Quality of life of survivors of paediatric intensive care

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Summary

Objective: The mortality rate in paediatric intensive care units (PICU) has fallen over the last two decades. More advanced treatment is offered to children with life-threatening disease and there is substantial interest in knowing whether long term outcome and quality of life after intensive care are acceptable.

Setting: 12-bed paediatric and neonatal intensive care unit

Intervention: Prospective follow-up study with telephone interview 1 and 2 years after discharge.

Methods: Four domains of quality of life (physical function, role function, social-emotional function and health problem) were recorded by calculating the health state classification (HSC) index. Outcome was classified good (HSC 1.0–0.7), moderate (HSC 0.69–0.3), poor (HSC 0.29–0) and very poor (HSC <0).

Results: 661 patients were admitted to the PICU in the year 2001 with a mortality within the unit of 3.9%. Over 2 years follow-up there were 21 additional deaths (3.2%). 574 patients could be followed up after 1 year and 464 patients after 2 years. After two years the outcome was good in 77%, moderate in 15% and poor in 8%. Patients with respiratory disease had the best outcome, similar to those admitted for neurological and medical reasons. Patients admitted for postoperative care and for cardiovascular disease had a poorer quality of life. 31% of the children had preexisting health care problems and 21% of all patients had new chronic disease after intensive care.

Conclusion: The majority of survivors admitted to the PICU have a good outcome. The overall mortality rate doubled if assessed two years after discharge.

Key words: paediatric index of mortality; functional outcome; intensive care unit; quality of life

Introduction

Paediatric intensive care as a moderately young medical discipline has considerably improved over the last two decades, with mortality rates reported at 20% in the 1980s and 5.3% by 1998 [1, 2].

Unlike in adult medical care, where 50% of a hospital budget is spent on the last 6 weeks of life, many children surviving intensive care should have the prospect of a full life with good quality. Assessment of quality of life after paediatric intensive care is important but has been the subject of few studies in the past. Most of these studies were confined to selected patient groups such as after car-diac arrest or head trauma [3–5]. Of the previous studies examining long term quality of life in children admitted to intensive care, two were performed in Australia and one in the Netherlands [6–8]. None of these studies, however, used two sequential interviews of parents or guardians to determine possible change in quality of life over time. The purpose of this study was (i) to evaluate long-term outcome of paediatric intensive care, (ii) to determine whether quality of life changes over time, (iii) to measure post intensive care mortality, and (iv) to quantify utilisation of health care resources before and after intensive care.

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Methods

All children and infants admitted to the mixed neonatal and paediatric intensive care unit of the University Children's Hospital, Bern, Switzerland in the year 2001 were eligible for the study, except premature infants of less than 38 week postconceptional age. The study location is a tertiary referral paediatric intensive care unit (PICU), which cares for all paediatric patients from 0 to 16 years of age in a population of approximately 1.5 million. New-

born babies requiring intensive care are referred from maternity hospitals of the region. The PICU has 12 beds and is staffed by four full time paediatric intensivists and residents providing 24-hour medical cover. Data on hospital admission, intensive care, paediatric mortality scores and data of short and long term outcome were prospectively collected. Institutional ethics committee clearance for data collection and telephone interview was obtained and parents/guardians were approached during intensive care admission for written informed consent.

Intensive care data

Demographic data were collected on all children including parameters such as age, gender and length of stay (LOS). Clinical data were collected such as intubation rate, length of intubation (LOI) and main diagnosis on admission using 6 different groups: respiratory, cardiovascular (excluding cardiac surgery), postoperative (including cardiac surgery), neurology, accident (including head trauma) and medical. Further, we assessed risk of mortality using the paediatric index for mortality (PIM) obtained within the first hour of PICU admission [9].

Short and long term outcome assessment

For short term outcome the mortality rate during intensive care stay was obtained. Mortality post intensive care was obtained at 12 and 24 months. A standardised questionnaire [6, 10] and outcome status was evaluated 12 and 24 months after intensive care by two members of the study group (JA, AK). Data were obtained via a structured telephone interview with parents or guardians. Searches in the hospital database and in the online phone book were conducted to achieve higher response rates. Paediatricians and general practitioners were contacted to retrieve contact details of families who moved.

