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Assessing sociodemographic differences (or lack thereof) in prenatal diagnosis of congenital heart defects: a population-based study

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ABSTRACT

Objectives: Our main objective was to assess sociodemographic differences in the probability of prenatal diagnosis of congenital heart defects (CHD); we also looked at differences in termination of pregnancy for fetal anomaly (TOPFA).

Design: Prospective cohort observational study.

Setting: Population-based cohort of CHD (live births, TOPFA, fetal deaths) born to women residing in the Greater Paris area (Paris and its surrounding suburbs, N=317 538 total births).

Participants: 2867 cases of CHD, including 2348 (82%) live births, 466 (16%) TOPFA and 53 (2%) fetal deaths.

Primary and secondary outcome measures: Differences in the probability of prenatal diagnosis by maternal occupation, geographic origin and place of residence; differences in the probability of TOPFA.

Results: 29.1% (95% CI 27.5% to 30.8%) of all CHD were prenatally diagnosed. Probability of prenatal diagnosis was similar by maternal occupation, geographic origin and place of residence. In contrast, there were substantial differences in the probability of TOPFA by maternal geographic origin; differences by maternal occupation and place of residence were generally smaller and not statistically significant.

Conclusions: Our findings suggest that an appropriate health system organisation aimed at providing universal, reimbursed specialised services to all women can provide comparable access to prenatal diagnosis for all sociodemographic groups. In contrast, we found substantial differences in TOPFA for women of different geographic origins, which may reflect women's preferences that should be respected, but that can nonetheless lead to the situation where families with fewer resources will be disproportionately responsible for care of newborns with more severe forms of CHD.

Strengths limitations of this study

- Our analyses were based on data from a large, prospective, population-based cohort study of congenital heart defects (CHD).
- There is paucity of information on sociodemographic differences in prenatal diagnosis of CHD, which constitute an important group of congenital anomalies. This limitation in data is particularly true in case of population-based data.
- We report an absence of disparities in prenatal diagnosis of CHD; this constitutes an exception rather than the rule in the studies of disparities in health service use. This, in turn, suggests that such disparities are not inevitable in the setting of an appropriate healthcare organisation and financing.
- We only examined a limited set of sociodemographic factors: maternal occupation, geographic origin and department of residence. We lacked data on maternal education, paternal education, family income and other important individual-level characteristics, as well as data on small area-level indicators of socioeconomic context.
- We were not able to examine women's knowledge or preferences, including whether or not the practices or outcomes of prenatal diagnosis reflected their informed decision-making.

INTRODUCTION

Congenital heart defects (CHD) are the most frequent group of major congenital anomalies, accounting for almost 1% of all births.[1 2] Despite considerable progress in the medical and surgical management of CHD,[3–7] they remain the most important cause of infant mortality due to congenital anomalies. Moreover, survivors may have considerable short-term morbidity and long-term adverse neurodevelopmental outcomes.[8–16]

Sociodemographic differences in use of health services and outcomes are ubiquitous and amply documented.[17–20] This includes the case of congenital anomalies[21–25] even if much of this literature is concerned with the specific case of Down syndrome.[23 26–29] Little

population-based data exist on sociodemographic differences in the prevalence, diagnosis, management or outcomes of CHD. In a retrospective population-based cohort study, Pinto *et al*[30] looked at census as well as detailed clinical data in a state-wide surveillance programme and found that the probability of prenatal diagnosis was not associated with census data. In another study in the USA, using centre-based data for infants who underwent surgery or catheter intervention, Peiris *et al*[31] found that individual-level sociodemographic factors and medical insurance were associated with the probability of prenatal diagnosis.

Prenatal diagnosis and optimal postnatal management of CHD can result in secondary prevention of mortality and improved long-term outcomes for CHD.[3–5 9 16] Sociodemographic disparities in prenatal diagnosis of CHD could therefore lead to poorer outcomes for groups with less access to prenatal diagnosis. In addition, prenatal diagnosis can allow the opportunity for women to make an informed decision regarding their pregnancy, including the option of termination of pregnancy for fetal anomaly (TOPFA) in case of severe, incurable CHD.

