Variables Affecting the Decision Making to Uptake Prenatal Testing

Abstract

The women’s decision to uptake prenatal testing is complex, involving different factors. We conducted a Cross Sectional study to investigate variables influencing this choice, with particular attention to socio-demographic, obstetric history and midwifery care variables.

Background: With the increased routinization of prenatal testing, there has been a corresponding attention to parents’ decision-making. We are interested to explore those factors affecting the couple’s choice to improve antenatal care and enable parents to be aware and to make an informed choice.

Methods and findings: A sample of 448 consecutive women with a low-risk of having fetal abnormalities was interviewed to collect socio-demographic, obstetric history and antenatal care information. We identified that factors related to the use of non-invasive testing were: previous miscarriage, received antenatal counselling on prenatal testing, number of antenatal appointments and lack of maternal knowledge about prenatal testing. Regarding invasive prenatal testing factors increasing the use were: maternal age, single status and antenatal counselling.

Conclusion: This study highlighted the complexity of decision-making in this context and emphasized the importance of the continuity of antenatal care.

Keywords: Prenatal testing; Fetal; Malformation

Abbreviations: DS: Down Syndrome; CVS: Chorionic Villi Sampling; cffDNA: Cell-Free Fetal DNA Test

Introduction

Aneuploidy screening or diagnostic testing should be discussed with all women early in pregnancy [1]. At the first contact with a health care professional woman should be informed about screening for Down syndrome. This will provide the opportunity for further discussion before embarking on screening [2]. Professional guidelines recommend that all pregnant women, regardless of age, should be offered prenatal screening for fetal aneuploidy [3,4]. The aim of the currently available screening testing is actually to identify, with the highest possible sensitivity and specificity, those women who present an increased risk of having a foetus with anomalies. Their results can be used to determine the need for subsequent karyotyping of fetal cells using amniocentesis or chorionic villi sampling (CVS) [5]. The invasive prenatal testing is intended to determine, with as much certainty as possible, whether a specific genetic disorder or condition is present in the foetus.

Counselling for aneuploidy is needed to inform parents about chromosomal disorders, to provide information regarding their specific risk of carrying a foetus with aneuploidy. All the available options give the opportunity to make an informed choice regarding screening or diagnostic test.

Research on prenatal screening highlighted the complexity of
decision-making in this context, focusing on social and ethical factors affecting decision-making and, in some cases, impede autonomous, informed decision-making [6,7].

The choice of screening test is affected by many factors, including a desire for information before delivery, prior obstetric history and family history. Literature shows that the choice of uptake a prenatal diagnosis testing is influenced by maternal age [8-10], ultrasound abnormality [8], previous miscarriage [8], parity [8,9], use of assisted reproduction technology [8,10,11], ethnicity [8,9], education [9], nationality [9,12], informed choice [11-13], personalized counselling [10-14], emotional support [12], personal values [8,9,15], risk perception [10,12], prenatal diagnosis considered as routine care [16].

The aim of this research is to investigate variables influencing the maternal choice to uptake prenatal testing for foetal aneuploidy with particular attention to socio-demographic, obstetric history and midwifery care variables. This could help to understand the social effects of prenatal screening technologies, but also women’s needs, to enable healthcare professionals to support them in the process of decision making, offering the most appropriate midwifery care.

Methods

This is a cross-sectional study of a cohort of consecutive women who delivered from 1 September 2011 to 31 October 2011. The study was conducted in the obstetric unit of two large maternity hospitals in Northern Italy: Maternity Hospitals Buzzi and San Gerardo Hospital - MBBM Foundation, with both approximately 3,000 births/year.

The sample size was calculated from the prevalence of the "invasive test" in the general population by 20% (*), with a 97% significance level. The inclusion criterion was having a low risk pregnancy for foetal aneuploidy. The exclusion criteria were as follow: ultrasound diagnosis of malformation; having a child with a chromosomal or congenital disorder; personal or family history positive for hereditary or congenital diseases; and exposure to teratogenic agents, including infectious and physical agents, maternal health factors, environmental chemicals and drugs. Additional exclusion criteria were perinatal death or a newborn with a malformation, failure to give informed consent and insufficient understanding of the Italian language.

