Is there pressure from society to terminate pregnancy in case of a fetal anomaly?

Perceived pressure in the decision making

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ABSTRACT

The increasing use of prenatal screening techniques will undoubtedly lead to more terminations of pregnancy for fetal anomalies. In many societies such terminations are at stake and there is doubt whether parents take such decisions autonomously. In two large cohorts of Dutch patients we assessed the patients' perception of pressure experienced during the decision process regarding termination or otherwise. Pressure from society was perceived by approximately 6 percent of the parents. The vast majority of participants (83-92%) had felt no pressure at all. Participants, who indicated to have perceived pressure from others, had more unfavourable psychological outcomes.

INTRODUCTION

Prenatal diagnosis enables couples to terminate pregnancy in case of fetal chromosomal and/or morphological anomalies. The increasing use of prenatal screening will undoubtedly lead to more diagnoses of fetal anomaly and hence more terminations of pregnancy for this reason. The decision to opt for prenatal testing and to terminate pregnancy in case of anomalies should be the decision of the parents only, and pressure is to be avoided. In many societies, terminations are at stake and there is doubt whether parents take decisions autonomously. Termination of pregnancy is a complex decision that may lead to long-term psycho-emotional morbidity ^{1,2}. We could not find any studies (on the effects) of perceived pressure during the process of deciding for termination for fetal anomalies. Therefore, we assessed to what extent and from whom parents perceived pressure, and whether such pressure affected psychological well-being later on.

PARTICIPANTS, METHODS, AND RESULTS

We investigated perceived pressure at decision-making in the context of two large questionnaire studies on psychological sequelae of termination of pregnancy for fetal anomalies. The studies were conducted in three university and five general hospitals in the Netherlands. One study was retrospective, and involved couples who had made the decision to terminate pregnancy 2 to 7 years earlier; the other was a prospective study in couples who were recruited before termination and were assessed on average 4 months after termination. Men and women filled out questionnaires individually. Altogether 79% of the women and 62% of the men participated in the retrospective study and these figures were 74 and 58%, respectively, in the prospective study. The questionnaires were mainly directed at the psychological outcome and factors that helped coping with the loss. Three of the questions addressed explicitly the perceived pressure during the process of decision-making. The results are shown in Table 1. Most participants (83-92%) indicated that they had experienced no pressure during decision-making. Results of the retrospective and prospective studies were concordant. Women who indicated that they had experienced pressure in their decision-making process showed more signs of complicated grief 3 (p = 0.003) and depression 4 (p = 0.005) at follow up. For men these differences were not significant. Moral values of society had played a role for approximately 6 to 7% of women and less for men. These included the belief that handicapped children were not respected enough in society and the fear that society would blame the parent for having a handicapped child. Pressure from religion was rare. Three to 7% of participants had felt pressure from the medical staff. Perceiving pressure from the staff should clearly be differentiated from being influenced during an essentially non-directive counselling process ⁵. We addressed this issue separately. Sixty percent of all parents indicated that their

gynaecologist had had a substantial influence on the decision. The same holds true, to a lesser extent, for other medical professionals. However, it was the partner who had the highest influence on the decision (79-88%).

Table 1. Perceived pressure during decision-making for termination of pregnancy.

	Retrospective study 2-7 years after termination		Prospective study 4 months after termination	
	Women	Men	Women	Men
Number of participants	196	153	217	169
No perceived pressure	83%	92%	86%	89%
Perceived pressure*				
Family / friends	4%	1%	4%	2%
Medical staff	7%	5%	5%	3%
Religious community	1%	1%	1%	1%
Moral values of society	7%	1%	6%	5%

^{*}More than one answer possible

DISCUSSION

The present study shows that in the Netherlands the vast majority of couples that decide to terminate pregnancy because of a fetal anomaly do so on their own account without perceived pressure from society. Pressure at decision-making should be avoided, if only because of the negative association with complicated grief and depression at follow up in these women. The percentage of perceived pressure from medical staff and society found in this study are low (1-7%). We should continue our efforts to keep these figures low through careful wording during consultation with patients, as well as in publications or in media outlets.

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