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Midwives' attitudes to and knowledge about a newly introduced foetal screening method

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Midwives' attitudes to and knowledge about a newly introduced foetal screening method

A number of screening procedures are offered by midwives during pregnancy and the number is increasing rapidly. The measurement of nuchal translucency is a fairly new ultrasound method for antenatal screening, primarily for Down syndrome. The results give a better risk calculation than maternal age alone and can mean a decrease in the number of invasive procedures needed to identify this syndrome prenatally. The aim of this study was to gain insight into the midwives' point of view concerning the introduction of the method in two different hospitals. In one hospital it had been introduced as part of a research project while in the other it had been integrated as an offer in the antenatal care programme. A questionnaire was sent to the 80 midwives working in the antenatal clinics

servicing these two hospitals. A total of 79% of the questionnaires were answered. The results indicate that in both districts, the similarities are greater than the differences with regard to the midwives' education, knowledge and their own opinions of their ability to inform pregnant women about the method. Although most of the respondents were positive to it, a number of midwives felt that, in general, information about foetal diagnosis was a difficult part of their work, mentioning both ethical and practical aspects. This highlights the need for continuing education, standardized policy and an ongoing ethical debate.

Keywords: screening, nuchal translucency, midwives, maternity care, education, information, ethics.

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Introduction

Screening for foetal malformations

The number of screening procedures offered during the first and second trimester of pregnancy has increased rapidly during the last few years. Information about the methods available must be given early in pregnancy, often at the first visit to the midwife – the booking visit. Midwives need to have accurate and up-to-date knowledge of these procedures, especially when discussing the different methods of foetal diagnosis with expectant parents. It is important that the parents can make an informed choice to accept or decline the procedures offered.

Ultrasound in the second trimester is the most widespread screening procedure offered for foetal diagnosis. Two methods that are commonly available as screening methods for Down syndrome are serum screening from

maternal blood, often called triple test (1) and the measurement of nuchal translucency (NT) using ultrasound (2).

Counselling is especially important when the method offered is a screening technique, not giving a definitive answer (3). Green found, in a survey of obstetricians in England and Wales, that inadequate resources for counselling, when offering a screening procedure, was considered a major problem, while women not understanding the test was even more problematic (4). Health professionals have to deal with the questions that arise after screening procedures have been performed. Their knowledge of the procedure and the interpretation of the results can vary as a study from South England has shown (5). Professional and personal conflict has also been described concerning ethical questions in relation to foetal screening for Down syndrome (6). Midwives have not always been involved in the process leading up to the introduction of a new method (7).

Screening for Down syndrome

Down syndrome, first described in 1866 (8), is the most common and the most widely known chromosomal abnormality and has therefore been the subject of extensive research. In many countries, amniocentesis has been

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offered to women over the age of 35, as the risk for carrying a foetus with Down syndrome increases with maternal age. If all women in this age group accept the offer, 20–30% of the foetuses with Down syndrome would be identified prenatally. The interest given to noninvasive procedures is due to the fact that they can be used to better select a risk group than age alone, thus reducing the number of invasive procedures needed to detect a foetus with Down syndrome (9). Invasive procedures, needed for a definitive diagnosis, carry an increase miscarriage rate of at least 1–2% (10). For every affected foetus identified two women, with healthy pregnancies, miscarry as a result of the procedure. Most babies with Down syndrome are born to women under the age of 35, so a noninvasive method of screening would better select women for invasive testing without increasing the number of invasive procedures and subsequent miscarriages. Both triple test and NT are used for this – alone or in combination. NT, which is a fluid-filled space under the skin at the back of the neck, can be measured using ultrasound and is present in all foetuses between gestational weeks 10–14. An increased NT in relation gestational week, in combination with maternal age, can be an indication that the foetus has Down syndrome (2) and invasive testing should be offered. When the foetus has increased NT and a normal karyotype, it has been shown that there is an increased risk for cardiac malformation (11). Triple test is, at present, taken early in the second trimester and also gives a different risk assessment than age alone (12).

