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Women's decision making regarding prenatal screening for fetal aneuploidy: A qualitative comparison between 2003 and 2016

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ABSTRACT

Objective: Situational factors of prenatal screening have changed in recent decades. To explore the effect of a changing context on women's decision making, differences and similarities in the decision-making process of pregnant women regarding prenatal screening for fetal aneuploidy between two periods in time were studied.
Design: A qualitative comparison was made between a dataset of 22 semi-structured interviews with pregnant women from 2003 and a newly collected dataset with 19 semi-structured interviews from 2016.
Findings: Overall, women reported similar considerations in their decision-making process in 2003 and 2016, suggesting that decision making has not essentially changed. However, for some women, costs and societal views as to what is acceptable did appear to impact the decision-making *process*. Moreover, new screening possibilities (e.g. improved test characteristics and including more conditions to be screened) seemed to impact the decision *outcome*.
Conclusions: Since most women based their decisions mainly on their personal values and personal experiences rather than on situational factors, the results suggest that the changing context with regard to prenatal screening had no major effect on women's decision making. It therefore seems unlikely that future changes in the field of prenatal screening will drastically change the decision-making process of pregnant women as long as informed and deliberate decision making is safeguarded.

Introduction

Prenatal screening for fetal aneuploidy, including Down syndrome (trisomy 21), Edwards syndrome (trisomy 18) and Patau syndrome (trisomy 13), is a well-established practice in many countries. The prenatal screening landscape has altered in recent decades due to new technologies, societal changes and changes in policy. This is also the case for the Netherlands, where most changes occurred over the last ten years (Van El et al., 2012). These changes include the introduction of a national screening program in 2007, the inclusion of Edwards syndrome and Patau syndrome in the screening program in 2011, and changes in reimbursement of screening. Moreover, in 2014 non-invasive prenatal testing (NIPT) using cell-free DNA was introduced for women with an increased risk (≥1/200) of a child with fetal aneuploidy based on first-trimester combined testing (FCT) (Oepkes et al., 2016). Since 2017 NIPT has been available as first-tier screening test within the national screening program for low-risk women.

New developments concerning prenatal screening, such as the introduction of NIPT, are often discussed because of the ethical and social aspects involved (Vanstone et al., 2014). The disorders that are screened for cannot be cured, and women are confronted with ethical questions regarding the value of disabled life and possible decisions regarding pregnancy termination (Garcia et al., 2008). Being a safe and highly accurate test, there are concerns that NIPT might lead to routinization or uncritical use of testing, and social pressure, and that this will consequently lead to less-informed decision making (Van den Heuvel et al., 2010; Lewis et al., 2013; Van Schendel et al., 2014; Vanstone et al., 2014; Van Schendel et al., 2017). In the Netherlands, where the uptake of FCT screening is relatively low (~34%) (Carbo and Bom, 2017) compared to other European countries, the fear of routinization has fuelled the societal debate on the value of "disabled life" in relation to screening (Van Schendel et al., 2017).

With the growing possibilities in prenatal screening, it is considered increasingly important that women make informed decisions about whether or not to participate (Van den Heuvel et al., 2010; Vanstone

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et al., 2014). Women must be provided with balanced and accurate information, and make a deliberate decision in alignment with their values (Van den Berg et al., 2006). To facilitate informed and deliberate decision making, it is important to gain insight into women's decision-making process, including potential barriers. How people make decisions depends on characteristics of the decision maker (e.g. educational level, personal values), characteristics of the decision (e.g. complexity of information), and characteristics of the situation (e.g. social norm, costs) (Timmermans, 2013).

Several studies identified *situational* factors affecting decision making related to women's social environment, the phenomenon of normalization or routinization of screening practice, test characteristics, and costs (St-Jacques et al., 2008; Etchegary et al., 2008; Potter et al., 2008; Reid et al., 2009; Bakker et al., 2012; Carroll et al., 2013; Crombag et al., 2016a). Women's social environment is important in shaping their views on and knowledge about both screening itself and on the conditions screened for (Etchegary et al., 2008; Reid et al., 2009). In countries where prenatal screening is part of routine prenatal care, less informed choices about having screening are made (Van den Berg et al., 2005; Lewis et al., 2017). Test characteristics such as a low detection rate and miscarriage risk are reasons not to participate in screening (Van den Berg et al., 2005; Reid et al., 2009; Bakker et al., 2012). Moreover, some women decline testing because of the costs (Bakker et al., 2012).

