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Socioeconomic barriers to making informed decisions about maternal serum screening for
Down syndrome: Results of the National Perinatal Survey of 1998 in France

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Abstract

Objective: To evaluate socioeconomic disparities in serum screening for Down syndrome and in particular, to assess whether they are more likely to reflect limits in access or information, or rather informed decision-making.

Methods: A nationally representative sample of 12,869 women were interviewed after birth. Analyses included multinomial logit models.

Results: We found substantial disparities in the likelihood of test not offered, could not be offered due to late prenatal care and in particular, not knowing whether screening was done. Except in the case of nationality, there was essentially no evidence for differences in refusing the test.

Conclusion: Socioeconomic disparities in screening for Down syndrome are mostly due to limits in access or information rather than an exercise of informed choice.

Introduction

Antenatal screening with the measurement in the maternal serum of various analytes that can indicate a high risk of Down syndrome in the fetus has come to play a key role in prenatal testing for Down syndrome¹⁻³. In general, prenatal testing programs for congenital anomalies are most often advocated and evaluated by public health professionals principally based on their potential for reducing the birth prevalence of congenital anomalies⁴. However, ideally, the primary goal of prenatal testing programs should be to maximize the opportunity for informed decision-making about the tests. Hence, while obviously important, the objective of making the most effective and efficient use of the techniques available in order to detect the largest possible number of affected fetuses should ultimately be given less importance than women's exercise of informed choice. It therefore becomes necessary in the evaluation of prenatal testing programs to not only examine the correlates of prenatal testing but also the reasons that might preclude its use. In particular, with regard to disparities in testing, it is important to assess the extent to which differences might reflect limits in access or information rather than an exercise of informed choice.

Prenatal diagnosis for Down syndrome in France has expanded considerably in recent years from a system essentially based on offer of amniocentesis for women 38 years of age or greater to a regulated system of universal access to both ultrasound and maternal serum screening^{5,6}. Use of ultrasound screening has increased steadily since 1996 and is now routinely offered for measurement of nuchal translucency. Since January 1997, a governmental decree stipulates that serum screening for Down syndrome should be proposed to all pregnant women. National health insurance reimburses the costs of antenatal ultrasound and serum screening, and also provides coverage for amniocentesis for women who at serum

screening or ultrasound are found to be at high risk (the threshold set at 1/250) of carrying a fetus with Down syndrome. Health care providers are required by law to inform women of the purpose of serum screening and the implications of its results⁷; they must produce a written statement attesting to the fact that information was provided and women must give their informed consent for the test to be done.

With increasing use of serum screening, it is important to study socioeconomic barriers that might exist for women to make an informed decision about screening. Previous studies have shown socioeconomic disparities in the use of amniocentesis in several countries including Australia^{8,9}, France^{10,11} and the United States¹²⁻¹⁴. In addition, a recent study suggests that knowledge of Down syndrome and screening might vary in women from different ethnic groups¹⁵. In general, however, little information is available on the effects of socioeconomic factors on serum screening.

We assessed the role of several socioeconomic factors in determining women's use of serum screening and in particular, the extent to which socioeconomic differences in use of screening might reflect limits in access or information, or informed decision-making. Specifically, using a nationally representative sample of women who gave birth in France in 1998, we examined socioeconomic differences in the likelihood of test not offered, could not be offered because of late prenatal care, or refused; we also assessed whether women knew if screening had been done. While a consensus does not exist about the precise definition of an informed decision for prenatal testing⁴, in order to make an informed choice, at a minimum, women need to be offered the test and know that the offer was made. Hence, any disparities in the likelihood of test not offered, or of women not knowing if the test was offered would reflect limits in access or information rather than informed decision-making. On the other

hand, differences in refusing the test could be due to an exercise of informed choice.

Materials and Methods

Data for the study are from the National Perinatal Survey of 1998. Details of the design and implementation of survey are described elsewhere¹⁶. Briefly, the survey is a nationally representative sample of all births (live births + still births) in France during a one week period (N=13,478). Two sources of information were used: 1) a face-to-face interview of women after child birth to obtain sociodemographic characteristics and data on prenatal care, and 2) medical records to obtain data on labor and delivery, and the infant's condition at birth.

During the interview, both the questions and the responses were read out to women. The question on serum screening was as follows: "Did you have serum screening for finding out the risk of Down syndrome?". Possible responses were: 1) 'yes', 2) 'no, not offered', 3) 'no, you refused', 4) 'no, visit too late', 5) 'no' (no reason given) and 6) 'does not know'. Socioeconomic variables included: maternal education, profession, nationality, marital status (living as a couple), paternal profession, health insurance at the beginning of pregnancy, and whether women reported foregoing a medical test while pregnant because of financial reasons. In addition, maternal age and parity were considered as potential confounders or effect modifiers. Maternal age was estimated at the end of first trimester using maternal age at birth and the gestational age.

