

Three decades of pediatric intensive care: Who was admitted, what happened in intensive care, and what happened afterward*

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Objective: To describe the characteristics of children admitted to intensive care in 1982, 1995, and 2005–2006, and their long-term outcome.

Setting: Pediatric intensive care unit in a university-affiliated children's hospital.

Design/Methods: Information for 2005–2006 admissions was obtained from pediatric intensive care unit database, and long-term outcome was ascertained through telephone interviews. Results were compared to previous cohorts from 1982 and 1995.

Results: A total of 4010 children were admitted on 5250 occasions. Readmissions increased from 11% for 1982 to 31% in 2005 to 2006 ($p < .001$). In 2005–2006, fewer children were admitted after accidents ($p < .001$), or with croup ($p < .001$), or epiglottitis ($p = .01$), and 8% were treated with noninvasive ventilation compared to none in 1982 ($p < .0001$). Among children aged ≥ 1 month, pediatric intensive care unit length of stay remained constant. The risk of death predicted by the Pediatric Index of Mortality (PIM) remained constant (approximately 6%) between 1995 and 2005–2006. The proportion that died in the pediatric intensive care unit fell from 11.0% in 1982 to 4.8% in

2005–2006 ($p < .001$). Among children aged ≥ 1 month, proportion admitted with a preexisting moderate or severe disability was similar: 12.0% in 1982 and 14.6% in 2005–2006 ($p = .11$), but the proportion with a moderate or severe disability at follow-up increased from 8.4% in 1982 to 17.9% in 2005–2006 ($p < .001$). The proportion of children aged ≥ 1 month who either died in the pediatric intensive care unit or survived with disability did not improve: it was 19.4% in 1982 and 22.7% in 2005–2006.

Conclusion: Over the last three decades, the length of stay in the pediatric intensive care unit and the severity of illness have not changed, but there has been a substantial reduction in pediatric intensive care unit mortality. However, the proportion of survivors with moderate or severe disability increased significantly. Some children who would have been allowed to die in 1982 and 1995 were kept alive in 2005–2006, but survived with disability. This trend has important implications for our patients and their families, and for the community as a whole. (*Pediatr Crit Care Med* 2010; 11:549–555)

KEY WORDS: children; pediatric intensive care; epidemiology; outcome; quality of life

Pediatric intensive care has changed greatly over the last 25 yrs. Intensive care is now offered to some children with complex and chronic diseases who would not have been admitted in the past (1–3), and some critically ill children who would previously have died survive because of improvements in in-

tensive care. These changes have resulted from different attitudes to disability, better understanding of critical illness, specialized training in pediatric intensive care, centralization of pediatric intensive care services, advances in pediatric cardiac surgery, improved perioperative care, and new treatment modalities (1–6).

Pediatric intensive care should not only attempt to save the lives of critically ill children, but should also strive to maximize the quality of those lives. Measures of the effectiveness of pediatric intensive care should, therefore, include physical and psychological sequelae, as well as the quality of life in survivors and their families (7–10). A full evaluation of long-term outcomes is fundamental to the evaluation of the effectiveness of intensive care, in resource allocation, and in planning the long-term care of patients after discharge from the intensive care unit (ICU) (10–12). There have been eight

studies of cohorts of consecutive admissions to ICUs of at least 150 children who were followed up for ≥ 6 months: three from Australia (7, 12, 13), and one each from the Netherlands (14), India (15), United Kingdom (16), Switzerland (17), and Sweden (18).

The analysis of trends in pediatric ICU (PICU) populations requires accurate data collection, trained research assistants, standardization of definitions and methods, and the use of a clinical database. At the Royal Children's Hospital (RCH) in Melbourne, we have had the benefit of such a system for nearly three decades. We previously reported the characteristics and outcomes of children admitted to our PICU in 1982 and 1995 (12, 13). The purpose of the current study is to examine 1) the characteristics of children admitted to the PICU in 2005 and 2006 with a focus on preexisting disease burden, survival, functional outcome, and quality of life; and 2) trends in the characteristics and

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long-term outcomes of children admitted to the PICU in 1982, 1995, and 2005–2006.