Quality of life was assessed using the health state classification system. This has been validated in a survey research project and has been previously used for outcome assessment in paediatric intensive care [6, 10, 11]. Health state is defined on the basis of a classification (HSC) covering four health state domains including physical function (mobility and physical activity), role function (self-care and role activity), social-emotional function (emotional wellbeing and social activity) and health problem. Physical function is attributed to 6 levels, role function to 5 levels, social-emotional function to 4 levels and health problem to 8 levels. Each level is assigned a numerical value. Health state (U) for individual patients was obtained using the formula

$$U = 1.42 \, (m_1 \, m_2 \, m_3 \, m_4) - 0.42$$

where m_1, m_2, m_3, and m_4 are the multiplicative utility factors for the four investigated domains. Since some of the health states assessed in a reference population were considered to be worse than death, some utility values are below zero. All possible health states therefore lay between 1.00 and –0.21, whereas 1.00 is considered healthy, 0 dead and 0 to –0.21 worse than death. Outcome using the assessed health state classification was assigned to four categories: good outcome (HSC 1.0–0.7), moderate outcome (HSC 0.69–0.3), poor outcome (HSC 0.29–0) and very poor (HSC <0).

In addition to health state data, information was obtained on (i) preexisting medical conditions related to grounds of PICU admission, (ii) change of preexisting medical condition after intensive care, (iii) new medical condition after intensive care (iv) special care resource utilisation pre- and post-intensive care, (v) use of medication and (vi) medical follow-up by specialists at a tertiary referral centre. A preexisting medical condition was defined as chronic disease requiring regular medical follow up. A new medical condition was defined as a new chronic disease after intensive care requiring regular medical follow-up. Special care utilisation before and after intensive care was defined as speech therapy, hearing therapy or hearing aid, regular physiotherapy/rehabilitation, special care in nursery or day school for disabled children, and home care. Use of medication was defined as regular therapy for underlying chronic disease.

Statistics

Data are presented as median and interquartile range (IQR).

Results

Patient demographic

A total of 661 eligible patients were admitted during 2001, of whom 270 (41%) were female and 391 (59%) male. Readmitted patients were only counted once for follow-up and mortality rate. Twenty-seven patients (3.9%) died during the intensive care stay. Death was associated with chronic illness in one third, an acute event (infection, accident) in another third and cessation of life support in the final third. A further 21 patients (3.2%) died within the next 24 months after intensive care, of whom 19 (12 children, 7 neonates) within the first 12 months. Median age on admission was 11.3 months (IQR 0.5 months–5.5 years; range 0 days–20 years). Median length of stay was 2 days (IQR 1–4 days; range 0–54 days). 309 children (45%) were intubated and ventilated for a median period of 1 day (IQR 0.2–3.1 days; range 0.1–44.7 days). 208 neonates (<4 weeks of age) (31%) were admitted, of whom 123 on the first day of life immediately after delivery. Reasons for PICU admission are shown in Table 1. Figure 1 shows patient flow during the 24-month follow-up period.
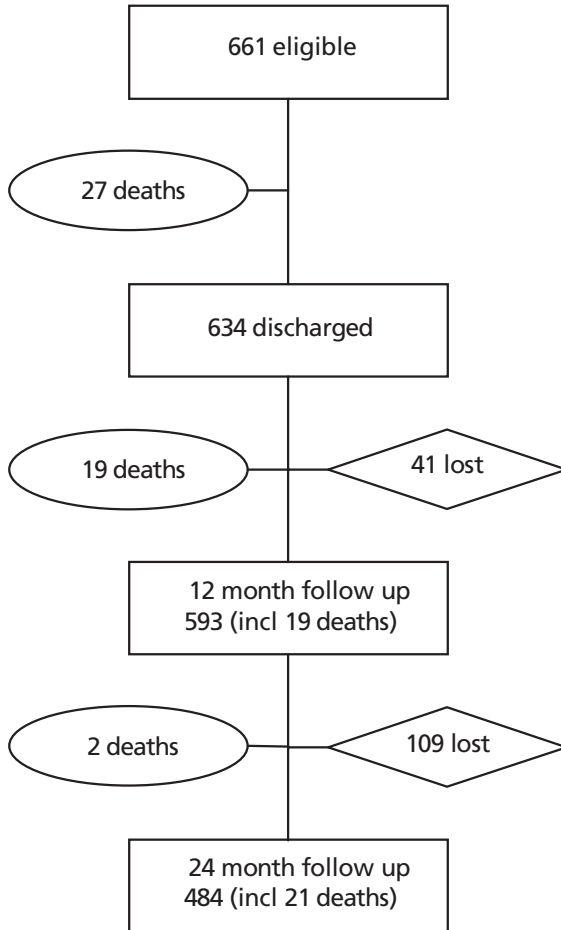
Quality of life

