

# Children's Self-Reported Quality of Life After Intensive Care Treatment\*

Gillian A. Colville, MPhil<sup>1,2</sup>; Christine M. Pierce, MBBS<sup>1</sup>

**Objectives:** Study was to establish children's own views of their outcome.

**Design:** Prospective cohort study: A number of studies have reported on parental/clinician reports of children's quality of life after intensive care treatment. The aim of this

**Setting:** Twenty-one bed PICU in a tertiary Children's Hospital.

**Patients:** Ninety-seven children aged over 7 yr, with no preexisting learning difficulties, consecutively admitted to PICU over an 18 month period

**Interventions:** Patients completed the Pediatric Quality of Life Inventory and a post-traumatic stress screener, at 3 months and again at 1 year ( $n = 72$ ) after discharge from PICU.

**Measurements and Main Results:** At 3 months post-discharge, the mean total Pediatric Quality of Life Inventory score reported by the PICU group was lower than that reported in the literature for a non-clinical community sample (PICU mean = 79.1 vs community mean = 83.9,  $p = 0.003$ ), but by 1 year, they were comparable (82.2,  $p = 0.388$ ). The mean physical functioning subscale score

remained lower (PICU mean=81.6 vs. community mean=88.5,  $p = 0.01$ ), but improved significantly from 73.4 at 3 months ( $p = 0.001$ ).

Sub-group analyses revealed that the elective group reported higher emotional functioning than the community sample (91.0,  $p=0.005$  at 3 months and 88.2,  $p = 0.038$  at 1 year vs community mean=78.5), and made significant gains in social functioning between timepoints (79.1 to 91.4,  $p = 0.015$ ).

Finally, although total PedsQL scores at 1 year were not associated with measures of severity of illness during admission, they were significantly negatively associated with concurrent post-traumatic stress symptom scores ( $r = -0.40$ ,  $p = 0.001$ ).

**Conclusions:** The self-report version of the Pediatric Quality of Life Inventory proved to be a feasible and sensitive tool for assessing health related quality of life in this group of PICU survivors. (*Pediatr Crit Care Med* 2013; 14:e85–e92)

**Key Words:** outcomes; posttraumatic stress; quality of life; traumatic brain injury

As survival rates improve for children treated in the PICU, there has been a shift in focus to outcomes other than mortality. A recent study, reporting on one centre's experience over a 25-yr period, found that although the death rate had halved, the proportion of survivors with moderate to severe disability had significantly increased (1). This is

obviously a concern but, as Morrison (2) points out, disability and acceptable quality of life are not mutually exclusive. The World Health Organization has specified that health is more than simply the absence of disease and should ideally be conceptualized as encompassing functional outcome and subjective well-being (3). However, to date, few prospective studies have examined health-related quality of life (HRQOL) in heterogeneous groups of PICU survivors (4).

## \*See also p. 233.

<sup>1</sup> Paediatric Intensive Care Unit, Great Ormond Street Hospital for Children, London, UK.

<sup>2</sup> Paediatric Psychology Service, St George's Hospital, London, UK.

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For information regarding this article, E-mail: [gcolvill@sgul.ac.uk](mailto:gcolvill@sgul.ac.uk)

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## Existing Studies of HRQOL in PICU Survivors

Gemke et al (5) found that the majority of children had good outcomes at 1 yr, both in the sense of absence of impairment and in relation to their premorbid status. However, for some children in their sample, emotional health appeared to deteriorate over the year, despite their physical improvement. This finding is consistent with the growing literature on long-term psychological outcomes in this population (6–8).

Subsequent studies examining HRQOL in heterogeneous PICU populations have also found that the majority of children have good outcomes (9–13). However, they are difficult to compare because of their variability in terms of casemix

**TABLE 1. Studies of Parent/Clinician Report of the Health-Related Quality of Life of Heterogeneous Samples of Children After Pediatric Intensive Care Treatment**

| First Author  | Country         | Year | <i>n</i> | Measure | Age Range     | Follow-Up  | Main Findings   |
|---------------|-----------------|------|----------|---------|---------------|------------|---|
| Gemke (5)     | The Netherlands | 1995 | 254      | HUI-2   | > 1 yr        | 1 yr       | 73% improved or same as preadmission                              |
| Morrison (9)  | Australia       | 2002 | 432      | RAHC    | Median 2.3 yr | 3–24 mos   | 59% “normal” quality of life; 32% “fair” quality of life          |
| Taylor (10)   | Australia       | 2003 | 868      | HUI-1   | 0–29 yr       | 2.3–6 yr   | 26% “in full health”; 84% “favorable” quality of life             |
| Jayshree (11) | India           | 2003 | 150      | HUI-2   | > 1 yr        | 1 yr       | 75% improved or same as pre-admission                             |
| Jones (12)    | United Kingdom  | 2006 | 1455     | HUI-2   | > 6 mos       | 6 mos      | 27% “in full health” but significant levels of morbidity at 6 mos |
| Ambuehl (13)  | Switzerland     | 2007 | 574; 464 | HUI-1   | 0–20 yr       | 1 yr; 2 yr | 77% “good outcome” at 2 yr  |

HUI-1 = Health Utilities Index Mark 1 (14); HUI-2 = Health Utilities Index Mark 2, also known as MAHSC (Multiattribute Health Status Classification) (15); RAHC = Royal Alexandra Hospital for Children Measure of Function (16).

and response rates, their use of different outcome measures, and their different lengths of follow-up (Table 1). Also, despite recommendations that children’s own subjective report of HRQOL should be sought (4), the majority of studies rely on parent or clinician report. This is important given the evidence that the agreement between parent and child report is relatively poor, particularly in relation to emotional and social aspects of HRQOL (17). Only two recent studies have attempted to establish the views of former PICU patients *directly* in relation to their quality of life, but neither of these report on heterogeneous samples (18, 19).

