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## **DECISIONS CONCERNING POTENTIAL LIFE-SUSTAINING TREATMENTS IN PAEDIATRIC NEPHROLOGY**

*Multicentre study in French-speaking countries*

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Running title: reflections on life-sustaining treatments in paediatric nephrology

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## **Abstract**

**Background:** Few studies have looked at the way in which decisions to withhold or to withdraw potential life-sustaining treatments (LST) are taken in paediatric nephrology. The aim of this work was to evaluate such practices in all nephrology centres in French-speaking European countries, so that guidelines could be drawn up and discussed by professionals.

**Methods:** Semi-directed interviews were used to question health-care professionals prospectively. We also retrospectively analysed the medical files of all children (n= 50) for whom a decision to withhold or to withdraw LST had been taken in the last five years. The doctors (n=31) who had been involved in the decision-making process were interviewed.

**Results:** All 31 of the French-speaking paediatric nephrology centres in Europe were included in this study. Eighteen of these centres had made decisions about whether to withhold or to withdraw LST in the previous five years. Subsequent quality of life, based on long-term living conditions, was the principal criterion used to make decisions. Criteria affecting relational aspects of life and the child's prognosis were also considered. The decision-making processes (DMP) were not always collective even though interactions between doctors and the rest of the medical team seemed to be a key element. The parents' involvement in the DMP differed between centres.

**Conclusions:** The criteria used to decide whether to withhold or to withdraw LST are not standardised and no specific guidelines have been established.

**Keywords:** dialysis, ethics, life-sustaining treatments, nephrology, paediatric, treatment withholding or withdrawal

## **Introduction**

Decisions as to whether to withdraw or to withhold treatment have to be made for 82 to 87% of patients in neonatology units [1-2] and for 30 to 58% of patients in paediatric intensive care units [3]. The decision to stop dialysis is the second most common cause of death for adult nephrology patients in the United States and Canada after cardiovascular diseases, affecting between 16 and 17% of patients with end-stage kidney failure [4-5]. However, no studies concerning the frequency of such decisions in paediatric nephrology have been published. The aims of this study were to record the decisions made in different clinical situations and to discuss the decision-making processes used by health-care professionals in various situations with the aim of improving them. Improved decision making guidelines are requested by the French-speaking Paediatric Nephrology Society (SFNP), which supported this study.

## **Methods**

This study was designed jointly by experts from the SFNP and from the Medical Ethics Laboratory at the Faculty of Medicine of Necker-Enfants-Malades Hospital.

### *Organisation of the study*

University hospitals are the only centres in France to have paediatric nephrology departments. The heads of all these departments were contacted. We also contacted all other French-speaking university hospitals in Europe that use the same medical practices and in which the hospital environment is similarly organised.

All 31 French-speaking paediatric nephrology centres in Europe were included: 25 in France, 2 in Switzerland, 3 in Belgium and 1 in Luxembourg.

The two-step study was carried out by an investigating doctor during 2001. The two steps were as follows:

1. Study of the medical files of children suffering from kidney diseases for whom a decision to withhold or to withdraw LST had been made between January 1995 and January 2001.

In the initial analysis, an evaluation grid was used to collect data concerning 11 items possibly associated with the decision-making process [3, 6-8]: prediction by the doctor of a poor subsequent quality of life, presence of a severe neurological handicap, association with a severe extra renal disease, consequences of the child's disease for the family, opinion of the family, renal insufficiency from birth, social context, suffering of child resistant to major analgesic treatments, likelihood of survival, treatment failure and cost.

We also collected data concerning the practical aspects of the withdrawal or withholding of treatment: the administration of sedatives/analgesics to suppress pain even if there was a risk of respiratory depression and death, the written transcript of the medical end-of-life decision in the medical file (observation or hospitalisation summary), the existence of a written order not to resuscitate the patient, cases in which the doctors decided to withdraw/withhold treatment but treatment was continued, the delay between the decision and the patient's death, the time at which the decision was taken, and any analysis by an ethics committee before taking the decision.

Finally, we collected data concerning the characteristics of the child: the age of the child at the time of the end-of-life decision, the nature of the disease and whether the child had undergone renal transplantation.

2. Semi-directed, face-to-face interviews were carried out with the doctors involved in LST decisions. These interviews were recorded, with the doctor's consent in accordance with the conditions of the medical secrecy act. The questions asked are listed in table 1. We collected the

following data concerning the doctor: age, sex and number of years as a practising paediatric nephrologist. All of the data collected from the medical files and from interviews were recorded anonymously.

### *Analysis of the results*

The medical files were analysed with a standardised grid. We classified children into two groups on the basis of age - under 1 year (group 1) and over 1 year (group 2) - as both the renal diseases encountered and the medical care required differ for these two groups [9-10].