After exclusion of women with missing data on screening, the study population consisted of 12,346 women less than 38 years of age and 523 women 38 years of age or greater. 4.2% of women had missing data on screening. In general, missing data were more frequent for women in lower socioeconomic groups. Socioeconomic factors that were most strongly associated with higher odds of missing data on screening were maternal education,

nationality, and national health coverage. Marital status, maternal and paternal profession had no significant effect on the odds of missing data on screening except when the mother or the father had no profession, and in particular when paternal profession was missing.

We limited the analysis of the effects of socioeconomic factors on screening to women who were less than 38 years of age for two reasons. First, the threshold age in France for reimbursed amniocentesis based on maternal age criterion alone is 38 years. Therefore, socioeconomic disparities in screening are likely to have different reasons and implications for women less than 38 years of age as compared with those 38 years of age and older, the majority of whom use amniocentesis with or without serum screening. Second, the number of women 38 years of age and older was not sufficient for the intended analyses.

Statistical Analysis

We used the chi-square test for univariable, and multinomial logit¹⁷ models for multivariable analyses. In the multinomial models, the reference category for screening was ‘yes’ and the reference group for each socioeconomic factor was chosen to represent the largest group (or one of the largest groups) for that socioeconomic factor. We report the multinomial results in terms of relative risk ratios (RRR), which correspond to the exponentiated value of a coefficient for a given socioeconomic factor and category of response. Hence, relative risk ratios represent the likelihood of for example, screening ‘no, not offered’ as compared with ‘yes’ for one socioeconomic group vs. another.

In the context of the multinomial models the relative probability of a given outcome category, say category 2, relative to the reference outcome, say category 1, may be written as:

$$\frac{\Pr(y = 2)}{\Pr(y = 1)} = e^{X\beta^{(2)}}, \text{ where } X \text{ and } \beta^{(2)} \text{ are vectors of data and coefficients}$$

for outcome category 2, respectively.

The ratio of this relative risk for a one-unit change in a variable i is the relative risk ratio

(RRR), which may be represented as:

$$RRR = \frac{e^{\beta_1^{(2)}x_1 + \dots + \beta_i^{(2)}(x_i+1) + \dots + \beta_k^{(2)}x_k}}{e^{\beta_1^{(2)}x_1 + \dots + \beta_i^{(2)}x_i + \dots + \beta_k^{(2)}x_k}} = e^{\beta_i^{(2)}},$$

where $\beta_i^{(2)}$ is the coefficient for the variable i and outcome category 2.

All statistical analyses were done using the STATA statistical software¹⁸.

Results

Overall, 66.6% of women had serum screening; 8.3% refused, 16.2% were not offered screening, 2.9% had a prenatal visit that was too late to allow screening, 1.8% did not have screening (reason other/unknown), and 4.2% did not know if screening was done (Table 1). Screening status varied significantly between women who were less than 38 years of age and those 38 years of age and greater (Table 1, χ^2 test, $p < 0.001$); in particular, a substantially higher percentage of women 38 years of age and greater were not offered screening.

Tables 2 and 3 report on the associations between socioeconomic factors and screening. Table 2 shows the percentage of women in each screening category by socioeconomic group, whereas Table 3 shows the multinomial relative risk ratios (RRR) that compare the likelihood of screening categories ‘no, refused’, ‘no, not offered’, ‘no, visit too late’, ‘no, reason not given’ and ‘does not know’ with the reference category of ‘yes’ (i.e., test done). For example, the RRR of 2.9 (95% CI, 2.2-3.9) for unskilled workers in the category ‘no, test not offered’ suggests that the likelihood of test not offered compared with ‘yes’ was about three times higher in unskilled workers than in women who were in the professional category (Table 3).

All of the socioeconomic factors in the study were strongly associated with screening (Tables 2 and 3). Proxies of lower socioeconomic status were associated with lower likelihood of screening and higher frequencies of test ‘not offered’, ‘visit too late’, ‘no test, reason not given’ and in particular with ‘does not know’. In contrast, lower socioeconomic status was not in general associated with a higher probability of refusing screening. The only exception was nationality, where the relative risk ratios for refusal were significantly higher for women who did not have French nationality (Table 3).

In general, the effects of socioeconomic factors on the reasons for not using screening varied considerably across different factors. Maternal education was most strongly associated with knowledge of whether screening had been done ('does not know'). Education was also associated with the likelihood of 'test not offered', 'visit too late', and 'no test, reason not given'. For all of these response categories, but in particular for 'does not know', there was a 'dose-response' relationship between level of maternal education and screening. Differences were substantial in magnitude, in particular in the case of screening not offered and more so for women who did not know whether screening was done. On the other hand, there was little evidence that maternal education predictably affected the likelihood of refusing the test.