## AIM OF THIS STUDY

The main aim of this study was to add to the literature in this field by eliciting children’s own views about their quality of life in the year following their discharge from intensive care, using a well-validated assessment tool, the Pediatric Quality of Life Inventory (PedsQL (20)).

It was hypothesized that children’s self-report of HRQOL, after treatment in the PICU, would initially be lower than that of healthy children, but would improve over time.

## METHODS

### Design

This was a prospective cohort study, nested within another study which was designed to examine the relationship between children’s memories of PICU and their posttraumatic stress symptoms (21, 22). Ethical permission for the study was granted by the hospital Ethics Committee. Parents and children were provided with separate, age-appropriate information sheets about the research, and written informed consent was obtained from the parents of all participants.

### Sample

The setting was a 21-bed ICU in a tertiary Children’s Hospital, in an inner city area. Families of surviving children, aged over 7 yr and consecutively admitted over an 18-month period, were approached by letter, 6 wk after discharge from PICU, to take part in the research project. Children were excluded if they had significant learning difficulties, or if they were not registered with a general practitioner. The lower age limit of 7 yr was determined by the requirements of the main study.

### Procedure

Demographic and medical data were obtained from the child’s medical record. Illness severity was measured using the Pediatric Index of Mortality score (23). Social deprivation was measured using the Townsend Deprivation Index, a summary score derived from postal district census data relating to car ownership, employment status, home ownership, and level of accommodation overcrowding (24).

During the initial face to face interview, 3 months after discharge, children completed the PedsQL (20) and the Children’s Revised Impact of Event Scale (CRIES-8 (25)), which measures posttraumatic stress symptomatology. A year after discharge, the children were contacted by post and asked to complete the CRIES-8 and PedsQL again. If they did not return the questionnaires after a second mailing, they were given the option of providing their responses to the researcher over the telephone, or in the course of an outpatient attendance.

### Measures

The 23-item PedsQL is made up of four separate subscales which measure physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items). It has well-established

reliability and validity (26), and is available for children to complete in three separate versions for ages 5–7 yr, 8–11 yr, and 12–18 yr. (Proxy-report versions, for completion by a parent or caregiver, are also available for children aged 2–18 yr.)

The informant is required to indicate how much of a problem each item has been on a scale of 0 = “never a problem” to 4 = “always a problem.” Items are reverse scored, averaged, and transformed to a scale of 0–100, with higher scores indicating fewer problems. In addition to the individual scale scores, it is possible to compute the total score (the mean of the four summed scale scores), the physical health summary score (equivalent to the physical functioning score), and the psychosocial health summary score (the mean of items on the three scales addressing emotional, social, and school functioning). Missing items can be imputed if at least 50% of the items on the scale or subscale in question have been completed (<https://www.pedsql.org/score.html>).