The interviews were analysed double-blind, by two evaluators, using an analysis grid. The two evaluators met to discuss their results with the aim of reaching a consensus in cases of disagreement. The data from the interviews and from the medical files were analysed by Excel and Statistica. The results are expressed as absolute values and as percentages. The  $\chi^2$  test ( $p < 0.05$ ) was used for comparisons.

## **Results**

Eighteen of the 31 centres had files concerning the withdrawal or withholding of LST in the five-year study period. These 18 centres saw a total of 440 children with end-stage renal disease and a decision was made to stop treatment in 50 of these cases (11.5%). Thirty-one of the 34 paediatric nephrologists involved in making these decisions were interviewed; three refused to participate. Such decisions are refused on principle at one centre and the last children in this situation were seen more than five years ago in the other 12.

### ***The children***

Twenty-seven of the children (54%) were less than one-year-old when the decision was taken (group 1). The decision was taken when the child was less than two months old in 80% of these cases and when the child was less than one month old in 62%. The mean age was 45 days (range: 0 days to 8 months). Twenty-three of the children (46%) were aged over one year when the decision was taken (group 2), with a mean age of 9.7 years (range: 1.3 years to 18 years).

Group 1 included children with chronic and acute diseases, whereas all the children in group 2 had chronic diseases (see table 2). Two children in group 2 had undergone a kidney transplants.

### ***Characteristics of the doctors***

Seventeen (55%) of the 31 doctors interviewed were men. The mean age of the doctors was 48.5 years (range: 33 to 61 years). The mean number of years of practice as a paediatric nephrologist was 18.2 (range: 3 to 34 years).

### ***End-of-life Decision***

#### ***In the medical files***

The reasons for the decisions to withhold or to withdraw LST are given in table 3 (several responses could be given in a single file). The frequency of the reasons concerning subsequent quality of life and damage to the central nervous system differed significantly between groups 1 and 2 (chi<sup>2</sup> test,  $p < 0.05$ ). No significant differences were observed between the groups for the other criteria. In group 1, the decision to stop treatment was made during hospitalisation following birth in most cases (88%), with the child never being taken home. In contrast, for group 2, the decision was taken during a nephrological monitoring visit in 53% of cases. The difference is statistically significant ( $p = 0.01$ ).

The type of treatment withdrawn or withheld is shown in table 4. Sedatives, including morphine-related products and their derivatives, were prescribed when treatment was withdrawn or withheld in 15 cases in group 1 and seven cases in group 2 ( $p=0.05$ ).

The end-of-life decision was noted in the patient's medical file in 27 cases. The reasons for the decision were explained in 25 cases. An order not to resuscitate the patient was explicitly written in the medical files of 18 patients.

The mean time between taking the decision and the patient's death was 6.3 days in group 1 and 206.88 days (6.8 months) in group 2 ( $p=0.04$ ).

### ***Interviews***

The question "What are the most important criteria when making decisions?" was used to identify the reasons for making the end-of-life decision. The replies given by the doctors were analysed using the grid (Table 5).

### **Decision-making process**

#### *The opinions of the medical and paramedical teams*

In most cases, the doctor alone or the doctor and the paramedical team initiated the discussion (Table 6).

In ten centres, decisions were taken during formal meetings involving the doctors and the paramedical team, at which everyone was allowed to speak. In five centres, the doctors decided collectively after individual, informal discussions with members of the paramedical team. In two centres, decisions were taken during meetings including members of the team selected on the basis of their length of time in practice and their favourable opinions concerning non-treatment. In one centre, the head of department took the decision after consulting his co-workers and the



paramedical team. In no case did the referring doctor decide alone and in no case was the medical decision imposed on the team without prior discussion.

### *The opinions of the parents*

The doctors stated that they had provided the parents with information concerning the prognosis and future of the child (n=17) and the failure of treatment (n=11). Two doctors were unable to answer this question as their head of department was the only health professional to see and to inform the parents. One doctor said that the parents were not informed of the decision to withhold treatment. For 21 doctors, informing the parents consisted largely of gradually helping the parents to accept the medical decision. In other cases, the point of view of the parents was taken into account in two ways. In five cases, all of the medical information available was given to the parents as objectively as possible, to enable the parents to decide for themselves. In five other cases, the information was given with the aim of obtaining the parents' point of view and the doctors then took the final decision, knowing the parents' opinion.

In two cases, the doctors chose to stop dialysis, but this was not done because the parents disagreed.

### *The opinion of the child*

The participation of the child in the decision-making process was explored during the interviews by the question "If the child has a sufficiently high intellectual capacity and is old enough, to what extent do you allow him/her to participate in your discussions?" Twenty-six doctors thought that, in their cases, the child did not have the intellectual capacity required (severe damage of the central nervous system) or was not old enough (neonatal period). Four doctors said that they took into account the child's desire to live.

