

Children with chronic conditions in pediatric intensive care  
units located in predominantly French-speaking regions:  
Prevalence and implications on rehabilitation care need and  
utilization.

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GFRUP/RMEF chronic diseases in PICU study group

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## **Abstract**

**Objective:** To estimate the prevalence of chronic conditions and/or disability in intensive care units admitting children (PICU) or both neonates and children (NPICU), and to describe available rehabilitation resources.

**Design:** A cross-sectional study on two separate days, using a web questionnaire.

**Setting:** NPICU/PICUs affiliated to the *Groupe Francophone de Réanimation et Urgences Pédiatriques* and the *Réseau Mère-Enfant de la Francophonie*

**Patients:** Children > 1 month of gestationally corrected age.

**Measurements and Main Results:** Disability was defined as a Pediatric Overall Performance Category (POPC)  $\geq 3$  before admission and chronic conditions as hospitalization since birth or the presence before admission of any condition requiring on-going pediatric subspecialty care that was expected to last  $\geq 12$  months. Intensivists indicated what rehabilitation services he would have ideally prescribed (“perceived needs”) and those provided. Of 45 affiliated units 8 PICUs and 15 NPICUs participated. Staff included or had access to a psychologist (11 and 5, respectively), a social worker (10 and 3), a physiotherapist (11 and 12), a «psychomotrician» (2 and 8), a child educator (1 and 6), and a speech-language pathologist (0 and 6). Among 289 recorded ICU-days, 236 were analyzed (excluding those for children admitted after surgery): 57 concerned children hospitalized since birth and 179 children admitted from home. Among these 179 recorded ICU-days, 107 concerned children with chronic conditions (including 50 concerning disabled children) and 72 previously healthy children. Thus, prevalence of chronic conditions, including children hospitalized since birth, was 67%. Rehabilitation services included: respiratory physical therapy (552 visits), musculoskeletal physical therapy (71), neurological physical therapy (37), rehabilitation for swallowing (11), and for speech-language disorders (1), representing 79% of perceived needs.

**Conclusions:** Prevalence of chronic conditions in NPICU/PICU was 67%. More attention must be paid to the rehabilitation care needs of patients during their NPICU/PICU stay and after discharge.

**Introduction:**

The case-mix of children hospitalized has dramatically changed in the last decade (1, 2). The proportion of children with chronic diseases and/or disability is increasing: being up to 50% in some pediatric hospitals (3-15). The consequences of this progression on the case-mix in Pediatric Intensive Care Units (PICU) have not yet been studied, and the specific needs that are generated have not been estimated (16). Therefore, members of the Groupe Francophone de Réanimation et d'Urgence Pédiatrique (GFRUP) and of the Réseau Mère-Enfant de la Francophonie (RMEF) undertook a cross-sectional study in order to determine what is the prevalence of chronic conditions and/or disability in the critically ill patients in Pediatric Intensive Care Units (PICUs) and units caring for both neonates and children (Neonatal and Pediatric Intensive Care Units: NPICUs), and to estimate what clinical resources are available for them.

**Methods:**

All French-speaking NPICU/PICUs affiliated to the GFRUP (n=41) and the RMEF (n=6) were asked to participate. All children older than 1 month of gestationally corrected age (defined as age minus premature period) and hospitalized in NPICU/PICUs on March 16 and May 6, 2004 were eligible for inclusion. Because two units were involved in humanitarian programs consisting of admitting children from developing countries for surgery, children admitted for a postoperative stay were excluded. Indeed, these children are specifically selected because their chronic diseases are curable with one-time surgery without requiring any medical follow-up.

*Data Collection and Data Management:*

In this cross-sectional study, data were collected on two separate days, named recorded ICU-days. Patients were considered only once if present on the two days while all data regarding care were taken into account. The following data were anonymously collected by the attending intensivist of each unit: NPICU/PICU staff, unit organization, and patients' characteristics. Data on patients included: demographics, date of NPICU/PICU admission, acute and chronic diagnoses, main acute or chronic organ failures (defined as failure justifying the NPICU/PICU stay), Pediatric Risk of Mortality score (PRISM) at h24 (17), Pediatric Logistic Organ Dysfunction score (PELOD) at admission and on the days of survey (18), Pediatric Overall Performance Category score (POPC) before admission (19, 20), and health care that were provided on the days of survey (i.e. mechanical ventilation, parenteral and enteral feeding, vasoactive drugs, dialysis, tracheal tube, tracheostomy, central line, gastro-jejunostomy, arterial catheter, intracranial pressure measurement device, bladder catheter, and all rehabilitation care). To assess the need for rehabilitation care, the attending intensivist was asked to indicate both what rehabilitation services he would have prescribed if all competencies had been available in his unit ("perceived needs") and what rehabilitation services were effectively provided on the days of survey ("provided services"). After the two days of survey, date of discharge from NPICU/PICU was also prospectively registered for all children, in order to calculate the length of stay (NICU/PICU LOS).