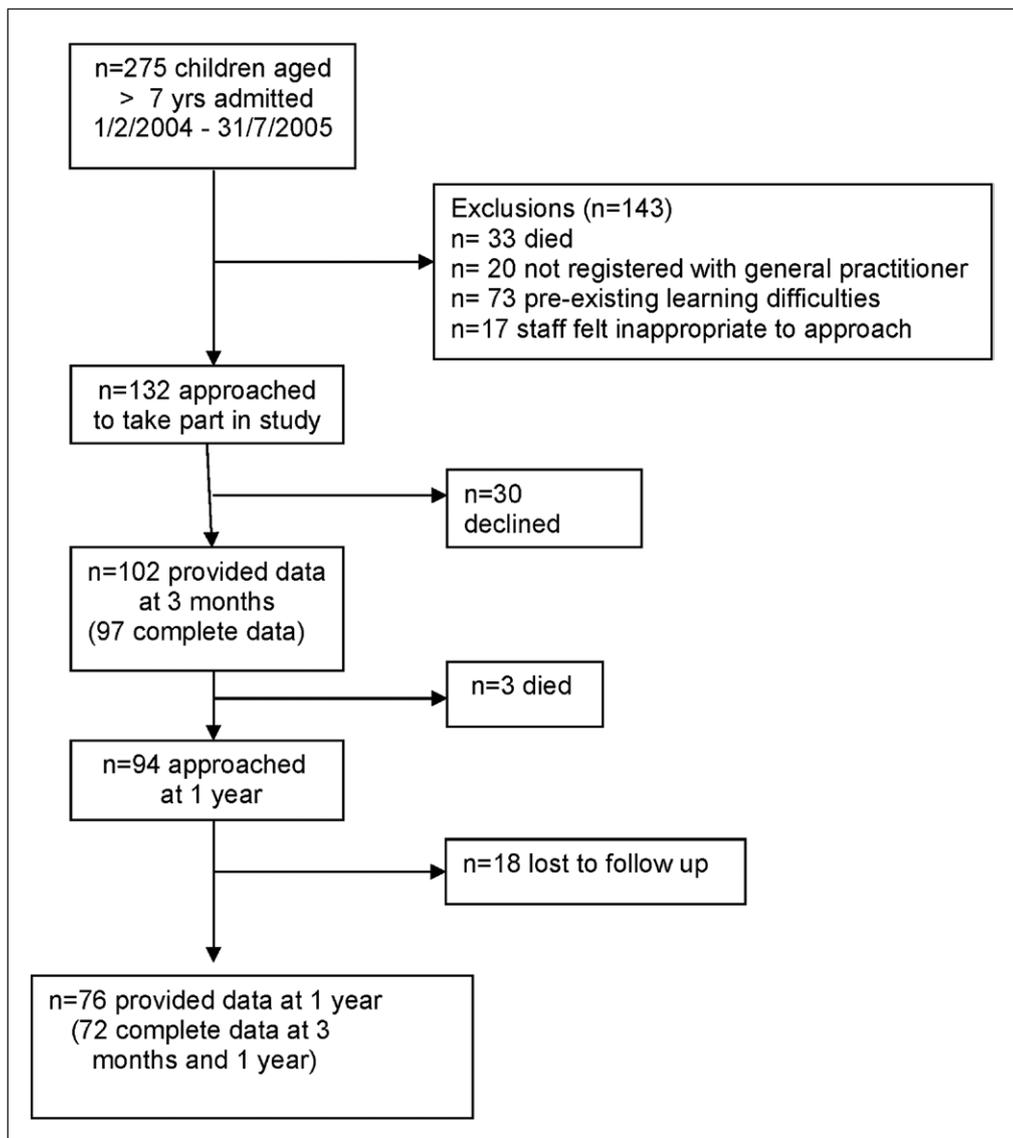
The PedsQL has been recommended for its psychometric properties and brevity, and for the wide age range it covers, in two recent reviews of measures of HRQOL in children (27, 28). It has also been shown, in a number of studies internationally, to discriminate between healthy children and those with a wide range of health conditions, including asthma, cancer, and diabetes (29–31). Norms based on large community samples exist for children in the United States (32) and the United Kingdom (33), and the scales are available in over 60 foreign languages (26).

Posttraumatic stress symptoms were measured using the CRIES-8, an 8-item screener for posttraumatic stress symptoms in children aged 7–18 yr, which has established reliability and validity (25). It is a modified version of the Impact of Event Scale (34), the most widely used screener internationally for posttraumatic stress disorder in adults, and has been used with children who have experienced many types of trauma including war, disaster, and road accidents (35, 36). A cut-off score

of greater than or equal to 17 has been found to classify correctly over 80% of children with a clinical diagnosis of posttraumatic stress disorder (37).

### Statistical Analyses

Children’s scores on the PedsQL were compared with the national norms available for healthy children in the United Kingdom by means of a series of Student’s *t* tests, in accordance with standard methodology in this field (33). Differences in total and subscale scores between 3 months and 1 yr were examined using paired *t* tests, for the children with complete data at both time-points. Associations with measures of illness severity and levels of posttraumatic stress were calculated using nonparametric Spearman correlations, as not all these variables were normally distributed. A level of  $p < 0.05$  was taken to indicate statistical significance. Statistical analyses were performed using SPSS 16.0 software (SPSS, Chicago, IL) and <http://www.quantitativeskills.com/sisa/statistics/t-test.htm>.



**Figure 1.** Flow diagram showing progress through stages of study.

**TABLE 2. Sample Characteristics of Children Completing Pediatric Quality of Life Inventory 3 Mos After Discharge From the PICU (*n* = 97)**

|   | Frequency <i>n</i><br>(%) or Median<br>(Range) |
|---|--|
| Age (yr)                                | 11 (7–17)                                      |
| Male sex                                | 55 (57%)                                       |
| Ethnic category (white United Kingdom)  | 54 (56%)                                       |
| Social deprivation <sup>a</sup>         | 49 (51%)                                       |
| Length of stay (d)                      | 2 (0–38)                                       |
| Pediatric Index of Mortality (23) score | 5 (1–42)                                       |
| Mechanically ventilated                 | 90 (93%)                                       |
| Reason for admission                    |  |
| Elective surgery                        | 15 (15%)                                       |
| Traumatic brain injury                  | 36 (37%)                                       |
| Other emergency                         | 46 (47%)                                       |

<sup>a</sup>Defined by proportion in the most deprived quintile, using the Townsend Deprivation Index (24).

## RESULTS

### Recruitment and Attrition

All children aged 7 yr or older, who were discharged alive between 1 February 2004 and 31 July 2005, were considered for inclusion in the study. In addition to the planned exclusions, unit staff deemed it inappropriate to contact 17 children for the following reasons: self-harm (*n* = 3), palliative care (*n* = 4), discharged ventilated (*n* = 4), and acquired severe brain damage incompatible with completion of the study questionnaires (*n* = 2 as a result of meningitis and *n* = 4 as a result of a head injury) (Fig. 1).