France pursues an active policy of prenatal surveillance with egalitarian intentions and well-codified rules and regulations that aim at providing universal, reimbursed specialised services to all women. Three ultrasound examinations are recommended as part of the programme for prenatal surveillance; one at the first trimester (11–14 weeks of gestation), a second one at the second trimester (20–25 weeks) and a third around 34 weeks of gestation. In practice, a substantial number of women have more than three ultrasound examinations and only a small minority less than three.[32] Prenatal diagnosis of structural congenital anomalies is done for the most part at the second trimester ultrasound; only a small minority are detected either at the first or the third trimester (in particular, those associated with intrauterine growth restriction) ultrasound examination. In case of severe, incurable anomalies, TOPFA is authorised with no limit of gestational age after certification by two experts in dedicated centres for prenatal diagnosis.

Using data from a population-based prospective cohort study of CHD, we sought to assess any differences in the probability of prenatal diagnosis of CHD by maternal occupation, geographic origin and place of residence; we did so for all CHD combined and, separately, for 'isolated' cases of CHD (ie, CHD excluding those cases associated with chromosomal or other anomalies). We also looked at sociodemographic differences in the probability of TOPFA.

MATERIALS AND METHODS

Data source

We used data from the EPICARD (EPIdémiologie des CARDiopathies congénitales) study, which is a population-based prospective cohort study with long-term follow-up of all children with a CHD born to women in the Greater Paris area (Paris and its surrounding suburbs). All cases (live births, TOPFA, fetal deaths) diagnosed in the prenatal period or up to 1 year of age in the birth cohorts between 1 May 2005 and 30 April 2008 born to women residing in Greater Paris were eligible for inclusion. Diagnoses were confirmed in specialised paediatric cardiology departments and for the majority of TOPFA and fetal deaths by a standardised pathology examination. When a pathology examination could not be done, the diagnoses were confirmed by a paediatric cardiologist (LH) and a specialist in echocardiography (J-MJ) in the EPICARD study group, using the results of prenatal echocardiography examination.

Multiple sources of data including all maternity units, paediatric cardiology and cardiac surgery centres, fetal and neonatal pathology departments, neonatal and paediatric intensive units, infant units and outpatient clinics in Greater Paris and a neighbouring tertiary care centre were regularly consulted to attain completeness of case registrations. Informed consent was obtained from study participants. The last cases included in the study were those in the 2008 birth cohort who were diagnosed in 2009. Follow-up of children in the EPICARD cohort is ongoing and will include assessment of children's health and neurodevelopmental outcomes until at least 8 years of age.

Details of coding and classification of cases for the EPICARD study are given elsewhere.[33] Briefly, two paediatric cardiologists in the EPICARD study group (LH, DB) attributed by consensus to each case, one, or in <20% of cases, two or more six-digit code(s) of the long list of the International Paediatric and Congenital Cardiac Code (IPCCC).[34] The IPCCC is a comprehensive coding system (the long list of IPCCC includes >10 000 individual codes) and its use in most clinical and epidemiological studies requires regrouping of individual anomalies. A newly proposed classification, the anatomic and clinical classification of CHD (ACC-CHD), accomplishes this regrouping on the basis of anatomic and clinical criteria.[33]

Each case was classified into 1 (and only one) of the 10 main categories of the ACC-CHD. This classification scheme is based on a multidimensional approach encompassing anatomy, echocardiography, clinical and surgical management criteria. ACC-CHD includes 10 main categories, ordered in accordance with the direction of blood flow, and 23 subcategories. It is designed to use the code numbers of the long list of IPCCC but can accommodate International Classification of Diseases, 10th Revision (ICD-10) codes.

Study population

Our initial study population included 2867 cases of CHD (including live births, fetal deaths and TOPFA). Information on prenatal diagnosis and TOPFA was available for all cases. In total, 274 (9.6%) cases had missing

data for maternal occupation and 16 (0.6%) had missing data for geographic origin of the mother; of the latter, 13 (0.5%) cases had missing data on both maternal profession and geographical origin. Overall, 277 (10%) cases had missing data on maternal profession and/or geographical origin. The proportion of cases with a prenatal diagnosis was comparable for cases with complete information on maternal occupation and geographic origin (28.6%) versus for all cases (29.1%) combined (ie, including those with missing data on maternal occupation and/or geographic origin). The probability of TOPFA after prenatal diagnosis was lower, 36.4%, for cases with complete information on maternal occupation and geographic origin vs 41.4% for the overall study population.

The maternal occupation data in our study come from medical records. They reflect women's 'usual' occupation at the time or right before pregnancy. On the basis of occupation categories devised by the French National Institute of Statistics and Economic Studies (INSEE), we used the following maternal occupation categories, which generally represent the order of highest to lowest occupation categories in France: Professional (N=613), Intermediate (N=492), Administrative/Public service (N=309), Other (N=442) and None (N=737). The Administrative/Public service category includes clerical workers and lower echelon public service employees. The group Other included the following categories that comprised a relatively small number of women in each category in our population: artisan, small business owner, shopkeeper, shop assistant, service worker, skilled worker and unskilled worker.