Data were extracted from hospital charts and data entry was done by intensivists in a protected web-based database. The development of the internet interface for data input and output was carried out by GEREQ Company (Gestion Recherches Quebec, Montreal, Canada), taking into account the regulations of the Food and Drugs Administration with respect of safety and confidentiality requirements. An epidemiologist (DP) managed the database and carried out the analysis. Patient data were collected anonymously, and a nominative list was held by investigators for further quality controls. Data on units and caregivers were nominative and were analyzed by the

Département d'Information Médicale (*Hospices Civils, Lyon, France*) that was authorized by the French authorities to manage a nominative database of health professionals (21).

*Definitions:*

For children hospitalized from home, disability was defined as a Pediatric Overall Performance Category ((POPC)  $\geq 3$  before admission and chronic conditions, as suggested by Feudtner et al, as the presence of existence before hospital admission of any medical condition requiring pediatric subspecialty care expected to last at least 12 months (5, 19). For patients hospitalized since birth, disability was not assessed because the POPC before admission was not applicable. All of them were considered as having chronic conditions according to the fact that we included only patients older than 1 month of gestationally corrected age.

We considered as “rehabilitation subspecialists” all the following care-givers: *Physiotherapist*, rehabilitation specialist who uses physical methods to maintain or restore functional ability, including musculoskeletal physical therapy (using joint mobilization, manipulation, massages) and respiratory physical therapy (physical methods to clear patients’ respiratory tracts and improve respiratory capacity); *speech-language pathologist*, rehabilitation specialist who uses rehabilitative methods to treat speech-language or swallowing disorders; *child educator*, non-healthcare professional who uses stimulation games to develop practical skills and improve child development; “*psychomotrician*”, rehabilitation specialist who uses exercises or games to overcome deficit by improving motor or sensitive pattern (neurological physical therapy), not to confuse with psychometrician. The activity specific to these specialties is defined as follows: respiratory physical therapy: visits of a healthcare professional using physical methods to clear patients’ respiratory tracts and improve respiratory capacity; musculoskeletal physical therapy: visits of a healthcare professional using joint mobilization, manipulation, and massages to restore functional ability; neurological physical therapy: visits of a healthcare professional using exercises to overcome motor deficit or improve motor pattern; rehabilitation for speaking disorders: visits of a healthcare

professional using rehabilitative methods to treat speech-language disorders; rehabilitation for swallowing disorders: visits of a healthcare professional using rehabilitative methods to treat swallowing disorders.

*Statistical methods:*

Medians and proportions were computed using SPSS software version 11.5 (Apache Software Foundation- Chicago-IL, USA). Values are expressed as median with ranges, and 95% confidence interval was computed using normal approximation.

*Ethical considerations:*

Because no intervention was carried out during this descriptive epidemiological study, the Institutional Review Board of the participating centers waived the need for signed informed consent. According to the French law (22), study design and database management were approved by a French national review board (*Comité Consultatif sur le Traitement de l'Information en Matière de Recherche dans le domaine de la Santé*) on November 27<sup>th</sup>, 2003.

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**Results:**

*Participating units*

Among the 45 NPICU/PICUs affiliated to the GFRUP/RMEF, 23 (51%) representing 64% of beds of the consortium participated in the study (8 PICUs and 15 NPICU/PICUs): 19 from France, 2 from Switzerland, 1 from Belgium, and 1 from Canada (see the list in appendix). Most PICUs (21/23) were university-affiliated tertiary care units. Median total number of beds per unit was 13 [5-24]; 2003-

median annual number of admissions were 241 [52-850] and 200 [0-430] for children and newborns, respectively. Characteristics of caregiver staff are given in Table 1. Medical staff in NPICU/PICUs included: 3.0 [1.5-8] physicians, 2.0 [0-7] physicians in training, 39.5 [16-90] nurses, and 7.0 [1-21] nursing assistants who help nurses by giving basic and hygienic care, feeding and similar duties.

### *Patients*

One hundred and thirty eight children were included on March 16, and 151 on May 6, 2004. Fifty three children were excluded because of post surgery status. Because 21 children were present on both days of survey, characteristics of patients are given referring to 215 patients, of whom 42 were hospitalized since birth and 173 were admitted from home. Among the 173 patients admitted from home, 102 had chronic conditions, of whom 49 were disabled. Thus, including children hospitalized since birth, a total of 144 had chronic conditions representing 67% of children [95% confidence interval: 61-73].

Patients' categories are summarized in Figure and the study population is presented in Table 2. Among the 71 previously healthy children, the main acute diagnoses were trauma, near-drowning and burns (25%), pneumonia and bronchiolitis (19%), status epilepticus (6%), poisoning (6%), meningitis and/or encephalitis (6%). The main underlying diagnoses of the 144 children with chronic conditions are presented Table 3.

Median age of children retained in the study was 1.1 year (0.1 to 25), median PELOD score on the day of survey was 1 (0 to 71). Median length of stay (LOS) was 14 days (0 to 1263). For children admitted from home, median POPC before admission was 1 (1 to 6), median PRISM score was 7 (0 to 52), and median PELOD score at admission was 2 (0 to 60).

