn. Bij een verder gevorderde zwangerschap hebben familie en vrienden vaak ook een deel van de moeilijke beslissingsperiode meegemaakt. Ze hebben soms zelf het kind ook gezien of de begrafenis bijgewoond. Zij weten waar het verdriet over gaat. Hoe werkelijker het verlies is voor de omgeving, des te groter is de kans op begrip voor de beslissing en op voldoende steun in de periode nadien.

De omgeving kan echter ook een negatieve werking hebben. Een op de vijf vrouwen geeft aan dat zij zich voor haar beslissing heeft moeten verdedigen Soms is er puur onbegrip. Een man:

> ‘Ze snappen er niets van. Ik moet blij zijn, dat ik zo’n kind niet hoef te krijgen!’

> Soms ook is er sprake van een morele veroordeling, of van de angst daarvoor. Zo zegt een vrouw:

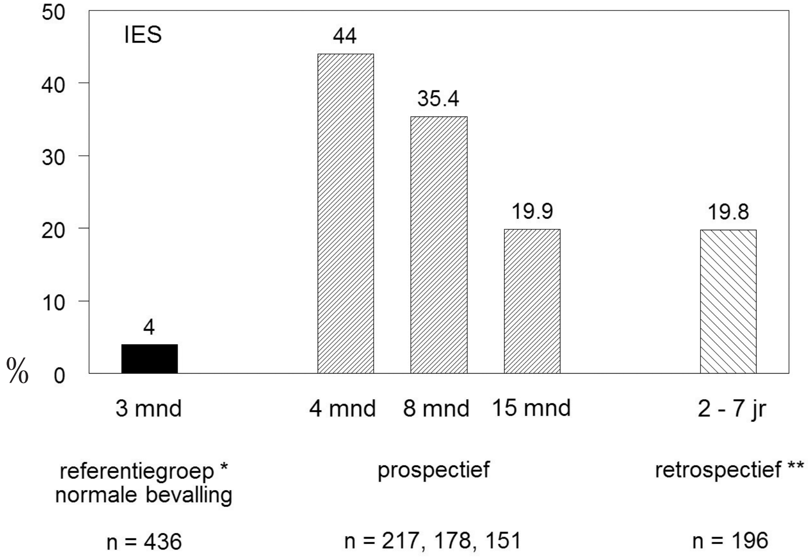
> ‘We hebben het haast aan niemand verteld, want we wonen in een heel christelijk dorp.’

De rolverdeling in het rouwproces van de ouders onderling is vaak karakteristiek verdeeld met de man die de steunende en de vrouw die de lijdende rol op zich neemt. De vrouw was toch veel lijfelijker bij de zwangerschap betrokken en had meestal ook al een sterkere binding met het kind dan de man. Bovendien is zij degene die de bevalling of curettage moest ondergaan. De man zal in de meeste gevallen het huishouden draaiende houden, zaken als begrafenis of crematie regelen en vaak snel weer aan het werk gaan. In de omgeving van de man is het soms ook minder vanzelfsprekend dat uitvoerig over dit alles gepraat wordt. Beide partners kunnen last van deze rolverdeling hebben. De man komt nauwelijks toe aan zijn gevoelens van verdriet, boosheid en verwarring; de vrouw verwijt de man dat hij zo gemakkelijk weer overgaat tot de orde van de dag. Als onderling praten niet goed mogelijk is, kan dit leiden tot verwijdering en zo een aanslag op de relatie betekenen. Mogelijk verklaart dit ook waarom de man vaak nog lange tijd afhoudend is tegenover een nieuwe zwangerschap. Hij blijkt angstiger te zijn voor de kans op herhaling van afwijkingen bij het kind dan de vrouw (hoofdstuk 5) [18]. Ook in de seksuele relatie kan de gebeurtenis een sterke invloed hebben. De behoefte aan intimiteit is vaak groot in deze situatie. De herinnering aan het gebeurde kan echter een negatieve lading geven aan alles wat met seksualiteit te maken heeft. Dat geldt ook voor verschillen in verwerkingswijze en het gevoel van biologische onvolwaardigheid.

In alle psychologische metingen die we in dit onderzoek hebben gedaan (rouw, post traumatische stressklachten, algemene klachten, en depressie) scoren de mannen minder problematisch dan de vrouwen. Mannen en vrouwen reageren ook verschillend in factoren die een rol spelen bij de verwerking. Het hebben van een religie bijvoorbeeld blijkt bij de mannen een veel groter negatief effect te hebben dan bij de vrouwen (hoofdstuk 5) [18].

