RENAL DISEASES AND SOCIAL INEQUALITIES IN ACCESS TO TRANSPLANTATION IN FRANCE

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Translated by Paul Reeve

This document is a translation of:

Christian Baudelot *et al.*, « Maladies rénales et inégalités sociales d'accès à la greffe en France », *Population* 2016/1 (Vol. 71), p. 23-51.

Available online at :
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http://www.cairn-int.info/article-E_POPU_1601_0023--renal-diseases-and-social-inequalities.htm
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How to cite this article :

Christian Baudelot *et al.*, « Maladies rénales et inégalités sociales d'accès à la greffe en France », *Population* 2016/1 (Vol. 71), p. 23-51.

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Renal Diseases and Social Inequalities in Access to Transplantation in France

Social inequalities in health are a major public concern. Some of these inequalities are currently not well documented, and are thus largely absent from debate. One important health issue is renal disease and access to the corresponding therapies (dialysis and renal transplant). These two therapeutic options have very different consequences in terms of labour market participation and physical well-being. Renal transplants offer patients an enhanced quality of daily life and a longer life expectancy, but this option is limited by organ availability. Here, drawing on two recent surveys, Christian Baudelot, Yvanie Caillé, Olivier Godechot *and* Sylvie Mercier *examine socially differentiated access to these two therapies and explore the underlying mechanisms. At each stage in the disease and its treatment, a cumulative process puts the least educated patients at a disadvantage in terms of access to a kidney transplant.*

Renal diseases remain invisible and silent until an advanced stage. Between two and three million persons in France have a renal disease, but most are unaware of it. These diseases lead to two risks: increased cardiovascular morbidity and degradation of renal function, culminating in end-stage renal disease (ESRD). At this stage, when the kidneys no longer function, two replacement therapies are available: dialysis and transplant (see Appendix). The latter is the most effective therapy for patients of all ages in terms of survival, quality of life, and cost-effectiveness for the healthcare system (HAS, 2014). Yet in France, dialysis is most often offered as a first-line therapy, and a majority of patients who have reached the ERSD stage are treated in this way. Among the 76,000 persons in France currently treated for end-stage renal disease, 55% are in dialysis and 45% have received transplants. Two recent surveys (Baudelot et al., 2014, 2015) have highlighted social inequalities in access to these two therapies. Regardless of

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age and sex, patients who have completed some higher education are more likely to receive transplants than others. This inequality of access by level of education is also seen in different categories of treatment: patients who receive a transplant from a living donor (the best therapeutic option) are more educated than patients who receive a kidney from a deceased donor, and patients receiving the forms of dialysis that offer greater autonomy – home dialysis and self-care dialysis – are also more likely to hold a post-secondary qualification than others.

This situation affects patients' quality of life in many ways, and notably their ability to hold a job, a good indicator of a life comparable to that of most working-age adults. Transplants are less likely to interfere with continued employment than dialysis, regardless of level of education. How can such large differences by educational level be explained? This article attempts, within the limitations of the available data, to better understand the origins of these inequalities in access to the best therapy for renal diseases (renal transplantation), and the relationships between the different factors that produce these inequalities.

I. Sources

We draw on two recent surveys that are relevant to understanding social inequalities in access to therapy for renal diseases.

The 2012 États généraux du rein survey

A patient questionnaire was drawn up jointly by all the stakeholders of a kidney patients' forum known as États généraux du rein (EGR)[1] who were represented on its scientific committee. The survey was administered over a six-month period, from July to December 2012, with the help of patients' associations and hospital federations which disseminated the questionnaire to healthcare centres and patients' homes. A total of 8,613 completed questionnaires were returned, including 6,185 paper questionnaires and 2,428 by Internet (at the time, the population of ESRD patients was estimated at 74,000). In terms of age and sex, the sample was highly representative of the population of all ESRD patients, as recorded in the Renal Epidemiology and Information Network (REIN) registry. This survey offers new information on patients' social characteristics by way of a variable indicating their level of education – their most recent educational qualification – which is a first in nephrology.[2]

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(1) http://www. renaloo.com

(2) Level of education offers a good approximation of social status. "Education is probably the indicator most widely used in epidemiological surveys and follow-up data, because it offers a number of advantages: it is easy to obtain, it generally remains stable over individuals' lives (after they complete their education), it does not depend on current labour market status and thus provides information on the socioeconomic status of non-employed individuals; it is also unaffected by later state of health, and is easily comparable in international studies." *Indicateurs de suivi des inégalités sociales de santé* [Indicators for monitoring social inequalities in health], Report of the Haut conseil de la santé publique, 19.06.2013.

This is the first time that persons previously and currently affected by renal failure have been consulted on this scale in France. This body of data provides wide-ranging information on the ways in which patients experience their diseases and treatments (Baudelot et al., 2014, 2015). The full results of this survey are presented in the final report of the États généraux du rein (EGR, 2013).

The 2011 Quavi-REIN survey

This second survey was carried out under the aegis of the Agence de la biomédecine (ABM), by the department of epidemiology and clinical assessment of the Nancy university hospital. This cross-sectional survey was administered in 2011 by self-completed questionnaire to patients in the 21 regions who were members of the REIN network in 2009. The survey sample included 2,909 ESRD patients stratified by region and age, including 1,251 dialysis patients and 1,658 transplant recipients. The questionnaire included a medical variable drawn from the REIN and CRISTAL registries of the ABM, indicating the patients' initial diagnosis (this information was provided by nephrologists at the time of registration) and a number of social variables: occupation, employment status, company size, salary and income levels, and level of education as measured by the last educational qualification obtained. The educational distribution of the population was very similar to that measured by the EGR survey. The employment status of patients aged 25-65 was measured at two points: before reaching ESRD, and after beginning replacement therapies; i.e. dialysis or transplantation.

The EGR survey has the merit of revealing new information, but does not include a medical variable on the nature of the patients' pathologies. Although the survey population is large (N = 8,613), it was not obtained via a systematic sampling process. It consists of volunteers, and thus cannot be considered representative, even though the age and sex distribution corresponds to that of the total population. The Quavi-REIN survey sample, by contrast, was randomly drawn from an ABM patient register, after stratification by age and region. It includes variables identifying the original renal pathology and the region, as well as the dates of onset of end-stage renal disease (first dialysis), registration on the waiting list, and the first transplant (with or without a preceding period of dialysis). It thus provides an opportunity to analyse more fully the emergence of observed social inequalities, although age at diagnosis is not included in the data.

II. Hypotheses and factors associated
with inequalities in access to care

Three families of factors, which are not mutually exclusive, can be identified.

Pathology and/or blood group

Certain renal diseases that affect the poor more than the wealthy are contraindicated for kidney transplantation, or have potentially poor transplant

outcomes. The distribution of different renal diseases varies across social groups (Quavi-REIN survey). Greater absolute numbers of working class people are affected by vascular diseases, diabetes, and obesity, and consequently by their effects on renal function. The kidney is ultimately affected, but it is not the cause of the disease. More educated patients are more likely to develop disorders of more specifically renal origin, such as genetic diseases (polycystosis, etc.), glomerulonephritis, and systemic diseases. Pathologies in the first group (vascular diseases, diabetes, obesity) are more likely to contraindicate transplant, and thus delay registration on the transplant waiting list, than pathologies in the second group.[3] The category "unknown diseases" in the REIN database designates renal pathologies that are too advanced at the time of diagnosis for the nephrologist to confidently identify their cause. Patients in this category often come to hospital as an emergency case.

The Quavi-REIN survey confirmed that individuals with low levels of education are over-represented on the renal transplant waiting list. This means that these populations wait longer for a compatible kidney. The principal factors that increase waiting time are blood group and anti-HLA immunization.[4] To what extent are these factors correlated to patients' social characteristics?

Blood group B (9% of the French population) is much more common in populations with origins in certain parts of Africa, who also exhibit higher prevalence and faster progression of renal insufficiency. It is likely that patients

Table 1. Distribution of renal diseases by patients' level of education

Highest qualification	Diabetes mellitus and vascular diseases (%)	Genetic diseases and polycystoses (%)	Glomerulonephritis, systemic disease, and tubulointerstitial diseases (%)	Unknown (%)	Total	Number of individuals
Primary	24	15	40	20	100	724
Lower secondary	18	18	42	23	100	536
Upper secondary	12	23	47	18	100	594
Higher ed. ≤ 3 years	12	21	49	17	100	392
Higher ed. > 3 years	11	22	52	15	100	285
Total	17	19	45	19	100	2,531

Interpretation: Among respondents with a primary education, 24% have diabetes mellitus or vascular disease.
Source: Quavi-REIN survey, REIN registry, Agence de la biomédecine.

