ORIGINAL ARTICLES

Long term survival and state of health after paediatric intensive care

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Abstract

Survival and state of health were assessed one year after discharge in 468 children admitted to an intensive care unit (ICU). ICU mortality was 7.5%, cumulative hospital mortality 8.3%, and one year mortality 10.5%. An established six domain health status classification was used, comprising sensation, mobility, emotion, cognition, self care, and pain to determine the presence, type, and severity of chronic health impairment. This classification has not been validated for infants, who were therefore excluded. After one year, of the 254 patients eligible for analysis, 80 (31.5%) had no overall health impairment (no affected domains) preceding admission; of these, 11 had died in ICU and 69 were long term survivors, among whom 45 recovered to perfect health. There was overall health impairment (≥ 1 affected domain) preceding admission in 174 of 254 patients (68.5%). However, after one year, overall state of health was improved or equal to the preadmission state in 164 of 226 survivors (72.6%). In domain-specific health, the proportion improving or remaining unchanged varied from 77.9% (emotional functions) to 89.4% (mobility and pain). Consequently, despite the large number with health impairment before admission, cumulative one year survival was favourable and health status in three quarters of the population was preserved.

(*Arch Dis Child* 1995; 73: 196–201)

Keywords: paediatric intensive care, health related quality of life, outcome assessment, quality assurance.

corrected for severity of illness, longitudinal assessment of morbidity change and health related quality of life have become important supplementary outcome measures.

Instruments assessing health related quality of life have been restricted to questionnaires for adults (for example, the Nottingham health profile,⁸ sickness impact profile,⁸ quality of wellbeing index,⁸ and short form 36⁹). Few studies have addressed long term health after paediatric intensive care, and those that have have used rather cursory *ad hoc* health state classifications.^{1 7 10} Recently Feeny *et al* have devised a generic multidimensional health status classification for children, including both type and severity of sequelae.¹¹ This classification was formerly used to assess children with cancer¹² and extremely low birth-weight babies.¹³ We previously established the feasibility, reliability, and validity of a version suitable for paediatric intensive care unit (ICU) patients.¹⁴ The purpose of the present study was to assess long term survival and health related quality of life of children admitted to an ICU.

Methods

PATIENTS AND ICU CHARACTERISTICS

Data on all patients admitted during one year (1 January 1992–31 December 1992) were collected prospectively. Approval of the institutional review board was granted and all parents were informed about the purpose of the study; informed consent was obtained before inclusion. The study location is a tertiary paediatric ICU for all patients aged 1 month to 16 years, except trauma patients who are admitted to dedicated centres nearby. The unit has 10 beds, accommodating about 500 patients per year, and is part of a 180 bed university children's hospital. The ICU is staffed by full time paediatric intensive care specialists, a cardioanaesthesiologist, an intensive care fellow, and house officers providing 24 hour cover.

HEALTH STATUS ASSESSMENT

The multiattribute health status classification (MAHSC),¹¹ table 1, was developed as a comprehensive generic health status measure for children. It comprises an extension of a similar paediatric multiattribute system, derived from

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Accepted 18 April 1995

Intensive care medicine has made important contributions to the survival of critically ill patients, but requires expensive equipment and a large staff.^{1–3} Success of intensive care is usually presented as mortality rate adjusted for severity of illness, disregarding long term survival and functional outcome.^{4–6} More children with complex previously fatal defects are treated by prolonged high technology care and there is growing concern for their long term prospects.^{1 7} Although fewer die, length and quality of survival in these patients is uncertain. Accordingly, in addition to mortality

