Chapter 9

Maternal decision to terminate pregnancy in case of Down syndrome

The decisional process in case of Down syndrome

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ABSTRACT

Objective: This study explores decisional processes regarding termination of pregnancy because of Down's syndrome and aims to identify possibilities for improving counseling.

Study design: Seventy one women completed questionnaires four months after termination of pregnancy for Down's syndrome, including motivations for the decision, reasons for doubt, perceived influence and/ or pressure at decision-making and satisfaction with the received healthcare.

Results: Child related motivations to the termination were the most frequently mentioned, but almost all women indicated also motives of self-interest. Twenty-one percent of women reported much doubt. Perceived influence of the medical staff was substantial, but most women felt that they had not been put under pressure. Satisfaction with the caregivers was high.

Conclusion: Women acknowledge that self-centred motives play an important role. Medical caregivers are amongst the most important persons for women who decide to terminate pregnancy because of Down's syndrome.

INTRODUCTION

Improved screening techniques and strategies for identifying fetal anomalies have led to a more widespread use of Down's syndrome (DS) screening and diagnosis, and to an increased number of terminations of pregnancy (TOP) for DS [1]. It has been shown that after a diagnosis of DS 85 to 95% of the women decide to terminate pregnancy [1-4]. Little is known about the process of parental decision-making and available data are either casuistic or based on small numbers [5-8]. Recently, Skotko published the results of a postal questionnaire study in 141 mothers who continued their pregnancy after prenatal diagnosis of DS before 24 weeks of gestation [9]. The aim of that study was to describe the counseling process and to identify points for improvement. It was suggested that similar data on women who decided to terminate pregnancy because of DS would be a welcome addition to the literature (Commentary, AJOG; March 2005, p 3A). We conducted such a study in 71 women to get insight into psychological, social, and moral aspects of this decision and to suggest possibilities for improving health care and counseling

SUBJECTS AND METHODS

The study is part of a longitudinal study in 217 women who had their pregnancy terminated for various fetal anomalies. The current study focuses on 71 women who terminated their pregnancy because their baby had DS without anatomic anomalies incompatible with life having been ascertained. The latter was judged important as decisions to terminate pregnancy may be different in lethal versus non-lethal fetal conditions. Compatibility with extra-uterine survival was assessed by the treating physician. Women were recruited prospectively, from January 1999 to October 2002 just before or during hospital admission for termination of the pregnancy. Eight Dutch hospitals participated and it was always the attending physician who explained the study and requested participation. The ethics committees of all participating hospitals had approved the study design. Four months after termination, the women filled out extensive standardized questionnaires, that had been designed with the help of responses given to open ended questions in a previous study in 40 couples [10] and were tested in a pilot group thereafter.

Variables studied were socio-demographic and medical characteristics, motivations for the decision to terminate, possible reasons for doubt during the decision period, and levels of perceived influence and pressure of the social circle and the medical attendants. We further assessed satisfaction with the medical support before, during and after the procedure, and with the information given. Finally, we investigated possible feelings of regret on the decision and intentions for future pregnancies. The questionnaires included categorical measures (yes/no and 5-point scales) and continuous variables. For the 5-point scales, ranging from 1 (very much) to 5 (not at all), the answers to possibilities 1 and 2 (very much and substantial) were considered as positive outcome and then expressed as a percentage.

SPSS for Windows (version 10.1, SPSS Inc., Chicago, Ill.) was used for data management and statistical analysis. Results were summarized with the use of standard descriptive statistics. Groups were compared using the Chi-square test or Fisher exact test, when appropriate.

RESULTS

Of 104 women who had terminated their pregnancy because of DS, 80 women agreed to participate (77%). Nine women were excluded because of lethality or likely lethality (4 and 5 cases, respectively) caused by additional fetal anomalies. The results are therefore based on data of 71 women. Socio-demographic and obstetric characteristics of the participants are given in Table 1. All partners were male and two women were single. The study group was highly educated and at relatively advanced age. The latter is due to the policy in the Netherlands at the time of this study: serum or ultrasound screening for DS was not routinely offered to pregnant women. Therefore, maternal age > 36 years was the main indication for invasive prenatal diagnosis.. The distribution of 76% induced labor, versus 21% dilatation and evacuation is due to the fact that terminations beyond 14 weeks of gestation were usually done by induction of labor. All but two of the respondents described their pregnancy as a formerly wanted (from the beginning (77%), accepted and welcome (20%)) pregnancy.

