Midwifery ∎ (∎∎∎∎) ∎∎∎–∎∎∎

Contents lists available at ScienceDirect

Midwifery

journal homepage: www.elsevier.com/midw

Making sense of the situation: Women's reflection of positive fetal screening 11–21 months after giving birth

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ARTICLE INFO

Article history:
Received 22 April 2013
Received in revised form
3 October 2013
Accepted 31 October 2013

Keywords:
False positive
Antenatal screening
Experience
Life-world phenomenology

ABSTRACT

Objective: we aimed to gain insights into women's reflection on their experience of receiving a false-positive screening result for fetal anomalies, more than 11 months from birth.
Design and setting: the women constituted a subgroup of participants in a larger cohort study ($n=1111$) where the purpose was to explore women's experience of maternity services, their health, well-being, attitudes and expectations during pregnancy and after birth. Semi-structured interviews were collected from 14 women 11–21 months after birth who had been screened positive for fetal chromosomal abnormality in early pregnancy. The method of life-world phenomenological approach was used in data collection and analyses.
Finding: four themes were identified: *first reaction*, *framing of the news*, *I am not an island* and *pregnancy lost and regained*. With few exceptions, their experience can be seen as a pathway from shock to balanced feeling where women have made sense of what happened and have dealt adequately with their situation.
Conclusion: this study indicates that few women still experience anxiety and concerns in relation to positive fetal screening result more than 11 months from birth. They however remember vividly their first reaction and how the result was presented. As such, the findings have implications in the clinical context meaning that framing of the news on face-to-face level, extended information about the test results, help to sort out mixed feelings and support from a named midwife are of importance.

Introduction

Following the implementation of nuchal translucency (NT) screening for all pregnant women, concerns related to positive result of the screening and the psychological effect it might have for some women were raised (Williams et al., 2005). As an association between increased NT measurement at ultrasound examination at 11–14 weeks and Down's syndrome has been shown, NT screening is now routinely available to pregnant women with the main aim of enhancing their reproductive choices (National Institute for Health and Clinical Excellence (NICE), 2008/2010; Kristjánsdóttir et al., 2010). The combined test result for Down's syndrome is estimated by combining maternal age, fetal NT and maternal serum-free β-hCG and PAPP-A at 11 to 13+6 weeks. Women whose risk score is above the set cut-off are designated screen positive and offered invasive testing like amniocentesis or Chorionic villus sampling (CVS) for karyotype (Leung et al., 2003). In a study by Spencer et al. (2003) the uptake of invasive testing among women who screen high risk was 77% and another study showed the rate of invasive testing increasing with the estimated risk from about 2% for those with a risk score of less than 1 in 1000 to about 90% for those with a risk of more than 1 in 100 (Avgidou et al., 2005). In a large multicentre study, sensitivity of the test to detect Down's syndrome was estimated to be about 92.6% and the false-positive rate was 5.2% (Nicolaides et al., 2005). The older the women are, the better the DR (*detection rate*) of the screening, resulting in that significantly fewer invasive procedures are needed to find a single case of Down's syndrome among women over 40 years of age (Marttala et al., 2011).

As such, younger women are more vulnerable to false-positive screening results, which must be considered when providing information to women or prospective parents in early pregnancy (Green et al., 2004). Whereas the use of these techniques has created certainty for some women and has led to fewer invasive diagnostic tests, it has at the same time created uncertainty as the result is based on a prediction of risk. This calls for the need for women/prospective parents to understand the meaning of the '*false-negative and false-positive*' terminology.

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0266-6138/$ - see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.midw.2013.10.024

Several researchers have concluded that women are unprepared for high-risk result (Michie et al., 2003), and that a positive test result raises women's anxiety level (Baillie et al., 2000; Kleinveld et al., 2006). In 1993 Rothman described the development of '*tentative pregnancy*' as a consequence of a positive test result. This was explained as the pregnancy being 'put on hold' or not experienced as *real* until the possibility of having to consider termination of the pregnancy subsides (Rothman, 1993).

In a Swedish study women who screened high risk showed strong reaction of anxiety when receiving the result, and when interviewed two months after birth some of them expressed that they still suffered from this experience (Georgsson-Öhman et al., 2006). In some studies residual feeling of anxiety, after a normal diagnostic test result, has been shown to attribute to a generalised feeling that something unexpected might affect the pregnancy and sometimes this feeling continues as fear about fetal abnormality (Baillie et al., 2000).