Although it is known that situational factors and context play a role in women's decision making, it is not known in which way and to what extent they play a role. Considering the fast-changing prenatal screening landscape, with increasing access to and use of screening for an increasing number of conditions, a study that compares the decision-making process among women over specific time periods in one country is relevant to gain more insight into the influence of situational factors on women's decision-making process.

In the Netherlands prenatal screening for fetal anomaly is subject to governmental license, which means that offering screening without such license is not allowed (Van El et al., 2012), although women can chose to buy tests abroad. Currently midwives provide initial prenatal care for 87% of Dutch pregnant women (Perined, 2016). Most women who indicate they want to be informed about prenatal screening are counselled by midwives (Martin et al., 2018). Between 2001 and 2004, a large-scale research project was conducted among ~3000 pregnant women in the Netherlands to study the implications of the introduction of a nationwide prenatal screening program (Kleinveld et al., 2007). Women were offered first-trimester prenatal screening in a research context, since no national screening program existed at that time. As part of this project, 22 women were interviewed about how they described their decision-making process regarding prenatal screening.

The aim of the current study was to explore the differences and similarities in the decision-making process of pregnant women regarding prenatal screening for fetal aneuploidy by comparing the interview data from 2003 with new data gathered in 2016. The results of this study provide insight into the potential effects of changes in the field of prenatal screening on, and its implications for, the decision-making process of pregnant women.

Methods

This study used a unique design in which qualitative data from two different points in time were compared using a dataset of semi-structured interviews from 2003 (unpublished data) and a newly collected dataset with semi-structured interviews from 2016. The interviews enabled women to describe the decision-making process in their own words. In this way, in-depth information was obtained.

Screening was offered by means of nuchal translucency (NT) measurement or FCT in 2003 and 2016, respectively, (Fig. 1). Table 1 shows an overview of the differences in context in which the two datasets were collected. The study was approved by the VUMC Medical Ethics Committee.

Participants

In 2003 as well as in 2016, purposive sampling was used to select participants. This resulted in a sample consisting of both women who declined screening and women who accepted screening.

In 2003 the participants were selected from a cohort of pregnant women who were included in a randomized controlled trial (RCT). This cohort was recruited via several midwifery and gynecological practices in both urban and non-urban areas in the Netherlands. As part of this RCT, one group of women was offered information on prenatal screening by means of an NT measurement in a consultation by the women's midwife or gynecologist (for more details see: Van den Berg et al., 2005; Kleinveld et al., 2007). A selection of women was asked to participate in additional interviews. In 2016 several midwifery practices in Amsterdam and non-urban areas were approached to participate. The midwives of these practices asked pregnant women whether they were willing to be interviewed. In addition, some women were recruited from the researchers' network.

Similar inclusion criteria were used in 2003 and 2016. Women needed to speak/understand Dutch or English and to be at least 18 years old. Women were interviewed after they had received information on either NT measurement (2003) or FCT (2016). Table 2 shows the participants' characteristics at the time of interview. Almost half of the women interviewed in both years had screening. Most women were between a gestational age of 10 and 15 weeks.

Procedure

The first dataset consisted of 22 semi-structured interviews and was collected between October 2002 and April 2003 (in this article referred to as 2003). The second dataset consisted of 19 interviews, collected between February and April 2016. In 2002 an interview guide was developed under supervision of the last author (psychologist and expert in patient decision making). In 2016, slight adaptations were made related to changes in screening practice, but they were kept to a minimum to ensure that the data could be compared. The following topics were included: offer of information on screening, reasons whether or not to participate in screening, social context, perception of Down syndrome and perceived risk of having a child with Down syndrome, diagnostic testing and further decisions, and personal values.

All interviews were conducted at the participant's home or over the phone and lasted 30–90 min each. The interviews were conducted by three researchers from the study in 2003 (MvdB, CvG, AK) and two other researchers (MvB, DvdI) in 2016. Prior to the interviews, written informed consent was taken. Audio recordings and field notes were made. After the interviews, women were asked to fill in a short questionnaire on their age, marital status, religion/religiousness and educational level. Data collection continued until data saturation was reached.

Data analysis

The interviews were transcribed verbatim. The data were thematically content analyzed using ATLAS.ti 7. First, the transcripts were read in detail. Subsequently codes were created, based on recurring topics. Four researchers were involved in coding (MvB, LH, DvdI, OD). Four interviews from each period were coded independently by at least two researchers and the codes were discussed afterwards until consensus was reached. The remaining interviews were coded by one researcher (MvB). The codes were clustered and categorized, and merged into themes. After this, the themes of the data from 2003 were compared and contrasted with the themes in 2016. Representative quotes were selected to illustrate the similarities and differences in decision making between 2003 and 2016.

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