

Long-term quality of life of patients treated in paediatric intensive care unit

Branka Polic · Julije Mestrovic · Josko Markic ·
Marija Mestrovic · Vesna Capkun · Ina Utrobicic ·
Mira Jukica · Marija Radonic

Received: 1 June 2012 / Revised: 11 September 2012 / Accepted: 17 September 2012
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Abstract The changes in long-term quality of life (QOL) of children treated in paediatric intensive care unit (PICU) were investigated in relation to their QOL before critical illness together with the influence of underlying chronic health condition and severity of illness estimated by Paediatric Index of Mortality 2 on the long-term outcome. This study included 189 children treated in PICU and 179 children from outpatient clinics as controls. QOL was evaluated according to the Royal Alexandra Hospital for Children Measure of Function (RAHC MOF). The long-term QOL in 70 % of children treated in PICU was good, although there was a significant diminution of QOL in children treated in PICU in comparison with their preadmission scores and

with the children from outpatient clinics who served as controls ($p < 0.001$). Severity of illness had a significant impact on children's QOL ($p = 0.016$) 6 months after treatment in PICU. Twenty-four months after discharge, the RAHC MOF score was still decreased in 19 % of children treated in PICU, and in significantly more patients with a chronic health condition (CHC) treated in PICU, than in their peers from outpatient clinics ($p = 0.029$). Reduced QOL was significantly more frequent in children with neurodevelopmental disability than in children without CHC 24 months after discharge from PICU ($p = 0.013$). **Conclusion:** Acute illness has a significant impact both on children with and without CHC after treatment in PICU 6 months after discharge. Twenty-four months after discharge, comorbidity was identified as the decisive factor for diminished QOL in children after PICU treatment.

B. Polic (✉) · J. Mestrovic · J. Markic · M. Mestrovic
Department of Pediatrics, Pediatric Intensive Care Unit,
University Hospital of Split,
Spinciceva 1,
2100 Split, Croatia
e-mail: branka.polic1@st.t-com.hr

V. Capkun
Department of Nuclear Medicine, University Hospital of Split,
Spinciceva 1,
Split, Croatia

I. Utrobicic
Educational Institute of Public Health-Split and Dalmatia County,
School Health Services,
Omiska 28,
Split, Croatia

M. Jukica
Department of Physical Medicine, University Hospital of Split,
Spinciceva 1,
Split, Croatia

M. Radonic
Department of Pediatrics, Hospital of Dubrovnik,
Misetica 2,
Dubrovnik, Croatia

Keywords Child · Intensive care · Chronic health condition · Severity of illness · Neurodevelopmental disability · Long-term quality of life

Introduction

The increased interest for measuring the quality of life (QOL) in children arises from the changing epidemiology of children's diseases and significant improvement in treatment. Several previous studies revealed good QOL in majority of children after treatment in paediatric intensive care unit (PICU) [1, 19, 23]. The preadmission comorbid status was found to be an important denominator of QOL after intensive care, due to its continuous impact on patients' condition [10, 11]. Although the evaluation of long-term QOL is more significant when put in the context of patients' pre-morbid status, the preadmission data were collected only in a few studies [2, 9, 11, 13]. Furthermore, the studies carried out so far did not have a control group of patients for

comparison with patients treated in PICU. Therefore, the purpose of this study was to evaluate the preadmission QOL and the follow-up long-term QOL of children treated in PICU, to compare the QOL of patients treated in PICU to the control group and to evaluate the influence of chronic health condition (CHC) on the long-term outcome after treatment of an acute illness that required hospitalization in PICU.