Of the 132 families approached, 102 (77%) agreed to take part. The children in non-recruited families were older and had slightly shorter stays (Table S1, Supplemental Digital Content 1, <http://links.lww.com/PCC/A51>), but otherwise the two groups were comparable in terms of demographic and medical variables. In all, 97 children provided sufficient data on the PedsQL, 3.1 (0.8) months after discharge, for the calculation of a total score. Their sample characteristics are provided in Table 2.

Of this sample, three children died between 3 months and 1 yr, and a further 18 were lost to follow-up (five families had moved, two children were felt to be too unwell to complete questionnaires by parents, two parents did not want the child reminded of the hospital admission, and the remainder did not respond to postal or telephone reminders). In total therefore, 76 of 94 (79%) of those who had provided full PedsQL data at 3 months and were still alive at 1 yr provided follow-up data at 1 yr. Of these, 72 children provided enough data for the calculation of a total PedsQL score, 13.0 (2.1) months after discharge, with the majority (*n* = 42)

**TABLE 3. Changes in Children's Self-Reported Health-Related Quality of Life Over the Year Following Discharge From Pediatric Intensive Care (*n* = 72)**

| Pediatric Quality of Life Inventory <sup>a</sup> | Whole PICU Sample ( <i>n</i> = 72)     |  |                       | Elective ( <i>n</i> = 11)             |                                       |                       |
|--|--|--|-----------------------|---------------------------------------|---------------------------------------|-----------------------|
|  | Scores 3 Mos After PICU Discharge      | Scores 1 Yr After PICU Discharge       |                       | Scores 3 Mos After PICU Discharge     | Scores 1 Yr After PICU Discharge      |                       |
|  | Mean (SD)                              | Mean (SD)                              | <i>p</i> <sup>b</sup> | Mean (SD)                             | Mean (SD)                             | <i>p</i> <sup>b</sup> |
| Total score                                      | 78.3 (14.5)                            | 82.2 (15.7)                            | <b>0.036</b>          | 71.5 (13.9)                           | 79.6 (15.2)                           | <b>0.004</b>          |
| Physical health summary score                    | 73.4 (22.5)                            | 81.6 (22.2)                            | <b>0.001</b>          | 58.2 (22.9)                           | 69.3 (26.3)                           | <b>0.011</b>          |
| Psychosocial health summary score                | 81.4 (12.2)                            | 82.4 (15.0)                            | 0.608                 | 79.6 (10.2)                           | 85.0 (11.9)                           | 0.069                 |
| Emotional functioning subscale                   | 83.3 (17.2)                            | 82.0 (20.3)                            | 0.625                 | 88.6 (15.8)                           | 88.2 (13.1)                           | 0.934                 |
| Social functioning subscale                      | 87.4 (14.3)                            | 90.4 (15.1)                            | 0.154                 | 79.1 (14.3)                           | 91.4 (13.1)                           | <b>0.015</b>          |
| School functioning subscale score <sup>c</sup>   | 71.7 (17.8) <sup>(<i>n</i> = 57)</sup> | 74.9 (17.1) <sup>(<i>n</i> = 57)</sup> | 0.299                 | 66.3 (17.5) <sup>(<i>n</i> = 8)</sup> | 72.5 (15.4) <sup>(<i>n</i> = 8)</sup> | 0.413                 |

<sup>a</sup>Scores range from 0 to 100, with higher scores indicating fewer problems.

<sup>b</sup>Scores at 3 mos were compared with those at 1 yr using two-tailed Student's *t* test for paired data.

<sup>c</sup>These subscale scores could not be compared for the 15 children who had not yet returned to school at 3 mos.

opting to complete questionnaires by telephone. Children who provided sufficient PedsQL data for analysis at both timepoints did not differ significantly from those who only provided data at 3 months, in terms of medical or demographic characteristics, or in relation to their scores on the PedsQL or the CRIES-8 at 3 months. (Table S2, Supplemental Digital Content 1, <http://links.lww.com/PCC/A51>).

### PedsQL Data

The PedsQL questionnaires were straightforward to complete in a short time and children's responses showed good internal consistency (Cronbach  $\alpha = 0.83$ ). The school functioning subscale could not be computed for 21 participants who had not yet returned to school by 3 months, but otherwise the extent of missing data was minimal at 2%, reducing to less than 1% at 1 yr.

### Comparison With PedsQL Norms for Healthy Children ( $n = 97$ )

The mean group scores on the PedsQL at 3 months are provided in Supplemental Figure 1 (<http://links.lww.com/PCC/A54>) for the sample as a whole ( $n = 97$ ) and for three subgroups (elective admissions [ $n = 15$ ], children with traumatic brain injury [TBI] [ $n = 36$ ], and children admitted for another emergency reason [ $n = 46$ ]), and compared with healthy norms. The mean scores for total PedsQL, the physical functioning subscale, and the school functioning subscale were significantly lower in the PICU group, as a whole, at 3 months. However, the emotional functioning subscale score was *higher* than that of healthy children. This finding specifically reflected the higher mean score on this dimension for the electively admitted subgroup.

