Screening in the Childbearing Year: Midwives' Scientific Knowledge and Its Use in Decision Making

Dépistage pendant la grossesse: Connaissances scientifiques des sages-femmes et leur utilisation dans la prise de décision

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ABSTRACT

The objective of the study was to explore New Zealand midwives' perception of their knowledge of genetics and embryology and its application to their practice. The study design was based on a self-completed postal questionnaire using convenience sampling. The questionnaire was sent to independent midwifery practices and Maternity units in New Zealand, specifically focused on currently practising Registered Midwives.

The degree of perceived knowledge varied between practitioners, as does its use in practice to discuss issues with women. The majority of midwives indicated that they did not have enough knowledge specifically in genetics to discuss those issues. Most midwives gained their knowledge through formal and informal methods. The study concluded that midwives need to have available, professional development opportunities in the area of genetics and embryology in order to effectively facilitate informed choice when offering the various tests and treatments during the childbearing year.

KEYWORDS

Embryology, genetics, informed decisions, midwifery practice.

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RÉSUMÉ

Le but de l'étude visait à examiner la perception des sages-femmes de la Nouvelle-Zélande par rapport à leurs connaissances de la génétique et de l'embryologie et de leur application dans leur pratique. L'enquête a été effectuée selon la méthode de l'échantillonnage de proximité au moyen d'un questionnaire postal à remplir par les participants. Le questionnaire a été envoyé à des pratiques sages-femmes indépendantes et unités de maternité de Nouvelle-Zélande, plus particulièrement celles où il y a présentement des sages-femmes autorisées qui pratiquent.

Le degré de connaissances perçues variait parmi les praticiennes, de même que le degré d'utilisation dans leur pratique respective lors de discussions de problèmes avec les femmes. La majorité des sages-femmes ont indiqué qu'elle n'avait pas suffisamment de connaissances, particulièrement dans le domaine de la génétique, pour discuter de ces problèmes. La plupart des sages-femmes ont acquis leurs connaissances de façon formelle et informelle. L'étude a conclu que les sages-femmes doivent avoir accès à la formation professionnelle dans le domaine de la génétique et de l'embryologie afin d'être mieux en mesure de présenter des options éclairées quand vient le temps de suggérer divers tests et traitements durant la grossesse.

MOTS CLÉS
Embryologie, génétique, décisions informées, pratique sage-femme.

Cet article a été évalué par des pairs.

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Introduction

As a result of increasing development and refinement of obstetric technology prospective parents are faced with the dilemma of making an informed decision about the use of this technology in the surveillance of their pregnancy, unborn baby and newly born child. With this decision-making comes the responsibility of caregivers to provide information to parents and direct them to where they can get further information in order to make informed decisions. In New Zealand the caregiver who would be providing that information is, for the majority of women, a midwife.[1]

This paper explores the place of knowledge in decision making and discusses the results of a research project that explored the genetic and embryological knowledge midwives have and how they use it in practice. This paper briefly explores informed decision-making, the factors that influence it and presents the findings of the research project.

Screening/diagnostic tests

In the twenty-first century there is an increasing number of screening and diagnostic tests to offer parents, from genetic screening in the preconception period to the Guthrie test in the early days of the newborn's life.[2] It has also been noted that the scope of practice for all health personnel has changed with advances in knowledge achieved through the Human Genome Project.[3,4,5,6] This increasing knowledge and technology provides many opportunities and challenges to midwives and those seeking to become pregnant. Screening tests are used to give a risk ratio, which would then indicate the need for diagnostic testing. For example, the nuchal translucency scan done early in pregnancy gives women a risk ratio for fetal abnormality. The amniocentesis, which could follow, gives a diagnosis of, for example, Down's syndrome. The Guthrie test in the postnatal period uses markers, some genetic, to diagnose metabolic disorders in baby. These tests and others are designed to confirm the normal and detect problems so that decisions can be made about becoming pregnant, remaining pregnant or initiating treatment. Consequently, there may be a need to work with women seeking genetic counselling. In some areas genetic counselling is considered to be a vital aspect of antenatal care as some parents seek screening for congenital malformations and genetically inherited disorders.[7, 5] It is therefore important that a midwife have an understanding of the tests available.

