Effects of knowledge, education, and experience on acceptance of first trimester screening for chromosomal anomalies

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Abstract

Objectives. To assess pregnant women’s knowledge and understanding of first trimester prenatal screening (nuchal translucency, maternal serum free beta-human chorionic gonadotrophin and pregnancy-associated plasma-protein-A), to evaluate the impact of a new information booklet and investigate the effects of education and experiential knowledge of congenital disabilities on the perceived likelihood of accepting prenatal screening. Design. A quasi-experimental quantitative study with a self-completion questionnaire. Setting. Five different maternity care clinics in Iceland. Population. Expectant mothers in first trimester of pregnancy (n = 379). Material and methods. Expectant mothers were divided into two groups, an intervention and a control group, both receiving traditional care and information. The intervention group additionally received an information booklet about prenatal screening and diagnosis. Main outcome measures. Women’s knowledge score of prenatal screening. The correlation between education, knowledge score, experiential knowledge of congenital disabilities, and the likelihood of accepting prenatal screening. Results. More than half of the women (57%) believed they received sufficient information to make an informed decision about screening. Knowledge scores were significantly higher for the intervention group (with mean 4.8 compared with 3.7 on a 0–8 scale, p < 0.0001). Those with higher scores were more likely to accept screening (p < 0.0001). Women with experiential knowledge of congenital anomalies in their own families were more likely to accept prenatal screening (p = 0.017). Conclusions. Various factors, e.g. experiential knowledge, education and information about prenatal screening affect the likelihood of participation in prenatal screening programs. More information results in better knowledge and higher uptake rate.

Key words: Prenatal screening, patient information, genetic counseling, experiential knowledge

Introduction

Fetal karyotyping using cells obtained via amniocentesis has been technically possible from 1966 (1) and used since then to detect fetal chromosomal aneuploidy. Initially, in some Western countries, a prenatal diagnosis in the second trimester by amniocentesis was offered to women aged 35 and over (2). In the 1980s, the association between low maternal serum alpha-fetoprotein and trisomy 21 was described and general biochemical screening for aneuploidy in the second trimester of pregnancy was subsequently offered in some countries (3). Currently, prenatal screening differs in various parts of the world, but nuchal translucency measurement in the first trimester combined with biochemical markers are now widely offered (4).

In Iceland, prenatal diagnosis by amniocentesis was made available to all women aged 35 years or over in 1978. In 1998, an ultrasound examination at
12–14 weeks and assessment of fetal nuchal translucency as a marker for chromosomal aneuploidy were introduced (5). The first trimester combined screening is now offered to all pregnant women in Iceland, following the Fetal Medicine Foundation model and the NICE guidelines (5–7). At the time of the study, over 70% of pregnant women accepted first trimester prenatal screening (8). In addition, an ultrasound scan for structural anomalies at 19–20 weeks has been offered to all pregnant women since 1985 which more than 99% of pregnant women accept (9). Prenatal care is free of charge and a part of general health care. However, there is a fee for first trimester prenatal screening (approximately €50) as this is considered an optional service.

Limited information is available on how knowledge of prenatal screening, education level and former experience of disability affect the decision to participate in prenatal screening. Etchegary et al. (10) used qualitative analyses to examine the importance of experiential knowledge on decision making regarding prenatal screening. They found that former experience could influence women’s decision either in favor or against screening. Other studies have also shown that pregnancies and life experiences affect women’s decisions on prenatal screening (11–13).