METHODS

Information for this review was obtained from the clinical database maintained prospectively in the RCH PICU over the past 27 yrs. Demographic information about children admitted to the PICU is entered into the database by research nurses who have been trained in data collection and data entry. The database contains information about all admissions, with diagnoses coded according to the guidelines published by the Australian and New Zealand Pediatric Intensive Care Registry (19). In this study, we used only the single diagnosis coded as the main reason for each child's admission to the ICU. The database also includes patient demographics, length of stay, preadmission health status, therapeutic intervention, clinical classification score, and outcome (in PICU and long term).

The RCH PICU is an 18-bed, multidisciplinary unit with a catchment population of approximately 5.2 million children and adults. The unit admits critically ill children from the states of Victoria, Tasmania, and southern New South Wales. RCH is the Australian national center for heart transplantation, and is the Victorian center for pediatric trauma, cardiac surgery, bone marrow transplantation, and liver transplantation. The RCH PICU also runs the service for the transport of critically ill children in Victoria and provides pediatric extracorporeal life support for Victoria, and for many children from other states.

All children admitted in the 24-month period from January 1, 2005 to December 31, 2006 (abbreviated to 2005–2006) were included in the study. Information collected from this cohort is compared with two cohorts of children admitted to the same PICU in the 12 months from July 1, 1982 to June 30, 1983 (abbreviated to 1982) (13), and the 12 months from January 1, 1995 to December 31, 1995 (abbreviated to 1995) (12). After 1982, a separate neonatal ICU was established at the hospital; consequently, neonates admitted in 1982 had a wide variety of diseases, and neonates admitted in 1995 and 2005–2006 had mainly congenital heart disease.

The Pediatric Index of Mortality (PIM) model was developed at RCH Melbourne (20) and has been collected for every child admitted since January 1996. A revised PIM2 model was published in 2003 (21). Providing the data are accurate, PIM provides a reliable guide to the risk of mortality and severity of illness at the time of admission to the PICU. As another measure of the severity of illness, children were grouped according to the type of therapeutic intervention required: not intubated, intubated but not ventilated, ventilated but

not intubated, intubated and ventilated but no inotrope, and intubated and ventilated with inotrope.

The preadmission health status (before the onset of the illness leading to ICU admission) and the long-term functional outcome were assessed by specially trained research assistants, who used a standardized questionnaire to obtain a modified Glasgow Outcome Score (MGOS) (13). Categories for the MGOS were defined as normal or functionally normal (both intellectually and physically); mildly disabled but likely to lead an independent existence; moderately disabled and dependent on care; severely disabled and totally dependent on care (including children in a persistent vegetative state); and death. Children who survived as normal or with a mild disability were considered to have a favorable outcome. Each child had one follow-up outcome evaluation, in which the child's parent or guardian was interviewed on the telephone by a member of the database team. Children who had reached adulthood at the time of the outcome assessment and were living independently were interviewed directly. Infants <1 month of age at the time of admission to the PICU were not included in the MGOS assessment.

Quality of life was evaluated, using the Health Status Utility index (22). The index has four categories, each representing different levels of functioning with respect to physical function (mobility and physical activity), role function (self-care and role activity), social and emotional function (social and emotional activity), and health problems. All levels within each category are assigned a numerical value, from which an overall health state utility value (HSUV) is calculated. All values are between 1.00 and –0.21, where 1.00 is healthy, 0.00 is dead, and negative values reflect a very severe disability, which is scored as a state worse than death. Four outcome categories were assigned: good (HSUV, 1.00–0.70), moderate (HSUV, 0.69–0.30), poor (HSUV, 0.29–0.01), and very poor (HSUV, <0.00). Children <2 yrs of age at the time of follow-up were not assigned an HSUV score.