Data on geographic origin were based on women's declaration as noted in their medical records. In many (most) cases, this reflects women's place of birth. However, this is not necessarily the case and geographic origin in our data ultimately reflects how women define their geographic origin. It is important to note that, in France, it is in general illegal to obtain and record race or ethnicity data. Hence, geographic origin should not be equated with ethnicity. Moreover, women of the same geographic origin may very well be of different ethnicity.

We classified the geographical origin of the mother into four categories representing the major groups in France: France (N=1370), North Africa (N=526), Other (sub-Saharan) Africa (N=393) and Other origins (N=562). The latter group mostly comprises women of European origin other than France.

In total, 972 women in the study population were residents of Paris, 702 residents of Hauts-de-Seine, 684 of Seine-Saint-Denis and 509 of Val-de-Marne; the latter three are the adjoining suburbs of Paris. Even if important heterogeneities exist in the sociodemographic characteristics of both residents of Paris and its suburbs, particularly in case of Seine-Saint Denis, those residing in the suburbs tend to have on average a lower sociodemographic status as compared with residents of Paris.

Statistical analysis

We calculated the proportion of cases with a prenatal diagnosis and TOPFA after a prenatal diagnosis with 95% binomial exact CIs overall and by maternal occupation, geographic origin and place of residence for: (1) all cases of CHD combined, (2) 'isolated' cases of CHD, excluding those associated with chromosomal or other anomalies; 'isolated' cases of CHD could include one or more types of CHD but no other anomalies. We used logistic regression models to estimate the adjusted effects associated with maternal occupation, geographic origin and place of residence on the odds of prenatal diagnosis and TOPFA in models that also included maternal age. We also estimated logistic models that included all of the above plus categories of ACC-CHD in order to take into account any variations that may exist in the distribution of categories of CHD across socioeconomic groups; this was done as the probability of prenatal diagnosis and TOPFA is known to vary substantially across different groups of CHD.[1 6 35]

RESULTS

Study population

Table 1 shows the characteristics of the study population. The majority (60%) of women were 25–34 years of age and approximately 30% were 35 years of age or older. Almost half of all women were of French origin, 18% from North Africa and 14% from other African origins. Overall, 24% of women were in the Professional (highest occupation) category and 28% declared no maternal occupation. One-third of women resided in Paris and the remaining were, in relatively similar proportions, residents of the three surrounding suburbs of Paris.

Prenatal diagnosis

Table 2 shows the proportion of all fetuses (live births, stillbirths and TOPFA combined) which had a prenatal diagnosis of CHD. Overall, 29% of all cases and 23% of 'isolated' cases of CHD were prenatally diagnosed. The probability of prenatal diagnosis for all CHD was somewhat higher (adjusted OR 1.4, 95% CI 1.1 to 1.9) for women aged 38 years and older; however, for 'isolated' CHD, there were no statistically significant differences by maternal age.

We also found essentially no significant disparities in the probability of prenatal diagnosis by maternal occupation, geographic origins or place of residence. This was true both for all and 'isolated' cases of CHD. Moreover, the adjusted ORs of prenatal diagnosis for all and isolated cases of CHD estimated using a model that included maternal occupation, geographic origin and place of residence, as well as maternal age and categories of ACC-CHD, were close to one and the differences were not statistically significant (table 2). Additional detailed descriptive data on the probability of prenatal diagnosis by maternal characteristics as well as

Table 1 Characteristics of study population in the EPICARD study

	N	Per cent
Age (year)		
<25	313	11.0
25–34	1692	59.4
35–37	408	14.3
>37	435	15.3
Occupation		
Professional	613	23.6
Intermediate	492	19.0
Administrative/Public service	309	11.9
Other	442	17.1
None	737	28.4
Geographic origin		
France	1370	48.1
North African	526	18.4
Other African	393	13.8
Other origins	562	19.7
Department of residence		
Paris	972	33.9
Hauts-de-Seine	702	24.5
Seine-Saint-Denis	684	23.9
Val-de-Marne	509	17.7
Congenital heart defects		
Isolated	2031	70.8
Associated with chromosomal anomalies	397	13.9
Associated with anomalies of other systems	439	15.3
Pregnancy outcome		
Live births	2348	81.9
TOPFA	466	16.3
Fetal deaths	53	1.8

EPICARD, EPIdémiologie des CARDiopathies congénitales; TOPFA, termination of pregnancy for fetal anomaly.