The families of 574 patients (91% of all 634 patients discharged from the PICU) could be contacted for complete telephone interview after 12 months and 463 after 24 months (73%). Patients who died after discharge from the ICU are included in the calculations at 12 and 24 months as poor outcome with an HSC of 0. The baseline data of the patients we could not contact did not differ from the study population with respect to severity of illness: PIM 0.02 (IQR 0.01–0.06) and 0.02 (IQR 0.01–0.08); length of stay 1 day (IQR 1–3) and 2 days (IQR 1–4) and intubation rate 44% and 45% respectively. The proportion of non-German- or French-speaking parents was 13% in the

Table 1

Reason for PICU admission (diagnostic groups).

	Respiratory	CVS	Post-op	Neurology	Accident	Medical
Neonates n = 208	52%	10%	6%	0.5%	8%	24%
Infants/children n = 453	18%	10%	34%	16%	9%	13%
Total n = 661	24%	10%	26%	12%	9%	19%

CVS: Cardiovascular system, Post-op: after surgery.

Figure 1
Patient flow over the 24 months follow-up period.

661 eligible

27 deaths

634 discharged

19 deaths — 41 lost

12 month follow up 593 (incl 19 deaths)

2 deaths — 109 lost

24 month follow up 484 (incl 21 deaths)

Table 2

Outcome groups
12 and 24 months after PICU discharge (including all deaths after discharge).

	Good	Moderate	Poor	Very poor
12 months				
Neonates (n = 180)	89%	6%	5%	0%
Infants/children (n = 413)	76%	19%	5%	0.5%
Total (n = 593)	80%	15%	5%	0.3%
24 months				
Neonates (n = 145)	85%	8%	7%	0%
Infants/children (n = 339)	74%	18%	8%	0%
Total (n = 484)	77%	15%	8%	0%

the HSC subscores between diagnostic groups. The power of this study is too low to investigate the correlation of PIM, length of stay, intubation rate or length of ventilation and quality of life after 12 or 24 months.

Table 4 shows the number of children within the different PIM risk groups as well as those who died while in the PICU and those who died during follow-up. Not surprisingly, the high-risk group had a higher mortality in the unit and a higher mortality during follow-up as well.

Two hundred and fifteen children (47% of infants/children) had preexisting disease and 144 (22% of the whole cohort) developed new chronic disease after intensive care. Parents reported that the preexisting medical condition had become worse in 23% of these children. 263 children (40%) required follow-up by a specialist and 166 (25%) used regular medication for their illness. Fifty-six (12% of infants/children) required special care before the PICU and 129 (20% of the whole cohort) after the PICU.

follow-up group and 15% in the patients who could not be contacted.

Outcome in the four health state categories at 12 and 24 months after intensive care are shown in Table 2. Two patients displayed very poor outcome after 12 months and both died in the following year. The number of patients with a poor outcome increased from 30 to 37 after 24 months, including those who died in the meantime. Table 3 shows health state outcome and reason for PICU admission for all patients with a complete follow-up after 24 months. Interestingly, there is no difference in

Discussion

Outcome in the PICU is commonly measured by mortality rates. In daily practice any paediatric intensivist is more commonly confronted with questions of quality of life after intensive care than

mortality, because overall mortality has fallen to less than 5% and a high percentage of children admitted to the PICU have chronic medical conditions. In general the outcome is good and approx-

Table 3

Health state classification (HSC) of all patients with complete follow-up (including deaths) listed in five diagnostic groups at 12 months' and 24 months' follow-up.

	Respiratory	CVS	Post-op	Neurology	Accident	Medical
n = 484	161	39	108	62	42	72
12 months						
Median (IQR)	1 (0.87–1)	1 (0.68–1)	1 (0.67–1)	1 (0.71–1)	0.92 (0.65–1)	1 (0.81–1)
24 months						
Median (IQR)	1 (0.81–1)	0.87 (0.67–1)	0.92 (0.70–1)	1 (0.67–1)	1 (0.69–1)	1 (0.76–1)

Table 4

Mortality rate in the different PIM groups during PICU admission and during the 24 months' follow-up period.

	PIM <1%	PIM 1-<5%	PIM 5-<15%	PIM 15-<30%	PIM >30%
On admission n = 661	23%	49%	18%	4.9%	5.1%
Death in PICU n= 27	0%	0.9%	0.9%	0%	2.2%
Death during follow-up n = 21	0.3%	0.4%	0.6%	0.3%	1.5%
Total deaths n = 48	0.3%	1.4%	1.5%	0.3%	3.8%

imately 80% of all children enjoy good quality of life after intensive care. Some important and significant facts regarding PICU outcome need careful consideration.