Materials and methods

This prospective follow-up study was conducted in the multidisciplinary ten-bed PICU of the University Hospital of Split between June 2006 and December 2008. Children aged 10 to 18 years were eligible for the study. The children from outpatient clinics, with the same demographic characteristics and matching preadmission health status and QOL, served as controls. AZPNIC Registry codes were used for the classification of diagnoses [21]. The mortality risk was scored according to the Paediatric Index of Mortality (PIM) 2 [22]. Chronic health conditions were defined as ongoing physical, developmental, behavioural, or emotional conditions that required health and related services of a type and amount beyond what is usually required by children in general [15]. A chronic health condition had to be diagnosed at least 1 year prior to the study. Neurodevelopmental disabilities were defined according to the adaptation of Crocker's categorization of developmental disabilities and mental retardation [3]. Royal Alexandra Hospital for Children Measure of Function (RAHC MOF), generic health-related quality of life scoring system was applied for evaluating the outcome [6]. The optimal age for Family Rating scale of RAHC MOF is over 10 years. The system was used previously, and the methodology is already described in detail [17]. As the result, the potential total score of 100 is divided into three categories: a score between 1 and 30 indicates a poor quality of life, score between 31 and 70 a fair quality of life and score between 71 and 100 a good quality of life. For children treated in PICU, the preadmission QOL was obtained by interviewing the parents or guardians at time that was considered convenient for them. The parents/guardians were asked again 6 and 24 months after discharge from PICU by telephone interview to answer the same questions. The control group of children matched the children treated in PICU with regard to gender, age and preadmission QOL. The children with CHC in the control group also matched their pairs in associated chronic health condition. This matching was made using a qualitative approach in which two expert clinicians evaluated patients' medical charts and medical history with regard to several important clinical indicators. These data were then combined with information obtained using in-depth interviews with children's parents who also provided valuable insight into

children's medical conditions. This complex qualitative analysis was used as a basis for comparing the health condition of children with CHC from outpatient clinics with those with CHC before their treatment in PICU. The parents/guardians of children in the control group were also contacted by telephone for another QOL evaluation 6 and 24 months later. The influence of chronic health condition and severity of illness scored with PIM 2 on long-term QOL was also evaluated. The hospital ethics committee gave clearance for data collection and parents/guardians signed the informed consent.

Statistica 7.0 software package was used to perform statistical analysis of the data. χ^2 and Mann–Whitney test were used to compare the samples of children among different demographic and clinical characteristics. Impacts of outcome measures on QOL were calculated by forward stepwise logistic regression (Wald). A significance level of 95 % ($p < 0.05$) was considered in all statistical values.

Results

In the study period, 200 children meeting inclusion criteria were treated in PICU. Out of them, eight (4 %) children who died and three children whose parents were unwilling to participate in this study were excluded. Out of 189 eligible children, 120 (63 %) were males. The PICU-treated children were subdivided into two groups. The majority (153, 81 %) of patients were previously healthy, and the second group were patients with an underlying CHC. Among the patients with CHC treated in PICU, 19 had a neurodevelopmental disability. The control group consisted of 179 matching children, and 14.5 % of them had CHC.

Medical diagnoses were the leading reason for PICU admissions. Significantly more children with surgical diagnoses were in the group of children without CHC than in the group of children with CHC ($\chi^2 = 5.83$; $df = 1$; $p = 0.016$). There were no differences between values of PIM 2 at admission to PICU among children without and with CHC ($z = 0.60$; $p = 0.547$). The characteristics of children treated in PICU and controls are shown in Table 1.

Logistic regression was used in the analysis of the impact of severity of illness, expressed as PIM 2 score, on the worsening of patients' RAHC MOF 6 months after the treatment in PICU. Values of PIM 2 are subdivided into four groups and every next value of PIM 2, which is higher than the one before, showed more probability for worsening of QOL. The result of the same analysis 24 months after discharge was insignificant ($\chi^2 = 1.726$; $df = 3$; $p = 0.631$) (Table 2).

There were no significant differences in the preadmission values of RAHC MOF score between children treated in PICU and controls. However, the RAHC MOF differences between children treated in PICU and the control group

Table 1 Characteristics of children treated in PICU and children from outpatient clinic

		Children treated in PICU		Children from outpatient clinic	
		Without chronic health condition	With chronic health condition	Without chronic health condition	With chronic health condition
Sex (no.)	Male	104	25	102	15
	Female	55	16	51	11
Age (months) ^a		186 (120–216)	184 (120–212)	184 (122–210)	185 (120–216)
Admission (no.)	Urgent	155	33		
	Elective	4	8		
Diagnosis (no.)	Surgical	76	11		
	Medical	83	30		
Leading diagnosis (no.) ^b	Injury	57	2		
	Neurological	3	17		
PIM 2 (value) ^a		1.17 (0.21–99)	1.12 (0.27–56.36)		
Mechanical ventilation (days) ^a		2.00 (0.5–36)	4.00 (0.5–8)		
PICU stay (no.)	≤1 day	92	22		
	>1 day	67	19		

PICU paediatric intensive care unit, PIM paediatric index of mortality

^aMedian (minimum to maximum)

^bAccording to ANZPIC Registry

were significant 6 months later and remained significant 24 months after discharge (Table 3).