ACC-CHD groups are provided in online supplementary annex 1.

Table 3 shows the proportion of prenatal diagnosis for live births only. Overall, approximately 20% of all cases and 18% of 'isolated' cases of CHD among live births were prenatally diagnosed. Older women had higher proportions of prenatal diagnosis for all CHD but not for 'isolated' CHD only.

The proportions of prenatal diagnosis across the sociodemographic groups examined were generally similar and there was no evidence of lower odds of prenatal diagnosis for women in lower occupation groups or those from different geographic origins (table 3).

Terminations of pregnancy for fetal anomaly (TOPFA)

Table 4 shows the proportion of all and 'isolated' cases of CHD with TOPFA following prenatal diagnosis of the CHD. Overall, approximately 41% of all cases and 28% of 'isolated' cases of CHD that were prenatally diagnosed had a TOPFA. We found no statistically significant differences in the probability of TOPFA by maternal age, occupation or place of residence. However, the proportion of cases with TOPFA was substantially lower for women of African origin and those without a profession. In the logistic regression models that adjusted the effects for a given sociodemographic factor for its association with others, there remained statistically significant and substantial differences in the adjusted odds of TOPFA by geographic origin but not by maternal occupation or place of residence. Women of African origin were less than half as likely to opt for a TOPFA after prenatal diagnosis of an 'isolated' CHD. Additional detailed descriptive data on the probability of TOPFA by maternal characteristics as well as ACC-CHD groups are provided in online supplementary annex 2.

DISCUSSION

In summary, using population-based data from 2867 cases of CHD, we found no evidence of socioeconomic differences, by maternal occupation, geographic origin or place of residence, in the probability of prenatal diagnosis of CHD. The likelihood of prenatal diagnosis was similar across the sociodemographic groups both for the total number of cases of CHD and for live births only. We did, however, find substantial differences in the probability of TOPFA after a prenatal diagnosis of CHD, particularly for women of different geographic origins. In particular, women of African origin were more likely to continue their pregnancy after prenatal diagnosis of CHD. These findings were robust to adjustment for maternal age and the spectrum of severity of CHD, accounted for by an ACC-CHD.[33]

In general, absence of sociodemographic disparities in health service utilisation and outcomes is the exception rather than the rule.[17–20] This is also the case in the field of congenital anomalies, although relatively little data exist for anomalies other than Down syndrome.[22–25 28] To the best of our knowledge, this is the first population-based study to specifically assess individual-level sociodemographic differences in prenatal diagnosis and TOPFA of CHD. Our results imply that the potential advantage of prenatal diagnosis, which can lead to both a more informed decision regarding the pregnancy and a more optimal postnatal management of newborns with CHD, is equally shared across sociodemographic groups in our population.

France pursues an active policy of prenatal surveillance with egalitarian intentions. In spite of this policy, previous studies have shown sociodemographic differences in prenatal screening, diagnosis and live birth prevalence of Down syndrome in France.[28 36] However, it appears that disparities in prenatal diagnosis of Down syndrome have decreased substantially over time,[37] suggesting that changes in practice and implementation of policies aimed at universal reimbursed access to prenatal diagnosis services have resulted in widespread diffusion of prenatal screening services for Down syndrome for all women. Our results further suggest that in the case of

Table 2 Prenatal diagnosis of CHD according to maternal characteristics in the EPICARD study