Results from different screening studies for the detection of Down syndrome vary, the first coming from centres of excellence. It takes time for the same standard to be reached outside pioneer centres (13), which is an added complication when informing about reliability. A constant search is going on for new markers for Down syndrome, for example, the measurement of foetal nasal bone length, which seems to be promising and might well become an established routine method (14).

Information and informed choice

Parents are encouraged to make an informed choice about the degree of information they wish to be given (15). The midwife, when she is the primary caregiver, is the key person in imparting this. Health professionals are rarely given any training in how to impart information in the most optimal way (16). For a decision to be a truly informed one, two requirements must be met, according to Cooper (17). These are that the person providing the information has imparted the important facts and made sure that the person receiving them has fully understood them, their implications and that it is an option. This can be a problem with the type of information required concerning the methods for Down screening, as both serum screening and NT give a different risk estimation than age

but not a definite answer. In Green's (4) survey of obstetricians, half of them considered that the midwives lack of knowledge about Down screening was a problem. Sadler (5) has shown, in her study of obstetricians, general practitioners and midwives in South England, that factual knowledge about triple test was poor, especially regarding the questions concerning how effective the test was as a screening procedure (specificity, sensitivity and positive prediction value). This was also supported by more recent studies of midwives' knowledge both by Samwiil (18) and Bramwell and Carter (19), their results showing the same trend. Samwiil (18) also found that the midwives never felt quite confident when counselling women about the procedure. The problem is not made easier by the fact that NT screening involves an ultrasound investigation, which is popular among parents-to-be (20).

The situation in Sweden

Triple test and NT have not been part of the general antenatal care offered in Sweden. Both methods have been available on request, but not on a nationwide basis. During the last few years a multicentre, randomized-controlled trial (RCT) of NT has taken place in the country. The aim of the trial was not to evaluate NT as a method, but to see if an ultrasound investigation performed in these gestational weeks could replace the 18th week scan for the assessment of foetal anatomy.

In the south of Sweden one hospital's Ultrasound Department has taken part in this study while the Ultrasound Department at the hospital serving the rest of the district has had the expertise available to provide the method on request but not the resources to offer it generally. The method has been reported in the popular press, but all hospitals not taking part in the RCT have been asked not to offer NT as a routine until the trial is finished and evaluated (9). In connection with its introduction, all midwives, from both hospitals in the area, were given the opportunity to attend different types of teaching sessions about the method.

Aim

The aim of the study was to investigate midwives' attitudes to and knowledge about a newly introduced foetal screening method.

Method

Both authors, who are practising midwives, constructed a questionnaire with 20 questions. The second author has worked with obstetric ultrasound for many years and has also passed the standardized theoretical test needed to perform NT. The questions were predominantly of multiple-choice type, short answer or used Visual Analogue

Scales (VAS) (21). The questionnaire was first tested on four experienced midwives, from an adjacent district, who were asked to complete it and give their comments. Adjustments were made after these suggestions.

The first four questions consisted of background facts about the midwives, their years in the profession and the number of mothers they cared for annually. The respondents were also asked three questions about which type of information/training they had been given with yes/no answers. The six questions about their own roll in imparting information concerning NT used VAS, multiple choice or short answer questions. Five questions were given to test the respondent's knowledge of the procedure and its results (three multiple choice and two open questions requiring short answers). The questions about knowledge were elementary and based on the type of question a woman would ask her midwife about NT. These included the weeks in which NT can be measured, the percentage of positive screening procedures and the detection rate for Down syndrome. These were constructed after reviewing the literature and also based on our own experience.

One question was a translation into Swedish of a question used by Green (4) which concerned the problems encountered when offering screening for Down syndrome. The final question was an open question about the midwives personal attitudes to NT as a screening method.