A high acceptance rate for first trimester screening seems to reflect women’s perception of the program as a part of traditional care in pregnancy (14–17). However, the World Health Organization (18) and the Council of Europe (19) have policies recommending that a decision on screening should be made without coercion and that prospective parents should be given adequate prior information. A number of researchers have also argued that an informed choice without pressure or coercion can only be made when all the relevant information has been given and understood (20–22). This approach is consistent with the basic premise of genetic counseling. However, in many countries screening is not offered by genetic counselors, but by those providing midwifery or obstetric care. In those cases, women may be referred for genetic counseling after an abnormal or high risk result is obtained through the screening process. Results of several studies have suggested that participating parents did not have enough knowledge of the screening and its consequences to ensure informed choice (14,23,24). In contrast, in the Netherlands, where it was not standard practice to offer prenatal screening in the first trimester, a study found women’s knowledge of prenatal screening sufficient for informed decision making (25). Another important issue is how the attitude of the health care professional giving the information affects the decision making. In some studies, this has been found to be important (26), while in an Australian study most participants made their own decision without regard to the professional’s views (27). Nevertheless, health care professionals need to ensure that clear information on prenatal screening is given in a neutral fashion (28).

In a quantitative questionnaire study, we aimed to assess how women’s knowledge of prenatal screening, their education level and experiential experience of disability affected their perceived likelihood of accepting first trimester prenatal screening. We investigated how and from whom they obtained their information and how they preferred to receive it. We also studied whether information given by health care professionals was considered to be sufficient for making an informed decision. Lastly, we tested the impact of a new information booklet on prenatal screening and diagnosis.

**Material and methods**

The study was quasi-experimental and conducted in 2006 in five clinics. Two merged prenatal clinics, that is, the Prenatal Diagnostic Unit at Landspítali and The Centre for Maternal Care, were located in Reykjavik city. The Seltjarnarnes Health Clinic was in a suburban town of Reykjavik, and Akranes Hospital Health Care Center and Akureyri Hospital were in rural town areas. The control group consisted of women receiving conventional prenatal care while the intervention group comprised women attending the same clinics after publication of an information booklet. Due to a delay in the introduction of the booklet, there were more women in the control group than in the intervention group. All women received oral and written information about the pregnancy, what to expect and what tests were offered. The new information booklet specifically described the first trimester screening and prenatal diagnosis, the most common chromosomal abnormalities and the added risk of miscarriage following an invasive procedure.

Data were collected via an anonymous self-completion questionnaire (see supplement S1) at the first prenatal care visit. Study inclusion criteria were: (i) age 18 years or older, (ii) being in the first trimester of pregnancy, (iii) first prenatal appointment, (iv) ability to give informed consent, and (v) fluency in Icelandic. No information was gathered about the partners but they occasionally helped in answering questions.

The study was approved by the National Bioethics Committee (no. 06-003), the clinic chiefs and registered with the Data Protection Authority. To preserve respondent confidentiality, average scores for each center are presented.
The questions were initially developed by the first author and amended after evaluation in a focus group of 20 pregnant women to test face validity.

The questions were then reviewed and revised after suggestions by relevant staff and co-authors. Formal tests of reliability were, however, not conducted prior to the study.

Study questions related to demographic information, where, how much and from whom pregnant women received their information, from whom they preferred to receive information, their knowledge of prenatal screening and diagnosis, if and how much the received information helped in decision making. We also asked about former experience of birth defects and how it affected decision making.

Knowledge was assessed by combining answers to four relevant questions. The first was a five part yes/no question (part II, no. 1) on what prenatal screening involved, the second question (part II, no. 3) was a yes/no question listing different possible birth defects and asking whether they were included in the screening program. The third and fourth questions were ‘What is prenatal screening?’ (part II, 6) and ‘What is prenatal diagnosis?’ (part II, 7), with free-text answers. The score for each of these questions was standardized in the interval 0–2, and the knowledge score was the sum of the scores for the four questions in the interval 0–8.

Participants were asked: ‘How likely are you to accept an offer of prenatal screening for congenital defects?’ (part I, 13). Answers were graded on the scale 1–10 (1 = very likely, 10 = very unlikely). A binomial variable, ‘likely to accept screening’, was defined as 1 (yes) if the answer was between 1 and 4, otherwise the score was 0 (no).

