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Introduction of non-invasive prenatal testing as a first-tier aneuploidy screening test: A survey among Dutch midwives about their role as counsellors

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A B S T R A C T

In 2014, non-invasive prenatal testing (NIPT) for trisomies 21, 18 and 13 was added to the Dutch prenatal screening program as part of the TRIDENT study. Most (85%) pregnant Dutch women are counselled for prenatal aneuploidy screening by primary care midwives. This will remain when NIPT is implemented as a first-tier screening test. We therefore investigated midwife counsellors': 1) Knowledge about NIPT; 2) Attitudes towards NIPT as first-tier screening test; and 3) Experiences with informing clients about NIPT. Between April-June 2015, an online questionnaire to assess knowledge about NIPT, attitudes towards NIPT, and experiences with NIPT was completed by 436 Dutch primary care midwives. We found that 59% midwives answered ≥7 of 8 knowledge questions correctly. Continuing professional education attendance and more positive attitudes towards prenatal screening for Down syndrome were positively associated with the total knowledge score (β = 0.261; p = 0.007 and β = 0.204; p = 0.015, respectively). The majority (67%) were in favor of replacing First trimester Combined Test with NIPT, although 41% preferred to maintain a nuchal translucency measurement alongside NIPT. We conclude that midwives demonstrated solid knowledge about NIPT that may still be improved in some areas. Dutch midwives overwhelmingly support the integration of NIPT as a first-tier screening test.

Introduction

In the Netherlands, as in many other countries, there is an ongoing debate on the place and costs of non-invasive prenatal testing (NIPT) in the prenatal screening program (Dondorp et al., 2015; Henneman et al., 2015; Oepkes et al., 2016a). NIPT involves the analysis of cell-free DNA (cfDNA) in a maternal blood sample, which can be done from 9 or 10 weeks of gestation (Benn et al., 2015). Fetal DNA in maternal plasma originates from the placenta. NIPT can be used to screen for trisomy 21, 13 or 18 with a high accuracy, both in high risk and low risk populations (Gil et al., 2015; Taylor-Philips et al., 2016). In addition, NIPT can also be used to screen for sex chromosome anomalies (Benn, 2016), although currently not used for this purpose in the Netherlands (Oepkes et al., 2016b). Despite the favorable test characteristics of NIPT, false positive results do occur, signifying that a NIPT result indicating a trisomy still has to be confirmed by invasive testing for diagnostic certainty (Bianchi et al., 2014). Nevertheless, the introduction of NIPT has re-shaped the use of prenatal testing in many countries; the use of invasive tests and procedure-related iatrogenic miscarriages has decreased significantly (Oepkes et al., 2016b; Warsof et al., 2015).

In 2015, the International Society for Prenatal Diagnosis (ISPD) and Royal College of Obsetricians and Gynaecologists (2014) supported the use of NIPT as a first-tier screening test for all pregnant women

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(Benn et al., 2015; RCOG, 2014). NIPT has a higher detection rate and lower false positive rate than the first trimester combined test (FCT) (Benn et al., 2015), which involves measurement of nuchal translucency (NT) and maternal serum markers. However, opinions about the availability of NIPT in publicly funded healthcare systems are mixed, mainly reflecting concerns about the relatively high costs of NIPT compared to the FCT (Benn et al., 2015; Oepkes et al., 2016a). As NIPT use increases simultaneous to the evolution of policy, science, and evidence about the test, front line clinicians are challenged to keep abreast of the latest developments. For instance, clinical providers have reported difficulty maintaining up-to-date knowledge about the scope of NIPT, about the differences between tests characteristics offered by different laboratories, and reasons for false-positive NIPT results (Benn and Chapman, 2016). Recognizing these challenges, the American College of Medical Genetics and Genomics (ACMG) has stated that the introduction of NIPT should be accompanied by thorough education of counsellors, decisions about handling costs and healthcare policy decisions around NIPT (Gregg et al., 2013).

In the Netherlands, prenatal screening for fetal aneuploidy requires a governmental license according to the Dutch Population Screening Act. The aim of the Act is to protect the public from potential harm of screening (van El et al., 2012). A license proposal was submitted to the Ministry by the Dutch NIPT Consortium (represented by all institutions, organisations and stakeholders involved with NIPT). After obtaining a license in April 2014, NIPT for trisomy 21, 18 and 13 was added to the Dutch prenatal screening program as part of the TRIDENT study (Trial by Dutch laboratories for Evaluation of Non-Invasive Prenatal Testing) (Oepkes et al., 2016b). Within this context, NIPT is offered by Dutch university clinical genetic laboratories using an in-house validated test. If pregnant women waive their right not to know anything about prenatal screening, they are counselled for aneuploidy screening by a certified counsellor. These counsellors have to participate in continuing professional education about developments regarding counselling for prenatal anomaly screening in general and, as part of the TRIDENT study, on relevant aspects of NIPT (Oepkes et al., 2016b). At the time of this study, NIPT was only available for women at high-risk (≥ 1:200) for fetal aneuploidy based on the FCT or medical history such as a previous child with Down syndrome (Health Council of the Netherlands, 2013). Given this situation, many pregnant women who were not eligible for NIPT within the TRIDENT study, chose to pay for commercially offered NIPT in other countries, often supported – counselling and taking blood- by local midwives/hospitals who sent their samples abroad (Health Council of the Netherlands, 2016a).

