

Establishing a Midwife-led Fetal Down Syndrome Screening Clinic in a Public Hospital

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Objective:

Down syndrome (DS) is the commonest chromosomal abnormality at birth. To meet the increasing demand for DS screening in advanced maternal age, a midwife-led clinic was established in an Obstetric Unit of a public hospital. This study / review aimed to evaluate the effectiveness of such a strategy.

Methods:

Our unit established a weekly half-day 3 hours clinic, run by a single midwife, looking after six women and their partners. There were four such midwives, all of whom had been specially trained for ultrasound measurement of nuchal translucency (NT), an essential feature of DS testing and accredited by the Fetal Medicine Foundation (FMF), United Kingdom. The screening programme was undertaken during weeks 11 to 13+6 of gestation. Couples received information on DS screening in the form of a leaflet and a video presentation. This was followed by individual consultation, during which the options for various DS screening tests (first-trimester combined screening, fully integrated screening, partial integrated screening, and second-trimester biochemical testing) were discussed. Ultrasound examination was then performed to measure the crown-rump length to ascertain gestational age, and NT measurement according to FMF recommendations and maternal blood tests for biochemical markers arranged. The whole process was conducted by the same midwife on a one-to-one basis. A review of the results pertaining to the first 100 women was undertaken.

Results:

The sensitivity of our DS screening was 100%, and the false-positive rate was 12%. A total of 13 invasive tests were performed for women testing positive. Among them, one DS conceptus was diagnosed. A questionnaire study showed all the women were satisfied with the service.

Conclusion:

As the demand from pregnant women for more sophisticated maternity services is increasing, establishment of midwives-led clinics could maximise the midwife's role in providing holistic care for expectant mothers.

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Introduction

Down syndrome (DS) is the commonest chromosomal abnormality at birth. It is also the most common genetic cause of neurodevelopmental delay. It is associated with a number of malformations of varying severity¹. Prenatal diagnosis of DS traditionally relies on amniocentesis or chorionic villus sampling (CVS). Both are associated with increased risk of miscarriage (0.5-1%)^{2,3}. To reduce the number of these unnecessary invasive procedures and associated fetal loss, a variety of effective alternative screening modalities have developed. They range from biochemical screening of second-trimester maternal serum in the 1970s to first-trimester screening based on nuchal translucency (NT) and maternal serum biochemistry in the 1990s, and lately, integrated screening taking advantages of both first- and second-trimester screening⁴. All these screening tests take the maternal age into account for risk assessment. Their success and safety has led to the proposition that advanced maternal age (AMA) of 35 years or older is no longer the sole indication for invasive procedures⁵.

Nowadays, up to 30% of women deliver their babies when they are 35 years old or older. In order to reduce unnecessary invasive procedures and any associated fetal loss, our unit implemented a new policy from 1 April 2006. This entailed DS screening offered routinely for AMA, with CVS or amniocentesis being performed only for mothers with positive screening test results or the presence of major fetal anomalies detected by ultrasound^{6,7}. There are around 1100 eligible AMA pregnant women per year; in whom the uptake of screening exceeds 95%^{6,7}. The increasing demand and workload for this service is costly, if all the screening is performed by obstetricians only⁸. Furthermore, the number of specialist trainees has remained very low during the period of year 2000 to 2005⁹. Thus, in recent years the number of obstetric specialists has been decreasing. Moreover, the shortage in suitably trained specialists was particularly marked in public hospitals.

To meet the increasing demand for DS screening in AMA, since 1 July 2008 a midwife-led dedicated clinic was therefore established. This clinic can be regarded as means of counteracting the shortage of obstetricians who could undertake such screening. Moreover, by means of this clinic the role of modern midwives can be extended.

Worldwide Implementation of Down Syndrome Screening

Such screening has been incorporated, to a certain extent, into the health care systems of most developed countries, usually at the level of tertiary care, but its availability could be expanded so as to screen the general population.

Since 2007, the United Kingdom, National Health Service has offered DS screening to all women. The Dutch Health Council concluded that a combination of DS screening tests performed in the first trimester was the method of choice in routine practice¹⁰. Other countries including Denmark, New Zealand, and Australia are currently attempting to implement national screening strategies for DS¹¹⁻¹³.