Table 1 Multiattribute health status classification system

Attribute	Level	Description
Sensation	1	Able to see, hear, and speak normally for age
	2	Requires equipment to see or hear or speak
	3	Sees, hears, or speaks with limitations even with equipment
	4	Blind, deaf or mute
Mobility	1	Able to walk, bend, lift, jump, and run normally for age
	2	Walks, bends, lifts, jumps, or runs with some limitations but does not require help
	3	Requires mechanical equipment (such as canes, crutches, braces, or wheelchair) to walk or get around independently
	4	Requires the help of another person to walk or get around and requires mechanical equipment as well
	5	Unable to control or use arms and legs
Emotion	1	Generally happy and free from worry
	2	Occasionally fretful, angry, irritable, anxious, depressed, or suffering 'night terrors'
	3	Often fretful, angry, irritable, anxious, depressed, or suffering 'night terrors'
	4	Almost always fretful, angry, irritable, anxious, or depressed
	5	Extremely fretful, angry, irritable, or depressed, usually requiring hospital admission or psychiatric institutional care
Cognition	1	Learns and remembers school work normally for age
	2	Learns and remembers school work more slowly than classmates as judged by parents and/or teachers
	3	Learns and remembers very slowly and usually requires special educational assistance
	4	Unable to learn and remember
Self care	1	Eats, bathes, dresses, and uses the toilet normally for age
	2	Eats, bathes, dresses, and uses the toilet independently with difficulty
	3	Requires mechanical equipment to eat, bathe, dress, or use toilet independently
	4	Requires the help of another person to eat, bathe, dress, or use the toilet
Pain	1	Free of pain discomfort
	2	Occasional pain. Discomfort relieved by non-prescription drugs or self control activity without disruption of normal activities
	3	Frequent pain. Discomfort relieved by oral medicines with occasional disruption of normal activities
	4	Frequent pain; frequent disruption of normal activities. Discomfort requires prescription narcotics for relief
	5	Severe pain. Pain not relieved by drugs and constantly disrupts normal activities

Adopted from Feeny *et al*¹² with permission.

the quality of wellbeing index⁸ which has been used for outcome assessment of very low birth-weight infants.² It focuses primarily on functional abilities from a patient's perspective rather than on diagnosis related disorders. A full description of the development process has been reported elsewhere.^{11 12} The classification consists of six domains: sensation, mobility, emotion, cognition, self care, and pain. These domains have been empirically selected by a representative sample of parents of school age children, who identified their relative importance from a total of 15 different health domains.¹⁵ The system was originally used in evaluating survivors of childhood cancer.^{11 12 16} In these studies, fertility was included as domain of particular relevance to patients treated with cytotoxic drugs. With the consent of the original authors we excluded it for our more heterogeneous group of paediatric ICU patients. Functioning within each attribute was represented by four or five hierarchical levels, varying from healthy to poor, depending on the absence or level of impairment. The state of health of a particular subject is described as a profile by a six element vector (x_1 x_2 x_3 x_4 x_5 x_6 ; for example 1 3 2 3 4 1) in which x_i describes the level (1 to 4 or 5) for domain i . This implies that the system is capable of representing 8000 different profiles, although the number encountered in practice will be considerably less because there is a certain degree of dependence between some domains. The levels for each domain are meant to be interpreted as developmentally

appropriate for the age of the subject. Classification is done by an observer well known to the patient, for example a parent or dedicated nurse. The system has not been validated for children under 12 months of age.^{14 16}

DATA COLLECTION AND ANALYSIS

On admission, age, diagnosis, primary referring specialty, and acute severity of illness were registered. Survival was determined on ICU discharge, on hospital discharge, and one year after ICU discharge. Acute severity of illness on the day of admission was assessed with the PRISM score, which quantifies mortality risk based on the weighted sum of 14 routinely obtained clinical and laboratory measures of physiological instability.⁶ Its institution independent predictive accuracy has been prospectively established in tertiary care paediatric ICUs.^{6 17} We also recorded health status before admission and one year after discharge from the ICU. Preadmission health status, averaged over the three months preceding admission, was assessed by questionnaire, completed during a structured parental interview within 48 hours following the ICU admission. Excluded from health status analysis were infants under 1 year of age, in whom MAHSC has not been validated, and survivors who stayed less than 24 hours (mainly patients for postoperative monitoring). One year after discharge health status was assessed by an identical mailed questionnaire completed by the parents.

Overall health status was expressed as the number of affected domains, regardless of the degree of dysfunction. A score of 0 reflects uncompromised overall health, 6 reflects impairment in any degree of all domains. Changes were described by comparing the number of affected domains before admission with that one year after discharge.

