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Results of a two-year survey.

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Abbreviations: DRNO; do-not-resuscitate order – GFRUP; Groupe Francophone de Réanimation et Urgence Pédiatriques (French-speaking group of paediatric intensive and emergency care) – PICU; paediatric intensive care unit– POPC score; Paediatric Overall Performance Category score – PRISM score; Paediatric Risk of Mortality score

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Objective: to evaluate feasibility of the GFRUP's guidelines for limitation of treatments in PICU. **Design**: two-year prospective survey. **Settings**: 12-bed French PICU at a university hospital. **Patients** were included when limitation of treatments was anticipated. **Results**: among 967 admitted children, 55 were included, with a two-day median delay. They were younger than others (24 months *vs.* 60), had higher PRISM score (14 *vs.* 4), higher POPC score at admission (2 *vs.* 1) - all p<0.002. Thirty-four died (50% of deaths). A limitation decision was made without meeting for 7 children who all died: 6 do-not-resuscitate orders (DNRO), 1 withholding decision. Decision-making meetings were organized for 31 children, and led to 12 DNRO (6 deaths, 6 survivals), 4 withholding (1 death, 3 survivals), 14 withdrawing (14 deaths), and 1 continuing decision (survival). After limitation, 21 children died (31% of deaths), and 10 survived (POPC 4). Thirteen procedures were interrupted because of death and 11 because of "clinical improvement" (POPC 4). Parents' opinion was obtained after 4 family conferences (for a total of 110 min), 3 days after inclusion. The 1st meeting was planned for 6 days after inclusion, held on the 7th day; 80% of parents were immediately informed of the decision, which was implemented 0.5 day after. **Conclusions:** GFRUP's procedure was applicable in most cases. The main difficulties were anticipating the correct date for the meeting and involving nurses in the procedure. Children for whom the procedure was interrupted because of "clinical improvement" and who survived in poor condition without a formal decision pointed out the need for medical criteria for questioning, which should systematically lead to a formal decision-making process.

In developed countries more than 70% of children die in hospital, mainly in paediatric intensive care units (PICU). [1, 2] Forgoing life-sustaining treatment decisions are made for 30 to 40% of dying children. [3 [4] [5]

Although formal English-language guidelines for withholding or withdrawing treatment in critically ill children are available since the nineties, French-language recommendations were lacking until recently. [6, 7, 8] Because of this lack, and because several studies have demonstrated that French-speaking intensive care units did not follow US guidelines [9], the French-speaking group of intensive care organized a workshop, including PICU nurses and physicians, parents, palliative care specialists, philosophers, and persons that had conducted ethics research. This group worked from 1999 to 2000 and its conclusions were published in July 2002 as a book that was disseminated to all French PICUs. [10] Recently, French paediatric guidelines were derived directly from this text and validated by the Ethics Commission of the French Paediatric Society; the proposed procedure is summarized in table 1. [11] Contrary to English language guidelines that regard parents as the most appropriate bearers of decisional authority, French guidelines are more physician centred, recommending that parents choose their level of involvement, without shifting the weight of responsibility for the decision on them.

The purpose of this study was to evaluate the feasibility of the procedure, to record related medical and paramedical time utilization, and to point out ethical problems that could be implied by the procedure itself.

Table 1: The five steps of the procedure proposed by the French speaking group of intensive care physicians [11].

