Antenatal care implications of population-based trends in Down syndrome birth rates by rurality and antenatal care provider, Queensland, 1990–2004

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ABSTRACT

Objective: To assess whether the rates of Down syndrome births in Queensland vary according to rurality (ie, whether the mother lives in a rural or urban area) and type of antenatal care provider, and to consider any implications for antenatal care.

Design and setting: Population-based study of Down syndrome births in Queensland between 1990 and 2004, stratified by rurality and type of antenatal care provider (private obstetrician, public hospital or shared care).

Results: Since 2000, there has been a large fall in maternal-age-adjusted rates of Down syndrome births among mothers living in urban areas (–14.3% per year; 95% CI, –22.7%, –5.0%) and among mothers receiving their antenatal care from private obstetricians (–27.5% per year; 95% CI, –37.6%, –15.8%). Similar decreases have not occurred among mothers living in rural areas (0.0%; 95% CI, –11.7%, 13.1%) or among mothers receiving antenatal care from public hospitals (+2.9%, 95% CI, –10.3%, 17.9%).

Conclusion: Possible reasons for the observed trends include unequal access to antenatal screening; confusion about screening guidelines and protocols; late presentation for antenatal care; and differences in attitudes to screening and termination of pregnancy among expectant parents, such that they may choose not to have screening or not to act on a positive screening test result.

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For many years, maternal age was used as the criterion for whether to offer screening for Down syndrome. Women older than 35 years (or 37 years in some states of Australia) were deemed to be at sufficiently high risk of Down syndrome to warrant the offer of an invasive diagnostic test (amniocentesis or chorionic villus sampling). However, this strategy was not very effective, as only 30%–40% of cases can be detected in this way.[1]

Innovations in screening for Down syndrome over the past two decades mean that upwards of 85% of cases can now be detected with a false positive rate of 5% (Box 1). Several expert groups,[10,11] including the Royal Australian and New Zealand College of Obstetricians and Gynaecologists,[7] now recommend a population-based approach to Down syndrome screening — that is, offering screening to all expectant mothers. Australia does not currently have a coordinated, population-based screening program for Down syndrome (as it does for breast and cervical cancer), although Medicare rebates can be claimed for screening tests. However, cost may still be a barrier to screening, as the rebate does not cover the full cost to expectant parents.

As with other forms of screening, there are risks. Principal among these is the risk of losing a normal fetus as a consequence of invasive diagnostic testing among the 5% of pregnancies in which the screening result is a false positive. Other harms include the false reassurance associated with a false negative screening result and the needless worry associated with a false positive result.

The aim of our study was to assess whether rates of Down syndrome births in Queensland vary according to rurality (ie, whether the mother lives in an urban or rural area, as defined below) and type of antenatal care provider, before and after the year 2000. Besides maternal age, there are no known risk factors for Down syndrome that could affect population-based rates.[1] We therefore reasoned that any residual variation in Down syndrome birth rates, after adjusting for maternal age, might be due to factors associated with screening, which became more widely available in Queensland around 2000.

METHODS

Data

Data were obtained from the population-based Queensland Perinatal Data Collection (QPDC) for the years 1990 to 2004, the most recent continuous period for which complete data were available in a consistent format. The QPDC includes information on all live births and all stillbirths of at least 20 weeks' gestation or 400 g weight. All cases of Down syndrome identified during the birth episode are registered with the QPDC.

Measurement of rurality was based on the usual residence of the mother. "Urban" comprised the south-east corner of Queensland (ie, the local government areas of Brisbane, Logan, Redlands, Ipswich, Pine Rivers, Caboolture and Redcliffe; and the Gold Coast and Sunshine Coast). The rest of the state was defined as "rural".

Categories of antenatal care provider available in the QPDC include:[8]

- private obstetrician in own private practice;
- public hospital (includes public hospital clinics, hospital-based midwifery clinics and community-based midwifery programs);
- private midwife; and
- shared care (includes any combination of two or more of the other categories, as well as care shared between general practitioner and public hospital).

Statistical analysis

The mean annual percentage change in the rate of Down syndrome births was estimated using Poisson regression analysis. To allow for possible differences in age of mothers over time or by rurality or antenatal care provider (eg, older mothers tend to visit private obstetricians rather than public hospital clinics), all models included 5-year categories of maternal age. We fitted an interaction term between period (before or after 2000) and year to the Poisson models to assess whether there was a statistically significant difference in the mean annual percentage change before and after 2000.