### *Ethics committees*

An ethics committee was consulted at 22.2% of centres, thus opening up the debate to non-doctors. Seven of the medical files (14%) were submitted. All the medical files submitted concerned

decisions relating to the initiation or non-initiation of dialysis. This procedure was systematic for two centres in Switzerland. The other cases were at two centres in France when there was disagreement between the medical team's decision and the wishes of the family. In six cases, the committee supported the medical decision not to carry out dialysis. In one case, the ethics committee felt unable to be the final judge, but helped the medical team to reflect further.

## **Discussion**

This study shows that paediatric nephrology centres confronted with the decision to withdraw or to withhold LST feel the need for collective decision-making. This situation arises frequently as our results show that one tenth of children with end-stage renal disease are concerned in centres that have encountered this situation in the last five years. We observed differences in the ways such decisions are made and our results confirm those of Devictor [3]; the parents are not systematically involved in the decision, discussion procedures are not standardised and may even be absent, and no clear medical criteria are available for making these decisions.

This highlights the need to consider guidelines. We clarified several steps of the procedures based on the answers given by professionals, the analysis of files and the analysis of existing guidelines [11-13]. In order to identify useful criteria, our study was mainly based on the 34 cases (68%) in which the decision made seemed satisfactory. Guidelines could structure the decision-making process, but it is important that they are not too rigid so that each case can be considered individually.

### **Need to prepare decisions: role of meetings involving all of the medical and paramedical staff**

Ethics theory suggests that the absence of any guidelines has a negative effect on the organisation of the discussion that occurs before the final decision is made [14]. Furthermore, the need for group

thinking has already been shown in case reports [14-15]. Individual reflection on this subject needs to be replaced by a policy of discussion, so that a consensus can be reached within the department on the basis of decision-making procedures and criteria [16].

### **Recommendations for organizing the discussion and structuring the decision-making process**

Except in rare cases, the decision to stop or to withhold LST should be made in several stages rather than instantaneously:

#### **1. Assessment of the prognosis**

This mostly concerns the medical team. Our study shows that both negative (those favouring the withdrawal of treatment) and positive (those favouring the continuation of care) criteria should be taken into account.

Negative criteria: neonatal renal insufficiency, incurable extrarenal disease

Positive criteria: isolated renal insufficiency not during the neonatal period.

#### **2. Assessment of the quality of life**

These criteria are often considered to be the most important. However, they are extremely complex and health-care professionals generally lack reliable tools for predicting quality of life [17-21].

From our results, we can suggest a series of criteria:

Negative criteria: severe neurological handicap affecting relationships, impossibility of providing social help or finding an adapted care centre (after extensive research by a social assistant with expertise in the field).

Positive criteria: child well integrated in the family or an adapted social structure.

Note that pain and the technical difficulties associated with caring for patients with end-stage kidney disease are not criteria, given the progress that has been made in dialysis centres [22-23]. It

is also important to note that the quality of life can only be estimated by a team after collecting data concerning: the child in his or her hospital (nurses, psychologists, auxiliaries, doctors) and external (GPs, paediatricians, teachers) environments, and the social level of the family (social assistance).

### **3. Circulation of information between members of the paramedical team and their role in the decision-making process**

The complexity of these criteria is such that information concerning medical care and therapy must be shared between the doctors and the paramedical team. Similarly, data concerning the roles played by family members in caring and the daily life of the patient should be shared. Consensuses should be drawn up by professionals during group meetings and entered into the medical file. Finally, a report that can be consulted by members of the team, according to the terms of the shared medical secrecy act [24], should be written.

### **4. Information given to the child and parents, and their roles in the decision-making process**

In our study, nearly all of the children concerned were unable to take part in the discussion, either because they were handicapped or because they were newborn. In some cases the parents were involved and in others they were not involved.

The need to inform the parents both of the diagnosis and the therapeutic possibilities is highlighted both in national [24-26] and international [27-28] publications. The doctor must obtain consent from minors if possible, but the ultimate decision falls on those with parental rights [26].

Information should be given to the parents, with or without the child, during repeated interviews with the medical team concerning the consequences of the various solutions available: no renal replacement therapy and treatment options in the absence of such treatment, outcomes of stopping or continuing dialysis, outcome of not transplanting the patient [20]. Clear and informative language should be used during these discussions. A trusted individual, as stated in the (French)

Law of the 4th March 2002 on patients' rights, may help the family [24]. This may be a friend or member of the family or a doctor from another medical team that advises the family. Whatever the decision reached, the family should be offered counselling, both to help them cope and also to help them to assess the consequences of the decision on the family; no publications have described the effects of such decisions, whether the choice be to allow the child to die or to continue to receive long-term treatment.