Domain-specific health status was described as a profile reflecting functional level within each of the six domains. Domain-specific health status one year after discharge was compared with preadmission health. Changes therein were described for each domain to interpret functional outcome in relation to preadmission health. A positive change corresponds to an improved level within a health domain and a negative change to a deteriorated level.

STATISTICS

Data analysis and descriptive statistics were performed with SPSS/PC+ statistical software. The χ^2 test was used to compare non-parametric variables. The relation between admission day mortality risk and overall preadmission health status was assessed with correlation analysis. A probability value (p) < 0.05 was considered significant.

Results

Overall, 468 patients accounting for 538 admissions were observed during the study

Table 2 One year outcome related to preadmission overall health status (expressed as number of affected domains)

Panad*	Patients (%)	Mortality		Alive after ≥ 1 year	Number of affected domains after one year						
		ICU	<1 year		0	1	2	3	4	5	6
0	80 (31.5)	11	0	69	45	13	3	6	0	1	1
1	42 (16.5)	0	1	41	20	12	3	3	3	0	0
2	40 (15.7)	4	3	33	10	4	5	5	7	2	0
3	29 (11.4)	1	0	28	0	2	4	11	5	3	3
4	30 (11.8)	1	1	28	1	1	1	6	16	2	1
5	22 (8.7)	1	4	17	0	0	0	1	3	12	1
6	11 (4.3)	1	0	10	0	0	0	1	1	3	5
Total	254 (100)	19	9	226	76	32	16	33	35	23	11

*Panad=preadmission number of affected domains.

Overall health status improved in 58 (=sum of all numbers below the 'iso-health status line') of 226 patients (that is, 25.7%) and deteriorated in 62 (=sum of all figures above the iso-health status line) of 226 (that is, 27.4%).

period. Mean age was 55 (median 24.6) months, mean length of ICU stay was 4.4 (median 2) days. Thirty five patients died in the ICU (7.5%) and four died during their subsequent hospital stay (total hospital mortality 8.3%); 10 died in the first year following discharge (cumulative one year mortality 10.5%). Comparative assessment of preadmission and one year postdischarge health status was precluded in the following: patients younger than 12 months on admission ($n=182$), survivors who stayed less than 24 hours in the ICU ($n=17$), non-survivors ($n=28$), and survivors whose parents failed to return the second questionnaire ($n=15$). Consequently, after one year 254 patients (226 survivors and 28 non-survivors) were available for assessment of survival and health status.

Table 2 shows the one year outcome (survival and overall health status) in relation to preadmission overall health status. For 32 survivors follow up health status was missing (17 short stay patients and 15 non-responders). Eighty patients (31.5%) had no overall health impairment (no affected attributes) before admission. Eleven of these died in the ICU, and 45 of 69 survivors were in perfect health after one year. From the diagonal 'iso-health status line' it can be inferred that in 106 (=45+12+5+11+16+12+5) of 226 survivors (46.9%) the number of affected domains before admission equalled the number of affected domains after one year. Irrespective of the magnitude of change, overall health status improved in 58/226 (25.7%) and deteriorated in 62/226 (27.4%). Most changes in overall health status were small, that is, only one domain more or less affected, indicating that in the large majority overall health differed little, if at all, from that before

admission. In 24 of 69 survivors with uncompromised preadmission health a decline in overall health status was found, the majority (13) having a single affected domain on follow up. Major negative changes in the number of affected domains were found in a small number of previously healthy patients: 6/69 had three affected domains after one year, 1/69 had five, and 1/69 had six affected domains. The latter two patients were admitted after acute devastating illness (meningococcal septicaemia and submersion).

In table 3 we compare preadmission overall health status, stratified by referring clinical specialty, and overall health status one year after discharge. There were 123 patients (48.4%) referred by non-surgical specialties, mostly following emergency admission for acute severe illness. The majority had no or a single domain of their health status affected (73/123=59.3% had ≤ 1 affected domain before admission and 57/102=54.9% had ≤ 1 affected attribute after one year). In cardiovascular surgical patients average overall health status had improved on follow up; the proportion of patients with ≤ 1 affected domain increased from 37/65=56.9% upon admission to 41/60=68.3% one year after ICU discharge ($p<0.05$). Among other surgical patients a minority had no or a single domain health impairment (12/66=18.2% had ≤ 1 affected domains before admission and 10/64=15.6% had ≤ 1 affected domains one year after discharge). The proportion with ≥ 5 affected domains was highest in other surgical patients, mostly in relation to those with severe encephalopathy admitted following major orthopaedic surgery.