1.	*Questioning about the* appropriateness *of the treatments* - Questioning about the appropriateness the treatments is part of the role of all categories of caregivers. Routinely, it consists of choosing the treatments that give the greatest proportion of medical benefits in comparison to harms. - When the questioning is expressed by the child or his/her parents, caregivers must inform the physicians so it can be taken in account. - Physicians must give true information to both parents and paramedical staff, and must encourage and arrange for team questioning during routine staff meetings.
2.	*Organizing a special decision-making meeting* - Medical reasoning implicitly assumes that the best interests of the child are ensured by medical knowledge. When medical reasoning alone is not able to respond to questioning, physicians must organize a special decision-making meeting in order to take into account factors other than medical. - This meeting must be anticipated, scheduled and announced in order to permit all caregivers in charge of the child to be present.
3.	*Explanation of the decision* - A decision must be made at a special decision-making meeting that must be exclusively devoted to the problem. - A medical analysis of the situation must be the first step undertaken at the special meeting. - Following the medical analysis, it may appear that the problem was falsely deemed ethical, and that medical reasoning is able to respond to the questioning. It may also appear that some medical elements were lacking and that the meeting must be rescheduled. - If the ethical conflict is validated, non medical factors must be taken into account in decision making. It consists of human factors (acceptability of the treatments by the child or his/her parents, quality of life, etc.), and sociocultural factors (ethical and deontological principles, risks of litigation, etc.). - An authentic debate is proposed for resolving ethical conflicts. All treatment options, from maximal therapy to palliative care must be considered and their consequences must be appreciated. - Principles of ethics of communication must be respected during the discussion, all arguments must be taken into account, and opportunities for speaking should be fairly managed.
4.	*Decision making* - Because debating requires that all caregivers are used as decision-making agents, collegiality is a necessary condition for decision making, but it does not ensure the quality of the decision by itself. - Collegiality must be considered as a help for the physician making the decision, but it must not shift the weight of the decision onto paramedical staff. - If there is a consensus, decision to limit life supporting treatments, a modality must be chosen. Decisions could include a do-not-resuscitate order in case of cardiac arrest, withholding new therapies, or withdrawing current therapies.
5	*Implementing the decision* - A decision must be announced to the child, parents and paramedical staff. - Time must be given to parents to accept or contest the decision and they must be asked if they want to be present at the bedside when the decision is implemented.

Patients and methods

This prospective study was carried out from September 2002 to August 2004 in a 12 bed French tertiary PICU at a university hospital. All children that were consecutively admitted during this period were included. A specific paper file was completed during the PICU stay as soon as one member of the medical staff anticipated that an ethics discussion could be necessary. This population was defined as “question raising children”. Patients’ severity was assessed by the Paediatric Risk of Mortality score (PRISM), and performance at admission and discharge were assessed by the Paediatric Overall Performance Category score (POPC). [12, 13] Dates, durations, places, and actors were recorded at each step of the decision-making process. Parents’ wishes were classified into three categories: maximum supportive care, not expressed, and limitation of treatments. Parents’ reactions after the decision were classified into three categories: opposition, resignation, or approval. Results were expressed as median values, and ranges in brackets. Fisher’s exact test and Wilcoxon’s signed rank test were used for qualitative and quantitative comparisons, respectively, as well as Spearman’s test for correlations. $P < 0.05$ was considered as statistically significant.

Results

Between September 2002 and August 2004, 967 children were admitted (7877 days of stay), and 68 died (7%). Median age was 58 months (1-565), PRISM score was 5 (0-52), and length of stay was 3 days (1-575). Discussion on limitation of treatments was considered as necessary in 55 children (5%), with a median two-day delay after admission (0-173). Length of stay of the question-raising children was 14 days (1-178); prevalence of ethical questioning was 8.4 per 100 PICU days of stay.

Characteristics of question-raising children

Significantly, the 55 question-raising children were younger than the others , had a higher PRISM score, higher POPC score at admission, and higher POPC score at discharge . Among them, 34 (59%) died, which represented 50% of all deaths. The 21 question-raising children who survived were younger, had a higher PRISM score and a higher POPC score at discharge than the 878 non question-raising survivors. The POPC score at admission was not different. These data are given in table 2. Among the 55 question-raising children (45%) had chronic disease before admission. Main

organ failures at admission were: neurological (49%), respiratory (27%), cardiovascular (22%), and digestive (2%). Organ failures leading to questioning were: neurological (83%), cardiovascular (9%), and respiratory (7%).