### **5. What to do in cases of disagreement**

If members of the medical team disagree with the parents or each other, a committee including a specialist in paediatric nephrology can be requested. This opinion, which would be only consultative, may shed new light, but the final decision is up to the doctor managing the patient. This doctor should try to obtain approval from the parents after obtaining the committee's report. These committees should consist of representatives of all carers, of various schools of thought, and of patients' associations, as well as social workers and experts in the fields of paediatric nephrology and ethics. These committees would be able to analyse all difficult cases and provide a basis for the considerations of the health care teams.

### **Conclusion**

This study shows how sensitive the topic of withholding or withdrawal LST is in paediatric nephrology centres. Our analysis of the practices within these centres led us to suggest guidelines for the decision-making process. These guidelines should be further discussed with the health-care professionals themselves and their representative societies so that they can be adapted to the real situations encountered.

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**Table 1: Questions asked during the semi-directed interviews**

How many children per year require renal substitution treatment (dialysis, transplantation)?

Within your paediatric nephrology department, how are decisions concerning the withholding or withdrawal of life-sustaining treatments taken?

What are the most important criteria when making decisions?

Who generally initiates discussions concerning the withholding or withdrawal of life-sustaining treatments?

What types of information do you provide to parents concerning the withholding or withdrawal of treatment and the final decision?

If the child has a high enough intellectual level and is sufficiently mature, to what extent do you allow him/her to participate in the discussions?

**Table 2: Aetiology of renal diseases in the 50 children concerned by decisions to withdraw or to withhold LST**

	<b>group 1: n=27</b> (under the age of 1 year)	<b>group 2: n=23</b> (over the age of 1 year)
Nephrotic syndrome	6	4
Polycystic kidney disease	5	2
Urinary malformations	4	3
Congenital abnormalities	1	6
Twin-twin transfusion syndrome	1	0
Nephronophthisis	0	2
Perinatal asphyxia	4	0
Renal vein thrombosis	3	0
Acute renal failure following surgery	2	0
Haemolytic uremic syndrome	1	0
Others*	0	6

\*: Chronic renal failure following glomerulonephritis (1), chemotherapy (1), neurogenic bladder complicating spina bifida (1), perinatal asphyxia (2), neurofibromatosis 1 (1)

**Table 3: Analysis of the decision-making criteria recorded in the 50 patient files. Several reasons are possible for each child**

	<b>group 1: n=27</b> (under the age of 1 year)	<b>group 2: n=23</b> (over the age of 1 year)
Subsequent quality of life	18	10
Severe neurological handicap	8	19
Severe extrarenal disease	6	13
Consequences of the disease for the family	7	4
Survival unlikely	5	5
Opinion of the family	5	3
Renal insufficiency at birth	3	4
Social context	0	2
Suffering of the child	2	0
Treatment failure	1	1
Cost	0	0

**Table 4: Type of treatment withdrawn or withheld**

	<b>group 1: n=27</b> (under the age of 1 year)	<b>group 2: n= 23</b> (over the age of 1 year)
Renal replacement therapy withheld	17	20
Withdrawal of dialysis and death linked to the complications caused by this withdrawal	8	1
Dialysis continued but occurrence of multisystem organ failure leading to death	2	0
Dialysis without transplantation	0	2

**Table 5: Analysis of the decision-making criteria cited by the 31 doctors interviewed**

Subsequent quality of life (n=22)	Defined by long-term living conditions, as predicted by the doctor (n=9), by the relationship between the child's prognosis and the burden of the treatment (n=8), by the possibility of autonomy from the parents and of social insertion (n=4), by the possibility of a normal life without handicap (n=1)
Severe neurological handicap (n=21)	If it was severe enough to compromise the relationships the patient could establish (n=19), but not a valid reason for non-treatment if the child was well integrated into his family or social circle (n=2)
Consequences for the family (n=21)	Due to the intrusive nature of treatment (n=18), due the disease disrupting the affective links between the child and the family (n=3)
Severe extrarenal disease (n=17)	Such as cancers and incurable diseases (n=9) or severe handicaps or malformations (n=8)
Opinion of the family (n=15)	Only of value if the family was completely informed of all the medical findings concerning the child.
Renal insufficiency from birth (n=10)	Because this element affects the difficulty experienced when trying to manage intrusive treatments.
Social context (n=7)	Due to familial problems or a poor social and cultural level
Suffering of the child (n=7)	If it was resistant to major analgesic treatments
Survival unlikely (n=6)	
Treatment failure (n=3)	With the most up to date scientific knowledge (n=2)
Financial cost (n=0)	

**Table 6: Who initiated the discussions? (n=31 centres)**

Doctor	17
Various	5
Nurses and doctors	5
Nurses, family and doctors	2
Nurses	1
Family	1