Naast de hierboven al genoemde verschillen in de verwerking van mannen en vrouwen, bleek in het retrospectief onderzoek dat beide partners zelden of nooit tegelijkertijd een pathologische score hadden op de vijf onderzochte uitkomsten van rouw, posttraumatische symptomen, angst, depressie en lichamelijke klachten (zie figuur 1 en 2 van hoofdstuk.4) [22]. Terwijl ook in dit lange termijn onderzoek de mannen een minder problematische verwerking vertoonden dan de vrouwen, gaf toch acht procent van de mannen aan nog erg veel moeite te hebben met de zwangerschapbeëindiging van destijds.

De tevredenheid over de begeleiding en de voorlichting van de hulpverleners was over het geheel genomen groot (o.a. hoofdstuk 9) [16]. Maar de ouders misten goede voorlichting over de periode nadien en 23 procent van de vrouwen geven aan dat zij meer nazorg van het ziekenhuis hadden willen hebben. Zevenentwintig tot 40 procent van de vrouwen blijkt psychologische hulp te hebben gehad (hoofdstuk 5 en 9) [16, 18] .



Figuur 1. Percentage vrouwen met posttraumatische stress symptomen boven de grenswaarde van pathologie (Impact of Event Scale (IES). Grenswaarde voor pathologie: ≥ 26, * E. Olde (2006)[25], ** IES-R omgerekend naar IES.

In de bovenstaande figuur wordt het percentage vrouwen weergegeven die voor posttraumatische stress symptomen een score hadden boven de grens voor pathologie, gemeten in drie verschillende onderzoeken.

Er is hiervoor gebruik gemaakt van de Schokverwerking lijst (Impact of Event Scale (IES) die wereldwijd een van de meest gebruikte instrumenten is voor het vaststellen van de gevolgen van traumatische gebeurtenissen [23, 24]. Met de uitkomsten van de IES kan men geen diagnose van de aandoening posttraumatische stress stoornis (PTSD) stellen. Wel is bekend, dat ongeveer de helft van de mensen die boven de grenswaarde scoren, ook werkelijk lijden aan een posttraumatische stress stoornis volgens de criteria die gelden voor PTSD (DSM-IV).

- In de eerste kolom is ter vergelijking het onderzoeksresultaat opgenomen van vrouwen die een paar maanden tevoren een normale bevalling hadden doorgemaakt en dezelfde IES vragenlijst hadden ingevuld. In deze groep was het percentage dat scoorde boven de voor deze vragenlijst algemeen aangehouden grenswaarde logischerwijs, in vergelijking met de vrouwen na een zwangerschapsafbreking aanzienlijk lager (4%) [25].
- De drie middelste kolommen geven het resultaat aan van de metingen bij vrouwen die 4, 8 en 15 maanden na het afbreken van hun zwangerschap de lijst invulden. In deze groep blijkt na 4 maanden ruim 40 procent van de vrouwen boven de grenswaarde te scoren. Dit betekent overigens niet dat deze vrouwen abnormaal reageerden, het is meer een illustratie van hoe ingrijpend deze gebeurtenis is en dat het in feite heel gewoon is wanneer vrouwen in deze periode nog forse problemen

hebben. In de daaropvolgende metingen nemen de percentages significant af. Toch blijkt zestien maanden na de zwangerschapsafbreking nog 19 procent van de vrouwen een score van boven de grenswaarde voor posttraumatische stress symptomen te hebben. Van de groep vrouwen die bij de eerste meting een hoge uitslag hadden bleek dat eenderde van hen ook in de laatste meting nog boven de grenswaarde scoorde (hoofdstuk 6). Een problematische verwerking in de eerste periode blijkt daarmee een van de belangrijkste voorspellers voor latere problematiek te zijn, zoals ook beschreven wordt in een recent overzichtsartikel over algemene rouwverwerking van Stroebe e.a. [2].

- De laatste kolom geeft het percentage aan van vrouwen die 2 tot 7 jaar voor de meting een afbreking hadden meegemaakt. Het percentage boven de grenswaarde voor pathologie was niet veel lager dan in de laatste meting na anderhalf jaar en dit cijfer bleek stabiel te zijn, ongeacht hoeveel jaar het geleden was dat de afbreking had plaatsgevonden (hoofdstuk 3) [4].

Een bijzondere uitkomst door het hele onderzoek heen was dat ouders een zwangerschapsafbreking voornamelijk als een traumatische gebeurtenis ervaren en niet zozeer als een verlies. Wanneer we kijken naar de uitkomsten van specifieke rouwmetingen in plaats van naar posttraumatische stress symptomen, blijkt dat zowel vrouwen als mannen bij de vragen over rouw nauwelijks boven de grenswaarden scoren (hoofdstuk 3, figuur 1 en hoofdstuk 5) [4, 18].