Statistics

The free-text answer questions were scored blindly and independently for content by four different health care professionals (midwives), followed by review of discrepant scores by two other health care professionals (a nurse and the first author, a genetic counselor). The software packages SPSS 11 (SPSS Inc.) and Matlab (The MathWorks) were used for statistical analyses. The statistical significance of differences between proportions was tested using the Fisher’s exact test. Logistic regression and the t-test were used to investigate the relationship between the knowledge score and the proportion of women likely to accept the screening offer. Linear regression was used to investigate the relationship between knowledge score, education and age. The t-test was used to assess significance of the effect of introducing the booklet on knowledge.

Results

Four hundred women consented to participate and 95% (n = 379) completed the questionnaire. Of those 63% (n = 237) were in the control group and 37% (n = 142) were in the intervention group (Table 1). The age range was 18–44 years. In the control group, the average age (± standard deviation), and average number of previous children, miscarriages and stillbirths were 29.7 ± 5.7 years, 0.97, 0.52 and 0.02, and in the intervention group 29.6 ± 5.4 years, 1.01, 0.41 and 0.02. The age distribution and data on the number of previous children, miscarriages and stillbirths were in concurrence with the Icelandic population in general. The expressed likelihood for accepting the screening offer was also in concurrence with the actual uptake into the program. Since the questionnaires were returned anonymously, we were not able to examine the demographic characteristics of the few non-responders (n = 21) with those who contributed data.

The majority, or 66% (n = 251), wanted all available information about prenatal screening and diagnosis, while less than 2% (n = 7) wanted no information at all. Fifty-nine percent of women (n = 219) preferred receiving oral and written information while information via a webpage was favored by 54% (n = 204). The preferred communicator of information was a

<table>
<thead>
<tr>
<th>Location</th>
<th>Control group (no booklet)</th>
<th>Intervention group (received booklet)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Akranes</td>
<td>26 (62%)</td>
<td>16 (38%)</td>
<td>42</td>
</tr>
<tr>
<td>Akureyri</td>
<td>50 (67%)</td>
<td>25 (33%)</td>
<td>75</td>
</tr>
<tr>
<td>Seltjarnarnes</td>
<td>18 (72%)</td>
<td>7 (28%)</td>
<td>25</td>
</tr>
<tr>
<td>PDU and CMC*</td>
<td>143 (60%)</td>
<td>94 (40%)</td>
<td>237</td>
</tr>
<tr>
<td>Total</td>
<td>237 (63%)</td>
<td>142 (37%)</td>
<td>379</td>
</tr>
</tbody>
</table>

*Prenatal Diagnostic Unit and Centre for Maternal Care in Reykjavik combined.

Note: PDU, prenatal diagnostic unit; CMC, centre for maternal care.
midwife selected by 63% \((n = 240)\), followed by a doctor selected by 32% \((n = 120)\).

All participants were asked how useful they found the information received at the maternity care clinics for the decision making regarding prenatal screening. The information was found to be ‘very useful’ or ‘quite useful’ by 63% \((n = 240)\), but the remaining 37% \((n = 139)\) found the information either ‘not very useful’ or did not answer the question. When asked whether they considered the information to be sufficient to make an informed decision, 57% \((n = 216)\) answered yes, 11% \((n = 42)\) answered no and 28% \((n = 106)\) were not sure. The information they had received came from obstetricians 53% \((n = 201)\), maternity care staff 46% \((n = 175)\), friends 40% \((n = 151)\), the media 22% \((n = 83)\) and relatives 20% \((n = 78)\). Only 5% \((n = 20)\) had received information from a general practitioner.

Table 2 shows the mean knowledge score of women in the different clinics and the proportion likely to accept a screening offer. The knowledge score was significantly higher in Reykjavik, compared with the other locations. The proportion of expectant mothers likely to accept a screening offer was also higher in Reykjavik, but the difference was not significant.