### *Supportive treatments and technically assisted services*

On the two days of study, we recorded 136 days of mechanical ventilation (58% of the 236 recorded ICU-days), 26 days of sympathomimetic drug infusion (11%), 69 days of parenteral feeding



(29%), 132 days of enteral feeding (56%), and 5 days of dialysis (2%). Details of supportive treatments that were given on these two days of survey and monitoring devices that were in place are given in Table 4.

*Rehabilitation care.*

Among the 236 recorded ICU-days, we observed 552 respiratory physical therapy visits, 71 musculoskeletal physical therapy visits, 37 neurological physical therapy visits, 11 swallowing rehabilitation visits, and 1 speech-language rehabilitation visit (Table 5). The proportion of rehabilitation services perceived as needed that were effectively provided was 94% for respiratory physical therapy, 63% for musculoskeletal physical therapy, 40% for neurological physical therapy, 22% for swallowing rehabilitation, 7% for speech-language rehabilitation. The ratios of provided services to perceived needs for each group are given in Table 5.

## Discussion

This two-day cross-sectional study shows that the prevalence of chronic conditions and disability in children hospitalized in NPICU/PICU was 67%. Regarding rehabilitation care, it suggests a gap between perceived needs and effectively provided services.

There is some evidence in the medical literature suggesting a dramatic change in the case-mix observed in PICU. Briassoulis et al. evaluated reported data on 1629 consecutive admissions in a Greek PICU from 1996 to 2001 (2). Patients with significant comorbidity represented 38% of the admitted children, and disabled patients 22.1%. The investigators assessed the progression of resource utilization by analyzing PICU LOS and length of mechanical ventilation (LOMV). They reported that the LOS/LOMV ratio increased over time, following a similar trend of the proportion of patients with comorbidity. These authors published in 2005 another prospective five-year study that included 1586 PICU children; they observed an increasing longitudinal trend of patients with inherited metabolic disease or with genetic influences, more PICU readmissions, a longer mean LOS in PICU and a higher mortality rate (1). In a four-month prospective study that was carried out in 9 French NPICU/PICUs in 1994, Martinot et al. recorded on 712 critically ill children (23), of whom 45% had chronic conditions defined as the need for repeated hospitalizations and/or a follow-up by a pediatric subspecialist; the expected death rate, as estimated by the PRISM score, was less than 1% in 22% of children. The underlying disease was considered as possibly lethal during childhood in 13 children (1.8%). Thirty children (6%) had a malignant disease, 40 (9%) a congenital cardiac abnormality, 14 (3%) an abnormality of the central nervous system (3%), and 28 (5%) multiple congenital malformations (23). One hundred and thirty three children (19%) had POPC >3 (24).

In our study children who were never discharged since birth (some were transferred from a NICU to a PICU while others stayed in a NPICU) represented near 20% of the population. The POPC score of this population was abnormal mostly because they were dependant to some

technology. The most frequent diagnoses were quite similar to those reported by Auburtin, including bronchopulmonary dysplasia and enterocolitis (25).

In the PICUs not admitting neonates that participated in our study, the proportions of patients with chronic diseases (including children hospitalized since birth) and/or previous disability were respectively 67% and 23%. In a one-year prospective study, Dosa et al. examined the proportion of “children with special health care needs” among 248 consecutive unscheduled PICU admissions (26). These children were previously defined by the American Academy of Pediatrics as those “who have, or who are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond the required by children generally” (27, 28). In this study, children with chronic conditions represented 45% of unscheduled admissions, and their relative risk of PICU admission was 3.3 [IC 95%: 2.5 to 4.2] compared to the others. This risk reached 6.6 when only considering children with chronic conditions before two-year of age. Among the 112 children with chronic conditions, 26 (32 %) had received home technology-assisted care (tracheostomy, mechanical ventilation, parenteral or enteral nutrition) before the study (26). A third of the unscheduled PICU admissions was attributable to a preventable event (n=36) according to an adapted from McConnochie et al classification (29). These preventable events were significantly less frequent in the group of children receiving technology-assisted care (n=7; 19%) than in the others (n=29; 28%). Thus, the available data provided by our study and the literature support the assumption that critically ill children with chronic conditions and/or disability represent an important part of the population cared in PICUs.

Our study gives original data about rehabilitation resources available in NPICU/PICUs and on their utilization that were not detailed in previous reports (30, 31). Because of the differences in professional status, role, and involvement according to country (i.e. in France, physiotherapists and “psychomotricians” are both involved in neurological physical therapy), we took care to record both staff and rehabilitation care data, taking into account different definitions (32). The data that we report show that the availability of specific services (speech-language pathologists,

physiotherapists, parents' training for technically assisted care by PICU nurses), and specific medical services (coordinating multiple subspecialists, developing care plan with families, multidisciplinary meetings) are required in the PICU in order to offer optimal care programs to patients with disability and/or previous chronic conditions.

