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Pregnant women's experiences, needs, and preferences regarding information about malformations detected by ultrasound scan

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ABSTRACT

Objectives: The aim of the study was to explore pregnant women's experiences of received information in relation to fetal malformation detected on ultrasound.
Method: An exploratory descriptive design was used. Semi-structured interviews with women who continued their pregnancy and women who chose to terminate were audiotaped, the information pathway described, and the text subjected to qualitative content analysis.
Results: Most of the women who expected a baby with an abnormality experienced the information given as insufficient, often misleading, conflicting, or incoherent, and sometimes negative. Important factors for interaction between women and caregivers were timing, duration, and manner of the initial dialog and ongoing support. Positive interactions improved the women's ability to understand the information, fostered feelings of trust and safety which reduced their anxiety.
Conclusion: Women expressed dissatisfaction both regarding the care-givers' methods of giving information and apply for information from different specialists and continuity. The study highlights important factors which may be helpful to the professionals for improving the information to this vulnerable group of women.

Introduction

It is a well-documented challenge for women to understand information about fetal ultrasound examination in general [1] and that the challenge increases when difficult information about malformation or increased risk for chromosomal aberrations is included [2]. Women often think of the ultrasound examination as a confirmation of the health of the fetus rather than as a medical examination and are therefore often not prepared for malformations or anomalies to be detected [1,3–6]. Pregnant women have a good knowledge of the second trimester ultrasound examination although the quality of information could be improved [7] such as information from health professionals about the capability and limitations of the scan [8]. Information before and also during the ultrasound examination is an important factor for the women's experience and understanding of the examination [9]. In Sweden, an ultrasound examination is offered to all pregnant women in the second trimester and is organized within the National Health Care System. Specially trained midwifes usually perform routine scans and if it occurs an abnormal finding a fetal specialist must be consulted [10].

Detection of a fetal malformation may lead to termination of the pregnancy. Swedish abortion law states that a termination can be performed on request from the woman before gestational week 18 + 0. After gestational week 18 + 0 the termination must be approved by the National Board of Health and Welfare [11]. In some studies age, type of malformation, viability of the fetus and expected quality of life for the child after birth have been shown to be crucial factors in the woman's decision to continue or terminate the pregnancy [12]. In a study by Redlinger-Grosse et al. [13] religious reasons, personal conviction, and life values were the most important factors when making a decision to terminate or not.

Abnormal ultrasound findings generate more worry to the parents-to-be compared to normal findings [14,15]. Information about fetal malformation may be traumatic to parents-to-be [16] and appropriate psychological care is as important as medical and social follow-up [17]. In some cases the malformation is easily diagnosed at the first examination, but in other cases the findings on ultrasound are vague, requiring either further diagnostic tests (e.g., amniocentesis or chorionic villous biopsy) or additional

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ultrasound examinations to make a final diagnosis [18]. Larsson and colleagues [15] have shown that pregnant women can cope with information about a questionable finding, but the judicious manner and timing of providing the information can greatly reduce unnecessary anxiety. It has been shown that caregivers have difficulty discussing options in a way that women can understand when a fetal malformation is detected [16]. Adequate, repeated, and customizable information would facilitate the caregiver's decision of how and when best to inform the mother-to-be of the diagnosis [13].

A review by Statham et al. [19] found that few studies have shown the psychological effects of continuing a pregnancy when a fetal malformation is diagnosed. Parents may have mixed feelings, and it is crucial to prepare them for where and when the baby will be born, what it will look like, and what will happen to the baby after birth. Communication and teamwork are essential as is planning to deal with practical problems. In order to optimize and provide the best possible care for both women who terminate their pregnancy and those who continue, it is vital that we learn what information women need and prefer when a fetal malformation is detected.

The aim of the study was to explore pregnant women's experiences of received information in relation to fetal malformation detected on ultrasound.

Methods

Participants and procedure

Participants for the study were recruited among pregnant women at four clinics in Stockholm who were diagnosed through ultrasound with a malformed fetus, independent of the difficulty of the malformation.

However, women who expected babies with sex chromosome abnormalities, which may be on the borderline of what can be regarded as normal, were excluded to avoid influencing the women to perceive these babies as abnormal.

The selection of participants was purposeful, and ongoing data collection took place from September 2007 to June 2009. A total of 27 women were recruited after a detected fetal malformation or anomaly; 16 continued their pregnancy and 11 terminated. They were informed verbally by caregivers at the ultrasound units about the aim and the method of the study and they received written information as well. Later, the first author contacted them by telephone to confirm participation. None of the women declined to participate. The interviews were performed 2–4 weeks after termination, in gestational week 30 for those continuing the pregnancy, or three weeks after diagnosis if the malformation was detected after week 30.

Data collection method

The interviews were performed by the first author, a registered midwife who has worked for several years as an ultrasonographer and is educated in interview technique. A semi-structured interview guide ensured that the same basic questions were used in all interviews [20]. The participants were asked first to describe how they experienced receiving the information about the results of the ultrasound examination. Further clarifying questions were asked, for example, "What kind of information were you given?" "How did you understand and feel about the information?" "Did you need further or better information?" When the questions from the interview guide had been asked and answered, the informants were invited to supplement the information with anything else they wanted to share. The informants chose the time and setting for their individual interview; 13 were conducted at an ultrasound unit, 7 at the office of the interviewer, and 7 at the informant's home or work. All interviews were audiotaped. They lasted between 35-113 minutes and were transcribed verbatim by the first author.

Women who were not fluent in Swedish were offered an interpreter in order to be able to participate. The first author, who performed the interviews, did not contribute to the care of the women.

Data analysis

Qualitative content analysis was used [21] and is a flexible method for analyzing text that focuses on the characteristics of language as communication, with attention to the relationship between smaller units in the text and the content or contextual meaning of the whole [22].

The analysis was performed in six steps; (1) the first author listened and read through the interviews several times to obtain an overall impression of the full material; (2) meaning units (words, sentences, or paragraphs related to each other through their content and context) were identified; (3) meaning units were condensed to preserve relevant core expressions; (4) units were coded and categorized into subcategories; (5) categories were built from the subcategories; (6) and categories were united in comprehensive themes. The validation of all steps was considered carefully; the first and last author checked the analysis independently and discussed their findings several times before reaching final agreement [21]. Examples from the procedure are presented in Table 1.

Ethical considerations

A prerequisite for the authors was to obtain written consent and to ensure that the consenting women understood their right to withdraw from the study. Asking women for their consent so soon after they had been given information about a fetal malformation would put both the woman and the person asking for consent in an awkward situation. Therefore the first author elected that the specialist to inform the women about the study and ask for their consent to be contacted by the first author. There was also preparedness for to refer the woman to a welfare officer if she indicated she felt depressed.

The study was approved by the regional ethical committee, Karolinska Institutet, Dnr: 2007/702-31/1.

Table 1
Example of qualitative content analysis of two meaning units, condensed and categorized through sub-category and category to overall theme.

Meaning units	Condensed meaning units	Subcategory	Category	Theme
She did not explain the context. She said, "This is only what I suspect, but it is very clear what it is on this photo," and then she circled these bowels over and over again"	Misleading medical information	Neither correct nor valid information	Confusing information	Need for professional support when meeting the unexpected
And then she said, "Well maybe you haven't taken folic acid properly. You have to think about such things you know"	Substantiated information about possible causes for the detected malformation			