Informed decision making

In New Zealand, as elsewhere, much has been made of the need for health care consumers to be fully informed when making health decisions.[7] The Health and Disability Consumers' Code of Rights makes the expectation of informed decision making quite clear.[8] It is the role of the Lead Maternity Caregiver (LMC) to provide information to parents during the childbirth experience to enable them to make these decisions.[9] It is also evident that in New Zealand the midwife is that person for the majority of women as they are the LMC in 73% of cases[1] and are involved in all childbirth experiences. In the Standards for Practice of The New Zealand College of Midwives[10] standard two states that "the midwife upholds each woman's right to free and informed choice and consent throughout the childbirth experience" (p.9). There is also evidence that women prefer to be involved in decision-making and feel greater control when they do.[11] However, in the postal study done by O'Cathain et al[11] a large minority, 46% of the over 3000 women felt they did not make informed choices about all things during their maternity care. So there are ethical and legal requirements of practitioners for ensuring informed decisions are made about screening and diagnostic tests during the childbearing year. It behoves midwives to ensure clients are making fully informed decisions about the screening and diagnostic tests offered during the childbearing year. The caregiver must have a good knowledge of all aspects of these tests in order to facilitate informed choice and consent. Not only does the care provider need this knowledge but they must be willing and able to discuss the information with clients.

Women's Knowledge

There is evidence that the information needed to make informed decisions may not reach all women, or they do not understand it and so decisions are not fully informed.[13,14,15,16,17] Freda et al[14] carried out a qualitative research project where they interviewed women who had been given information from a provider and had seen a video tape about maternal serum alpha-fetoprotein screening. Although a small study, the researchers found that overall the women did not meet all the set criteria for informed consent: consent must be voluntary, the client must be competent, consent must be informed, and the information must be understood. The conclusion from this study was that consent was given without women fully understanding the tests or the implications of the tests.[14] In 1997, Fairgrieve[15] did a follow-up audit to assess women's views of protocols of a serum screening programme for Down's syndrome and Neural Tube defect. The audit used a self-completed questionnaire with 1774 women including women at increased risk for Down's syndrome or neural tube defect. Some of the at-risk women were interviewed using a semistructured questionnaire. The findings showed an inadequacy of information and explanation of the tests and highlighted the role of the midwife as being the main source of information.

An Australian study of 200 women found that only 26.5 % of parents knew their baby had undergone newborn metabolic screening (Guthrie test) despite it having been carried out on 98% of the babies.[13] This study found that those with English as their first language, with a higher education level and of Caucasian origin had a higher knowledge level compared to other women in the study, while single women older than 35 and with English as their first language had a greater uptake of the tests. An earlier study by Thornton et al[17] with 1691 women investigated whether more individual discussion around prenatal testing specifically, various blood tests, and ultrasound screening, would influence the uptake of these tests and anxiety levels of parents. The study found that clients who received more information and had an opportunity to discuss that information felt they understood the tests better and thus we can assume were better able to make informed choices. These clients also scored lower on anxiety scales than those who attended early antenatal classes. An additional study done in Finland and published by Santalahti et al[18] found some indication that clients were not given or did not understand the information regarding tests offered nor understood the risks. There was also much evidence from the women's stories that having the tests was the accepted thing to do, which calls into question the idea that informed consent was sought.

Smith and Marteau[16] stated that midwives may lack the knowledge of the tests provided or be unable to communicate the information women require about the tests. They undertook a study of practitioners' interactions with women during antenatal consultations with 215 pregnant women between 10-12 weeks of pregnancy and of mixed ethnicity, age and parity. Thirty-seven midwives, midwifery students and obstetricians within six hospitals in the United Kingdom participated in the study. The findings of this study indicated that the information women received on antenatal and fetal anomaly screening was insufficient for the woman to make an informed decision.

Practitioners' Knowledge

As would be expected the caregivers' knowledge and training in this area can affect the communication and thus informed decision-making. Samwill[19] found, in her survey of 169 midwives working in a large Trust in England, that 41% felt they did not have enough knowledge to facilitate informed consent in the area of testing for Down's Syndrome, while only 39% felt confident in counselling in this area. Wray and Maresh,[20] who conducted a prospective study using a structured questionnaire, had similar findings. They received replies from 245 midwives and obstetricians regarding their knowledge, roles and unit policies in the area of prenatal screening. Among the midwives, 40% indicated a lack of perceived ability to facilitate informed choice for women. They also found that there was a lack of knowledge of unit guidelines in the area of prenatal testing. Wray and Maresh[20] further discovered that caregivers felt they were inadequately trained in this area, with 79% of midwives feeling they needed further training around pre-test counselling, and 65% feeling they needed further training around informed choice. Fairgrieve,[15] in her study, found that midwives have a major role to play in providing information to women around testing for neural tube defect and Down's syndrome but that they found this a difficult role. The conclusion from this study is that midwives need continuing education and support in order to fulfil this role.