Six months after discharge, the preadmission values of RAHC MOF score decreased in 26 % of children treated in PICU, and the decrease of RAHC MOF was found in 3 % of children from the control group ($\chi^2=36$; $df=2$; $p<0.001$). Twenty-four months after discharge, RAHC MOF score was still decreased in 19 % of children treated in PICU and in 1 % of children of the control group ($\chi^2=26.8$; $df=2$; $p<0.001$).

Table 2 Impact of PIM 2 on worsening of RAHC MOF 6 and 24 months after discharge

PIM 2 ^a	Worsening of RAHC MOF 6 months after discharge in relation to increase in PIM 2 ^b OR (95 % CI)	Worsening of RAHC MOF 24 months after discharge in relation to increase in PIM 2 ^c OR (95 % CI)
<0.82	1.5 (1.1–2.2)	1.1 (0.8–1.6)
0.82–1.16		
1.161–2.24		
>2.24		

PIM paediatric index of mortality, RAHC MOF Royal Alexandra Hospital for Children Measure of Function

^aValues of PIM 2 are subdivided into four groups

^bEvery next value of PIM 2 shows higher probability for worsening which is significant ($p=0.016$)

^cImpact of the highest values of PIM 2 on the worsening of QOL is not significant ($p=0.631$)

The continued decrease of RAHC MOF after 24 months occurred in significantly more patients with CHC treated in PICU than in their peers from outpatient clinic (Table 4). Not any child with CHC from the outpatient clinic was admitted to PICU in the study period, but there were ten children with CHC who were readmitted to PICU more than once.

In further analysis, children with neurodevelopmental disabilities were set apart from the whole group of children with CHC. The decrease of RAHC MOF was significantly more frequent in children with neurodevelopmental disability than in children without a chronic condition ($z=2.5$; $p=0.013$), while the difference between children without CHC and patients with other CHC was insignificant ($z=1.67$; $p=0.095$).

Discussion

Death is a relatively rare event in PICU. Therefore, in evaluating hospital care, patient long-term outcome has become the cornerstone of measuring the effectiveness of PICU management. The long-term QOL will remain good for the majority of children treated in PICU [1, 2, 9, 11, 13, 14, 19, 23].

Severity of illness is an important indicator of QOL of children treated in PICU [8, 19, 28]. The severity is estimated by using various scoring systems and usually the higher score represents a more critical condition. Both mortality

Table 3 Preadmission RAHC MOF score of children treated in PICU and controls, 6 months later and 24 months after discharge

RAHC MOF		Children in PICU, no. (%)	Children from outpatient clinic, no. (%)	<i>p</i> ^a
Preadmission	1–30	11 (6)	3 (2)	0.119
	31–70	22 (11)	17 (9)	
	71–100	167 (83)	159 (89)	
After 6 months	1–30	8 (4)	3 (2)	<0.001
	31–70	62 (33)	20 (11)	
	71–100	119 (63)	156 (87)	
After 12 months	1–30	8 (4)	3 (2)	<0.001
	31–70	50 (26)	18 (10)	
	71–100	131 (70)	158 (88)	

^a χ^2 test

rate and poor quality of life after the stay in PICU are closely correlated with the highest values of those scores [1, 8, 12, 19]. In our study, higher values of PIM 2 are significantly correlated with the worsening of QOL 6 months after discharge. However, the long-term QOL as assessed 24 months after discharge was not significantly influenced by PIM 2. This improvement shows the decline of long-term impact of acute illness on QOL. In addition, QOL was significantly diminished 6 months after discharge compared to preadmission values. However, when the post-discharge QOL was re-evaluated after 24 months, we found substantial reduction in the number of patients with diminished QOL. This long-term improvement of QOL is similar to previously published results [1, 4, 14, 19]. The observed changes that include the immediate worsening and the subsequent improvement of QOL after PICU treatment indicate a significant effect of the critical acute illness in the period immediately after discharge. Obviously, the physiological convalescence process takes time, and the adverse effect of acute illness or injury vanishes over a longer period of time in the majority of children. QOL of children from outpatient clinic remained unchanged in the study period.