Most of the children (44%) who died were in the group with high mortality risk (>30%) on PICU admission. Our study results indicate that mortality risk assessment at PICU admission may predict long-term mortality. However, our study was not designed and powered to investigate prospectively the long term predictive power of PIM. Two previous Australian studies described a similar doubling of mortality rate approximately 2 years after intensive care [6, 7]. The Melbourne study showed that a high PIM score (>30%) at PICU admission predicts increased long-term mortality. In this study they reported that 50% of all children in PIM risk group >30% died within the 6-year follow-up. In our study 71% of all children in the PIM group >30% died within 2 years following the PICU. In adult acute intensive care mortality figures were originally reported using 28-day survival, but currently there is a tendency to report a 60-day (or longer) survival rate. On the basis of our results we suggest that long term outcome for paediatric patients should include at least 2 years' follow-up because mortality rate figures doubled when assessed 2 years after PICU.

Quality of life after PICU was measured using a health state classification covering four domains assessing mobility and physical activity, role function, social-emotional function and health problem [10, 12]. A similar outcome assessment was used in the Melbourne study. Our study results were very similar and show a good overall outcome. Patients with cardiovascular disease and after accidents (including head injury) had a poorer outcome than patients with respiratory, general medical and neurological problems. Two patients with a very poor outcome assessed after 12 months died within the following 12 months. Very poor outcome is regarded as worse than death. Twenty-four months after the PICU 8% of all children had

a poor outcome. Interestingly, almost half the children admitted to the PICU had a preexisting chronic disease related to the reason for PICU admission. Every fifth child needs special care, in the form of physiotherapy, rehabilitation, speech therapy or special school, after intensive care. One third of all children were regularly followed up by a specialist and 16% required regular medication. In summary, the number of children utilising health care resources post-PICU increases, indicating that children requiring intensive care are more likely to be dependent on health care resources after the PICU. The results of this study confirm the general experience of any PICU, that more children with preexisting chronic illness are admitted to the PICU, the illnesses including genetic disease, cardiac disease and previously extreme premature infants.

Our study has a number of limitations. All information on outcome was obtained using a telephone interview as the most practical and cost-effective method for follow-up. Information obtained by parents or carers is obviously biased [13]. However, we employed a structured telephone interview using an outcome tool which had been previously validated in children [6, 10]. An updated version of the HSU index is currently available. We chose to use an older version of the HSU allowing direct comparison with previous studies [6]. We acknowledge that HSU is not validated for children under 2 years. Using different tools at 12 and 24 months, however, would make comparison impossible and, as mentioned, in previous studies was an important reason for choosing this tool. We could follow up 94% of all children admitted to the PICU after 12 months and 76% after 24 months. We compared the non-contacted patients and their demographic data with the follow-up group and found no difference in baseline data. Assuming similar mortality in the group lost to follow-up we are bound to speculate that post-PICU mortality must be higher than reported and that a figure of approximately 8% (additional 5–7 deaths) is

more accurate. PIM has been designed to predict outcome for infants and children and has been calibrated in units which do not routinely admit neonates. Only one hospital in the original PIM calibration study admitted preterm neonates [9]. We therefore excluded all premature babies from analysis, but included all other newborns presenting e.g. with neonatal sepsis, meconium aspiration or hypoxic ischaemic encephalopathy. Compared to the initial data set for PIM calibration our study included a higher percentage of infants <28 days of age (8.1% and 32% respectively). The study describes a single centre outcome, but ours is the only unit admitting paediatric patients for a distinct region of approximately 1.5 million people. The follow-up data contained some information on health care utilisation after the PICU but it was not possible to estimate the costs. Our study results tend to support the fact that if a child suffers from a chronic medical condition it is more likely to be admitted to the PICU.

Quality of life after PICU is a permanent hot topic at any PICU ward round. Our study results may afford some insight into this difficult discussion. In general the outcome is good. But when the possibility of death is discussed with parents, mortality risk in the long term may be discussed as well. For any paediatric intensivist, a good outcome is probably defined as those in the first two groups of the health state classification (good and moderate). Poor or even very poor outcome is obviously less desirable. In our study 8% of all children admitted to the PICU had a poor outcome. A similar outcome after neonatal intensive care is described for extreme premature babies. This figure, in our opinion, represents a considerable burden for any health care system but probably reflects what is acceptable to society.

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