From the literature it appears that there is a lack of informed choice being made by women when it comes to the screening tests available during the childbearing year. Given the implications of positive and negative tests all parents are entitled to be fully informed about what is available and the possible implications thereof. In New Zealand it is the health professional, predominately the midwife and GP, who should facilitate informed decision making and the concern is that this may not be happening. One of the reasons for that may be a lack of knowledge on the part of the health professionals.

Methods

This study developed from a teaching session with midwifery students where the scientific knowledge of genetics and embryology was related to practice. From there an interest developed in learning whether midwives felt they had sufficient knowledge in these areas and how they used that knowledge in their practice. A self completed structured questionnaire was designed that examined the midwives perception of their knowledge of genetics, genetic screening, genetic counselling and embryology, and embryological screening and how they used it in practice. The areas of knowledge explored were:

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- Genetics
- Genetic screening
- Genetic counselling
- Embryology
- Embryological screening

A convenience sample was used and participants were recruited through an advertisement in the National Newsletter of the New Zealand College of Midwives. The questionnaire was available at a midwifery conference and distributed to practitioners' mail slots in the local maternity units. Participants were limited to midwives who were practising currently or within the last two years. All participants were English speaking. Demographic data on type of midwifery education and any other relevant education, years of practice and type of practice was collected. Questions in the survey related to how they gained the scientific knowledge targeted by the study and whether they felt they had sufficient knowledge to discuss relevant issues with clients. It also asked about which screening or diagnostic tests they used and how often and whether they used the scientific knowledge in their various discussions with women. The tests referred to included:

1. Genetic screening
2. Chorionic villus sampling (CVS)
3. Genetic counselling
4. Nuchal fold translucency
5. Morphology scan
6. Amniocentesis
7. Alpha Feto Protein (AFP)
8. Triple test
9. Guthrie test

These discussions covered: pre-pregnancy counselling, pre-test and post-test counselling, lifestyle choices and awareness of the progress of their pregnancy and baby's development.

Ethics approval for the project was obtained from Massey University Human Ethics Committee. Consent for participation was taken as given when participants returned the completed questionnaire in a reply paid self addressed envelope. All questionnaires were anonymous.

Results

Forty-two completed questionnaires were returned from various centres in New Zealand including

Table 1: Level of Education

Education	# of respondents
BMid	15
MA	2
Other	13
Advanced Diploma in Nsg/Mid	4

Key
BMid - Bachelor of Midwifery
RM - Registered Midwife
DHB - District Health Board
MA - Master of Arts
RN - Registered Nurse
RGON - Registered General and Obstetric Nurse

Table 2: Registration Status

Registration Status	# of respondents n=42
RM	**42**
+ RN	12
+ RGON	15

Table 3: Work Setting

Work Setting	# of respondents (n=49)
DHB	18
Caseloading/ Community	31

Auckland, Wellington, Christchurch and Dunedin. All participants answered all questions except one who did not indicate the year she obtained midwifery registration. Demographics of the group can be seen in Tables 1 to 3.

Years of practice for the midwives since their Midwifery registration ranged from 32 to 2 years with 27 individuals qualifying as a midwife since 1992. The midwives worked in a wide range of practice settings from providing primary maternity care in the community to working within a tertiary maternity setting including those who were employed by a DHB (District Health Board) as caseload midwives. Some midwives worked in more than one setting. This accounts for the difference between the numbers for the work setting and the total participants.

The study investigated where the midwives gained their knowledge and whether they felt they had enough specific knowledge to inform various discussions with women. The areas of knowledge investigated included genetics, genetic counselling, genetic screening, embryology and embryological screening. As can be seen from Table 4, most report gaining the knowledge from their midwifery studies. When asked if they felt they had enough knowledge of these topics to discuss issues with women the majority (66%) indicated no. In the area of genetic counselling 89 % felt they did not have sufficient knowledge. There were a small number who indicated they were unsure whether they had enough knowledge in these areas to discuss these issues with women.

