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Original article

The role of the neuropediatrician in pediatric intensive care unit: Diagnosis, therapeutics and major participation in collaborative multidisciplinary deliberations about life-sustaining treatments' withdrawal

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ABSTRACT

Background: In Pediatric Intensive Care Unit (PICU) two types of population require the intervention of neuropediatricians (NP): chronic brain diseases' patients who face repetitive and prolonged hospitalizations, and patients with acute brain failure facing the risk of potential neurologic sequelae, and both conditions may result in a limitation of life-sustaining treatments (LLST) decision.

Objective: To assess NP's involvement in LLST decisions within the PICU of a tertiary hospital.

Method: Retrospective study of medical reports of patients hospitalized during 2014 in the Necker-Hospital PICU. Patients were selected using keywords ("cardiorespiratory arrest", "death", "withdrawal of treatment", "palliative care", "acute brain failure", or "chronic neurological disease"), and/or if they were assessed by a NP during the hospitalization. Demographic and medical data were analysed, including the NP's assessment and data about Collaborative Multidisciplinary Deliberation (CMD) to discuss potential LLST.

Results: Among 1160 children, 274 patients were included and 142 (56%) were assessed by a NP during their hospitalization for diagnosis (n = 55) and/or treatment (n = 95) management. NP was required for 59%–100% of patients with neurological acute failure, and for 14–44% of patients with extra neurological failure. A LLST decision was taken after a CMD for 27 (9.8%) of them, and a NP was involved in 19/27 (70%) of these decisions that occurred

Abbreviations: PICU, Pediatric Intensive Care Unit; NP, Neuropediatrician; CMD, Collaborative Multidisciplinary Deliberation; WWT, withdrawal/withholding of treatment; PPP, Pediatric Palliative Physician; LLST, limitation of life-sustaining treatments.

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during the hospitalization (n = 19) or before (n = 8).12 patients died thereafter the LLST decision (40% of the 30 dead patients).

Conclusion: NP are clearly involved in the decision-process of LLST for patients admitted in PICU, claiming for close collaboration to improve current practices and the quality of the care provided to children.

1. Introduction

Every medical practice should be governed by basic ethical principles, and intensive care medicine is not an exception.[1–3] Indeed, because of the very nature of intensive care itself, ethical questions arise almost daily, particularly when it comes to brain dysfunction. Intensive care usually implies treatments and/or technology supporting an organ failure, but it does not necessarily offer a cure, especially when brain dysfunction is present.

On the one hand, in Pediatric Intensive Care Units (PICU), patients with acute brain failure are often admitted.[4] In these various conditions treatments or technology administered in PICU may sustain life, but may not always cure the disease that caused brain failure, nor brain damage, thus leading to further possible neurological impairments and disabilities. On the other hand chronic brain diseases are usually severe and incurable illnesses, and patients often face pulmonary decompensation[5,6] leading to repeated and long-lasting hospitalizations in the Intensive care unit,[7] where treatments and technology may support the pulmonary failure, but not cure the disease itself nor the patients' impairments (impaired mobility, squelettal and pulmonary deformations due to impaired muscle tone, impaired swallowing …). In those various medical conditions, all members of the health's team must abide by the best interest of the child, in palliative care cases as well as in curative care situations.

Four broad treatment groups have been identified in standards for pediatric palliative care in Europe.[8] Groups 1, 3 and 4 include patients with neurological diseases. Group 1 comprises patients with life-threatening conditions for which curative treatment may be feasible, but can fail (e.g. brain tumor). Group 3 includes patients with progressive diseases for which no curative treatment is available with consecutive ineluctable degradation. Such patients necessarily require palliative treatment (e.g. neuromuscular or neurodegenerative disorders). In group 4 children present with irreversible non-progressive conditions and a severe disability causing extreme vulnerability to health complications (e.g. severe cerebral palsy, congenital malformations).

Despite considerable advances in intensive care medicine, neuroprotection efficacy is limited and severe acute brain failure as well as decompensated chronic brain disease may not be cured or have their consecutive deficiencies reversed to an acceptable level. Thus brain injury is one of the most frequent proximate cause of death in PICU.[4] In those cases, it may be legitimate to carry on with thoroughly chosen treatment in the child's best interest. Therefore a careful planning is required for withholding or withdrawal from further invasive intensive care. Withdrawal or withholding treatment (WWT) does not inevitably mean systematic or immediate death.[9] Indeed, palliative care may be understood as a technical and comprehensive care model, ranging from long-term life-treatment to deep continuous sedation maintained until death, as allowed in France by the Leonetti-Claeys Law.[10]