The relation between overall health status and acute severity of illness on admission is shown in table 4. Most patients who died in the ICU had an uncompromised preadmission health status (11/19) and were admitted with high mortality risk (8/12 with mortality risk $\geq 15\%$ died). On the other hand, patients with most impaired preadmission health status had low mortality risks. This group mainly consisted of postoperative patients, following elective surgery for complex malformations. All six patients who had more than one affected domain and high mortality risks died in the ICU (four had CNS disorders, one had dermatomyositis, and one suffered from a complex congenital heart defect). However, no correlation was found between mortality risk and the number of affected attributes before

Table 3 Frequencies (%) of domains affected on admission and one year after discharge

No of affected domains	Non-surgery*		Cardiovascular surgery†		Other surgery‡	
	Admission	1 Year	Admission	1 Year	Admission	1 Year
0	52 (42.3)	45 (44.1)	22 (33.8)	27 (45.0)	6 (9.1)	4 (6.3)
1	21 (17.1)	12 (11.8)	15 (23.1)	14 (23.3)	6 (9.1)	6 (9.4)
2	17 (13.8)	5 (4.9)	13 (20.0)	7 (11.7)	10 (15.1)	4 (6.3)
3	5 (4.1)	11 (10.8)	11 (16.9)	6 (10.0)	13 (19.7)	17 (28.3)
4	16 (13.0)	17 (16.7)	2 (3.1)	4 (6.7)	12 (18.2)	12 (18.8)
5	8 (6.5)	9 (8.8)	2 (3.1)	1 (1.7)	12 (18.2)	14 (21.9)
6	4 (3.3)	3 (2.9)	0 (0.0)	1 (1.7)	7 (10.6)	7 (10.9)
Total	123 (100)	102 (100)	65 (100)	60 (100)	66 (100)	64 (100)

*Non-surgery include all patients referred by non-surgical specialties; main subgroups are: respiratory diseases, (non-surgical) cardiovascular diseases, neurologic diseases, renal diseases, gastroenterological diseases, immunohaematological diseases, etc.

†Cardiovascular surgery patients largely comprise postoperative patients after repair of (mostly congenital) cardiac malformations.

‡Other surgery patients mainly comprise postoperative patients referred by other surgical specialties (general paediatric surgery, orthopaedic surgery, urology, neurosurgery, etc).

Table 4 Mortality risk group by overall health status, expressed as the number of affected domains on admission

No of affected domains	Mortality risk group					Total ^{ICU deaths}
	Very low $p \leq 1\%$	Low $1 < p \leq 5\%$	Medium $5 < p \leq 15\%$	High $15 < p \leq 30\%$	Very high $p > 30\%$	
0	36	28 ²	4 ¹	2 ¹	10 ⁷	80 ¹¹
1	25	12	4	1	—	42
2	30 ¹	5	3 ¹	1 ¹	1 ¹	40 ⁴
3	18	10	—	1 ¹	—	29 ¹
4	19	9	1	—	1 ¹	30 ¹
5	15	6	—	—	1 ¹	22 ¹
6	7	3	—	1 ¹	—	11 ¹
Total	150 ¹	73 ²	12 ²	6 ⁴	13 ¹⁰	254 ¹⁹

Superscripts denote ICU deaths (not indicated if no deaths occurred), other figures the total number of patients; p denotes mortality risk in %.

admission ($r^2=0.02$) and mortality risk and the number of affected attributes after one year ($r^2=-0.02$).