A national screening policy must inevitably result in a growing number of requests for first-trimester screening¹⁴ and an increasing familiarity with such tests among pregnant women. Thus, in addition to obstetricians, more suitably trained personnel are needed to meet the growing demand for NT measurements. They could be recruited from primary care physicians, midwives, and ultrasound technicians. With the implementation of a national screening policy in Denmark, the number of infants born with DS and the rate of invasive procedures was noticeably reduced¹³.

Acceptability of Down Syndrome Screening by women

In the study by Gourounti et al¹⁵, most women (96%) had a positive attitude towards DS screening; only 4% of women appeared not in favour. Yet another study showed that 99% of women had positive attitudes¹⁶.

In a retrospective study reviewing the trend for prenatal invasive testing for DS screening in Hong Kong from 1997 to 2005, the proportion of AMA women who underwent such screening increased from 31 to 65%, while the proportion who underwent invasive testing decreased from 76 to 40%¹⁷. The decreasing uptake of invasive diagnostic tests by AMA women suggests that DS screening was increasingly accepted. Similar findings have been reported from the US and Denmark^{13,18}. In our unit, the uptake of DS screening by AMA women was 97%⁶.

Value Adding of Midwife-led Service

Studies indicate that midwives' job satisfaction

had increased as midwife-led care facilitates their use of midwifery skills more appropriately and enables them to practise in an autonomous manner^{19,20}.

Moreover, midwives could bring additional skills and benefits to their patients²¹. Thus, they spent more time talking to mothers²², and were more flexible in tailoring care to meet patient needs. Strong evidence showed that women valued not only the additional time with midwives²³, but also facilitated improved communication skill and education. Besides, midwives' assessment of women was holistic²¹, and encompassed religious beliefs, family dynamics, as well as social and cultural aspects. Women expressed increasing satisfaction and felt more prepared for parenthood as they had better support and advice from such midwife-led care^{24,25}.

Essential Training and Development

Experienced midwives with more than 10 years' experience in prenatal diagnosis and a Master's Degree were recruited to commission the midwife-led clinic in the Obstetric Unit of a Kowloon West Cluster public hospital of the Hospital Authority (HA). These midwives provided information about prenatal screening and diagnostic procedures, counselling for high-risk prenatal screening results and therapeutic terminations of pregnancy, assisted obstetricians during invasive tests, and were involved in disclosure of abnormal results. The development of this new service was supported by appropriate education and training and was protocol-driven. Formalised training was provided to enhance midwives' professional knowledge and associated skills in order to prepare them for their extended roles.

Ultrasound Training

Obstetric ultrasound training was a certified, integrated course designed and organised by the HA, consisting of lectures and clinical attachments. Upon completion and passing the examination, participants were awarded certificates, which are recognised by the HA.

Each trainee was required to perform at least 100 dating scans, 200 anomaly scans, and 50 growth scans, under direct in-house supervision. After completion of the training programme, the trainees were assessed by two assigned examiners from HA. During the examination, the trainees are requested to perform a

first-trimester dating scan, a second-trimester anomaly scan, and a growth scan.

Nuchal Translucency Training

The NT training involved attending a whole day class and practical training, offered after successfully completing a written examination. During practical training, the trainees were allowed to practise NT screening on pregnant volunteers under the supervision of a certified NT provider. After completion of the didactic portion of the NT training session, every trainee needed to complete 10 NT ultrasound scans in their institution. Copies of the scans were sent to an expert trainer for confirmation. Once the accuracy of the NT scans were approved by the NT trainer, the trainee was certified in first-trimester screening by Fetal Medicine Foundation (FMF) of the UK. Recently, the FMF training course has been transformed into web-based learning facility (<http://www.fetalmedicine.com/fmf/>).

Over the past 12 years, the midwife-based obstetric ultrasound service in this hospital has gradually taken some services previously provided by obstetricians, including dating scans since 1998, and anomaly scans since 2004. Midwives were competent in identifying the fetal structural abnormalities and referring the respective mothers to obstetricians for further management. The next step was a midwife-led clinic.