Table 2: Comparison of ethical question-raising and non question-raising children

	Non question raising children median (min – max)	Question raising children median (min – max)	Comparison (Fisher)
All children	n = 912	n = 55	
Age (months)	60 (1 – 565)	24 (3 – 479)	p=0.005
PRISM score	4 (0 – 52)	14 (1 – 52)	p<0.0001
POPC at admission	1 (1 – 5)	2 (1 – 5)	p=0,019
POPC at discharge	1 (1 – 6)	6 (3 – 6)	p<0.0001
Survivors	n = 878	n = 21	
Age (months)	59 (1 – 564)	17 (4 – 431)	p=0.002
PRISM score	4 (0 – 41)	10 (1 – 35)	p<0.0001
POPC at admission	1 (1 – 4)	1 (1 – 4)	p=0.933
POPC at discharge	1 (1 – 5)	4 (1 – 6)	p<0.0001
Deceased children	N = 34	n = 34	
Age (months)	55 (2 – 496)	41 (1 – 37)	p=0.378
PRISM score [12]	31 (0 – 52)	17 (0 – 52)	p<0.001
POPC at admission [13]	1 (1 – 5)	3 (1 – 5)	p=0.047

PRISM: Paediatric Risk of Mortality – POPC: Paediatric Overall Performance Category.

Decision-making procedure

The decision-making procedure was interrupted without a formal treatment decision for 24 of the 55 question-raising children, and completed for 31 children, leading in to 12 do-not-resuscitate orders (DNRO), 4 withholding decisions, 14 withdrawing, and 1 decision to continue treatments. Twenty-one children died after a limitation decision (31% of total deaths). These data are detailed in figure 1. Age, PRISM and POPC scores at admission for the 11 children for whom the decision-making procedure was interrupted due to clinical improvement were not different from those for whom the procedure was completed.

In the population for whom the procedure was completed, the median delay for initiating the process was two days after admission. The median delay for obtaining mothers' opinion was 3 days after inclusion and 4 days for fathers (not statistically significant). The first special decision-making meeting was planned 6 days after inclusion, held on the 7th day after inclusion, and parents were informed of the decision on the same day. There was a positive correlation between the delay of expression of parents' opinions and the date of the first special decision-making meeting (p=0,008).

These data are summarized in table 3.

Table 3: dates, delay and time utilisation for decision making procedures

	Median (minimum – maximum)			Comparison between the groups (Fisher)
	Entire question raising population (n = 55)	Group in which procedure was interrupted (n = 24)	Group in which procedure was completed (n = 31)	
Delay of ethical questioning (days after admission)	2 (0 to 173)	1 (0 to 14)	2 (0 to 173)	p = 0,834
Number of preliminary family conferences	3 (0 to 14)	2 (0 - 6)	4 (0 to 14)	p = 0,005
Medical time utilization by preliminary family conferences (min.)	90 (0 to 490)	77 (0 - 180)	110 (0 to 490)	p = 0,068
Date of fathers' opinion record (days after inclusion)	2 (-1 to 70)	1 (0 - 3)	4 (-1 to 70)	p < 0,0001
Date of mothers' opinion record (days after inclusion)	2 (-1 to 70)	1 (0 - 3)	3 (-1 to 70)	p < 0,0001
Date of first decision meeting (days after inclusion)	-	-	7 (0 - 69)	-
Number of special decision meetings	-	-	1 (0 to 3)	-
Total medical time utilisation for decision-making (min.)		-	320 (20 to 950)	-
Date of presentation to parents (days after inclusion)	-	-	7 (0 to 69)	-
Time utilisation to present the decision to parents (min)	-	-	20 (0 to 60)	-
Date of decision implementation (days after inclusion)	-	-	7,5 (0 to 69)	-
Time between decision implementation and discharge or death			1 (0 to 135)	
Length of stay (days)	12 (1 to 178)	7,5 (1 to 42)	24 (2 to 178)	p < 0,0001

Period before decision

As recommended in the guidelines, a senior expert was asked to give an opinion on prognosis in 25 children, including the 24 for whom the procedure was completed.