One year postdischarge domain-specific health status is shown in the figure, and table 5 gives the change of domain-specific health status compared to before admission. The proportion of patients without impairment one year after discharge ranged from 79.6% with respect to pain to 50.0% with respect to mobility. However, from table 5 we infer that domain-specific health did not change in most patients – a pattern similar to overall health status. The proportion with unchanged domain-specific health status varied from 65.5% in emotional functions to 83.2% in both sensory and cognitive functions. Occasionally, severe health impairment was found in previously healthy patients. As with overall health status, major deterioration occurred when patients survived a severe acute disease associated with an acknowledged risk of chronic sequelae (for example, near-drowning, meningococcal septicaemia). Mobility improved in about one fifth (51/226=22.6%) of the patients, mainly because of a subgroup of patients ≥ 1 year of age who had had correction of congenital cardiac malformations. Deterioration of mobility was found in 24/226 (10.6%). Deterioration with respect to emotion was found in 50/226 (22.1%). In cognition a deterioration was found in 28/226 (12.4%) who failed age appropriate develop-

Frequencies of levels within domains one year after discharge from intensive care unit.

mental and cognitive performance following ICU discharge. In self care and pain domains approximately the same number deteriorated as improved.

Discussion

Most studies assessing performance of paediatric intensive care are restricted to comparative analysis of intensive care unit mortality rates corrected for severity of illness. In a previous study we showed that in our population observed mortality rate agreed closely with PRISM score based expected ICU mortality. This indicated that performance with respect to mortality met well acknowledged international standards of tertiary paediatric intensive care.¹⁷ However, with an increasing proportion of patients with chronic health impairment, mortality reduction is not the only way of measuring effectiveness of intensive care. As well as assessing survival, our aim in this study was to examine health related quality of life using appropriate measuring instruments which allowed us to register both the type and the severity of sequelae.^{8 18 19} This is difficult in children because such instruments should cover a wide range of age related functional disabilities.^{20 21} The multidimensional character of the MAHSC, with a range of levels for each attribute, allows us to account for combinations of different attributes of health. Psychometric functions were found to be highly satisfactory.¹⁴ The instrument is suitable for assessment by proxies (for example, parents and clinicians), which is the preferred option for those children not able to give their own appraisal. An important disadvantage is that the system has not been validated for infants, who represent many paediatric ICU admissions and are frequently submitted to advanced medical technologies (for example, corrective surgery for congenital anatomical malformations). We might expect that in this group early treatment is accompanied by recovery or by considerable reduction of pre-existing morbidity. Consequently, including this age group would be particularly relevant for long term outcome assessment. Although one study reports the utilisation of a generic health status measure in infants under one year,¹⁰ reliability and validity remain to be established.²¹ We found that in children aged one to three years, health classification requires careful assessment and some domains (cognition, emotion) may require interpretation or prognostic appraisal, yet the reliability and validity of the MAHSC remained very satisfactory.^{14 16} The difference between data collection on admission (structured interview) and after one year (mailed questionnaire) was considered to have little impact as on both occasions the parents responded to identical questionnaires.

The significance of including both acute and long term mortality and changes in health as independent measures in outcome assessment studies is illustrated by the lack of relation between acute severity of illness (that is, mortality risk on the day of admission) and

Table 5 Frequencies (%) of change in functional levels within each domain

Change of level within domain	Sensation	Mobility	Emotion	Cognition	Self care	Pain
Worse						
-4	NA	0 (0.0)	0 (0.0)	NA	NA	0 (0.0)
-3	0 (0.0)	2 (0.9)	0 (0.0)	1 (0.4)	3 (1.3)	1 (0.4)
-2	11 (4.0)	2 (0.9)	6 (2.7)	5 (2.7)	6 (2.7)	2 (0.9)
-1	18 (8.0)	20 (8.8)	44 (19.5)	22 (9.7)	18 (8.0)	21 (9.3)
Equal						
0	188 (83.2)	151 (66.8)	148 (65.5)	188 (83.2)	172 (76.1)	178 (78.8)
Better						
+1	8 (3.5)	47 (20.8)	27 (11.9)	8 (3.5)	21 (9.3)	21 (9.3)
+2	1 (0.4)	3 (1.3)	1 (0.4)	2 (0.8)	5 (2.2)	3 (1.3)
+3	0 (0.0)	1 (0.4)	0 (0.0)	0 (0.0)	1 (0.4)	0 (0.0)
+4	NA	0 (0.0)	0 (0.0)	NA	NA	0 (0.0)
Total	226 (100)	226 (100)	226 (100)	226 (100)	226 (100)	226 (100)

Changes of functional levels within each domain are expressed as preadmission level minus 1 year postdischarge level for each domain; 28 non-survivors and 15 non-responders were excluded because of missing follow up health status.