By 1 yr, the available data ( $n = 72$ ) shows that the mean total PedsQL score was no longer significantly different to that of the healthy comparison sample, and that although the elective subgroup's physical functioning was still significantly lower than the norms, their reported emotional functioning remained significantly *higher*.

### Changes in PedsQL Scores Over Time ( $n = 72$ )

Paired comparisons for the 72 children for whom it was possible to calculate total PedsQL scores at both timepoints are presented in Table 3. Total PedsQL score and physical functioning improved significantly for the group as a whole, between 3 months and 1 yr after discharge. Subgroup analyses showed, in addition, that the elective subgroup made significant gains over the year in relation to their total PedsQL score, their social functioning score, and their physical functioning score, although the latter continued to remain lower than that of the healthy comparison group (Table S3, Supplemental Digital Content 1, <http://links.lww.com/PCC/A51>). The TBI subgroup also reported a significant improvement in their physical functioning over the year. None of the other statistical comparisons within subgroups over time were significant at the  $p < 0.05$  level.

### Associations With PedsQL Total Score at 3 Months and at 1 Yr ( $n = 72$ )

Associations between objective indicators of severity of illness at the time of admission and PedsQL total score were not significant at 3 months or at 1 yr post-discharge (Table 4). In contrast, concurrent posttraumatic stress symptoms were

| Emergency ( $n = 61$ )                       |  |              |  |  |       |
|--|--|--------------|--|--|-------|
| Traumatic Brain Injury ( $n = 27$ )          |  |              | Other ( $n = 34$ )                           |  |       |
| Scores 3 Mos After PICU Discharge            | Scores 1 Yr After PICU Discharge             | $p^b$        | Scores 3 Mos After PICU Discharge            | Scores 1 Yr After PICU Discharge             | $p^b$ |
| Mean (SD)                                    | Mean (SD)                                    |              | Mean (SD)                                    | Mean (SD)                                    |       |
| 81.4 (14.5)                                  | 85.3 (13.3)                                  | 0.193        | 77.9 (14.5)                                  | 80.7 (17.6)                                  | 0.387 |
| 79.3 (19.7)                                  | 88.5 (12.6)                                  | <b>0.007</b> | 73.7 (22.8)                                  | 80.1 (25.0)                                  | 0.12  |
| 83.1 (12.7)                                  | 83.2 (15.3)                                  | 0.976        | 80.7 (12.7)                                  | 81.0 (16.0)                                  | 0.932 |
| 82.4 (19.2)                                  | 83.2 (19.3)                                  | 0.87         | 82.2 (16.0)                                  | 79.1 (22.9)                                  | 0.413 |
| 91.1 (13.2)                                  | 89.4 (15.9)                                  | 0.507        | 87.0 (14.7)                                  | 90.8 (15.4)                                  | 0.309 |
| 74.3 (17.1) <sup>(<math>n = 21</math>)</sup> | 76.0 (13.3) <sup>(<math>n = 21</math>)</sup> | 0.75         | 71.2 (18.6) <sup>(<math>n = 28</math>)</sup> | 74.8 (18.2) <sup>(<math>n = 28</math>)</sup> | 0.449 |

**TABLE 4. Associations Between Objective Measures of Severity of Illness, Posttraumatic Stress and Quality of Life (n = 72)**

|  | Spearman Correlations |          |                     |                         |                    |          |                    |          |                   |          |
|--|-----------------------|----------|---------------------|-------------------------|--------------------|----------|--------------------|----------|-------------------|----------|
|  | 2. Days               |          | 3. CRIES-8 at 3 Mos |                         | 4. CRIES-8 at 1 Yr |          | 5. PedsQL at 3 Mos |          | 6. PedsQL at 1 Yr |          |
|  | <i>r</i>              | <i>p</i> | <i>r</i>            | <i>p</i>                | <i>r</i>           | <i>p</i> | <i>r</i>           | <i>p</i> | <i>r</i>          | <i>p</i> |
| 1. Pediatric Index of Mortality on admission <sup>(n=71)</sup>     | -0.18                 | 0.141    | 0.31                | 0.008 <sup>(n=70)</sup> | 0.19               | 0.108    | -0.02              | 0.900    | 0.05              | 0.688    |
| 2. Length of stay (d)  |                       |          | -0.08               | 0.491                   | 0.02               | 0.886    | -0.02              | 0.880    | 0.01              | 0.946    |
| 3. Posttraumatic stress score at 3 mos (CRIES-8) <sup>(n=71)</sup> |                       |          |                     |                         | 0.45               | <0.001   | -0.17              | 0.148    | -0.21             | 0.075    |
| 4. Posttraumatic stress score at 1 yr (CRIES-8)                    |                       |          |                     |                         |                    |          | -0.13              | 0.288    | -0.40             | 0.001    |
| 5. Quality of life score at 3 mos (PedsQL)                         |                       |          |                     |                         |                    |          |                    |          | 0.45              | <0.001   |
| 6. Quality of life score at 1 yr (PedsQL)                          |                       |          |                     |                         |                    |          |                    |          |                   |          |