Data analysis and descriptive statistics were performed with Stata version 10 (Stata-Corp LP, College Station, TX); the `comproc` command was used for receiver operating characteristic analysis, and Fisher's exact test was used to compare proportions. StatXact version 4 was used to perform the Cochran-Armitage trend test. The human research ethics committee at RCH confirmed that this review has been carried out according to the principles governing human research.

RESULTS

Patient characteristics are presented in Table 1. During the three study periods, 4010 critically ill children were ad-

mitted to the PICU on 5250 occasions. The median time of follow-up was 2.7 yrs (range, 2.5–3.0 yrs) in 1982, 3.5 yrs (2.5–6.0 yrs) in 1995, and 1.1 yrs (0.5–2.9 yrs) in 2005–2006. Children needing more than one admission to the ICU during a study period were classed as having been readmitted (Table 1); in 2005–2006, the number of readmissions within 48 hrs of discharge from PICU was 101 (19.4%) of 520 admissions among children with a preexisting moderate or severe disability, and 194 (8.2%) of 2368 admissions among children who were normal or had a mild disability ($p < .0001$). Of the 98 children who stayed in the PICU for ≥ 21 days in 2005–2006 (Table 1), 61 were aged ≥ 1 month, and 17 (28%) had a preexisting moderate or severe disability; the long-term outcome was known in 33 of the 61 children: nine (27%) had a moderate or severe disability, and 17 (52%) died. The number of children admitted with epiglottitis was 53 in 1982, five in 1995, and one in 2005–2006 ($p < .01$). The number of children admitted with croup was 46 (220 PICU days) in 1982, 36 (43 days) in 1995, and 73 (119 days) in 2005–2006 (a 24-month period) ($p < .001$).

In 1982, many low-birth weight neonates were admitted to the PICU; these infants have a long length of stay in the ICU and a high mortality rate. Information about length of stay, mortality, and long-term outcome is therefore presented separately for children aged ≥ 1 month at the time of admission. Of the 338 infants <1 month of age admitted in 2005–2006, 272 (80%) had congenital heart disease and 53 (16%) had bronchiolitis.

In 2005–2006, 58% of patients were lost to follow-up. To determine whether these children were representative, we compared the proportion of survivors with and without follow-up according to five important variables (Table 2). The preexisting health status and the admission diagnostic categories were similar in both groups, and there were no significant differences in the rates of intubation, respiratory support, or inotrope therapy ($p > .1$ for all comparisons). We, therefore, consider that the follow-up patients were sufficiently representative of the ICU population as a whole to be used in the subsequent analysis and discussion.

Table 3 shows the relationship between the admission diagnostic category and the preexisting health status and long-term follow-up health status among children admitted in 2005–2006. The 69