Since brain injury is one of the most frequent proximate causes of death in PICU,[4] it is necessary for ICU physicians and neuropediatricians (NPs) to collaborate in order to make reasonable decisions concerning brain disease diagnosis and to determine the appropriate level of treatment in the child's best interest. Indeed neurological disorders belong to the Complex Chronic Conditions defined in 2000 by Feudtner et al.,[11] for which simultaneous delivery of different modes of care, from cure-seeking or life-sustaining to comfort-seeking or family-supportive, is warranted to ensure every patient an adequate level of care throughout his medical journey.[12] As medical experts of acute brain failure, NP must collaborate with the PICU team, but also act as lifelong care medical consultants. They can also intervene as external consultants whose hindsight allows them to provide better help in diagnosing as well as in the therapeutic decisions.

In this study, we aimed at describing the involvement of NP when it comes to withdrawing or withholding life-sustaining treatments within the PICU, for patients with acute brain failure, or severe chronic brain damage. A further objective of this study was to provide a description of the modalities of NP's intervention in PICU for children with a neurological injury.

2. Methods

2.1. *Patients selection*

All children who were admitted in the"Necker-Enfants Malades" hospital PICU in Paris, France, between January 1st 2014 and December 31st 2014 were screened through the PICU database. This is the medical PICU of a tertiary medical center providing medical care for any critical organ failure and post-operative transplantations, for patients aged from 28 days to 18 years. We retrospectively reviewed electronic and paper notes from both hospitalization reports and medical observations.

Patients whose hospitalization reports and/or medical observations contained specific keywords ("cardiorespiratory arrest", "death", "withdrawal of treatment", "palliative care", "acute brain failure", or "chronic neurological disease") or a report of an examination conducted by a NP during the period of hospitalization, were selected.

2.2. *Patient variables*

For selected patients we collected data about medical history (age, sex, reason for admission in PICU, preexisting pathologic conditions, previous PICU hospitalizations, preexisting withdrawn/withheld treatment, preexisting neurological status including developmental delay, and previous neuropediatric follow-up), conditions of hospitalization (duration, modalities and duration of ventilatory support, type of department at the end of the PICU hospitalization, death), the NP's conclusions (neurological examination, diagnosis, treatment's proposal, anticipated functional prognosis, participation to CMD).

Finally we collected data about any possible collaborative multidisciplinary deliberation (CMD) and the final decision that emerged from that CMD, with specific concerns about any potential medication received after a LLST decision (amines, sedative drugs, ventilation, sedation, analgesia). We also collected data about the participants in that CMD and the parents' point of view to the proposed medical decision.

3. Results

1160 patients were hospitalized in 2014 in the PICU of "Necker-Enfants-Malades" hospital. Among them, 274 (23.5%) were included in the study (mean age 58 months (range 2 days; 18 years; male n = 175 (57,3%)). As show in Fig. 1, most of the patients were less than 2 years old when they came to PICU. Patients were hospitalized for numerous reasons of admission, summarized in Table 1. Among them, 148 (54%) were hospitalized because of an acute neurological event: seizures and status epilepticus (n = 85), stroke (n = 17), coma (n = 12), central nervous system infection (n = 11) or inflammation (n = 7), movement disorders (n = 4) and expert view (n = 5). NP was required for 59%–100% of these patients with acute neurological events. The others, which were hospitalized with extra neurological failure or diseases were seen by NP in 14–67%. They came for respiratory deficiency (n = 46), extra-neurological deficiency (n = 29) or infections (n = 15), post-surgery or graft (n = 13), malaise (n = 9), cardiorespiratory arrest (n = 8) or inherited metabolism disorder (n = 7).

Among the included patients, 142 (52%) required a NP assessment for diagnosis (n = 55) and/or treatment management (n = 95). Whenever necessary, the NP saw the patients a mean 2.1 (1.6; 2.6) times during the hospitalization. In case of a cardiorespiratory arrest or of an inflammatory brain etiology, the NP came at least 3 times during the hospitalization.

Thirty (10.9%) of these 274 patients died in the PICU during the study period. Among them, 12 (40%) died after LLST decision.

Among all 274 first-step selected patients, a LLST decision was made after a CMD for 27 (9.8%) patients. The median age at the time of decision was 28 months (Range 1–144), 13 (48%) patients were males. Their median duration of hospitalization was 19.3 days (range 1–116). The reasons for admission in the PICU were an acute brain failure resulting from a malaise (n = 3), a cardiopulmonary arrest (n = 4), a decompensated chronic brain disease (n = 10), a severe cardiopathy (n = 2), a cardiopulmonary graft (n = 1), severe haemopathy (n = 2) (immunologic deficiency (n = 1), leukemia (n = 1)), 1 severe hypotonia, 1 West syndrome, 1 myopathy, 1 CHARGE syndrome and 1 had an inherited metabolic disorder. Overall among those 27 patients, 17 (63%) presented with neurological symptoms before the hospitalization, including 4 patients suffering from severe encephalopathy without eye-contact nor head control, 6 (22%) were followed for chronic disease without neurological symptoms and 4 (15%) did not have any medical history before the PICU admission.