Table 1. Obstetric and socio-demographic characteristics of the participants. Data are presented percentage or as mean, SD, and range.

Number	71
Age at TOP* (yr)	37.9 (3.0); 30-44
Education (%)	
Low	14.3
Medium	38.6
High	47.1
Religion (yes; %)	55.7
Gestational age (wk)	17.9 (3.2); 12-24
Method of diagnosis (%)	
Chorionic villus sampling	36
Amniocentesis	64
Method of termination (%)	
Dilatation and evacuation	21.1
Induction of labor	76.1
Selective reduction	2.8
Prior elevated risk total (%)	83.1
maternal age	77.5
genetic / other	5.6
No prior elevated risk: screening or accidental	16.9
Children at TOP (yes; %)	74.6

*TOP: termination of pregnancy

Table 2 addresses motivations to terminate pregnancy. Women indicated to what extent various motivations had played a role in their decision towards termination. In the questionnaire, the questions referring to the various motivations were listed randomly. Afterwards, we grouped them into two categories: 1) motivations relating to the unborn child's interest, 2) motivations relating to the woman's own interest, the relationship with her partner, or the interest of other children. Child related motivations scored highest: 45 to 92% of the women recognized themselves in one or more statements. All women had filled in at least one child-related motivation. Concern for the welfare of the other children in the family was named by 73 % of respondents. Statements related to self concern or concern about the partner were recognized as applicable by 6 to 64 % of women, issues about burden scoring highest, issues about finances or societal blame scoring lowest. All but one of the women had filled in at least one self- or family-related motivation

Table 2. Motivations for termination of pregnancy. Presented are the percentages of the 71 women who agreed (very much – substantially) to the statements in two categories (more than one answer possible).

Related to the infant	**%**
The child would never be able to function independently	92
I considered the anomaly too severe	90
I considered the burden for the child itself too heavy	83
I worried about the care of the child after my/ our death	82
I considered the uncertainty about the consequences of the anomaly to high	78
I thought the respect for handicapped children in our society is too low	45
Related to the respondent/family	**%**
I considered the burden too heavy for my other child(ren)	73
I considered the burden too heavy for myself	64
I did not want a handicapped child	63
I thought I would be unhappy of having this child	61
I considered the burden too heavy for my relationship	55
I was afraid of regretting afterwards if I would have this child	45
I thought it would obstruct my career too much	23
I would feel imperfect (lower self esteem) having a handicapped child	11
I acquiesced in the wish of my partner to terminate the pregnancy	11
I considered the financial burden too high	6
I was afraid to be blamed for continuing the pregnancy of a handicapped child	6

Levels of doubt during the decision process to terminate or to continue pregnancy were also assessed with a 5-point scale. Thirty-five percent of the responding women indicated that they did had had no doubt at all in taking the decision to terminate, whereas twenty one percent indicated to have experienced high levels of doubt (very much or substantial). The latter group had a more advanced gestational age ($p < 0.05$) and showed more feelings of regret ($p < 0.05$) four months after TOP than

women with no doubt at all. In Table 3 the various reasons for these feelings of doubt are described, listed in order of occurrence. The most frequent reasons were conflict between reason and emotion, guilt about ending their child's life, and disagreement with the partner. Four women (6%) indicated to have current feelings of regret about the termination. Three of these only experienced this occasionally and one really regretted her decision.