Table 1. Admissions to intensive care in 1982, 1995, and 2005–2006

	1982	1995	2005–06
Children, all ages, by diagnosis	974 in 12 mos	1032 in 12 mos	2004 in 24 mos
Cardiovascular	354 (36%)	454 (44%)	813 (41%)
Respiratory	197 (20%)	198 (19%)	547 (27%)
Other medical	56 (6%)	128 (12%)	195 (10%)
Neurological	58 (6%)	75 (7%)	165 (8%)
Accident/trauma	127 (13%)	135 (13%)	146 (7%)
Postoperative, noncardiac	35 (4%)	42 (4%)	138 (7%)
Neonates, medical	147 (15%)	0 (0%)	0 (0%)
Children, all ages, by intervention	n = 974	n = 868, 164 missing	n = 2004 (1002/yr)
Not intubated, not ventilated	248 (25%)	229 (26%)	509 (25%)
Intubated, not ventilated	111 (11%)	21 (2%)	11 (1%)
Not intubated, ventilated	0 (0%)	1 (0%)	167 (8%)
Ventilated, no inotrope	334 (34%)	271 (31%)	601 (30%)
Ventilated, with inotrope	283 (29%)	346 (40%)	716 (36%)
Children, all ages	n = 974	n = 1032	n = 2004 (1002/yr)
Median age (range), mo	14 (0–213)	19 (0–352)	22 (0–596)
Prior moderate-severe disability	Not recorded	Not recorded	250/1918 (13%)
Long-term follow-up, with deaths	974 (100%)	868 (84%)	855 (43%)
Follow-up median (range), yr	2.7 (2.5–3.0)	3.5 (2.5–6.0)	1.1 (0.5–2.9)
In ICU ≥21 days: n, days	20 (2%), 993 (24%)	18 (2%), 787 (23%)	98 (5%), 4670 (43%)
Died during 1st PICU admission	139 (14.3%)	69 (6.7%)	70 (3.5%)
All deaths in PICU	148 (15.2%)	80 (7.8%)	103 (5.1%)
All deaths	199 (20.4%)	141 (13.7%–16.2%) ^a	121 (6.0%–14.2%) ^a
Children, aged ≥1 mo	n = 700	n = 882	n = 1733 (867/yr)
Median age (range), mo	34 (1–213)	31 (1–352)	36 (1–596)
Prior moderate-severe disability	84 of 700 (12.0%)	102 of 732 (13.9%)	248 of 1702 (14.6%)
Follow-up moderate-severe disability	59 of 700 (8.4%)	68 of 732 (9.3%)	128 of 717 (17.9%)
Long-term follow-up, with deaths	700 (100%)	732 (83%)	717 (41%)
Died during 1st PICU admission	70 (10.0%)	51 (5.8%)	55 (3.2%)
All deaths in PICU	77 (11.0%)	61 (6.9%)	84 (4.8%)
All deaths	100 (14.3%)	106 (12.0%–14.5%) ^a	94 (5.4%–13.1%) ^a
Admissions	n = 1097	n = 1265	n = 2888 (1444/yr)
Readmission, all ages	121 (11%)	233 (18%)	884 (31%)
Readmission within 48 hr, all ages	20 (1.8%)	45 (3.6%)	295 (10.2%)
Median stay in days (range), all ages	2.9 (0–142)	1.1 (0–150)	1.3 (0–228)
Total PICU patient days, all ages	4127 (mean, 3.8)	3470 (mean, 2.7)	5399/yr (mean, 3.7)
Median stay in days, age ≥1 mo	1.0 (0–92)	1.0 (0–150)	1.1 (0–228)
Total PICU days, age ≥1 mo	2499 (mean, 3.2)	2719 (mean, 2.5)	4201/yr (mean, 3.3)

ICU, intensive care unit; PICU, pediatric intensive care unit.

^aRange: the lower limit assumes that no child died after being lost to follow-up (121 of 2004 = 6.0% for 2005–2006, all ages); the upper limit excludes children who were lost to follow-up (121 of 855 = 14.2%).

children admitted with neurologic disease had poor outcomes: 19% had a pre-existing moderate or severe disability (compared with 13% of the other 759 children), and 48% died or had a moderate or severe disability at follow-up (compared with 29% of the other 759 children). Table 4 shows the relationship between the health status before admis-

sion to the PICU and the long-term health status after discharge from the PICU among children aged ≥1 month at the time of admission to the PICU in 1982, 1995, and 2005–2006. Table 5 shows the risk of death as predicted by PIM1 at the time of admission to the PICU in 1996, and by PIM1 and PIM2 in 2005–2006 (20, 21). Table 6 compares the

mortality among neonatal medical admissions (most of whom were low-birth weight babies) to the mortality among other infants <1 month of age (most of whom had congenital heart disease); in children aged ≥1 month at the time of admission to the PICU, the mortality rate among children who were previously normal or had a mild disability is compared to the mortality rate among children who previously had a moderate or severe disability.

The quality of life in patients aged ≥2 yrs at the time of the follow-up telephone call was good (HSUV, 1.00–0.70) in 608 (84%) of 727 surviving children in 1995, and in 262 (66%) of 400 surviving children in 2005–2006 ($p < .0001$). This information was not available for the 1982 cohort.

