

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 take³. 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 questionnaire⁹ 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.

Predictor	Dependent variable												
	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)													
Gestational age (week)	0.142 *							0.143 *	0.201 **			0.154 *	
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
<i>Step 1: predictors</i>										
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	
<i>Step 2: partner support</i>										
F model	-5.91 ***	1.80	-4.47 *	2.11	-0.78	0.91	-1.75 *	0.82	-1.95 **	0.69
R ² on step 2	4.36 ****		4.03 ****		2.45 *		3.44 **		4.98 ****	
	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 R² 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
<i>Step 1: predictors</i>								
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	
<i>Step 2: partner support</i>								
F model	-1.12	0.81	-1.41 #	0.79	-4.22 **	1.34	-0.43	0.38
R ² on step 2	1.52		1.57		3.54 ***		**	
Change in R ² ¶	0.058		0.060		0.125		0.107	
	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 R² on steps 1 and 2, and the significance of F-change.

† logistic regression.

They also experienced feelings of doubt ($\chi^2 = 17.5$, $df = 1$, $p < 0.0001$) and regret ($\chi^2 = 17.7$, $df = 1$, $p < 0.0001$) 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).

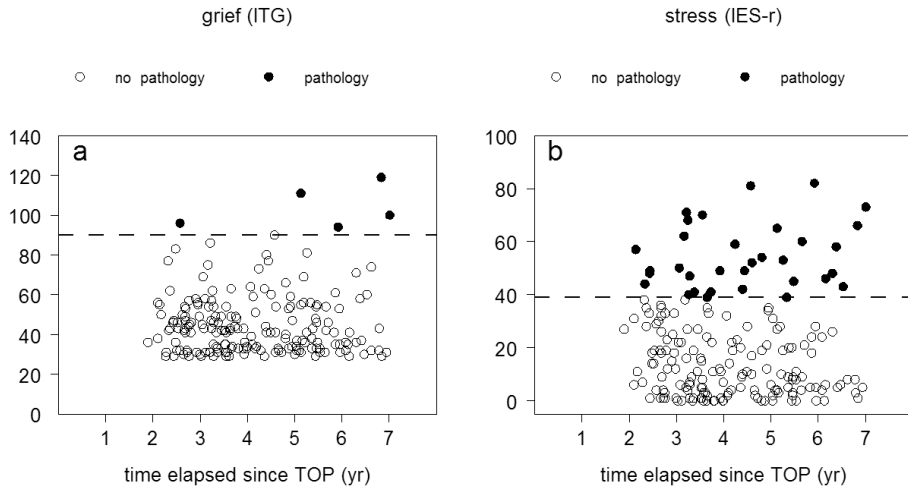


Figure 1. Levels of grief (a) and posttraumatic stress symptoms (b) in relation to the time interval since TOP. Dotted lines represent established cut-off levels (90 and 39, respectively).

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; $p = 0.041$).

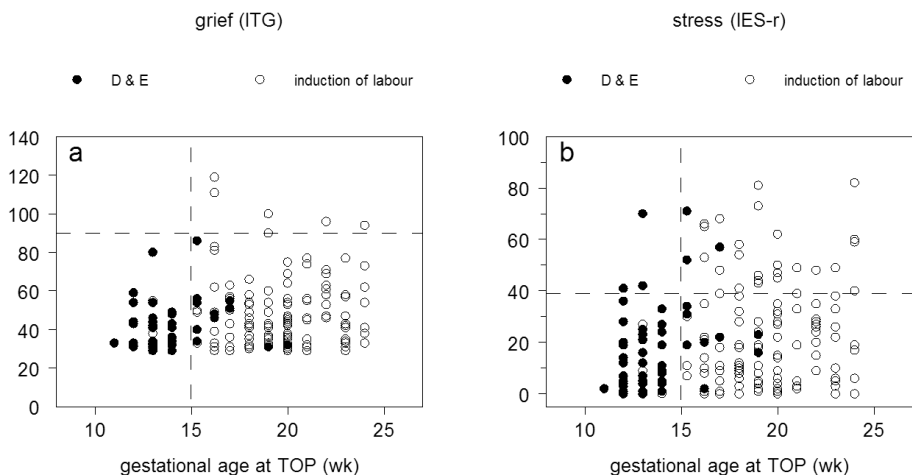


Figure 2. Levels of grief (a) and posttraumatic stress symptoms (b) in relation to the gestational age at TOP in women whose pregnancies were terminated by dilatation and evacuation (D&E) or induction of labour. Horizontal dotted lines represent established cut-off levels (90 and 39, respectively). Vertical 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 morbidity¹⁷⁻¹⁹. 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 consistent²⁷. 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}. Hunfeld²⁰ 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 delivery³⁰.

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 education³¹. In one study of normal pregnancies more adequate use of coping mechanisms was found in women with a high level of education³². 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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