Table 3. Reasons for doubt at the decision to terminate the pregnancy. Presented are the percentages of women who agreed (very much – substantially) with the statements. (more than one answer possible)

	%
My reason was in conflict with my feelings	49
I had the feeling of killing a child	43
My partner and I disagreed	38
The severity of the anomaly was uncertain	14
The consequences were incalculable for me	14
I felt cached off guard	13
It conflicted with my religion	7
My knowledge of the anomaly was insufficient	6
I was afraid of the procedure/ complications of the termination	6
I had doubt about the diagnosis	3

Perceived influences from the various contacts during the decisional process are shown in Table 4. The partner, gynecologist, family/ friends and geneticist where contacted most frequently. The perceived influence during the period of decision-making was highest for the partner (74%) and ranged between 18 and 45 % (from low to high) for primary health care providers, medical specialists and social workers, family/friends and religious counselors. Separately we asked the women whether they had perceived pressure during the decision process. Altogether 9 of the 71 responders (13%) felt they had experienced any pressure. The perceived pressure had its origin in 'values of society' (n = 6), religious society (n = 3), family or friends (n = 2), and medical staff (n = 1) (more than one answer was possible). Furthermore, thirty percent of all women indicated that they had to defend their decision to other persons.

Table 5 shows the percentage of women who had contacted various groups of health care providers before, during, and in the months after TOP, and in case of contact, the proportion of women who evaluated the quality of this contact as 'very much' or 'substantially' satisfying. Gynecologists, geneticists, nursing staff, and social workers were judged most positively by participants. Additionally, women's satisfaction with the kind of information given in the successive stages of the process was assessed. The information given about the procedure of prenatal testing was felt as satisfying by 91% of responders, about the diagnosis of DS by 89%, and about the procedure of the TOP by 83%. The information regarding the period after TOP scored

lowest (68%). The counselors in 66% of cases addressed the possibility of continuing pregnancy. Women, who indicated that the option of continuation of pregnancy was not raised, appeared to be the ones who had reported less doubt during the decision process, as compared to the ones who indicated that both options were discussed ($p = .002$). Eighty-nine percent of women indicated to have received information about the possibility of professional psychological help and 40% had actually made use of this possibility. Thirty percent of the women stated that they would have appreciated to have had contacts with other parents with a DS diagnosis, but only one of them really had had such a contact. Eight percent of the women indicated that they did not dare to embark on a new pregnancy for fear of recurrence.

Table 4. Perceived influences from external contacts on the decisional process. Presented are the percentages of women who had contacted the various groups or persons in the decisional period and, in case of contact, the percentages of women who judged the influence of these persons on their decision as 'very much' or 'substantial.

	% contacted	**% that perceived influence as 'very much' or 'substantial'**
Partner	97	74
Gynecologist	97	33
Family /friends	84	37
Geneticist	70	42
Social worker	51	37
Family doctor	46	25
Midwife	40	18
Other persons with comparable experience	25	25
Religious counselor	16	45

Table 5. Satisfaction with the support of caregivers before, during and in the four months after TOP. Presented are the percentages of women who had contact with specific caregivers and, in case of contact, the proportion of women who evaluated the quality of this contact as 'very much' or 'substantially' satisfying.

	Contacted %	**Satisfied %**
Gynecologist	99	88
Nursing staff	97	88
Family doctor	80	74
Geneticist	68	88
Midwife	62	71
Social worker	59	88
Religious counselor	28	58

DISCUSSION

Termination of a wanted pregnancy following an adverse diagnosis in the unborn child is a major life event [11-14]. Grief for the – self chosen- child loss is often associated with conflicting feelings of relief, guilt, doubt, loss of self esteem, and moral bewilderment [6, 10, 14-17]. In the current study, we focused on aspects of the decision to TOP in 71 prospectively recruited women whose fetus has been diagnosed with DS.

Four months after termination, child related motivations to terminate pregnancy were predominant, but self and family related motivations played an important role too. Doubt about the decision to terminate was mainly related to the conflict between reason and emotion, feelings of guilt about ending a life, and disagreement with the partner. There were high levels of satisfaction with the information received about the procedure of prenatal testing and the implications of a child with DS. The decisional process was influenced most by the partner and much less by (health) caregivers or family and friends. Because being influenced should be clearly differentiated from the feeling of pressure during an essentially non-directive counseling process (Clarke, 1997), we addressed the latter item separately. Pressure (as a negative connotation of influence) was felt by a low percentage of women, with 'values of society' as the most frequent origin (8%) and pressure by medical staff in only one of the 71 women. In a retrospective study and in our total prospective cohort 'pressure' was felt by 17 and 14% of women, respectively [18]. Others found a percentage of sixteen percent[19]. Satisfaction with the support by the most intimately involved caregivers was high.

