

# 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<sup>1</sup>, 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<sup>2,3</sup>. For the Netherlands, Leschot<sup>4</sup>, and Thomassen-Brepols<sup>5</sup> 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<sup>6</sup>. 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	XXY	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	XXY	5	15	PG iv	sw
36	family history	US	left ventricle hypoplasia	5	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 =  $\alpha$ -fetoprotein

US = Ultrasonography

MD = muscular dystrophy

PG = Prostaglandin;

sw = Social worker;

AC = Amniocentesis

D&amp;C = Dilatation and curettage;

mw 1 = Midwife 1;

CVS = Chorionic villus sampling;

D&amp;E = Dilatation and Extraction;

mw 2 = Midwife 2;

tc = Transcervical;

iv = intravaginal

ta = Transabdominal;

*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.

*Dependency 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 3<sup>rd</sup> and 4<sup>th</sup> 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<sup>2-5, 7-9</sup>. 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<sup>10</sup> 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<sup>11,12</sup>.
- 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<sup>7,8,10,13</sup>.
- 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<sup>3,7</sup>. 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<sup>2,13,14</sup>. 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<sup>7,15</sup>, the time-lapse in our study is relatively long (mean 4.7 days). Adler and Kushnick<sup>16</sup> 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<sup>14</sup> 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<sup>7,11,12</sup>. 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<sup>3,17</sup>. 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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