(3) To receive a transplant, a patient must first be registered by a nephrologist on the national waiting list managed by the Agence de la biomédecine.

(4) HLAs (human leukocyte antigens) are proteins located at the surface of cells that allow the immune system to distinguish the body's own cells from other cells. The human body is able to produce specific antibodies against HLAs from other people. This can occur through contact with these foreign antigens, following blood transfusion, pregnancy, or a previous transplant, for example. This is described as immunization. If a patient is immunized against a large number of HLAs, it can become more difficult to find a compatible organ for transplantation. An organ with these antigens would trigger a rejection response in the recipient's immune system.

who are immigrants or descendants of immigrants from these regions, who form a population with a lower average level of education, make up a significant proportion of group B patients who are awaiting a transplant. On 1 January 2012, there were 1,460 such patients, or 16.1% of the total number of patients on the waiting list, and they had been waiting for much longer than other groups.

Are there links between antibody status and social status? One possible factor is the higher frequency of pregnancy in populations with a lower level of education. But it is difficult to pursue this point further and identify possible correlations between level of education and other causes of immunization such as blood transfusions or previous transplants (Footnote 4).

Medical care and organization of the healthcare system

Nephrology is a highly compartmentalized speciality, and communication between its two components, dialysis and transplantation, is very limited. These two complementary and competing therapies exist as two separate spheres within nephrology. Transplants are carried out only in university hospitals and in departments with a large research component. Dialysis is divided roughly equally between public and private institutions, and community structures. Over time, it has become an integrated and financially profitable industrial system, with its own laboratories, clinics, and manufacturers of equipment and supplies. The generalization of a fee-for-service system, with dialysis costs entirely covered by the French social security, associated with the guarantee of a "captive clientele" (in the majority of cases, for three sessions a week) has created an incentive for public and private institutions to increase the number of dialysis stations for accounting reasons. Under the fee-for-service system, dialysis generates a large income for the institutions that provide it. It is also among the most profitable of all medical activities (DREES, 2014). In 2015 the French Court of Auditors (Cour des comptes) published a report on the particular structure of this treatment system. They observed large disparities in the orientation and care of patients, insufficient recourse to transplantation (notably from living donors), and disproportionate use of the most high-tech dialysis methods. The report also highlighted the adverse effects of this profit-seeking approach on patients' trajectories: ineffective strategies for prevention and care of renal diseases, premature initiation of dialysis in some cases, insufficient referral for transplantation (Cour des Comptes, 2015). To explain this situation, which penalizes both patients and the public health insurance system, the report pointed up the shortcomings of the dialysis financing system (fee-for-service payments to institutions and nephrologists), which creates incentives to favour in-centre dialysis, the most high-tech and costly dialysis option, to the detriment of alternative options.

There are also large geographic inequalities in waiting list registration, waiting times, and access to transplantation. These inequalities are precisely

measured each year in the REIN report issued by the Agence de la Biomédecine. In 2011, median waiting times ranged from 7.4 months (minimum) to more than 52 months (maximum). Strategies for registration on the list, which themselves vary widely between regions and even institutions, can also play a role. The less restrictive strategies observed in some regions have a manifest impact on the level of shortage and thus on waiting times. They prolong waiting times, but decrease the effect of level of education on access to the waiting list. In these regions, the filter effect of pathologies associated with poverty, such as diabetes and obesity, is much lower. These strategies reflect regional medical rationales that are clearly favourable to transplantation: practitioners in these regions provide information more widely and more systematically, reducing the effects of privileged access by the most highly educated patients to medical advice and longer consultations.

This hypothesis can be illustrated with two "extreme" examples. In 2011, 87% of dialysis patients under age 60 were on the waiting list in the Paris region (Île-de-France). The corresponding figure in the Provence-Alpes-Côte d'Azur (PACA) region was only 36%. These differentials were even more marked for older patients. Median waiting times in the two regions reflect the respective levels of mismatch between supply and demand: 36.7 months in Île-de-France versus 12.6 months in PACA.

Another factor in the care of renal disease concerns the ways in which decisions to allocate an organ are influenced by positive or negative expectations about how the patient will behave after the transplant. Negative expectations play a role, for example, in liver transplants. They "explain" in part why patients with alcoholic cirrhosis are less often offered a liver transplant, even though their prognosis is no different from that of non-alcoholic patients. A recent article showed that in the United States, black and low educated patients are substantially more likely to be allocated a kidney on "expanded criteria" – i.e. a kidney that comes from an older or less healthy donor, and that is thus of lesser quality (Mohandas, 2013). The major role of patients' insurance coverage in the United States is well-known, notably with regard to transplantation. ESRD therapies are very costly. Patients without private insurance depend on Medicare, which covers transplantation and immunosuppressive treatment expenses for a maximum of three years (Gill et al., 2013). After this period, for patients under age 65 who are not diabetic, medication is no longer reimbursed. This results in a high rate of treatment discontinuation, which in turn largely explains why survival rates five years or more after kidney transplant in the United States are lower than those in countries where immunosuppressants are covered indefinitely. It has also been shown that transplant teams in the United States are more reluctant to register and transplant socially disadvantaged patients, notably because they often have no health insurance (Morgan, 2013).

This reasoning does not apply in France, where all patients are fully covered by the health insurance system for an unlimited period, and where renal

transplants are distributed on the basis of a score based on efficacy and equity criteria that, in theory, leave no room for such considerations. However, exemptions are granted for locally allocated kidneys which, in 2012, represented 46.8% of the organs transplanted in France. A kidney is considered local when it is allocated to a transplant team in the same institution or network as the unit that harvested it. The local team is then required to allocate the organ on the basis of the scores of the recipients on its local list, but is free to decide on the basis of other criteria, provided that it has good grounds for doing so. In total, in the year 2009, 43 out of every 100 harvested kidneys were transplanted locally.

It can be hypothesized that in certain cases, transplant surgeons decide to preferentially allocate the best organs, an increasingly rare resource, to patients whose level of education suggests that they will better understand the constraints of a transplant and will follow instructions more scrupulously. In any case, this is the pattern found in the United States (Janezko, 2013; Tandon, 2013). In a survey of American nephrologists, the three most often cited reasons for excluding certain patients from the waiting list were inadequate social support (70% of respondents), "limited understanding of the transplant process due to patient's inadequate education" (56%), and age above 65 (53%). In France, data on the actual use of such exclusion criteria are not currently made publicly available.

Patients' social characteristics and how they cope with their disease

Individuals with a relatively high level of education and who exercise a higher-level occupation are more likely to pay attention to their health and to warning signs of disease, particularly by monitoring blood pressure (Boltanski, 1971). More educated individuals are also better able to find their way around the world of medicine, and more often gain access to the best therapies (Leclerc et al., 2000). They are also the best informed, in nephrology as in other pathologies. They are more likely to report having been well or very well informed on the two categories of transplant (living or deceased donor) and, above all, they are more likely to "often or continuously" seek out information on their diseases and therapies beyond what they learn from their nephrologist. According to the EGR survey, in 2012 this was true of 14% of patients with less than secondary education, 33% of those who had completed secondary school and 42% of those with at least three years of higher education (EGR survey). Members of the most educated social groups are also known to see physicians earlier and more often than members of the working class. They also apparently have fewer difficulties in effectively implementing strategies to preserve renal function: consuming a diet low in salt and protein, controlling blood pressure, etc. Their renal diseases also tend to develop more slowly, giving them an advantage in access to systems for early detection and diagnosis and to more effective therapies for slowing the course of the disease.

How can the respective effects of these three families of factors be measured?

As we have seen, inequalities in access to transplantation seem to result from several classes of factors with different origins. To better understand the hierarchy of these factors, and to determine whether they are cumulative or mutually compensatory, the ideal solution would be to have reliable objective indicators for each of these three families of factors, and to run a multivariate analysis to determine the relative weight of each one. At present, these indicators are not all available.[5] The Quavi-REIN survey data include reliable indicators for the first family of factors (initial pathology reported by the nephrologist), the second (region, waiting times before registration on the list and for a transplant), and the third (patients' level of education). No variable is available, however, to test the role of blood group, immunization, or negative expectations. Likewise, our data cannot be used to measure the effect of the duality of the treatment system on inequalities in access to transplantation. We are thus limited to measuring these inequalities at the individual level.