Skotko (2005) performed a unique questionnaire study in the United States, 0 - > 20 years (mean 4.4 years) after the prenatal diagnosis of DS in 141 women who had decided to continue their pregnancy [9]. Although satisfied with the care, the majority of respondents expressed frustration with the information and counseling process: test results of diagnosis had not always been conveyed in person, there was a perceived lack of information on DS, and a lack of referral to DS support groups. The women of our cohort were generally more positive about counseling and support, which might be due to the fact that both gynecologists and geneticists are more familiar with TOP in case of DS than with a continuation of the pregnancy. It may also be due to the fact that our study concerned more recent data. Also Skotko found a higher satisfaction among women who had more recent experiences The latter study covers a long period from 1982 till 2002 whilst our study was restricted to terminations between 1999 and 2002. In our population the given information regarding the period after TOP was considered suboptimal. This also parallels Skotko's findings and is clearly a challenge for improvement of care.

The following findings from our study may have implications for clinical practice.

1) In the decisional process the partner has a key role: his reported influence on the decision appeared to be by far the most important one. In motivations relating to TOP more than 50% of women mentioned fear of (too) heavy burden on their relationship. Disagreement with the partner was mentioned as a reason for doubt by 38% of the women, and 11% of them indicated to have acquiesced in

their partners wish to terminate. Therefore, it is essential to involve always both partners in the counseling.

2) The responses women gave concerning causes of doubt demonstrate the complex and conflicting aspects of the decision. The percentage of women with high or considerable level of doubt in the decision period was relatively large (21%). Data on this subject is lacking in literature. It may well be that this group is extra vulnerable to maladjustment. Caregivers should be attentive to this phenomenon and should offer psychological assistance in case of difficulties in decision-making.

3) It is standard practice of non-directive approach always equally to discuss both options of continuing and termination the pregnancy in counseling of fetal anomaly In the current study only 66% of women indicated that they had been counseled regarding both options. This does not seem correct, but is likely to reflect the clear decision to terminate pregnancy in part of the women. We found a strong association between the assertion of the women that this option to continue pregnancy had not been discussed and their lack of doubt at decision-making ($p = .002$). One may wonder if the option to continue pregnancy in women with no doubt at all should be discussed as thoroughly as in the other women.

4) In the literature on decisional processes following adverse prenatal diagnosis, the level of uncertainty about the precise manifestation of the disorder in the child is an important determinant [3, 19]. Especially DS is characterized by a large diversity of expression which cannot be ascertained prenatally. Although only 14% of the interviewed women mentioned uncertainty as a cause of doubt, addressing this issue explicitly and discussing the questions in detail might contribute to better coping.

5) Our results as well as those of Skotko show that support groups or contact with other parents in similar situations is an underused and maybe undervalued way of helping those clients.

6) Almost all women stated that self-interest had played a role in their decision to terminate a DS pregnancy. Self-interest may sometimes lead to feelings of guilt. Possible feelings of guilt should definitively be mentioned and discussed during counseling. And, if clearly present, persistent and interfering with daily functioning, psychological assistance is indicated.

7) Norms and moral values of society did play a role of considerable importance. Thirty percent of the women indicated that they had had to defend their decision to TOP one or more times. Almost half of them had the opinion that in nowadays society there is a lack of respect for handicapped people (reason of doubt at decision making, Table 2). And, finally, the factor 'values of society' was most frequently named as cause of perceived pressure. Clinicians should emphasize to the mother/ father that whatever decision they make, a considerable part of their social environment may have negative comments on their decision as they probably also would have in case the opposite decision would have been made.

The questions asked to the women in this study were sometimes confronting and painful. Yet, especially these questions led to recognition and were mentioned by many respondents as very positive for coping. The women completed the questionnaires in a remarkably open and self-consistent way. Termination of an initially wanted pregnancy after diagnosis of DS proved to be a profoundly difficult decision for a substantial part of women. More data about reasons for doubt and motivations for the ultimate decision to terminate pregnancy may be beneficial as well for the mother as for the medical caregivers.

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