It was the first admission for 9 (35%) of these patients, that were not followed by a NP before. Among the other 18

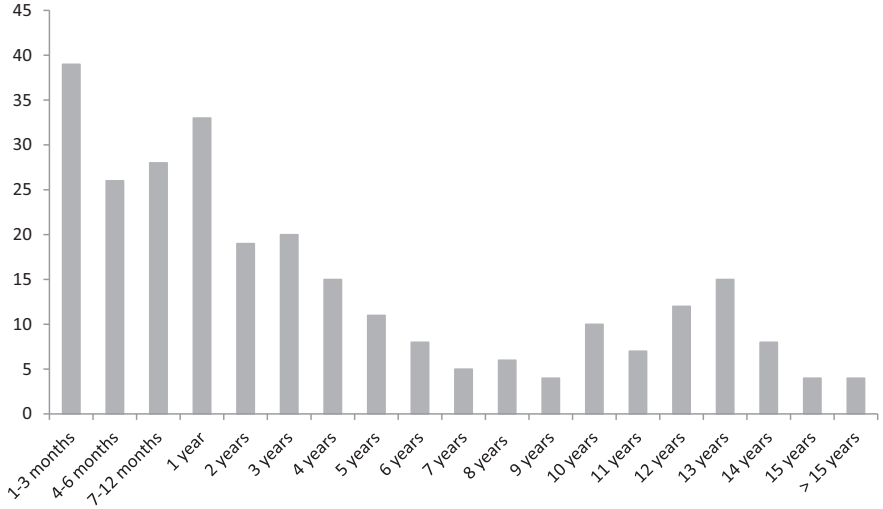

Fig. 1 – Age ranges of the 274 patients. The majority of the patient was less than 2 years old at the time of the PICU hospitalization.

Table 1 – Patients description and NP involvement in PICU according to motive for admission.

Reason of hospitalization	Mean Age (month)	Anterior PICU hospitalisation	Withdrawal or withholding decision before hospitalisation	Neurological development before hospitalization[c]		Purpose of NP consultation				Average length of stay (days)	NP Participation at multidisciplinary concertation	Withdrawal or withholding decision in the current PICU hospitalization (with/without NP)	Death	
				No communication, no head control	Normal	Total	Diagnosis	Treatment	Mean number of consultation				(with/without limitation)	% of hospitalization
Seizure (n = 85)	64	28 (32%)	0	4 (5%)	33 (39%)	50 (59%)	12	38	1.9	4.9 (1:52)	2	0	0	0
Respiratory deficiency (n = 46)	49	27 (58%)	6[a] (13%)	4 (8%)	10 (22%)	15 (33%)	7	8	2.2	26.1 (1:158)	5	2 (2/0)	6 (3/3)	13%
Other deficiency (n = 29)	62	11 (38%)	0	1 (3%)	13 (45%)	13 (44%)	5	9	2.1	15.0 (1:53)	3	4 (1/3)	6 (3/3)	10%
Vascular – stroke (n = 17)	99	4 (24%)	0	0	13 (76%)	12 (70%)	3	9	2	4.6 (1:27)	0	0	0	0%
Other infections (n = 15)	36	4 (27%)	1 (15%)	0	7 (15%)	4 (27%)	2	3	1	5.7 (1:24)	0	0	3 (0/3)	20%
Post surgery – graft (n = 13	53	8 (62%)	0	0	5 (38%)	5 (38%)	2	3	1	27.9 (3:80)	1	1 (1/0)	4 (1/3)	31%
Coma (n = 12)	67	2 (17%)	0	0	9 (75%)	8 (67%)	4	7	2.4	10.1 (1:84)	0	0	0	0%
Central nervous system Infection (n = 11)	54	1 (9%)	0	0	11 (100%)	8 (72%)	4	4	2.4	5.3 (1:16)	0	0	1 (0/1)	9%
Malaise (n = 9)	3	2 (22%)	0	2 (22%)	4 (44%)	6 (67%)	3	3	1.7	5.1 (2:13)	4	3 (2/1)	0	0%
Cardiorespiratory arrest (n = 8)	39	1 (13%)	0		2 (29%)	3 (38%)	0	3	3.7	4.6 (1:21)	3	4 (3/1)	6 (3/3)	75%
Central nervous system Inflammation (n = 7)	100	1 (14%)	0	0	7 (100%)	6 (86%)	4	3	3.2	8.7 (2:38)	0	0	1 (1/0)	14%
Inherited metabolic disorder (n = 7	56	4 (57%)	0	0	2 (27%)	1 (14%)	1	0	1	2.2 (1:4)	1	1 (1/0)	2 (1/1)	29%
Movement disorders (n = 4)	60	1 (25%)	0	0	2 (50%)	4 (100%)	3	3	1.3	3.3 (2:5)	0	0	0	0%
Expert opinion (n = 5)	14	5 (100%)	1[b] (20%)	1 (20%)	0	3 (60%)	3	0	2.7	9.0 (1:15)	3	4 (3/1)	1 (1/10)	20%
Other extra neurologic disorders (n = 6)	58	2 (33%)	0	0	3 (50%)	4 (67%)	2	2	1.5	13.0 (2:54)	0	0	0	0%
Total (n = 274)	57	101 (36%)	8 (3%)	11 (4%)	121 (44%)	142 (52%)	55	95	2.1	11.5 (1:158)	22	19 (13/6)	30 (12/18)	11%