Using the variables available in the survey data, we can, however, attempt to assess the relative contribution of each of these three factors – initial pathology, region, level of education – after controlling for sex and age. To do so, we use logistic regression models on the probability of obtaining a transplant, all other things being equal, and so-called Cox proportional hazards models of waiting times, which account for differences in speed of access to transplantation. In terms of structure and interpretation, the Cox model is very similar to a logistic regression model: it accounts for the time taken to move from one state to another. It models the rate of exit from a given state (from dialysis to transplant), taking account of the fact that certain exits are "censored": they had not yet been observed at the time of the survey and may occur later. The model thus measures the difference in the odds of going from one state to another after an equivalent time spent in the first state. This proportional hazards model can be written as follows:

$$h_i(t) = h_0(t) \cdot exp(\, b_1.x_{i1} + ... + \; b_k.x_{ik}),$$

where x_{ik} represents the value of the explanatory variable k for individual i, b_k the estimated parameter for this variable, and $h_0(t)$ an undefined baseline hazard function. The latter can be interpreted as the risk of experiencing the event for an abstract reference individual whose individual characteristics x_{ik}

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(5) An ongoing longitudinal survey will soon be able to measure these factors, but the first results will not become available for several years. The CKD-REIN (Chronic Kidney Disease) cohort consists of 3,600 patients followed for at least five years in order to "understand how lifestyle, environment, genetics, and medical practices interact in chronic kidney disease". The project coordinator is Bénédicte Stengel, and it includes 11 institutional partners: several universities and university hospitals, INSERM, the Agence de la biomédecine, the Centre national de génotypage [National genotyping centre], the Picardie Biobanque, and Arbor Research (United States).

are all zero at time *t*. In this model, the odds ratio $h_i(t)/h_j(t)$ of experiencing the event for two individuals *i* and *j*, who differ on a single characteristic x_k, does not depend on time *t*, only on the ratio $exp(b_k.x_{ik})/exp(b_k.x_{jk})$. Note that we deliberately chose not to introduce age at the time of the survey, which can be considered as a "post-treatment" variable that depends on the dependent variable (here, precisely, the treatment received). Although year of birth is not "post-treatment", survival itself depends on the treatment received, making age at the time of the survey endogenous. Moreover, if we were to introduce age at the time of the survey in addition to age at the onset of ESRD, the probability of transplantation would increase with age at the time of the survey, no doubt reflecting the higher survival rate of transplant recipients in comparison to dialysis patients for a given age at ESRD onset. The introduction of this variable, suspected of endogeneity, also leads to larger and more significant differences by level of education.

III. Results

Inequality in access to therapies was reflected in EGR survey data by the coexistence of three populations with highly differentiated levels of education: dialysis patients who were not registered on the national transplant waiting list (73% had lower secondary education, 27% had completed upper secondary or higher education); patients (still) in dialysis but who were registered on the waiting list (65% lower secondary, 35% upper secondary or higher); and patients who had already received a transplant (44% lower secondary, 56% upper secondary or higher). Dialysis patients not registered on the waiting list thus had a lower level of education than those who were registered, who in turn were less educated than those who had received a transplant. The samples for each of these three populations are large enough to neutralize random variations (3,497 nonregistered dialysis patients, 1,534 registered dialysis patients, 1,625 transplant recipients).

Such differences in the distribution are akin to a selection process, since the immense majority of transplant recipients were previous dialysis patients who went through the two preceding stages, i.e. non-registered dialysis patient and then registered dialysis patient. But the explanation for this process is far from simple (Figure 1).

The EGR survey also established that the number of years between the initial diagnosis of renal disease and the terminal stage, when replacement therapy is used, increases consistently with patients' level of education. For the whole population of respondents who had received replacement therapy before responding to the survey, the mean interval was 5.2 years. Dividing the population into groups by level of education, group means ranged from 2.9 years with primary education to 7 years or more for individuals with two or more years of

Figure 1. Distribution of patients by educational level
in the three stages of the process (patients aged 45-60)
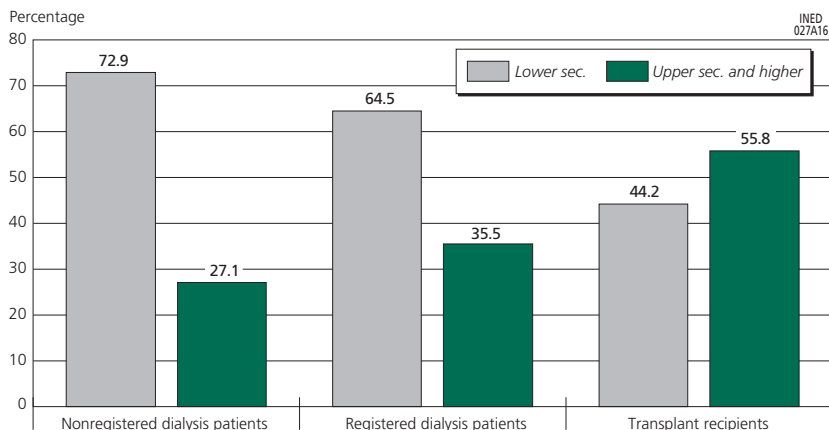
Source: EGR survey.

higher education.[6] The intervals for those with lower secondary or upper secondary education fell between these values. Time is a strategic variable in this context: when the interval is longer, patients have more time to learn about the different therapies available and choose the one best adapted to their pathology and living conditions. This inequality widens even further when dialysis and transplant patients are measured separately. Whatever their level of education, the period between diagnosis and end-stage disease is longer for transplant recipients than for dialysis patients. But this period also increases with level of education. It varies from as little as two years for dialysis patients with primary education to nearly ten years for the most educated transplant recipients (Figure 2). Is this a question of later diagnosis or faster disease progression?

Medical factors do not explain all the differences

Table 2 presents the statistical results of the Quavi-REIN survey and indicates the probability of receiving a transplant and of being registered on the waiting list for a transplant, for a comparable situation. The regressions performed here with more precise models (incorporating, for example, waiting time for a transplant) and a larger set of explanatory variables (region, registration on the waiting list, and type of disease) confirm the results of the EGR survey as well as the descriptive results established by an earlier study on the same data (Baudelot et al., 2014, 2015). Here again, the largest differences in access to transplantation are found between patients with different renal diseases:

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(6) The breakdown by level of education was slightly different in the two surveys. In the Quavi-REIN survey, the levels were "primary", "lower secondary", "upper secondary", "up to 3 years higher education" and "more than 3 years higher education". In the EGR survey, they were "no qualifications", "lower secondary diploma" "upper secondary diploma", "up to 2 years completed higher education" and "more than 2 years completed higher education".

Figure 2. Mean interval between diagnosis and end-stage renal disease by type of replacement therapy and educational level
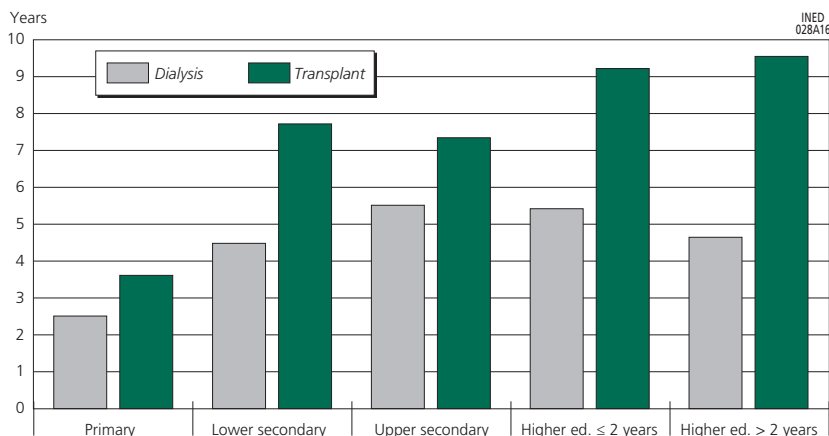
Source: *États généraux du rein* survey.

all other things being equal, a patient with end-stage renal disease due to a genetic condition is more than four times more likely to receive a transplant than a patient with diabetes or a vascular disease. The principal factor explaining inequality in access to transplant between patients is indeed a medical one. However, this does not cancel out the effect of education, which is far from negligible: all other things being equal, persons with more than three years of higher education are still more than twice as likely to receive a transplant as those with a primary education. Whatever the time spent in dialysis, individuals with more than three years of higher education are 1.6 times more likely to cease dialysis due to a kidney transplant than persons with no more than primary education (Table 2).