During the study, 180 preliminary family conferences were carried out to discuss the possible limitation of treatments, which represented 5131 minutes of medical time. In the population in whom the procedure was completed, there was a median of 4 family conferences and the total duration was 110 minutes (table 3). A nurse was present during 31 family conferences, including 22 for children for whom the procedure was completed. The referring resident was present during 42 family conferences, including 25 for children for whom the procedure was completed.

Thirty-seven mothers expressed wishes, including 23 in the population for whom the procedure was completed. Thirty-three fathers expressed wishes, including 18 in the population for

whom the procedure was completed. Details of these wishes are given in table 4.

Table 4: Parents' wishes before the decisions and reactions after its presentation.

	Group in which procedures were interrupted n = 24		Group in which decision was made without special decision making meeting n = 7		Group in which a special decision making meeting was organized n = 24	
	Fathers	Mothers	Fathers	Mothers	Fathers	Mothers
Parents' wishes :						
Limitation	9	10	1	1	18	21
Maximal treatments	5	3	0	0	0	2
Not expressed	9	11	6	6	6	1
Parents' reaction :						
Approval	-	-	1	1	16	17
Resignation	-	-	0	0	5	5
Opposition	-	-	0	0	0	0
Not formally announced	-	-	6 [a]	6 [a]	3 [b]	1 [b]

a : in this group (except one case), poor prognosis and futility of treatments were simultaneously presented, during a single family conference, because of emergency situation.
b : because of the absence of one of the parents at the family conference.

Special decision-making meetings

Thirty-two special decision-making meetings were organized for 24 children: one in 15 patients, two in 7 patients, and three in 1 patient. The duration was 30 minutes (30-110), number of physicians and nursing staff members were 6 (3 – 12) and 2 (0-3), respectively. Nurses had worked a median of 4 days at the patient's bedside (0-30). Three special decision-making meetings were organized without any nursing staff member and 9 with a nurse who was at the patient's bedside for the first time. The PICU chief (or his representative) was present at all special decision-making meetings. Parents were informed that there would be a special decision-making meeting in 14 cases, they knew the date in 1, and they were not formally informed in 17.

During the 24 first special decision-making meetings, there were 2 decisions to continue all treatments, 9 DNRO and 12 decisions to limit treatments. During the seven second special decision-making meetings, one decision to continue treatments was changed into DNRO, one DNRO was confirmed, and five decisions to continue treatments were changed into a decision to withhold/withdraw the treatments. During the single third special decision-making meeting, the decision of withholding treatments was changed into withdrawing. Final decisions are given on figure

1.

Decisions were made without a special decision-making meeting for seven children, who all died (6 DNRO, and 1 decision to withhold a liver transplantation project). These children were older (92 months *vs.* 4, p=0.012), and had a higher PRISM score (29 *vs.* 11, p=0.009) than those for whom a special decision-making meeting was organized.

Among children for whom the procedure was completed, six decisions were made whereas one of the parents had not formally expressed any wish during the family conferences, and two voiced their opposition to the limitation of treatment. In this group, there was one decision to continue treatment according to parents' wishes, four DNROs, and three withholding decisions.

Presenting and implementing decisions

The decision was presented to parents, during a median 20 minute (10-60) family conference, for 22 of the 24 children for whom a special decision-making meeting was organized, and in one of the seven emergency situations. The decision was approved by at least one of the parents in 18 cases and parents were resigned in 5. In six situations in which a decision was made without a special decision-making meeting, poor prognosis and the futility of treatment were presented during a single family conference. Reactions were not formally expressed and/or recorded.

Delay in implementing the decision was 0.5 day (0-69). Both nurse and physician were present at the bedside during the implementation of the decision in the 14 cases of withdrawing life-sustaining treatments. The option of being present was offered to parents for 13 of the 14 children, and they were present for 6.

Children's outcomes according to decision are indicated in figure 1. All of the seven children for whom a DNRO was given at a special meeting, survived. Among the four children for whom a withholding decision was made at a special meeting, three survived and one died. All the 14 children for whom a decision to withdraw treatments was made at a special meeting died. All the seven children for whom a limitation decision was made without formal meeting died. Eight of the nine children who survived despite DNRO were referred to the paediatric neurology department with a severe encephalopathy, and one returned home for palliative care. The POPC score for these patients was 4 (3-5) at discharge. The POPC score of the 11 patients for whom the procedure was interrupted because of clinical improvement was 4 (1-4) at discharge.

