

# 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<sup>1-14</sup>. 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<sup>15,16</sup>. Symptoms of posttraumatic stress (PTS) were measured by the Impact of Event Scale (IES)<sup>17,18</sup>. 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<sup>17</sup>. The Symptom Checklist-90 (SCL-90), was considered to assess the level of generalized psychological malfunctioning<sup>19,20</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 assessing post partum depression<sup>21,22</sup>. The following cut-off points were considered as indicative of pathologic outcome: ICG:  $\geq 90$ <sup>15</sup>, IES:  $\geq 26$ <sup>9,23</sup>; SCL-90:  $\geq 204$  (95<sup>th</sup> percentile); EPDS  $\geq 12$ . We also used the Generalized Self Efficacy Scale (GSE)<sup>24</sup>, 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)<sup>26</sup>. 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 ( $\beta = -0.45$ ,  $n = 18$ ,  $p = 0.013$ ); IES ( $\beta = -0.43$ ,  $n = 22$ ,  $p = 0.002$ ); SCL ( $\beta = -0.16$ ,  $n = 21$ ,  $p = 0.056$ ); and EPDS ( $\beta = -0.18$ ,  $n = 29$ ,  $p = 0.023$ ), 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
<i>Psychological measures</i>	
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 ( $\pm$  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

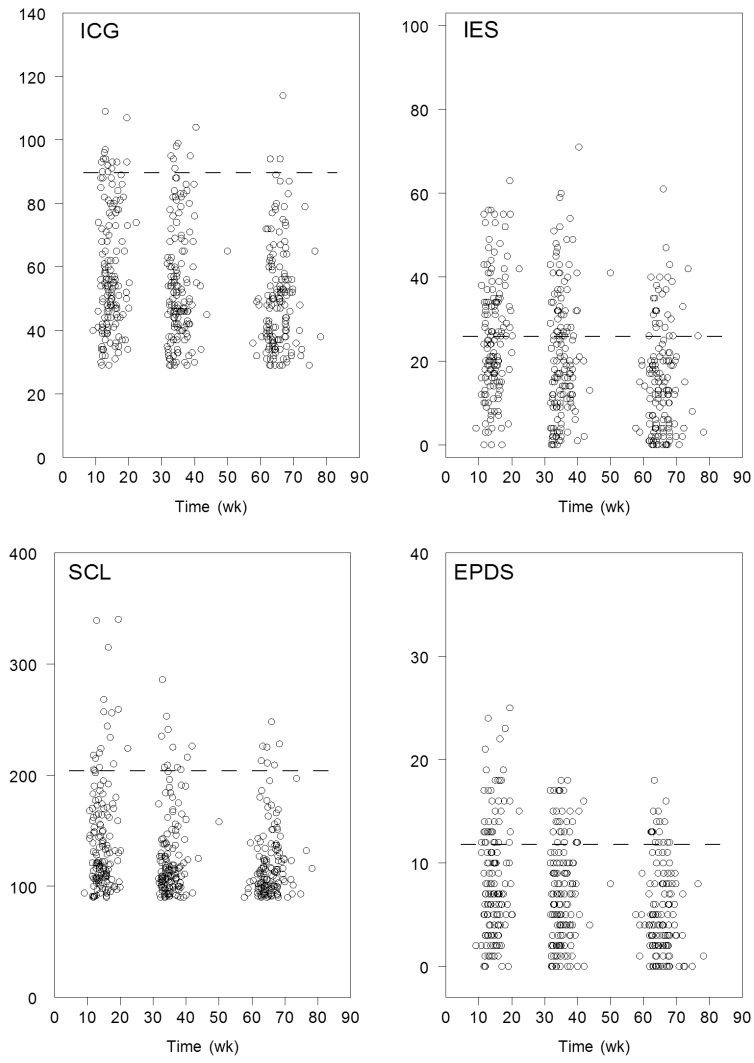
¶ : compared with reference category 2 ('moderate-poor' and 'not at all' combined); # : compared with reference category 3 ('not at all').

**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.

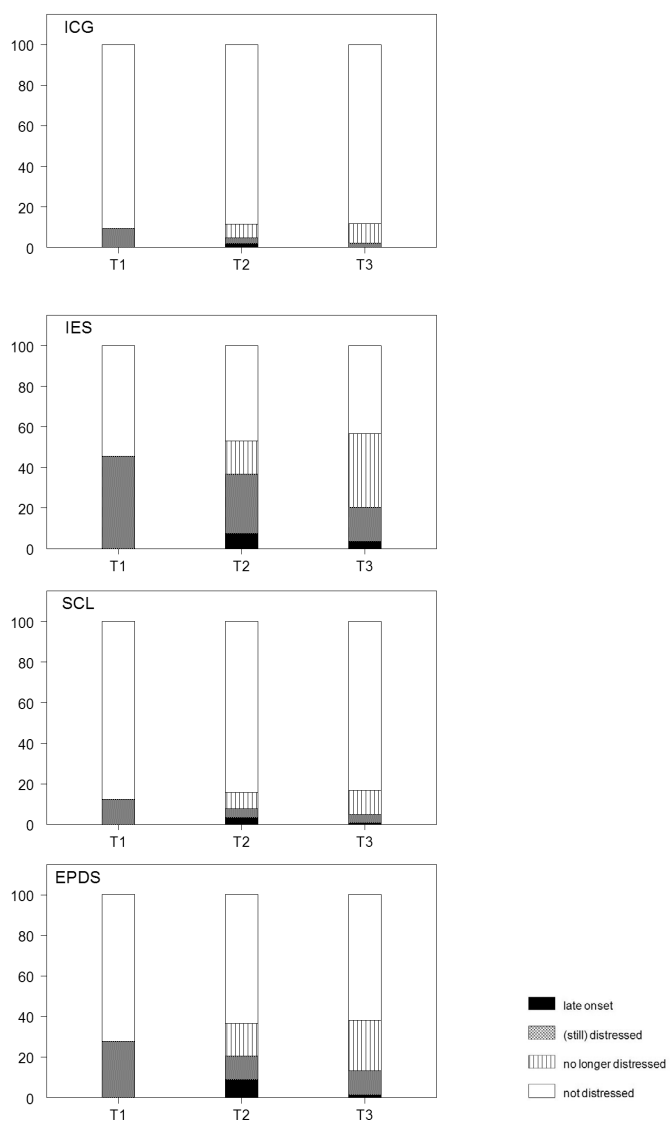
Pathology	Grief (ICG)	Posttraumatic stress symptoms (IES)	Psychological malfunctioning (SCL)	Depression (EPDS)
Cut-off level	≥ 90	≥ 26	≥ 204	≥ 12
T1	n = 14; 9.5%	n = 67; 45.6%	n = 18; 12.2%	n = 41; 27.9%
T1, T3, not T2	n = 3; 21.4%	n = 24; 35.8%	n = 6; 33.3%	n = 13; 31.7%
T1, T2, and T3	n = 2; 14.3%	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) (n = 21 vs 23)	Posttraumatic stress symptoms (IES) (n = 17 vs 18)	Psychological malfunctioning (SCL) (n = 17 vs 17)	Depression (EPDS) (n = 16 vs 18)
<i>Step 1:</i>				
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 <sup>2</sup> on step 1	0.432	0.403	0.377	0.478
<i>Step 2:</i>				
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 <sup>2</sup> on step 2	0.478	0.425	0.465	0.528
Change in R <sup>2</sup>	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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