Registration on the waiting list

These regressions provide further details about the time in the patient's trajectory when the difference by level of education emerges. To receive a transplant, a patient must first be registered by a nephrologist on the national waiting list managed by the Agence de la biomédecine. As columns 6 to 9 of Table 2 show, it is at this stage that significant differences between groups arise, all other things being equal, whether in the probability of registration (column 8) or in the delay until registration occurs (time between first dialysis and registration, column 9). Once patients are registered, on the other hand, and whatever the subsequent transplant waiting time, the overall significance of the education variable is much lower than in regressions on access to transplantation for the entire population and/or those registered on the waiting list. The comparison of the Kaplan-Meier curves clearly illustrates this point (Figures 3, 4, and 5). The profiles of the curves for time before access to transplantation by level of education are very similar to those of time before

Table 2. Odds of being a transplant recipient and being registered on the waiting list

	Descriptive statistics (%)	Odds of being a transplant recipient				Odds of being on the waiting list				Odds of being a transplant recipient / on the waiting list			
		Crude prop. (%)	Crude OR	OR (log. reg.)	OR (duration)	Crude prop. (%)	Crude OR	OR (log. reg.)	OR (duration)	Crude prop. (%)	Crude OR	OR (log. reg.)	OR (duration)
	1	2	3	4	5	6	7	8	9	10	11	12	13
Overall or Constant	100	59		6.15		61		26.71*		89		3.4	
Level of education													
Primary	29	40	Ref.	Ref.	Ref.	42	Ref.	Ref.	Ref.	89	Ref.	Ref.	Ref.
Lower secondary	21	58	2.09***	1.20	1.14	63	2.34***	1.43*	1.29**	87	0.81	0.76	0.90
Upper secondary	23	68	3.22***	1.59**	1.43***	71	3.34***	1.81**	1.50***	90	1.17	0.98	1.03
Higher ed. ≤3 years	16	70	3.42***	1.37	1.36***	75	4.09***	1.70**	1.35***	88	0.91	0.81	0.95
Higher ed. > 3 years	11	72	3.76***	1.91***	1.63***	70	3.17***	1.70*	1.61***	95	2.42*	1.76	1.18
Sex													
Male	63	57	Ref.	Ref.	Ref.	60	Ref.	Ref.	Ref.	88	Ref.	Ref.	Ref.
Female	37	61	1.18·	1.07	1.03	63	1.13	1	1.07	91	1.3	1.15	1.01
Age at ESRD[a]													
Age or *Lower third*	m=52	85	21.46***	0.81**	0.87***	90	41.47***	0.77**	0.88***	93	2.20***	1.02	0.95
Age ^ 2 or *Middle third*	(e.t.=18)	71	9.35***	1.006***	1.004***	75	12.88***	1.007***	1.004***	90	1.47*	0.999	1.000
Age ^ 3 or *Upper third*		21	Ref	0.999***	0.999***	19	Ref.	0.999***	0.999***	86	Ref	0.999	0.999
Disease													
Diabetes mellitus	17	27	Ref.	Ref.	Ref.	32	Ref.	Ref.	Ref.	81	Ref.	Ref.	Ref.
Genetic	20	77	8.83***	4.21***	2.11***	80	8.47***	3.98***	1.72***	92	2.62***	2.31**	1.28*
Glomerulonephritis	45	60	3.98***	1.78***	1.50***	63	3.60***	1.45*	1.30**	89	1.84**	1.49	1.22
Unknown	19	65	4.92***	3.25***	1.77***	67	4.29***	2.97***	1.53***	92	2.72***	2.03*	1.31*
Region													
Nord-Pas-de-Calais	6	38	Ref.	Ref.	Ref.	44	Ref.	Ref.	Ref.	84	Ref.	Ref.	Ref.
Alsace	3	57	2.10**	3.47***	1.66*	59	1.88*	4.03***	1.70***	89	1.52	1.82	0.87
Auvergne	3	54	1.90*	2.44*	1.50	65	2.38**	5.00***	1.55***	77	0.62	0.75	0.77
Basse-Normandie	2	74	4.55***	7.31***	2.67***	72	3.30**	5.46***	1.93**	97	6.11	7.59	1.41
Burgundy	2	50	1.60	2.67	2.13**	51	1.35	2.60	1.95*	94	3.15	2.58	0.95
Brittany	6	62	2.63***	4.74***	2.83***	64	2.29***	6.05***	2.36***	89	1.48	1.78	1.22

Table 2 (cont'd). Odds of being a transplant recipient and being registered on the waiting list

	Descriptive statistics (%)	Odds of being a transplant recipient				Odds of being on the waiting list				Odds of being a transplant recipient / on the waiting list			
		Crude prop. (%)	Crude OR	OR (log. reg.)	OR (duration)	Crude prop. (%)	Crude OR	OR (log. reg.)	OR (duration)	Crude prop. (%)	Crude OR	OR (log. reg.)	OR (duration)
	1	2	3	4	5	6	7	8	9	10	11	12	13
Centre	3	54	1.86*	3.27**	1.58*	54	1.51	3.07**	1.63*	91	1.94	2.40	0.81
Champagne-Ardenne	2	69	3.54***	4.29***	2.18***	78	4.43***	7.72***	2.31***	86	1.14	1.29	1.09
PACA and Corsica	13	43	1.23	1.96**	1.33	48	1.17	2.22**	1.31	85	1.05	1.25	0.87
Haute-Normandie	3	48	1.45	2.20*	1.88**	46	1.10	2.11	1.51	88	1.34	1.42	1.54
Île-de-France	15	70	3.75***	3.67***	1.47**	66	2.46***	2.14**	1.51**	99	14.32***	14.06***	0.65**
La Réunion	2	42	1.16	1.17	1.02	56	1.62	1.91	1.47	70	0.42	0.55	0.45**
Languedoc-Roussillon	7	53	1.80*	2.50**	1.37	52	1.39	2.34**	1.40	90	1.65	1.60	0.60**
Limousin	2	75	4.68***	9.85***	2.34***	78	4.42***	12.09***	2.24***	95	3.33	4.16	1.14
Lorraine	5	62	2.66***	4.74***	2.30***	59	1.81*	3.01**	1.91***	100	+inf	+inf	1.34
Midi-Pyrénées	4	57	2.15**	3.55***	1.51*	66	2.52***	6.15***	2.71***	85	1.03	1.18	0.46***
Pays de la Loire	5	69	3.61***	4.10***	1.99***	78	4.48***	8.93***	1.90***	82	0.83	0.99	0.81
Picardie	3	58	2.17**	1.88	1.40	71	3.07***	3.47**	1.52*	78	0.67	0.70	0.86
Poitou-Charentes	2	68	3.38***	7.04***	2.97***	65	2.4*	6.40***	2.20***	95	3.24	4.24	1.62*
Rhône-Alpes	13	66	3.17***	5.17***	2.12***	71	3.13***	7.70***	1.76***	89	1.57	1.81	0.75
Number of observations	2,512	2,512	2,512	2,512	2,512	2,252	2,252	2,252	2,252	1,519	1,519	1,519	1,519
Pseudo R^2			37	34			44	38			12	8.6	

Interpretation: 11% of the population have more than 3 years of higher education; 72% of these individuals received a transplant, or 3.76 times more than individuals with primary education (effect significant at the 0.1% level). All other things being equal, they were 1.9 times more likely (effect significant at the 1% level) to receive a transplant than persons with primary education (odds ratio calculated using a logistic regression model); whatever the time spent in dialysis, individuals with more than three years of higher education are 1.63 times more likely to leave dialysis by way of a kidney transplant than individuals with a primary education (odds ratio calculated using a Cox proportional hazards model).

(a) To model the probability of receiving a transplant or being registered, age is defined as age at first dialysis or, for persons not receiving dialysis, age at registration on the waiting list. For the purpose of studying the conditional probability of receiving a transplant for patients who are registered, we use age at registration. As age is a continuous variable, to calculate the descriptive statistics (crude proportions and odds ratios), age was divided into three thirds (cells in italics). The mean and the standard deviation in parentheses are given for the descriptive statistics. We use the continuous variable (first, second, and third degree) for all regression models.

Coverage: The probability of being registered on the waiting list was studied in the population that experienced a period of dialysis before registration, excluding persons who had received (or were awaiting) a pre-emptive transplant. The probability of receiving a transplant was studied in the whole population, excluding patients for whom data were lacking for some of the variables listed in the table.