The levels of education and the average knowledge score in each education group are given in Table 3. The knowledge score correlated significantly and positively both with the level of education \((\rho < 0.0001)\) and with age \((\rho = 0.000)\). Multiple of the knowledge score on education and age showed both explanatory variables to be significant for the knowledge score. A two-tailed Fisher’s exact test showed a significant difference \((p = 0.033)\) in the 69% \((n = 261)\) likelihood of accepting a screening offer among those with an university or high-school education compared to the 57% \((n = 216)\) in the group with an elementary school or vocational education. The expectant mother’s age alone had no effect on the acceptance likelihood.

A logistic regression was used to investigate the relationship between the proportion of women likely to accept a screening offer and the knowledge score (Figure 1). The resulting formula for proportion of women likely to accept was

\[
P = \frac{1}{1 + \exp(-0.654 - 0.326 \times (\text{knowledge score}))}
\]

The coefficient for the relationship was significantly different from zero \((p<0.0001)\). Education was not an independent factor in multiple regression of likelihood of accepting screening, knowledge and education.

The mean knowledge score and the likelihood of accepting a screening offer for both groups in the different clinics is shown in Table 4. The average knowledge score for those who received the information booklet was 1.1 points higher, compared with those who did not \((p < 0.0001)\). Two of the questions requested free text answers to describe prenatal screening and prenatal diagnosis. The intervention group showed significantly more knowledge

<table>
<thead>
<tr>
<th>Location</th>
<th>(n)</th>
<th>Knowledge score mean</th>
<th>Likely to accept screening offer</th>
<th>(p)-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PDU and CMC</td>
<td>237</td>
<td>4.5</td>
<td>167 (70%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Seljarnarmes</td>
<td>25</td>
<td>4.1</td>
<td>16 (64%)</td>
<td>0.8</td>
</tr>
<tr>
<td>Akranes</td>
<td>42</td>
<td>3</td>
<td>24 (47%)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Akureyi</td>
<td>75</td>
<td>3.5</td>
<td>41 (55%)</td>
<td>0.0002</td>
</tr>
<tr>
<td>Total</td>
<td>379</td>
<td>4.1</td>
<td>248 (65%)</td>
<td></td>
</tr>
</tbody>
</table>

*Prenatal Diagnostic Unit and Centre for Maternal Care in Reykjavik combined.

The \(p\)-values give the significance of the average knowledge score for the actual location being different from the average of the other locations. Note: PDU; prenatal diagnostic unit; CMC, centre for maternal care.

<table>
<thead>
<tr>
<th>Highest level of education</th>
<th>(n)</th>
<th>Knowledge score mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elementary school</td>
<td>69 (18%)</td>
<td>3.3</td>
</tr>
<tr>
<td>Vocational education</td>
<td>25 (7%)</td>
<td>3.5</td>
</tr>
<tr>
<td>High school (finished at age 20)</td>
<td>70 (19%)</td>
<td>3.8</td>
</tr>
<tr>
<td>University education</td>
<td>196 (52%)</td>
<td>4.7</td>
</tr>
<tr>
<td>Did not answer question</td>
<td>16 (4%)</td>
<td></td>
</tr>
</tbody>
</table>

*The first 10 years of education is the same for all in Iceland and finishes with a standardized exam the year students turn 16.

*Vocational education is for either two or four years depending on the nature of the study. Some students doing a four year study then go to university.

*High school ends with a university entry exam.
One question dealt specifically with knowledge about the types of trisomies detected by the screening. Knowledge on trisomy 21 was not significantly different between the groups, while there was a significant difference in the knowledge about trisomies 13 and 18 ($p = 0.005$). Overall, the proportion of women likely to accept a screening offer was higher or 68% ($n = 96$) among those who received the information booklet compared to 64% ($n = 151$) among those who did not, but the difference was not statistically significant.

The personal experience of birth defects and proportion of women likely to accept screening is shown in Table 5. Out of 379 participants, 20.8% ($n = 79$) had experience of birth defects, personally, among descendents, their spouse or close relatives and of these, 76% ($n = 60$) were likely to accept screening.