Collaborative Multidisciplinary Deliberation were organized to discuss any LSST potential decision.

[a] 5/6 experienced a Life threatening event.

[b] This patient also experienced a life threatening event.

[c] Neurological development was considered normal when there was not any neurological pathology.

patients, which had already been hospitalized in PICU, 7 were followed by a NP in the same hospital.

For 8 (30%) patients, LLST decisions were already made before the studied PICU admission because of their severe neurological condition, with consecutive definite severe dependence and fraught cares. All these patients suffered from severe chronic brain diseases (4 congenital brain malformations, 3 inherited metabolic diseases, 1 congenital myopathy) and were thus previously followed up by a NP, who had taken part in the LLST decision, before any life threatening event for 2 of them. For the 6 others patients, the LLST decision had been made after a life threatening event during a PICU hospitalization. During this study, 6 of those patients were admitted in PICU for a respiratory failure, 1 for fever of unknown origin, and 1 for abdominal pain. Seven needed ventilatory supports (6 non-invasive ventilation and one ventilation on permanent tracheotomy). For those patients, the treatment decisions were always taken with the assistance of a NP, and in agreement with the PICU team, some patients were admitted in PICU in a context of fraught load of cares to ensure the patient's best comfort and care. During this PICU hospitalization they received all possible care needed by their acute condition, with respect to the former decision, and the referent NP did not visit the patient. None of these patients died during the studied PICU stay. After hospitalization, 2 of them went directly back home, 5 were in–home hospitalized and 1 went to another PICU.

For the other 19 (70%) patients, the decision to withhold or withdraw a treatment was made during their studied hospitalization in the PICU. Their features are presented in Table 2. Among them, 9 patients (47%) had a normal neurological examination before their admission, and only 2 (11%) did not have any medical history before admission.

A NP examined 13/19 of these patients and took part in the CMD in 12 cases (92%). In the last case he was absent but gave his written point of view before the deliberation. There could have been more than one CMD for the same patient. In one case, NP took part in 3 CMD for the same patient, in 4 cases, he took part in 2 CMD for the same patient.

A NP took part in three additional CMD that didn't lead to LLST decision.

12/19 patients (63%) died after a LLST decision was made during the current PICU hospitalization (none of the patients, who had a LLST decision prior to the study, died during the current hospitalization). Those patients represented 40% of the 30 deaths among the 274-selected patients. The death features of these 12 patients are presented in Table 3. Death occurred quickly after decision, about less than 24 h. Most of withdrawal decisions concerned hemodynamic (n = 2) and/or respiratory (n = 4) treatment. For withholding decision, it was often a refusal to implement invasive ventilation (n = 6), heart massage or amine therapy (n = 7). Sedation was always individually adjusted to patient anxiety and level of consciousness required.

Overall among the 27 patients with a LLST decision, 15 (56%) were assessed by a NP during their hospitalization (2 for a second opinion, and 13 to take part in LLST decision) and the NP met their parents during the hospitalization for 14 of them (93%).

A NP intervened with these patients a median 2.3 times (Range 1–5), for neurological assessment and/or to take part in a CMD. In all cases, the NP was called by the PICU team for its diagnosis expertise (15%), or to manage neurological treatments possibly associated with palliative care (85%). All in all the NP participated in a CMD about 22 patients, to discuss the appropriate level of care in the child's best interest, which resulted in 13 (59%) LLST decisions. There could have been more than one CMD for the same patient. Three of these CMD did not end in LLST. The flow-chart (Fig. 2) summarizes the NP's involvement for these patients. As we can notice in Fig. 3, several other practitioners were also involved in LLST decisions.