Significance levels: *** p < 0.001; ** p < 0.01; * p < 0.05; no asterisk: p < 0.1.
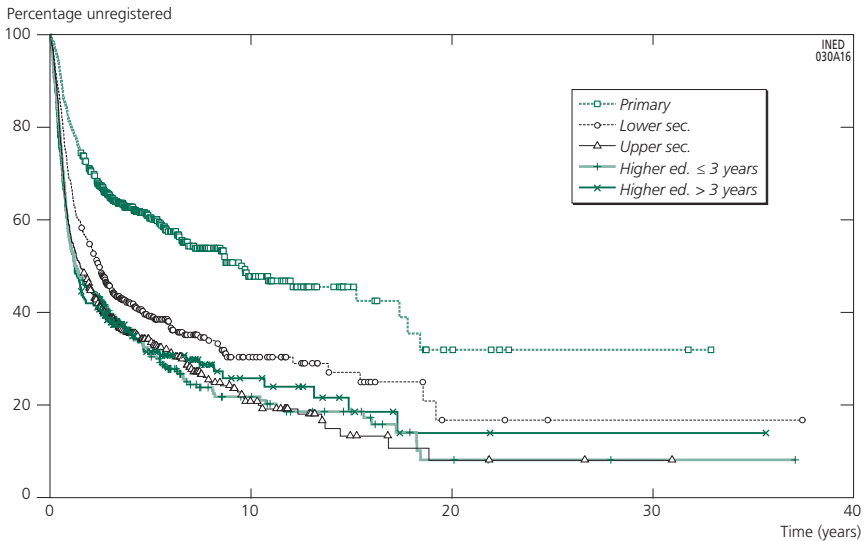
Source: Quavi-REIN survey.

Figure 3. Waiting time before obtaining a kidney transplant for the whole ESRD population, by level of education

Percentage still in dialysis
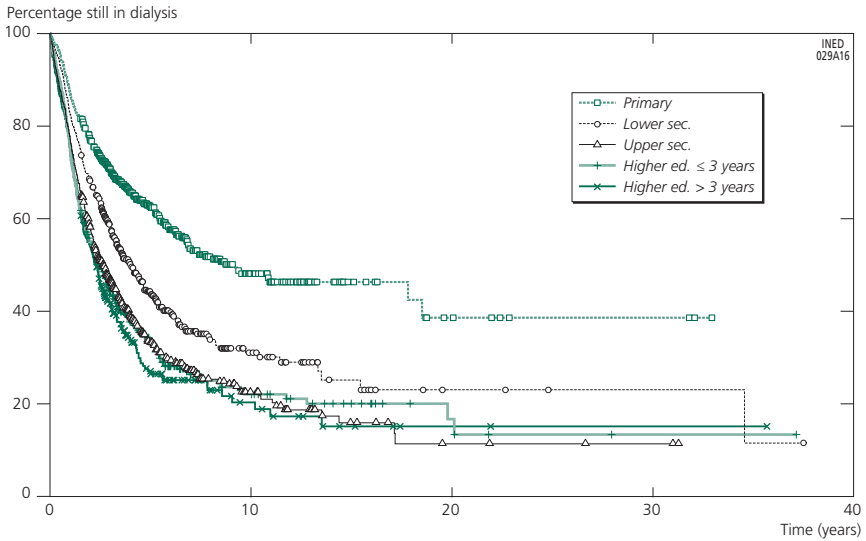
Interpretation: These Kaplan-Meier curves show the proportion of the ESRD population still in dialysis that has not yet received a kidney transplant. Five years after beginning dialysis, 62% of patients with primary education are still in dialysis.
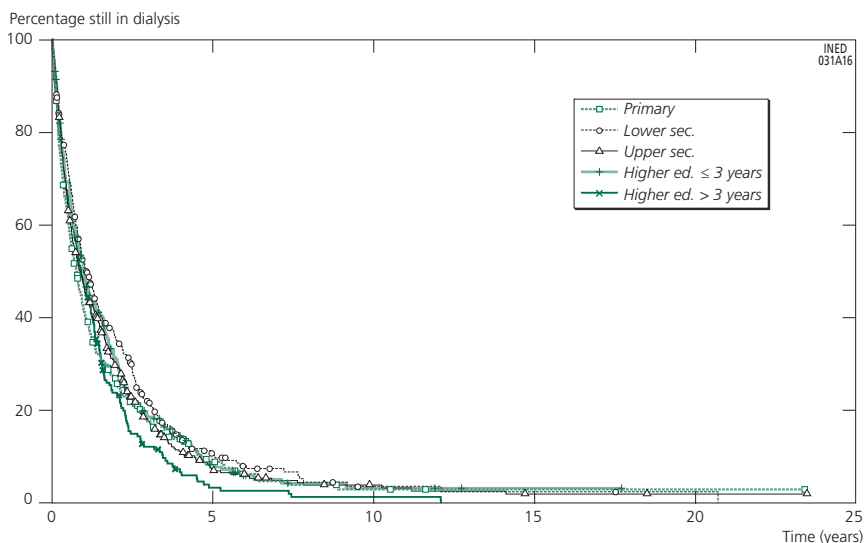
Source: Quavi-REIN survey.

Figure 4. Waiting time until registration on the kidney transplant waiting list, by level of education

Percentage unregistered

Interpretation: These Kaplan-Meier curves show the proportion of the ESRD population not yet registered on the waiting list to obtain a kidney. Five years after beginning dialysis, 59% of patients with primary education are still in dialysis.

Source: Quavi-REIN survey.

Figure 5. Waiting time before obtaining a kidney transplant among patients registered on the waiting list, by level of education

Interpretation: These Kaplan-Meier curves show the proportion of the population registered on the kidney transplant waiting list. Two years after registration, 23% of patients with primary education had not yet received a transplant.
Source: Quavi-REIN survey.

access to registration (Figures 3 and 4), which themselves differ substantially from the profiles of access to transplantation after registration (Figure 5).

The only other significant differences that explain why not all those on the waiting list had received a transplant at the time of the survey are medical in nature (columns 12 and 13 of Table 2): all other things being equal, patients with genetic and "unknown" pathologies are twice as likely to have received a transplant as patients with vascular diseases or diabetes.

The different categories of transplant

While transplantation is currently the best possible therapy for ESDR, not all grafts are of equal quality. The best outcomes are achieved with a pre-emptive transplant from a living donor. This has been amply demonstrated by studies in numerous countries. A pre-emptive transplant is one that is performed directly, without a previous period of dialysis. While only a small minority of transplants in France are pre-emptive (354, or 12% of the 3,074 kidney transplants performed in 2013), this option avoids all the medical, social, and human costs of dialysis. These transplants work better and longer than those performed after one or more years of dialysis, and it has been clearly shown that the longer the preceding period of dialysis, the greater the failure rate of a subsequent transplant (Meier-Kriesche and Kaplan, 2002).

As well as alleviating the shortage of organs from deceased donors, transplants from living donors guarantee that the transplanted organ will be of excellent quality. Numerous examinations ensure that only kidneys with optimal function are harvested. The standards applied in France are among the most selective in the world: individuals whose renal function is below 80% of the maximum level are excluded from donating. Ischaemia time – that is, the waiting time before the harvested organ is transplanted – is reduced to a minimum, as the procedures are organized simultaneously. Moreover, the availability of a living donor is the scenario most conducive to pre-emptive transplantation, although only 135 of the 354 kidneys transplanted pre-emptively in 2013 (35%) were from a living donor. All of these conditions ensure the best possible conditions for survival of the graft.

The Quavi-REIN survey shows that this optimal scenario is not evenly distributed across all social categories (Table 3). In the observed sample, 8% of individuals with up to three years of higher education received a transplant from a living donor. Columns 3 and 4 present the odds ratios, as calculated by the multinomial model, between the probability of remaining in dialysis versus receiving a transplant from a deceased donor, and of receiving a transplant from a living donor versus a deceased donor. All other things being equal, this group's probability of receiving a transplant from a living donor rather than a deceased donor was 1.88 times higher than that of persons with primary education (significant at the 10% level). When levels of education are grouped together, the odds of patients with upper secondary or higher education obtaining a transplant from a living rather than a deceased donor were 1.66 times higher (significant at the 5% level) than those of patients with a primary or lower secondary level of education.

The two final columns present the odds ratios, as calculated by the multinomial model, for the probability of either remaining in dialysis or receiving a pre-emptive transplant, as opposed to receiving a transplant after dialysis. All other things being equal, persons with more than three years of higher education were 2.3 times more likely to receive a pre-emptive as opposed to a standard transplant than persons with primary education (significant at the 5% level). In both cases, the more highly educated had an advantage.