All the midwives that worked at the antenatal clinics (ANC) in the district and that referred their mothers for NT to one of the two hospitals were asked to take part. Their names were obtained from the midwifery managers for the areas concerned. The questionnaire, with a stamped addressed envelope and a covering letter explaining the study and stressing that taking part was optional, was sent to them personally at their place of work. The midwives who did not wish to participate were asked to return their questionnaires unanswered. The envelopes were number coded so that reminders could be sent out to the ones that had not replied, the code list was destroyed after the second reminder had been given. The questionnaire was anonymous.

The results from the multiple choice and VAS questions were computer analysed using SPSS and resulting in a mean and SD. Manifest content analysis was used for the open question (22). The answers were categorized and quantified into two themes. These emerged from and corresponded to the content of the material. This analysis was discussed during the process to increase validity.

Results

Of a total of 80 questionnaires, 63 replies were received, which gave a reply frequency of 79%. Of the remaining 17 questionnaires, two were returned unanswered, without comment while in four cases comments were given. Two

midwives stated that due to earlier sick leave they lacked time to complete it and one midwife had changed her employment so the questions were no longer relevant to her. The fourth midwife declined to answer due to the coding system used on the envelopes. Eleven questionnaires were not returned. Of the 63 that answered, five midwives stated they had not received or looked for information about NT. These five questionnaires were excluded from further analysis, which left 58 completed questionnaires.

The midwives, on average, had worked as such for 17 years and with antenatal care for 11 years. The total number of pregnant women these midwives cared for per year was 4500.

Satisfaction with own knowledge

Teaching about NT had been attended by 68% of the midwives and 48% had also searched for information from varying sources. The form of teaching or information given varied from only written to a half-day of lectures on the subject and other combinations of these two. The midwives were asked to mark on a VAS the degree of satisfaction they felt with their own knowledge when informing women about NT. On the scale 0 was equivalent to 'Not at all' and 10 to 'Absolutely'. This question had a mean score of 6.0 (SD = 2.5, range: 0–10).

Who should give the information and counselling about nuchal translucency prior to taking the test?

The midwives were asked to which degree they felt it correct that they, as primary care givers, should give preliminary information about the method to the women they cared for. On this VAS, 0 was equivalent to 'Do not agree' and 10 'Agree completely'. The midwives showed a tendency to agree that they were the right people to give this information (mean 7.0, SD = 2.7, range: 0–10). If problems arose, or if they had any questions about the method, the midwives seemed to know where to turn. Only one midwife answered she did not know. This question had no fixed alternatives and where the midwives would look for additional knowledge varied. The Department of Obstetrics and the Department of Obstetric Ultrasound were frequently mentioned, as was the Specialist Antenatal Clinic. One midwife wrote 'to those who consider the method to be of use'.

Midwives' experience of the women's understanding of nuchal translucency

Women's understanding of the method was judged as fairly good by the midwives (Fig. 1).

The midwives that thought women had difficulty in understanding the information also thought that their own

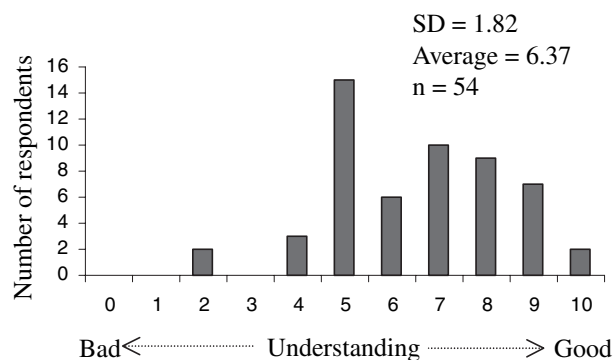


Figure 1 The midwives' impressions of how well women understand the information they are given about nuchal translucency.

knowledge was lacking. Despite this fact they still considered the midwife to be the most suitable person to give information about the method.