3.1. *Argument for LLST*

Unavailability of curative treatment or incurable pathology with a reduced quality of life was the main decision-criteria, reported in 22 patients (81%). Among those, 18 (66%) suffered from neurological diseases, 2 (7%) from hematologic diseases, 2 (7%) from an acute heart failure.

The absence of visual contact, without interfering sedative drugs, was another major reported decision-criteria to LLST.

Table 2 – Features of patient with LLST decision in PICU when assumed or not by NP (n = 19).

Total (n = 19)	Patient assumed by NP	No NP consultation
	13 (68%)	6 (32%)
Reason of hospitalization		
Malaise (n = 3)	2	1
Cardio respiratory arrest (n = 4)	3	1
Multidisciplinary expertise (n = 4)	3	1
Respiratory deficiency (n = 2)	2	0
Acute cardiac failure (n = 2)	1	1
Hematologic failure (n = 2)	0	2
Metabolic failure (n = 1)	1	0
Transplantation (n = 1)	1	0
Average length of stay (days)	22.6	14.5
Neurological follow-up before hospitalization	1 (8%)	–
NP involvement in CMD	12 (92%)	–
NP relatives consultation	12 (92%)	–

Most patients assumed by NP didn't have previous neurological follow-up. NP met relatives in 92% of cases.

Table 3 – Treatment features in the dead patients after LLST decision.

	Cause of death	Analgesic/Sedative therapy	Ventilatory support at the time of death	NP involvement (Y/N)	Withdrawal decision	Withholding decision	Time between decision and death (hours)
1	Intestinal necrosis	Morphine 0.02 mg/kg/h	Oxygenotherapy	N	–	- No heart massage - No invasive ventilation - No dialysis	NA
2	Acute respiratory distress syndrome/aspergillosis	Midazolam Sufentanil	Invasive ventilation	N	–	- No antifungal therapy	≈24
3	Intracranial haemorrhage	Morphine 0.02 mg/kg/h Midazolam Propofol	–	Y	–	- No invasive ventilation	≈30
4	Anoxo-ischemic brain failure	–	–	Y	- Extubation	- No heart massage	≈20
5	Acute respiratory failure	Midazolam Sufentanil Atracrium	–	N	- Extubation	- No heart massage - No dialysis	NA
6	Multiorgan dysfunction	«deep sedation»	NA	N	- Stop dialysis	- No dialysis - No increasing ventilation	≈6
7	Obstructive respiratory deficiency	NA	–	Y	–	- No ventilatory assistance	NA
8	Cardio respiratory arrest/Choc	–	–	Y	- extubation	- No increasing amine therapy	≈1
9	Cardio respiratory arrest	–	–	Y	- Extubation - Stop Amines	–	≈1
10	Accidental extubation	Midazolam Sufentanil	Oxygenotherapy	Y	–	- No intubation - No heart massage	≈12
11	Cardiac acute failure	Morphine 0.04 mg/kg/h	Non invasive ventilation	Y	- Stop amines	- No intubation - No heart massage	NA
12	Acute respiratory failure	Midazolam Sufentanil	High flow oxygen therapy	N	–	- No intubation -no ventilatory assistance - No heart massage	≈6

Death occurred quickly after decision, about less than 24 h. Most of withdrawal or withholding decisions concerned hemodynamic and respiratory distress. Sedation was always adjusted to patient anxiety and level of consciousness required. NA: Not available.

