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Pregnancy termination due to fetal anomaly: Women's reactions, satisfaction and experiences of care

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ABSTRACT

Objective: to explore what women who have had a pregnancy terminated due to a detected fetal malformation perceived as having been important in their encounters with caregivers for promoting their healthy adjustment and well-being.
Method: an exploratory descriptive design was used. Semi-structured interviews were audiotaped, and the information pathway described. The text was processed through qualitative content analysis in six steps.
Setting: four fetal care referral centres in Stockholm, Sweden.
Participants: 11 women opting for pregnancy termination due to fetal malformation.
Findings: in-depth understanding and compassion are important factors in providing the feeling of support people need so they are able to adapt to crisis. The women emphasised that the caregivers have to communicate a sense of responsibility, hope and respect and provide on-going care for them to feel assured of receiving good medical care and treatment. Aside from existing psychological conditions, the women identified as having emotional distress directly after termination and for at least the following three months. Most women experienced a range of negative emotions after pregnancy termination, including sadness, meaninglessness, loneliness, tiredness, grief, anger and frustration. Still some of this group had positive reactions because they experienced empathy and well-organised care.
Conclusion and implications for practice: The most important factors associated with satisfaction regarding pregnancy termination due to a fetal malformation are the human aspects of care, namely state-dependent communication and in-depth understanding and compassion. The changes in care most often asked for were improvements in the level of standards and provision of adequate support through state-dependent communication, in-depth understanding and compassion, and complete follow-up routines and increased resources. Targeted education for the caregivers may be suited to ensuring that they properly meet needs of their patients.

Introduction

As improvements in ultrasound technology increase the detection rate of severe structural fetal abnormalities, more women are requesting a pregnancy termination (Levi, 1998; Deborah et al., 2009). Additionally, it has been shown in Sweden that a nuchal translucency ultrasound combined with biochemical analysis in early pregnancy has contributed to 16% increase in terminations of pregnancies because of chromosomal defects, in the last 10 years. However, the number of newborn children with Down syndrome remains constant (1 per 700–800 births) (National Board of Health and Welfare, 2012). Deciding to terminate a pregnancy can be difficult, and people go through a process to justify the decision (Asplin et al., 2013a). Normative moral principles, (i.e., moral rules and/or moral judgments) are introduced once the choice is made (Garcia et al., 2008). Distress is always a component when dealing with the knowledge of an antenatal malformation detected during an obstetric ultrasound examination. When a pregnancy termination is chosen because of the diagnosed fetal malformation, the pregnancy loss may involve a grieving process with high levels of grief and anxiety (Mashiach et al., 2013). One study reported that grief and post-traumatic symptoms remained between two and seven years after the event (Korenromp et al., 2005) whereas in another

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study, contrary to what was expected, traumatic stress at four years was not significantly different to that experienced at 14 days (Kersting et al., 2005). Kersting et al. (2009) showed that the neural activation underlying acute grief in women after pregnancy termination due to fetal abnormality is the same as those involved in physical pain. The process is often complicated by feelings about decision-making and the procedure (i.e., late termination and/or induction of labour) that follows (Neidhardt, 1986; Geerinck-Vercammen and Kanhai, 2003; Sandelowski and Barroso, 2005; Ekelin et al., 2008). The therapeutic options are limited. A detected fetal malformation is traumatic both for the parents-to-be and for the caregivers (Demyttenaere et al., 1995; Salvesen et al., 1997). Antenatal health care is the site of some of the most intimate relationships women may have with health care providers (McCoyd, 2009). If the caregivers fail to inform, advise and support the women, it may lead to negative consequences for the women during the bereavement following an antenatal diagnosis (Lloyd and Laurence, 1985; Lilford et al., 1994; Asplin et al., 2012). The caregiver's emotional sensitivity and possible negative attitudes may complicate the emotional picture for the women (Bracken, 1978; Adler, 1979).

