

Reasons For Low Uptake Of Amniocentesis Using an Age-Only Screening Policy

F.M. Lai, Y Chua and G.S.H. Yeo

Department of Maternal Fetal Medicine

KK Women's & Children's Hospital, Singapore

Introduction

Singapore is an island republic with a residential population of 3.1 million spread across 647.8 square kilometers, of which 77.0% are Chinese, 14.0% Malays, 7.6% Indians and the remaining 1.4% of other origin (Singapore Department of Statistics, 1998). Down Syndrome is the most common chromosomal anomaly. It occurs in 1.4 to 1.8 per 1000 livebirths, or 56 to 72 Down Syndrome births for a population of about 40,000 livebirths a year.

Unlike in the United Kingdom or United States of America, more than half of Down Syndrome babies are born to older mothers in Singapore. This is because of the relatively higher proportion of older mothers delivering in Singapore.

Between 1988 to 1999, it was the policy of KK Women's and Children's Hospital (KKH) to offer amniocentesis to these older mothers as a tool for prenatal diagnosis of Down Syndrome. In this study, the current uptake rate of amniocentesis was found to be 43% among older mothers. This is lower in comparison with uptake rates of around 80% in the United Kingdom.

Aim

- To establish the uptake rate of amniocentesis among older mothers
- To examine the influence of patient factors and prenatal counseling
- To ascertain the impact of structured counseling on the uptake rate of amniocentesis

Materials and Methods

- Our survey was conducted over 2 periods, from 1 February to 30 June 1999 and from 11 January to 11 May 2000.
- All mothers, aged 35 years or older, who delivered in our hospital, were interviewed by a research assistant using a standardized questionnaire in two languages (English and Chinese).
- Of the 1791 older mothers, 1366 (76%) had agreed to and undertook the full interview. 587 of them had amniocentesis, giving an uptake rate of 43%. Of the 425 women who did not consent to interview, 184 had amniocentesis done, giving a similar uptake rate of 43%. The case records of all these women, regardless of whether they were interviewed, were also reviewed for additional information.

- The patients' biodata, social, education and economic background, knowledge and attitude towards Down Syndrome and amniocentesis, events surrounding the current pregnancy, counseling received and reasons for or against amniocentesis were recorded.

Results and Discussion

Demographics

- Total number of deliveries in KKH over the 9-month period was 11,904.
- Proportion of mothers 35 years or older was 15%.
- This is consistent with our national age distribution of mothers at delivery. Over the last decade, there has been a trend towards women delaying childbirth and there is a steady increase in percentage of mothers over 35 years old, from 8.3% in 1985 to 16.8% in 1997. In contrast, the proportion of older mothers is only 9.2% in the United Kingdom and 12.2% in the United States of America.

Amniocentesis Uptake

- The uptake rate of amniocentesis among older mothers was 43%. The characters†

Table 1 Characteristics of older maternal interviewed who had or did not have amniocentesis

Characteristic	Number (n=1366)	Number (%)
Age (years)		
<35	10	0.7
35-39	100	7.3
40-44	400	29.3
45-49	500	36.6
≥50	356	25.9
Parity (number of children)		
0	10	0.7
1	100	7.3
2	400	29.3
3	500	36.6
≥4	356	25.9
Education (highest level)		
Primary	10	0.7
Secondary	100	7.3
Tertiary	1256	91.9
Income (monthly)		
<\$1000	10	0.7
\$1000-\$1999	100	7.3
\$2000-\$2999	400	29.3
\$3000-\$3999	500	36.6
\$4000-\$4999	356	25.9
≥\$5000	10	0.7
Prior knowledge of Down Syndrome (none)		
None	10	0.7
Accurate	100	7.3
Inaccurate	1256	91.9
Parity (compared with parity ≥4)		
0	10	0.7
1	100	7.3
2	400	29.3
3	500	36.6
≥4	356	25.9

Down Syndrome Livebirths

- There were 4 Down Syndrome babies delivered to the 1791 older mothers during the study period (1 in 448).
- Three of the mothers had booked late or had no antenatal care. The fourth had prenatal diagnosis of Down Syndrome but she decided then to keep the pregnancy.
- In the year of 2000, there were 1236 amniocentesis done in our hospital for maternal age indication. Nine cases of Down Syndrome were diagnosed from the procedures (1 in 137), of which 8 were terminated.

Pattern Of Booking

- Among those interviewed and had amniocentesis done, only 5% (32 of 587) had booked later than 22 weeks and 1% (4 of 587) had not seen a doctor at all before 20 weeks.
- Among those interviewed but did not have amniocentesis, 41% (317 of 779) had booked late at KKH but even then, only 5% (36 of 779) had not had contact with a doctor before 20 weeks.

- This implies that more than 95% of our older mothers would have had the opportunity to receive timely counseling regarding Down Syndrome and amniocentesis to be done in the second trimester. This is because termination of pregnancy is allowed up to 24 weeks gestation in Singapore.

Reasons For Not Having Had Amniocentesis

- 5% presented to a doctor after the second trimester too late for prenatal diagnosis.
- 18% booked early but were not informed of the option of prenatal diagnosis. Most of their first contacts were either the general practitioner or the government polyclinic doctor.
- 75% declined the procedure after counseling. The main reasons cited for refusing the procedure are listed in Table II.