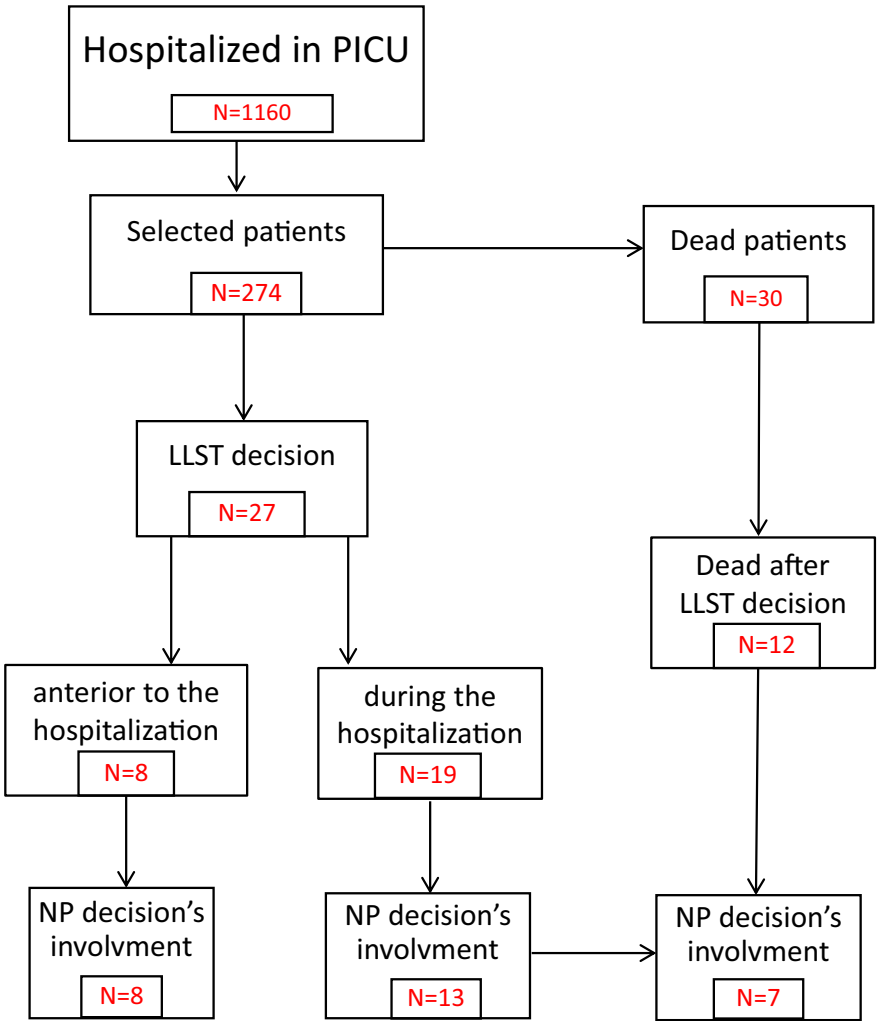

Fig. 2 – Flow chart of the analysis of Neuropediatricians involvement in LLST decision in PICU.

Indeed 6 (22%) of the 27 LLST-patients did not have any eye-contact before the PICU hospitalization and 9 (33%) lost eye-contact during the hospitalization (before the decision to withdraw/withhold treatment). By contrast, among the 1160 patients hospitalized in PICU in 2014, only 6 other patients were reported without any eye-contact prior to admission; no treatment withdrawal or withholding decision was made for those patients.

At last an expected poor prognosis related to serious neurologic or cardiologic sequelae was reported in 21 patients (77%).

In one case, the parents disagreed with the medical LLST decision in a context of severe brain lesions after prolonged cardio-respiratory arrest in a 9 year-old girl. Consecutively the parents' opinion was respected and the LLST decision was thus not applied. In another case concerning a 5 year-old boy with diffuse brain damage and consecutive profound and multiple disabilities, whereas LLST had been decided during two CMD, the medical decision could not be exposed to the parents due to their presumed psychological difficulties to hear and accept such a decision, that was thus neither applied.

In some others cases (n = 2), parents at first declined the LLST decision, but they finally agreed with the medical decision after clear explanation was delivered by the medical team. Of note, in our study, neither parents nor children asked for a CMD to discuss potential LLST.

4. Discussion

To our knowledge, this is the first pediatric study focusing on the implication of NPs in PICUs. In this study, we investigated the involvement of NPs in the PICU, for both patients with acute brain failure who required specific diagnostic assessment with potentially curative treatment available, and those for whom the acute brain failure with consecutive neurological sequelae lead to a LLST decision. The mere fact that more than a half of patients selected in our study were evaluated by a NP suggests that NPs have a major role to play in providing optimal patient care, as well as in making diagnosis and assessing prognosis while considering ethical principles, especially during CMD. As a matter of fact, NPs have the expertise to assess the brain lesion, with both its