Dutch midwives provide initial prenatal care for 85% of Dutch pregnant women, and offer counselling for fetal anomaly screening (FCT and Fetal Anomaly Scan) to all clients (www.perinnet.nl 2013). Since the introduction of NIPT as a second-tier test in 2014, midwives have been informing their clients about NIPT as possible follow-up test. If pregnant women opt for FCT they pay ~€165 (Oepkes et al., 2016b). Clients with elevated risk based on FCT are referred to a Center for Prenatal Diagnosis, to be counselled for NIPT by a prenatal screening specialist (i.e. obstetrician, maternal fetal medicine specialist). If clients choose to opt for follow-up testing, including NIPT, testing is reimbursed by the compulsory health insurance after subtraction of a deductible of ~360 euros (Oepkes et al., 2016b).

If NIPT becomes available for all pregnant women as a first-tier screening test, it will necessitate major changes in the field of prenatal screening and counselling. One significant change is the type of healthcare provider who will provide counselling for NIPT. In the TRIDENT study aimed at high-risk women, prenatal screening specialists offered pretest counselling. If NIPT becomes more widely available as first-tier screening, midwives will assume the burden of pretest counselling because they provide early prenatal care to most pregnant Dutch women (http://www.perinatreg.nl/ 2013). Therefore, it is important to know more about factors that may or may not require additional attention prior to and during implementation of counselling for NIPT as a first-tier screening test by midwives. When it comes to healthcare implementations, Grave et al. (2006) and Légaré et al. (2008) suggest focusing on three main factors: professionals' knowledge, attitudes, and behavior.

Little is known about the knowledge of NIPT among counsellors for prenatal screening, although some studies suggest this knowledge is insufficient (Allyse et al., 2015; Farrell et al., 2016). Global evidence indicates that providers' attitudes towards the availability of NIPT for all pregnant women as a first trimester screening test is positive (Benn et al., 2014; Hill et al., 2012, 2014; Musci et al., 2013; Tamminga et al., 2015; Yotsumotu et al., 2012). Most frequently mentioned concerns about implementing NIPT as first-tier screening are the potential for less informed decision-making by pregnant women based on concerns that offering NIPT could become routinized, or merged into the barrage of blood draws that accompany pregnancy visits (Allyse et al., 2015; Verweij et al., 2015). Less research has been done about the provision of pre-test counselling for NIPT, including the content and quality of this service. Research from the US shows that clinicians have adopted NIPT more quickly than anticipated in their clinical practice, also because of strong public demand, and, as a consequence, without sufficient training (Allyse et al., 2015). This might be problematic since it is known that genetic counselling in general needs optimization especially with regards to providing decision-making support (Martin et al., 2015; Roter et al., 2006). In this study we investigated midwives': 1) knowledge about NIPT; 2) perceived competence with counseling women about NIPT; 3) attitudes towards NIPT as first-tier prenatal aneuploidy screening; and 4) behavior and experience with NIPT.

Methods

Design

We used an online cross-sectional survey of primary care midwives.

Participants and procedure

In 2015, 1984 midwives were active in Dutch primary care practice (Van Hassel, 2016). The majority, 98% of Dutch midwives are members of the Royal Dutch Organization of Midwives (KNOV). In April 2015, we circulated an invitation letter containing a link to the questionnaire to all primary care midwifery practices known by the KNOV (N = 529 practices). All midwives at each practice were asked to complete the questionnaire as an individual. To increase response rates, a call to complete the questionnaire was placed in an online newsletter of KNOV, and emails were sent by some coordinators of regional Perinatal Networks to individual midwives within their region. After three weeks, a reminder was sent to all midwifery practices. Data were collected till June 2015. Vouchers worth 25 euros were raffled among the participants.

Survey instrument

A questionnaire was constructed based on questionnaires used in previous Dutch studies (Verweij, 2014; Tamminga et al., 2015; van Schendel et al. 2015, 2016) and a review of the literature by a multidisciplinary team including representatives of midwifery, gynecology, psychology, clinical genetics and health sciences. The research team deliberated about the validity of the questions and the need for additional questions. The resulting questionnaire assessed background characteristics (gender, age, religiosity, work field (Primary midwifery-led care or midwife and sonographer), years since graduation, postal code (first two numbers), and whether participants had attended Continuing Professional Education (CPE) about NIPT). It also included items to assess knowledge about NIPT, perceived counseling competence, attitudes towards NIPT as first-tier screening test and behavior and experience with NIPT.