6.2 Hulpverleners

De hulpverlening bij het afbreken van de zwangerschap op grond van ernstige afwijkingen van het ongeboren kind, is zoals gezegd, een multidisciplinaire aangelegenheid. Dit betekent dat overdracht en communicatie tussen de verschillende echelons van groot belang zijn. Een van de eerste voorwaarden van de hulpverlening is dat de ouders een contactpersoon hebben waarop zij terug kunnen vallen, zonodig ook nog jaren later. Veel hulpverleners hebben geen ervaring in rouwbegeleiding op dit speciale gebied. In Nederland bestaat tot dusver geen patiëntenvereniging, in tegenstelling tot bijvoorbeeld Schotland en Engeland waar de stichtingen SAFTA en CARE inmiddels gerenommeerd zijn. In ons land gebeurt opvang en nazorg incidenteel in de academische ziekenhuizen, bij de Klinisch Genetische Centra en bij FIOM-instellingen. Wel is er inmiddels een goed lopende internet zelfhulpgroep (zie eind van dit hoofdstuk). Dertig procent van de vrouwen met een afbreking vanwege een diagnose van Down Syndroom gaven aan dat zij behoefte hadden aan gesprekken met lotgenoten, maar slechts 1 procent van hen bleek zo’n contact te hebben gehad (hoofdstuk 9) [16].

De duur van de verwerking blijkt bij het grootste deel van de ouders een half tot anderhalf jaar in beslag te nemen. Veel ouders zijn hier niet op voorbereid en ook de omgeving vindt vaak dat na enkele weken de grootste problemen wel over moeten zijn. Het is onze ervaring dat het zinvol is ouders te waarschuwen voor een mogelijk lange duur van verwerking. Vooral vrouwen zullen zich dan minder onzeker of abnormaal voelen als zij niet aan het verwachtingspatroon van de omgeving voldoen. De moeilijkste periode lijkt drie tot vijf maanden na de ingreep te zijn. De medische begeleiding is dan inmiddels afgerond en professionele hulp voor (rouw)begeleiding wordt meestal niet spontaan aangeboden. De vrouw zal zich relatief vaak richten op een nieuwe zwangerschap als het belangrijkste hulpmiddel tegen depressieve gevoelens. Er zijn aanwijzingen dat het binnen niet al te lange tijd opnieuw zwanger worden inderdaad helpt bij de verwerking. Hulpverleners moeten er op bedacht zijn dat met name rondom de geboorte van een volgend kind, deze gebeurtenis en alle gevoelens daaromheen weer in volle hevigheid in de gedachten terug zullen komen. Dit is iets wat de ouders vaak niet verwachten en waar ze zich schuldig over kunnen voelen omdat dit het genieten van hun pasgeborene in de weg staat.

Naast de psychologische uitkomsten hebben we gezocht naar risicofactoren voor een problematische verwerking. Een aantal hiervan zijn al besproken, enkele worden nog verder uitgewerkt.

De mate van steun die door de partner wordt gegeven blijkt van groot belang voor een goede verwerking. Hulpverleners moeten zich bewust zijn van de vaak vooral vrouwgerichte benadering. Enkele mannen gaven aan dat zij zich buitengesloten hadden gevoeld. Het is belangrijk de gesprekken zoveel mogelijk met beide ouders samen te voeren, ook al geeft juist de man soms aan geen behoefte te hebben aan enige vorm van begeleiding. Voorlichting over de periode na de afbreking en de mogelijk lange duur van de rouw, over het bestaan van professioneel begeleide lotgenoten groepen en (internet) zelfhulpgroepen kan mensen helpen. Daarbij kan ook het normale verschil in rouwverwerking tussen partners inzichtelijk gemaakt worden: vaak wordt het zich groot houden van een van beiden door de ander uitgelegd als een vorm van onverschilligheid.

De duur van de zwangerschap blijkt van invloed te zijn op de verwerking: een verder gevorderde zwangerschap geeft meer kans op een problematische verwerking. Deze uitkomst was echter minder uitgesproken dan wij als onderzoekers verwacht hadden en dan wat uit de gesprekken bij het eerste onderzoek naar voren leek te komen.

Een belangrijke predictor voor goede verwerking blijkt de persoonlijkheidsfactor ‘zelfredzaamheid’ te zijn. In het longitudinale onderzoek hebben wij in alle drie keren dat de ouders de vragenlijst invulden een aantal vragen gesteld over deze eigenschap. Anders gezegd: over hoe iemand zelf denkt om te kunnen gaan met problemen. De uitkomsten van deze lijst bleken in de loop van de tijd bij de deelnemers niet te veranderen De mate van zelfredzaamheid blijkt een belangrijke voorspeller te zijn voor een goede of juist problematische verwerking (Hoofdstuk 5) [18].