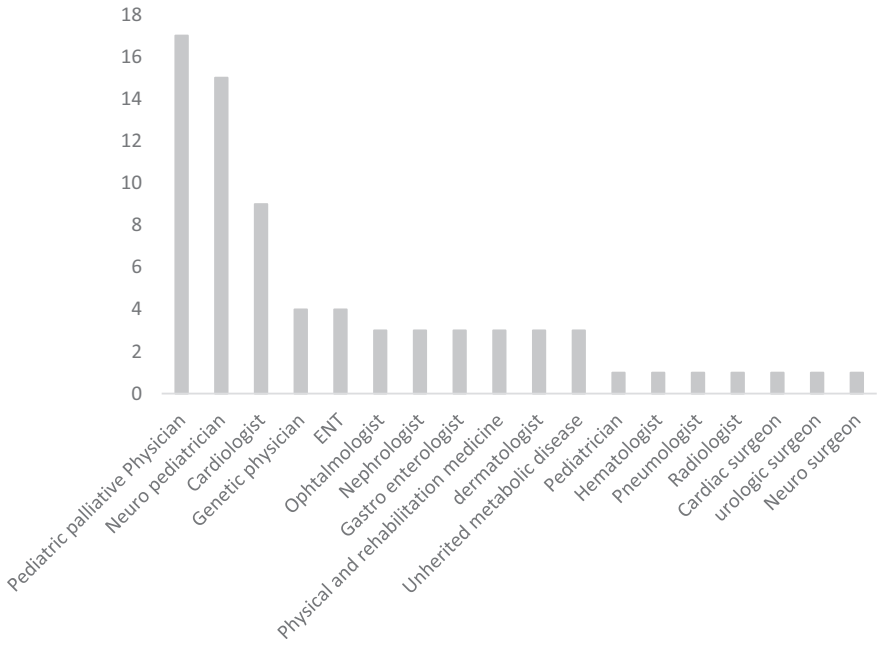

Fig. 3 – Specialists involvement in patients with withdrawal or withholding decision (n = 27). Multidisciplinary care was the rule for all patients.

clinical and potential neurophysiological and imaging symptoms, to perform a diagnosis and to issue predictable prognosis whenever possible.

Indeed, the assistance of a NP is essential to get a proper and reliable expert diagnosis as well as an appropriate treatment in the cases of acute brain injury, for instance stroke, epilepsy or inflammatory disorders. The Necker Enfants-Malades hospital is a pediatric hospital specialized in rare diseases with a large amount of paediatric subspecialties: neurologic and metabolic disorders, immune-hematologic disorders, cardiac, renal, hepatic pathologies, etc. Of note in our hospital, Children requiring a neurosurgical treatment are referred to a specific PICU (and were thus not included in our study). An average of 40%–60% of the patients referred to the PICU of the tertiary centres come from a specialized unit of the hospital or suffer from chronic conditions.[7,13] In our study we found the same proportion with only 44% of the cases involving naïve patients with neurologic disorders before PICU entry, particularly in cases of cardiac arrest, infectious diseases or secondary brain impairment. We were able to demonstrate that in 52% of the cases, the NP visited the child more than twice and the duration of hospitalizations in the PICU was approximately 11 days.

In the context of PICU, where administered treatments are usually devoted to sustaining life, death often occurs after a LLST. Indeed in a recent study it was reported that 44/62 (71%) patients died after a LLST in a Japanese PICU between 2010 and 2014.[14] In our study, 12/30 (40%) patients died after a WWT. Death occurred quickly after WWT in our study, about less than 24 h. This can be explained because of withdrawal of life sustaining treatments. We have shown that, NPs are mainly involved in such decisions, before hospitalization as well as during hospitalization. Indeed, all patients with an anticipated withdrawal or withholding decision were followed by a NP, even if they had never been followed in our hospital before. The more frequent decision-criteria in the decision to withhold or withdraw treatment were unavailability of curative treatment or incurable pathology with a reduced quality of life. As an aggravating factor, lack of visual contact was often reported to reinforce the decision. Nevertheless, the balance between benefits and the degree of suffering endured in each hospitalization must be first considered to make an ethical and reasoned decision. Moreover, the recommendations state that one has to act in the "child's best interest", however, this is being left to the assessment of the medical team for whom it is difficult to predict the child's future quality of life, which relies not only on visual contact but on a complex array of clinical assessments, which themselves are multifaceted.

In France decisions to withhold or withdraw life-sustaining treatment in the pediatric context are indeed only possible after a CMD (April the 22th 2005 law, revised in February 2nd 2016 and called the Leonetti-Claeys law).[10]

These CMD require the presence of several specialists, including potentially NPs and may also include other paediatric specialists who bring their specific experience and knowledge, when required. Among them, pediatric palliative physicians (PPP) play a key role when it comes to decisions to withdraw or withhold treatment. Indeed, as already demonstrated, they do play many roles in this decision process. First, they bring another type of knowledge, focusing on sedative drug pharmacology and pain treatment.[15] They also have a communication expertise around eliciting patient and family preferences and integrating them into serious decision making.[16,17] Furthermore, their experience in end-of-life sustaining treatment improves the quality of care provided to the children and thus allow the PICU team to have a global vision of the patient and his/her relatives. This collaboration

between both the intensivists (PICU), the specialists (e.g. NP) and PPP aims at improving practice, with new perspectives in the patients management including both specific potentially curative and supportive cares, for the patient's best interest. The high number of patients who could have been referred to a NP (23%) and the reasons for their hospitalizations were quite similar to other studies that have already been reported. Furthermore, palliative care seems to be more efficient in patients with brain failure, whether acute or chronic, than in patients with others deficiencies.[18–20] Surprisingly, in studies conducted on adult patients, neurologists seem to loose their central role as main partners in withholding decisions whereas the palliative unit is more involved.[21]

Frequently, CMD was organized because of a life threatening event. We showed that it is possible, even if it is not common, to organize a LLST decision before any life threatening event. This CMD had the same modalities before any PICU hospitalization than those organized during PICU hospitalization. These make it possible to limit the sufferings related to a hospitalization.