Of the remaining 300 participants, 63% ($n = 188$) were likely to accept screening ($p = 0.017$). Of those with personal experience of congenital anomalies in biologically related persons (categories 1–4, $n = 110$), 72% ($n = 80$) were likely to accept screening. Of the remaining (categories 5–8, $n = 123$), 60% ($n = 74$) were likely to accept screening. This difference was, however, not significant ($p = 0.055$).

**Discussion**

There is an ongoing debate on whether the parental knowledge and understanding of prenatal screening is sufficient to ensure informed choice (20,21,24,25,29,30). It is difficult to determine the information needed as societies are different and women differ in
their level of prior knowledge and information requirements. In contrast, the issues of informed consent and informed choice for prenatal screening have been widely discussed; we have not found quantitative studies investigating the effect of experiential knowledge on the likelihood of accepting first trimester prenatal screening. Two recent qualitative studies have been reported (10,17). In this quantitative study we investigated how knowledge, education, location, experiential knowledge and information on prenatal screening affected the perceived likelihood of participation in a screening program.

Our cohort of nearly 10% of all pregnant women in Iceland was a good reflection of the Icelandic population (8,31) and their general demographic, social and education level was similar to other Nordic countries (32). Given the high percentage of returned questionnaires, it is likely that the results reflect the attitudes of the women approached to participate in the study. Due to the anonymous responses we cannot analyze this further. The perceived likelihood of participating in the screening program was in accordance with the actual screening uptake (70%) (8). The general attitude towards prenatal screening was in concurrence with other studies (30). We therefore suggest that the results can be used to provide information about the situation in other societies where people have similar cultural and educational background.

Women who make an informed choice regarding prenatal screening are more satisfied with the decision and will experience less decisional conflict (25). Over 60% of participants found the information received at maternity clinics very or quite useful for their decision making and 57% found them sufficient. Although prenatal screening has been offered for a decade, there are still gaps in women’s knowledge about the screening program, as clearly seen when they were asked to use their own words to describe prenatal screening and diagnosis. Some of the answers indicated that the terms ‘prenatal screening’ and ‘prenatal diagnosis’ had the same meaning. There is, however, a fundamental difference between screening and diagnosis and it is important to make sure that this is understood.

It has been suggested that the educational level of the expectant mother can influence the decision regarding prenatal screening and a higher education level may result in less participation due to better understanding of the possible dilemma of diverse outcome (30). In contrast, we found that those with more education were slightly more likely to accept the screening offer, but education turned out not to be a significant factor by itself in a multiple logistic regression model of the acceptance likelihood on both knowledge and education. We therefore conclude that education affects the likelihood of accepting screening indirectly by increasing women’s knowledge on screening and the conditions for which it is offered. As the risk of trisomy increases steeply with age, it is of interest that the age of the woman alone did not affect the likelihood of accepting screening. This suggests that the exact magnitude of the risk is not a major factor in women’s decision on participation in prenatal screening.

We evaluated the effect of a new information booklet on the knowledge of prenatal screening and diagnosis. The intervention group showed increased knowledge, especially on topics less familiar to the general public. The control group already had good knowledge on trisomy 21, and this knowledge was difficult to improve with an information booklet. However, the booklet introduced two rare conditions, trisomy 13 and trisomy 18, in a similar way as trisomy 21. The knowledge about these two trisomies increased significantly within the intervention group, indicating the educational effect of the information booklet. We conclude that the added information in the form of a booklet increases understanding and knowledge, although women prefer other types of information delivery as well. We found knowledge to positively correlate with likelihood of accepting