CRIES-8 = Children's Revised Impact of Event Scale; PedsQL = Pediatric Quality of Life Inventory.

significantly associated with *lower* quality of life on the PedsQL at 1 yr, for the sample as a whole. Closer examination of these associations, broken down by subgroup, revealed that this association between posttraumatic stress and lower quality of life was strongest for emergency admissions, and in particular the TBI subgroup (Table S4, Supplemental Digital Content 1, <http://links.lww.com/PCC/A51>). This finding may be related to the lower rate of posttraumatic stress in the elective subgroup. A year after PICU discharge, the numbers of children scoring above the clinical cut-off on the CRIES-8 were as follows: *n* = 0 of 11 (0%) for the "elective" subgroup; *n* = 11 of 34 (32%) for the TBI subgroup; and *n* = 7 of 27 (26%) for the "other emergency" subgroup.

(Further information on the associations between children's posttraumatic stress symptoms and their memories of PICU, sedation levels, and parents' symptoms is provided elsewhere [21,22]).

## DISCUSSION

In what is believed to be the first study of *self-reported* HRQOL, in a heterogeneous sample of children treated in ICU, the majority of children's responses on the PedsQL were comparable with community norms by the end of the first year after discharge. Although children's scores on the physical functioning subscale remained below the norms, they did improve significantly over the year. These findings are consistent with the available literature on quality of life of this group of children, as assessed by clinicians and parents. They are also noteworthy, given the fact that many in this sample had been very seriously ill, as demonstrated by the number who were artificially ventilated, the high proportion of children with moderate/severe brain injury and the

significant number of children who were still off school, 3 months after discharge from PICU.

Subgroup analyses revealed important differences between subpopulations of the sample, particularly with regard to the group who were admitted electively. This group actually reported *higher* than average emotional well-being at 3 months, and at 1 yr, after their PICU treatment. This finding is interesting given that, as a group, they had a significant level of pre-existing disability and reported lower than average levels of physical functioning on the PedsQL at both timepoints studied. In addition, they reported a significant improvement in social functioning over the year.

Also, although significant gains in physical functioning were reported, between 3 months and 1 yr, for the sample as a whole, the subgroup analyses suggested that these gains were more marked for the elective and the TBI subgroups than for the other emergency admissions. These findings demonstrate that it is important to be aware of the heterogeneity of experience and the very different contexts which apply to children in the PICU, when examining data on their long-term quality of life outcomes.

Although, in this study, objective measures of severity of illness during admission were not associated with the child's subsequent quality of life ratings, posttraumatic stress levels were found to be negatively correlated with total PedsQL scores at 1 yr. Similar findings have emerged in studies of the survivors of adult intensive care treatment (38) and pediatric burns (39), indicating the importance of the psychological impact of illness and injury on quality of life, in the longer term. The lack of a significant association with objective measures of severity of illness is also consistent with the findings of Calvert et al (40), who administered the parent-proxy version of the PedsQL to the parents of 47 children with TBI, and found that measures of severity

of injury were associated with functional outcome, but not with emotional or behavioral features at 6-month follow-up.

The questionnaire was well received by the children interviewed, straightforward to complete in less than 10 mins, and simple to score. It was sensitive enough to pick up differences between elective and emergency admissions within the same population; to distinguish PICU survivors from the normal population on a number of dimensions and to determine changes in scores over time.

However, in terms of its applicability more generally to children following intensive care treatment, there were two problems. The first problem related to the fact that a significant minority of the children who agreed to take part were unable to complete the school functioning subscale at 3 months, as they had not yet returned to school after their critical illness. This problem was also reported in another acute sample of children who were asked to complete the PedsQL after their attendance at a hospital emergency department (41). Fortunately, according to the instrument's scoring instructions, the absence of items for the school functioning subscale does not preclude the calculation of the total score or the psychosocial summary score.

The second and more serious limitation, relating to the use of the self-report version of the PedsQL, was the fact that a large number of children were not able to complete it by themselves, because of significant communication problems, which were related to their developmental delay or acquired neurological deficits. This limitation would, however, apply equally to any other self-report measure.

### Strengths and Limitations

The principal strengths of this study were that it was prospective and that it obtained information directly from the children it sought to describe. In addition, the fact that population norms were available for the PedsQL enabled realistic comparisons to be made with data from nonclinical community samples. This is in contrast to a number of studies of quality of life after PICU, which have described children's outcomes in terms of the proportion reporting no impairment in any life domains. It could be argued that this practice is erroneous, given that even the healthiest of children are unlikely to function optimally, across all quality of life domains, all of the time.

It must be conceded, however, that the results are likely to have been positively biased by the exclusion of the children who suffered the severest brain damage, who were terminally ill, or whose parents felt they were too ill to be interviewed. Also, the absence of information on the children's previous functioning is another study limitation, but an inevitable one in a sample largely made up of emergency admissions. One way around this, methodologically, would be to ask informants to provide a retrospective estimate of premorbid functioning, using the same instrument.

Furthermore, given the inclusion criteria relating to age and cognitive ability, and the particular casemix in the unit studied, these findings may not generalize to other PICU survivors.