Eligibility was ascertained and informed consent was signed during the last antenatal appointment, which took place at the maternity ward within 48 h after birth. We decided to interview women after childbirth so do not to interfere in any way in their decision whether or not to perform prenatal testing.

On this occasion, women were interviewed by a trained midwife who collected data regarding social and demographic variables, obstetric history and antenatal care characteristics, including the use of non-invasive (ultrasonography and serum biomarker testing) and invasive (amniocentesis, CVS) prenatal diagnosis testing. During the literature search we did not find any available tool. In the absence of an instrument we defined a new semi-structured questionnaire with the aim to collect all the information needed. The questionnaire was provided, partly filled from the birth register data and partly through a direct interview. The questionnaire consisted of 3 sections. The first and second sections involved socio-demographic data, obstetric history information and the course of pregnancy with particular attention to the weeks at the first prenatal visit, number of prenatal visits, number of SCAN and the use of assisted reproductive technology. The third section consisted of 24 closed questions and 8 opened questions, of them 4 related to the non-invasive testing and, the same 4 repeated questions, related to the invasive test one.

The 4 opened questions were analyzed as follows. The first question listed the foetal aneuploidy that women think a prenatal testing could investigate, while the second one expressed the percentage of chromosomal abnormalities that could be discovered according to women. Women’s answers were categorized as “I don’t know”, “few” if ≤ 30%, “half” if ≥ 40% but ≤ 60%, “lots” if ≥ 70 and ≠ 100%, “all” if equal to 100%.

The third question enquired if the test’s result give the assurance to have a healthy baby, women’s answer were categorized into “I don’t know”, “yes”, “no”.

For the fourth question, following a content analysis, we divided women’s answers into 14 areas for the non-invasive test and in 16 areas for the invasive test.

We planned a calibration phase to test the questionnaire with the purpose to identify potential critical issues and make changes. The questionnaire has been administered to 50 women, they understood the items and a correspondence between questions and answers were noted. Therefore, we did not make any variations to the original instrument. All data were recorded in the Collection form by a research midwife and checked by a supervisor.

The local ethical committee approved the study (REK number 2010/377).

The collected data were checked for completeness and overall consistency. Descriptive statistics were performed overall. Continuous variables are described as means and standard deviation, and categorical variables are described as percentages.

Age was analyzed as a binary variable (>35 years or <35 years) according to the remarkably increased risk of carrying a foetus with DS among women aged 35 years and older and the national health service’s payment for the invasive procedure among women in that age groups. The number of ultrasound (US) examinations was dichotomized into ≤ 3 or > 3 as this is the number recommended by the Italian health service. Univariate and multivariate logistic regression models were used to determine the binary status indicating the selection or non-selection of prenatal testing and possible related factors. Statistical significance was defined as a two-tailed p values below 5%. The software used was Excel for data collection and SAS/STATVR software for data management, checking and analysis.

Results

A total of 358 women were screened between the two Maternity
Units. 58 of them did not meet the inclusion criteria as showed in Table 1.

Table 2 shows socio-demographic and obstetric history variables. During pregnancy 56.7% of the women had a private consultant-led care and 43.4% choose the public service (30.7% hospital care; 12.7% community care). Women had an average of 8 antenatal appointments (SD 2.06), from a minimum of 3 up to 15 appointments; they performed an average of 7 SCAN (SD 3.18), from a minimum of 2 up to 15 SCAN. 36.6% of women had 4 or more SCAN. When we considered information that women had before getting pregnant, 16% of them affirmed they did not know that prenatal testing existed.

Prenatal invasive tests were the most known by women: Amniocentesis known by 74% of women, CVS by 47% and Nuchal Translucence Test by 26% of women.

Non-invasive prenatal testing

Women receiving information about prenatal screening testing were 76.7% (n=230), 83% of them had information from the healthcare professional at the beginning of pregnancy. 17% only, received an antenatal counselling before decision making, among them 47% did not remember who was the counsellor.