Lawson and Turriff-Jonasson (2006) suggested lower bonding levels throughout pregnancy following maternal serum screening and receiving a favourable result did not increase women's attachment to the fetus. They conclude that normal screening result is not sufficient for reassuring women about the health of the fetus and relate that to the nature of the screening as a probability test. Another more recent study showed that the process of maternal–fetal attachment might be interrupted and psychological distress following antenatal diagnostic procedures underestimated. Women in this study who underwent antenatal diagnosis experienced more psychological distress and anxiety when compared to women in early pregnancy or women who had undergone a 20-week scan. Their main conclusion was that women who develop an emotional attachment to their fetus are more at risk of experiencing anxiety about the pregnancy and their unborn child (Allison et al., 2011). The method of screening might however be of importance as the visual confirmation of pregnancy and reassurance about the well-being of the fetus by ultrasound seem to be of great importance to women and enhance attachment to the pregnancy and the fetus more than serum screening (Yarcheski et al., 2009). Marteau et al. (1992) stated that making choices about screening are meaningless if women are likely to have little understanding about the screening and its implications. Since then, studies have reported on women's inadequate knowledge regarding antenatal screening (Kohut et al., 2002) although this might be affected by a number of demographic factors (van den Berg et al., 2005; Gourounti and Sandall, 2008), and the method of information giving or lack of support (Asplin et al., 2013).

Studies of women's reflections of high-risk screening result, almost a year or longer from birth, are however limited but will add to further development of clinical care. On the basis of the knowledge that there is no treatment during pregnancy for many of the anomalies screened for, it is of importance to know how women react to a positive screening result and how this experience affects their life during pregnancy and after birth.

In this paper we describe women's reflections and memory of their experiences in relation to a positive screening result for chromosomal anomalies, more than 11 months after giving birth. We seek to identify factors which are defined as helpful by the women and could be used for both clinicians and the couples involved. Qualitative method has a potential role in this context as the aim is to answer questions about the meaning of this experience for women who have screened high-risk (Green and Thorogood, 2004).

Method

Descriptive phenomenology with a reflective life-world approach was chosen as a method for this study. This method aims to describe the complex and varied experiences of individuals in the everyday world as it appears and based on this the analysis seeks to understand and clarify the meaning of them in a way that widens our understanding (Dahlberg et al., 2001; Giorgi, 2012).

The method involves three basic elements, a description that is detailed, precise and favours understanding and meaning over interpretation (Giorgi, 1997; Dahlberg et al., 2001; Giorgi, 2012). Secondly Giorgi (2012) advises the researcher to begin with the 'correct attitude' (p. 4) or what he calls *the phenomenological reduction*. This means that the researcher has to develop a sensitivity and self-awareness to her pre-understanding of the phenomenon, her knowledge, theoretical standpoint or experiences from the beginning so as not to interfere with the meaning of the phenomenon as experienced by the individual. The last step involves search for meaning through data analysis (Dahlberg et al., 2001; Giorgi, 2012).

Participants

In Iceland NT measurement is performed in two places, but the combined test and fetal diagnostic tests are all done at the prenatal diagnostic unit, in Reykjavík. In 2009, 73% of all pregnant women in the country had combined testing, where 4.1% screened positive. In this group 77% accepted the diagnostic test (Bjarnadóttir et al., 2010). Early antenatal screening is optional and women have to pay for the procedure (Kristjánsdóttir et al., 2010).

The women participating in this study constituted a subgroup of participants in a larger cohort study ($n=1111$) where the purpose was to explore women's experience of maternity services, their health, well-being, attitudes and expectations during pregnancy and after birth. The women answered postal questionnaires around pregnancy week 16, at 5–6 months and 18–24 months post partum. The participants in this study had attended antenatal care at 13 of 26 health care centres from all over the country. A total of 29 (3.5%) women were eligible for this study as they had answered positively if their NT measurement alone and/or combined test indicated an increased risk. Three of them lived in the rural areas at the time of the study. After interviewing the first 14 women who accepted the invitation to participate, saturation was reached (Kvale, 1996).

Data collection

The interviews, which lasted from 45 to 90 minutes, were tape-recorded and transcribed verbatim. Time and place for conducting the interviews were chosen by the women at their convenience. During the interview dialogue the women were encouraged to describe their feelings and experiences as openly and freely as possible and the initial question usually was: '*Can you describe to me how you remember the situation when you were told that your fetus had an increased risk of having a structural and/or a chromosomal anomaly?*' The researcher asked the women to give examples and followed up answers and asked for clarification when appropriate. These open and yet focused questions are according to Englander (2012) the phenomenological way of conducting semi-structured interviews and necessary to get as complete a description as possible of the women's lived experience of the phenomenon and its meaning to them.

Ethical consideration

All participants had previously consented to participate in the interview study. Written information was provided and their right to refuse participation and withdraw their consent at any time

Please cite this article as: Kristjansdottir, H., Gottfredsdottir, H., Making sense of the situation: Women's reflection of positive fetal screening 11–21 months after giving birth. Midwifery (2013), http://dx.doi.org/10.1016/j.midw.2013.10.024