Even though there are no precise recommendations concerning its indications, respiratory physical therapy is frequently provided to adults in ICU (32-34). We observed a similar trend in the participating NPICU/PICU where more than 80% of the 672 rehabilitation visits during the 236 recorded ICU-days were devoted to respiratory physical therapy. All NPICU/PICUs have access to this competency because it is mandatory to do so according to European recommendations for adult ICUs and French legislation for PICUs. The fact that all wished respiratory physical therapy visits were not effectively provided, suggests that the availability was not optimal (22, 35).

Musculoskeletal therapy and neurological physical therapy were the second and the third most frequent categories of rehabilitation services that were provided. The number of provided visits (71 and 37, respectively) was considerably lower than respiratory physical therapy visits, even among disabled children in whom neuromuscular diseases predominated (Table 2). Recently, the European Academy of Rehabilitation Medicine published the "White book of physical and rehabilitation medicine in Europe". It is noticed that rehabilitation specialists must be involved as soon as possible during the acute phase, even within the ICU (36). Operational guidelines that could be used to objectively estimate the need for rehabilitation care are lacking; this is why we recorded physicians' perceived needs, in order to assess discrepancy between the need and the offer in rehabilitation care. However, the small number of musculoskeletal and neurological visits provided is obviously contrasting with the great proportion of disabled children. It remains to be determined if the rehabilitation services provided in NPICU/PICU fulfill what is required by critically ill children.

A speech-language pathologist was available in only 26% of NPICU/PICUs. It was never observed that a specialist in this field devoted 100% of his time to the NPICU/PICU. The presence

of a tracheal tube, a tracheostomy, or a nasogastric tube is known to disrupt the normal physiology of swallowing and desensitize the laryngopharyngeal area (37, 38). These physical effects, combined with the deprivation of eating pleasure secondary to parenteral or continuous enteral feeding, should be particularly harmful in neonates and young infants because it might jeopardize their ability to eat by the oral route and to develop their language. The American Speech-Language-Hearing Association recently defined the role of speech-language pathologist in NICU, namely in contributing to the NICU developmental care plan (with a focus on communication and feeding/swallowing), in order to enhance development and prevent sequelae (39). In our study, all speech-language pathologist visits were provided to children who were hospitalized since birth. It points out that the need for the speech-language pathologist competency remains after the neonatal period, even though their role in the PICU is not yet clearly defined.

Our study has some limitations. First, it is a cross-sectional study performed on two different days in spring: therefore, it is probably not representative of diseases with seasonal variation, like bronchiolitis, which can change the proportion of patients admitted with chronic diseases and/or disability. Second, all children who were admitted after surgery were excluded. Our study must be considered as giving data about medical case mix that represents only part of NPICU/PICU activity. Third, no guidelines about what rehabilitation services must be given were provided to the participating ICU; we thus recorded physicians' perceived needs, even though self declarative studies are causes of biases (40)

Apart from these limitations, this study gives original data about NPICU/PICU case mix and staff resources. Its multicenter international design and the inclusion of all patients probably make it representative of NPICU/PICUs medical activity.

**Conclusions:**

The proportion of children with chronic conditions and/or disability who are nowadays hospitalized in NPICU/PICU is important. As a consequence, it can be expected that the need for rehabilitation care is increasing. Further studies are required to better characterize what are the needs for rehabilitation care of children admitted to NPICU/PICUs with previous chronic disease and/or disability, and to estimate if the services offered fulfill these needs.

**GFRUP/RMEF chronic diseases in NPICU/PICU study group:**

The study was conceived and organized by Robin Cremer. Francis Leclerc critically reviewed the study proposal. Dominique Ploin managed the database and carried out the analysis. The manuscript was written by Robin Cremer with the help of Dominique Ploin, Francis Leclerc, and Jacques Lacroix.

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Data were collected in the NPICU/PICUs of the following centers: American Memorial Hospital, CHU de Reims, France; Centre Hospitalier Universitaire Vaudois, Lausanne, Switzerland; Hôpital Clemenceau, CHU de Caen, France; CHU Sainte Justine, Montréal, Canada; Hôpital

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**References:**

1. Briassoulis G, Filippou O, Mavrikiou M, et al: Current trends of clinical and genetic characteristics influencing the resource use and the nurse-patient balance in an intensive care setting. *J Crit Care* 2005, 20:139-146.
2. Briassoulis G, Filippou O, Natsi L, et al: Acute and chronic paediatric intensive care patients: current trends and perspectives on resource utilization. *QJM* 2004, 97:507-518.
3. Bethell CD, Read D, Neff J, et al: Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions--revised. *Ambul Pediatr* 2002, 2:49-57.
4. Bethell CD, Read D, Stein RE, et al: Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambul Pediatr* 2002, 2:38-48.
5. Feudtner C, Christakis DA, Connell FA: Pediatric deaths attributable to complex chronic conditions: a population-based study of Washington State, 1980-1997. *Pediatrics* 2000, 106:205-209.
6. Feudtner C, Hays RM, Haynes G, et al: Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. *Pediatrics* 2001, 107:E99.
7. Feudtner C, Silveira MJ, Christakis DA: Where do children with complex chronic conditions die? Patterns in Washington State, 1980-1998. *Pediatrics* 2002, 109:656-660.
8. Kuhlthau K, Ferris TG, Beal AC, et al: Who cares for medicaid-enrolled children with chronic conditions? *Pediatrics* 2001, 108:906-912.
9. Neff JM, Sharp VL, Muldoon J, et al: Identifying and classifying children with chronic conditions using administrative data with the clinical risk group classification system. *Ambul Pediatr* 2002, 2:71-79.
10. Perrin JM, Kuhlthau K, Walker DK, et al: Monitoring health care for children with chronic conditions in a managed care environment. *Matern Child Health J* 1997, 1:15-23.