In the area of which tests are used in practice, we found that all tests are offered to some degree. The majority of respondents offered tests such as nuchal fold translucency, Guthrie test (neonatal metabolic screening), morphology scan and amniocentesis. Forty (95%) of the forty-two respondents did the Guthrie test on all babies. Most of the tests listed, such as Chorionic Villus Sampling, (CVS) were offered if indicated, by risk or request.

The majority of midwives reported that they do use knowledge of genetics in the various discussions, but

Table 4: Where knowledge was gained

Source of Knowledge	Number
Midwifery Education	39
Nursing Education	7
Self directed	12

Note: A number of individuals received their knowledge from more than one source.

Table 5: Percentage of practitioners who used specific knowledge to discuss particular tests

Genetics Knowledge	Responses (%)	Embryological knowledge	Responses (%)
Nuchal fold translucency	81%	Nuchal fold translucency	<.5%
Morphology scan	57%	Morphology scan	14%
Guthrie test	98%	Guthrie test	<.5%
Amniocentesis	83%	Amniocentesis	<.5%

Table 6: Perceived sufficiency of level of overall knowledge

Case Loading N=29		Hospital N=18	
No	Yes	No	Yes
72%	28%	55%	45%

fewer use their knowledge of embryology. Some individuals did not answer all of the questions. Table 5 shows four of the common tests and the percentage of practitioners who used genetic or embryological knowledge to inform discussions with women.

The data were also analyzed according to place of work (Table 6). Of the 29 case-loading midwives 72% felt they did not have enough knowledge in three or more of the areas, with 43% indicating all areas. While 28% indicated they had enough knowledge in three or more of these areas. For the eighteen who worked predominantly in the hospital (55%) indicated they did not have enough knowledge in any or most of the areas, five (41%) indicating they had adequate knowledge in some but not all areas. The areas varied between respondents. Three participants (4%) indicated that they felt they had enough knowledge in all or most of the areas.

Table 7a: Percentage of practitioners who perceived adequate level of knowledge to discuss issues based on qualification
(Bachelor of Midwifery n+15)

Area of Knowledge	Response (%)
Genetics	50%
Genetic Screening	50%
Genetic Counselling	0%
Embryology	60%
Embryology Screening	40%

Table 7b: Percentage of practitioners who perceived adequate level of knowledge to discuss issues based on qualification
(Other Midwifery Education n=27)

Area of Knowledge	Response (%)
Genetics	70%
Genetic Screening	50%
Genetic Counselling	81%
Embryology	66%
Embryology Screening	70%

The researchers had an interest in determining whether there was a difference between the perceived level of knowledge, pathway to midwifery education and tests offered during the childbearing year (Tables 7a and 7b). In New Zealand, at the time of this study the Bachelor of Midwifery (BMid) as entry to midwifery practice has been in place for approximately ten years. Therefore, those midwives with an Advanced Diploma in Midwifery, would have been registered prior to about 1995 and thus for a longer period of time than those with a Bachelor of Midwifery. The results in Tables 7a and 7b show that 50% of those who had a Bachelor of Midwifery felt they had enough knowledge of genetics and genetic screening to discuss relevant issues. No practitioner felt they had enough knowledge to discuss genetic counselling. Sixty percent of those with a BMid felt they had enough knowledge about embryology to discuss relevant issues with women. While 40% felt they had sufficient knowledge about embryological screening to discuss these issues. In comparison, of those who obtained their midwifery registration with an advanced diploma, 78% felt they had enough knowledge of genetics to discuss issues with women. While 50% had enough knowledge of genetic screening, 81% felt they had enough knowledge of genetic counselling. In contrast to those with a BMid 66% felt they had sufficient knowledge of embryology and 70% indicated they had enough knowledge of embryological screening to discuss issues with women.