The poorest and least educated patients are affected by a cumulative disadvantage. They are more often concerned by pathologies that are contraindicated for transplantation or that complicate the transplant procedure and make the outcome more uncertain. They wait longer than others to be registered on the waiting list and, whether or not they receive a transplant, they are only qualified to do jobs requiring levels of physical energy that are difficult to reconcile with their state of health. The "work-resources" component of the Quavi-REIN survey gathered information on two distinct moments in the trajectory of patients aged 25-65 years: before and after reaching end

Table 3. Probability of receiving therapy (remaining in dialysis, living donor transplant, pre-emptive transplant) vs. another therapy, multinomial regression

Overall-constant	Simple prop., deceased donor transplant (%) 1	Simple prop., living donor transplant (%) 2	Dialysis vs. deceased donor transplant 3	Living vs. deceased donor transplant 4	Standard transplant (%) 5	Pre-emptive transplant (%) 6	Dialysis vs. standard transplant 7	Pre-emptive vs. standard transplant 8
Overall/Constant	55	4	0.19	0.06*	54	5	0.16	0.07*
Level of education								
Primary	39	2	Ref.	Ref.	38	2	Ref.	Ref.
Lower secondary	56	3	0.83	0.93	54	4	0.87	1.42
Upper secondary	63	6	0.64**	1.42	60	8	0.69*	2.38**
Higher ed. ≤3 years	62	8	0.79	1.88·	63	7	0.81	1.99*
Higher ed. > 3 years	65	7	0.54**	1.68	64	8	0.57**	2.26*
Sex								
Male	53	4	Ref.	Ref.	53	5	Ref.	Ref.
Female	57	5	0.92	1.07	55	6	0.93	1.09
Age at ESRD								
Age or *Lower third*	76	9	1.23**	1.1	78	8	1.22**	0.94
Age ^ 2 or *Middle third*	68	3	0.994***	0.996	65	6	0.994***	1.001
Age ^ 3 or *Upper third*	20	1	1.00005***	1.00003	19	2	1.00005***	0.9999
Disease								
Diabetes mellitus	27	1	Ref.	Ref.	26	2	Ref.	Ref.
Genetic	72	5	0.24***	2.07	70	7	0.23***	1.28
Glomerulonephritis	55	5	0.57***	1.94	53	7	0.58***	1.82
Unknown	60	6	0.30***	2.30	62	5	0.29***	1.15
Region								
North	33	6	Ref.	Ref.	36	3	Ref.	Ref.
Mediterranean and Réunion[a]	45	1	0.45***	0.19***	42	5	0.52**	1.42
Ile-de-France	60	10	0.27***	0.85	64	6	0.28***	1.08
Parisian basin[b]	56	3	0.30***	0.30*	54	5	0.33***	1.09
East	55	5	0.23***	0.54	56	5	0.24***	1.01
West	63	3	0.20***	0.30*	55	11	0.23***	2.42
South-west	59	5	0.19***	0.51	62	1	0.19***	0.28
Centre-east	60	5	0.21***	0.51	60	5	0.22***	1.09
Number of observations	2,531		2,531		2,531		2,531	
Pseudo R²			31%				30%	

stage renal disease. The transition from one to the other is accompanied by a massive decrease in labour force participation rates, whose scale varies according to the type of therapy received. The rate fell from 63% to 17% among dialysis patients who had not been offered a transplant, from 78% to 51% among those who received a transplant following a period of dialysis, and from 78% to 59% among those who received a transplant without a previous period of dialysis. All were aged below 65 years at the time of the survey (Figure 6).

Figure 6. Labour force participation rate of patients aged below 65 before and after onset of end-stage renal disease, by type of therapy
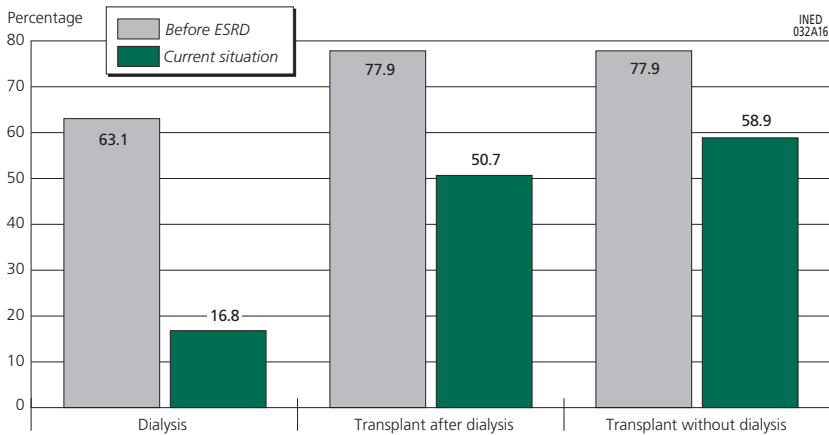
Source: États généraux du rein survey.

IV. Discussion

Social inequality in access to transplantation is not a French exception

The international literature shows clearly that social inequality in access to transplantation revealed by the EGR and Quavi-REIN surveys is not specific to France. Many studies based on large samples have been published in respected journals in the United Kingdom and North America, as well as in Brazil, Germany, Hungary, Australia, and New Zealand. Whatever the variable, all reveal large social disparities by income, level of education, and ethnic origin. Low socioeconomic status is associated with higher incidence of renal pathologies, more frequent transition to end-stage renal disease, inadequate dialysis, and reduced access to transplantation, compounded by the effects of poor general health (Patzner et al., 2012). Black and Hispanic patients wait longer than others before being registered on waiting lists (Joshi et al., 2013). The literature on the effects of these factors on access to transplantation is very substantial and explicit, as the title of one publication suggests: "Do you need to stay in school to get a kidney transplant?" (Fink, 2008). Evidence

shows that there are large disparities between African Americans and Caucasians, as well as between Hispanics and Caucasians.

Many factors explain these disparities: the "preferences" of patients and doctors, socioeconomic status, insurance coverage, level of education, and immunological factors. One article examined the action of all of these causes of inequality in access to transplantation in the United States. (Joshi et al., 2012). Individuals at the top of the socioeconomic pyramid are more likely to receive transplants from living donors than individuals at the bottom (Grace et al., 2013; Gill et al., 2012). Survival data on both dialysis and transplantation by income, level of education and ethnic origin show that in both cases, patients live longer if they are white, educated, and affluent (Kimmel et al., 2013; Begaj et al., 2013). Poor and black patients are more likely to be allocated a kidney on expanded criteria (Janezko, 2013).

Renal diseases are not an exception in the medical landscape

The social distribution of these diseases follows a pattern that is also found in most other pathologies. Here too, different social categories do not benefit equally from the medical progress resulting from preventive measures implemented at the three stages of the disease. Lesser exposure to risk factors decreases incidence of the disease. Although no particular occupations have been identified as particularly nephrotoxic, the fact that the least educated population categories are more likely to suffer from arterial disorders, diabetes, and obesity suggests that poor nutrition and hypertension, two major risk factors for kidney damage, are not monitored and managed to the same extent in all segments of society. Similarly, in showing that the number of years separating initial diagnosis from ESRD increases progressively with level of education, the EGR survey confirms that different social classes do not adhere equally to the specific dietary and lifestyle constraints that can slow the course of the disease. Finally, at the most advanced stage, when replacement of renal function becomes necessary, the most educated groups more often benefit from the best available therapy, namely transplantation.

Theoretical models of disability are also fully applicable to the effects of renal pathologies on patients' quality of life, insofar as changes in renal function lead to disabilities or activity limitations and, over time, to major social disadvantages, and even to exclusion from employment (Verbrugge and Jette, 1994). For the least educated groups who often have physically demanding jobs, regular dialysis sessions and poor overall health make it difficult to stay in employment. This contrasts with the situation of more educated patients, who more often benefit from a transplant, and who typically perform sedentary jobs requiring work that is more intellectual than physical.

The life course of these patients can be seen in terms of the "accumulation" model in life course epidemiology, and notably its longitudinal dimension, which looks at how medical and social disadvantages accumulate over the life

course. Neither dialysis nor transplantation provide a cure for the disease, and the side effects of treatments, as well as accelerated ageing, limit the number of activities that patients are able to perform, among which employment is the most strategic (Blane et al., 2007; Link and Phelan, 1995).

Organ donations: efficacy or equity?

Renal pathologies do, however, present an original characteristic. ESRD can be treated in two ways, one of which, transplantation, is now clearly the best in terms of life expectancy, quality of life, and public cost. Among all the results presented in this article, the most spectacular relates to the observed difference, in terms of social inequalities, between two stages in the treatment process: registration on the waiting list and access to transplantation. There are large differences in registration by level of education, but once this threshold has been crossed, these differences are no longer found for access to transplantation. What explains this contrast? Once patients are registered on the list, apart from the above-mentioned possibility of giving priority to transplants performed in the hospital where the organ is harvested, it is no longer physicians who decide whether or not a patient will receive a transplant, but a score calculated by an algorithm.