Een vraag bij dit alles is in hoeverre het aanbieden van psychologische hulp is geïndiceerd.

In onderzoek naar rouw en verwerking van traumatische gebeurtenissen is tot dusver nog nooit een positief effect aangetoond van routinematige verwijzing voor psychologische ondersteuning [2, 3]. De verklaring hiervoor wordt gezocht in het feit dat mensen een sterk herstellend vermogen hebben en dat mogelijk een dergelijk verwijzingsbeleid daar afbreuk aan kan doen. Mensen met een duidelijk verhoogd risico en vooral mensen die zelf om hulp vragen blijken wel baat te hebben bij deze hulp. Daarom is het in ieder geval belangrijk dat alle ouders geïnformeerd worden over het beschikbaar zijn van deze hulp. Wat in ons onderzoek duidelijk wordt is dat de ouders de mogelijkheid van psychologische ondersteuning zeer waarderen.

In het voorafgaande hebben wij twee keer een advies voor verwijzing gegeven: wanneer ouders erg veel twijfels hebben bij het maken van de keuze om de zwangerschap te continueren of te laten afbreken en wanneer in de eerste periode na de afbreking de verwerking erg problematisch blijkt te zijn. Het lijkt het meest zinnig om ouders in te lichten over het met name in de eerste maanden vaak moeizame verwerkingsproces en over het feit dat een aantal ouders langdurige problemen hiervan kan ondervinden. Maar tegelijk kan worden benadrukt dat het merendeel deze gebeurtenis goed en op eigen kracht blijkt te verwerken. Een lage drempel voor het maken van een tussendoor / extra afspraak bij problemen is belangrijk, om zonodig vroegtijdige verwijzing voor psychologische hulp te kunnen aanbieden.

7. TEN SLOTTE

In deze bijdrage hebben wij getracht inzicht te geven in de specifieke problematiek die een niet gewild maar toch zelfgekozen verlies met zich mee brengt. Daarnaast hebben we aandacht geschonken aan anticiperende rouwbegeleiding door de klinische begeleiders. Het verwerken van en rouwen om een zwangerschap die vanwege afwijkingen afgebroken is, blijkt een ongrijpbaar en haast verboden verdriet te zijn. Onze uitkomsten laten echter zien dat uiteindelijk het overgrote deel van de ouders (80 – 90%) de zwangerschapsafbreking goed verwerkt.

Een paar weken moet je voor god spelen.
Jij beslist over leven en dood.
Over een kind dat je zo graag hebt gewild.
Over een kind waarvan je te veel,
maar ook te weinig weet.
Over een kind dat je wilt beschermen tegen de
boze buitenwereld, die je ineens zelf bent.

Janny Ruardi en Jan-Willem Vos

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Dankwoord

DANKWOORD

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De onderzoeksbegeleidingscommissie: Prof. dr. N.J. Leschot, Mw. dr. H. Van den Boer-van den Berg, Mw. M.G. de Boer, Prof. dr. F.A. Beemer en Prof. dr. J.G. Nijhuis. De uit zo verschillende richtingen komende kennis was een bron van wijsheid en soms een corrigerend geweten. Waarvoor mijn grote dank.

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Maar Klaas
mijn lief
niet hier

je Marg.

Curriculum vitae

CURRICULUM VITAE

1942	Geboren in Hengelo (O)
1955 - 1961	Gymnasium alpha, Catharina Lyceum Eindhoven
1961 - 1964	Opleiding tot verloskundige in Heerlen, Vroedvrouwenschool, St. Elisabeth Ziekenhuis, Heerlen. Opleider Dr. R. Omers
1964 - 1965	Klinisch verloskundige in Maternité Clinique Dr. Bohler, Luxemburg-stad, Luxemburg
1965 - 1967	Studie Wijsbegeerte aan de Universiteit Utrecht
1965 tot 2005	Klinisch verloskundige in het Universitair Medisch Centrum Utrecht (voorheen AZU)
1980 - 1988	Onderzoek naar de betrouwbaarheid van echografie bij de diagnostiek van neuraalbuisdefecten in de vroege zwangerschap Begeleider: Prof. dr. H.W. Bruinse
1982	Opleidingen echoscopie neuraalbuisdefecten in Schotland, (Prof. dr. Christi) en in het Kings College Hospital Londen (Prof. dr. Campbell)
1989 - 1998	Onderzoek / patiëntenbegeleiding na zwangerschapsbeëindiging op genetische indicatie, onder leiding van Prof. dr. J. Bergsma, psycholoog
1997 - 1999	Onderzoeksvoorstel en subsidieaanvraag promotieonderzoek
2005 - 2006	Afronding promotie onderzoek

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