Maternal and paternal profession both affected screening status and the relationships were in general similar in that professional categories most likely to have the highest reported serum screening were professional, intermediate, public administration and commerce for both maternal and paternal professions. Women without a profession, unskilled workers and women who were farmers were least likely to have screening. When the paternal profession was farmer however, women reported a high rate of screening, low frequencies of lack of screening for any reason, and also a low proportion of 'does not know'.

Women of French nationality had the highest proportion of screening and the lowest frequency of 'not offered', 'visit too late', 'no, reason not given' or 'does not know'. Women of other European, North African, and other African nationalities had substantially lower frequencies of screening and considerably higher proportions of 'not offered', 'visit too late', 'refused', 'no, reason not given', and in particular 'does not know'.

Women who lived without a partner, those without health insurance and those who reported financial difficulty in procuring medical exams during their pregnancy were less

likely to have screening and more likely to forego screening for any reason or not know whether screening was done. In particular, women without health insurance had about a 8-9 fold higher risks of reporting ‘no, visit too late’, ‘no, reason not given’ and ‘does not know’ as compared with ‘yes’(Table 3).

Table 4 shows results of the multinomial analysis that adjusts the effect of each socioeconomic factor for maternal age and parity as well as the other socioeconomic variables in the study. Results showed that the adjusted effects of each of the socioeconomic factors remained overall significant (Likelihood ratio tests, $p < 0.001$) but of substantially lesser magnitude as compared with the unadjusted effects; in addition, the adjusted effects of subgroups were in many cases not statistically significant. In general, the *relative* magnitudes, and the directions of the effects of socioeconomic variables did not change considerably with adjustment; i.e., for each socioeconomic factor the relative effects across categories of screening (i.e., not proposed, refused, etc.) remained approximately the same. For example, the effect of maternal education remained strongest for ‘does not know’ and nationality remained significantly associated with ‘test refused’. Overall, results of the unadjusted as well as the adjusted multinomial analyses showed that the effects of socioeconomic factors on the reasons that might preclude the use of screening were differential both in terms of the direction and the strength of their associations with the specific reasons that prevent the use of screening; in addition, the effects of socioeconomic factors were shown to be to some extent independent of one another.

Discussion

Our results suggest that substantial socioeconomic disparities in serum screening for Down syndrome persist even in the context of a system that in principle provides universal reimbursed access and stipulates legal rules and procedures to encourage informed decision-making. Disparities exist in the frequency of screening as well as the reasons that preclude its use and in particular in whether women know if the test has been done. Women with lower levels of education, those without a profession or those in manual labor, women of foreign nationalities, and those not covered by the national health insurance all reported substantially lower use of screening. Results of multinomial analysis suggests that these socioeconomic effects are differential and to some extent independent of one another.

The greatest socioeconomic disparities were in the likelihood of women knowing their screening status. Overall, however, and in particular for women from disadvantaged socioeconomic groups, the most important reason that precluded use of screening was test not offered, which occurred for one out of every six women. On the other hand, except for the case of nationality, socioeconomic groups did not systematically differ in the likelihood of refusing screening. Taken together, these findings suggest that socioeconomic disparities in serum screening are for the most part related to limits in access or information rather than an exercise of informed choice.

Prenatal testing should include an explanation of the significance and implications of the results of the tests. It has been suggested that the information provided prior to antenatal screening should also include, at a minimum, a detailed description of the biological, cognitive or psychological impairments associated with specific disabilities, the implications of disabilities for day-to-day functioning, as well as, a discussion of the laws governing

education, entitlements to family support services, access to buildings and transportation, and financial assistance to disabled children and their families, and literature by disabled people and their family members¹⁹. Previous literature about screening^{4,15,20} suggests that a wide gap remains between the reality of testing and provision of such comprehensive level of information. Our findings further imply that the information barrier is particularly large for disadvantaged socioeconomic groups and especially for women with lower levels of education.

In addition, and notwithstanding the debate about the definition of an informed decision⁴, it can be argued that the categories ‘no, refused’ as well as ‘yes’ would only indicate informed decisions provided that adequate and appropriate information was provided in a non-directive manner, and was understood and used as the basis for the women’s decisions. The overwhelming majority (96%) of women who had screening reported that they had received an explanation prior to testing¹⁶. However, previous studies suggest that for a substantial proportion of women the information is not adequate or completely understood⁷. Our findings and those of others¹⁵ suggest that lack of information and communication might more adversely affect informed decision-making for serum screening in women of lower socioeconomic groups and in particular women with lower levels of education.