Discussion of Results

The midwives who participated in the study came from a range of educational backgrounds, practice settings and length of experience in the midwifery workforce. They work in various settings, some in both the community and hospital. Some of the respondents indicated that if they were independent midwives they would discuss the issues, indicated in the study, with women. Although practitioners in all settings used most of the commonly offered tests it would appear that they might be inadequately prepared to counsel women. One participant indicated she referred women for all but the Guthrie test, which may be an indication that practitioners are relying on other professionals to counsel the woman. However, as health professionals, midwives are required to ensure women are fully informed prior to consent for testing. This finding indicates that informed consent may not occur prior to testing. There is a possibility that some survey questions were misunderstood. Some of the results also indicate that practitioners are not exposed to women at all times during the childbearing year. For example, most case-loading midwives first meet women toward the later part of the first trimester, after confirmation of pregnancy. Therefore, although within their scope of practice[21], the opportunity does not arise to discuss issues such as early dating scans or nuchal translucency scan. Hospital-based midwives provide episodes of care during the antenatal, intrapartum or postnatal period and there would be limited opportunity to discuss most of these issues with women, except during an inpatient episode.

The study found that about half the midwives use their knowledge of genetics and embryology to inform some discussions. However, there are areas in which their knowledge base is inadequate. The results confirm findings from previous studies by Wray and Maresh[20] and Samwill[19] that practitioners felt they lacked the knowledge to counsel women about these tests. From this we can also surmise that women may not be getting full information from midwives to enable them to make fully informed decisions, a finding that supports that of Santalahti et al.[18]

There appeared to be a marked difference between midwives with Bachelors of Midwifery and those without a Bachelor of Midwifery, with the latter group indicating they felt they had enough knowledge. There may be two possible explanations for this. One possible explanation is that this knowledge is not covered adequately in the Bachelor of Midwifery programmes. The other possible explanation is that in New Zealand the Bachelor of Midwifery programme has been the route to qualification since 1995 and so those midwives have less practice experience compared to the midwives who obtained their education prior to that time. More time may provide more opportunity to gain this knowledge through self directed learning and experience.

Limitations

Although this study gives us a glimpse into an area of midwives' knowledge it cannot be generalised to the midwifery population in New Zealand. The sample numbers are too small. Given that the number of practising midwives in New Zealand is approximately 250022; the 42 respondents represent only .017% of the practising midwife population. There is also the fact that the convenience sampling technique used may not be representative of the practicing midwifery population of New Zealand.

It was clear from some of the responses that not all tests are available in all jurisdictions and that some midwives did not practice in situations that exposed them to women during all parts of their pregnancy. So some questions did not apply to all 42 respondents. Some midwives also answered the questions by indicating they would discuss these issues with women if they were independent midwives.

Several questions could have been worded differently as a few midwives indicated they did not use some tests within their practice. However, as an LMC they would undoubtedly refer women, for example, for a Morphology scan. Clarity around these questions may have assisted here. It would also have been beneficial to clearly ask whether the midwives discussed these tests with women prior to and after the tests were done. It would also have been useful to ask the midwives if they would like further education/updating in this area.

Conclusion

Informed decision making is an important part of the health system in New Zealand and is an integral part of the midwifery partnership. It is the duty of midwives to ensure that when they offer women various diagnostic and screening tests they can assist women in making an informed choice about the use of these tests. This does not mean that midwives require extensive education in this area but that they have a good understanding of the science behind the tests and can discuss this with women. There is also indication that some practitioners in New Zealand feel they do not have adequate information about the tests and issues around the tests to counsel women effectively.

The implications of this research are that midwives need to be offered either in their undergraduate study, postgraduate study, or through workshops, information about the embryology and genetics behind these tests. Regular updates on new technology, the science and implications need to be available to midwives. Client information leaflets that are easy to read are useful but insufficient. A full discussion to ensure informed decision making is required.[17] Adequate information for health professionals and women must be available to women and midwives to ensure they feel confident that informed decisions have been made. In this time of heightened awareness of health consumers' rights and public safety it is in the interest of midwives to ensure informed decision making.

A question for future research would be to investigate how midwives facilitate informed choice around the various screening and diagnostic tests during the childbearing year. A study, investigating women's experience of informed decisions making during the childbearing year, is also needed.

Informed decision making is an important component of maternity care. Health professionals have a responsibility to ensure clients are fully informed about all tests and procedures. This study found that some practitioners' feel they lack knowledge in the area of decision-making during the childbearing year. This is an area that should be addressed so midwives can ensure the best possible care for women during their childbearing experience.

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