	Prenatal diagnosis														
	All CHD								Isolated CHD*						
	N	Per cent	OR	95% CI	p Value†	Adjusted OR‡	95% CI	p Value†	N	Per cent	OR	95% CI	p Value†	Adjusted OR‡	95% CI	p Value†
	2867	29.1		27.5 to 30.8					2031	23.0		21.2 to 24.9				
Age (year)																
<25	313	29.7	1.1	0.8 to 1.4	0.09	1.0	0.7 to 1.4	0.09	222	23.9	1.0	0.7 to 1.5	0.86	0.9	0.6 to 1.4	0.53
25–34	1692	28.2	Ref			Ref			1284	23.2	Ref			Ref		
35–37	408	27.9	1.0	0.8 to 1.3		1.0	0.8 to 1.4		280	21.4	0.9	0.7 to 1.2		1.1	0.7 to 1.6	
>37	435	34.3	1.3	1.1 to 1.7		1.4	1.1 to 1.9		229	24.5	1.1	0.8 to 1.5		1.3	0.9 to 1.9	
Occupation																
Professional	613	26.9	Ref	Ref	0.11	Ref	Ref	0.39	467	20.8	Ref	Ref	0.05	Ref	Ref	0.34
Intermediate	492	28.3	1.1	0.8 to 1.4		1.2	0.9 to 1.7		385	23.1	1.1	0.8 to 1.6		1.1	0.8 to 1.7	
Administrative/ Public service	309	23.6	0.8	0.6 to 1.2		0.8	0.6 to 1.2		236	16.5	0.8	0.5 to 1.1		0.7	0.4 to 1.1	
Other	442	29.6	1.1	0.9 to 1.5		1.0	0.7 to 1.4		295	24.4	1.2	0.9 to 1.7		1.1	0.7 to 1.7	
None	737	31.3	1.2	1.0 to 1.6		1.0	0.7 to 1.5		500	25.8	1.4	1.0 to 1.8		1.1	0.7 to 1.7	
Geographic origin																
France	1370	27.7	Ref	Ref	0.12	Ref	Ref	0.62	1030	21.8	Ref	Ref	0.24	Ref	Ref	0.90
North African	526	28.1	1.0	0.8 to 1.3		0.9	0.7 to 1.3		360	21.9	1.0	0.8 to 1.3		0.9	0.6 to 1.3	
Other African	393	33.6	1.3	1.0 to 1.7		1.2	0.8 to 1.6		251	25.5	1.2	0.9 to 1.7		1.1	0.7 to 1.7	
Other origins	562	30.6	1.1	0.9 to 1.4		1.1	0.8 to 1.4		380	26.3	1.3	1.0 to 1.7		1.0	0.7 to 1.4	
Department of residence																
Paris	972	28.8	Ref	Ref	0.31	Ref	Ref	0.13	702	21.1	Ref	Ref	0.39	Ref	Ref	0.44
Hauts-de-Seine	702	29.5	1.0	0.8 to 1.3		1.1	0.8 to 1.4		523	23.3	1.1	0.9 to 1.5		1.2	0.9 to 1.7	
Seine-Saint-Denis	684	31.3	1.1	0.9 to 1.4		0.9	0.7 to 1.2		428	25.5	1.3	1.0 to 1.7		1.0	0.7 to 1.5	
Val-de-Marne	509	26.3	0.9	0.7 to 1.1		0.8	0.6 to 1.0		378	23.5	1.2	0.9 to 1.6		0.9	0.6 to 1.3	

*Isolated CHD: excluding chromosomal or other anomalies.
†p Value of the Wald test.
‡Adjusted OR for age, geographic origin, occupation, department of residence and categories of CHD (ACC-CHD[33]).
ACC, anatomic and clinical classification; CHD, congenital heart defects; EPICARD, EPIdémiologie des CARDiopathies congénitales.

Table 3 Prenatal diagnosis of live births with CHD according to maternal characteristics in the EPICARD study