Among the 300 women interviewed, 59.7% (n=180) did a non-invasive prenatal testing, we asked them if the test was offered, suggested or prescribed as define in Table 3. The remaining 15% (n=25) of women decided by their own to perform a screening test, before the first antenatal appointment. The prescription of the prenatal testing increases from 30% to 35.8% when the antenatal care is led by a private Obstetrician.

Invasive prenatal testing

Women who received information about invasive prenatal testing were 58.7%, from them 89.2% was informed by the healthcare professional at the beginning of pregnancy. 24% of women had an antenatal counselling before decision making, among them 18% did not remember who the counsellor was. Between all women we obtained a mean satisfaction score about the information received=6.3 with a SD score=3.11.

Among the 300 women interviewed, 21.7% (45) did an invasive prenatal test (86.2% performed an amniocentesis and 13.9% a CVS).

For 23.1% of women the reason to perform an invasive test was parental or maternal choice, only 4.6% had a high risk result to the prenatal non-invasive test, 53.9% of women perceived the invasive test as offered by the healthcare professional during pregnancy.

Women’s knowledge and decision making

Women’s knowledge on conditions that non-invasive and invasive prenatal testing can investigate as presented in Table 4. Women’s answers are divided into different categories for both non-invasive and invasive prenatal testing.

Figure 1 shows the women’s opinion about the percentage of foetal aneuploidy a non-invasive or invasive prenatal testing could investigate. 12% of women though that non-invasive prenatal testing could give assurance to have a healthy baby, while 31% of women thought the same about the invasive prenatal testing. If there was at least a single wrong answer out of the first 3 opened questions, we considered that a woman did not have a good knowledge about the prenatal testing.
39% of women did not have a correct knowledge about the aim of the non-invasive prenatal testing and 35% about the invasive prenatal testing.

Figures 2 and 3 show the reason why women choose to uptake one of the 2 prenatal testing.

We identified different factors influencing women’s choice to uptake or not the non-invasive prenatal testing, that we categorized into 14 areas: 5 of them influenced the choice to uptake the test, 2 reasons had an impact to not perform any test, 7 influenced both choices. We identified different factors influencing women’s choice to uptake or not the invasive prenatal testing, that we categorized into 16 areas: 6 of them influenced the choice to uptake the test, 8 reasons had an impact to not performing any test, 2 only influenced both choices.

Factors influencing the decision to uptake prenatal testing

An analysis was performed to identify the socio-demographic, obstetric history and antenatal care variables that affect the decision-making to perform non-invasive or invasive prenatal testing. Table 5 shows results of the univariate and multivariable logistic regression model for non-invasive prenatal testing. In the univariate analysis, factors that were significantly related to the decision making to undergo non-invasive prenatal testing were: previous miscarriage, received antenatal counselling on prenatal, number of antenatal appointments and lack of maternal knowledge. These relationships were still present in the multivariate model. Regarding invasive prenatal testing factors significantly related in the univariate model were: maternal age, marital status, education, living children ≥ 1, attending antenatal public health care, number of scan (Table 6). In the multivariate model, factors that significantly increased the OR (odds ratio) of undergoing invasive testing were: maternal age, single status, antenatal counselling on prenatal testing.

Discussion

Our attempt is to explore for the first time variables influencing factors involved in the process of decision making to uptake a non-invasive or invasive prenatal testing. We found factors associated to the antenatal care and to the maternal characteristics playing a different role based on the type of test.

From our data we observed a relevant antenatal care medicalization, with a high number of antenatal visits and SCAN. These data are a picture of the Italian contest [17]. According to some researchers, service delivery has an impact on women’s use of prenatal testing as confirmed in our study, in which private service care led by gynecologists was related to an increased use of prenatal testing. This may be due to the way tests are offered during antenatal visits, in fact in our study prenatal testing has been offered to 26% of women only, the remaining women perceived the test as a suggestion or a prescription. The key determinant of the choice regarding prenatal testing is the woman’s a priori inclination towards the procedure [18-21], in our sample we found that 14% of decision making was driven by their personal opinion before any antenatal counselling.