DISCUSSION

In our study, the incidence of questioning about the appropriateness of treatment was 5% of admitted children, representing more than 8% of PICU days. The decision-making procedure was interrupted for 44% of children and completed for 56%. In most cases where the recommendations were applied, the main difficulties encountered were finding an appropriate time for a special decision-making meeting and involving the nursing staff in the procedure.

Because our patients were included before questioning began, our study, when compared with previous ones recording modes of death. [3, [4], [5], provides original data. The incidence and prevalence of ethical questioning were both high, reflecting a high level of routine questioning as encouraged by GFRUP's guidelines. Question-raising children were younger and had worse severity and performance scores at admission than the others, pointing out previous quality of life and severity of illness as questioning factors. Survivors in the question-raising population had a worse performance score at discharge than other survivors, which points out risk of disability as an other questioning factor. Dead children in the question-raising population had less severe PRISM score than other children who died, pointing out the role of questioning (and probably the role of decision) in mortality rate. The 11 children for whom the procedure was stopped without a formal decision because of "clinical improvement" pointed out the problem of the medical conditions for initiating the procedure. Was the GFRUP's procedure fair for these 11 children who survived with severe neurological sequels? Was their situation fairly judged in order to prevent a disability that could not be accepted by their family? Given that they eluded the complete procedure, this question remains unanswered. Definitions of ethical criteria (namely about neurological status and prognosis) that should systematically require the continuation of the process until a formal decision is made should be the next step in developing the guidelines.

Our study also provides data about the feasibility of the procedure. Among the 31 children for whom the procedure was completed, the main GFRUP's recommendations were applicable in most cases, namely early ethical questioning, parents' wishes recording, formal decision-making meeting, and formal presentation of the decision to parents. The seven bedside decisions did not contradict GFRUP's guidelines. Because these children had a higher PRISM score, we can postulate that these decisions actually corresponded to emergency situations, in which planning a special meeting would

not be realistic.

The main difficulties in implementing the guidelines were anticipating the correct date for the meeting (mostly scheduled for the following day) and involving nurses in the procedure. Procedural elements that were proposed by GFRUP are strongly inspired by Habermas' philosophical theory about the ethics of discussion [14]. Authentic debate, which is proposed for resolving ethical conflicts, requires that all caregivers are used as decision-making agents, and thus, that nurses take part in the procedure. In our study, ten special decision-making meetings were organized without a nurse, or with a nurse who was in change of the patient for the first time. In our study, nurses were present at less than 20% of family conferences. This lack of participation contrasted with their constant presence at the patient's bedside at the time of implementation of the decision, corresponding with a more traditional role. In our PICU, conditions for nurses' participation have been previously formally discussed, in order to make it compatible with French legal texts that define their role (literally in French "own role of nurses"). [15] The fact that physicians have previously analysed medical conditions before considering the possible limitation of treatment, was recognized as protecting nurses from transgressing their legal role. The lack of nurses' participation, even partly explained by the difficulties in scheduling family conferences and decision-making meetings, suggested that their level of involvement in the procedure remained lower than ideally conceptualised in the authentic debate philosophical model.

Even if formal US guidelines have been available since 1994, whether practices in US PICUs follow guidelines or not remains unknown. [6, 16] However, data obtained from a recent European study, pointed out interesting trends, which might help assess the effect of guideline implementation in our PICU. This study prospectively compared forgoing life-sustaining treatments in 27 PICUs from South-European countries (mainly French ICUs), *vs.* 12 PICUs from North-European countries. [5]. The authors noticed that the decisions were more often documented in Northern PICUS (100% *vs.* 48%; p=0.001), that parents' opinions were more often recorded (62 *vs.* 42%; p=0.06), and that parents were more often informed of the decision (95% *vs.* 68%; p=0.01). They attributed these differences to the use of guidelines in North-European countries. [6, 7, 8] Our data were in accordance with those obtained from North-European countries; illustrating the positive role of guidelines in formalising and documenting the decisions. Also, the interval between the decision and its application