Organ scarcity has led most countries to establish waiting lists, and to define rules for distribution and allocation of organs harvested from brain-dead individuals. In France, these rules are based on two principles: equity between patients and medical efficacy.

In terms of medical efficacy, defined as the "degree to which an intervention accomplishes the desired or projected outcomes", organ allocation takes account of tissue group compatibility (number of donor-recipient incompatibilities in the six HLA loci), and of the age difference between donor and recipient.

In terms of equity, a statistical index of "ease of access to transplantation", which favours patients for whom it is difficult to find a suitable organ for immunological reasons (notably due to anti-HLA immunization) is also an important criterion, as is the time since registration on the list and since the start of dialysis.

Each of these factors is weighted and fed into a national algorithm which calculates a compatibility score for all patients on the waiting list each time a new graft becomes available. A list of potential recipients is then drawn up, in decreasing order of priority. It is not surprising, then, that this algorithm should be indifferent to patients' level of education. Indeed, its neutrality is a sign of its quality, showing that it ensures equality of treatment between patients. This is not true "upstream", at the stage of registration on the waiting list, where nephrologists' decisions about whether or not to include a patient is by no means anonymous. At this stage, the decision is made in full awareness of all the patient's characteristics, including not only medical but also other individual and behavioural aspects. It cannot be ruled out that, under these

conditions, a medical efficacy criterion – whereby doctors preferentially register patients whose state of health and personal characteristics lead them to expect a greater life expectancy benefit from scarce donated organs – wins out over the criterion of equity. This is currently only a hypothesis and cannot be validated using the available data, but studies in other countries have shown that it is well-founded (Janezko, 2013; Tandon, 2013). Jon Elster (1992) extensively studied the different justice criteria that are applied in allocating scarce resources, and notably in the case of organ donations. He highlighted the tension between two types of logic: need (who is most in need of a transplant at a given moment?) and social efficiency (which potential transplant recipient will maximize collective well-being?). Efficiency also means maximizing total remaining life-years, i.e. giving priority to young people with long life expectancies who will adhere to their therapeutic regimen. Comparing two countries, one where organs are scarce, the other where they are abundant, he shows that countries where the resource is scarcer focus more on efficiency criteria. This choice may favour the most educated.

The available data do not allow us to identify the wide spectrum of reasons why patients are not registered on the waiting list for an organ. However, surveys on the question performed in other countries suggest some hypotheses that are worth testing: low expectations of graft survival in light of the patient's behavioural characteristics, patients' decisions, the institutional logic of healthcare centres, inter-regional differences in medical cultures, incentive effects of pricing systems, pressure from the management of public and non-profit institutions and from the shareholders of private institutions, etc. Only through an independent survey endowed with sufficient resources will it be possible to assess the respective roles of these factors in France.

Conclusion

Various measures could be taken to attenuate these social inequalities. The first step would be to stop acting as if they cannot exist, but rather to acknowledge and address the problem, in line with the first recommendation of the report of the Haut conseil de la santé publique, *Sortir de la fatalité* (Breaking with fatalism). The addition of social variables, level of education and a "geographical index of social disadvantage", to the registry of the Agence de la biomédecine will contribute substantially.[7] It would also be useful for each nephrology department to address these questions, examining its own practices in the light of this issue, by seeking, for example, to measure the existence and scale of the phenomenon in local context.

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(7) To compensate for the lack of individual socioeconomic data, the socioeconomic characteristics of areas of residence are often used. In France, "ecological disadvantage indices" have been developed for this purpose. The IRIS code, the most widespread of these, is inspired by the "deprivation index" created by UK authorities at the ward level.

Beyond this necessary awareness, corrective actions may also be considered, notably the expansion of living donor transplants, which could alleviate the shortage of organs from deceased donors.

In general, all improvements in access to the waiting list and to transplantation will help to reduce these social inequalities. Since the États généraux du rein, there has been a marked institutional determination to see such changes through. In December 2015, the Haute autorité de santé published a code of good practice for access to the national renal transplant waiting list. They specify categories and criteria for registering patients approaching the terminal stage of chronic renal insufficiency (including elements from the pre-transplant assessment) as well as a periodic review of the reasons for non-registration.

Experiments on care pathways in renal insufficiency, to be carried out as part of the national health strategy, will be initiated in 2016 in six regions. One of the main stated objectives of these initiatives is to promote access to the transplant waiting list. Two new measures will be introduced to achieve this goal:

- notification, information, and orientation systems for patients, designed to offer them the freedom to choose their own care pathway and therapies, as part of a medical decision made jointly with their physician;
- multidisciplinary coordination meetings, collegial review of patients' files – by medical experts from different disciplines, but also by paramedics – to ensure that patients receive the forms of care best suited to their individual needs and that correspond to their own choices.

These two measures may contribute to creating a situation where patients' care pathways no longer depend exclusively on a single nephrologist, but instead include a collegial dimension and, above all, take account of the patients' own preferences.

In the same spirit, for all patients approaching the replacement therapy stage who are aged under 70 (and beyond, in the absence of obvious contraindications and in line with their wishes), a systematic pre-transplant consultation with a renal transplantation team could help to narrow the differences in access between social groups.

Finally, the fee-for-service system for dialysis influences patient care choices and may be holding back the development of transplantation. In its annual report on the application of the 2015 laws on the financing of the French social security system, the Cour des comptes showed that the fee-for-service payments received by institutions, and the way in which independent nephrologists are paid to perform dialysis both create incentives favouring in-centre dialysis, the most high-tech and costly form of dialysis. These work to the detriment not only of other dialysis techniques and of access to transplantation, but also of care strategies aimed at slowing or stopping the development of renal disease before the replacement stage (Cour des comptes, 2015).

To remedy this situation, the Cour des Comptes recommends that the system for reimbursing renal insufficiency treatment be modified with a view to rebalancing the budgets allocated to in-centre dialysis with respect to those for prevention, organ harvesting and transplantation. Such a reform would no doubt be decisive in attenuating the impact of social inequalities.

Patients also have a role to play. Their capacity to take an active part in their own care decisions and pathways and to emancipate themselves from the power of the physician are also important ways of reducing social inequalities. Organizations representing health system users could use therapeutic education and other support initiatives to raise patients' awareness of their rights, better equip them to discuss with health professionals on an equal basis, without being spoken down to or infantilized, and find information, support, and resources. Such initiatives must give priority to the most vulnerable groups if they are to attenuate inequalities rather than amplify them.

These measures would also considerably reduce the proportion of health spending that goes to nephrology. In France, a year of dialysis costs the national health insurance system around €80,000 (Blotière et al., 2010). Spending linked to a transplant is approximately equal in the year of the operation, but then decreases sharply, to around €20,000 per year. The 71,000 ESRD patients in France receiving treatment by dialysis (55%) or kidney transplant (45%), represent an overall medical cost of around €4 billion; 82% of this amount, or around 3% of the total budget of the national health insurance system (around €140 billion), is spent on dialysis.

This is one of the most significant paradoxes in nephrology. Contrary to many other pathologies, the least expensive therapy for ESRD is also the most effective. It is not the wealthiest who represent the greatest cost to the healthcare system, but the poorest, who nonetheless continue to receive inferior care.

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APPENDIX

Renal disease therapies

For patients with end-stage renal disease (ESRD), whose kidneys permanently cease to function, their survival depends on one of two "replacement techniques": haemodialysis (or simply dialysis) and renal transplantation.

In haemodialysis (55% of patients in France), two modes of treatment are possible:

- *"Autonomous" hemodialysis (30% of dialysis patients):*
  - Home haemodialysis

Patients can undergo haemodialysis in their own home. A family member is generally required to be present to assist the patient in case of problems during the session.

  - Self-care dialysis

Patients who do not wish to be treated at home or who do not have space to install the required equipment can use self-care dialysis. In this case, the patient goes to a local dialysis unit where there is one nurse for every six to eight patients, depending on their degree of autonomy.

- *Non-autonomous hemodialysis (70% of dialysis patients):*
  - In-centre haemodialysis

In this form of dialysis, nurses prepare the machine, connect and disconnect the patients' blood supply, and monitor the session. A doctor is present during each session. Patients undergo three four-hour dialysis sessions per week.

  - Hemodialysis in a medically supervised dialysis unit

This type of unit is used by patients who are not autonomous, but who do not need such "close" medical supervision. A physician is not systematically present for every session.