RESULTS

Queensland as a whole

From 1990 to 2004, there were 876 Down syndrome births in Queensland, an average of 58 births per year (range, 47–70 births). Over the same period, there were 717 616

1 Detection rates for antenatal Down syndrome screening methods for a false positive rate of 5%

Screening method	Detection rate
Maternal age > 35 years	30%–40%
First trimester[2-4]	
Fetal nuchal translucency	70%
Maternal serum markers (PAPP-A, β-hCG)	60%
Fetal nuchal translucency and maternal serum markers	80%–90%
Second trimester[4-6]	
Maternal serum triple test (AFP, hCG, uE_3)	65%–70%
Maternal serum quad test (AFP, hCG, uE_3, dimeric inhibin A*)	80%–90%[1,7,8]
Combined first and second trimester[4-6,9]	
Integrated† nuchal translucency and maternal serum screening	95%
Integrated† maternal serum screening	85%
Stepwise sequential‡ maternal serum screening	80%

AFP = α-fetoprotein. hCG = human chorionic gonadotrophin. β-hCG = free β-subunit of hCG. PAPP-A = serum pregnancy-associated plasma protein A. uE_3 = unconjugated oestriol. * Testing is currently only available in Victoria. † Screening is done in both the first and second trimesters, but a single risk estimate is reported to the expectant mother only in the second trimester. ‡ Screening is done in both the first and second trimesters, and results of the first trimester screen are reported to the mother so she can act on them at the time. The detection rate depends on the sequence of tests used (an indicative figure is given here). ◆

births to Queensland mothers: 44 842 in 1990, increasing to 50 409 in 2004. The proportion of births to mothers older than 35 years increased from 9.0% in 1990 to 17.1% in 2004.

About 35% of mothers in Queensland received antenatal care from a private obstetrician; 35% received shared care; and 29% received care only from a public hospital. Only a few mothers received antenatal care from a private midwife or had no antenatal care, and these, along with women whose antenatal care provider was not specified, were excluded from the analysis (< 2%).

Trend analysis for all of Queensland showed that maternal-age-adjusted rates of Down syndrome births fell by 1.3% per year between 1990 and 1999, but this small decrease was not statistically significant. However, between 2000 and 2004, there was a large and statistically significant fall of 9.2% per year (Box 2).

Down syndrome births by rurality and type of antenatal care

For rural areas, trends were stable over the entire period 1990–2004. In contrast, the annual change in rates of Down syndrome births in urban areas differed significantly between 1990–1999 and 2000–2004 (–0.8% versus –14.3%, respectively) (Box 2).

For mothers receiving antenatal care from a private obstetrician, there was a non-significant fall of 2.9% per year in Down syndrome births between 1990 and 1999, but a significant fall of 27.5% per year from 2000 to 2004. In contrast, for women receiving shared care or public hospital care, the annual change in rates of Down syndrome births over the two time periods was similar and the differences were not significant: –1.9% (1990–1999) versus –2.4% (2000–2004) for shared care and +1.0% (1990–1999) versus +2.9% (2000–2004) for public hospital care (Box 2).

Cross-sectional analyses showed that before 2000 there were small non-significant differences in the birth rates for Down syndrome by rurality and antenatal care provider. However, for 2000–2004 there were large and statistically significant differences. Specifically, the age-adjusted rate for mothers who lived in rural areas was 34% higher (rate ratio, 1.34) than the rate for mothers living in urban areas; the rate for mothers receiving antenatal care from public hospitals was 56% higher than for mothers who attended a private obstetrician; and the rate for mothers who received shared antenatal care was 43% higher than for mothers attending a private obstetrician (Box 3). These relative effects were similar for all women, whether under or over 35 years of age (Box 4).

Women living in rural areas of Queensland have less access to private obstetricians than women in urban areas. To investigate whether this might be associated with the urban–rural disparity in Down syndrome birth rates, we fitted three separate Poisson regression models to the 2000–2004 data (Box 5). The addition of rurality to the model containing antenatal care provider (and vice versa) resulted in only minor changes to the rate ratios, suggesting that the excess of Down syndrome births in rural areas is not related to less access to private obstetricians.