The French PICUs have modified their practices to meet the requirements of the Leonetti-Claeys Law but have also had to make significant changes to be in line with the specific recommendations of the Intensive Care Scientist Society.[3,7,10]

Discussing ethics in health-care matters such as Autonomy, Beneficence, Non-maleficence and Distributive justice[22,23] is particularly relevant when it comes to primitive or secondary brain disorders.

Although current best practice guidance actively encourages children's participation in the decision making process, the patients who find themselves in critical situations have no motor autonomy and are unable to give their own point of view.[22,24] Parents remain the main interlocutors. The relatives must be kept fully informed on the patient's condition, in particular regarding issues of limiting and withdrawing treatment. Although decisions are ultimately up to the medical staff, it is unwise to limit or withdraw treatment without the agreement of the relatives.[22] Cases of disagreement between the medical team and the parents remain exceptional as far as our study as enabled us to judge and in both cases the parents' decision was respected. The principle of autonomy is really difficult to implement without the child's agreement, because of the subjective predictions of the parents and the medical staff about the child's quality of life after intensive care hospitalization, and the LLST decision-process must be done with an acute sense of responsibility. NP was present during the interview with the parents of the children for whom a decision to withdraw treatment was made. As an expert, a NP is able to use his experience of brain impairment and long term follow-up of surviving patients as a basis to communicate with the medical team and the PICU caregivers but also with the parents. It is interesting to note that only 40% of the patients for whom a LLST decision was made died in the premises of the PICU a few days later. In all others cases, the children were sent back to a neurologic unit to get supportive and palliative care with recommendations to follow, should a second acute event occur (respiratory distress or status epilepticus). However, another thorny issue remains: the poor health-related quality of life of surviving patients. The concept of "relative futility" is dangerous as it introduces an unknown and potentially highly variable factor—namely, a doctor's assessment on the patient's quality of life.[22,25] The change of the adjective "reasonable" to the adjective "relative" has been discussed to give doctors more latitude in deciding whether a treatment is ethically justified. In case of chronic disorders with severe neurological impairment, the experience of the child's assigned medical staff and of the parents is an important fact to take into consideration. All these questions remind us of the absolute necessity of a real expertise in paediatric neurology, but also in ethical and principles and palliative medicine.

This study has several potential limitations. This is a retrospective chart review and the only data available at the time of review was the data that had already been gathered in the medical record. Thus, some of the NPs consultation reports may be missing in the analyzed files, because of an oversight from NPs to report on their consultations. Furthermore, the clues for the decision making and its management might be difficult to understand for those collecting data without knowing about the situation or the patient's history. Nonetheless, similar studies were conducted on adults to determine the part played by the various partners in the withdrawal decision-making.[21,26]

5. Conclusion

The role of neuro pediatricians in the withdrawal or withholding decision process for patients admitted in PICU really makes sense; he acts as a neurological disease expert, and often as a medical advisor for children. To achieve it, NPs have to work closely with the PICU team, and others medical and paramedical specialists, particularly with PPP, which have a real expertise in ethical and supporting care. This common and close collaboration will allow the improvement of practices and a better quality of care for children.

What's known on this subject (29/40 mots)

Brain injury is one of the first causes of admission and death in PICU, claiming for specific neuropediatric expertise to ensure best diagnosis and treatment's process and decision.

What this paper adds (40/40 mots)

In PICU, most of NPs interventions are devoted to diagnosis and/or specific treatment management. However NPs are also involved in most withdrawal/withholding decisions, since in such cases forecast severe handicap altering quality of life might claim for the limitation decision.

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Contributors' statement page

JT was responsible for the study conceptualization and design, collected the data, analyzed and interpretated them, made the statistical analysis, drafted and revisited the manuscript for intellectual content. JT had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

DB, MLV and LSB were responsible for the study conceptualization and design, drafted and revisited portions of the manuscript for intellectual content.

MK, MH participated in analysis and interpretation of the data, drafted and revisited portions of the manuscript for intellectual content.

ID was responsible for the study design and conceptualization, and revisited portions of the manuscript for intellectual content.

Conflict of interest

On behalf of all authors, the corresponding author states that there are no conflicts of interest.

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