For renal transplantation (45% of patients) there are two sources of organs:
  - Deceased donors (85% of transplant patients)
  - Living donors (15% of transplant patients)

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REFERENCES

ABM (Agence de la biomédecine), 2011, *Rapport annuel REIN (Réseau Epidémiologie et Information en Néphrologie)*, 297 p.

BAUDELOT C., CAILLÉ Y., MERCIER S., 2015, "Activités professionnelles et ressources des insuffisants rénaux", *Surveillance de la qualité de vie des patients insuffisants rénaux chroniques terminaux, Enquête Quavi-Rein 2011*, Agence de la biomédecine.

BAUDELOT C., CAILLÉ Y., MARTINEZ F., MERCIER S., 2014, "La tête et les reins, inégalités sociales en néphrologie", *Actualités néphrologiques Jean Hamburger,* Hôpital Necker, Lavoisier, pp. 69-85.

BLANE D., NETUVELI G., STONE J., 2007, "The development of life course epidemiology", *Revue d'épidémiologie et de santé publique*, 55(1), pp. 31-38.

BEGAJ I., KHOSLA S., RAY D., SHARIF A., 2013, "Socioeconomic deprivation is independently associated with mortality post kidney transplantation", *Kidney International,* 84(4), pp. 803-809.

BLOTIÈRE P.-O., TUPPIN P., WEILL A., RICORDEAU P., ALLEMAND H., 2010, "Coût de la prise en charge de l'IRCT en France en 2007", *Néphrologie & thérapeutique*, 6(4), pp. 240-247.

BOLTANSKI L., 1971, "Les usages sociaux du corps", *Annales. Économies, sociétés, civilisations*, 26(1), pp. 205-233.

COUR DES COMPTES, 2015, "L'insuffisance rénale chronique terminale : favoriser des prises en charge plus efficientes", *Rapport sur l'application des lois de financement de la sécurité sociale,* chapter X, pp. 347-377.

DRESS, 2014, "La situation économique et financière des cliniques privées à but lucratif", Études *et résultats*, 878, 4 p.

EGR, 2013, "La voix des patients", *Rapport final des États généraux du rein.*

ELSTER J., 1992, *Local Justice: How Institutions Allocate Scarce Goods and Necessary Burdens*, New York, Russell Sage Foundation, 283 p.

LECLERC A., FASSIN D., GRANDJEAN H., KAMINSKI M., LANG T., 2000, *Les inégalités sociales de santé*, INSERM, Paris, La Découverte, 448 p

FINK J.C., 2008, "Do you need to stay in school to get a kidney transplant?", *American Journal of Kidney Disease*, 51(5), pp. 717-718.

GILL J.S., TONELLI M., 2012 "Penny wise, pound foolish? Coverage limits on immunosuppression after kidney transplantation", *The New England Journal of Medicine*, 366(7), pp. 586-589.

GILL J., DONG J., ROSE C., JOHNSTON O., LANDSBERG D., GILL J., 2013, "The effect of race and income on living kidney donation in the United States", *Journal of the American Society of Nephrology*, 24(11), pp. 1872-1879.

GRACE B.S., CLAYTON P.A, CASS A., MCDONALD S.P., 2013, "Transplantation rates for living – but not deceased – donor kidneys vary with socioeconomic status in Australia", *Kidney International*, 83(1), pp. 138-145.

HAS, 2014, "Évaluation médico-économique des stratégies de prise en charge de l'insuffisance rénale chronique terminale en France", Haute autorité de santé.

Janeczko L. L, 2013, "Why nephrologists exclude patients from referral for kidney transplant: A survey", American Society of Nephrology's annual meeting in Atlanta.

Joshi S., Gaynor J.J., Ciancio G, 2012, "Review of ethnic disparities in access to renal transplantation", *Clinical Transplantation*, 26(4), E337-E343.

Joshi S., Gaynor J.J., Bayers S., Guerra G., Eldefrawy A. et al., 2013, "Disparities among Blacks, Hispanics, and Whites in time from starting dialysis to kidney transplant waitlisting", *Transplantation*, 95(2), pp. 309-318.

Kimmel P.L., Fwu C.W., Eggers P.W., 2013, "Segregation, income disparities, and survival in hemodialysis patients", *Journal of the American Society of Nephrology*, 24(2), pp. 293-301.

Link B., Phelan J., 1995, "Social conditions as fundamental causes of disease", *Journal of Health and Social Behavior, Extra Issue: Forty Years of Medical Sociology: The State of the Art and Directions for the Future*, 35, pp. 80-94.

Meier-Kriesche H.U., Kaplan B., 2002, "Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes", *Transplantation*, 74, pp. 1377-1381.

Mohandas R. Casey M.J., Cook R.L., Lamb K.E., Wen X., Segal M.S., 2013, "Racial and socioeconomic disparities in the allocation of expanded criteria donor kidneys", *Clinical Journal of the American Society of Nephrology*, 8(12), pp. 2158-2164.

Morgan E., Grams B., Chen P.H., Coresh J., Segev D., 2013, "Preemptive deceased donor kidney transplantation: Considerations of equity and utility", *Clinical Journal of the American Society of Nephrology*, 8, 8 p.

Patzer R.E., McClellan W.M., 2012, "Influence of race, ethnicity and socioeconomic status on kidney disease", *Nature Reviews Nephrology*, 8(9), pp. 533-541.

Tandon A., 2013, "Why nephrologists exclude patients from referral for kidney transplant: A survey", American Society of Nephrology's annual meeting in Atlanta.

Verbrugge L.M., Jette A.M., 1994, "The disablement process", *Social Science Medicine*, 38(1), pp. 1-14.

Christian BAUDELOT, Yvanie CAILLÉ, Olivier GODECHOT, Sylvie MERCIER • **RENAL DISEASES AND SOCIAL INEQUALITIES IN ACCESS TO TRANSPLANTATION IN FRANCE**

Renal diseases are invisible and silent up to an advanced stage. Renal transplant is today the most effective therapy at all ages of life in terms of survival and quality of life, and is also the least expensive for French health system. Yet, whatever their age or sex, patients with a lower level of education less frequently receive transplants. Various independent factors produce these social inequalities: the nature of renal pathologies, resulting partly from patients' lifestyles; the degree of attention paid to initial symptoms and the existence of two types of replacement therapy (dialysis and transplant) practiced differently in the private and public sectors. Patients with the highest level of education are in a better position to negotiate the system than the others. The results presented in this article are based on data from two national surveys of renal patients conducted in 2011 and 2012.

Christian BAUDELOT, Yvanie CAILLÉ, Olivier GODECHOT, Sylvie MERCIER • **MALADIES RÉNALES ET INÉGALITÉS SOCIALES D'ACCÈS À LA GREFFE EN FRANCE**

Les maladies rénales sont invisibles et silencieuses jusqu'à un stade avancé. La transplantation est aujourd'hui le traitement le plus efficient à tous les âges de la vie en termes de survie et de qualité de vie, mais aussi pour le système de santé. Or, quels que soient le sexe ou l'âge, les patients les moins instruits y ont moins souvent accès que les autres en France. De nombreux facteurs indépendants concourent à ces inégalités sociales : la nature des pathologies rénales en partie produites par le mode de vie, l'attention prêtée aux premiers symptômes, mais aussi l'existence de deux traitements de suppléance (la dialyse et la transplantation) qui se pratiquent dans des univers professionnels différents. Les mieux armés pour s'orienter dans ce système sont les patients les plus instruits. Les résultats présentés dans cet article sont issus de deux enquêtes nationales menés en 2011 et en 2012 auprès de patients en insuffisance rénale.

Christian BAUDELOT, Yvanie CAILLÉ, Olivier GODECHOT, Sylvie MERCIER • **ENFERMEDADES RENALES Y DESIGUALDAD SOCIAL EN EL ACCESO AL TRASPLANTE EN FRANCIA**

Las enfermedades renales son invisibles y silenciosas hasta un estadio avanzado. El trasplante es actualmente el tratamiento más eficaz a toda edad, en términos de longevidad y de calidad de vida, y también para el sistema de salud. Ahora bien, en Francia, cualquiera que sea el sexo o la edad, los enfermos menos instruidos tienen un menor acceso al trasplante que los otros. Los factores que concurren a ello son numerosos: la naturaleza de las enfermedades renales provocada en parte por el modo de vida, la atención prestada a los primeros síntomas, y también la existencia de dos tratamientos supletorios (la diálisis y el trasplante) que se practican en universos profesionales diferentes. Los pacientes mejor armados para orientarse en este sistema son los más instruidos. Los resultados presentados en este artículo provienen de dos encuestas nacionales aplicadas a enfermos renales en 2011 y 2012.

Translated by Paul Reeve.