Because the percentage of births to older mothers is increasing, the number of Down syndrome births should have increased, all else being equal. More specifically, if the age-specific rates for 1990 to 1999 had continued, there would have been about 70 Down syndrome births in 2004 (a crude rate of 1.4 per 1000 births, compared with the current crude rate of 1.0 per 1000 births) instead of the 49 reported. Moreover, if the age-spe-

2 Mean annual percentage change in maternal-age-adjusted rates of Down syndrome births in Queensland by rurality and type of antenatal care provider, 1990–1999 and 2000–2004

	Mean annual percentage change (95% CI)		
	1990–1999	2000–2004	*P**
Rurality†			
Urban	–0.8% (–3.7%, 2.1%)	–14.3% (–22.7%, –5.0%)	0.01
Rural	–0.3% (–3.8%, 3.2%)	0.0% (–11.7%, 13.1%)	0.82
Type of antenatal care provider			
Private obstetrician	–2.9% (–7.3%, 1.7%)	–27.5% (–37.6%, –15.8%)	< 0.01
Shared	–1.9% (–6.9%, 3.4%)	–2.4% (–14.5%, 11.4%)	0.94
Public hospital	+1.0% (–4.3%, 6.6%)	+2.9% (–10.3%, 17.9%)	0.86
Total (Queensland)	*–1.3% (–4.1%, 1.6%)*	*–9.2% (–16.2%, –1.7%)*	*0.04*

* *P* values are for interaction between period and year: $P < 0.05$ indicates that the mean annual percentage change in maternal-age-adjusted rates of Down syndrome births for 1990–1999 was statistically significantly different from that for 2000–2004. † Whether the mother lives in a rural or urban area (defined in Methods). ◆

3 Maternal-age-adjusted rates for Down syndrome in Queensland by rurality and type of antenatal care provider, 1990–1999 and 2000–2004

	1990–1999			2000–2004		
	Adjusted rate per 1000 births	Adjusted rate ratio (95% CI)	*P*	Adjusted rate per 1000 births	Adjusted rate ratio (95% CI)	*P*
Rurality						
Urban	1.19	1.00*		1.03	1.00*	
Rural	1.41	1.17 (0.99, 1.38)	0.069	1.39	1.34 (1.07, 1.69)	0.01
Type of antenatal care provider						
Private obstetrician	1.12	1.00*		0.90	1.00*	
Shared	1.37	1.17 (0.96, 1.43)	0.115	1.26	1.43 (1.08, 1.89)	0.01
Public hospital	1.39	1.18 (0.95, 1.45)	0.127	1.39	1.56 (1.17, 2.08)	< 0.01

* Reference category. ◆

cific rates for women who received their antenatal care from private obstetricians could be replicated across the whole of Queensland, the number of Down syndrome births would have been as low as 27 (a crude rate of 0.5 per 1000 births).

DISCUSSION

Since 2000, there have been significant falls in the maternal-age-adjusted rates of Down syndrome births among mothers who live in urban areas and mothers who receive antenatal care from private obstetricians. But similar decreases have not occurred among mothers living in rural areas or those receiving antenatal care from public hospitals.

The hypothesis that factors associated with screening are responsible for these trends could not be directly tested with the data available to us. Specifically, we did not have data on measurements of nuchal translucency (NT), serum screening or terminations in relation to rurality or type of antenatal care provider. Consequently, our results are suggestive but not definitive.

The lack of established risks factors for Down syndrome, other than maternal age, makes it difficult to suggest other factors that might account for the observed trends. We therefore think that factors associated with screening provide the best explanation for the patterns observed in the data. These include unequal access to screening; confusion about screening guidelines and protocols; late presentation for antenatal care; and differences in attitudes to screening and termination of pregnancy among expectant parents, such that they may choose not to have screening or not to act on a positive screen result.

Unequal access

Accurate ultrasound measurement of NT requires properly trained operators with good ultrasound machines. These are in short supply, and this, along with the need for tight quality control, means that services to measure NT are (and are likely to remain) confined to urban centres.

Issues of access may not be as critical for first trimester serum screening, as serum can be collected in rural areas and transported to a central laboratory for analysis. However, first trimester serum screening alone has a detection rate of 60% — significantly lower than the 80%–90% obtained when it is combined with NT measurement (Box 1). In areas without easy access to trained ultrasonographers, one suggestion has been to offer combined first and second trimester serum screening, which has a detection rate of 80%–85%. (Box 1). Such a strategy is attractive, as experts have warned against personnel without proper training performing NT measurements, even in areas with unmet demand.[12]