was less than one day, lower than reported in South-European countries. This result, supports the hypothesis that formalising the procedure leads to the better preparation of parents for a decision. [17] In our study, the 30% proportion of deaths following a decision to forgo life-sustaining treatments remained close to the 30% proportion reported among South-European countries, and lower than the 47% proportion reported among Northern countries. [5] It was also comparable to the proportion reported by two recent studies from countries with a predominant Latin culture. [18, 19] It remains lower than the 53% proportion reported by Burns in a recent prospective study from the USA. [20] Moreover, in our study as in Devictor's study of a South-European country group, causes of ethical questioning were largely dominated by neurological failure, whereas respiratory failure dominated in North-European countries. This remaining congruence with data reported from other Latin countries leads us to hypothesise that the implementation of a formal procedure does not change the incidence of ethical questioning or the ethical principles on which the resolution of ethical conflicts are based.

In a previous 4-month study carried out in 33 French PICUs, 80% of decisions were made at a decision-making meeting, a nurse was present in 50% of cases and parents in 6%. [4] Parents' wishes were known in 72% of cases, 10% of the parents knew that a decision-making meeting would be organised, and decisions were presented to parents in less than 19% of cases. [4] The paper was accompanied by an editorial entitled "the parents should not be excluded from the decisions of limitation". [21] In our study, data about parents' wishes before the decision and their reactions after it was presented (table 4) showed that physicians did not search for informed consent, but for the absence of opposition. The guidelines recommend giving parents the choice of their level of involvement in the procedure, which represents a dual ethical purpose of recording their wishes without shifting the weight of decision onto them. Conceivably, the absence of informed consent may classify these decisions as a form of malpractice, but GFRUP's guidelines claimed that the right of parents to full autonomy does not exclude their right not to take part in decision-making. The positive correlation between the dates of the expression of parents' wishes and dates of decision indicated that parents' autonomy was taken into account. It appears that the GFRUP's guidelines remain more physician-centred (paternalistic?) than policy expectations would suggest for the USA, but in a recent qualitative study, Carnevale et al. have demonstrated that French parents agreed that life-support decisions should be made by physicians. [22] Recently, the French law about patients' rights at end of

life ratified that the decision must be made by the physician that is in charge of the patient, after recording parents' wishes and asking for the opinion of a colleague. [23, 24]

Our study had some limitations. First it involved a single PICU, one that participated in the development of the guidelines. Our study must be considered as a pilot study; a twenty-centre prospective study is about to start in few months. The second limitation is due to its self-monitoring design. In order to avoid biases of declarative studies, we took care to only record objective data, such as facts, dates, actors etc. [25] Because of the absence of an independent investigator, decision motivations and discrepancies between perception by physicians and nursing staff could not be studied. Nevertheless, quantitative studies remain useful for evaluating the implementation and feasibility of guidelines, for inducing local reflection on practices, and for orienting qualitative studies. We chose to detail all the types of decisions separately (figure 1), instead of pooling in order to perform statistics, because it is more illustrative of the variety of situations and more representative of their complexity. Practices could be optimally surveyed in a permanent PICU network, with a common database. This database could be anonymously fed by members, who would receive their individual position compared with the summary of median practices of the entire group.

CONCLUSION

The GFRUP's guidelines seem to be fully applicable in most cases and to have a positive effect on better formalising procedures, and better informing parents and preparing them for the decision, but probably not modify the ethical principles on which the decisions are based. Main difficulties identified were anticipating the correct date for decision-making meeting and involving nursing staff members in the procedure. Children for whom the procedure was interrupted without a formal decision raised the question: was the decision fair for them? This pointed out the need for medical criteria, which should systematically impose the continuation of the decision-making process toward a formal decision, in order to ensure a fair decision in each case.

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