<table>
<thead>
<tr>
<th>Experience</th>
<th>n</th>
<th>Likely to accept screening offer</th>
<th>p-Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self</td>
<td>9</td>
<td>6 (67%)</td>
<td>&gt;0.1</td>
</tr>
<tr>
<td>Offspring/spouse</td>
<td>13</td>
<td>10 (77%)</td>
<td>&gt;0.1</td>
</tr>
<tr>
<td>Close relative</td>
<td>57</td>
<td>44 (77%)</td>
<td>0.033</td>
</tr>
<tr>
<td>Other relative</td>
<td>31</td>
<td>20 (65%)</td>
<td>&gt;0.1</td>
</tr>
<tr>
<td>Close friend</td>
<td>24</td>
<td>14 (58%)</td>
<td>&gt;0.1</td>
</tr>
<tr>
<td>Acquaintance</td>
<td>51</td>
<td>34 (67%)</td>
<td>&gt;0.1</td>
</tr>
<tr>
<td>Co-worker</td>
<td>34</td>
<td>20 (59%)</td>
<td>&gt;0.1</td>
</tr>
<tr>
<td>Client</td>
<td>14</td>
<td>6 (43%)</td>
<td>&gt;0.1</td>
</tr>
<tr>
<td>No experience</td>
<td>167</td>
<td>105 (63%)</td>
<td>&gt;0.1</td>
</tr>
</tbody>
</table>

The p-value column shows the significance of the close relative group being more likely to accept a screening offer than the other groups combined.
screening offer. This is consistent with a study by Thornton et al. where participation in screening for Down syndrome was slightly increased when extra information was offered individually (33).

The perceived likelihood of participation in the prenatal screening program was only slightly increased among those receiving the information booklet and the difference was not statistically significant. The focus of the booklet was to improve informed choice, rather than increase uptake. Relevant patient advocate groups were asked to evaluate the information to ensure that it was as neutral as possible. The neutral information perhaps explains why we found a statistically significant increase in the knowledge score between the intervention and control groups, but not in the likelihood of accepting screening.

The results from this study can be used to guide improved delivery of information. It is of concern that the information material provided was not considered sufficient by almost half of the women. An information booklet may not meet the needs of all parents. Two-thirds of participants wanted both written and oral information, a midwife as their initial source of information followed by a medical doctor. It is of interest that a similar number of women said that their information source was friends, family and media. In contrast, only 5% mentioned the general practitioner. Some women wanted an extra consultation with the health care professionals where the information is discussed and explained. This finding is supported by the findings of others (17,28). Skirton and Barr found that the majority of parents wanted individualized professional information while access to books or websites recommended by health professionals would be useful in supporting decision making (17). Discussion may enable women to place the information into the context of their own lives and circumstances in a way that written information cannot.

The influence of previous experience of disability on the likelihood of accepting screening was shown by Skirton and Barr who reported that knowing about the life of someone with a disability was an important factor in making the screening decision (17). The majority of our participants reported some personal experience of congenital anomalies or disability, ranging from self and very close relatives to clients or acquaintances. The type of anomaly or disability was not specified. The Skirton and Barr study did not specify, as we did, to whom the experience relates to (17); therefore, participants in their study may have reported their experience from a much broader range of social contexts. However, it could be argued that any experiential knowledge pregnant women regard as influential is important, regardless of the relationship between her and the person with the disability. Recently, Etchegary et al. (10) reported the findings from a qualitative study where both empathetic and embodied experiential knowledge of congenital anomalies affected women’s decision to participate in prenatal screening. Our findings that pregnant women’s previous experience of congenital anomalies or disability increased the acceptance likelihood are consistent with the results from both of these studies. Neither of these studies looked at the direct correlation between knowledge and acceptance of prenatal screening.

Although we have identified some factors that affect the likelihood of accepting prenatal screening, they explain women’s decision making only in part as their opinions differ widely. Other factors not addressed in this study are personality traits and partner attributes. Clinical practitioners are well aware of how knowledge and prior experience can affect an individual woman’s decision in different ways. It would be of particular interest to further study how and why knowledge and prior experience increase the likelihood of accepting prenatal screening and to what degree these factors reflect on women’s personal values and/or their expectations from society.

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### Declaration of interest:

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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