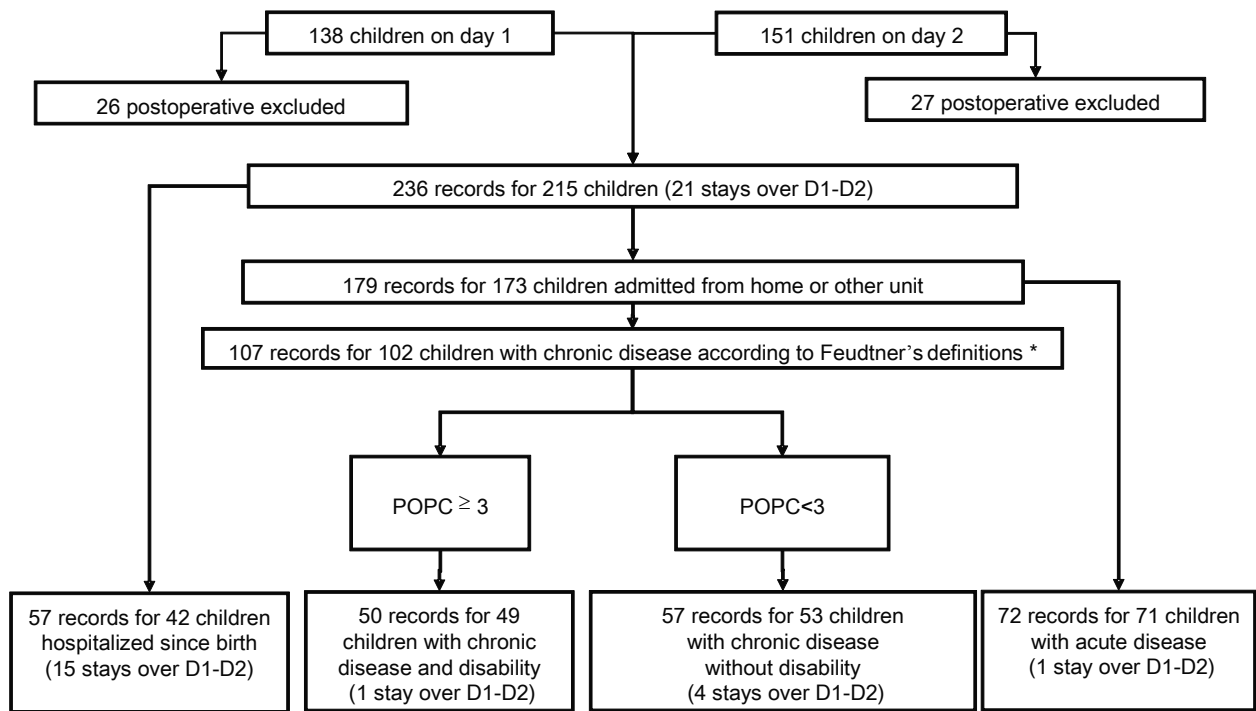


11. Sacchetti A, Sacchetti C, Carraccio C, et al: The potential for errors in children with special health care needs. *Acad Emerg Med* 2000, 7:1330-1333.
12. Sneed RC, May WL, Stencil CS: Training of pediatricians in care of physical disabilities in children with special health needs: results of a two-state survey of practicing pediatricians and national resident training programs. *Pediatrics* 2000, 105:554-561.
13. Srivastava R, Norlin C, James BC, et al: Community and hospital-based physicians' attitudes regarding pediatric hospitalist systems. *Pediatrics* 2005, 115:34-38.
14. Weller WE, Minkovitz CS, Anderson GF: Utilization of medical and health-related services among school-age children and adolescents with special health care needs (1994 National Health Interview Survey on Disability [NHIS-D] Baseline Data). *Pediatrics* 2003, 112:593-603.
15. Ziring PR, Brazdziunas D, Cooley WC, et al: American Academy of Pediatrics. Committee on Children With Disabilities. Care coordination: integrating health and related systems of care for children with special health care needs. *Pediatrics* 1999, 104:978-981.
16. Schein RM, Quartin AA: Severe chronic disease with acute physiologic disturbance: a role for intensive care. *Crit Care Med* 2000, 28:3099-3100.
17. Pollack MM, Ruttimann UE, Getson PR: Pediatric risk of mortality (PRISM) score. *Crit Care Med* 1988, 16:1110-1116.
18. Leteurtre S, Martinot A, Duhamel A, et al: Validation of the paediatric logistic organ dysfunction (PELOD) score: prospective, observational, multicentre study. *Lancet* 2003, 362:192-197.
19. Fiser DH: Assessing the outcome of pediatric intensive care. *J Pediatr* 1992, 121:68-74.
20. Fiser DH: Outcome evaluations as measures of quality in pediatric intensive care. *Pediatr Clin North Am* 1994, 41:1423-1438.
21. Loi 78-17 du 06 janvier 1978 relative à l'informatique, aux fichiers et aux libertés. In: *Journal Officiel de la République Française "Lois et Décrets"*. 1978: 227.