	Prenatal diagnosis														
	All CHD								Isolated CHD*						
	N	Per cent	OR	95% CI	p Value†	Adjusted OR‡	95% CI	p Value†	N	Per cent	OR	95% CI	p Value†	Adjusted OR‡	95% CI	p Value†
	2348	19.5		17.9 to 21.1					1885	17.5		15.8 to 19.2				
Age (year)																
<25	264	20.8	1.2	0.9 to 1.7	0.004	1.0	0.7 to 1.5	0.05	204	17.7	1.0	0.7 to 1.5	0.62	0.8	0.5 to 1.4	0.44
25–34	1409	18.0	Ref			Ref			1183	17.1	Ref			Ref		
35–37	334	18.0	1.0	0.7 to 1.4		1.1	0.7 to 1.5		265	17.0	1.0	0.7 to 1.4		1.1	0.7 to 1.6	
>37	322	26.7	1.7	1.3 to 2.2		1.6	1.1 to 2.2		217	20.7	1.3	0.9 to 1.8		1.3	0.9 to 2.0	
Occupation																
Professional	524	17.6	Ref	Ref	0.07	Ref	Ref	0.37	441	16.3	Ref	Ref	0.09	Ref	Ref	0.33
Intermediate	426	20.4	1.2	0.9 to 1.7		1.2	0.8 to 1.7		367	19.4	1.2	0.9 to 1.8		1.1	0.8 to 1.7	
Administrative/ Public service	268	15.7	0.9	0.6 to 1.3		0.8	0.5 to 1.2		225	12.4	0.7	0.5 to 1.2		0.7	0.4 to 1.1	
Other	366	21.0	1.3	0.9 to 1.8		1.1	0.7 to 1.6		273	19.1	1.2	0.8 to 1.8		1.1	0.7 to 1.7	
None	621	22.9	1.4	1.0 to 1.9		1	0.7 to 1.5		465	20.4	1.3	0.9 to 1.8		1.0	0.7 to 1.7	
Geographic origin																
France	1129	17.5	Ref	Ref	0.03	Ref	Ref	0.68	958	16.3	Ref	Ref	0.44	Ref	Ref	0.96
North African	455	21.8	1.3	1.0 to 1.7		1.1	0.8 to 1.6		342	17.8	1.1	0.8 to 1.5		1.0	0.6 to 1.5	
Other African	315	24.1	1.5	1.1 to 2.0		1.3	0.8 to 1.9		232	20.3	1.3	0.9 to 1.9		1.1	0.7 to 1.8	
Other origins	437	19.2	1.1	0.8 to 1.5		1.0	0.7 to 1.4		343	19.0	1.2	0.9 to 1.7		1.0	0.7 to 1.5	
Department of residence																
Paris	794	18.6	Ref	Ref	0.04	Ref	Ref	0.10	657	16.1	Ref	Ref	0.34	Ref	Ref	0.50
Hauts-de-Seine	598	20.2	1.1	0.8 to 1.4		1.1	0.8 to 1.6		487	17.7	1.1	0.8 to 1.5		1.2	0.8 to 1.7	
Seine-Saint-Denis	544	22.8	1.3	1.0 to 1.7		1.0	0.7 to 1.3		399	20.3	1.3	1.0 to 1.8		1.1	0.8 to 1.6	
Val-de-Marne	412	15.5	0.8	0.6 to 1.1		0.7	0.5 to 1.0		342	16.4	1.0	0.7 to 1.5		0.9	0.6 to 1.3	

*Isolated CHD: excluding chromosomal or other anomalies.
†p Value of the Wald test.
‡Adjusted OR for age, geographic origin, occupation, department of residence and categories of CHD (ACC-CHD[33]).
ACC, anatomic and clinical classification; CHD, congenital heart defects; EPICARD, EPIdémiologie des CARDiopathies congénitales.

Table 4 Association between termination of pregnancy (TOPFA) and maternal characteristics in fetuses with prenatal diagnosis in the EPICARD study

	TOPFA														
	All CHD								Isolated CHD*						
	N	Per cent	OR	95% CI	p Value†	Adjusted OR‡	95% CI	p Value†	N	Per cent	OR	95% CI	p Value†	Adjusted OR‡	95% CI	p Value†
	835	41.4		38.1 to 44.9					468	27.6		23.6 to 31.9				
Age (year)																
<25	93	40.9	0.9	0.6 to 1.4	0.05	0.8	0.4 to 1.4	0.38	53	32.1	1.1	0.6 to 2.0	0.08	1.0	0.4 to 2.5	0.65
25–34	477	43.8	Ref			Ref			298	30.2	Ref			Ref		
35–37	114	45.6	1.1	0.7 to 1.6		1.2	0.7 to 1.9		60	23.3	0.7	0.4 to 1.3		1.0	0.4 to 2.6	
>37	149	31.5	0.6	0.4 to 0.9		0.7	0.5 to 1.2		56	14.3	0.4	0.2 to 0.8		0.5	0.2 to 1.5	
Occupation																
Professional	165	43.0	Ref	Ref	0.08	Ref	Ref	0.42	97	24.7	Ref	Ref	0.61	Ref	Ref	0.25
Intermediate	139	33.8	0.7	0.4 to 1.1		0.8	0.5 to 1.4		89	19.1	0.7	0.4 to 1.4		1.2	0.5 to 3.0	
Administrative/ Public service	73	41.1	0.9	0.5 to 1.6		1.1	0.6 to 2.1		39	28.2	1.2	0.5 to 2.8		2.2	0.7 to 6.9	
Other	131	38.9	0.8	0.5 to 1.3		1.2	0.7 to 2.1		72	27.8	1.2	0.6 to 2.3		2.5	0.9 to 6.6	
None	231	30.3	0.6	0.4 to 0.9		0.8	0.4 to 1.3		129	20.9	0.8	0.4 to 1.5		1.1	0.4 to 2.9	
Geographic origin																
France	380	46.1	Ref	Ref	<0.0001	Ref	Ref	0.0004	225	29.8	Ref	Ref	0.08	Ref	Ref	0.01
North African	148	26.4	0.4	0.3 to 0.6		0.4	0.2 to 0.6		79	16.5	0.5	0.2 to 0.9		0.2	0.1 to 0.5	
Other African	132	34.9	0.6	0.4 to 0.9		0.6	0.3 to 1.0		64	25.0	0.8	0.4 to 1.5		0.4	0.1 to 1.0	
Other origins	172	48.8	1.1	0.8 to 1.6		1.1	0.7 to 1.8		100	33.0	1.2	0.7 to 1.9		0.7	0.3 to 1.5	
Department of residence																
Paris	280	42.1	Ref	Ref	0.25	Ref	Ref	0.88	148	25.7	Ref	Ref	0.14	Ref	Ref	0.23
Hauts-de-Seine	207	38.7	0.9	0.6 to 1.2		0.9	0.6 to 1.4		122	27.1	1.1	0.6 to 1.8		1.2	0.6 to 2.5	
Seine-Saint-Denis	214	38.8	0.9	0.6 to 1.3		0.9	0.6 to 1.5		109	22.9	0.9	0.5 to 1.5		0.5	0.2 to 1.2	
Val-de-Marne	134	48.5	1.3	0.9 to 2.0		1.1	0.7 to 1.8		89	37.1	1.7	1.0 to 3.0		1.2	0.6 to 2.7	

