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 <sup>1-4</sup>. 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 <sup>1, 2, 4-11</sup>. 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 <sup>12, 13</sup>. 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 <sup>14</sup>. Symptoms of posttraumatic stress (PTS) were measured by the Impact of Event Scale (IES) <sup>15, 16</sup>. 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 <sup>17, 18</sup>. 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 <sup>19, 20</sup>. Indicative of pathologic outcome were the following cut-off points: ICG:  $\geq$  90 <sup>14</sup>, <sup>21</sup>; IES:  $\geq$  26 <sup>3, 16</sup>; SCL-90: women  $\geq$  204, men  $\geq$  170 (95<sup>th</sup> percentile), EPDS  $\geq$  12. We used the Generalized Self Efficacy Scale (SES)<sup>22</sup>, 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

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

<sup>\*</sup> 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 1 women	level	Cut-off level Scores in women women men N = 217	Scores in men N = 169	Female-male Pathology Pathology Fisher difference <sup>1</sup> women <sup>2</sup> men <sup>2</sup> test	Pathology Pathol women <sup>2</sup>	Pathology men <sup>2</sup>	Fisher
Grief (ICG)	06 06 ≥	06	59.0 (20.4); 29-109	59.0 (20.4); 29-109 47.8 (16.6); 29-114	p <.0001	%2.6	2.4%	p <.005
Posttraumatic Stress Sympt. (IES) ≥ 26	> 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) $\geq 204$ 170 145.6 (53.1); 90-361 121.5 (36.6); 90-268 p <.0001	> 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	12	8.4 (5.6); 0-25	5.5 (5.2); 0-20	p <.0001	28.2%	15.8%	p <.005

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

<sup>2</sup> 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.  $TOP = termination \ of \ pregnancy. \ Empty \ cells \ indicate \ a \ correlation \ with \ p > 0.05.$ 

		rief CG)	Symp	. Stress otoms ES)	Malf	Psych. unct. (290)	Depr	Partum ession (DS)
Predictor	Ŷ	ð	Ŷ	đ	Ŷ	ð	Ŷ	3
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
Gestational age	.21 .002	.29 .0001	.16 .019			.27 .0001		
TOP procedure (D&E=1, med ind=2)		.23				.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				.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	.27 .0001	.21	.30 .0001	.22	.32	.24	.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	Posttr. Stress	Gen. Psych.	Post Partum
	(ICG)	Symptoms (IES)	Malfunct. (SCL-90)	Depression (EPDS)
Variable	$\beta$ (SE)	$\beta$ (SE)	$\beta$ (SE)	$\beta$ (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 <sup>2</sup> 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 <sup>2</sup>	0.046 ***	0.028 *	0.090 ****	0.085 ****
R <sup>2</sup> on step 2	0.144	0.097	0.114	0.113
Step 3:				
Doubt decision	3.60 (1.07) ***	1.36 (0.85)	7.49 (2.85) **	0.83 (0.30) **
period				
F model	9.39 ****	4.86 ****	7.03 ****	6.77 ****
Change in R <sup>2</sup>	0.047 ***	0.012 N.S.	0.036 **	0.033 **
R <sup>2</sup> on step 3	0.191	0.109	0.150	0.146
Step 4:				
Self-efficacy	-0.81 (0.27) **	-0.36 (0.22)	-2.54 (0.72) ****	-0.29 (0.08) ****
(GSE)				
F model	9.31 ****	4.30 ****	8.13 ****	8.20 ****
Change in R <sup>2</sup>	0.031 **	0.008 N.S.	0.049 ****	0.056 ****
R <sup>2</sup> on step 4	0.222	0.117	0.199	0.202

<sup>\*</sup> 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	Grief	Posttr. Stress	Gen. Psych.	Post Partum
	(ICG)	Symptoms (IES)	Malfunct. (SCL-90)	Depression (EPDS)
Variable	$\beta$ (SE)	$\beta$ (SE)	$\beta$ (SE)	$\beta$ (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 <sup>2</sup> 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 <sup>2</sup>	0.024 *	0.016 #	0.067 ****	0.012 N.S.
R <sup>2</sup> on step 2	0.168	0.102	0.191	0.089
Step 3:				
Doubt decision	2.69 (1.01) **	2.68 (0.79) ***	7.27 (2.19) ***	0.46 (0.34)
period				
F model	8.75 ****	6.23 ****	10.39 ****	3.38 **
Change in R <sup>2</sup>	0.051 **	0.065 ***	0.060 **	0.010 N.S.
R <sup>2</sup> on step 3	0.219	0.167	0.251	0.099
Step 4:				
Self-efficacy	-0.72 (0.24) **	-0.26 (0.19)	-1.64 (0.53) **	-0.32 (0.08) ****
(GSE)				
F model	9.04 ****	5.52 ****	10.70 ****	5.66 ****
Change in R <sup>2</sup>	0.041 **	0.010 N.S.	0.045 **	0.084 ****
R <sup>2</sup> on step 4	0.260	0.177	0.296	0.183

<sup>\*</sup> 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 <sup>12, 13, 23</sup>. 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 <sup>3</sup>. 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 <sup>6,7</sup>. By way of comparison, three months after a normal delivery, pathologic PTS symptoms (IES, >26) were only found in four percent of the mothers <sup>24</sup>. 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 <sup>2</sup> 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 <sup>6</sup>. 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 <sup>8</sup>.

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 <sup>25</sup>.

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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