22. Décret n° 2006-74 du 24 janvier 2006 relatif aux conditions techniques de fonctionnement auxquelles doivent satisfaire les établissements de santé pour pratiquer les activités de réanimation pédiatrique et de surveillance continue pédiatrique. *Journal Officiel de la République Française n° 22 du 26 janvier 2006*:1313.
23. Martinot A, Leteurtre S, Grandbastien B, et al: [Characteristics of patients and use of resource in French pediatric intensive care units. Le groupe francophone de Réanimation et Urgences pédiatriques]. *Arch Pediatr* 1997, 4:730-736.
24. Martinot A, Grandbastien B, Leteurtre S, et al: No resuscitation orders and withdrawal of therapy in French paediatric intensive care units. Groupe Francophone de Réanimation et d'Urgences Pédiatriques. *Acta Paediatr* 1998, 87:769-773.
25. Auburtin B, Saizou C, Dager S, et al: [Prolonged length of stays in pediatric intensive care. Retrospective study of 100 stays]. *Arch Pediatr* 2001, 8:158-165.
26. Dosa NP, Boeing NM, Ms N, et al: Excess risk of severe acute illness in children with chronic health conditions. *Pediatrics* 2001, 107:499-504.
27. McPherson M, Arango P, Fox H, et al: A new definition of children with special health care needs. *Pediatrics* 1998, 102:137-140.
28. Newacheck PW, Strickland B, Shonkoff JP, et al: An epidemiologic profile of children with special health care needs. *Pediatrics* 1998, 102:117-123.
29. McConnochie KM, Roghmann KJ, Kitzman HJ, et al: Ensuring high-quality alternatives while ending pediatric inpatient care as we know it. *Arch Pediatr Adolesc Med* 1997, 151:341-349.
30. Nipshagen MD, Polderman KH, DeVictor D, et al: Pediatric intensive care: result of a European survey. *Intensive Care Med* 2002, 28:1797-1803.
31. Odetola FO, Clark SJ, Freed GL, et al: A national survey of pediatric critical care resources in the United States. *Pediatrics* 2005, 115:e382-386.

32. Norrenberg M, Vincent JL: A profile of European intensive care unit physiotherapists. European Society of Intensive Care Medicine. *Intensive Care Med* 2000, 26:988-994.
33. Nava S: Rehabilitation of patients admitted to a respiratory intensive care unit. *Arch Phys Med Rehabil* 1998, 79:849-854.
34. Nava S, Ambrosino N: Rehabilitation in the ICU: the European phoenix. *Intensive Care Med* 2000, 26:841-844.
35. Ferdinande P: Recommendations on minimal requirements for Intensive Care Departments. Members of the Task Force of the European Society of Intensive Care Medicine. *Intensive Care Med* 1997, 23:226-232.
36. Gutenbrunner C, Ward BA, Chamberlain M: White book on Physical and Rehabilitation Medicine in Europe. *J Rehabil Med* 2007:6-47.
37. American Speech-Language-Hearing Association: Role of speech-language-pathologists in swallowing and feeding disorders: Technical report. *ASHA Desk Reference* 2001, 3:181-199.
38. Robert D: Les troubles de la déglutition post intubation et trachéotomie. *Réanimation* 2004, 13:417.
39. American Speech-Language-Hearing Association: Role and responsibilities of Speech-Language pathologists in the Neonatal Intensive Care units: Guidelines. *ASHA Desk Reference* 2005, available online at <http://asha.org/members/deskref-journals/default>.
40. Adams AS, Soumerai SB, Lomas J, et al: Evidence of self-report bias in assessing adherence to guidelines. *Int J Qual Health Care* 1999, 11:187-192.

**Figure: Study flow chart**



\*: Feudtner et al. (5) – POPC: Pediatric Overall Performance Category (19).

**Table 1: Availability of the rehabilitation competencies in 23 centers**

| Rehabilitation subspecialty                | Centers where the expertise is available |                                   |                      |
|--|--|-----------------------------------|----------------------|
|  | Within-<br>NPICU/PICU staff<br>n (%)     | Within-hospital<br>staff<br>n (%) | Unavailable<br>n (%) |
| Physiotherapist <sup>(a)</sup>             | 11 (48%)                                 | 12 (52%)                          | 0 (0%)               |
| Speech-language pathologist <sup>(a)</sup> | 0 (0%)                                   | 10 (43%)                          | 13 (57%)             |
| Child educator <sup>(a)</sup>              | 1 (4%)                                   | 13 (57%)                          | 9 (39%)              |
| “Psychomotrician” <sup>(a)</sup>           | 2 (9%)                                   | 12 (52%)                          | 9 (39%)              |
| Psychologist                               | 11 (48%)                                 | 10 (43%)                          | 2 (9%)               |
| Social worker                              | 9 (39%)                                  | 10 (43%)                          | 4 (17%)              |

(a) See the definition in methods.