*Isolated CHD: excluding chromosomal or other anomalies.
†p Value of the Wald test.
‡Adjusted OR for age, geographic origin, occupation, department of residence and categories of CHD (ACC-CHD[33]).
ACC, anatomic and clinical classification; CHD, congenital heart defects; EPICARD, EPIdémiologie des CARDiopathies congénitales; TOPFA, termination of pregnancy for fetal anomaly.

CHD there may be little if any important sociodemographic barriers to effective access to prenatal diagnostic services. It is possible, however, that these results may not necessarily be representative of other settings in France, as the wide availability of specialised services in our population is not always the case elsewhere.

In France, three ultrasound examinations are recommended as part of the programme for prenatal surveillance; one at the first trimester (11–14 weeks of gestation), a second at the second trimester (20–25 weeks) and a third around 34 weeks of gestation. In practice, a substantial number of women have more than three ultrasound examinations and only a small minority less than three.[32] Prenatal diagnosis of structural congenital anomalies is done for the most part at the second trimester ultrasound; only a small minority are detected either at the first (in particular neural tube defects) or the third trimester (in particular those associated with intrauterine growth restriction) ultrasound examination. In 2005, the National Technical Committee for Ultrasound Examinations issued recommendations for a minimum of two images of the heart, including the four-chamber and the short-axis views. This guideline for fetal ultrasound examination has come to be legally recognised and is likely to have contributed to a generally higher quality of ultrasound examination of the heart in our population.

In addition, the organisation of prenatal diagnostic services is well codified and includes in particular the constitution of 48 multidisciplinary centres for prenatal diagnosis across the country, including four in Paris and five in its surrounding suburbs. By law, the severity of the fetal anomaly must be certified by two experts from these centres in order for the TOPFA to be authorised. For cases in which either TOPFA is not an appropriate decision ('curable' or not sufficiently severe anomalies) or for which women opt to continue their pregnancy even if the experts consider that TOPFA is an acceptable option, the centres play an important role in the perinatal management of cases to optimise care for mothers and their affected newborns. Mandates for the exclusive coordination of prenatal diagnosis services by these multidisciplinary centres are likely to have contributed to a wider availability of high-quality prenatal diagnostic services in our population.

With regard to the sociodemographic differences observed in the probability of TOPFA, to the extent that these may reflect true differences in women's preferences, they do not constitute a 'problem' to be remedied. The primary objective of prenatal diagnosis, including the option of TOPFA in case of severe, incurable anomalies, should be the opportunity for women to make an informed choice[38] regarding their pregnancy. Hence, if women with certain sociodemographic characteristics are more likely than others to opt for continuing their pregnancy after prenatal diagnosis of a severe CHD, such differences in women's decisions should be respected. However, the possibility that such apparent differences in preferences may in fact be in part related to factors associated with healthcare providers, particularly miscommunication between providers and pregnant women from different cultural backgrounds, should also be considered.[39]

Approximately 10% of cases had missing information for maternal occupation and/or geographic origin. However, the proportion of cases with prenatal diagnosis for those with complete information and the overall study (including those with missing data) was essentially the same, whereas the probability of TOPFA was somewhat (5%) lower for the cases with complete information on sociodemographic characteristics versus the overall study population. We have no à priori or empirical reason to believe that this relatively small difference may have biased our estimates of sociodemographic differences in the probability of TOPFA. Although we cannot be certain, it is likely that cases with TOPFA may overall have less information available on sociodemographic characteristics of women and this is not necessarily, or at least not predominantly, the case for some sociodemographic groups more than others.