DISCUSSION

Who Was Admitted to Intensive Care

A total of 4010 children were admitted on 5250 occasions during the three time periods (Table 1). The proportion of children aged ≥1 month who had a preexisting moderate or severe disability was 12.0% in 1982 and 14.6% in 2005–2006; this 21% increase was not statistically significant ($p = .11$). When the medical neonates admitted in 1982 were excluded, there was little change in the age of the children admitted: The median age of children aged ≥1 month was between 31 months and 36 months in 1982, 1995, and 2005–2006.

There was a decrease in the proportion of children admitted after accidents from 13% in 1982 to 7% in 2005–2006 ($p < .001$), due largely to a reduction in motor vehicle accidents because of improved compulsory child restraints, strict enforcement of speeding, and drunk-driving laws, and an aggressive road-safety advertising campaign (23). There was also a reduction in the number of children admitted with epiglottitis from 53 in 1982 to 1 in 2005–2006 because of *Haemophilus influenzae* type b immunization. In 1992, we published a randomized trial showing that corticosteroids reduced the severity of croup among children in intensive care (24). In 1982, before the paper was published, children with croup spent 220 days in the PICU. Subsequently, steroids were given to all children presenting to our hospital

Table 2. Children of all ages admitted to intensive care in 2005–2006 who survived: Children who were lost to follow-up compared with children who were followed up

	Lost to Follow-Up	Followed Up
Preexisting health status	n = 1090	n = 710
Normal	744 (68%)	486 (68%)
Mild disability	210 (19%)	130 (18%)
Moderate disability	81 (7%)	57 (8%)
Severe disability	55 (5%)	37 (5%)
Diagnostic category	n = 1149	n = 734
Cardiovascular	441 (38%)	315 (43%)
Respiratory	324 (28%)	194 (26%)
Other medical	117 (10%)	66 (9%)
Neurological	95 (8%)	58 (8%)
Accident/trauma	87 (8%)	54 (7%)
Postoperative (noncardiac)	85 (7%)	47 (6%)
Endotracheal intubation	731 of 1149 (64%)	494 of 734 (67%)
Respiratory support	824 of 1149 (72%)	552 of 734 (75%)
Inotropic agents	403 of 1149 (35%)	287 of 734 (39%)

Table 3. Relationship between diagnostic category, preexisting health status, and long-term follow-up health status in children of any age admitted to intensive care in 2005 and 2006

Diagnostic Category	Health Status				Death ^a
	Normal	Mild Disability	Moderate Disability	Severe Disability	
Cardiovascular, n = 349 (42%)					
Preexisting health status	223 (76%)	96 (32%)	27 (9%)	3 (1%)	—
Follow-up health status	203 (69%)	54 (19%)	35 (12%)	3 (1%)	54 (18%)
Respiratory, n = 221 (27%)					
Preexisting health status	153 (69%)	22 (10%)	19 (9%)	27 (12%)	—
Follow-up health status	134 (61%)	17 (8%)	23 (11%)	18 (8%)	29 (13%)
Other medical, n = 78 (9%)					
Preexisting health status	61 (78%)	9 (12%)	4 (5%)	4 (5%)	—
Follow-up health status	41 (53%)	14 (18%)	6 (8%)	5 (6%)	12 (15%)
Neurological, n = 69 (8%)					
Preexisting health status	48 (70%)	8 (12%)	6 (9%)	7 (10%)	—
Follow-up health status	25 (36%)	11 (16%)	9 (13%)	12 (17%)	12 (17%)
Accident/trauma, n = 58 (7%)					
Preexisting health status	56 (97%)	1 (2%)	0 (0%)	1 (2%)	—
Follow-up health status	38 (66%)	9 (16%)	5 (9%)	1 (2%)	5 (9%)
Postop noncardiac, n = 53 (6%)					
Preexisting health status	27 (50%)	11 (20%)	6 (11%)	10 (19%)	—
Follow-up health status	20 (39%)	11 (20%)	6 (11%)	10 (19%)	6 (11%)
Total, n = 828 (100%)					
Preexisting health status	567 (68%)	147 (18%)	62 (7%)	52 (6%)	—
Follow-up health status	461 (56%)	116 (14%)	84 (10%)	49 (6%)	118 (14%)

^aThe mortality rate is expressed as a percentage of the number of children with a known outcome (died or follow-up health status known).

with severe croup, and children with croup spent only 36 days in the PICU in 1995, and 59 days per year in 2005–2006.