NA=not applicable as the domains sensation, cognition, and self care each have four levels, therefore -3≤ level change ≤3.

health status before admission and after one year. Health impairment one year after discharge from the ICU was present in 66.4% of survivors. The majority were health impaired before admission. Generally, observed changes in health were minor: most frequently only a single domain was affected, or a single level change within a specific domain was observed. Overall state of health one year after discharge improved or was equal to preadmission health in 72.6% of survivors; equal or improved domain-specific health varied from 77.9% (emotional functions) to 89.4% (for mobility and pain). Major deterioration both in overall and domain-specific health status was observed in only a small proportion of previously healthy patients, admitted with an acute devastating illness with a well recognised chance of poor outcome. We found a frequent, although small, deterioration in emotional state related to prolonged fear persisting after ICU discharge. This finding suggests that more attention should be given to this aspect during and after ICU admission in childhood.

Few studies are available to compare with our results. In a retrospective study, assessing long term outcome of admission to paediatric ICU, Butt *et al* found a cumulative mortality of 14.3% and overall health impairment on follow up in 58%.⁷ Health status remained unchanged in 68.7%, deteriorated in 8.3%, and improved in 8.7% compared to preadmission. We found a lower overall cumulative mortality, accompanied by a higher percentage with overall health impairment on follow up. The latter finding was probably related to the higher frequency of preadmission health impairment in our population, due to differences in case mix. Changes in health status occurred more frequently than those described by Butt *et al*,⁷ probably because we used a more refined health measuring instrument and because our study was prospective.

Studies by the devisors of the MAHSC can be compared in some detail. Among survivors of childhood leukaemia, overall health was normal in 42%, one domain was affected in 32%, and ≥2 domains in 26%.¹² In another study, investigators from the same institution showed that overall morbidity in very low birthweight children at the age of 8 years was

substantially greater than in children from a reference group.^{13 22} In our more heterogeneous population of ICU patients, the average overall health status was worse than in these studies. In adults, cumulative one to two year mortality of patients admitted to an ICU varies from 23–69%, with 10–68% of survivors regaining their previous state of health.^{23–27} In combination with the higher *a priori* life expectancy of children, even after intensive care, these results also suggest that intensive care for children is more cost-effective than for adults.^{23 28}

Treatment decisions in individual patients should not depend on assessing health status; nevertheless such an assessment may contribute to discussions about prognosis with the patient's family. More importantly, this approach might generate information on how different patient groups within a population might benefit from intensive care. The system can be linked to a health status utility index calibrating health related quality of life, thus enabling an estimate of how many quality adjusted life years (QALYs) are gained by a particular programme.^{2 18 22 29} In a random sample of parents of school age children, the multiattribute utility function has facilitated appraisal of utility scores for all possible health states based on a selected number of preference measurements.^{13 29} Although the QALY concept may be criticised for placing explicit and population averaged values on health, it may be preferable to implicit judgments made daily, such as whether to admit a severely disabled patient to an intensive care unit.

In conclusion, we found favourable long term survival of children admitted to intensive care and a good functional outcome in terms of preservation of health, indicating an overall beneficial effect. Analogous studies which assess survival and health status simultaneously, including interinstitutional comparison, will contribute to the appraisal of paediatric intensive care.

Supported by grant 92-56A from the Dutch Ministry of Health. We are grateful to professor George W Torrance and professor David H Feeny, Centre for Health Economics and Policy Assessment, McMaster University, Hamilton, Canada, for providing us with a preliminary version of the multiattribute health status classification system and for helpful discussions. We acknowledge Jaap Rodenburg RN, Mariëtte Zuure-Schiphorst RN, and Eva Brilstra MSc for expert data collection.

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