Half of the children excluded from this study had communication problems related to pre-existing learning difficulties. Establishing the views of such children is clearly a particular challenge in this field, although Noyes (42) has described creative ways of doing this, in relation to the subjective experience of long-term ventilation. In practice, it may be that proxy report is the best option to employ to gauge quality of life for this group of patients: a recent example of this approach is provided by Conlon et al (43), who used the parent-proxy version of the PedsQL to measure HRQOL outcomes for long-term PICU patients. Researchers should, however, be mindful that the experiences and needs of some subgroups of PICU patients may be different to those of others, just as the experience of certain subgroups of parents has been found to be different (44).

Finally, although the initial recruitment rate was acceptable at 77%, and there was no evidence that dropouts were systematically different to completers, there was a significant amount of attrition by 1 yr. This was despite the number of attempted contacts made, and would have been even higher if telephone follow-up had not been possible. The challenges inherent in longitudinal follow-up of this sort have been recognized by others in the field (45). As they point out, it is important that clinicians are not deterred from sharing their experiences of trying to measure outcomes, in order that solutions to common problems can be identified (45).

In a recent editorial on this subject, Morrison has commented on the dearth of information on outcomes and called for units to develop protocols to monitor the quality of life of PICU survivors after discharge (2). The PedsQL is a measure which has the advantage of being widely used in pediatric and community settings in the United States where, to date, there have been no reports on the quality of life in children after intensive care. In addition, it is brief, has good psychometric properties, and is available in a number of languages, in both self-report and parent-proxy versions.

In summary, this study demonstrates that it is possible to obtain meaningful quality of life data, directly from many children who have received intensive care treatment. This suggests there could be a role for self-report questionnaires, such as the PedsQL, as part of the comprehensive follow-up of children after discharge from PICU. Routine use of such measures has the potential both to extend our knowledge of the comparative outcomes of different subpopulations in the PICU, and, at the clinical level, to improve our understanding of the recovery journey of the individual patient.

### REFERENCES

1. Namachivayam P, Shann F, Shekerdemian L, et al: Three decades of pediatric intensive care: Who was admitted, what happened in intensive care, and what happened afterward. *Pediatr Crit Care Med* 2010; 11:549-555
2. Morrison W: Mortality, morbidity, and pediatric critical care. *Pediatr Crit Care Med* 2010; 11:630-631
3. World Health Organization: Constitution of the World Health Organization Constitution Basic Document. Geneva, Switzerland, World Health Organization, 1948
4. Knoester H, Grootenhuys MA, Bos AP: Outcome of paediatric intensive care survivors. *Eur J Pediatr* 2007; 166:1119-1128