4 Rates of Down syndrome births by maternal age, rurality and type of antenatal care provider, 2000–2004

	Number of Down syndrome births	Number of total births	Maternal-age-adjusted rate per 1000 births	Maternal-age-adjusted rate ratio (95% CI)	*P*
Rurality					
Maternal age < 35 years					
Urban	101	129 063	0.75	1.00*	
Rural	78	78 895	1.00	1.34 (0.99, 1.80)	0.06
Maternal age ⩾ 35 years					
Urban	82	27 525	2.92	1.00*	
Rural	47	11 678	3.94	1.35 (0.95, 1.94)	0.10
All ages					
Urban	183	156 588	1.03	1.00*	
Rural	125	90 573	1.39	1.34 (1.07, 1.69)	0.01
Type of antenatal care provider					
Maternal age < 35 years					
Private obstetrician	51	62 488	0.69	1.00*	
Shared	66	76 821	0.88	1.25 (0.86, 1.82)	0.25
Public hospital	59	67 021	0.93	1.32 (0.90, 1.94)	0.16
Maternal age ⩾ 35 years					
Private obstetrician	45	19 108	2.33	1.00*	
Shared	40	10 328	3.80	1.65 (1.08, 2.52)	0.02
Public hospital	43	9 365	4.49	1.88 (1.24, 2.86)	< 0.01
All ages					
Private obstetrician	96	81 596	0.90	1.00*	
Shared	106	87 149	1.26	1.43 (1.08, 1.89)	0.01
Public hospital	102	76 386	1.39	1.56 (1.17, 2.08)	< 0.01

* Reference category. ◆

Confusion about screening protocols

It would not be surprising if there was confusion about Down syndrome screening, given that the field has evolved rapidly in the past two decades.[13,14] The huge volume of data on the attributes and types of different tests is confusing, both to health care providers and expectant parents.[15] A 2002 Australian survey of health care professionals allied to a tertiary level maternity hospital found that less than 10% were able to provide accurate information on the characteristics of the various screening tests.[16] To help expectant parents make informed choices, educational materials and clear, plain-English guidelines should be developed.[15]

Late presentation for antenatal care

The relatively high rates of Down syndrome births among mothers receiving antenatal care in public hospitals may be attributable, at least in part, to mothers presenting too late for first-trimester screening. Women prefer to be screened in the first trimester rather than the second,[17,18] as pregnancy terminations are safer and more private in the first trimester and may be associated with less psychological distress. Also, with later screening, more mothers with a positive screening result may decide not to proceed to a diagnostic test and possible termination of pregnancy.

Different attitudes to screening among expectant parents

Some commentators have argued that the availability of screening for Down syndrome has resulted in expectant parents being confronted with unprecedented ethical dilemmas and responsibilities.[19] The available evidence suggests that many expectant parents do not make decisions about Down syndrome screening lightly and, in particular, do not take the implications of a positive result lightly. In one qualitative study, mothers reported having thought carefully through their own moral values before they had screening.[20]

Based on a review of seven studies, Biggio et al estimated that 30% of women with a positive screening test decide not to proceed to diagnostic testing and 10% of women with a positive diagnostic test decide not to have a termination.[21] A useful extension of our study would be to investigate issues around parental decisions about whether to have screening and whether to act on the results of screening, and whether such decisions vary according to sociodemographic factors such as rurality, affluence or ethnicity.

5 Summary of Poisson regression models to assess whether less access to private obstetricians was related to the rural excess of Down syndrome births, Queensland, 2000–2004

	Maternal-age-adjusted rate ratio (95% CI)	*P*
Model 1: Rurality		
Urban	1.00*	
Rural	1.34 (1.07, 1.69)	0.01
Model 2: Antenatal care provider		
Private obstetrician	1.00*	
Shared	1.43 (1.08, 1.89)	0.01
Public hospital	1.56 (1.17, 2.08)	< 0.01
Model 3: Rurality and antenatal care provider		
Urban	1.00*	
Rural	1.31 (1.04, 1.65)	0.02
Private obstetrician	1.00*	
Shared	1.44 (1.08, 1.90)	0.01
Public hospital	1.51 (1.13, 2.01)	0.01

* Reference category. ◆

Concluding comment

In 2002, the Medical Services Advisory Committee summarised the evidence for NT screening[22] and subsequently recommended that consideration be given to public funding of NT screening, in conjunction with first trimester serum screening, by incorporating these services into existing early pregnancy services.

Recent economic analyses have shown that population-based screening probably represents value for money.[21-23] When the costs of screening are offset against the lifetime costs of caring for a person with Down syndrome, screening is less costly than no screening at all, regardless of which screening strategy is used. Some regard such calculations as distasteful because of the impossibility of placing a monetary value on human life. However, few would disagree with the principle that all expectant parents should be provided with the same information and have the same access to services so that they all have the same choices.

COMPETING INTERESTS

None identified.

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