**Table 2: Characteristics of the 215 patients**

|   | Children with chronic conditions because hospitalized since birth (n=42) | Children hospitalized from home               |  |                           |
|---|--|---|--|---------------------------|
|   |  | with chronic conditions and disability (n=49) | with chronic conditions but no disability (n=53) | previously healthy (n=71) |
| <b>Demographics: median [range]</b>       |  |   |  |                           |
| Age at ICU admission (months)             | 1 [0 <sup>(a)</sup> -14]   | 33 [2-324]                                    | 10 [2-234]                                       | 41 [0.5-224]              |
| Age at day of survey (months)             | 5 [1-36]   | 34 [3-324]                                    | 10 [2-235]                                       | 42 [1.5-224]              |
| Length of stay in ICU (days)              | 110 [6-1263]   | 14 [1-766]                                    | 14 [1-1014]                                      | 8 [1-878]                 |
| <b>Severity scores: median [range]</b>    |  |   |  |                           |
| PRISM at ICU admission                    | NA <sup>(b)</sup>  | 11 [0-52]                                     | 6 [0-28]   | 7 [0-46]                  |
| PELOD at ICU admission                    | NA <sup>(b)</sup>  | 2 [0-60]                                      | 2 [0-30]   | 8 [0-42]                  |
| PELOD at day of survey                    | 1 [0-21]   | 1 [0-60]                                      | 0 [0-22]   | 1 [0-71]                  |
| POPC score before ICU admission           | NA <sup>(b)</sup>  | 4 [3-5]                                       | 1 [1-2]  | 1 [1-1]                   |
| <b>Main chronic organ failures: n (%)</b> |  |   |  |                           |
| Neurological and neuromuscular            | 5 (12) <sup>(c)</sup>  | 23 (47)                                       | 6 (11)   | NA                        |
| Cardiovascular                            | 3 (7) <sup>(c)</sup>   | 5 (10)  | 16 (30)  | NA                        |
| Respiratory                               | 22 (52) <sup>(c)</sup>   | 9 (18)  | 7 (13)   | NA                        |
| Renal                                     | 2 (5) <sup>(c)</sup>   | 0 (0)   | 3 (6)  | NA                        |
| Digestive                                 | 8 (19) <sup>(c)</sup>  | 3 (6)   | 8 (15)   | NA                        |
| Blood and immunological                   | 0 (0) <sup>(c)</sup>   | 2 (4)   | 6 (11)   | NA                        |
| Metabolic                                 | 2 (5) <sup>(c)</sup>   | 6 (12)  | 4 (8)  | NA                        |
| Cancer                                    | 0 (0) <sup>(c)</sup>   | 1 (2)   | 3 (6)  | NA                        |
| <b>Main acute organ failures: n (%)</b>   |  |   |  |                           |
| Respiratory                               | 29 (69)  | 25 (51)                                       | 21 (40)  | 27 (38)                   |
| Neurological                              | 3 (7)  | 7 (14)  | 10 (19)  | 25 (35)                   |
| Cardiovascular                            | 2 (5)  | 9 (18)  | 13 (25)  | 9 (13)                    |
| Digestive                                 | 6 (14)   | 2 (4)   | 6 (11)   | 7 (10)                    |
| Other                                     | 2 (5)  | 6 (12)  | 3 (6)  | 3 (4)                     |

NA: Not Applicable – PRISM: Pediatric Risk of Mortality (17) – POPC: Pediatric Overall Performance Category (19) – PELOD: Paediatric Logistic Organ dysfunction - (\*) p<0,001 for comparison between groups – (a) because of the presence of units that admitted both neonates and children - (b) because the score is not validated for prematures - (c) Failures justifying the NPICU/PICU remaining stay.