Enabling the parents to make an informed and autonomous choice in further testing has been an essential part of good maternity care [22].

National and international literature [23,24] recommend that healthcare professionals should give to women and their partners all the information on prenatal testing at the first antenatal appointment, to allow time for reflection and informed decision-making.
When we explored women’s reasons to uptake prenatal testing through the opened questions, we noted the same factors could impact on the decision to uptake or not a non-invasive prenatal testing; while, when taking into account the invasive prenatal testing, factors influencing maternal choice are specifically related to a single choice only.

Among factors with an impact on the decision to uptake a non-invasive test, a previous miscarriage is an experience in a woman’s life that could not be changed, probably leading to an increase of maternal concern about the risk of invasive procedure related miscarriage [12,25].

From the statistical analysis three more factors appear to increase the choice to uptake a non-invasive prenatal test, they are: had an antenatal counselling on prenatal testing during pregnancy, number of antenatal appointments and women who do not have a good knowledge about the aim of each testing. Parents who received an antenatal counselling on prenatal testing are those showing an interest on this theme, the need to have more information is a preparatory step towards the decision. Women, who do not have a good knowledge about prenatal testing, often have higher expectations about them and are confident they will give assurance about the foetus health. The number of antenatal appointments represents an indirect factor reflecting the antenatal care that a couple received during pregnancy, probably provided by a private Obstetrician. According to the Literature the differences in communication attitudes between obstetricians and midwives must also be considered [26]. Women attending antenatal public healthcare undergo less antenatal appointments, compared to those women attending private antenatal care. This relationship could be explained from the different education or citizenship status between women attending public or private service [21]. Moreover private Obstetrician are the healthcare professional prescribing more often prenatal testing, influencing also the use of them, with the risk that they become part of the routine care.

Pregnant women who underwent prenatal testing as part of routine prenatal care tended to take it without really considering its implications. They usually did not pay attention to real meaning of it until the positive test result was presented to them [27]. This implies that a large number of women are not making informed decisions about having prenatal testing [28].

From the multivariate analysis we could identify variables having an independent role on the decision to uptake an invasive prenatal test: maternal age ≥ 35 years, marital status and received an antenatal counselling.

Other authors reported advanced maternal age as a variable influencing the decision to uptake an invasive prenatal test, due to maternal age related risk of Down syndrome [13]. Our data confirm the literature data; moreover an increase in the use of invasive tests could be explained because it is covered from the National Healthcare System for women >35 years old.

The marital status is associated with less use of invasive prenatal test; this could be due to concerns, fear or anxiety felt from a single woman growing a baby with pathological conditions by her.

Figure 2  Maternal reason to perform or not a non-invasive test.

Figure 3  Maternal reason to perform or not an invasive test.
own. Having longer marriage duration was reported as correlated with up taking a prenatal testing [27].

This result, which is not congruent with our study, may indicate that uptake varies widely from country to country and this may be partly due to healthcare practices and regulations related to prenatal screening and diagnostic tests as well as cultural and religious attitudes about disability and termination of pregnancy.

Having a prenatal counselling increases the maternal choice to uptake an invasive prenatal testing. The interpretation about this data could be the same we gave above for the non-invasive prenatal testing.

Our study is not without limitations. It involved two centers in the same metropolitan area, and the results may not be generalizable to other contexts. The interview was administered after the antenatal testing decisions were made and after the delivery of the baby, to avoid to interfere with couple’s general well-being and serenity. Some of the variables related to the parental decision making as the antenatal care, counselling and maternal knowledge, are associated with the antenatal pathway. A midwife-led care from the beginning of pregnancy, as recommended from the literature [29], contributes to the continuity of care and enables to provide an antenatal counselling for couples. With this model of care parents could have enough information to make an informed choice and be aware about their process. This appears especially important following the introduction of Cell-free fetal DNA test (cffDNA) which decreased the use of prenatal invasive testing, but requires addition time to make parents aware to perform an informed choice. Given that cffDNA test has a much higher sensitive when compared with any of the current screening programs, Menezes et al. suggested that it is even more imperative that women understand the conditions