5. Gemke RJ, Bonsel GJ, van Vught AJ: Long-term survival and state of health after paediatric intensive care. *Arch Dis Child* 1995; 73:196–201
6. Colville G: The psychologic impact on children of admission to intensive care. *Pediatr Clin North Am* 2008; 55:605–616
7. Rennick JE, Rashotte J: Psychological outcomes in children following pediatric intensive care unit hospitalization: A systematic review of the research. *J Child Health Care* 2009; 13:128–149
8. Davydow DS, Richardson LP, Zatzick DF, et al: Psychiatric morbidity in pediatric critical illness survivors: A comprehensive review of the literature. *Arch Pediatr Adolesc Med* 2010; 164:377–385
9. Morrison AL, Gillis J, O'Connell AJ, et al: Quality of life of survivors of pediatric intensive care. *Pediatr Crit Care Med* 2002; 3:1–5
10. Taylor A, Butt W, Ciardulli M: The functional outcome and quality of life of children after admission to an intensive care unit. *Intensive Care Med* 2003; 29:795–800
11. Jayshree M, Singhi SC, Malhi P: Follow up of survival and quality of life in children after intensive care. *Indian Pediatr* 2003; 40:303–309
12. Jones S, Rantell K, Stevens K, et al; United Kingdom Pediatric Intensive Care Outcome Study Group: Outcome at 6 months after admission for pediatric intensive care: A report of a national study of pediatric intensive care units in the United Kingdom. *Pediatrics* 2006; 118:2101–2108
13. Ambuehl J, Karrer A, Meer A, et al: Quality of life of survivors of paediatric intensive care. *Swiss Med Wkly* 2007; 137:312–316
14. Torrance GW, Boyle MH, Horwood SP: Application of multi-attribute utility theory to measure social preferences for health states. *Oper Res* 1982; 30:1043–1069
15. Feeny D, Furlong W, Barr RD, et al: A comprehensive multiattribute system for classifying the health status of survivors of childhood cancer. *J Clin Oncol* 1992; 10:923–928
16. Dossetor DR, Liddle JL, Mellis CM: Measuring health outcome in paediatrics: Development of the RAHC measure of function. *J Paediatr Child Health* 1996; 32:519–524
17. Upton P, Lawford J, Eiser C: Parent-child agreement across child health-related quality of life instruments: A review of the literature. *Qual Life Res* 2008; 17:895–913
18. Knoester H, Bronner MB, Bos AP, et al: Quality of life in children three and nine months after discharge from a paediatric intensive care unit: A prospective cohort study. *Health Qual Life Outcomes* 2008; 6:21
19. Noyes J: Comparison of ventilator-dependent child reports of health-related quality of life with parent reports and normative populations. *J Adv Nurs* 2007; 58:1–10
20. Varni JW, Seid M, Rode CA: The PedsQL: Measurement model for the pediatric quality of life inventory. *Med Care* 1999; 37:126–139
21. Colville G, Kerry S, Pierce C: Children's factual and delusional memories of intensive care. *Am J Respir Crit Care Med* 2008; 177:976–982
22. Colville G, Pierce C: Patterns of post-traumatic stress symptoms in families after paediatric intensive care. *Intensive Care Med* 2012; 38:1523–1531
23. Pearson G, Stickley J, Shann F: Calibration of the paediatric index of mortality in UK paediatric intensive care units. *Arch Dis Child* 2001; 84:125–128
24. Townsend P, Phillimore P, Beattie A: Health and deprivation: Inequality and the North. Andover, Croom Helm, 1988
25. Yule W: Anxiety, depression and post-traumatic stress in childhood. In: *Child Psychology Portfolio*. Sclare I (Ed). Windsor, UK, NFER-Nelson, 1997, pp 35–38. Available online at: <http://www.childrenandwar.org/measures>. Accessed January 30, 2011
26. Varni JW, Burwinkle TM, Seid M: The PedsQL as a pediatric patient-reported outcome: Reliability and validity of the PedsQL Measurement Model in 25,000 children. *Expert Rev Pharmacoecon Outcomes Res* 2005; 5:705–719
27. Eiser C, Morse R: The measurement of quality of life in children: Past and future perspectives. *J Dev Behav Pediatr* 2001; 22:248–256
28. Janssens L, Gorter JW, Ketelaar M, et al: Health-related quality-of-life measures for long-term follow-up in children after major trauma. *Qual Life Res* 2008; 17:701–713
29. Varni JW, Burwinkle TM, Rapoff MA, et al: The PedsQL in pediatric asthma: Reliability and validity of the Pediatric Quality of Life Inventory generic core scales and asthma module. *J Behav Med* 2004; 27:297–318
30. Varni JW, Burwinkle TM, Katz ER, et al: The PedsQL in pediatric cancer: Reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. *Cancer* 2002; 94:2090–2106
31. Varni JW, Burwinkle TM, Jacobs JR, et al: The PedsQL in type 1 and type 2 diabetes: Reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales and type 1 Diabetes Module. *Diabetes Care* 2003; 26:631–637
32. Varni JW, Burwinkle TM, Seid M, et al: The PedsQL 4.0 as a pediatric population health measure: Feasibility, reliability, and validity. *Ambul Pediatr* 2003; 3:329–341
33. Upton P, Eiser C, Cheung I, et al: Measurement properties of the UK-English version of the Pediatric Quality of Life Inventory 4.0 (PedsQL) generic core scales. *Health Qual Life Outcomes* 2005; 3:22
34. Horowitz M, Wilner N, Alvarez W: Impact of Event Scale: A measure of subjective stress. *Psychosom Med* 1979; 41:209–218
35. Stallard P, Velleman R, Baldwin S: Psychological screening of children for posttraumatic stress disorder. *J Child Psychol Psychiatry* 1999; 40:1075–1082
36. Smith P, Perrin S, Dyregov A, et al: Principal components analysis of the Impact of Event scale with children in war. *Pers Individ Dif* 2003; 34:315–322
37. Perrin S, Meiser-Stedman R, Smith P: The Children's Revised Impact of Event Scale (CRIES): Validity of a screening instrument for PTSD. *Behav Cogn Psychother* 2005; 33:487–498
38. Schelling G, Stoll C, Haller M, et al: Health-related quality of life and posttraumatic stress disorder in survivors of the acute respiratory distress syndrome. *Crit Care Med* 1998; 26:651–659
39. Landolt MA, Buehlmann C, Maag T, et al: Brief report: Quality of life is impaired in pediatric burn survivors with posttraumatic stress disorder. *J Pediatr Psychol* 2009; 34:14–21
40. Calvert S, Miller HE, Curran A, et al: The King's Outcome Scale for Childhood Head Injury and injury severity and outcome measures in children with traumatic brain injury. *Dev Med Child Neurol* 2008; 50:426–431
41. Mistry RD, Stevens MW, Gorelick MH: Health-related quality of life for pediatric emergency department febrile illnesses: An evaluation of the Pediatric Quality of Life Inventory 4.0 Generic Core Scales. *Health Qual Life Outcomes* 2009; 7:5
42. Noyes J: Enabling young 'ventilator-dependent' people to express their views and experiences of their care in hospital. *J Adv Nurs* 2000; 31:1206–1215
43. Conlon NP, Breatnach C, O'Hare BP, et al: Health-related quality of life after prolonged pediatric intensive care unit stay. *Pediatr Crit Care Med* 2009; 10:41–44
44. Graham RJ, Pemstein DM, Curley MA: Experiencing the pediatric intensive care unit: Perspective from parents of children with severe antecedent disabilities. *Crit Care Med* 2009; 37:2064–2070
45. Taylor AB, Butt W: The evaluation of outcome following paediatric intensive care: The major issues identified. *Clin Intensive Care* 2000; 11:239–244