Table II Reasons Cited For Declining Amniocentesis (n=591)

Table II Reasons Cited For Declining Amniocentesis (n=591)

Reasons for Refusing Amniocentesis	Number (#/percentage)
Would not have abortion	207 (35)
Perceived risk not high enough	182 (31)
Fear of miscarriage	85 (14)
Spouse refused	36 (6)
Pain	23 (4)
Cost	21 (4)
Others	35 (6)
Serum screening -> low risk	24
Forgot/busy	3
Reasons unclear	8

Factors Affecting Decision For Or Against Amniocentesis

- We found that the factors that were significantly different between those who decided for amniocentesis and those who decided against amniocentesis were race, religion, income, education, prior knowledge of Down Syndrome, previous livebirths and the person counselling. (Table III).

Table 3 Factors Affecting Decisions For Amniocentesis Uptake

Factors	p-value	Odds Ratio	95% Interval	Confidence
Race (compared with Chinese)	0.0001*			
Malays	0.0001*	0.1577	0.0891 - 0.4388	
Indians	0.9636	0.9925	0.4822 - 2.0428	
Religion (compared with others)	0.0002*			
Catholics	0.0095†	0.3758	0.1794 - 0.7872	
Protestants	0.0000*	0.2892	0.1640 - 0.5096	
Buddhists	0.1316	0.7052	0.4479 - 1.1105	
Hindus	0.0800	0.4681	0.1973 - 1.1105	
Hindus	0.5285	0.7414	0.2924 - 1.8799	
Education (compared with none or primary)	0.2228			
Secondary	0.0763	0.6456	0.3979 - 1.0474	
Pre-U or Vocational	0.7834	0.6816	0.0443 - 10.4922	
Tertiary	0.1277	0.6995	0.4417 - 1.1079	
Income (compared with income <\$1000)	0.0050*			
\$1000 - \$1999	0.3749	0.9497	0.4995 - 1.8057	
\$2000 - \$2999	0.6416	1.1680	0.6074 - 2.2458	
\$3000 - \$3999	0.1357	1.7048	0.9459 - 3.4357	
\$4000 - \$4999	0.0213*	2.6557	1.1564 - 6.0969	
≥\$5000	0.0775	1.9478	0.9291 - 4.0832	
Prior Knowledge of Down Syndrome (none)	0.0024*	0.4683	0.2289 - 0.7287	
Accurate Prior Knowledge	0.0003*	0.3708	0.2156 - 0.6378	
Inaccurate	0.0088*			
Parity (compared with parity ≥4)	0.0078*	2.5186	1.2749 - 4.9755	
1	0.0460*	1.9458	1.0118 - 3.7420	
2	0.0018*	2.7673	1.4538 - 5.2675	
3	0.1620	1.6226	0.7971 - 3.3032	

*statistically significant (p<0.05)

- Mothers who were significantly more likely to have amniocentesis done were the Chinese, those from higher income homes, those who have heard about and have accurate knowledge of Down Syndrome and the low parity mothers.

Influence Of Counselor

- Women who received counseling from the trained nurse counselor or the KKH Obstetrician had a significantly higher chance of deciding for amniocentesis compared to those counseled by the general practitioner.
- However, this could represent a selection bias, as many of these patients may have already been keen for prenatal diagnosis before their referral to KKH for further counseling.
- Majority of mothers felt that the nurse counselor had given them the most adequate and appropriate information during counseling. This could be due to the time that the nurse counselor is able to devote to the patient and also in many instances, these patients would have been primed by their doctors before receiving further counseling from the nurse counselor.

- On the other hand, we found that a handful of patients had probably received directive counseling against amniocentesis. Their counselors included general practitioners, private obstetricians as well as obstetricians from our hospital. The reasons and nature of their advice unfortunately could not be elicited.

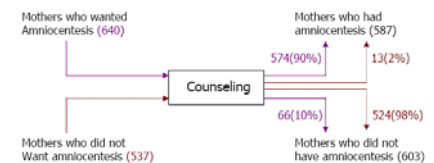
CONCLUSION

Before this survey was conducted, the assumption had been that the majority of older mothers who did not avail themselves of prenatal diagnosis had not heard about Down Syndrome or had presented themselves too late to a doctor for prenatal diagnosis. This survey shows that the majority of older mothers have heard of Down Syndrome and that the majority also had ample opportunity for their care-providers to broach the subject of prenatal diagnosis. The role of the primary care physician in recognizing and identifying mothers for counseling was crucial. More should be done in increasing awareness among these doctors as 1 in 6 older mothers were not given the opportunity to choose prenatal diagnosis as this was not discussed (or the mothers did not remember it being discussed) during the consultation.

Previous studies have found significant bias when individual obstetricians or family physicians counsel. From our mothers' standpoint, structured counseling by nurse practitioner provides the best information and necessary aids to help make their decision for or against amniocentesis. The contents of counseling should therefore be audited and kept consistent in order to ensure its non-directive nature.

However, despite expressing satisfaction that counseling was adequate and comprehensive, we realize that most of our older mothers did not change their decision for or against amniocentesis after counseling. This decision was influenced mainly by the mothers' racial, religious and socioeconomic background. Counseling probably served only to reaffirm their decision for or against amniocentesis. As seen from Figure 1, the majority of mothers did not change their decision towards amniocentesis after counseling.

Figure 1 Outcome of Counseling (mothers who booked early enough and given options of prenatal diagnosis)



As such, despite a sharp rise in the number of mothers receiving structured counseling, we find that the amniocentesis uptake rate has not changed significantly. Better counseling did not result in increased uptake rate of amniocentesis. However, we must realize that the aim of our prenatal counseling service should not be to achieve 100% amniocentesis uptake, diagnosis and termination of Down Syndrome pregnancies, but rather, it is to ensure that all mothers are given sufficient information to make their own informed choice.