What Happened in Intensive Care

If the low-birth weight babies admitted in 1982 are excluded by considering only children aged ≥ 1 month at the time of admission, the median and mean length of stay in the PICU did not change

between 1982 and 2006 (Table 1). Because of the reduction in the number of admissions for epiglottitis and croup, the proportion of children who were intubated but not ventilated reduced from 11% in 1982 to 1% in 2005–2006 (Table 1); on the other hand, there was an increase in the use of noninvasive ventilation from 0% of children in 1982 and 1995 to 8% in 2005–2006 ($p < .001$). After allowing for these changes, there was little variation in the proportion of children who were not intubated and not

ventilated (25%), in the proportion of children who were intubated and ventilated (approximately 65%), or the proportion given inotropic drugs (approximately 35%). An increasing proportion of the deaths that occur in children's hospitals is taking place in the PICU (25), and palliative care is becoming an increasingly important part of pediatric intensive care practice (26); the mortality rate in our PICU is discussed below.

What Happened After Intensive Care

The proportion of readmissions within 48 hrs of discharge from the PICU increased from 1.8% in 1982 to 10.2% in 2005–2006 (Table 1). Among children with a preexisting moderate or severe disability in 2005–2006, the early readmission rate was 19.4%, which is very high; but even among children who were normal or had a mild disability, the rate was 8.2%. The rate of readmission within 48 hrs in adult ICUs has been reported to be 0.89%, 1.96%, and 3.3% (27–29), and it was 2.7% among 6661 children in intensive care in Sweden (18). So, the rate of 10.2% in Melbourne in 2005–2006 suggests that the very high demand for access to the PICU may have led to some children being discharged prematurely.

In 1982 and 1995, a high proportion of children were followed up, and they were under surveillance for approximately 3 years. However, in 2005–2006, 58% of children were lost to follow-up, and the median duration of surveillance was only 1.1 yrs. In 2005–2006, 121 children are known to have died; the true mortality rate is likely to be somewhere between 6.0% (121 of 2004) if no child died among those lost to follow-up, and 14.2% (121 of 855) if we exclude children lost to follow-up. The estimate of 14.2% is probably too high, because most deaths occur early before the child is lost to follow-up; but 6.0% will be too low because some children lost to follow-up are likely to have died, and other children would be expected to die between 1.1 yrs and 3 yrs after discharge from the PICU (17, 18). Table 1 includes the upper and lower estimates for overall mortality.

Although the higher loss to follow-up and the shorter duration of surveillance make it hard to compare long-term mortality in 2005–2006 with the earlier years, it is valid to compare mortality in the PICU. This fell substantially from 11.0% of 700 children aged ≥ 1 month at the

Table 4. Relationship between preexisting health status and long-term follow-up status in children aged ≥ 1 mo at the time of admission to intensive care