Implementation of the Midwife-led Clinic

The new midwife-led clinic was commenced since 1 July 2008. Its aims were to provide a comprehensive DS screening service for AMA pregnant women, and to develop and extend the role of midwives in this field. From the start of the service, there was strong commitment from the Maternal Fetal Medicine (MFM) subspecialists, midwife managers of the department, and the midwives themselves. Midwives were authorised and entrusted to: (1) select which women might be suitable for screening based on crown rump length (CRL) and corresponding gestational age, (2) refer to MFM subspecialists for ultrasound fetal abnormalities, and (3) provide appropriate education and counselling.

The Clinical Pathway Using a Protocol-based Approach

An ultrasound room was allocated for screening service sessions, which took place every week for half

a day. Usually six slots were allocated in each half-day session, run by a single midwife. For this purpose, there were four specially trained midwives accredited by the FMF for ultrasound measurement of NT, which is the essential component of DS screening.

The screening was performed during 11 to 13+6 weeks of gestation. First, the couples received general information on DS in the form of leaflets and a video presentation. Second, there was a consultation during which the options, implications, and limitations of the screening test were discussed. Third, based on the choice of the couple, one of the four DS tests (first-trimester combined screening, fully integrated screening, partially integrated screening, and second-trimester biochemical testing), and ultrasound examinations were performed. These entailed measuring the CRL to ascertaining the gestational age, NT measurements according to FMF recommendations, and maternal blood tests for biochemical markers' assays. The whole process was undertaken and followed by the same midwife on a one-to-one basis.

Women who tested positive received a report from the midwife within 2 to 3 days by phone. Those accepting the offer of a diagnostic test (CVS or amniocentesis) had the procedure scheduled as soon as possible. Women who tested negative receive a letter to that effect within 2 weeks.

The workflow of the clinic is shown in the Figure. The differences between the midwife-led and obstetrician-led DS screening are outlined in Table 1.

Quality Control of Nuchal Translucency Measurements

For quality assurance, NT measurements were both internally monitored and externally audited continually by the Prenatal Diagnostic Centre in Tsan Yuk Hospital, University of Hong Kong. The biochemical assays and calculation of DS risk based on cut-off values for local population were performed by the Prenatal Diagnostic Laboratory in Tsan Yuk Hospital.

Interdisciplinary Relationships

Supportive interactions and relationships with colleagues have potentially positive effects²⁶. Thus, obstetricians are very positive and supportive of the midwife-led clinic. They do not perceive midwives as encroaching on their territory, but rather as filling a gap and adding value to the existing service.

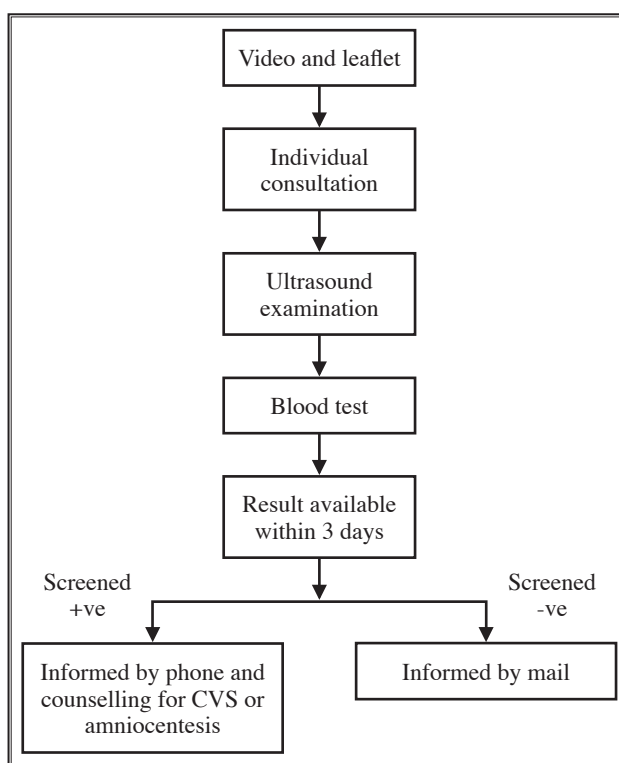


Figure. Workflow of the clinic

Some literature indicated that major obstacles to nursing practitioner development were the nurses themselves^{27,28}. In this department, midwife managers are very constructive and supportive, and encourage collaboration with obstetricians in the department. Junior midwives in the department therefore have a chance to achieve more, which engenders a sense of pride and accomplishment in delivering quality service.