Table 4 Worsening of RAHC MOF score in children with chronic health condition 24 months after discharge

	Children with chronic health condition		Total	<i>p</i> ^a
	Children treated in PICU	Outpatient children		
No. of children with decreased RAHC MOF after 24 months	6/41	0/26	6	0.029

^a χ^2 test

Children with a chronic illness have much lower QOL scores [20, 25], and higher susceptibility to acute insult, as already shown in previous studies [5, 16–18]. Children with CHC are more likely to be admitted to PICU [1, 5]. The presence of co-morbidities is associated with poorer QOL outcome after discharge from PICU [11, 19, 23]. The comparison of children with CHC and those without CHC is important for understanding the interaction of acute illness and chronic disease and the resultant post-discharge QOL. In our study, both patients with CHC and without CHC had worse long-term QOL, when compared to the peers from outpatient clinics.

Although the preadmission scores were not significantly different between the study group and the control group, the long-term QOL of children with CHC who were treated in PICU was significantly worse compared to children with CHC from outpatient clinics. Obviously, children with CHC who needed PICU treatment were more susceptible to acute insult than their peers from outpatient clinics. In the long term, chronic diseases of children treated in PICU continued to deteriorate, worsened their QOL and required repeated PICU admissions. Their worsening of long-term QOL was primarily the result of the type of pre-existing chronic condition. However, we cannot ignore the overlap between the negative effect of CHC and severe acute illness which required PICU treatment. As expected, their preadmission QOL was already worse than QOL of children without CHC. Children with CHC, and especially those with neurodevelopmental disabilities, are burdened with severe physical and cognitive difficulties, which can significantly impair their QOL. Children with neurodevelopmental disability are additionally susceptible to severe acute illness, especially to significant respiratory difficulties. Those children more often have poor or fair quality of life before an acute illness, as well as after treatment in PICU [17]. Therefore, children with neurodevelopmental disabilities had a significant reduction of QOL compared to children without CHC. The comparison between children with other CHC and without CHC was insignificant. Therefore, long-term QOL depends significantly on the nature and progression of a chronic illness [10, 24, 26].

The main limitation of this study is a small number of patients included in the study, which is the limitation of many other studies of post-PICU QOL. Furthermore, the generic measure used in this study, which focuses on issues common to all pathology, may not detect changes relevant to children with a specific illness. In addition, the collection of the data was made by telephone interview with parents or guardians. It is known that this method affects the results because parents underestimate their children's quality of life compared to child self-reports [7, 27]. However, this limitation is common for both the study and the control group and should therefore not influence the conclusions related to the

comparison of the two groups. Overall, the results of the study are important, since most of the previous studies gave static data by calculating only QOL after discharge from PICU. This is the first study, to our knowledge, where the data from children treated in PICU were compared with a control group of children from the community. These results should encourage further evaluation of the interaction between chronic and acute illnesses and how an acute illness affects the QOL of various groups of children with CHC.

The assessment of long-term QOL after discharge from PICU gives insights into effectiveness of PICU management. The information about post-discharge QOL is essential for a comprehensive evaluation of patient functioning after a life-threatening illness. The evaluation of possible consequences of a severe illness and PICU treatment helps us to identify children at risk for problems. Consequently, we can plan the level of post-discharge support that should be prepared and provided to the child. Such results also allow inter-institutional comparisons and appraisal of the health care which can contribute to the progress of PICU treatment.

In conclusion, although QOL of children after PICU treatment is affected by pre-morbid health status, an acute illness had a significant impact both on children without CHC and children with CHC 6 months after discharge from PICU. However, the re-evaluation 24 months after discharge revealed that co-morbidity significantly determined children's QOL. Therefore, the results of our study represent a new contribution to our knowledge on interaction between acute critical illnesses and CHC and their effects on long-term QOL of children treated in PICU.

Acknowledgments We thank the parents of the participants who completed the questionnaires and acknowledge the support of Croatian Ministry of Science, Education and Sport, grant no. 216-0000000-3391.

Conflict of interest The authors declare that they have no competing interests.

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