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The subjective value of a life with Down syndrome: Evidence from amniocentesis decision

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ABSTRACT

Using a simple theoretical decision model and an original database, we were able to elicit the distribution of the utility value of having a child with Down syndrome for a large sample of French pregnant women (n = 28,341) between 2003 and 2007. We found that, on a scale where the value of a fetal death is 0 and the value of a healthy child is 1, the mean value for a child with Down syndrome is about −0.6. Assuming that the policymaker used the same decision model as the women, we infer from the French amniocentesis reimbursement regulation an implicit social value for a child with Down syndrome of −2.5. We conclude from our study that the policymaker is more likely to prevent the birth of children with Down syndrome than French women themselves.

1. Introduction

Among the French population, the average risk of carrying a fetus with Down syndrome is about one in 700 (Seror, 2008). Amniocentesis provides an extremely reliable prenatal diagnosis.[1] However, it may involve a non-negligible risk of miscarriage (about 1%, see Alfirevic et al., 2009; Tabor et al., 1986) and has a significant monetary cost (approximately 500 Euros, see the French Health Authority survey, 2007). A preliminary screening test exists in the form of a blood sample that provides women with an estimation of their individual risk to give birth to a child with Down syndrome. About 80–90% of pregnant women have this preliminary test, which is very cheap and carries no risk. Therefore, a pregnant woman has to decide whether or not to have an amniocentesis test, being aware of the risk of giving birth to a child with Down syndrome. Under standard individual preferences, the choice will ultimately depend on the utility costs and benefits of the available options, i.e. the monetary costs associated with the amniocentesis procedure, the utility values of giving birth to a child with, or without, Down syndrome and the utility value of miscarriage. The policymaker may influence women's decisions by appropriately fixing the level of the amniocentesis reimbursement policy, thereby increasing or decreasing the individual costs associated with amniocentesis. Under standard welfare criteria, the socially optimal level of reimbursement should, in turn, depend on the social utility values of the different possible outcomes, and in particular, on the relative social utility value of the birth of a child with Down syndrome and the occurrence of miscarriage.

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[1] Amniocentesis consists in collecting a sample of the amniotic fluid from a pregnant woman's abdomen for analysis.

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In this paper, we investigate the possibility of performing some "reverse engineering", so as to deduce individual values from women's revealed by their actual choices, and social values revealed by the amniocentesis reimbursement policy. For this purpose, we take advantage of an original database which provides information on age, risk and amniocentesis choices of pregnant women who had the screening test in French maternity hospitals between 2003 and 2007. Using a simple decision model based on the assumption that women behave as expected utility maximizers, the distribution of the utility of having a child with Down syndrome can be inferred from actual women's decisions observed in the database. Our results show that, on a scale where the utility value of a fetal death is 0 and the utility value of a healthy child is 1, the mean utility value of giving birth to a child with Down syndrome is about −0.6. On the other hand, according to the French legislation of that same period, amniocentesis was fully reimbursed for pregnant women aged 38 or above (up to the year 2009) and for women facing an individual risk of giving birth to a child with Down syndrome which is higher than 1/250. Thus, under a similar decision model, we infer the policymaker utility value of the birth of a child with Down syndrome of −2.5. Indeed, the social utility value of the birth of a child with Down syndrome is much lower than the average mean of women on our database. This difference might have two non-exclusive explanations. First, the case might be that women do not internalize all social costs involved in educating and taking care of these children. Secondly, it may be that the individual affective, organizational and monetary constraints, involved in having a child with Down syndrome, are overestimated by the social planner.

This paper is organized as follows: Section 2 describes the main features of the amniocentesis decision and the database. Section 3 presents a simple theoretical model of amniocentesis decision, on which the rest of the paper will be based. Section 4 discusses the empirical strategy. Section 5 contains our empirical results. Finally, we further discuss the scope and limitations of our approach in the concluding section.

2. Institutional framework and data

In France, prenatal diagnosis has been regulated since 1997. The detection rate is estimated at approximately 73% (Muller et al., 2002). The false-positive rate, estimated at 7%, corresponds to the percentage of women advised to have amniocentesis, but who do not have a child with Down syndrome. Amniocentesis was unnecessary in the above case and could have caused the miscarriage of a healthy fetus. The preliminary screening method calculates a Down syndrome risk for each pregnancy. The risk computation is based on the mother's age and two maternal serum markers – beta-human chorionic gonadotropin (β-hCG) and alpha-fetoprotein (AFP). In accordance with French regulations, written consent is required from all women who take the screening test. The resulting risk is communicated to each woman. If amniocentesis is performed, a second written consent is required for fetal karyotype. In this document, the risk of amniocentesis-related miscarriage is estimated at 1%. Women then decide whether or not to undergo amniocentesis. Lastly, if the fetus has Down syndrome, the mother decides whether to continue or to terminate her pregnancy. About 95% of women in this case decide to terminate their pregnancy. Thus amniocentesis gives women an accurate result for Down syndrome – whereas the result of the screening test is inaccurate. The screening test enables the computing of a probability of giving birth to a child with Down syndrome and, furthermore, carries no risk. The main drawback of the amniocentesis procedure, however, is that it is an invasive procedure that can cause complications (Garrouste et al., 2011).

Our database contains a sample of 28,341 women who took the screening test between the 14th and the 18th week of pregnancy in French maternity hospitals, located mainly in Paris, between 2003 and 2007. There are 75 medical centers authorized to perform screening tests in France. These centers are located mainly in Paris and the Paris area, with a few smaller centers outside. In our database, women aged 38 or above were not representative of the set of pregnant women aged 38 or more in France, owing to the fact that some of them had accepted amniocentesis directly without a screening test.[2] In addition, women who were reluctant to undertake any action are not included in the database because they refused to do the screening test.

For each woman, our database includes age, some characteristics such as weight and pathology at the time of the screening test, smoking habits and geographic origins. It also includes individual risk, amniocentesis choice and post-amniocentesis outcomes. Table 1 presents descriptive statistics and enables the comparison between the low risk and the high risk group. Approximately 10% of women in our sample opted for amniocentesis. Their average age was around 30. The average women's weight was 65 kg. Approximately 10% of our sample smoked and 60% were European. Most of the women (88.7%) were in the low risk group. Approximately 3.2% of the pregnant women in the low-risk group decided to have amniocentesis, against 62.8% in the high-risk group. Women in the low-risk group are younger (30 versus 34.5 on average) owing to the fact that the risk of Down syndrome increases with age (see the French Health Authority survey, 2007). Overall, 0.17% of women were carrying a fetus with Down syndrome. The rate was around 1.06% in the high risk group and 0.05% in the low risk group. Thus, approximately 72% of fetuses with Down syndrome were in the high risk group,[3] and 28% in the low risk group. This corresponds to the false-negative rate, i.e. about 30% of fetuses with Down syndrome were not detected by the screening strategy (with a risk of less than 1/250. Table 2 shows that 1.06% of the women who had the amniocentesis test had a miscarriage, in comparison with 0.42% of women who did not have the test.

[2] The *Enquête Nationale Perinatale* survey conducted by the French Ministry of Health in 2003 found that approximately 2.3% of pregnant French women opt for amniocentesis without taking a screening test (Blondel et al., 2005).

[3] The proportion of fetuses with Down syndrome in the high risk group is calculated as: $(1.06\times3193)/(0.05\times25{,}148+1.06\times3193)\simeq0.72$.