In general, socioeconomic factors can be related to screening through several different mechanisms including those related to women themselves, their families, the health care system and the society at large. These mechanisms might affect: 1) access to services, 2) information conveyed or understood, 3) preferences including religious and cultural factors, particularly those related to abortion and 4) motivations or incentives for antenatal screening, which might be in part related to the opportunity cost of time of the mother²¹ and social views

and policies vis-a-vis individuals with congenital anomalies and other disabilities¹⁹.

Each socioeconomic factor is likely to affect use of screening through a distinct combination of mechanisms. Indeed our results suggest that the effect of socioeconomic factors on screening cannot be adequately summarized by considering the effects of any one given factor. Furthermore, within the same socioeconomic categories, maternal factors can have distinct effects as compared with paternal factors. For example, we found that when the maternal profession was farmer, women were less likely to use serum screening; the same was not true however when the paternal profession was farmer. More broadly, understanding the effects of socioeconomic factors on the use of screening and on the reasons that might preclude its use can inform policies that might be considered in addressing disparities in serum screening.

Our results suggest that maternal education is the most important predictor of knowledge and communication barriers for informed decision-making about screening. In addition, education is also independently related to effective access to screening. Maternal and paternal profession have independent effects related to access and information but not preferences. Nationality is related to preferences about prenatal testing but important barriers to access and in particular information, which might in part be related to difficulties with language and interactions with the health system, also exist for women of foreign nationalities. Finally, even though screening was fully reimbursable, pregnant women who had scarce financial means to pay for medical exams and more so, those not covered by national health insurance were also more likely to lack effective access to screening. In this context, the higher likelihood of ‘refusing’ the test in women with financial difficulties could also indicate lack of effective access rather than preferences of women, since screening was reimbursable but not

free.

In France, pregnant women have strong financial incentives to begin prenatal care early and obtain coverage by national health insurance²². While insurance coverage is generally provided, access to insurance might be more difficult for women in disadvantaged socioeconomic groups and in particular for those who are not legal residents of France. Overall, 98.5% of women in the study population were covered by national health insurance. Hence, lack of health insurance did not constitute a major barrier for screening at the population-level in France. Similarly, the proportion of women who reported financial difficulty in procuring medical exams during pregnancy was less than 2% in the survey¹⁶.

Overall, less than 3% of women did not have screening because of late prenatal care. Previous studies have reported that 96% of pregnant women in France benefit from early and adequate prenatal care^{23,24}. In the era of increasing availability of prenatal screening and diagnostic services, it becomes more important to encourage women to begin prenatal care early during their pregnancy. Several European countries provide strong incentives for women to begin prenatal care early and to maintain a regular schedule of visits²² and indeed the rate of late or inadequate prenatal care is significantly lower in these European countries as compared with the United States^{23,24}.

An important caveat that needs to be considered in the interpretation of our results is that actual screening status might have differed from women's responses. It is also possible that women who were less likely to know their status might have misreported their status in a systematic way; e.g., respond with 'test not offered'. Therefore, the socioeconomic differences we found in screening may not accurately reflect disparities in actual use of screening. However, any such 'recall bias' might represent, at least in part, lack of an

informed decision since it is plausible to presume that had an informed decision be made about the test, women would have recalled their status more accurately. In addition, the frequency of screening in our data, approximately 67%, is consistent with the results of the study by De Vigan and colleagues of screening rates in Paris maternity units²⁵.

A conceptually legitimate critique of the increasingly widespread use of prenatal testing has been that it is based on a medical definition and socially discriminatory view of disability and that widespread testing might reinforce this discriminatory view and practices that stem from it¹⁹. Another form of social discrimination related to prenatal testing, however, might result from lower use of antenatal screening due to barriers in informed decision-making for certain socioeconomic groups. Indeed, our results suggest that, socioeconomic disparities in the use of screening for Down syndrome are for the most part due to limits in access and information rather than preferences and an exercise of informed choice. Unless these disparities in use of serum screening are addressed, along with its increasing use as a strategy for lowering the birth prevalence of Down syndrome, the care of infants with Down syndrome is likely to be disproportionately given to families with less resources. Moreover, it is likely that this disparity also applies to other congenital anomalies that are subject to antenatal screening.

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Author Contributions

B. Khoshnood conceived the idea of the study, conducted the statistical analyses and wrote the first draft of the manuscript. B. Blondel and C. de Vigan participated in all discussions, contributed to the conceptualization of ideas and made suggestions about the required analyses. B. Blondel also assisted with details of the data items in the National Perinatal Survey. All authors contributed to the interpretation of findings and revisions of the manuscript.

Human Participation Protection

The national perinatal surveys, in their general form, received an authorization from CNIL (*Commission Nationale de l'informatique et des libertés*) for the National Perinatal Survey of 1995. CNIL was contacted in June 1998 with regard to the authorization of the National Perinatal Survey of 1998 and gave the opinion that a separate application for authorization was not required for the 1998 survey.

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