Preexisting Health Status	Long-Term Follow-Up Health Status				Death
	Normal	Mild Disability	Moderate Disability	Severe Disability	
Normal					
1982 (n = 553, 79%)	451 (82%)	43 (8%)	0 (0%)	8 (1%)	51 (9%)
1995 (n = 402, 55%)	294 (73%)	53 (13%)	9 (2%)	6 (1%)	40 (10%)
2005–2006 (n = 458, 64%)	318 (69%)	61 (13%)	17 (4%)	5 (1%)	57 (12%)
Mild disability					
1982 (n = 63, 9%)	4 (6%)	42 (67%)	0 (0%)	2 (3%)	15 (24%)
1995 (n = 228, 31%)	124 (54%)	56 (25%)	10 (4%)	2 (1%)	36 (16%)
2005–2006 (n = 140, 19%)	58 (41%)	42 (30%)	20 (14%)	3 (2%)	17 (12%)
Moderate disability					
1982 (n = 43, 6%)	0 (0%)	1 (2%)	23 (53%)	1 (2%)	18 (42%)
1995 (n = 78, 11%)	19 (24%)	10 (13%)	27 (35%)	3 (4%)	19 (24%)
2005–2006 (n = 62, 9%)	8 (13%)	1 (2%)	40 (65%)	8 (13%)	5 (8%)
Severe disability					
1982 (n = 41, 6%)	0 (0%)	0 (0%)	0 (0%)	25 (61%)	16 (39%)
1995 (n = 24, 3%)	1 (4%)	1 (4%)	0 (0%)	11 (46%)	11 (46%)
2005–2006 (n = 52, 7%)	3 (6%)	0 (0%)	1 (2%)	33 (63%)	15 (29%)
Total					
1982 (n = 700, 100%)	455 (65%)	86 (12%)	23 (3%)	36 (5%)	100 (14%)
1995 (n = 732, 100%)	438 (60%)	120 (16%)	46 (6%)	22 (3%)	106 (14%)
2005–2006 (n = 712, 100%)	387 (54%)	104 (15%)	78 (11%)	49 (7%)	94 (13%)

Table 5. Risk of death as predicted by the Pediatric Index of Mortality at the time of admission to the pediatric intensive care unit in 1996 and 2005–2006 (20, 21)

	Number of Admissions	Observed Deaths in ICU	Expected deaths in ICU	Standardized Mortality Rate
Jan. 1–Dec. 31, 1996, PIM1			PIM1	
All ages	1287	66 (5.1%)	84.99 (6.6%)	0.78 (0.60–0.95)
Age ≥ 1 mo	1161	54 (4.7%)	67.56 (5.8%)	0.80 (0.60–1.00)
2005–2006, PIM1			PIM1	
All ages	2888	103 (3.6%)	177.18 (6.1%)	0.58 (0.48–0.70)
Age ≥ 1 mo	2550	84 (3.3%)	143.15 (5.6%)	0.59 (0.47–0.72)
2005–2006, PIM2			PIM2	
All ages	2888	103 (3.6%)	149.41 (5.2%)	0.69 (0.57–0.83)
Age ≥ 1 mo	2550	84 (3.3%)	120.84 (4.7%)	0.70 (0.56–0.86)

ICU, intensive care unit; PIM, Pediatric Index of Mortality.

Table 6. Mortality in intensive care during any admission by age and preexisting health status: died/total (%)

	1982	1995	2005–06
Age <1 mo			
Neonatal medical admissions	31 of 147 (21%)	0	0
Other neonates (mainly cardiac) ^a	40 of 127 (31%)	19 of 150 (13%)	24 of 271 (8.9%)
Age ≥ 1 mo			
Previously normal, or had mild disability ^a	51 of 616 (8.3%)	44 of 630 (7.0%)	66 of 1454 (4.5%)
Previous moderate or severe disability ^a	26 of 84 (31%)	17 of 102 (17%)	13 of 247 (5.3%)

^aCochran-Armitage trend test, $p < .001$.

time of admission in 1982, to 6.9% of 882 in 1995, and to 4.8% of 1733 in 2005–2006 ($p < .001$). The reduction in mortality in 2005–2006 is partly explained by improvements in management, especially in infants with congenital heart disease (Table 6). However, the lower mortality in the 2005–2006 cohort was achieved at

the expense of a large increase in the number of children with moderate or severe long-term disability, particularly in the noncardiac population. Some of these patients would have been considered untreatable, and others would have been allowed to die while in intensive care in 1982 and 1995 (Table 6). Thus, a sub-

stantial proportion of the reduction in mortality is explained by different choices being made about when it is appropriate to offer or continue treatment. As a result, the proportion of children with a moderate or severe disability at long-term follow-up increased from 8.4% of 700 children in 1982 to 17.9% of 717 in 2005–2006, an increase of 112% ($p < .0001$). Although a preexisting disability increases the risk of a poor outcome (7, 12–15), the very large increase in long-term moderate or severe disability cannot be attributed entirely to the smaller and nonsignificant 21% increase in the proportion of children admitted with a preexisting moderate or severe disability.