Questions testing the midwife's own knowledge

In one question the midwives were asked to name the three parameters (maternal age, gestational week and NT in millimetres) that were included in the risk calculations for Down syndrome, 26% named all correctly, 43% named two correctly, 19% one correct answer and 12% did not answer the question. The remaining four questions that tested knowledge were combined (Table 1) – the highest mark being 4, average 2.2. No correlation was found between knowledge and background factors, form of education about NT or the midwives' satisfaction with their own knowledge (Spearman's correlation test). The question about additional investigations that should be performed if the karyotype was normal was the question that gave the highest number of incorrect answers, 64% answering incorrectly. 'No further investigations' was the

answer given by 36% of the midwives. The remaining 28%, who answered incorrectly, mentioned maternal anxiety and the additional cost incurred by the need for further investigations.

Problems when introducing a new screening method

With the introduction of a new screening procedure problems, both foreseen and unforeseen can be encountered so the questionnaire gave examples of problems that could arise for both the woman and the midwife (4). The midwives were asked to mark them as 'No problem', 'Somewhat problematic' and 'Major problem'. The anxiety caused by a false positive answer was considered to be the biggest problem, while refusing amniocenteses after testing positive was the least problematic. Not all midwives had answered these questions, the reply frequency varied between 83 and 95% for the different problems. The majority of the respondents found all the problems relevant, which is to say they had encountered problems about the anxiety the offer of NT could create, women not understanding the investigation, unnecessary ultrasound investigations and unnecessary amniocentesis.

Personal views on nuchal translucency as a method

This open question was answered by 84% (49 midwives). Two main categories emerged: 'Ethical considerations' and 'Information'.

Ethical considerations. A third of the midwives mentioned ethical reflections. They had thoughts about the choice the expectant parents might have to make and also the changes in the way society thinks about a handicap. The midwives were not only professionally affected by this aspect.

Table 1 The midwives' answers to the questions concerning knowledge

	Reply frequency, n (%)	Alternative	Reply frequency, n (%)
Weeks when investigation most suitably performed	57 (98)	Weeks 10–14 (correct)	49 (86)
		Weeks 12–16 (incorrect)	7 (12)
		Weeks 14–16 (incorrect)	1 (2)
How many percent can be expected to need further investigations?	47 (81)	Five women (correct)	20 (43)
		One woman (incorrect)	24 (51)
		Eight women (incorrect)	1 (2)
		Other answer in free text	2 (4)
How many cases can be diagnosed prenatal with 100% acceptance of nuchal translucency (NT) and of further investigations?	55 (95)	75–85% (correct)	40 (73)
		35–45% (incorrect)	10 (18)
		50–60% (incorrect)	5 (9)
Are any further investigations needed if karyotype is normal?	47 (81)	Foetal cardiac ^a (correct)	17 (36)
		Other (open question)	30 (64)

^aSonography.

To whose advantage is this? The women – society – and why? Who – what has given us the right to refuse anyone life. Today's society multifaceted (Midwife No. 61).

Many midwives mentioned that it was positive that NT, by better selecting a risk group, could reduce the number of miscarriages of healthy foetuses that result from amniocentesis. The fact that the method is a complement for those who want a more specific diagnosis than ultrasound alone can give but are afraid of invasive procedures, was also referred to. A point stressed was that the offer was given without the possibility to perform the investigation on all pregnant women that might wish for it, due to lack of resources.

Twelve midwives noted they were unsure about prenatal diagnosis in general. Three midwives wrote that they felt sympathy for the women of today and were pleased that they themselves already had their children, so that they did not have to make these choices.

Just another factor that reduces the woman's belief that she can give birth to a healthy baby. Less joy over the pregnancy. Focused on problems = more worry. A unrealistic belief in technology – many think that it gives infallible information and become worried first when they understand it's not so. Pleased than I'm not pregnant as things are today (Midwife No. 24).

Four midwives felt that the health care system could place the woman in an ethical dilemma just by offering an investigation. The offer could create angst and also, if accepted, give the woman information that she had not initially requested and perhaps did not want.

Good for the couples who want to know but worrying for many who haven't thought about it (Midwife No. 53).