Evaluation

To evaluate the effectiveness of the clinic, a review was undertaken of the first 100 women seen by the midwives. Measurements of outcomes included the detection rate, the false-positive rate, as well as women's satisfaction with the service.

Women's Satisfaction Survey

The results of the phone questionnaire survey demonstrated that 100% of women were satisfied with the service, and the information and explanations received (Table 2). Nearly all (96%) of the women were willing to have a midwife-led service again, if it was offered in their next pregnancy. Only 4% of women would prefer the screening to be performed by obstetricians, believing that it would be more accurate. Overall, women perceived the midwives as being professional, capable, and caring.

Table 1. Obstetrician- versus midwife-led Down syndrome screening clinic

| | Obstetrician-led screening clinic | Midwife-led screening clinic |
|----------|--|--|
| Pathway | <ul style="list-style-type: none"> • Woman is first seen and counselled by a midwife • Ultrasound examination is performed to measure the crown-rump length to ascertain gestational age and nuchal translucency by the obstetrician • Maternal blood sampling for biochemical markers, arranged by another midwife | <ul style="list-style-type: none"> • The whole screening process is performed and followed by the same midwife |
| Comments | <ul style="list-style-type: none"> • The entire process takes about 2 to 3 hours • During the process, the women could possibly contact 3 different members of the team | <ul style="list-style-type: none"> • The whole process takes around 30 to 40 minutes • During the process, women contact the same midwife throughout and build mutually beneficial rapport • Changing the service cuts waiting times and improves efficiency • The process allows time for obstetricians to concentrate on other clinical activities |

Clinical Outcomes

Review of the results demonstrated that the sensitivity of our screening service was 100%, and that the false-positive rate was 12%. A total of 13 invasive tests were performed for women who tested positive, among whom one DS conceptus was diagnosed. One fetus with anencephaly was missed during the 11 to 13+6 weeks scan, but in subsequent scan the fetal structural anomaly was detected. Our sample size was too small for any meaningful assessment of the clinical performance of the midwife-led DS screening clinic, but preliminary results were encouraging. Moreover, they were comparable to the overall DS detection rate of 90% and a false-positive rate of 11% in our new DS screening programme for pregnant women with AMA, which had been operating since 1 April 2006⁶. After introduction of the programme, there was a 7-fold reduction in the number of invasive tests to diagnose one case of DS⁶. Notably, the false-positive rate in our DS screening programme for women with AMA was higher than the 5% usually quoted for women of all ages. However, this phenomenon has also been reported in the literature^{4,5}.

Conclusion

Prenatal DS screening is now an established clinical practice in most obstetric units and the rate of uptake by women is high. One innovative option to meet demands was to establish a midwife-led clinic to provide this specific service. This can also be regarded as part of the professional development of midwives. Establishing such a clinic requires advanced and extended theoretical and

Table 2. Women's satisfaction survey (first 100 women) of the Down syndrome (DS) screening service

| Questions | Yes | No |
|---|------|-----|
| Did you receive adequate information and explanations during the consultation? | 100% | 0 |
| Were you satisfied with the midwife-led DS screening service? | 100% | 0 |
| Would you accept the same DS screening service again if offered in your next pregnancy? | 100% | 0 |
| Would you prefer to have the DS screening service performed by a midwife again? | 96% | 4%* |

* Preferred to have an obstetrician

clinical preparation for midwives. Collaboration and co-operation between obstetricians and midwives is crucial for the service to succeed. Review of our results on the first 100 women seen in our midwife-led DS screening service demonstrated that it was effective and seamless and engendered a high level of patient satisfaction.

In the future, midwife-led DS clinic sessions will no doubt increase to meet service demands, particularly when universal DS screening (regardless of maternal age) is introduced in all HA obstetric units. Continuous evaluation of the performance of the midwife-led DS screening service, continuous quality improvement, and modification of the service and workflow according to the changing demands are crucial for enhancing the care of pregnant women in Hong Kong.

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