**Table 3: Main underlying chronic diagnoses of the 144 patients with chronic conditions**

| Children with chronic conditions because hospitalized since birth (n=42)  | Children admitted from home with previous chronic conditions and disability (n=49)   | Children admitted from home with previous chronic conditions but no disability (n= 53)  |
|---|--|---|
| <i>Sequellae of prematurity (n=15)</i><br>- 11 BPD<br>- 3 enterocolitis<br>- 1 post anoxic encephalopathy<br><br><i>Congenital diseases (n=21)</i><br>- 5 congenital cardiopathies<br>- 4 respiratory tract malformations<br>- 3 congenital encephalopathies<br>- 2 chromosomal abnormalities<br>- 2 Hirschprung diseases (1 Ondine syndrome)<br>- 2 malformations of the central nervous system<br>- 1 inherited metabolic diseases<br>- 1 renal malformation<br>- 1 diaphragmatic hernia<br><br><i>Not classifiable (n=6)</i> | <i>Congenital disease n=41</i><br>- 7 neuromuscular diseases<br>- 7 chromosomal abnormalities <sup>(a)</sup><br>- 6 congenital cardiopathies <sup>(b)</sup><br>- 4 digestive malformations<br>- 4 degenerative encephalopathies<br>- 3 inherited metabolic diseases;<br>- 3 malformations of the central nervous system<br>- 3 facial malformations<br>- 2 immuno/hematological deficiencies<br>- 8 miscellaneous<br><br><i>Acquired chronic diseases n=8</i><br>- 2 BPD<br>- 2 post anoxic encephalopathies<br>- 3 miscellaneous encephalopathies<br>- 1 cancer | <i>Congenital disease: n=34</i><br>- 13 congenital cardiopathies<br>- 6 immuno/hematological deficiencies<br>- 6 digestive malformations<br>- 2 inherited metabolic diseases<br>- 3 endocrine diseases<br>- 2 respiratory tract malformations<br>- 2 malformations of the central nervous system<br><br><i>Acquired chronic diseases: n=12</i><br>- 3 cancers<br>- 2 acquired cardiopathies<br>- 2 acquired encephalopathies<br>- 5 BPD<br><br><i>Not classifiable: n=7</i> |

BPD: bronchopulmonary dysplasia – (a) including 5 with congenital cardiopathy – (b) including 5 with chromosomal abnormality.

**Table 4: Supportive treatments and medical devices on the two days of the survey**

|   | Children with chronic conditions hospitalized since birth<br>(57 recorded ICU-days) | Children admitted from home   |   |  |
|---|---|---|---|--|
|   |   | with previous chronic conditions and disability<br>(50 recorded ICU-days) | with chronic conditions but no disability<br>(57 recorded ICU-days) | previously healthy<br>(72 recorded ICU-days) |
| <b>Supportive treatments provided at days of survey n (%)</b> |   |   |   |  |
| Mechanical ventilation  | 38 (67%)  | 39 (78%)  | 26 (46%)  | 33 (46%)                                     |
| Vasoactive drugs  | 2 (4%)  | 8 (16%)   | 10 (18%)  | 6 (8%)                                       |
| Parenteral feeding  | 21 (37%)  | 15 (30%)  | 14 (25%)  | 19 (26%)                                     |
| Enteral feeding   | 39 (68%)  | 30 (60%)  | 33 (58%)  | 30 (42%)                                     |
| Dialysis  | 2 (4%)  | 0 (0%)  | 1 (2%)  | 2 (3%)                                       |
| <b>Medical devices in place at days of survey n (%)</b>       |   |   |   |  |
| Tracheal tube   | 21 (37%)  | 28 (56%)  | 24 (42%)  | 29 (40%)                                     |
| Tracheostomy  | 20 (35%)  | 13 (26%)  | 2 (4%)  | 4 (6%)                                       |
| Transcutaneous central catheter                               | 12 (21%)  | 13 (26%)  | 26 (46%)  | 26 (36%)                                     |
| Tunneled catheter or implantable port                         | 15 (26%)  | 4 (8%)  | 9 (16%)   | 2 (3%)                                       |
| Gastrostomy or jejunostomy                                    | 22 (39%)  | 14 (28%)  | 5 (9%)  | 3 (4%)                                       |
| Arterial catheter   | 5 (9%)  | 10 (20%)  | 8 (14%)   | 13 (18%)                                     |
| Intracranial pressure measurement                             | 0 (0%)  | 0 (0%)  | 1 (2%)  | 4 (6%)                                       |
| Bladder catheter  | 9 (16%)   | 14 (28%)  | 14 (25%)  | 22 (31%)                                     |



**Table 5: Details of rehabilitation perceived needs and provided services**

|   | Children with chronic conditions hospitalized since birth (57 recorded ICU-days) | Children admitted from home   |  |   |
|---|--|---|--|---|
|   |  | with previous chronic disease and disability (50 recorded ICU-days) | with previous chronic disease but no disability (57 recorded ICU-days) | previously healthy (72 recorded ICU-days) |
| <i>Provided services / perceived needs <sup>(b)</sup></i>   |  |   |  |   |
| Respiratory physical therapy <sup>(a)</sup>                 | 140/146  | 127/135   | 140/152  | 145/152                                   |
| Musculoskeletal physical therapy <sup>(a)</sup>             | 21/42  | 19/27   | 14/18  | 17/25                                     |
| Neurological physical therapy <sup>(a)</sup>                | 27/62  | 6/13  | 3/9  | 1/7                                       |
| Rehabilitation for speech-language disorders <sup>(a)</sup> | 1/11   | 0/2   | 0/0  | 0/0                                       |
| Rehabilitation for swallowing disorders <sup>(a)</sup>      | 11/37  | 0/3   | 0/2  | 0/6                                       |
| Total   | 200/298  | 152/180   | 157/181  | 163/190                                   |

(a): See the definition in methods – (b) The attending intensivist was asked to indicate both what he would have prescribed if all competencies had been available in his unit (“perceived needs”) and what rehabilitation services were effectively provided at the days of survey (“provided services”).