Many parents may not understand the purpose and possible consequences of the investigation. Instead they see the possibility to have a look at their child earlier than they would have done with the usual (18th week) ultrasound (Midwife No. 51).

Some midwives commented on the fact that it was not unusual for women to decline the offer of NT. As an example they mentioned that women from other cultures had a completely different view about foetal diagnosis, as abortion was not an alternative for them or if it was, only at a very early stage in pregnancy.

Information. The second category was views about information. This was mainly the information given to the couples but also to a certain extent the information the midwives themselves had been given from the hospital. There was not only concern about imparting correct information but also the midwives work situation and what the new task would mean. The time needed for the increasing amount of information that should be given was also a problem.

It takes a great amount of energy and time at the booking visit (Midwife No. 44).

The more foetal diagnostic investigations there are the more difficult it is for us to give the information (Midwife No. 25).

One midwife commented on the difficulties encountered when giving support to women who have declined the investigations offered.

It's a very precarious situation – to give support to the women that don't want foetal diagnosis (Midwife No. 27).

An offer or part of a research programme

There were very few differences between the answers given by the midwives who worked where NT was part of a research programme and those who worked where it was an offer. However, there were significant differences in three areas – midwives in the research project had looked for information themselves to a higher degree, received more written information and their views about amniocentesis also differed. More midwives working where NT was an offer thought that the women that requested NT should not be negative to the idea of having an amniocentesis performed. Other differences were found in the open question but these referred more, in a negative way, to the resources available at the two hospitals. It was not possible for all the women that requested NT, where it was not part of the research programme, to have the investigation performed within the relevant time period. At the other hospital it replaced the 18th week scan for the women having it performed, which was also considered to be a disadvantage. The midwives working in one small geographical area thought that the information about NT being available on request had been given too suddenly, without prior groundwork, which made them a little sceptical to the method.

Discussion

Reply frequency to this questionnaire was 79% (n = 58) which is higher than that reported by both Samwiil (18) 58% (n = 162) and Bramwell and Carter (19) 53% (n = 81) who also used postal questionnaires, although the number of respondents is less. This was due to the fact that NT screening has newly been introduced in Sweden and that there were the only 79 midwives in the county involved in it. The questionnaire was not tested on midwives in the system, as the number of midwives involved in informing about NT was already relatively small. This was a disadvantage. The four experienced midwives that read it and gave their comments had no personal experience of systematically giving information on the subject, which was also a disadvantage, although no individual question seemed to have caused problems for the

midwives that replied to the questionnaire. One of the questions concerning knowledge (name the parameters that are included in the risk calculation), seemed to be wrongly formulated, as many midwives did not mention the measurement of NT, probably taking it for granted, judging by the answers. Therefore, this question was not used in the correlation calculations.

The question of foetal screening seemed to be an issue the midwives had strong views about, as so many answered the questionnaire, despite heavy workloads. This was also mirrored in the number of those who answered the open question. Five midwives in the area had not received any instruction about NT nor had they searched for it themselves. It would have been an advantage to know if they were in any way involved in giving information.

There was one area where the midwives' knowledge of the consequences of increased NT was lacking. This was the fact that foetal cardiac ultrasound should be offered to women with a continuing pregnancy, in weeks 20–22. This possibility should be available, both for the women where karyotyping has been shown to be normal and to those who did not want to undergo invasive procedures. This fact and the time when it is performed can influence the women's primary acceptance of the NT test. Apart from this question, the percentage of correct answers concerning factual knowledge was higher than reported by both Sadler (5) and Samwiil (18) although did not reach 100%, which is considered optimal.

The midwife considered herself the best person to give the general basic information and counselling about NT. This is in agreement with Sadler's findings (5) where the majority of the respondents, both doctors and midwives, considered the ANC midwife to be the best and most suitable person for the task. In Sweden, the midwife is the first and often the only professional person, to meet the couple so early in pregnancy that the information about NT is relevant. The multidisciplinary approach that has been suggested by Bramwell and Carter (19) would be difficult to apply generally, due to the relatively short-time for parental reflection between information and decision-making.