Assuming that the prevalence of disability was similar among children followed up and those lost to follow-up, the proportion of children who either died in the PICU or survived with a long-term moderate or severe disability increased by 17% from 19.4% in 1982 to 22.7% in 2005–2006 (Table 1). This is similar to the 21% increase from 1982 to 2005–2006 in the proportion of children admitted with a moderate-to-severe disability, but neither trend is statistically significant.

The quality of life in children aged ≥ 2 yrs who were alive at the time of the follow-up telephone call was good (HSUV, 1.00–0.70) in 84% of 727 children in 1995, but in only 68% of 375 children in 2005–2006 ($p < .0001$). This information is not available for the 1982 cohort.

In 2005–2006, 98 (4.9%) of the 2004 children stayed in the PICU for ≥ 21 days (Table 1). Their admissions accounted for 43% of the total PICU bed days for 2005–2006. Forty-four of the 98 were lost to follow-up, 27 died, 11 had moderate or severe long-term disabilities, and only 16 were known to be normal or to have a mild disability. The high cost and poor outcomes in children who endure weeks or months of intensive treatment are of great concern (2, 30–32).

Limitations of This Study

There are several limitations to our study. First, follow-up information was available for only 43% of the 2005–2006 cohort, which is lower than for 1982 (100%) and 1995 (84%), and the follow-up was for a median of only 1.1 yrs, compared to approximately 3 yrs in 1982 and 1995. However, Table 2 suggests that the children in the follow-up sample were

representative of the group as a whole in the distribution of preexisting health status, diagnostic category, and requirements for endotracheal intubation, respiratory support, and inotropic support. The higher loss to follow-up and the shorter duration of follow-up mean that, although comparisons of mortality in the PICU are still valid, it is difficult to compare the long-term mortality rates in 1982, 1995, and 2005–2006.

Second, it may be thought undesirable that the MGOS was used to assess outcome in young infants and older adolescents, and that the assessment was made based on a verbal report from caregivers. The Glasgow Outcome Score is a global assessment of independent living and social integration (33). Its advantages are wide recognition, clinical relevance (34), and a high interrater reliability when assessed by experienced staff over the telephone (35). The MGOS is a practical and cost-effective method of obtaining information about health status without the need for additional professionals with specific skills in the application and analysis of more complex evaluation tools.

Third, the timing of the outcome assessment varied between children, and between 1982, 1995, and 2005–2006. A difference in the delay between PICU discharge and outcome evaluation could result in differences in the outcome measured, particularly in the minority of patients who need extensive rehabilitation after hospital discharge. The outcome status shortly after discharge is more likely to reflect both disease progression and the process of care received; and quality of life often improves over time because of an improvement in health as well as the greater experience of caregivers (7, 11, 17). The information required for the MGOS can only be obtained from a long interview lasting up to 2 hrs, and the process is dependent on the availability of the caregiver. Many of the calls were the result of multiple attempts to make contact; hence, the wide variation in time between discharge and the outcome call.

CONCLUSION

The reduction in mortality in our PICU between 1982 and 2005–2006 was achieved at the expense of a large increase in the number of children who survived with a moderate or severe long-term disability. This important finding is only available because we obtained infor-

mation about our patients' long-term health status. As well as providing essential clinical data, this information improves our understanding of the effectiveness of different medical interventions, and assists in the development of standards to guide the optimal use of resources (36).

The increasing number of survivors from pediatric intensive care who have a moderate or severe long-term disability has major emotional, practical, and financial implications for the individual and the family, and has important resource implications for the whole community.

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