A study by Makenzius et al. (2012) highlights that good treatment and individually based care is important for women's satisfaction when they have a termination. The study also emphasises that several women who had terminated their pregnancy not only wanted to discuss their decision but also to receive some understanding and affirmation, as a part of their adjustment. Patients' satisfaction is related to their individual experience in combination with their expectations (Pascoe, 1983) and to how the health care services are provided to meet the condition-specific needs (Marquis et al., 1983; Donabedian, 1988; Guldvog, 1999; Wen and Gustafson 2004). Studies show that methods of measurement of patient satisfaction vary widely (Haggerty, 2010) and the results of satisfaction surveys need to be interpreted with caution (Van Teijlingen et al., 2003). Patients' views of what is important in relation to the care they receive may be seen as an aspect of quality of care (Davies and Ware, 1988; Felce and Perry 1995; Calnan and Rowe, 2006; Vuori, 2007). Caregivers need to be aware that when an abortion is undertaken for reasons of fetal abnormality, the effects can be serious and long lasting and a strong and persisting grief, similar to that experienced for a stillbirth, is likely (Elder and Laurence, 1991; Zeanah et al., 1993; Salvesen et al., 1997).

Little research has been done on women's experiences of termination. Fetal diagnosis involves ethical and moral issues and is a subject of an ongoing debate in our society. Better information is needed about how to reduce the negative impact of the women's well-being of the risk factors related to termination. The quality of the structure around the treatment of these women, who are in a potentially vulnerable situation, has to be improved. It is therefore important to enhance our understanding about women's experiences and reactions when a fetal malformation is detected. It is important to learn more about how we as professionals can develop care in consultation with those needing a specialised nursing because of a termination.

The aim of the study was to explore what women who have had a pregnancy termination due to a detected fetal malformation perceive as being important in their encounters with caregivers for promoting their healthy adjustment and well-being.

Methods

Design and setting

This is an interview-based study of pregnant women with a malformed fetus, diagnosed by ultrasound, who independent of the severity of the malformation were invited to participate in the study. The participants were recruited between May 2008 and February 2010 from four major close by clinics in the Stockholm area, in Sweden. The clinics were chosen because they specialised in ultrasound examination. The clinics were contacted and informed about the study verbally and through written information about the study. Written consent was obtained from the director of the clinic. Women carrying a fetus with sex chromosome abnormalities, which might 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 women were informed verbally by caregivers at the ultrasound units about the aim and the method of the study and given written information as well. Later, the first author contacted them by telephone to confirm participation. Written consent from the women was obtained at the time of interview as well. None of the women declined to participate. Interviews were performed six months after termination so as not to interfere in a possible new pregnancy.

Data collection method

The first author, a registered midwife who has worked for several years as an ultrasonographer and is educated in interview techniques, conducted the interviews. She did not contribute to the care of the recruited women. The informants chose the time and setting for their interview. A semi-structured interview guide ensured that the same basic questions were used in all interviews (Patton, 2002). The participants were first asked to describe their experience in receiving the information about the results of the ultrasound examination. Further clarifying questions were asked about care, treatment and support. The informants were then invited to supplement the information with anything else they wanted to share. All the interviews were audio taped and transcribed verbatim by the first author. The interviews were performed consecutive and numbered with 1P (interview participant).

Data analysis

Qualitative content analysis (latent) was chosen to gain a more deep understanding compared to only descriptive analysis (Morse and Field 1995; Graneheim and Lundman, 2004). It is a flexible method for analysing 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 (Hsieh and Shannon, 2005). The analysis was performed in six steps: (1) the first author listened to and read through the interviews several times to obtain an overall impression of the 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 categorised into subcategories; (5) categories were built from the subcategories; (6) after a process of interpretation, focusing on discovering underlying meanings of the words or the content, categories were united in a comprehensive theme (Morse and Field 1995; Graneheim and Lundman, 2004). The validation of all steps was considered carefully; the first and last authors checked the analysis step two to six independently and discussed their findings several times before reaching final agreement.

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 soon after they have been given information about a fetal malformation

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