<table>
<thead>
<tr>
<th>Variable</th>
<th>Non-invasive prenatal test (n=)</th>
<th>Multivariable model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal age (≥ 35 years)</td>
<td>0.65 (0.407, 1.03)</td>
<td>0.07</td>
</tr>
<tr>
<td>Marital status</td>
<td>1.36 (0.66, 2.79)</td>
<td>0.39</td>
</tr>
<tr>
<td>Employed</td>
<td>1.25 (0.71, 2.18)</td>
<td>0.42</td>
</tr>
<tr>
<td>Education High school</td>
<td>0.80 (0.40, 1.62)</td>
<td>0.54</td>
</tr>
<tr>
<td>Public service care</td>
<td>1.08 (0.68, 1.72)</td>
<td>0.73</td>
</tr>
<tr>
<td>Gestational age at 1st visit (weeks)</td>
<td>0.92 (0.84, 1.02)</td>
<td>0.11</td>
</tr>
<tr>
<td>Number of visits</td>
<td>1.33 (1.16, 1.52)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Number of visits &lt; 3</td>
<td>1.35 (0.83, 2.17)</td>
<td>0.21</td>
</tr>
<tr>
<td>Miscarriage</td>
<td>2.37 (1.29, 4.35)</td>
<td>0.005</td>
</tr>
<tr>
<td>Living children ≥ 1</td>
<td>1.06 (0.81, 1.38)</td>
<td>0.67</td>
</tr>
<tr>
<td>Counselling</td>
<td>2.53 (1.26, 5.06)</td>
<td>0.008</td>
</tr>
<tr>
<td>Lack of maternal knowledge</td>
<td>0.448 (0.27, 0.72)</td>
<td>0.0009</td>
</tr>
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<table>
<thead>
<tr>
<th>Variable</th>
<th>Invasive prenatal test (n=)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maternal age (≥ 35 years)</td>
<td>11.33 (5.59, 22.96) &lt;0.0001</td>
</tr>
<tr>
<td>Marital status</td>
<td>0.379 (0.18, 0.77) 0.0078</td>
</tr>
<tr>
<td>Employed</td>
<td>1.28 (0.64, 2.58) 0.47</td>
</tr>
<tr>
<td>Education High school</td>
<td>4.96 (1.15, 21.3) 0.031</td>
</tr>
<tr>
<td>Public service care</td>
<td>0.313 (0.16, 0.58) 0.0003</td>
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<tr>
<td>Gestational age at 1st visit (weeks)</td>
<td>0.896 (0.79, 1.01) 0.077</td>
</tr>
<tr>
<td>Number of visits</td>
<td>1.06 (0.93, 1.21) 0.347</td>
</tr>
<tr>
<td>Number of US exams &lt; 3</td>
<td>2.76 (1.42, 5.35) 0.002</td>
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<tr>
<td>Miscarriage</td>
<td>1.45 (0.77, 2.72) 0.242</td>
</tr>
<tr>
<td>Living children ≥ 1</td>
<td>1.38 (1.04, 1.84) 0.023</td>
</tr>
<tr>
<td>Counselling</td>
<td>5.18 (2.85, 9.40) &lt;0.001</td>
</tr>
<tr>
<td>Lack of maternal knowledge</td>
<td>0.716 (0.39, 1.3) 0.271</td>
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that are being tested for and are given balanced and up to date information [30]. The decision to undergo prenatal testing involves sociocultural and ethical-moral systems as determining elements in the decision-making process. This underlines that counselling has a key role in driving informed decisions [31]. Pre-test counselling is therefore essential within antenatal care to ensure women understand limitations and advantages of prenatal testing and whether or not they would like to know information about their foetus and which actions uptake in case of an adverse result [30]. The need for fully informed consent in prenatal screening and testing has never been more urgent. It will also require training for development of approaches to pre-test and post-test and counselling that empower parents to decide whether to be tested and what to do after receiving their results [31].

References

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18 https://www.salute.gov.it/imgs/C_17_pubblicazioni_2381_allegato.pdf

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