Another limit of our study is that we only assessed sociodemographic differences across maternal occupation, geographic origin and place of residence using broad categories. Certainly, sociodemographic status and its possible effects on prenatal testing cannot be represented comprehensively using the characteristics included in our study.[40] In addition, we did not evaluate women's knowledge or preferences regarding prenatal diagnosis and TOPFA for CHD. Hence, we cannot know to what extent our results may reflect women's effective access to information and the possibility for informed decision-making. Finally, despite the large number of cases included in the cohort, we may have had relatively limited power to assess the independent effects associated with different dimensions of sociodemographic status. Therefore, the absence of statistically significant differences in TOPFA for certain groups of maternal occupation or by place of residence may have been in part due to limited power in the adjusted models.

Our study leaves several questions unanswered. An important set of questions relates to the possible existence, and thereby potential implications of any sociodemographic differences that might exist in the prevalence and the distribution of various types of CHD, which may in turn affect the overall severity of CHD across sociodemographic groups. CHD represent a heterogeneous group of anomalies[33 41 42] that may affect various aspects of the normal cardiac anatomy or function. Hence, a major challenge in evaluating clinical management and outcomes of CHD relates to the great heterogeneity that exists in CHD in terms of their prevalence, modalities of diagnosis, clinical severity and treatment options among others.

In the case of our study, the notion of 'severity' of CHD and how it should be defined, particularly when one is interested in sociodemographic differences in the prenatal diagnosis of (or pregnancy termination for)

CHD, does not seem obvious. The two well-established scores of severity (Risk Adjustment for Congenital Heart Surgery-1 method (RACHS-1) and Aristotle) are concerned with surgical cases only. In addition, these scores or any other classifications of CHD have not been formally evaluated in terms of their ability to predict the probability of prenatal diagnosis (or pregnancy termination).

In a previous study, we found that prenatal diagnosis, pregnancy termination and infant mortality differed greatly across the categories of this classification (ACC-CHD[6]). Therefore, in the present study, we adjusted our estimates of the associations between sociodemographic factors and probabilities of prenatal diagnosis and pregnancy terminations for ACC-CHD. However, the ACC-CHD classification needs to be further evaluated in terms of its predictive ability of probability of prenatal diagnosis and terminations of CHD. Moreover, it is not known whether or to what extent the prevalence of different types of CHD (whether in categories or for individual defects) may vary in relation to sociodemographic factors, or how any such variabilities may be correlated with clinical severity or probability (ease/modalities) of prenatal diagnosis (eg, possibility of prenatal diagnosis by a four-chamber view or not). We have undertaken a study to examine some of these questions, which are beyond the scope of the present one.

In conclusion, our results imply that the potential advantage of prenatal diagnosis, which can lead to both a more informed decision regarding pregnancy and a more optimal postnatal management of newborns with CHD, is equally shared across the sociodemographic groups in our population. This is at least in part the result of the active policy aimed at providing reimbursed universal access to prenatal diagnostic services for residents of France. In addition, the wide availability of specialised services in our population, as well as the well-codified organisation of prenatal diagnostic services by multidisciplinary centres for prenatal diagnosis, is likely to facilitate access to high-quality services in our population. The sociodemographic differences we found in the probability of TOPFA, particularly across categories of geographic origin, may represent true differences in women's preferences, but the role of healthcare providers, particularly communication issues between providers and pregnant women from different cultural backgrounds, should also be taken into account. In any case, these differences in TOPFA can result in disparities in the spectrum of severity of CHD at birth and thereby in the risk of adverse outcomes. Hence, families with fewer resources may become disproportionately responsible for the care of newborns with more severe forms of CHD.

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Contributors BK conceived the study in consultation with NL. TA conducted the statistical analysis under the supervision of NL and BK. LH and DB devised the classification of CHD. BK wrote the first draft of the article. FG, NL and J-MJ made substantial contributions to the interpretation of results and revisions of the manuscript. All the coauthors were part of the EPICARD Study Group and participated in the design and conduct of the study and contributed to the interpretation of results and critical revision of the manuscript.

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