The problem with the flood of information is similar for both parents and caregivers. Several midwives in the current study found it more and more difficult to keep up-to-date. Smith et al. (16) have shown that brief training interventions, consisting of 1-hour group discussions, focused around a video, could be of great use to caregivers, if it was given repeatedly. This was mandatory and time was set aside by clinic managers.

As counselling about prenatal diagnosis is becoming more complicated and complex, the task of imparting it should perhaps be given to specially trained and interested midwives. This is the case in some countries although in Sweden genetic counselling is a new roll for midwives.

Despite the problems encountered, most of the midwives were positive to NT screening, although some of them seemed to be doubtful in general about screening for Down syndrome. There is a risk that the midwife's personal views colour the information she gives. Ryder (6) has suggested that continuing education should include the opportunity to reflect on one's own attitudes and values and how these feelings might have an impact on ones work with women.

This study mirrors two ways of introducing a new method – on one hand as part of a research project and on the other as an offer, dependant on demand and interest. News about a popular investigation spreads quickly so demand increases in situations where one hospital offers it and another does not. This can in turn lead to a new method being adopted too quickly and, as a consequence, result in the situation where the midwife may lack knowledge in vital areas. Williams et al. (7) point out that midwives should be involved in decision-making about the policy concerning prenatal screening so that it is not 'An inevitable and inexorable process over which they had little, if any, control'. When midwives feel they are not part of this process, as the midwives in one geographical area felt, it might affect their attitudes when giving the information required.

Information should be nonjudgemental (17). Should a midwife discourage a woman from having NT measured if the woman is sure she would refuse to have an amniocentesis if testing positive? That the midwives who were part of the RCT had different views on this subject may mirror the fact that they thought the questions that the RCT would answer were of greater importance than just NT.

Several midwives wanted ongoing discussions about the ethical aspects and 12 were doubtful about foetal diagnosis in general. Jackson (23) points out that women often want to know the midwives' personal views about a method or type of treatment. It is, therefore, of great importance that teaching and information is given to midwives prior to the introduction of a new form of diagnosis requiring explicit information (16). It is also important that the information is of a uniform character, so that the information that they in their turn impart is similar if parents compare notes. This is especially important when introducing a new 'popular' investigation, which involves ultrasound and the possibility to 'see' the baby like NT (20, 15). If the measurement of foetal nasal bone length as described by Bunduki et al. (14) proves to be a significant parameter for Down screening, it can present even more ethical problems as it can be easily included in the second trimester routine scan without the parents being fully aware of it.

Conclusions

The results show that the introduction of a new foetal screening method is associated with practical difficulties

such as reaching all midwives working with antenatal care, with teaching/information offers. Hospital resources to meet demand can also be underestimated. In general, midwives were satisfied both with their own knowledge and with the way that they perceived women understood the information they gave. In most areas their own knowledge was acceptable, although not up to the desired 100%. The question that had the largest number of incorrect answers was about further investigations needed if the karyotype was normal. Only 36% of the midwives who answered this question knew that foetal cardiosonography (in gestational week 22) should be offered to continuing pregnancies with increased NT. The fact that this late investigation may be necessary can influence the parent's acceptance of NT. The midwives' greatest worry was the anxiety caused by false-positive results. The answers to the open question showed that the majority of midwives were positive to NT, even on a personal level, although a third of them were doubtful, from an ethical point of view, about the role of foetal diagnosis, in general. It seems apparent that there is a need for continuing education, standardized policy and an ongoing ethical debate in this area.

Author contribution

Maria Ekelin was responsible for data collection, statistical analysis and obtaining funding. Elizabeth Crang-Svalenius was responsible for supervision.

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Ethical approval

Ethical approval was granted by the Research Ethics Committee of the Medical Faculty of the University of Lund, LU (Reference number 570-00).

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