# **Adjustment to termination of pregnancy for fetal anomaly: a longitudinal study in women at 4, 8, and 16 months**

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**OBJECTIVE:** We studied psychological outcomes and predictors for adverse outcome in 147 women 4, 8, and 16 months after termination of pregnancy for fetal anomaly.

**STUDY DESIGN:** We conducted a longitudinal study with validated self-completed questionnaires.

**RESULTS:** Four months after termination 46% of women showed pathological levels of posttraumatic stress symptoms, decreasing to 20.5% after 16 months. As to depression, these figures were 28% and 13%, respectively. Late onset of problematic adaptation did not occur frequently. Outcome at 4 months was the most important predictor of

persistent impaired psychological outcome. Other predictors were low self-efficacy, high level of doubt during decision making, lack of partner support, being religious, and advanced gestational age. Strong feelings of regret for the decision were mentioned by 2.7% of women.

**CONCLUSION:** Termination of pregnancy for fetal anomaly has significant psychological consequences for 20% of women up to > 1 year. Only few women mention feelings of regret.

**Key words:** adjustment, fetal anomaly, psychological consequences, termination of pregnancy

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T ermination of pregnancy (TOP) for fetal reasons is a major life event.<sup>1-13</sup> Short-term psychological sequelae include depressive and grief reactions.<sup>14</sup>

There is uncertainty as to which women are at risk for problematic coping in the long run. The current study aims to investigate predictors of persistent problematic outcome that can be

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0002-9378/\$36.00 © 2009 Mosby, Inc. All rights reserved. doi: 10.1016/j.ajog.2009.04.007 identified before and during the first 16 months after TOP, in order to give clinicians instruments to effectively improve care for patients who terminate pregnancy for genetic reasons.

#### MATERIALS AND METHODS

Women undergoing TOP because of fetal anomaly < 24 weeks of gestation were approached by their treating gynecologist at the time of the TOP. In The Netherlands, at the time of the study, TOP up to 14 weeks was usually done with dilatation and evacuation and thereafter by inducing labor with prostaglandins. Three university and 5 nonuniversity Dutch hospitals participated. The study was conducted between January 1999-October 2002. Women were asked permission to be sent a research information letter. In that information letter they were requested to participate in what was called "an extensive anonymous questionnaire study." After written informed consent had been obtained, coded questionnaires were mailed at 4 months (Time 1, T1), 8 months (Time 2, T2), and 16 months (Time 3, T3) after TOP. The ethical committees of the participating hospitals had approved the study design.

The first part of the questionnaire contained questions on sociodemographic, medical, and obstetric history. A second part contained Dutch validated versions of 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 29-145.15,16 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 0-75.17 The Symptom Checklist (SCL)-90 was used 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 postpartum depression.<sup>21,22</sup> The following cutoff points were considered as indicative of pathologic outcome: ICG:  $\geq 90^{15,23}$ ; IES:  $\geq$  $26^{9,24}$ ; and SCL-90:  $\geq 204$  (95th percen-

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## Demographic and obstetric data at inclusion and subsequently where appropriate

Variable	n
Age, y	35.0 (4.4); 19-44
Education, %	
Primary school, high school	15.1
Secondary school	37.7
College or academic	47.2
Religious, %	59.6
Living children before termination, %	62.6
Gestational age at termination, wk	18.0 (3.5); 12-24
Method of termination, %	
Dilatation and evacuation	20.1
Induced labor	79.9
Viability, %	55.6
Down syndrome, %	37.4
Elapsed time termination to inquiry, wk	
T1	14.6 (2.4); 10-22
T2	35.4 (2.7); 32-50
T3	65.5 (3.3); 58-78
New pregnancy since termination, %	
T1	3.4
T2	34.1
T3	56.5

71, 4 mo after termination of pregnancy (TOP); 72, 8 mo after TOP; 73, 16 mo after TOP.

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tile). For the EPDS a cutoff of  $\geq 12$  was used to define high depressive symptomatology.<sup>25,26</sup> In addition we used the Generalized Self-efficacy Scale (GSE), a 10-item measure in a 4-point response format, with a possible total score ranging from 10-40.27 This instrument assesses self-confidence as a personality characteristic, with a high score reflecting that an individual believes that he or she can cope with difficult demands. A critical percentage of completed questions was a prerequisite for the use of the 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 last part of the questionnaire was especially designed for this study and

contained questions about perceived external pressure during the decision period (yes/no); questions about doubt during the decision period and about perceived partner support after TOP (both to be answered on a 5-point scale ranging from 1 [very much]-5 [not at all]); and questions about regret after TOP (to be answered on a 5-point scale ranging from 1 [very applicable]-5 [absolutely not applicable]). For statistical reasons, these categories were later regrouped from 5-3 to form new parameters. The questionnaire had been first tested in a group of 20 couples with a history of TOP for fetal anomaly.

The treating gynecologist was responsible for providing diagnosis and viability assessment. Down syndrome was singled out as a separate entity, because the majority of programs for prenatal screening and diagnosis focus on this disease. All demographic and obstetric variables considered as predictors, either assessed at T1 only once or on each of the 3 occasions, are shown in Table 1. The total scores on the ICG, IES, SCL-90, and EPDS at 4, 8, and 16 months after termination were considered as the outcome measures.

Software (SPSS, for Windows, version 12.01; SPSS, Inc, Chicago, IL) 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, SD, and ranges for continuous variables. Groups were compared for equivalence in baseline characteristics using the  $\chi^2$  test or Fisher exact test, as appropriate, for categorical measures and Student 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.

#### RESULTS

In all, 300 women were invited to participate, and 217 of them completed all questionnaires at T1, a participation rate of 72.3%. The 83 patients who did not participate did not differ from the participants with regard to the viability of the anomaly and the proportion of fetuses with Down syndrome. Subsequently, 178 and 153 women participated at T2 and T3, respectively. Of the 217 women who participated at T1, 147 (68%) women completed the questionnaires on all 3 occasions. The attrition group, ie, women who filled out the questionnaires at T1 but not at T2 and/or T3 (n = 70), differed from full participants (n = 147) in that this group contained more terminations at an early gestational age and more terminations by dilatation and evacuation, but the psychological outcome measures at T1 were similar.

Subject characteristics are presented in Table 1. The women were generally at advanced age, well educated, and all had a

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